# Dignity in Practice: An exploration of the care of older adults in acute NHS Trusts

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Preventing Abuse and Neglect in Institutional Care of Older Adults

A RESEARCH INITIATIVE TO ENHANCE DIGNITY IN CARE HOMES AND HOSPITALS



COMIC RELIEF

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# **Executive Summary**

# Background

Evidence from a number of recent national reports show marked variations in the level and provision of dignified care for older people in acute hospital Trusts. Lack of dignity results in many complaints and substantial media interest. There is also evidence that positive health and social outcomes result from ensuring patients receive dignified care. Whilst there is a growing international and UK literature exploring dignity in the care of older people, few studies have adopted a comprehensive approach that involves:

- Ascertaining the views of older people following discharge.
- Their family members or carers.
- Senior Trust managers and ward staff.
- Observation of care delivery.

## Aim of the Study

This study sought to build upon an earlier study undertaken by Tadd and Calnan (2005) (Dignity and Older Europeans), together with other research and national reports in order to develop a body of evidence derived from exploring the experiences of service user, those of their carers together with interviews and observation of the behaviours and practices of providers, from which explicit recommendations and guidance on the provision of dignified care can be developed. This aim was pursued through the following study objectives:

### **Objectives:**

- 1) Identify older people's and their carer's views and priorities in relation to dignified care.
- 2) Examine healthcare practitioners' behaviours and practices in relation to dignified care.
- 3) Identify the occupational, organisational and cultural factors that impact on dignified care.
- 4) Develop evidence-based recommendations and guidance for dignified care.

# Methods

These objectives were explored through an ethnography of four acute hospital Trusts in England and Wales. The Trusts were purposively selected according to their organisational characteristics, quality of care, resource use and involvement in dignity related initiatives. Indepth interviews were undertaken with recently discharged older people (65+) (n=40) and their relatives/carers (N=25) about their experiences and priorities in relation to dignified care. This was complemented by evidence from 617 hours of non-participant observation of practices and activities in 16 wards across the four acute NHS Trusts. The observation periods covered 24/7 in each of the 16 wards to identify patterns of practitioner behaviour. In-depth interviews were also undertaken with a range of frontline staff (N=79) and with purposive samples of middle and senior managers (N=32) to explore the occupational,

organisational and cultural factors which foster or detract from dignified care. The data from the observations and interviews at each site were pooled and analysed using an inductive thematic approach. Users (older people/carers) were involved with and informed of each stage of the research process.

As a means of validation, four stakeholder workshops for NHS managers and staff, voluntary organisations and policy makers (≈150) were held throughout the UK to determine how the emerging themes resonated with their experiences.

# Findings

The main findings are related to four overarching themes: 'Whose Interests Matter?'; 'Right Place – Wrong Patient'; 'Seeing the Person' and 'Influences on Dignified Care'.

'Whose Interests Matter?' explores the conflict of interest between the priorities of the Trust, those of the staff and of the patients.

The findings are discussed under the following headings:

- What matters is what is measured.
- The problem of risk and unintended consequences.
- Working the system and unintended consequences.
- Trust, blame and the culture of defensiveness.
- Protocols of care.
- Caring roles and the division of labour.
- Seeing the task.
- Staffing levels and the continuity of care.

The study shows that the majority of the staff interviewed are motivated to represent patients' interests but these motivations are frequently compromised by systemic and organisational factors. Setting acute Trust priorities on the basis of measurable performance indicators; a perceived culture of blame; the management of 'secondary risks'; high bed occupancy rates together with increased specialisation and rationalisation can all impact on the care of older people resulting in them being continually moved within the system. Furthermore, within the observed wards, local cultures have developed, often in the context of untenable staffing levels and a strictly demarcated and hierarchical division of labour. These factors can result in a failure to provide continuity of care and care which protects and promotes the individual's dignity.

'Right Place – Wrong Patient' refers to the almost unanimous view expressed by all participating Trust staff that the acute hospital is not the 'right place' for older people.

In this theme, the key message echoed by staff at all levels in each organisation, that the acute hospital is not the 'right place' for older people is explored. The prevalence of this view results in the physical environment, staff skills and education and the organisational processes frequently acting as barriers to delivering dignified care to older people.

Because acute wards are often poorly designed to meet the needs of their main users, those over 65 years, many acute wards are not ideal as a place to treat older people with dignity, as the physical environment is confusing and inaccessible. Many staff, whilst doing their best, are often ill-equipped in terms of their knowledge and skills to care for older people whose acute illness is often compounded by physical and mental co-morbidities. The atmosphere on the wards can be characterised as one of frenetic activity with little opportunity for engagement with individuals. That many interviewees recognised these issues but concluded that it was the older person who is in the *'wrong place'*, together with the assumption that there must be a better place for *'them'* to be, may suggest an underlying and widespread ageism.

'Seeing the Person' focuses on the impact of encounters that take place within the acute setting and the influence of these on the experience of dignity for patients, their relatives and staff. The findings discussed under this theme include:

- Participants' views of their care.
- Respectful communication.
  - Patronising older people.
  - Referred to as a task or number.
  - Being ignored.
- Power in place.
- Fundamental care.
  - Privacy.
  - Nutrition.
  - Using the toilet.
  - Washing and dressing.
  - Being informed.
- The views of relatives.
- Staff dignity.

Care provision is variable with no clear patterns as to why emerging. In no ward was care either totally 'dignified' or totally 'undignified' and variability occurred from ward to ward, in the same ward when different staff were on-duty, or at different times of the day. Care is largely task based and reactive to patient's requests for assistance, which can result in low self-esteem by reducing patients to a state of dependence. Key elements of dignified care include: respectful communication; respecting privacy; promoting autonomy and a sense of control; addressing basic human needs such as nutrition, elimination and personal hygiene needs in a respectful and sensitive manner; promoting inclusivity and a sense of participation by providing adequate information to aid decision-making; promoting a sense of identity; focusing on the individual and recognising human rights.

Undignified care is that which renders individuals invisible, depersonalises and objectifies people, is abusive or humiliating, narrowly focused and disempowers the individual.

The degree to which staff are treated with dignity and respect by their colleagues, managers, patients and carers is also variable and the role of the ward manager in promoting a respectful working environment is critical. The inability to deliver appropriate standards of care because of systemic or organisational factors was often seen to impact on staff members' sense of dignity and resulting in demoralisation.

The final theme of 'Influences on Dignified Care' identifies from the above findings the key influences on dignified care for older people. In this theme, the barriers and enablers to the provision of dignified care that have informed the suggested recommendations for change are highlighted and address the organisational and policy drivers, environmental and cultural aspects, as well as individual approaches to care provision.

Environmental barriers include:-

- the disempowering nature of acute wards which add to the disorientation experienced by many older people on admission to hospital.
- the concern engendered in many older people by being in close proximity to patients of the opposite gender.
- the boredom and dejection resulting from the loss of communal spaces and activities.
- the environmental hazards that the acute ward presents especially for older people whose acute illness is compounded by dementia, confusion and/or delirium.
- the lack of information about the personnel and ward routines.

Barriers to dignified care due to deficiencies in the knowledge and experience of ward staff include:

- a lack of attention paid to the care needs of older people in educational programmes.
- a lack of knowledge of the needs of people with dementia.
- the impact of increasing specialisation.
- the lack of training in relation to the provision of dignified care.

In terms of organisational processes, the main barriers are:

- the perpetual movement of older people both within and between hospital wards.
- the view that these patients should not be there anyway.

Enablers of dignified care include:-

- attention to the physical environment that takes account of the needs of older people including appropriate signage, careful use of colour, information and date boards, safe walking spaces and communal areas to improve social interaction and engagement.
- adequate space between beds to enable privacy especially when using hoists.
- gender specific washing and toilet facilities.
- staff appraisal systems which take account of the patient experience and offer opportunities for reflection on practice.
- appropriate staffing levels to meet the demands of patient care.
- sensitive delivery of fundamental care that takes account of individual patient needs, especially the need for privacy.
- the use of signs to prevent entry to the patient spaces when intimate care is being undertaken.
- courteous and respectful communication practices.
- respectful attitudes of staff to both patients and colleagues.

- social activities and engagement especially on wards that are exclusively for older patients.
- ward managers who have a visible presence on the ward and who foster collaborative team work.
- staff who are confident and competent in their expertise and feel supported by their managers.
- the use of volunteers to assist staff.
- organisational policies and operating procedures that place patient experience at the centre.
- Trust managers who demonstrate genuine involvement in both patient and staff experiences.

Based on the evidence from this study together with the cumulative evidence from the Dignity and Older Europeans study, and the research studies and reports cited in this study, the following recommendations are suggested to ensure that older people in acute NHS Trusts are treated with dignity.

## Recommendations

#### 1) Recommendations for the NHS as a System

- 1.1 Older people are the most frequent users of acute hospital services therefore ageist attitudes which result in comments such as '*They shouldn't be here*' are inappropriate. This key message should be clearly understood throughout the organisation.
- 1.2 The NHS should understand the need to design and operate its acute services to explicitly meet the needs of frail, older people. Such services will also meet the needs of other users.
- 1.3 The connection between policy and practice should be made explicit by translating what developments in policy mean in practice for both frontline staff and those responsible for implementation, to ensure that clear unequivocal messages are received.
- 1.4 Dignity and respect are core values that underlie the NHS Constitution, it is essential that all Trust and health boards are reminded by NHS chief executive(s) that they are responsible for all aspects of the quality of care and for ensuring that the values enshrined in the constitution become a practical reality for everyone in the organisation.

#### 2) Recommendations for Royal Colleges and Regulators of Professional Groups

2.1 The education of all healthcare professionals needs to be reassessed to ensure it is in line with the needs of the majority of patients in acute hospital Trusts – older people. This reappraisal must include a better understanding and appreciation of comorbidities, the nature and management of dementia and delirium and the complexity of older people's needs. Changes to professional curricula to better

reflect these needs and meet them in a dignified manner would be appropriate (see National Service Framework for Older People, DH 2001a).

#### 3) Recommendations for Commissioners

- 3.1 Commissioners should adopt an outcomes-based approach that includes outcomes relating to dignity and respect.
- 3.2 Commissioners should ensure that all older people with complex needs complicating acute illness are seen by a geriatrician in order to advise colleagues on management.
- 3.3 Commissioners should ensure that liaison services with old age psychiatry (or other specialist services for dementia/delirium) are provided in all acute settings.

#### 4) Recommendations for Trust Boards

- 4.1 Patient movement should be reduced by either: a lower bed occupancy rate which would allow more flexibility when trying to place patients according to specialism or gender or, by altering how the hospital is organised so that there is less emphasis on the spatial separation of specialisms. This could be promoted by:
- i) Shared care approaches and joint responsibility for patients whose conditions span specialisms.
- ii) Consultants and their teams undertaking 'patient rounds' rather than 'ward rounds'.
- 4.2 Trust boards should give attention to environmental design and where possible enable patients to participate in redesign/refurbishment projects. Specifically:
- i) Older people are the main users of acute hospitals. Therefore the NHS should understand the need to design and operate its acute services to explicitly meet the needs of frail older people. Such services will also meet the needs of other users.
- ii) All hospital refurbishments and new builds should incorporate dementia-friendly design as standard for all areas. This should include safe walking spaces and the helpful use of colour, lighting and signage to help orientate those with dementia or delirium.
- iii) The value of communal spaces on acute wards in terms of social engagement and activities should be recognised as a means of preventing deterioration and promoting recovery (BMA, 2011).
- iv) Minimum space requirements around bed areas should allow dignified care while using large hoists and other equipment. Secure, accessible storage space for patients' belongings should be available at all bed spaces.
- v) Clear definitions and information concerning single sex wards should be provided prior to admission to prepare older people for situations where there may be members of the opposite sex in adjacent bays or sharing bathing or toileting facilities.
- 4.3 Trust boards should ensure effective management by developing communication strategies that guarantee the free flow of information from 'board to ward' and 'ward

to board'. These strategies should be enhanced by visible and accessible middle managers and board members. The board members should accept responsibility for the day to day quality of patient care and therefore need to ensure that they are well informed about all aspects of the patient experience. Trust board meetings should focus on the experience of patients, both good and bad, and communicate the messages across all staff groups.

- 4.4 Trust boards should ensure effective implementation of policies through an awareness and understanding of the impact of policies and priorities on patient care and practices at the ward level. Resources to ensure privacy and dignity, such as the provision of adequate amounts of clean linen and nightwear must be seen as essential.
- 4.5 In relation to risk management, Trust boards need to balance the impact of risk management strategies against patients' experience. Professional staff must be reassured that they will be supported and enabled to decide when risks are worth taking to promote patient dignity.
- 4.6 Targets and clinical governance directives can create an over-emphasis on checklist based audit and measurement, which may fail to see the person and be detrimental to patient care and experience. Broader approaches to determine the quality of patient care and the experience of patients should be adopted, including regular observation of care by middle and Trust board managers and qualitative interviews with service users and their family members.
- 4.7 Trust boards must ensure a comprehensive and compulsory programme of both induction and continuing training for all staff groups in relation to the provision of dignified care and the needs of older people, especially those with dementia (See National Dementia Strategy, DH, 2009b).
- 4.8 Time must be available for staff to reflect on practice and to question inappropriate practices that have become accepted norms, such as forms of address; respecting people's space and belongings; and task driven activity at the expense of engagement with patients.
- 4.9 Trust boards should adopt human resource policies that embed dignified care in the organisational structure, especially those in relation to recruitment and staff appraisal, so that essential aspects of patient experience such as dignity and respect are included.
- 4.10 Trust boards should invest in leadership programmes for key staff, especially ward sisters/managers.

#### 5) Recommendations for Middle Managers and Clinical Leaders

5.1 Middle managers must accept responsibility for promoting dignity and hold teams accountable for delivering high quality, dignified care at all times. They must challenge undignified practices and reward dignified care.

5.2 Middle managers should develop ward leaders giving them more autonomy and support to manage their staff.

#### 6) Recommendations for Ward Managers

- 6.1 Ward managers should support staff in the delivery of dignified care and be willing to speak for them to ensure resources are in place to enable the delivery of care of an appropriate standard.
- 6.2 Ward managers must be willing to challenge inappropriate or poor practices and take necessary actions to ensure they do not recur.
- 6.3 Ward managers must foster team approaches to care and facilitate communication between team members, thereby ensuring that all staff are treated with dignity and respect.

#### 7) Recommendations for Staff

- 7.1 All staff must be willing to engage with organisational policies and strategies designed to deliver individualised care and recognise and respect every individual's need to be treated with dignity.
- 7.2 All staff must take account of older people's sensibilities especially in relation to the gender of staff delivering intimate and/or personal care.
- 7.3 All staff must be willing to reflect on the impact of their own actions on patients' experience of dignity.
- 7.4 All staff must be aware that ageism is a societal presence and therefore present in acute Trusts. This awareness should result in an acknowledgement that the 'bread and butter' work of acute hospitals is caring for older people and they should commit to always demonstrating respect and acting to safeguard the older person's dignity.

# The PANICOA Studies and Structure of the Report

# The PANICOA Studies

In 2008, Comic Relief joined forces with the Department of Health to establish PANICOA (Prevention of Abuse and Neglect in the Institutional Care of Older Adults). The collaboration combined Comic Relief's commitment to promoting the rights of older people with the Department's work on the 'Personalisation and Quality' agenda. Currently 10 research proposals are associated with this initiative, many of which directly involve older people (some with dementia), their carers, care home staff and managers and NHS staff. This study, *Dignity in Practice: An exploration of the care of older adults in acute NHS Trusts*, is funded by the NIHR-SDO and adopted by the PANICOA programme.

### **Structure of the Report**

The report is divided into three parts

#### Part One

- Chapter 1: Sets the scene against which the study was undertaken. It describes the recent history as well as the current context and background. It highlights key aspects of the NHS and acute sector, demographic change, the health characteristics of the ageing population, existing evidence about the care of older people and the policy landscape surrounding the recent attention paid to dignity in the care of older people.
- Chapter 2: Provides a review of the literature on dignity and dignified care. The focus is primarily upon recent discussions of dignity in relation to healthcare and in relation to the care of older people in particular. It is also primarily focused upon the UK context, although it does not exclude international literature, which may be of universal significance. The discussion is divided into three sections: discussions around the concept of dignity, the empirical literature on dignity, healthcare and the older person and discussion of the potential or actual impacts upon the dignity of service users and providers.
- Chapter 3: Describes the project methodology together with an account of the challenges encountered.

#### Part Two

Chapters 4, 5 and 6 describe the major findings and cover three overarching themes identified from the data: 'Whose Interests Matter?'; 'Right Place – Wrong Patient'; and 'Seeing the Person'. These themes belie the fact that the provision of dignified care is simply a matter of encouraging one or other staff group to behave appropriately. Instead, they show that when an individual's behaviour threatens patient dignity there are often complex systemic reasons underlying this. This complexity also indicates that at times it is difficult to separate cause and effect as they are each interrelated.

The approach adopted to the presentation and discussion of the findings is from the perspective of the broader organisational factors, down through those which operate at ward level and on to those most evident at the interpersonal level.

- 'Whose Interests Matter?' This chapter explores the systemic and Chapter 4: organisational factors that influence the delivery of dignified care to older people in acute hospital Trusts. The title reflects the findings in relation to the multiple and at times competing interests of NHS Trusts at the organisational, ward and individual level and how these impact on the provision and experience of dignified care for and by older people. By recognising these conflicts of interests some of the major barriers to dignified care for older people are identified including: the concentration on 'statistical measurement' as an indication of quality; performance management and the use of targets; the impact of risk management; the ways in which staff 'work the system'; the importance of organisational culture in relation to trust, perceptions of blame and defensiveness; governance and care protocols; and ward culture including the division of labour, care as a series of tasks, staffing levels and continuity of care. The chapter closes with a discussion of the impact of these on the quality of care and how trade-offs are made when balancing the various interests.
- 'Right Place, Wrong Patient' explores a key perception expressed by many Chapter 5: staff at all levels of the organisations involved in this study: the view that the acute hospital is not the 'right place' for older people. The prevalence of this view has resulted in the physical environment, staff skills and education and organisational processes acting as barriers to delivering dignified care to older people. Environmental barriers include: the disempowering nature of acute wards which add to the disorientation experienced by many older people on admission to hospital; the concern engendered in many older people by being in close proximity to patients of the opposite gender; the boredom and dejection resulting from the loss of communal spaces and lack of activities; the environmental hazards that the acute ward presents especially for older people whose acute illness is compounded by dementia, confusion and/or delirium; as well as the frequent lack of information about personnel and ward routines. Barriers to dignified care due to deficiencies in the knowledge and experience of ward staff include a lack of attention paid to the care needs of older people in educational programmes; a lack of knowledge of the needs of people with dementia; the impact of increasing specialisation and the lack of training in relation to the provision of dignified care. In terms of organisational processes, one of the main barriers is the perpetual movement of older people both within and between hospital wards, which is a direct consequence of both Trust priorities and the view that these patients should not be there anyway.
- Chapter 6: 'Seeing the Person' explores the ways in which dignity is enhanced or denied at the level of individual interaction. Fundamental to the experience of dignity is the sense that one matters as an individual. Any situation which detracts from this has the potential to damage one's sense of dignity and selfrespect by engendering feelings of worthlessness, embarrassment,

humiliation and such like. Conversely, situations that enhance recognition of the individual impact positively on the experience of dignity. Key elements of dignified care include respectful communication; a sense of control or power over one's situation including the need for information; delivery of fundamental care including respect for privacy, nutrition, elimination and hygiene and the overall approach to patient care. Although the major focus of the chapter is on the experience of the older person, examples are given also of how relatives and staff working in acute Trusts are sometimes treated in undignified ways.

#### **Part Three**

The concluding section of the report draws together the findings from the previous three chapters.

- Chapter 7: 'Influences on Dignified Care' summarises the major findings from the study addressed in the preceding three chapters. It also discusses some complexities involved in maintaining dignity and delivering dignified care. By bringing the themes together the key factors that influence the provision of dignified care for acutely ill older people are identified. The chapter reflects upon the most significant barriers to providing dignified care, as well as identifying positive examples of acute care with illustrations of Trust strategies, care management and frontline provision that enhance and enable dignified care and which have helped inform the recommendations for change.
- Chapter 8: Discusses the conclusions and makes recommendations for change.

Pseudonyms are used throughout the report to protect the anonymity and confidentiality of all participants, hospitals and wards.

# Chapter 1: Background to the Study

# Introduction

Maintaining the dignity of older people receiving health and social care has become a subject of growing concern in recent years.

Despite the interest and increasing emphasis on dignity within UK health policy, professional codes of practice and research literature, dignity remains difficult to translate into practice, especially in older people's care (Lothian and Philip, 2001; Tadd and Bayer, 2001; Philp, 2002; Tadd, Dieppe and Bayer, 2002; Jacelon, 2002, 2003 and 2004; Walsh and Kowanko, 2002; Seedhouse and Gallagher, 2002; Woolhead, Calnan, Dieppe and Tadd, 2004; Tadd 2005a and 2005b; Tadd and Bayer, 2006; Woolhead, Tadd, Boix-Ferrer et al, 2006; Revill, Campbell and Hill, 2007; Valentine, Darby and Bonsel, 2008; Goodrich and Cornwell 2008; Patients Association, 2009, 2010; Alzheimer's Society, 2009).

Why this should be so, is not clear.

Before giving an account of the Dignity in Practice study, it is important to consider the recent history as well as the current context and background against which this work was commissioned, developed and undertaken. To do so, the following sections will briefly discuss the key aspects of the NHS and acute sector, demographic change and the health characteristics of the ageing population, existing evidence about the care of older people together with the policy landscape surrounding the drive for dignity in the care of older people.

### The NHS and the Acute Sector

The NHS in England is governed by the Constitution (DH, 2009a), which establishes guiding principles and values, the rights to which patients, public and staff are entitled and the pledges it is committed to achieve. It also details the responsibilities that the public, patients and staff have to ensure that it can operate fairly and effectively. All NHS bodies and private and third sector providers supplying NHS services are required by law to take account of the Constitution in their decision-making and activities.

The seven principles of the Constitution (a number of which reflect various components of dignity such as equality, human rights, focus on the person, choice and participation) are:

- 1. The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion or belief. It has a duty to each and every individual that it serves and must respect their human rights.
- 2. Access to NHS services is based on clinical need not an individual's ability to pay. NHS services are free of charge, except in limited circumstances sanctioned by Parliament.
- **3.** The NHS aspires to the highest standards of excellence and professionalism in the provision of high-quality care that is safe, effective and focused on patient

experience; in the planning and delivery of the clinical and other services it provides; in the people it employs and the education, training and development they receive; in the leadership and management of its organisations; and through its commitment to innovation and to the promotion and conduct of research to improve the current and future health and care of the population.

- 4. NHS services must reflect the needs and preferences of patients, their families and their carers. The NHS is an integrated system of organisations and services bound together by the principles and values now reflected in the Constitution. The NHS is committed to working jointly with local authorities and a wide range of other private, public and third sector organisations at national and local level to provide and deliver improvements in health and well-being.
- 6. The NHS is committed to providing best value for taxpayers' money and the most effective, fair and sustainable use of finite resources. Public funds for healthcare will be devoted solely to the benefit of the people that the NHS serves.
- 7. The NHS is accountable to the public, communities and patients that it serves. The NHS is a national service funded through national taxation and it is the Government which sets the framework for the NHS and which is accountable to Parliament for its operation. However, most decisions in the NHS, especially those about the treatment of individuals and the detailed organisation of services, are rightly taken by the local NHS and by patients with their clinicians. The system of responsibility and accountability for taking decisions in the NHS should be transparent and clear to the public, patients and staff. The Government will ensure that there is always a clear and up-to-date statement of NHS accountability for this purpose.

These seven principles are underpinned by six core values of which, respect and dignity is the first:

**Respect and dignity.** We value each person as an individual, respect their aspirations and commitments in life, and seek to understand their priorities, needs, abilities and limits. We take what others have to say seriously. We are honest about our point of view and what we can and cannot do.

**Commitment to quality of care.** We earn the trust placed in us by insisting on quality and striving to get the basics right every time: safety, confidentiality, professional and managerial integrity, accountability, dependable service and good communication. We welcome feedback, learn from our mistakes and build on our successes.

**Compassion.** We respond with humanity and kindness to each person's pain, distress, anxiety or need. We search for the things we can do, however small, to give comfort and relieve suffering. We find time for those we serve and work alongside. We do not wait to be asked, because we care.

**Improving Lives.** We strive to improve health and wellbeing and people's experiences of the NHS. We value excellence and professionalism wherever we find it – in the everyday things that make people's lives better as much as in clinical practice, service improvements and innovation.

**Working together for patients.** We put patients first in everything we do, by reaching out to staff, patients, carers, families, communities and professionals outside the NHS. We put the needs of patients and communities before organisational boundaries.

**Everyone Counts.** We use our resources for the benefit of the whole community and make sure nobody is excluded or left behind. We accept that some people need more help, that difficult decisions have to be taken – and that when we waste resources we waste others' opportunities. We recognise that we all have a part to play in making ourselves and our communities healthier.

In July 2010, the NHS White Paper, Equality and Excellence: Liberating the NHS (DH, 2010a) was published, which sets out an ambitious programme intended to meet the following priorities:-

- Patient centred services.
- Focus on outcomes rather than process.
- Accountability, autonomy and democratic legitimacy.
- Promote better public health.
- Reform long term social care.

Currently, the NHS in England serves a population of 51 million and employs more than 1.3 million people (NHS, 2010) dealing with one million patients every 36 hours. In terms of bed numbers, figures for 2008/09 show that there were 121,688 beds in the acute sector (Harker, 2009).

There are 167 acute NHS Trusts of which 129 have achieved Foundation status. Hospitals are managed by acute Trusts to provide high-quality and efficient care and to develop and improve services according to need.

Acute Trusts employ the greatest share of the NHS workforce including clinical, managerial and support staff. Some acute Trusts are regional or national centres for specialised services and some are affiliated to universities and help to train health professionals.

In terms of performance, for overall quality of care, 37 acute or specialist Trusts were rated as excellent in 2008/09 (down by 22 percent on the previous year), 81 were rated as good, (up by 48 percent), 43 were rated as fair, (up by 25 percent) and eight were rated as weak (CQC, 2010a).

The major concerns identified by CQC were in relation to standards for safety reporting, infections management, safeguarding and staff training with less than 50 percent of NHS staff saying they experienced good development opportunities.

The NHS in Wales serves a population of approximately three million people and employs some 91,000 people. Secondary care is provided by seven local health boards and a specialist cancer Trust. The total number of acute beds in Wales in 2009/2010 was 10,072 (wales.gov.uk).

In terms of activity, more than 600,000 inpatient and day-cases are treated each year and over 1,059,000 people are seen in Accident and Emergency per year.

Wales has the highest proportion of older people with 22 percent of the whole population aged over state pension age compared with 19 percent in the UK as a whole.

# **Population Ageing**

Facts and figures concerning the ageing of not only the UK but the world population are reported almost every day. However, the starkness of the changes and the impact on health (and social) services is worth emphasising.

A House of Commons Research Paper (Hicks & Allen 1991) cataloguing the changing statistical trends over the last century, identifies that in 1901, life expectancy for males was 45, for females 49 and only 1.3 million people were over 65 (3.4 percent). In 2009, life expectancy for males was 77 and 82 for females, with 8.1 million people over the age of 65 (16 percent) and five percent over 80 years. It is estimated that girls born in 2010 will have a 50 percent chance of living to 100 years.

At the inception of the NHS in 1948, 48 percent of people died before the age of 65, whereas today that figure has fallen to 16 percent. Also, the number of people in the UK aged 85 years or over has doubled since 1983, while the number of people aged 65 years old or over has increased by 18 percent. By 2033, it is estimated that one in five people will be over 65 years with the greatest increase being in the oldest old (Wise, 2010).

Although the population figures themselves are of great interest, what is perhaps of greater significance is the language that is used to describe this demographic shift. There is talk of the 'silver-tsunami' of increasingly ageing people putting pressure on society; (Davies, 2010), the demographic 'time-bomb' ticking ominously away (Faith, 2010); and of the baby-boomers about to bankrupt the UK (Vallely, 2010). It is in relation to health services that the impact of the growth in the numbers of older people is most gloomily represented.

The increase in longevity is seldom celebrated as an important advance in terms of public health, reduced suffering or as offering greater individual or societal opportunity. It is only when a news item of an account of successful ageing is reported that everyone wants to know the secret of the individual's successful ageing (Tadd, 2000). Instead, as earlier research (Stratton and Tadd, 2005) has shown, many people fear ageing and its consequences and as is frequently the case when something is feared, it is stereotyped and ridiculed in a number of ways. It is important therefore to gain a clear picture of what the health characteristics of this ageing population are.

### **Health Characteristics of Older People**

The 2008 Health Survey for England (Natcen, 2010) showed that one third of people over 65 reported no chronic illness, while almost two-thirds of 65 year olds reported no illness which affected or limited their lifestyle, as did 50 percent of women aged 80 years and over. This reflects the key statistics of the 2001 Census which showed that 40 percent of 65 to 74 year olds experienced 'good health' in the previous year, 37 percent experienced 'fairly good'

health and of those over 85 years, 60 percent of women and 70 percent of men experienced 'good or fairly good' health. So, the image of old age as consisting solely of ill-health and dependence is not correct, though with advancing years and certainly in what is frequently referred to as the fourth age, functional decline is common (Staehelin, 2005).

Although the transition from the third to the fourth age varies substantially between individuals (for example 50 percent of 90 year olds live in their own homes), it is recognised that advancing years bring with them an increasing number of age-related conditions, which are likely to be chronic or long-term. These conditions, which are often multiple, result in functional, sensory or cognitive impairment, increased disability and dependence and increased frailty and its associated problems, as well as increased need for specialist housing or equipment, reliance on formal, family or institutional care and the use of more than one service (Oliver, 2010).

Older people are the greatest users of health related services with those over 65 years being five times more likely to see their GP. They also account for 70 percent of hospital bed days, 60 percent of hospital admissions, 80 percent of emergency readmissions and 80 percent of hospital deaths. Older people account for half of the recent growth in emergency admissions to hospitals (CHAI 2006). Seventy percent of the health budget is spent on those aged over 65, as is 80 percent of the medicines bill (Oliver, 2010).

Of the older people admitted to acute hospitals, 60 percent will have a mental disorder (RCP, 2005). Of these, 29 percent will suffer from depression, 20 percent will suffer from delirium, 31 percent will suffer from dementia and 22 percent will suffer from cognitive impairment (RCP, 2005). The importance of these figures for acute hospitals is that mental disorder adversely affects outcomes such as mortality, length of stay and future institutionalisation. Thus, older people make up the greatest proportion of users of acute NHS services and despite the physical condition(s), which may have brought them into hospital, more than half will have either an acute or chronic mental health problem.

# The Care of Older People in the NHS

### **Policy Developments**

Improving the standard of hospital care for older people in acute care became the centre of public attention in 1997. Through a series of articles in The Observer newspaper, Martin Bright, a journalist, launched the 'Dignity on the Ward' campaign when he wrote a moving series of accounts of the treatment his 88 year old grandmother received when she was admitted to hospital following a stroke. He wrote:

*"It's hard to believe just how grim our hospitals have become until you have personal experience of their collapse."* 

Older people, their relatives and their carers added their voices to the campaign and many spoke of their negative experiences of care. The government responded by commissioning an independent report from the Health Advisory Service, 'Not Because They Are Old' (HAS, 1998) which identified poor standards of care and a lack of dignity in the care of older people

on acute wards. Similar concerns were further evidenced in a survey on the views of older people on hospital care (Help the Aged, 1999).

This was followed by an investigation into the nursing care of older people by the Standing Nursing and Midwifery Advisory Committee in 1999. Their report, 'Caring for Older People: a nursing priority' published in 2001, found 'major deficits' in the standards of nursing care given to older patients in acute hospitals, with some of their most fundamental needs remaining unmet (SNMAC, 2001: iii). The report emphasised nurses' responsibilities, stating that these should not be shifted onto less qualified staff: 'Too many nurses regard fundamental skills such as bathing, dressing and assisting patients with feeding as tasks that can be delegated to healthcare assistants, often without supervision...qualified nurses should continue to be involved in the delivery of essential care' (SNMAC, 2001:13). The committee also published a guide to best practice in nursing older people, 'Practice Guidance: Principles, Standards and Indicators' (SNMAC, 2001).

'The NHS Plan: A Plan for Investment, a Plan for Reform' (DH, 2000) highlighted that older people make up for the largest single group of patients using the NHS, with people over 65 accounting for two-thirds of hospital patients and 40 percent of all emergency admissions. The importance of dignity, security and independence in old age was emphasised, as was the need to treat all patients (as well as NHS staff) as individuals with full respect for their dignity. A whole chapter was devoted to older people under the heading of, 'Dignity, Security and Independence in Old Age' and this made clear the expectation that the NHS would recognise the need to 'treat the person, not just the most acute symptoms', paying attention to aspects of care like nutrition and helping the older person with mobility. Age discrimination would no longer be tolerated in the NHS and there would be 'better and new services' for old people.

These early campaigns and reports resulted in the establishment of a National Service Framework for Older People, which was published in 2001 (DH, 2001a). The framework outlined a comprehensive strategy to ensure fair, high quality, integrated health and social care services for older people. It proposed a '10 year programme of action linking services to support independence and promote good health, specialised services for key conditions, and cultural change so that all older people and their carers are always treated with respect, dignity and fairness.' Standard Two of the framework, titled 'Person-centred care' requires managers and professionals to listen to older people, respect their dignity and privacy and recognise individual differences and specific needs, while Standard Four relating to general hospital care stated: 'Older people's care in hospital is delivered through appropriate specialist care and by hospital staff who have the right set of skills to meet their needs' (DH, 2001a:51).

'Standards for Better Health' published in 2004 (DH, 2004a), established the core and developmental standards covering NHS healthcare provided for NHS patients in England, including the need for healthcare organisations 'to have systems in place to ensure that staff treat patients, their relatives and carers with dignity and respect.'

'A New Ambition for Old Age: Next steps in implementing the National Service Framework for Older People' (DH, 2006a), identified dignity in care as one of the priorities for the second phase of the framework. It included clear priorities for improving services caring for older people with complex needs and for improving dignity both in care and at the end of life.

'The Essence of Care: Patient-focused benchmarking for health care practitioners' (DH, 2001b) 'focused on core and essential aspects of care that matter to patients and carers.' Following a consultation exercise in 2009, 'Essence of Care' has been updated (DH, 2010b) and now contains 12 benchmarks, including a specific module titled 'respect and dignity' (previously 'privacy and dignity'). The factors and indicators for this benchmark are:

Factors	Indicators
1. Attitudes and behaviours	People and carers feel that they matter all of the time.
2. Personal world and personal identity	People experience care in an environment that encompasses their values, beliefs and personal relationships.
3. Personal boundaries and space	People's personal space is protected by staff.
4. Communication	People and carers experience effective communication with staff, which respects their individuality.
5. Privacy – confidentiality	People experience care that maintains their confidentiality.
6. Privacy, dignity and modesty	People's care ensures their privacy and dignity, and protects their modesty.
7. Privacy – private area	People and carers can access an area that safely provides privacy.

The benchmarking process outlined in 'Essence of Care 2010' aims to identify best practice and to assist Trusts to develop action plans to remedy that which is poor.

In parallel with the publication of policy documents (2006a), the Department of Health launched its 'Dignity in Care' campaign, 'to put dignity at the heart of care' in (2006b). This included a dignity challenge that clearly stated what people could expect from high quality care services that respect people's dignity. These should:-

- have a zero tolerance of all forms of abuse.
- support people with the same respect you want for yourself or a member of your family.
- treat each person as an individual by offering a personalised service.
- enable people to maintain the maximum possible level of independence, choice and control.
- listen and support people to express their needs and wants.
- respect people's right to privacy.
- ensure people feel able to complain without fear of retribution.
- engage with family members and carers as care partners.
- assist people to maintain confidence and a positive self-esteem.
- act to alleviate people's loneliness and isolation.

The 'Dignity in Care' campaign (2006b) was backed up by dignity 'tests', promoted by local dignity champions and led for a year by a high profile dignity ambassador. A variety of resources were developed including a toolkit, good practice framework and a web-based

'Dignity in Practice SCIE Guide', all with the aim of raising the profile of dignity in care and promoting service improvement in local areas.

More recently, dignity and respect have attracted further attention as a central pillar of high quality healthcare delivery in the NHS, especially in relation to the management of older people. The importance of prioritising dignity in healthcare provision has been given strong support by its inclusion in key national performance indicators, the NHS Operating Framework (DH/NHS, 2009) and greater prominence in health and social care regulatory inspections.

In Wales, policy in relation to dignified care has been somewhat less developed than in England although dignity is recognised as an essential factor in ensuring good health, wellbeing and independence and as a key component of high quality care. As one of the five United Nations Principles for Older People (UN, 1991), dignity was highlighted as a key principle underpinning both the Strategy for Older People (WAG, 2003a) and the National Service Framework for Older People in Wales (2006). It is also an issue that in law the Commissioner for Older People in Wales must have regard to in undertaking their role.

In January 2007 in Wales, the Deputy Minister for Health and Social Services launched a national debate on dignity in care and called for positive and practical ideas on how Wales should follow the English example to improve dignity for older people in Wales. This resulted in wide-ranging comments from a variety of stakeholders including older people's forums, which included:

- ensuring basic quality of care is delivered consistently.
- improving communication skills of staff.
- listening to older people, putting them first.
- robust inspection of services.
- service models that promote independence not dependence.
- adequate resources and staffing/provision of services.
- improving the legal framework for protecting vulnerable people.

Other policy guidance also covered dignity and respect, including the 'National Minimum Standards for Care Homes and Domiciliary Care' (WAG, 2004) and the 'Fundamentals of Care' (WAG, 2003b) that set out the standards of care expected in broad terms. A common framework of healthcare standards to support the NHS in providing effective, timely and quality services across all healthcare settings was published in May 2005 (WAG).

In Wales, the seven health boards have both leadership and performance/delivery responsibilities to ensure that hospital and primary care services respect patient dignity. Joint commissioning and contract monitoring by both the NHS and local authorities (LA) are intended to play important roles in ensuring better standards. Health Inspectorate Wales (HIW) assess organisational compliance against the Healthcare Standards for Wales, while the Care and Social Services Inspectorate in Wales (CSSIW) undertake a similar role for social care. Through its role as workforce regulator, the Care Council for Wales (CCW) also addresses dignity in social care through training and staff development frameworks.

On October 1<sup>st</sup> 2007, the Deputy Minister for Health and Social Services announced a 'Dignity and Respect in Care' programme for Wales, which included holding a series of regional events to raise awareness and understanding of the key principles underpinning dignity. Copies of the multidisciplinary workbook on dignity developed in an EU funded study titled 'Dignity and Older Europeans' (Tadd, 2005c) were distributed to all NHS Trusts together with a range of other resources including small start up grants to kick-start work on dignity. Part of this programme included the establishment of a National Dignity in Care Co-ordinating Group to offer advice on the implementation of a three year programme.

In addition to policy development in relation to promoting dignity and respect in the care of older people, other organisations and professional bodies have also launched high profile campaigns. The British Geriatrics Society (BG), together with several other organisations, launched the 'Behind Closed Doors' campaign in 2006 (BGS, 2006). This emphasised the importance of patients being able to use the toilet in private in all care settings.

#### Other Drivers for Dignity

The Royal College of Nursing (RCN) has also held a campaign on dignity as 'the essence of nursing care and at the heart of everything nurses do as a profession.' The college directly emailed 70,000 of its members with a survey on dignity in care resulting in a report, 'Defending Dignity' (RCN, 2008). and the campaign 'Dignity: at the heart of everything we do'. The campaign 'products' were based on only 2,047 responses to the survey, which is less than three percent of the membership. The RCN campaign encourages the nursing workforce to prioritise dignity in care, centring on three integral aspects: respect, compassion and sensitivity.

The Nursing and Midwifery Council (NMC) has also published a document entitled, 'Guidance for the care of older people' (NMC, 2009) which sets out the principles to enable nurses to think through the issues and apply professional expertise and judgement in the best interests of older people in their care.

The question that automatically follows from this thrust of policy development, campaigns and publications is whether or not the situation has improved so that older people are treated with dignity and respect when experiencing NHS care? Evidence relating to this is discussed below.

# Are Older People in Hospital Treated With Dignity?

In 2007, the Healthcare Commission (CHAI) published a national report on dignity in care for older people while in hospital (CHAI, 2007a). This report was a review of 23 acute Trusts and found that standards in relation to privacy and dignity were most likely not to be met. As well as emphasising the importance of meeting dignity standards, especially those related to privacy, eating and drinking, it set out recommendations to hospital Trusts, health authorities, voluntary organisations and policy makers for action to improve the care and overall experience of older people in hospitals.

A common belief is that the current generation of older people are reluctant to complain. This is because those who are in their 70s experienced healthcare before the advent of the NHS. Consequently, they are more grateful and forgiving as, even with significant inadequacies, the NHS is a vast improvement on what existed before (Cornwell and Gearing, 1989).

Claims that in old age, the baby-boomers will be more critical and demanding of the healthcare than the previous generation (Huber & Skidmore 2003) are yet to be substantiated. It is thought that this group will be more vociferous and demanding, less likely to accept substandard care or facilities and wish to be consulted more about their care and treatment. In other words, the positive association between satisfaction with healthcare and age is based on a cohort effect rather than an age effect. In their investigation of this claim, Calnan et al (2003) suggest that an analysis of trends from the British Social Attitudes surveys from 1983 until 1999 provides little evidence to support such a view.

The latest British Social Attitudes survey (Natcen, 2010) found that the public are more satisfied with the NHS than at any time since 1984. Overall, 51 percent of people said they were satisfied with the NHS, compared with 34 percent in 1997 and 42 percent in 2000 when implementation of the Health Service reforms discussed above began. Dissatisfaction with the NHS fell from 50 percent in 1997 to 30 percent, which is the lowest level since 1984. General practice scored highest with 76 percent satisfaction, hospital outpatients scored 60 percent whilst inpatient care scored 49 percent. Individuals with recent personal experience of the NHS were more likely to express greater satisfaction than those whose comments relied solely on impressions from the media or from third party accounts.

Clearly, inpatient satisfaction scores may be very different from those of the general public which, until now, have indicated increasing levels of dissatisfaction over the long-term (Calnan et al, 2003).

Evidence of inpatient satisfaction is collected annually by the Care Quality Commission (CQC) which is the independent regulator for health and social care. The Commission's National Survey of Adult Inpatients (2010b) involved 72,000 people who were admitted to hospital in summer 2008. It highlighted that more patients rated hospital wards and bathrooms as 'very clean' compared to previous years, there was less use of mixed sex facilities and more of them had noticed doctors and nurses washing their hands between patients. Less positive findings were in relation to hospital food and information as approximately one tenth said that they were not told about the purpose of their take-home medication in a way they could understand and almost 50 percent were not told about the side-effects of their medication. Although this survey was undertaken across all age groups, older people comprised a considerable proportion of the sample as 40 percent of respondents were aged between 50 and 65.

Other evidence about the quality of care received by older people can be drawn from a variety of sources. The study Dignity and Older Europeans (Tadd 2005a;b) involved over 400 older people in focus group interviews and identified that they found it easier to recount their experiences of undignified care than those of dignified care.

One of the most influential accounts of the care of older people is the Eighteenth Report of the Joint Committee on Human Rights (JCHR, 2007). The Committee acknowledged that much of the evidence described excellent care experienced by many older people. However, they also reported that:-

"[M]any witnesses, including the inspectorates, providers and organisations supporting older people, expressed concern about continuing poor treatment of older people in health care."

Their principal concerns related to the following abuses of human rights:

- Malnutrition and dehydration (Articles 2, 3 and 8)
- Abuse and rough treatment (Articles 3 and 8)
- Lack of privacy in mixed sex wards (Article 8)
- Lack of dignity especially for personal care needs (Article 8)
- Insufficient attention paid to confidentiality (Article 8)
- Neglect, carelessness and poor hygiene (Articles 3 and 8)
- Inappropriate medication and use of physical restraint (Article 8)
- Inadequate assessment of a person's need (Articles 2, 3 and 8)
- Too hasty discharge from hospital (Article 8)
- Bullying, patronising and infantilising attitudes towards older people (Articles 3 and 8)
- Discriminatory treatment of patients and care home residents on grounds of age, disability and race (Article 14)
- Communication difficulties, particularly for people with dementia or people who cannot speak English (Articles 8 and 14)
- Fear among older people of making complaints (Article 8) (JCHR, 2007)

Further accounts of the quality of care of older people can be found in 'Patients not Numbers, People not Statistics', a report by the Patients Association, (PA, 2009) which describes a number of cases of inadequate inpatient care and the inadequacies of the NHS complaint system.

Age Concern first evidenced concerns about the malnutrition of older people in hospital in its report, 'Hungry to be Heard' (2006). A recent follow-up to that report 'Still Hungry to be Heard' (Age UK, 2010) shows that little improvement has been made and that:

- around 175,000 patients enter hospital malnourished and 185,000 leave malnourished. More than two thirds of nurses admit that hospitals do not ensure vulnerable patients receive the help they need to prevent malnutrition.
- one third of nurses admit they wouldn't trust the hospital to address a relative's malnutrition.
- around half of older people are not adequately screened for nutritional risk.
- around half have inadequate documentation of nutritional intake and support.

A high profile account of people (most of whom were older people) not being treated with dignity can be found in the report of the independent inquiry chaired by Robert Francis QC (DH 2010c). The reports states that the most alarming cases included, '…incontinent patients left in degrading conditions; patients left inadequately dressed in full view of passers-by; patients moved and handled in unsympathetic and unskilled ways, causing pain and distress; failures to refer to patients by name, or by their preferred name; and rudeness or hostility.' Francis goes on to state that '[H]owever difficult the circumstances, there is no excuse for

staff to treat patients in the manner described by some witnesses to the Inquiry. Respect for dignity must be a priority of care and must be at the forefront of clinicians' minds' (p.13).

Most recently a report by the National Patient Enquiry into Outcome and Death (NCEPOD), (2010) has highlighted that hospital care for two thirds of those over 80 years who had had surgery within the previous 30 days was inadequate. Geriatric specialists were not routinely involved, surgery was often delayed and lack of pain monitoring and relief was common despite its negative impact on cardiovascular recovery. Poor fluid intake and inadequate nutrition compounded the poor outcomes.

The situation for people with dementia has also been documented in a number of high profile reports (RCP, 2005; Alzheimer's Society, 2007; NAO, 2007; Alzheimer's Society, 2009; APPG, 2009; House of Commons, 2010). Variously these reports have documented concerns about the care given to older people with dementia who also have an acute condition. This group constitutes approximately 25 percent of the acute hospital inpatient population. With such a high proportion of patients with dementia, it is not surprising that 97 percent of the nursing workforce and managers stated that they are usually caring for someone with dementia and yet, despite this, basic training for managing people with this condition is lacking.

The main concerns highlighted in the above reports are that people with dementia remain in hospital longer, their outcomes are worse and on discharge they are more likely to be admitted to long-term care.

Particular risks include:-

- malnutrition and dehydration.
- inadequate pain relief.
- over sedation with antipsychotic medication.
- poor end of life care.
- a lack of dignity and respect.
- limited social interaction.
- poor involvement of the person or their families in decision-making regarding care.

To address these concerns and plan for the growing number of people with dementia in the coming years, the National Dementia Strategy was launched in February 2009, (DH, 2009b). According to the conclusions of the House of Commons Committee of Public Accounts (HCCPA, 2010), implementation of the strategy has been at best patchy and little has changed in the quality of care experienced by people with dementia.

From the foregoing, one can only conclude that despite there being some excellent care afforded to older people, there is some way to go before all older people receive high quality care, which respects their dignity.

Why the care afforded to some people is inappropriate or of a poor standard is likely to be complex, involving organisational, economic as well as individual factors, but ageist attitudes amongst certain staff can not be entirely dismissed. The use of derogatory language about older people has been creeping into healthcare in recent years, terms such as 'bed-blockers', 'frequent fliers' and 'acopia' are all examples of terms which emphasise the problematic aspects of older people's care by ascribing negative attributes to the older person themselves, rather than shortcomings in the design and delivery of appropriate services and care.

A retrospective study of the medical records of patients who were triaged in an Accident and Emergency department with 'acopia' as their presenting complaint, was undertaken over a fifteen month period between January 2005 and March 2006 (Kee and Rippingale, 2009). A total of 93 records were identified and of these 81 were retrieved. Of these, almost 94 percent of patients were aged over 65 with the median age being 85 years. Of these patients, only five had no active medical problems and 22 percent died. The majority had at least one co-morbid condition and over 12 percent of the patients had three or more such conditions.

The range of discharge diagnoses of these patients were as follows:-

- Sepsis 29%
- Malignancy 5%
- Depression 13%
- Dementia 13%
- Delirium 15%
- Renal Failure 7%
- Fracture 5%
- Fall 8%
- latrogenic 9%

Clearly, the use of such language can mean that urgent medical conditions are missed. Such language is also inappropriate, unprofessional and can lead to 'therapeutic nihilism', which would not be tolerated if applied to younger age groups (Oliver, 2008).

In nursing, a number of claims have been made that care and caring have been eroded (Maben and Griffiths, 2008; Corbin, 2008). This is also reflected in media reports and blogs that portray hospital staff and nurses in particular as uncaring and cavalier about respecting people's dignity. These reports often imply that this is a result of the change in nurse education that took place in the early 1990s and resulted in programmes moving into the higher education sector. But, such criticisms are too simplistic and there is little evidence to support the view that there was once a golden era of nursing in which dignity was centre stage.

Certainly, there have been significant changes over the past 50 years. One of the authors of this report's own personal experience of hospital care in the 1960s was not necessarily one of patients always being treated with dignity: Nightingale wards; back rounds; toilet rounds; precision bed-making; disdainful treatment by medical and senior staff; not to mention lying about unpleasant diagnoses. Such practices could hardly be described as dignified and are also echoed in other accounts (see also Hay, 1964; McSherry, 2010).

At that time, patients in acute care tended to be less frail and dependent (other than due to their presenting illness) as average life expectancy was shorter and patients tended to have

only one illness. Patients remained on the ward for longer. For example, length of stay following a cholecystectomy was in excess of 22 days; haemorrhoidectomy was 10 days; a fractured arm was four days; cataract surgery 10 days; coronary thrombosis 30 days; and hypertension 27 days (Forsyth and Logan, 1960). This meant that nurses had greater opportunities to come to know the person. Each ward usually had only one or two consultant teams, the ward sister was responsible for everything that happened on the ward, nurses had more time to spend in direct patient care as there was less paperwork, less pressure on beds, less technology and people's expectations of healthcare were not as high (http::www.nhshistory.net).

Nor, are nursing and healthcare enacted in a social or political vacuum. During the early 1980s a new breed of managers was recruited following the report of a management team appointed to investigate ways of improving the cost-effectiveness and efficiency of the NHS (Griffiths, 1983). The language of the new managerialism included terms such as consumer needs, consumer satisfaction, efficiency, productivity and measured outcomes. Together with a real reduction in beds and the loss of long stay elderly medical provision, nursing practice was pigeon-holed into measurable categories as part of newly introduced workload systems and categorisation of patients by degrees of dependence (Tadd, 1995). Certain elements of nursing that are highly valued by patients but not highly visible, such as emotional care and engaging in conversation, were largely disregarded by these workload studies.

Similarly, the caring role became disjointed so that patient care was broken down into its constituent parts with some allocated to healthcare support workers while other elements were assigned to housekeeping staff, such as aspects of nutrition. This resulted in fragmentation and loss of control of patient care as a 'holistic' venture. The ward sister's role changed into one of ward manager and housekeeping services were no longer under his/her direct control.

Over the ensuing years, these developments have gathered apace with the 'neoliberal' health reforms characterised by an emphasis on economic efficiency and rationalised services (Jacobson, 2010: 1545). Performance targets, throughputs, outputs, viewing people as units of activity and care as a series of episodes, especially when coupled with budgetary restraints, all militate against dignified care. It becomes easier to objectify people, seeing them as entities to do things to rather than as individual with needs. There is much evidence that such mechanistic ways of working affect how individuals perceive their moral role and agency (Tadd, 1995). The loss of control and increasing role fragmentation make it difficult to retain a sense of responsibility for the whole and this may be one reason to explain the growing call for those qualities that denote humanity (dignity, respect, compassion, empathy, kindness, person-centred approaches and such like) within the realms of healthcare. It is unlikely, therefore, that the failure to provide dignified care will be remedied by simply challenging individual health professionals to 'care more'.

# Chapter 2: Dignity and the Older Person: A Review of the Literature

# Introduction

The body of literature that addresses the concept and practice of dignity is broad, complex and rapidly evolving. Dignity has emerged as a topic of engaging and lively discussion, both within and across various academic disciplines such as philosophy, bioethics, nursing, medicine, social science and public policy.

Discussions of dignity in the context of the health, wellbeing and care of the older person have also attracted increased academic attention in recent years. This is partly as a result of growing awareness within academic, clinical and policy circles of rapidly changing population demographics. Average life expectancy, for instance, continues to climb: 'In England and Wales, life expectancy at birth in 1901 was 45.0 years for men and 48.8 for women. By 1951 this had increased to 65.7 and 70.7 years respectively. Life expectancy at birth has continued to improve steadily, reaching 76.2 (male) and 80.7 (female) years for 2001-03 in England Wales' (Tomassini, 2005, p.3). The proportion of the population made up by those over 50 is also increasing: 'In 1951, those aged 50-59 represented 43.0 percent, and those aged 85 and over made up just 1.6 percent of the 50 and over population total. In 2003, the two age groups represented 37.8 percent and 5.5 percent respectively of the older population' (Tomassini, 2005, p.3).

Such changes are set to continue: by 2031, a 77 percent increase is expected in the UK population aged 75 and over (Wise, 2010). This altered social landscape presents a particular challenge to the NHS: older people have been identified as being the heaviest users of the healthcare system (DH, 2008a) and concerns over the potential impact such changes will have, upon both service users and providers, continue to grow. A large body of academic literature has arisen in response to this and one of the most significant areas of concern that has emerged is the impact on patient dignity that it is thought these extra stresses upon the healthcare system may involve. As a large, vulnerable and ever-increasing population, the dignity of older people, most of all, is now at the forefront of concern.

# Search Strategy

In order to generate contextual information for this project, a broad literature review focusing on the central themes and research questions was first conducted. Data were retrieved using searches of large-scale academic databases (Philosopher's Index, Pubmed, Scopus, CINHAL and Ovid), with individual searches using various combinations of the terms, *elderly, older people, geriatric care, acute care, dignity, dignified care and concept of dignity* being conducted. A large amount and broad range of written material was retrieved using this method. Approximately 1,460 potentially relevant sources were identified. These consisted of peer-reviewed journal articles with additional reports from UK government charities and the media also being identified. The dates of publication for the more empirical/clinically-focused material ranged from 1990-2010 and 1974-2010 for the philosophical/bioethically-focused material.

In order to reduce the size and scope of this large data set, certain exclusions were made and areas of particular thematic relevance were identified. To ensure that the literature

remained relevant in light of changing clinical practice/public policy contexts, empirical/clinically focused material that was published prior to 2000 was excluded and material that was published in more recent years (2005 onwards) was given greater weight of consideration as this was after the Dignity and Older Europeans study which produced a large database of literature concerning dignity and older people. Material that was published around topics that were of peripheral interest to the current research questions (such as palliative care, patient grief and research ethics) were also excluded. Empirical/clinically focused material that centred on dignity and acute care, or the impacts on service provision were also given priority, as was philosophical/bioethically-focused material on the concept of dignity.

The number of articles left in the data set was reduced to approximately 450 after this targeted filtering process. Abstracts were closely analysed for the relevance of content, and those articles that were identified as being most relevant to the central research questions were selected for in-depth critical analysis.

Within this discussion of the literature on dignity, the focus is primarily upon discussions of dignity in relation to acute care generally and in relation to the care of older people in particular. It is also primarily based upon the UK context, although it does not exclude international literature, which may be of universal significance.

The discussion is divided into three sections: discussions around the concept of dignity; the empirical literature on dignity, healthcare and the older person; and discussion of potential or actual impacts upon the dignity of service users and providers. Certain significant themes such as dementia and Alzheimer's care, palliative care and the moving and relocation or 'perpetual motion' of older patients tend to emerge across all these areas of discussion.

# **Dignity and its Meaning**

Several analyses of dignity and reviews of the literature on dignity have been published in recent years (Jacelon et al, 2004; Jacobson, 2007; Anderberg et al, 2007; Griffin-Heslin, 2005; Johnson, 1998; Coventry, 2006; Fenton and Mitchell, 2002; Gallagher et al, 2008; Bridges et al, 2009). Before embarking on this review, it is useful to note themes of recurrent interest across this body of work.

Within the review and conceptual analysis literature, dignity is identified as being of central concern to discussions of healthcare and it is generally recognised that literature relevant to discussions of dignity originates from diverse fields of enquiry, including empirical interview-based studies, clinical ethics, professional practice, bioethics and bio-law as well as global ethics and discussions of universal human rights (Jacobson, 2007). The vague, ambiguous and difficult-to-measure nature of dignity is identified as being key to debates of dignity in healthcare (Griffin-Heslin, 2005) and the relevance of staff behaviour to dignified care is underlined (Gallagher et al, 2008; Baillie, 2008) as is the need for individual approaches if dignified care is to be achieved (Anderberg et al, 2007; Bridges et al, 2009).

Some reviews suggest that, once subject to critical analysis, the concept of dignity as it relates to healthcare and older people consists of component and related concepts such as privacy, autonomy, respect or self-identity.

# The Concept of Dignity

Despite being the central focus of much deliberation, public policy documents and high profile public service campaigns, a clear concise definition of the concept of dignity remains elusive. Dignity is a complex concept that has a long history of philosophical enquiry and which continues to attract much theoretical attention, especially in philosophical, bioethical and social-scientific literature. However, it remains an essentially contested concept (Gallie, 1956). Thus, although there is one concept of dignity, there are many conceptions of what this entails.

There is much discussion of whether moral concepts such as dignity can be said to consist in objective truth, or whether a morally relativist position is more suitable, and this has an impact upon any discussion of dignity. Whilst it is not within the scope of this discussion to analyse debates over the ontological foundations of moral concepts, it ought to be noted that this ongoing debate has an impact on discussions of the concept of dignity. Below, we discuss some of the major recent contributions to the debate on dignity and summarise the position of the debate as it now stands.

Lennart Nordenfelt has contributed greatly to contemporary discussions of dignity in general (Nordenfelt, 2002; Nordenfelt, 2004; Nordenfelt and Edgar, 2005), as well as dignity in the context of older people's care (Nordenfelt, 2003). His comprehensive analysis divides dignity into four distinct types: the dignity of merit, the dignity of moral stature, the dignity of identity and universal human dignity (referred to by the German word Menschenwürde). This recasting of dignity as consisting in several types, is a practical and useful response to the complexity and richness of the concept as it allows for the inclusion of many different contextual and practically-informed interpretations of dignity.

Of Nordenfelt's four types, Menschenwürde or human dignity, is distinct in that it necessarily pertains to all humans, and cannot be lost as it is an essential component of being human. Whilst the validity of claims such as this, which relate to the existence of objective foundations for moral concepts, are subject to a great deal of criticism, this particular conceptualisation of dignity is practically important in healthcare generally as it is upon such assumptions that the clinical commitment to providing equal treatment for everyone, regardless of social, economic, political or cultural factors, is built.

Whilst the existence of Menschenwürde is a given and is not contingent upon experience, each of Nordenfelt's other types of dignity are subjective and dependent upon external influences. They exist by degrees and can be lost or altered in response to an individual's practical, lived experience. Nordenfelt's 'dignity of identity' is of the most relevance to discussion of dignity in relation to the care of older persons. He tentatively defines it as 'the dignity that we attach to ourselves as integrated and autonomous persons, persons with a history and persons with a future' (Nordenfelt, 2004, p.75), and he maintains that it is this type of dignity that is most important in the context of illness and ageing. It is in the exploration of this kind of dignity that Nordenfelt's four-fold typology of dignity has a tangible impact upon discussions around the provision of care for older people.

Unlike Menschenwürde, dignity of identity can be taken from the individual; it can be diminished by the acts of others, by external events and particularly by injury, illness and old age. It is very closely linked to common notions of self-respect and our biographical conception of the self. It concerns our autonomy, our history, and our future, as well as our relationships with others. Humiliation in particular diminishes the dignity of identity and Nordenfelt notes that an individual's self-respect can 'easily be shattered' (Nordenfelt, 2004, p.75) via the cruel or thoughtless acts of other people. Older persons who are in a position of dependence when requiring health and social care are particularly vulnerable to loss of dignity via humiliation and acts of social exclusion, physical and psychological abuse or neglect and invasion of privacy are of particular concern.

Nordenfelt tries to demonstrate that the dignity of identity is not confined to being a psychological concept, or to being a subjective measure of self-worth. Instead, he connects it directly to autonomy and integrity, and suggests that often, dignity of identity is diminished because someone is socially marginalised or physically 'prevented from doing what he or she wants to or is entitled to do' (Nordenfelt, 2004, p.76). This loss of dignity is common to the experience of many older people, as they are among those who are most likely to suffer permanent debilitation, illness or injury and Nordenfelt points out that when an individual 'believes or knows that he or she will remain disabled for the rest of life' (Nordenfelt, 2004, p.76) their identity is often drastically and permanently altered in response.

In a response to Nordenfelt's work, Andrew Edgar challenges the assumption that humiliation is necessarily linked to the experience of illness or injury (Edgar, 2004). He points out that there is 'nothing self-evidently humiliating about any physical injury or disability' (Edgar, 2004, p.87). Rather, what leads to humiliation is the unjust or cruel treatment of individuals. He agrees with Nordenfelt, that it is the response of others to an individual's physical or mental state, which affects their dignity or identity. For example, when a vulnerable older patient is ignored, has their privacy invaded, or is physically or psychologically harmed by those who have a duty to care, humiliation occurs. Edgar underlines, however, that this response is not a given, as humiliation is very much contingent upon social and cultural factors.

Edgar here, provides a useful analysis of how the concept of dignity relates to healthcare. He shows that whilst respect for the dignity of identity ought to be at the forefront of care provision, humiliation and indignity are not unavoidable results of illness, injury or permanent vulnerability. Unfortunately, he notes elsewhere that '[M]odern social institutions that are structured by various forms of ageism can cut the elderly out of communication' (Edgar, 2003, p.120). Here, he suggests that institutional change, as well as change in the treatment of older persons, is necessary if humiliation is to be avoided and the dignity of identity is to be respected.

Matti Häyry (2004) puts forward another perspective on dignity, which deals directly with its complexity and broad scope for application. In a paper focusing on recent discussions of dignity in the field of bioethics, Häyry suggests that there are multiple valid and useful ways of looking at the concept. He believes that each interpretation ought to be valued for its own plausibility and that no one definition ought to trump others or dominate the debate. He points out that the resurgence of interest in dignity is a reaction to the perceived dominance of American principlism in bioethics. For him, talk of dignity offers a more

flexible and contextual framework for bioethical analysis. His analysis can shed light on how dignity ought to be used in relation to the provision of healthcare. He argues that a simple definition of dignity, however appealing as it may seem in practice, is not sufficient to capture the true depth and breadth of meaning that dignity holds. If narrow limits are placed on the discussion of the concept, constructive debate is hampered.

Häyry is clear that we ought to be very wary of those who 'seek to monopolise use of the term and insist that those who understand it differently should not use it' (Häyry, 2004, p.11). Instead, we ought to foster discussions between those who use the term dignity in different ways. In the context of older people's care, this would entail seeking the opinion of and listening to service users, service providers, policy makers and other stakeholders. Despite being primarily concerned with bioethics, Häyry's assertion that by encouraging debate and dialogue we can arrive at a richer understanding of what dignity means is both constructive and practically applicable.

During the course of a broad argument against moral relativism in clinical ethics, Edmund Pellegrino claims that the duty of physicians to protect the patient's dignity is an unquestionable and an essential moral absolute (Pellegrino, 2005). The protection of dignity is established as a subsidiary absolute, which emerges via full consideration of the implications of the primary moral absolute in clinical ethics to 'do good and avoid evil'. Pellegrino claims that illness is an essential element of human experience referring to it as a 'predicament no mortal can escape' (Pellegrino, 2005, p.474). He provides a simple and clear definition of the patient as someone who is suffering, who exists in an altered existential state and who is dependent and vulnerable.

Formal entry into the patient-physician relationship occurs when professional help is sought, which necessarily involves the physician promising knowledge and skill to be used primarily in the best interests of that patient. The moral end of clinical medicine is the good of a particular patient. Pellegrino claims that respecting and protecting patient dignity is an essential component of this practical and moral project. In defence of his thesis, he points out that respect for dignity has a long-standing history in moral philosophy, functioning as a foundation for many other moral absolutes.

Whilst he acknowledges that the primary and relevance of dignity as a moral concept has been contested in recent years (Macklin, 2003) Pellegrino claims that alternative foundational concepts, such as autonomy, are not sufficient. He also distinguishes between two types of dignity: inherent; and imputed. This step results in a weakness in his argument as he attempts to establish objective foundations for inherent dignity, by claiming that this is a moral absolute and (like Nordenfelt's Menschenwürde) an essential feature of human experience because it is fixed by 'Divine or natural law' (Pellegrino, 2005, p.478). The validity of this type of quasi-religious reasoning is particularly vulnerable to criticism and his argument loses some of its persuasive power.

Imputed dignity is established as being a perception, rather than an essential feature of moral life. It does not hold the unshakable connection to moral reasoning that inherent dignity supposedly has, but in the context of practical reasoning on dignity and older people, it is a more useful concept. Imputed dignity is that which can be lost, robbed or deprived. Those who are imputed with little or no dignity are the most vulnerable members of society as they can be 'deprived of their lives when they are a burden, used for experimental

purposes or discriminated against when they compete for justice' (Pellegrino, 2005, p.479). It is with concerns such as these, voiced throughout the empirical and policy-based literature on dignity and older people, that Pellegrino's work can make a valuable contribution.

In a contrasting paper, Michael H. Kottow claims that dignity, along with vulnerability and integrity ought not to be counted as normative moral principles. Instead they should be re-conceptualised as anthropological descriptions of shared human experience (Kottow, 2004). Whilst this may seem to weaken the case for placing dignity as central to an understanding of morality in clinical ethics, Kottow's particular relativistic approach does not entail rejection of these concepts as a basis for moral reasoning and action. He claims that vulnerability, integrity and dignity are concepts 'fundamental enough to inspire bioethical requirements of protection and human rights in the wake of social justice' (Kottow, 2004, p.281). They each carry sufficient moral weight to function as a foundation for deontic or duty based moral theories, which establish tangible rights and duties. They can, in this way, help to constitute and support public health policies and human rights declarations.

Dignity here is again explicitly linked to health and disease as the 'courageous defiance and uprightness' (Kottow, p.284) that is displayed in the face of endangered existence or death. Kottow makes it clear that the presence of disease does not automatically entail a lack of dignity, rather, it changes the character of dignity, as 'suffering and incapacity are experienced with tolerance, patience and when not removable, with resignation' (Kottow, p.285). The advantage of supporting a deontic theory, which weighs harm and benefits, is that specific, practical and social action can be demanded when the vulnerability, integrity or dignity of an individual is negatively affected.

Milton (2008) brings together theoretical understandings of dignity and considers their implications for healthcare practice. From a biomedical perspective, human dignity applies to all individuals so that loss of capabilities does not necessarily imply a loss to a person's dignity. Dignity that is attached to identity and self-respect, where self respect can be shattered, implies that a sense of dignity can be taken from someone as a result of events or the actions of others as well as by injury, illness and old age. Thus when healthcare professionals are asked about upholding dignity, they often refer to vulnerable groups such as the elderly and the very young.

"From this philosophical view, certain actions may affirm a sense of dignity, while other chosen actions may cause a lack of self-esteem or shatter selfrespect. These notions place importance on the healthcare practitioner's expert thoughts and actions as paramount to ensure that human dignity remains intact for persons who are considered dependent or vulnerable in various healthcare settings. Value priorities for the biomedical healthcare disciplines are articulated in ways that the term dignity is considered an unconditional right for all persons." (p.208)

Milton (2008) builds on earlier work by Rowson (2007) to argue that the language of rights can sometimes cause difficulties in the practice of care. Healthcare professionals can regard rights as factual descriptions rather than as an ethos of moral and ethical opinions about how people should treat each other.

The 'human-becoming view of dignity' that Milton (2008) refers to describes dignity as an unconditional acknowledgement of 'distinctiveness, regard and affirmation of the inherent worth of humankind that coexists with potential disregard for humankind' (p.208). This suggests that healthcare professionals should always pay attention to the potential disregard or the potential loss of something of value that can become embedded in healthcare relations. Examples of such relations may be being dismissed, labelled or judged. Milton (2008) refers to the prioritisation of biomedical decision-making and diagnosis of disease capabilities (the value of which has become intensified by evidence-based medicine) resulting in the lived experiences and wishes of people about their healthcare priorities, being overlooked or simply not taken into account, as one example of a loss of value that can become embedded in healthcare relations.

# **Empirical Literature**

There now exists a growing body of empirical literature that addresses dignity and the care of older people. This material has an important role to play in any discussion of such matters, building upon the theories that have arisen out of the conceptual debates. Empirical studies can usefully inform by linking discussions to lived experience. Debate can be lifted out of the realm of theory, towards a more practicable goal and implications for practice can be drawn directly out of such work. Here we highlight some of the most important empirical papers that have emerged recently, together with those which deal with dignity and the older person.

From a psychoanalytical perspective Lax (2008) explores older people's subjective accounts of getting older and some of the indignities that come with these experiences. Significantly, the cultural preoccupations of Euro-American western societies are shown in Lax's article to affect the older people's sense of self and self-respect:

"In our culture, being 'wise' is not sufficient; one also has to be physically fit and well functioning. Since the latter decreases with age, not being able to 'keep up' however that is defined, results in a decrease in self-respect. The intensity of such feelings is proportionate to the individual's former level of standards and the degree of narcissistic investment in same. Any and every impairment affects the self-image." (p.853)

In a qualitative study Mangset et al (2008) explores the factors that contribute to older stroke patients' satisfaction with rehabilitation care. They found that the core factor identified in interviews with older patients was to be treated with respect and dignity. This overarching factor was divided into five subcategories:

- Being treated with humanity.
- Acknowledged as individuals.
- Having their autonomy respected.
- Having confidence and trust in professionals.
- Dialogue and exchange of information.

In expressing satisfaction with their rehabilitation, patients tended to talk in general terms whereas when they were dissatisfied, they expressed this through more detailed descriptions of particular situations.

These more detailed descriptions tend to focus on situations where patients felt a lack of control, where they were moved from one examination to another with a lack of information: 'You don't know what you are doing or where you are going, the staff do as they like to you' (p.829). The importance of interpersonal aspects of care was also highlighted as essential to dignity being maintained: 'it's not like they degrade themselves or I'm degraded, but it's a situation in which we need each other' (p.829). Being acknowledged as a person by the staff exemplified through actions such as taking the time to greet them as they walk past was shown to be particularly important for older people. Although recognition of people's own experiences, skills and knowledge in managing their condition was emphasised, some older people were frustrated at being asked to make up their minds and judge their own condition. However, meaningful dialogue and information are shown to strongly influence satisfaction. As Mangset et al (2008) note:

"Being treated with respect and dignity are more closely associated with the patients' positive evaluation of services than involvement in treatment decisions. Other researchers have found that physicians seem to overestimate patient's desire to participate in decisions but underestimate their desire for information." (p.832)

A key paper by Matiti and Trorey (2008), who conducted qualitative interviews with older patients in hospital exploring their expectations of the maintenance of their dignity, identifies six key themes of importance to patients:

- 1. **Privacy**. Patients were satisfied that nurses managed the exposure of their bodies on most occasions, but expressed concerns about badly fitting or transparent curtains, the lack of space between beds and failure of staff to request permission before entering doors or curtains. The importance of staff ensuring that discussions with and about patients were held in private was emphasised, as was the need for staff to lower their voices. This was more pronounced when patients were hard of hearing. Older people also emphasised the importance of being left alone while using a bedpan or commode.
- 2. **Confidentiality.** Where the necessary transfer of information regarding the patient was undertaken was important, as the nurses' station, open wards and corridors were places where confidentiality was infringed. Indiscreet behaviour, shouting to other nurses for help, particularly if this was in relation to a patient's bed being wet and needing clean sheets were further causes for concern.
- 3. **Communication and the Need for Information.** Aspects of communication that older people felt would help maintain their dignity were: when nurses introduced themselves; asked permission before a procedure; created time to talk to patients; used an appropriate tone of voice; listening to patients; being polite; involving patients in conversations; giving patients opportunities to express their needs; nurses' body language corresponding with their language; making eye contact; providing enough information; carefully explaining procedures; seeking confirmation

of understanding about what is to be carried out; giving timely and up to date information; and not giving conflicting information. Further aspects of non-verbal communication included making eye contact during procedures like bed bathing. Patients felt that knowing what is being done to them minimised their embarrassment. Matiti and Trorey (2008) note that deciding how much information to provide is not straightforward; 'enough' will be different for each patient, however, avoiding conflicting information should be possible.

- 4. **Choice, Control and Involvement in Care.** Clear, unhurried explanation of possible alternatives was necessary as knowing what to expect gives patients control and maintains dignity: 'I do not accept that being a patient is being unintelligent...You nurses and doctors tend to discuss things among yourselves about my body' (p.2714). Patients also discussed how they disliked not being given the choice to do things themselves because it would take too long. Having tasks done when one is able to do them on their own made some patients feel undignified, as they were being treated like a child.
- 5. **Respect.** Attitudes towards older people that do not reflect them as valuable, equal human beings by, for example, leaving them waiting for lengthy periods for a bedpan then being agitated at the result, is an example of this kind of attitude. For Matiti and Trorey (2008) showing respect to older patients involved giving prompt attention; assessing patients for dignity needs; finding out from patients how these needs should be met; treating patients as equals; being sensitive when performing a procedure; making patients comfortable and being advocates for vulnerable patients.
- 6. **Decency and Forms of Address:** This included being asked for a preferred name and sticking to this rather than using condescending names or referring to a patient by bed number. Clothes, make-up and jewellery should not be removed unless there is a purpose for removing them and this purpose is explained to the patients. Patients felt uneasy and unsure of what and how many clothes to remove for procedures. The use of ill-fitting hospital gowns was also a cause for concern for some older people.

The study makes use of a phenomenological-hermeneutic approach and seeks to gather rich qualitative data by in-depth analysis of older person's interviews. Although it does not deal with issues concerning only older patients (and it specifically excluded patients with dementia and/or confusion on ethical grounds), this study remains relevant as the participants are recruited from acute wards and certain age-related patterns of experience are observed. The study seeks to highlight the perspectives of patients and finds that, whilst many participants were satisfied with the maintenance of their dignity during care, there nevertheless existed some level of dissatisfaction and in many cases dignity is still not being maintained to the standards expected by patients. Matiti and Trorey (2008) question whether staff are unaware of the situations that compromise dignity and suggest it may be to do with staff attitudes. However, they point to Walsh and Kowandko's (2002) study which showed that when a patient's dignity has been compromised, staff are usually aware that this has happened, but it is often out of their control and relates to time pressures, shortage of resources or poor facilities (curtains/gowns).

Matiti and Trorey (2008) make a case for listening to patients' views on the specific factors they see as important for maintaining dignity as this can lead to greater emotional comfort, a

sense of wellbeing and can also assist recovery. They suggest it is the responsibility of all staff to take an active role in maintaining dignity, which includes noticing and reporting things like poorly fitting curtains.

One of the key findings of Matiti and Trorey's study is that each individual's expectation of dignified care ought to be assessed and that this information should form the basis for practical action in the provision of care. They acknowledge that, although a great deal of public effort has been put into raising the profile of dignity in healthcare, it remains clear that mere talk of dignity is not enough. 'Maintain dignity at all times' is written in patients' case notes, but this is meaningless unless there is an identification of what needs exist in relation to this injunction as well as an action plan to meet these needs (Matiti and Trorey, 2008, p.2716). It is important therefore to assess patients in relation to their dignity needs at various points in their hospital stay and match these needs with appropriate nursing activities (p.2716). The point highlighted here is that we must continue to question what such injunctions mean in practical terms for each particular person involved.

The categorical breakdown of dignity identified reflects much of the discussion of dignity elsewhere (see, for instance Tadd, 2005a; Webster and Bryan, 2009; Baillie, 2009; Whitehead and Wheeler, 2008; Jonasson et al, 2010; Erien, 2007; Chochinov, 2007 and Woogara, 2005).

In the Dignity and Older Europeans study that frames analysis within the context of broader discussions of dignity and threats to dignity, Calnan et al provide us with a reconceptualisation that is founded explicitly upon an understanding of older people's experiences (Calnan et al, 2006). By addressing the conceptual, via analysis of the empirical, this paper is particularly valuable because it bridges the gap that can emerge between philosophical debates and social scientific discussions of dignity. The study focuses specifically upon meanings of dignity as they are constituted in everyday life experience. It approaches the subject with an explicit understanding of how old age, as a particular context, can serve to compound problems that are associated with the relationship between socioeconomics and illness, including how high levels of poor health and low income amongst older people fuel the growth of a dependent, and increasingly disengaged and socially excluded population. It is recognised here that old age is commonly associated with social and clinical decline and economic hardship, and that older people are likely to 'have their dignity and self-respect threatened both collectively as citizens and individually in everyday interactions' (Calnan et al, 2006, p.358).

The results of the empirical focus group data from the Dignity and Older Europeans study (Bayer et al, 2005) gives strong grounds for suggesting that, despite attracting some criticism for being overly abstract, difficult to define and practically inapplicable, the concept of dignity continues to be relevant to the practical, concrete concerns of older people. The conclusions drawn from the data parallel many of the points made in the conceptual literature, in that it is noted that dignity is a complex concept that is difficult to pin down or define in simple terms (Tadd et al, 2010). It is also noted that talk of indignity, or undignified treatment often dominates discussion as it was easier for people to talk about its absence, or about being treated in an undignified manner (Bayer et al, 2005). Older people's discussions of dignity mirror lay talk of health, in that both prove to be 'multidimensional'. Certain concepts, however, are closely related to understandings of dignity: 'equality', for instance, is raised as being a prerequisite for acceptance, recognition and therefore dignity.

Whilst the Dignity and Older Europeans study (Tadd, 2005a) focuses upon dignity in everyday life, rather than particularly in healthcare, this nevertheless emerges as an area of significant concern. Discussions of threats to dignity are widespread and participants often cite experiences of undignified health and social care 'most participants could give examples of how they or someone close to them had been the recipient of undignified care' (Calnan et al, 2006, p365). Issues relating to concerns over lack of privacy, lack of respect for bodily integrity and individual suffering are commonly raised in connection with healthcare. Feelings of embarrassment, shame and humiliation are associated with experiences of undignified care. The management of certain, specific practical issues is closely related to personal understandings of when dignified care entails: washing; dressing; using the toilet and ensuring that curtains are drawn, are experienced as significant.

Respect for patient autonomy and involvement in care also emerge as central, mixing tablets into patients' foods (Tadd and Bayer, 2006), for instance, is regarded as being an 'attack on patient dignity' and gender is highlighted as an issue that affects patient privacy and dignity. Female patients are often uncomfortable with intimate care being performed by male carers and feel vulnerable when being cared for in mixed wards (Tadd and Bayer, 2006). Some older people find the unsolicited use of first names and casual forms of address as undignified, but are often reluctant to voice their discomfort as they feel vulnerable and do not want to be perceived as 'old fashioned'. Polite and appropriately attentive care is experienced as dignified and conversely, caregivers' lack of time is experienced as detrimental to older patient's wellbeing (Calnan et al, 2005).

Many of the themes that emerge from analysis of the data in the Dignity and Older Europeans study (Tadd, 2005a, 2005b) relate to 'dignity of identity' and essential to this idea are understandings of self-respect, especially in relation to how an individual's appearance is perceived by others. Lack of attention to appearance from those caring for older people, for instance, is identified as being of particular concern and has a profound effect upon selfrespect. Older people's maintenance of their dignity is dependent to some degree upon resisting the stereotypes and patterns of social exclusion that are commonly associated with hold age and ageing (Edgar, 2004). Older people seek to highlight their individuality and resist being placed into categories that present them as being a homogenous, socially devalued group. Many older people feel their experience, knowledge and skills ought to be more widely valued and used and if they are to be included more generally in contemporary social life, their lives must be seen to have purpose and value (Edgar, 2004). Autonomy and maintenance of independence are issues of central concern for many older people. The struggle against increasing dependence and the fear of becoming a burden is a significant threat to dignity and many people believe that increasing the independence of older persons ought to be a prime focus of dignified service provision (Stratton and Tadd, 2005). Dignity is also commonly seen as being a fundamental human right that should be extended to all by virtue of their humanity. Old age is regarded as a particular threat to continued dignity because of the loss of influence, increasing vulnerabilities and the disadvantages that are experienced. Participants in the Dignity and Older Europeans study were concerned that they lacked a voice and the ability to exercise their right to live and die as they wished (Tadd and Bayer, 2006). Practical issues with finance were seen to be a particular threat to older people, as was being regarded as full and equal members of society (Calnan et al, 2006).

In another recent study, the perception of care providers' views of older people's dignity (Hoy et al, 2007) found that autonomy, personal identity and worthiness were the three themes that afforded a framework for protecting and promoting the person's dignity.

In two further papers that present the results of empirical study, Lesley Baillie explores experiences of dignity in the acute care setting (Baillie, 2007; Baillie, 2009). Whilst the study does not explicitly concern older patients, as they are amongst the heaviest users of acute healthcare in the UK, this research remains relevant. The work seeks to fill a perceived gap in empirical knowledge, responding to a 'dearth of research about patient dignity conducted in the acute care setting' (Baillie, 2007, p.30). The study made use of a multi-method approach that included interviews with both patients and staff. Again, in both papers, the fact that indignity, or undignified care is described more readily than dignity or dignified treatment is highlighted.

The major findings stressed in the first paper focus on the impact of staff behaviour in the maintenance of patient privacy for upholding dignity and that staff actions which 'help patients feel comfortable, in control and valued' (Baillie, 2007, p.30) are key in promoting patient dignity. Individual staff behaviour has a major impact on whether threats to dignity (which are to some degree, an unavoidable component of acute care) actually result in loss of patient dignity. Experiences of privacy enhancing or breaching treatment commonly reference practical issues such as the appropriate, or inappropriate use of screening or curtains. Bodily exposure is an area of prime concern. Patients also feel vulnerable because of inappropriate, undignified communication from staff and curt or authoritarian approaches also threaten dignity. Respectful communication on the other hand, can mitigate losses of patient dignity as it provides reassurance and offers the opportunity, for example, to consent to particular aspects of their care. Thus staff are able to use their professional behaviour to maintain patient dignity.

The second, more general, paper confirms the above findings and also identifies what patient dignity and threats to dignity comprise. Baillie's analysis shows that staff and patient conceptualisations of dignity are closely related. The emotional aspect of care is identified as being intimately linked to dignity, and feeling 'comfortable, in control and valued' (Baillie, 2009, p.24) are essential to experiencing dignity. Feelings of dignified comfort are not merely physical in nature, they relate to being relaxed, safe, happy and free from worry. Feeling valued is also important as dignity is associated with feeling cared for, in control and possessing self-respect and self-esteem. Physical appearance is significantly linked to feeling dignified and appropriate dress and avoidance of bodily exposure is again highlighted. The term that is most commonly linked to dignity here is respect. This holds particular significance for both staff and patients and the importance of mutual respect between the two groups is also highlighted.

This study's more general finding that old age, as well as impaired health, makes patients vulnerable to a loss of dignity, provides support for the conclusions made in much of the literature that looks at older people in particular. The fact that older patients are particularly vulnerable to loss of bodily integrity via inappropriate breaches of privacy is again highlighted. Other threats to dignity come in the form of inappropriate hospital environments, physical layouts, ward culture and leadership patterns.

In a paper focusing upon nursing and the critical care of older people, Jacelon and Henneman describe the particular barriers to humanistic, dignified care that are common (Jacelon and Henneman, 2004). This paper draws upon empirical evidence, drawn from focus group data from older people, building case studies which serve to highlight issues related to dignity in the critical care setting. The findings again echo two recurring themes common to much of the literature. Firstly, dignity is presented as being an essential concept to nursing and secondly, older people are especially vulnerable and more likely to experience the negative effects of barriers to dignified care. The paper particularly highlights the conclusion drawn by Baillie, in that it is found that the smallest interactions between staff and patients make a profound difference to the experience of dignified or undignified care. It is also noted that, whilst maintenance of patient dignity may not always be a conscious aim of all nursing practice, if high standards of care are provided, dignity is often promoted as a result. This relates to the fact that dignity is closely tied to other concepts, such as respect and privacy, which may be more likely to be at the forefront of a practitioner's concern. Another point made is that the maintenance and promotion of patient privacy is not a matter of concern for nursing staff alone. It is a matter of shared professional responsibility and for dignified care to be effective, it ought to be provided by all members of the multidisciplinary team.

A study by Russell and Middleton (2008) explores caregivers' perspectives about indicators of quality of life for people with dementia. Three indicators of quality of life are most significant from the accounts of carers. These are:-

- The physical body: especially the safety, cleanliness, comfort, nourishment and appearance of their relative's body and freedom of bodily pain. Food, both in having enough and having food appropriately provided was also important and loss of control over one's body and its functions was seen by relatives as a critical indicator of declining quality of life.
- The physical and social environment: carers saw their relative's physical environment as an important aspect of their quality of life such as having a single room, a window to look out of and fresh air. Social opportunities for interaction, both outside through going on trips and taking part in activities and inside by having access to communal areas was important, as was regular contact from caregivers.
- Treatment with respect and dignity: care that acknowledged and respected the dignity of the person with dementia was seen as a key indicator of quality of life. Carers referred to the indignity of certain practices such as being dressed by a stranger or having to be toileted in a hoist.

Constructs of quality of life and quality of care tended to be conflated by caregivers. An important role for caregivers was to interpret and represent the subjective experience of the person with dementia. Understanding what the person with dementia may be experiencing and advocating for what they would want if they could speak for themselves were viewed as important responsibilities. Russell and Middleton (2008) conclude by arguing that 'Quality of life needs to be understood from multiple perspectives. Caregivers' views are a central part of this understanding and should be used to inform future research and service development' (p.89).

Finally, a survey undertaken in 41 European countries to ascertain from lay individuals which aspects of non-clinical quality of care are most important showed that being treated with dignity was second after receiving prompt attention (Valentine et al, 2008).

# **Impact on Services for Older People**

As much of the empirical literature notes, it is often far easier to relate experiences of indignity or present examples of undignified care than experiences of dignity and dignified care. In order to balance this perspective and highlight some potentially beneficial or progressive approaches, we draw attention to literature that deals with excellence in the provision of dignified care and/or makes suggestions for changes in service provision, which may help deal with threats to dignity that older people face.

A recent paper explores how the care of older people with dementia has been successfully managed on an acute orthopaedic unit. Haak (2009) reports on a project that was implemented on two wards in an acute district hospital in Surrey to enhance the privacy and dignity of older patients. It involved three one-day workshops with clinical experts to promote staff awareness of dementia; the development of a six-bedded bay for female trauma patients with dementia (the Forget Me Not Bay) and the creation of a working group to facilitate developments in the care of these patients (Forget Me Not champions).

The project was established in response to a growing awareness that there were problems within the ward resulting in a lack of dignified care. Senior staff had noted that some staff-patient interactions caused distress to patients and their families and that care provision on the ward was overly task-orientated and disregarded the person. The needs, desires and wants of the patients were also being continuously overlooked. It was reported that whilst initial interest in the workshops was poor, staff quickly became enthused and in the run-up to the workshops 'discussions on issues of consent, human rights, task orientated care and restraint were being openly talked about amongst the team' (Haak, 2009, p.2). In the workshops, the clinical expert made an effort to speak from the perspective of the patient, encouraging development of an understanding of 'the world that a person with dementia might experience' (Haak, 2009, p.2) and practical ideas for care provision were explored in light of this. The staff response to the workshops was positive and they found the content was relevant and enhanced their understanding and knowledge of dementia care.

The creation of the six-bedded bay and the working group were practical developments that arose out of the workshop discussion. The specifics of each of these practical solutions highlight areas of concern about acute environments. To overcome such problems, the Forget Me Not Bay was decorated in order to provide a 'homely atmosphere with a sense of calm' (Haak, 2009, p.3) with artwork, home style lighting, games, craft materials, books, a fridge stocked with snacks and dietary supplements, DVDs and music being made available. The team created personal care plans allowing patients to communicate their preferences and dislikes. Active involvement of relatives is encouraged, as is the accessibility of personal belongings such as photos, blankets or clocks 'to promote a sense of self' (Haak, 2009, p.3). The development of the unit has had a positive impact on staff as well as patients. Nurses report that they enjoy working in this area because of the 'special and unique atmosphere' (Haak, 2009, p.3) that is created. Feedback on the environment, from patients, staff and relatives has been overwhelmingly positive.

The development of Forget Me Not champions was informed by an awareness of the need for multi-disciplinarity in the provision of care to these vulnerable patients. The team includes nurses, physiotherapists, occupational therapists and social workers. The main conclusion drawn from analysis of the project's success is that by increasing awareness and understanding of the needs of people with dementia, a more person-centred approach to care delivery emerges and dignity is promoted. It has been observed that a 'cultural shift' (Haak, 2009, p.4) has occurred in the ward as the provision of care has been adapted to meet the needs of the patients.

This particular approach to patient care practically reflects many of the themes that emerge in the conceptual and empirical literature on dignity, such as encouraging the inclusion of patients and their families in decision-making about care and protecting the patient's right to self-determination and autonomy. Their individuality and sense of identity is respected by encouraging personal items to become part of the care environment and their contentment and relaxation is facilitated by the provision of an inviting social space, which increases a sense of wellbeing and reduces anxiety. Privacy and confidentiality are enhanced by the provision of respectful nursing care that is informed by knowledge and understanding of dementia, as well as a designated clinical space designed specifically with the needs of these patients in mind.

This paper highlights the fact that despite there being many potential threats to dignity, thoughtful planning of care and the care environment can maintain and enhance the peoples' experiences of dignified care. By shaping the ward environment to fit the needs of the patient, rather than the organisation, staff or Trust, excellence in care which benefits all those involved can be achieved.

A project that sought to highlight excellence in the provision of dignified care to older people in the NHS was commissioned by Help the Aged and was reported (in five parts) to the Nursing Times (Davies, 2000a, b, c, d, d, e). The study does not seek to gauge general standards of practice, but instead highlights outstanding examples. Each report draws upon empirical work carried out on wards that have been nominated as sites of excellence in care. Whilst the discussion of dignity and the older person may have evolved somewhat since this publication, the report usefully highlights some vital aspects of dignified care.

The first case report (Davies, 2000a) provides an optimistic account of daily nursing practice. Pinewood Ward, Hillingdon Hospital is presented as being a prime site of excellence in care. The general social environment within the ward is built upon a calm and unhurried atmosphere where both patients and visitors feel welcome and comfortable, praising in particular the cleanliness of the ward and the accessibility of the staff. Patients feel they are not being treated as old, but instead benefit from attentive, friendly, smiling and responsive staff.

The report also describes how, when faced with practical challenges, the needs of the patient are consistently placed as central. Nursing staff have little space to themselves and are consequently physically present on the ward to a greater extent. It is claimed that this potentially difficult situation had been turned to the patients' advantage as lack of space, has resulted in increased contact between nurses and patients. It is also suggested that patients benefit from receiving care from a small and cohesive multidisciplinary team and both patients and staff support this view.

The team has successfully introduced novel initiatives for improving care, including a move towards biographical assessment of patients, a practice that actively encourages family and patient involvement in care planning. Nursing staff actively empower patients to do more for themselves by talking to them about their care and giving them increased choice and control. Each patient has a named nurse as continuity of care is seen as critically important and is especially valued by patients. Visitors are allowed on the ward at any time, which is felt to be of great benefit to patients and their families as the provision of care is orientated to their needs, rather than those of the staff or administration.

The second report (Davies, 2000b) also emphasises the importance of establishing a friendly and attentive atmosphere. Patients report feeling satisfied with the level of information-provision and with attempts to make the ward more homelike by encouraging people to wear their own clothes and providing non-clinical services such as hairdressing.

When faced with difficulties in communicating information, staff make repeated attempts to solve the problem. The report describes how this acute reception unit (ARU) has implemented seven-day consultant ward rounds as a way of increasing expertise and promoting effective discharge management of older patients, which is seen as a high-risk task. The ward environment is structured to avoid a strict hierarchy as the predominant emphasis is on teamwork and multi-disciplinarity. Nurse practitioners are viewed as an expensive but valuable asset to the team as their expertise means they are a source of expert information and support to all members of the clinical team.

The third report (Davies, 2000c) focuses on extremely well-equipped, busy and highly pressured acute medical wards. The wards studied benefited from imaginative upgrades, which created bright and pleasant environments. Carefully planned layouts have enhanced the experience of care. Again, homelike decorations are used and extra personal space is provided. A specific discharge lounge has been created, which ensures a more comfortable experience of discharge and transfer. The ward manager has made efforts to break down the institutional hierarchy and the staff do not wear uniforms that mark out their status as qualified nursing staff or healthcare assistants.

The ward has strong links to the outside community and is involved with charities and other social groups and it is thought that this has a direct positive impact on service provision. The decision to shift from mixed-sex to single-sex wards was informed by evidence gathered by the local pensioners' action group for example. In order to enhance patient involvement, a system of bedside handover has been adopted, which has helped nursing staff negotiate care and discuss treatment plans directly with patients. Particular efforts are made to protect bodily integrity and physical privacy, practical changes including installation of 'heavy' curtains and encouragement of staff to treat curtains as if they are dividing public and personal areas.

The fourth report (Davies, 2000d) looks at a 28-bed female acute medical ward. Patients and their relatives describe how they appreciate being kept well-informed by staff. The ward is designed to maximise space and create a relaxed environment. For example, a day room is decorated with plants and sofas and a large conservatory and a coffee-bar is open to patients and relatives to enable them to take time out and relax. The practice of establishing 'partnerships in care' with relatives enables staff to develop a broader picture of the person's

health and social needs, as well as a sense of community involvement. The maintenance of dignity had been specifically highlighted as an area of particular concern, and patient satisfaction has grown. The staff are attentive and respectful and manage to include time for 'the little things' that make a difference to the experience of dignified care.

These reports present positive descriptions of dignified care in practice. Whilst they may not engage in comprehensive critical debate, they are grounded in empirical observations and serve to highlight some successful approaches to providing dignified area. Again, many of the practical steps that have been taken seem to clearly reflect the concerns that are outlined in the empirical literature on dignity. Respect for privacy motivates the installation of heavy curtains, whilst an understanding of the need for self-respect and individuality motivates the provision of relaxing and homelike environments. Respect for autonomy and the patient's sense of control motivates patient and family inclusion in care planning.

# **In Conclusion**

This review, though necessarily limited, has shown that whilst any practical environment will involve some shortcomings and will continually create threats to patient dignity, conceptual discussions can inform empirical studies, which can in turn inform good practice.

# **Chapter 3: Methodology**

## Introduction

This chapter describes the study, its purpose, methods, study sites, participants, data collection methods and analysis, together with some of the challenges faced by the researchers. It is important to emphasise that in doing so pseudonyms have been used throughout to ensure anonymity and protect confidentiality. This practice will be followed throughout the remainder of the report so that neither individuals nor places can be identified.

# Study Aim

The aim of this study is to develop a body of evidence about dignified care provision for older people derived from exploring the experience of service users and their carers, the views of senior and ward staff working in acute NHS Trusts, together with observation of care within a number of wards in four acute Trusts. From this data, recommendations for the provision of dignified care would be developed.

### **Study Objectives**

The objectives were to:

- Identify older people's and their carer's views and priorities in relation to dignified care.
- Examine healthcare practitioners' behaviours and practices in relation to dignified care.
- Identify the occupational, organisation and cultural factors that impact on dignified care.
- Develop evidence-based recommendations and guidance for dignified care.

# Involvement of Stakeholders in the Research Process

Stakeholders including older people, relatives/carers, health service managers, senior healthcare professionals, representatives from advocacy organisations such as Age UK, the Stroke Association, Alzheimer's Society and Crossroads, regulatory bodies and policy makers/advisers, have been variously involved as members of the project advisory group, members of the research team, participants and/or involved in a series of workshops discussed at the end of this chapter.

It has been argued (Entwistle et al, 1998, 2008) that users should be involved in different stages of the research process because they make research more relevant to users' needs. Thus, meetings were held with groups of older people and relatives/carers of older people in planning this project. These groups were invaluable in discussing approaches to data collection, recruitment strategies and for piloting interview schedules. On their advice, the decision was taken to interview relatives/carers and older people separately as little research evidence is available as a guide.

Two older people and one older person who was also a carer of a spouse with dementia were employed as members of the research team to avoid 'token' representation, to ensure the study took due account of older people's concerns and that materials written for a lay audience would be accessible to older people. Their participation involved attendance at research team meetings; advising on the information sheets; advising on the interview guides; advising on interpretation and analysis of collected data; advising on lay reports; and involvement in dissemination. In this way, the research team were able to benefit from a broader service user input and experience throughout the study, whilst the service users themselves were able to advise researchers and make suggestions in a sustained manner. This approach also afforded support for service users and hopefully provided other benefits such as increased knowledge of research and services; meeting new people; attending conferences and presentations; increased involvement and interest; and increased confidence and self-esteem.

# Study Design: An Ethnography

The choice of study design was the subject of considerable debate before submission of the research proposal and during the early development of the research protocol. ethnographic approach was chosen as the most appropriate methodology for data collection, analysis and interpretation as Van Maanen (1979) describes it as useful to 'uncover and explicate the ways in which people in particular work settings come to understand, account for, take action and otherwise manage their day-to-day situation' (p.520). When applied in the study of the workplace, such an approach takes account of the complexity of activities, communications, social and organisational relationships that facilitate or obstruct care delivery. Ethnography is usually associated with a combination of gualitative methods (Bryman, 2008) primarily observation, interviews and documentary analysis and this study adopted two of these methods of data collection. Interviews were used to explore the perceptions of older people, their carers, ward staff and Trust managers about dignified care and the factors which influence it. Whilst observational methods were employed to appraise behaviour and practices and investigate the discrepancies between what people say, they do and what they actually do (Calnan and Tadd, 2005). The study objectives were therefore explored though an ethnography of four acute hospital Trusts in England and Wales.

# **Organisation of Data Collection**

The data collection was undertaken by two research teams from the universities of Cardiff and Kent. To ensure its iterative nature, site visits were made to the first two Trusts, initially so that the four wards where observation would take place could be identified in each Trust. Recruitment of local participants then commenced (discussed in detail below) and interviews of older people and their relatives/carers were held. Immediately following data collection and analysis the first two field studies commenced, beginning with interviews of Trust managers, followed by observation in the first two wards in each Trust. The research teams met frequently during this time to determine whether any modifications to the observation briefs were needed, to compare initial interpretations and identify key aspects on which to focus down. Observation in the final two wards was then undertaken. Following observation on the individual wards, interviews with ward staff were undertaken.

Data analysis from the first two study sites was completed and discussed by the research teams before embarking on site visits and field work in the final two Trusts. In this way, the iterative benefits of qualitative work can be maximised.

In-depth interviews were carried out with older people (age 65 or over) recently discharged from hospital (N=40) and their relatives/carers (N=25) about their experiences of acute hospital care. Face to face recorded interviews were undertaken with a range of staff on the 16 wards (N=79) and with purposive samples of Trust managers (N=32) at various levels with the Trusts' hierarchy. In this way, patterns of practitioner behaviour and the occupational, organisation and cultural factors that foster or detract from dignified care could be identified. These were complemented by evidence from 617 hours of non-participant observation of practices and activities in 16 wards across four acute NHS Trusts. The periods of observation sampled the entire 24 hour period across each weekday in each of the 16 wards.



Figure 1: Sources of data

The following sections describe the different stages of the research process, namely: sampling; recruitment; data collection and analysis.

# The Study Sites (NHS Acute Trusts)

The 30-month study was undertaken between May 2008 and November 2010. According to the Healthcare Commission, acute NHS trusts are major sources of complaints about dignity by older people (personal communication). The study sites were purposively selected to reflect a range of organisational and system characteristics that may impact on the provision of dignified care based on evidence from the Dignity and Older Europeans study (Tadd

2005a, b; Arino Blasco et al, 2005; Bayer et al, 2005; Calnan et al, 2005), policy developments and institutional initiatives.

# **Trust Selection Criteria**

Three criteria were used in the selection of Trusts. These included the organisational characteristics, ratings for quality of care and resource use and the extent to which the Trusts were actively engaged in dignity initiatives.

# 1) Organisational Characteristics

The Trusts all serve diverse urban/rural populations and are situated across England and Wales. All were teaching Trusts or associated teaching Trusts. Three Trusts were located in large urban conurbations and one in a semi-urban/rural location and all served populations of approximately half a million. In terms of in-patients bed numbers ranged from 1200 to 1800 approximately.

# 2) Quality of Care and Resource Use

Consideration was also given to Healthcare Commission ratings or comments made during the most recent visit by Health Inspection Wales (which does not use quality ratings). In one Trust, a number of concerns had been raised with regard to the patient experience. Another Trust was assessed as providing 'fair' quality of care and 'weak' use of resources, one as providing 'good' quality care and 'good' use of resources and one as providing 'fair' quality of care and 'excellent' use of resources.

# 3) Dignity Initiatives

As discussed in Chapter 1, prior to the commencement of the study, there had been considerable activity in relation to the provision of dignified care at both national and local levels in England (DH, 2000; 2001a; 2001b; 2004b; 2006a; 2006b). These initiatives resulted in the introduction of various dignity awards within health and social care. The aim being to embed dignity within health and social care policies and practices, such as ensuring that dignity is part of the core operating principles of the NHS, the NSF for older people and the inspection and regulatory frameworks.

All three English Trusts had developed strategies in relation to the provision of dignified care to a greater or lesser degree.

One had undertaken Trust-wide audits of fundamental care including dignity and respect and various projects including a Beacon ward project on leadership and one on transforming care had been established. Professional development days on dignity had been held for various levels of nursing staff. A 'Privacy and Dignity' policy had been introduced and attention to achieving the Same Sex Accommodation compliance had been emphasised in recent years. The Trust board had also requested the inclusion of dignity objectives in the Quality Improvement Strategy.

Another Trust had spent considerable time and resources on the promotion of patient dignity, while the other had developed an audit tool for older people's care and a training © Queen's Printer and Controller of HMSO 2011. This work was produced by Tadd *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. Project 08/1819/218 package on meeting their needs. A privacy and dignity/Essence of Care group held regular meetings and an immediate feedback questionnaire on daily menus had been launched which also sought patients' comments about their experience of dignity. Formal patient experience audits are regularly undertaken and patients complete a short survey about their experiences before discharge. Specific projects include 'Releasing time to care' and 'Productive ward' and these initiatives are the subject of frequent audits. These are referred to as part of the Trust's policy in addressing dignity, although how much of the time released is actually spent with patients is not identified. Aspects of patient experience had recently been included in staff appraisals, however many ward managers claim that staff appraisals are often neglected due to poor staffing levels.

Another Trust had no specific 'Dignity' or 'Dignity and Privacy' policy although managers believed dignity issues were incorporated into other policies and guidelines, including the Safeguarding Vulnerable Adults and the Patient Movement policies. A number of statements on the Trust website reflect the Trust's commitment to maintaining patients; dignity. The annual report on the results of the Patient Environment Action Team (PEAT) assessment has shown some deterioration in the 'Privacy and Dignity' score in one hospital.

Within the final Trust, a whistle blowing policy encouraging to report incidents involving inappropriate care or behaviours, was in use and a 'Dignity at Work' policy, supports staff in the workplace but Trust managers believe that staff are not as aware of these policies as they should be, although no specific action has been taken to remedy this. A number of audits and a pilot study to assess toileting and hygiene activities using the British Geriatrics Society 'Behind Closed Doors' (BGS, 2006) materials have been undertaken by interested staff, but these are not currently Trust-wide initiatives. There are training courses available to nursing staff on dignity, but there is no formal training for healthcare assistants (HCA) or other professional groups on issues relating to dignified care. The dignity courses are not mandatory and many ward sisters find releasing staff for training impossible due to inadequate staffing levels. Many wards have ward philosophies that include the provision of dignified care.

Other national dignity initiatives had variously influenced Trust strategies. Modern matrons, intended to improve the patients' experience, were introduced in England from 2002. Despite these new roles having some problems, they have provided a clear clinical lead for nursing in many areas and together with dignity champions have led to some positive impacts.

The Essence of Care benchmarking tool, which includes standards for dignity, is not applicable to Wales although there is a guidance document 'Fundamentals of Care' (WAG, 2003a) which has a section on respecting people.

In Wales, much less work has been undertaken on a national level. It was not until October 2007 that the Welsh Assembly Government announced a 'Dignity in Care' programme. This consisted of a consultation exercise involving service users and providers, followed by a brief implementation programme, which provided each NHS Trust with a small sum of money and educational materials on dignity in care. Prior to this, there were no dignity champions or networked activities to share good practice. In the Welsh Trust included in the study, a small number of awareness-raising sessions had taken place and some laminated privacy signs to

attach to bed screens had been purchased. The role of matron did not exist in the Welsh Trusts.

Within Wales generally, the ward sister role had evolved to one of ward manager taking them away from clinical care and leadership. Above ward manager level there were senior nurses whose roles were entirely managerial with no clinical leadership element. To address this, a Ministerial Task and Finish Group (Free to Lead – Free to Care; Empowering the Ward Sister/Charge Nurse) had been established to make recommendations for ensuring that ward sisters/charge nurses are empowered with the authority, knowledge and skills, to improve the environment of care and patient experience. This group produced a final report in summer 2008.

### The Wards

The acute wards were chosen in consultation with senior Trust staff. The research team requested two acute wards where older people are cared for along with other adults and, where possible, two wards that are exclusively for older people. In three of the Trusts it seemed that some wards had been chosen because standards of care were seen as good and some because there were concerns about standards. In only one Trust did it appear that the ward selection was random. The ward characteristics are shown below (see table 1) On many wards, the ward sister/charge nurses were very vague about staffing establishments so a clear picture of whole time equivalents and staff patient ratios is difficult to establish.

Ward	Specialism	Beds	Male patients	Female patients	Shifts/ 24hours	Qualified staff/shift	Unqualified staff/shift
Downlands 1	Frust		patients	patients	24110013	starry sint	starry sinit
Daffodil	Stroke	26	Yes	Yes	3	5/3/3	4/2/2
Carnation	Trauma/Orthopaedic	36	Yes	Yes	3	4/3/2	5/3/2
Marigold	Care of Older People	29	Yes	Yes	3	4/3/2	5/2/2
Rose	Acute dementia care	18	Yes	Yes	3	2/2/2	4/2/1
Westway Tr	ust						
Nelson	General Medicine (Quick Discharge)	38	Yes	Yes	3	5/4/4	5/4/4
Churchill	Stroke (Acute & Short Rehabilitation)	23	Yes	Yes	3	4/3/2	5/3/3
Drake	Care of Older People	28	Yes	Yes	3	4/3/3	4/4/3
Wellington	Rapid Rehabilitation (Older People)	38	Yes	Yes	3	4/4/4	4/4/4
<b>Uphill Trust</b>		•		1	1	1	•
Severn	Acute Medicine Older People	29	Yes	Yes	3	3/2/2	4/2/2
Ouse	Vascular & General Surgery	25	Yes	Yes	3	3/3/2	3/2/1
Wye	Respiratory Medicine	32	Yes	Yes	3	3/3/2	4/2/2
Thames	Trauma/Orthopaedic	11	No	Yes	3	2/1/1	1/1/1
Meadowfield Trust							
Oak	Care of Older People	32	Yes	Yes	3	3/2/2	5/3/2
Ash	Trauma/Orthopaedic	41	Yes	Yes	3	5/4/3	5/5/3
Elm	General Surgery	31	No	Yes	3	3/2/1	3/2/3
Beech	Specialist Rehabilitation Older People	24	Yes	Yes	3	2/1/1	4/3/2

### Table 1: Wards Included in the Study

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Increasing numbers of staff in every Trust are requesting to work long days of either 12 or 14 hours rather than the three-shift system which officially operates.

# The Participants

## 1) Older People

### Recruitment

Following ethics approval and appropriate local Research & Development (R&D) approval, participant recruitment was undertaken. In each location, the aim was to invite up to 20 older people discharged within the previous four weeks, (although this was in many cases unrealistic and a number of older people had been discharged for six to eight weeks) to participate in a semi-structured interview. On each ward, all patients over 65 years who had been discharged in the previous month were identified by senior clinical staff and invitation letters sent out.

Inclusion criteria were:

- Aged 65 years or over. No upper age limit.
- Two to four weeks post discharge from hospital.
- Cognitively and linguistically able to participate in interview.
- Able and willing to give informed consent.

Although the criteria stipulate that individuals must be cognitively and linguistically able to participate in the interview and able to give consent, this did not rule out participation of people with mild dementia or other cognitive impairments and four participants had diagnoses of early dementia. Also, relatives of three older people with moderate or severe dementia participated.

The research team was not involved in initial patient recruitment as written information about the study aims, the funder and sponsor, together with what participation would entail, was sent to all patients over 65 years discharged from the chosen wards by senior clinical staff, together with a consent form and an expression of interest form to be forwarded to the research team. Anyone returning a form indicating their interest in participating was then contacted by researchers and arrangements made for interview at a time and place convenient to the participants. A contact telephone number was given to all participants should any questions not addressed at the initial contact arise.

Written consent was obtained at interview to ensure full understanding. Participants were informed of their right to withdraw at any time, without giving reasons and without affecting their right to treatment or care. All participants were given assurances that their confidentiality and anonymity would be protected. This was explained so that participants had a clear understanding that immediately following transcription of the interview no identifying information would be held about them or associated with their responses. In particular, they were assured that their comments would not be disclosed to the Trust involved and permission to use anonymised quotes in reports or publications was sought.

All interviews took place at a time and location of the participants' choosing which was mainly in their own homes.

#### Sample of Older People

Across the four Trusts, 40 older people were interviewed although in three sites recruitment proved difficult (see table 2).

Trust	Number recruited
Downlands	8
Westway	21
Uphill	5
Meadowfield	6
Total	40

Table 2: Older People Recruited by Trust

In Downlands Trust, staff stated that 88 invitations were sent to participants discharged from the four wards. Responses from only two wards were received which resulted in eight older people being recruited. Similarly in Uphill, staff stated that 40 invitations were sent out across the four wards and this resulted in only five participants being recruited. One possible explanation for the difficulties in recruiting is that these older people are too ill, frail and/or confused to take part in this research, especially as the Trust records show that a significant number of older inpatients at that time were aged between 84-92 years. Both sets of interviews with older people took place between the months of November and January in two of the coldest winters and with Christmas intervening which could have adversely affected recruitment. As the research team did not directly recruit patients or their relatives/carers, it is not possible (and perhaps not appropriate) to 'estimate' response rates, especially as some invitations have been returned stating that the older person has died or been admitted to a care home. It should also be pointed out that low response rates from older people are well documented (Bayer 2010). For example, the National Dementia Audit (RCP, 2010) also has a very low response rate (only 256 questionnaires returned from the 145 participating acute wards) of no more than a five to ten percent at best.

The important question to address is whether the reduced recruitment results in a biased sample by recruiting people with a 'story to tell' and a number of points can usefully be made in relation to this. First, as most of the older people gave positive accounts of their care, this is unlikely to be the case. Second, by using observation as well as interview data, such an effect (if it did exist) would be balanced. Third, even with the smaller number of interviews than originally intended, theoretical saturation was achieved with no new data emerging from relatives or older people on either positive or negative accounts of care.

The average age of the older participants is 74.5 years and, as table 3 shows, the sample included a distribution of informants in their 60s, 70s and 80s (young-old and old-old). There were an equal number of male and female participants.

#### **Characteristics of Older People (N=40)**

#### Table 3: Age/Gender

Age	Male	Female
65 – 70 years	3	8
71 – 80 years	10	6
81 – 90 years	6	5
91 – 100 years	0	1
Not known	1	0
Total	20	20

In terms of marital status and living arrangements, these are shown in table 4 together with housing tenure.

Marital Status	N
Married	23
Widowed	13
Unmarried	3
Divorced	1
Total	40
Living Arrangements	N
Lives With Spouse	23
Lives Alone	15
Lives with Relative/Friend	2
Total	40
Housing type	N
Owner occupier	33
Rented	7
Total	40

#### Table 4: Marital Status/Living Arrangements/Housing Tenure

The participants were asked to score their current health status using a linear analogue scale where zero is the worst imaginable health state and one hundred is the best imaginable health state. Seventy percent (N=28) of the sample scored their health at 50 or better, with nearly 50 percent rating their health above 70. This reflects the key statistics of the 2001 Census, which showed that the majority of older people including those aged 85 years and over rate their health as good or fairly good.

Score	Number of Older People
0 - 9	0
10 - 19	1
20 - 29	1

#### **Table 5: Self Reported Health Status**

5

30 - 39

40 - 49	4
50 - 59	7
60 - 69	2
70 - 79	7
80 - 89	7
90 – 99	5
100	0
Missing data	1
Total	40

#### 2) Carers

#### Recruitment

Participants were asked for permission to contact their relative/carer and, if given, they too were sent an information sheet together with a request to contact the researcher if they were interested in participating. On contacting the researcher, a similar process as that specified above was undertaken to ensure fully informed consent was sought.

The decision to interview relatives/carers and older people separately was taken following consultation with groups of older people and carers during development of the protocol, as little research evidence is available as a guide. However, if an older person wished to be interviewed in the presence of a relative or carer the researchers accommodated this, as it was important for interviewees to feel comfortable and at ease.

Inclusion criteria were:-

- Aged 18 years and over. No upper age limit.
- Identified by an older person as being their main relative/carer.
- Cognitively and linguistically able to participate in interview.
- Able and willing to give informed consent.

### Sample of Carers

The recruitment of relatives/carers for interview was obviously influenced by the recruitment of older people in three of the sites, although in total 25 were interviewed across the four sites (Downlands = six, Westway = eight, Uphill = four, Meadowfield = seven).

### **Characteristics of Carers**

In relation to carers, 56 percent (N=14) were over the age of 55 years and 44 percent were over the age of 65 (N=11). 60 Percent (N=15) were female and 24 percent (N=6) had been caring for the person for more than 10 years.

Age	Ν
25-34	2
35-44	0

### Table 6: Age/Gender and Time in Caring Role

45-54	2
55-64	3
65-74	8
75-84	3
Missing data	7
Gender	Ν
Male	10
Female	15
Length Of Time Caring	Ν
0-1 years	1
1-5 years	2
5-10 years	0
More than 10 years	6
Missing data	16
Total	25

#### **Interviews with Older People & Their Carers**

Building on the Dignity and Older Europeans study findings from focus groups, older people's views of dignified care were examined through in-depth interviews. Topic guides were developed around the project aims and objectives based on the available literature and these were piloted.

During the interviews, leading questions were avoided. Direct questioning is potentially problematic for frail, older people as they may feel inclined to respond in a socially acceptable manner (Cannell and Kahn, 1968). Closed questions were avoided as these offer easy choices rather than the respondent answering fully using recall and personal experience (Smith 1987). Open-ended questions allowed informants to express their views in their own terms.

The interview guides explored the following topics:

- Beliefs and feelings about ageing.
- Beliefs and feelings about dignity and dignified care.
- The inpatient experience including the positive and negative aspects of their care.
- Interaction with professionals.
- Involvement in care planning and treatment decisions, together with the information given to support this.
- The environment.
- The care given to other patients.
- Improving care for older people.

Interviews with relatives/carers explored beliefs and feelings about the following topics:

- Their caring role and responsibilities.
- Dignity and dignified care.
- Their and their relative's experience of hospital care.
- Interaction with professionals

- Involvement in care planning and discharge plans.
- The environment.
- Care given to other patients
- Improving care for older people.

Permission to record the interviews was sought and verbatim transcriptions were made. Once transcribed, all audio recording were erased. Transcripts were coded so that all identifying information was removed to ensure anonymity and protect confidentially.

#### 3) Trust Managers

#### Recruitment

Inclusion criteria were:-

- Senior or middle management position within one of the four Trusts involved in the study.
- Responsibility for patient experience.
- Willingness to give informed consent.

Trust managers in each study site were sent information sheets and invited to be interviewed. Written informed consent was sought prior to the interview. Thirty-two Interviews were carried out with a range of informants as detailed in table 7.

Table 7:	Trust	Manager	Roles
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Downlands	Westway	
Chair Trust Board	Chief Executive	
Chief Executive	Director of Medicine	
Director of Medicine	Director of Nursing	
<ul> <li>Director of Nursing</li> </ul>	Director of Finance	
• Director of Finance and Information	Patient Experience Manager	
<ul> <li>Complaints/PALS Manager</li> </ul>	Director of Operations	
<ul> <li>Consultant Nurse for Older People</li> </ul>	<ul> <li>Human Resources Manager</li> </ul>	
Matron	<ul> <li>Director of Service Planning</li> </ul>	
N = 8	<ul> <li>Director of Pharmacy &amp; Facilities,</li> </ul>	
	<ul> <li>Consultant Nurse for Vulnerable Adults</li> </ul>	
	N = 10	
Uphill	Meadowfield	
Chief Executive	Chair Trust Board	
<ul> <li>Complaints/PALS Manager</li> </ul>	<ul> <li>Director of Nursing</li> </ul>	
<ul> <li>Director of Nursing</li> </ul>	<ul> <li>Orthopaedic Matron</li> </ul>	
Matron	<ul> <li>PALS/Volunteer Manager, Equalities Officer</li> </ul>	
Director of Facilities	<ul> <li>Associate Director of Learning and</li> </ul>	
N = 5	Occupational Development	
	<ul> <li>Surgical Matron</li> </ul>	
	<ul> <li>Practice Development Matron</li> </ul>	
	<ul> <li>Associate Director of Facilities and</li> </ul>	
	Performance	

		N = 9
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#### **Characteristics of Trust Managers**

The characteristics of the Trust managers are shown in table 8 below. Over 37 percent were aged over 55 years (N=12) and almost 60 percent were female (N=19).

Seventy-five percent (N=24) were graduates and over 40 percent (N=13) had been qualified for 26 years or more.

#### Table 8: Trust Managers' Age/Gender/Education & Length of Time Qualified

Age	Ν
25-34	1
35-44	8
45-54	9
55-64	10
65 or over	2
Missing data	2
Gender	Ν
Male	13
Female	19
<b>Education Level</b>	Ν
Degree	24
Tertiary Certificate	7
Missing data	1
Time Qualified	N
0-5 years	3
6-10 years	2
11-15 years	4
16-20 years	0
21-25 years	4
26-30 years	6
Over 30 years	7
Not Applicable*	6
Total	32

\* Denotes the number of participants who deemed that their role did not have a specific qualification.

### Data Collection from Trust Managers

In-depth interviews with senior managers explored the broader influences on the ability of the service/organisation to provide dignified care (Ormrod, 2003; Calnan and Ferlie, 2003) including organisational and cultural factors, which might foster or detract from the experience of dignity. More specifically, informants were asked about their role and responsibilities and their beliefs about the following topics:

- Ageing and dignity.
- Older people's care.
- Dignity and the staff.
- Organisational policies to promote dignified care.
- Individual responsibility for ensuring dignity.
- Priorities and resources.
- Complaints procedures.

Again, the steps described in the previous section to ensure anonymity and protect confidentiality were adopted

#### 4) Ward Staff

#### Recruitment

Inclusion criteria were:

- Employment that requires direct contact with in-patients within the chosen clinical areas.
- Willingness to give informed consent.

Seventy-nine staff from a range of occupational groups participated in in-depth interviews. The numbers from each Trust and their occupational categories are shown below in table 9.

Staff Occupations	Downlands	Westway	Uphill	Meadowfield	Total
Ward	4	4	4	3	15
Managers/deputies					
Senior Staff Nurses	1	2	0	0	3
Staff Nurses	7	4	2	6	19
Student Nurses	3	0	2	1	6
Health Care Assistants	4	4	3	3	14
Domestic Staff	1	1	3	0	5
Occupational	2	0	0	0	2
Therapist/OT Assistant					
Physiotherapist/	0	4	1	0	5
Physiotherapy Assistant					
Dietician	0	1	0	0	1
Activities Co-ordinator	1	0	0	0	1
Receptionists	3	0	0	0	3
Doctors	1	2	1	1	5
Total	27	22	16	14	79

Table 9: Ward Staff Occupations

### Ward Staff Characteristics

As shown in table 10 below, staff from a range of age groups participated in the interviews. Approximately 77 percent (N=61) were female, while almost 42 percent of staff (N=33) were graduates. Twenty-four percent of participants (N=19) were newly qualified.

Age	Ν	
16-24	17	
25-34	18	
35-44	15	
45-54	20	
55-64	7	
65 or over	0	
Missing data	2	
Gender	N	
Male	18	
Female	61	
Education Level	N	
Degree	33	
Tertiary Certificate	24	
A or O Levels	14	
High School	5	
Missing data	3	
Time Qualified	N	
0-5 years	19	
6-10 years	8	
11-15 years	6	
16-20 years	1	
21-25 years	4	
26-30 years	3	
Over 30 years	5	
Not Applicable*	32	
Total	79	

#### Table 10: Ward Staff Age/Gender/Education/Time Qualified

\* Denotes the number of participants who deemed that their role did not have a specific qualification.

#### Data Collection from Ward Staff

Information sheets including a declaration of interest in being interviewed were made available to all staff at the outset of the study and to new staff as they started on the ward. Staff were asked to return the declarations of interest to a central collection box within each of the wards. Researchers then contacted the staff and sought written informed consent. The right to withdraw from the study was made clear to all staff. All participants received assurances that their confidentially and anonymity would protected and their comments would not be shared with managers. They were also informed that neither the Trust nor the wards would be identified in any reports or publications. Specific permission to use anonymised quotes in reports or publications was sought. The interviews explored the following topics:

- The availability of organisational guidance on dignity.
- Particular aspects of patient care and staff behaviour from the observations.
- Ageing and dignity.
- Dignified care and factors that promote/inhibit it.
- Most enjoyable and least favoured aspects of their role.
- Ward organisation and Trust policies.
- Education and training on delivering dignified care and care of older people.
- Strategies to improve care for older people.

# **Observation of Acute Settings**

The non-participant observations totalled 617 hours across the 16 wards in the four acute Trusts (see table 11 below).

### Table 11: Hours of Observation by Trust

	Downlands	Westway	Uphill	Meadowfield	Total
Hours of	142.5	142	156.5	176	617
Observation					

Initially, a detailed observation brief building on the literature, findings from the Dignity and Older Europeans study, NHS and Trust policies including benchmarking and audits, together with data drawn from the interviews with older people and their relatives/carers, was developed and discussed. This extensive and detailed brief was piloted and found to be too detailed to be helpful as it was distracting researchers from the process of observation. The brief was then reduced to a series of key areas (see Appendix 2) to assist researchers to focus down onto key events, activities, interactions and types of care.

All staff were notified in writing of the observations and informed of when researchers would be available to answer their questions. Particular aspects of the observation were discussed with inpatients as a means of triangulation to check on the interpretation of events by researchers. There was an initial discussion with the ward manager on each ward before observation commenced to decide on the practicalities of the observation sessions and if requested, a verbal feedback was given at the end of the period of observation to discuss the overall impressions gained by the researcher and any specific issues, which they may wish to address.

Because a researcher's presence may affect interactions, the first set of observations on each ward was discarded to take account of reactive effects, which are reduced with subsequent exposure, particularly if the researchers are as unobtrusive as possible (Mays and Pope 1995). The effect of the observer's presence erodes over time and so four hours was spent in each ward before recording observations to promote observer habituation.

Observation sessions of between two to four hours were undertaken, throughout the 24 hours, on each day of the week. Approximately 40 hours of observation was undertaken on each ward over a period of three to four weeks as the longer the observer is in the setting, the more in-depth knowledge of the setting, the interactions and practices can be gathered. Considerable time is necessary to gain the trust of ward staff.

An agreed format for field notes was used and each record was systematically logged and referenced. Concise field notes were written at each observation period including records of activities, conversations (where possible), critical and discrete events, contexts and interactions. Notes were made of who was involved, what was happening, where actions or interactions took place, when (including the timing), and a record of the researcher's feelings and changes in views (Silverman 2000). Following Spradley (1979), condensed notes were expanded as soon as possible following the observation period and fieldwork journals were kept by the researchers. To ensure consistency across the study, the researchers undertook simultaneous observation sessions in each other's sites and compared field notes to ensure a consistent approach and interpretation of the observation brief was adopted.

Initial observation sessions were broadly focused, enabling the researchers to get a feel for the ward as a whole and allow any significant issues, both positive and negative, to emerge. Following this, researchers were able to 'funnel' their observations for example to ensure they were present at key times of activity or when particular staff were on duty.

The observations identified aspects of ward activity, processes and organisation that may promote or challenge the experience of dignity and witnessed the impact of Trust priorities on patient care and staff work. No intimate personal care was directly observed, for example researchers did not enter closed rooms or curtains as this in itself would infringe a person's dignity. Whilst a non-participant approach was adopted, in practice the observers did sometimes get involved with tasks such as making drinks, as well as conversing with patients or informing staff that their help was needed.

As mentioned above, non-participant observation overcomes the discrepancies between what people say they do, as in the focus group interviews in the Dignity and Older Europeans study (Calnan and Tadd, 2005) and what they actually do, thereby avoiding the bias inherent in individual accounts of actions (Mays and Pope, 1995; Mills et al, 1994; Hammersley and Atkinson, 1995). Such discrepancies were evident in this study and are illustrated by the following three examples (A; B; C) which show both the gaps between what senior managers believe about official policies and their implementation in practice and also between ward staff reports and actual practices. The latter might reflect attempts to conceal what staff members know is not best practices and/or the genuine belief that they were actually doing what they report.

### A) Managerial Accounts of Practices

"But there is a group of patients, particularly elderly, confused patients that we would look and say, "No, these aren't the right people to transfer these aren't appropriate" and certainly we wouldn't you know."

(Trust Manager Interview)

The phone rings, it is the transfer ward who are expecting Nellie. The nurse gives a verbal handover on the phone. The staff are not happy about this as they know Nellie does not want to go [it is midnight] and 'she is confused already'. However they ring Medical Admission Unit (MAU) who apparently already have a special 'transfer team' tonight whose sole task is to move patients around and ask for helping moving Nellie, saying that that will mean they have a bed on this ward for one of the MAU patients [this appears to be a win-win situation as the move is undertaken by other staff and they can take a patient from the MAU. I talk to the staff nurse about moving patients around like this especially at night. She says there was a patient admitted from another ward last night at 2.30 in the morning – she was asleep and woke up in the morning not knowing where she was. She comments that all this activity makes the night staff's night go more quickly but it's not good for the patients. I wonder if there is something in this – night staff want to keep busy, etc). The other staff nurse comes back from Nellie, 'I've just had a telling off – she didn't want to move – I said it's not my decision, I've got nothing - I don't agree with it.'

(Observation)

## B) Ward Staff Reports on Practice

- 9.30am: Mr Dodds in a single room is naked in bed expect for his pad and the door is open. He remains like this all the time I observe until visiting time. (Observation)
- 11.00am: The wife and daughter of Mr Dodds (the old man who was lying uncovered earlier) walk slowly down the corridor. I hear them saying, *'She said they go in every 5 minutes but he keeps pulling his nappy off.'* As I expected, they must have arrived to see him and found him uncovered (in observation they did not go in every 5 minutes to cover him). They go into the day room to talk to a staff nurse. The staff nurse says, *'He had some porridge this morning.'* The daughter asks, *'How much?'* Staff nurse says, *'I don't know if he had it all but he had some.'* (I'm not sure if anyone really knows how much he eats). The daughter then says she will give him something as he usually takes it from her. I saw her feeding him the day before. As they go back I hear the wife say, *'It's better now he's all covered up.'* (Observation)

### C) Ward Staff Reports on Practice

The receptionist comes to the nurses' station to say that Mr Adams the man with learning difficulties who was discharged yesterday has rung up again to ask if he has left his purse behind – it had five pound notes in it. The staff nurse who was on duty the previous evening says, 'No – he phoned last night, we looked for it.' The receptionist goes back to the phone at her desk to tell him while the staff nurse goes on about it not being our responsibly and how, 'That's why we don't lock things up then they become our responsibility.' Meanwhile, a healthcare assistant (HCA) is sitting with the new patient in bed

12 looking at a purse – she comes over to the nurses' station with it and luckily the staff nurse spots her and says, 'Oh, have you just found that?' She says, yes, the new patient has just found it in his locker. They call out to the receptionist who is now talking to Mr A and tells him the purse has been found. The staff nurse goes on saying, 'We looked for that last night.' (In reality, she just walked past the bed on the previous evening).

(Observation)

## **Data Analysis**

It was intended that a new software package based on Framework Analysis (FA) (Ritchie and Spencer, 1994) due to be released in autumn 2008 would be used in analysing the data. This was because FA is particularly appropriate where the aims/objectives are established in advance (for example by funding bodies) rather than emerging from a purely reflexive process and where specific information or recommendations are required. Although the general approach in FA is inductive, it also allows for inclusion of a *priori* understandings as well as emergent concepts. However, there was a six month delay in release of the software and when obtained, it was found to be unsuitable to use across teams in a non-networked environment. There were also significant 'bugs' and a low level of technical support, which made use of the package impractical. Because of the size of the potential data set (176 interviews and 617 hours of observation field notes), this was too large to manage using FA in a 'manual' mode. It was therefore decided that an inductive, thematic analysis using constant comparison would be adopted, with N-vivo 8 software to assist in data management and analysis.

How a large data set is organised can influence interpretation and analysis and considerable discussion took place as to the optimum arrangements. These discussions involved external experts as well as the advisory group and the research team. For example, senior researchers in Natcen and an independent expert in the use of CAQDAS were consulted about the various ways of sorting and managing the extensive data set including whether data from individual sites should be analysed exclusively within each site or whether data should be pooled and analysed across the sites.

It was finally agreed that the typed field notes, memos and verbatim interview transcripts should be pooled across the four sites and analysed thematically aided by N-vivo 8. This was particularly important for the approach, which was not to maintain the specificities of 'cases' but rather to identify overarching themes that, pieced together, would form a **comprehensive picture of the collective experiences** of older people and those working on acute wards, so that these could be logically be said to 'represent' (Popay and Williams, 1998) other similar acute Trusts across the UK.

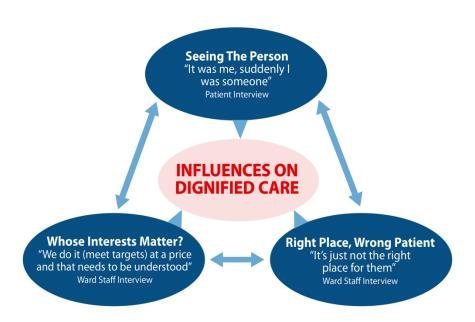
The approach to the data analysis was fundamentally interpretative, focusing on the processes by which meanings are created and negotiated. The study objectives were to explore what dignified care means to older people, their carers, people working on acute wards and managerial staff in acute NHS Trusts and, importantly, how these meanings are enacted and negotiated in practices of care. In response to this, we undertook a thematic analysis, ensuring the themes emerged from the data rather than being imposed by the research team. As is consistent with this approach, our data collection and analysis took © Queen's Printer and Controller of HMSO 2011. This work was produced by Tadd *et al.* under the terms of a 73 Project 08/1819/218

place simultaneously so that relevant literatures, past knowledge and experience of the research team and the process of interviewing and observation themselves, all informed the analysis and development of themes. A selection of transcripts were independently analysed by individual members of the research team and codes applied. This initial coding was discussed amongst the team, including the three service users, justified and refined and an initial coding framework of 24 codes was agreed and defined. This was then applied to all the transcripts and additional codes added or removed. This is essential to ensure the consistency with which codes are applied by different researchers on different occasions and therefore helps to ensure the reliability of the data. Frequent analysis meetings were held to discuss interpretations and refinements. From these codes, themes consisting of groups of codes were identified. The research team defined the themes as units derived from patterns of talk or actions such as conversation topics, recurring activities or feelings. Thus, themes were identified by 'bringing together components or fragments of ideas or experiences, which often are meaningless when viewed alone' (Leininger, 1985, p.60). When patterns emerged as a result of these emergent themes, we obtained feedback from our participants as well as drawing on the resources available to us through our advisory group, which included service users, representatives from a range of voluntary and statutory organisations and practitioners in order to validate our interpretations. This was also done during the interview process by asking participants to reflect on the meaning of their responses in order to check researcher interpretation.

To complement this approach, the comparative method was used to ensure that data from different people/sites was compared and contrasted until the team was satisfied that no new issues were arising as well as validating themes that arose across the various sites and individual participants. Comparative and thematic analysis are often used together to enable researchers to move backwards and forwards between transcripts, memos, observation notes and the research literature.

As well as being in keeping with an interpretative approach to the data, thematic analysis was used to sieve and pare our data in order to communicate the findings simply and effectively. Given the large amount of contextually laden, subjective and richly detailed data generated from the interview transcripts and observation field notes, this needed to be pared down to represent major themes or categories that best described the provision of acute care for older people. Ultimately, the analysis identified four overarching policy and practice themes (see Figure 2), which are discussed in the following four chapters.

#### **Figure 2: Key Themes**



# Validation of Findings

### **Involvement of Service Users**

Samples of the scripts were sent to the three service users who were members of the research team together with the initial coding framework developed from the literature and a priori knowledge of the researchers. Following discussion and agreement of the coding framework, the service users were then sent a sample of coded transcripts and field notes to agree researcher interpretation of the data.

### **Stakeholder Workshops**

In addition, four stakeholder workshops were held in Bristol, Manchester, Durham and London towards the end of the project. Each of these brought together a range of NHS managers and staff, voluntary organisations interested in or advocating for older people and policy makers (≈150 in total) to discuss the issues emerging from the study and determine how they resonated with their experience. Participants' views on policy and organisational changes they believed necessary to promote the dignity of older people were also sought.

The day consisted of an outline of the study methodology and the emergent key themes, interspersed with sessions where participants were invited to discuss the findings and their implications for policy and practice. A report of the workshops is included at Appendix 3.

## **Methodological Considerations**

Ethical approval for the study was gained from the South East Wales Research Ethics Committee where the procedural issues such as seeking informed consent, avoiding harm, confidentiality and anonymity were addressed. However, not all of the issues facing researchers can be addressed during this process as ethnographic studies necessarily involve issues arising as a result of the methodology or what Guillemin and Gillam, term 'ethics in practice' (2004). For example, how does one present oneself to a participant or setting to gain maximum 'information' (Fine, 1993) or, what steps one should take if, during an interview with an older person, it is disclosed that a health professional abused them? Or, during observation one sees neglectful or dangerous practice? These questions are not only methodological but also moral in nature, as they have implications for the integrity of the researcher and thus the study as a whole.

Another issue involves ensuring the rigour or quality of the research and an essential aspect of this involves critical reflection on the fact that all researchers are part of the social world in which they study, regardless of the approach they use. This in turn raises issues of subjectivity and bias when attempting to demonstrate the trustworthiness and integrity of their findings. It is therefore important that as the study is being carried out, researchers reflect back and forth on the research process, challenging their own perceptions and influences at all stages.

These and other considerations in relation to the quality of the study are discussed below.

## In Practice

Prior to embarking on the fieldwork, much discussion took place in relation to appropriate actions should researchers either observe or be made aware of harmful or neglectful These discussions involved the scientific advisor of the programme, senior practices. managers within the participating Trusts, advisory board members and the research team. In non-participant observation and other observational methods such as dementia care mapping, non-interference is the standard unless serious harm is likely (www.nursingtimes.net). If this was not the case, evidence of 'poor' practice would be difficult to gather. The human challenge of observing 'questionable' care is difficult for all researchers, but posed a professional challenge for one member of the team in particular. As a registered nurse she is bound by the NMC's (2008) professional code to ensure that the standard of care patients receive is appropriate and that there is no breach in the duty of care, which might result in individual harm. A protocol was developed (see Appendix 4) to deal with such events and it was agreed that where incidents would not cause serious and/or immediate harm, then the researcher should avoid direct intervention, but the ward manager/matron should be informed immediately following the event. Within the study, direct intervention was not necessary. However on a number of occasions, neglectful or poor practice was reported to the ward manager as its continued use could have resulted in harm to patients.

## Ensuring Rigour through Reflexivity

Every researcher's approach to data collection, organisation and analysis impacts on the results of the research and on how it is presented. There is no objective truth and different authors adopt different positions, for example, Husserl (1970) asserts that it is important to identify, examine and bracket out or reduce one's presuppositions and pre-understandings in order to enter the lived experience of the participants and appreciate their perspectives. In comparison, Heidegger (1962) argues that it is not possible or even desirable to bracket

personal beliefs and complete reduction is necessarily impossible. However, researchers should at least attempt to make their position explicit to better contextualise their understandings.

Three members of the research team undertook the majority of interviews, fieldwork and analysis. One spent many years as a nurse and senior lecturer in nursing before pursuing doctoral studies in applied ethics. She also coordinated the EU funded project Dignity and The second researcher is a social scientist with a theoretical and Older Europeans. substantive interest in medical sociology and in older people with dementia in particular. Her previous research was an ethnographic study of the care and treatment of older patients in emergency healthcare systems. The third researcher following a degree in psychology, qualified as an occupational therapist, working with older people in the community. She then moved into social services, continuing to research the needs and quality of services for both older and disabled people. A fourth team member is a medical sociologist who has worked in health policy and health services research and training for many years. He too was involved in the Dignity and Older Europeans study. In the current study, he played an important role in analysis meetings by raising questions and seeking justification for various interpretations, to promote collaborative reflection and debate. This helped to ensure that team members moved beyond their preconceived beliefs and prejudices to better represent the many voices and any conflicting opinions uncovered in the study. The regular analysis meetings offered the opportunity for team members to offer differing and sometimes conflicting perspectives and interpretations of the data and helped to facilitate enhanced reflexivity by supportive challenging.

## A Priori Assumptions

Two of the researchers involved in this study were also involved in the Dignity and Older Europeans study and were necessarily influenced by those findings as such prior knowledge cannot be set aside. It is also important to clarify that the key focus of this study is 'dignified care' rather than 'dignity' per se although of necessity one has a bearing on the other.

Certain aspects about dignity can be stated. It is essentially contested which refers to the fact that it is difficult to gain agreement upon its meaning in such a way that everyone might be satisfied. As seen in Chapter 2, this can have positive spin-offs by adding to the richness of the concept by considering widely differing views.

## A Model of Dignity

In terms of this study, the account of dignity which informed much of our thinking is that which was developed in the Dignity and Older Europeans study and which is widely cited especially on the Social Care Institute for Excellence website (http://www.scie.org.uk). This model of dignity highlights the objective and subjective elements. The objective aspect or 'human dignity' concerns the value that as humans we all possess (see for example the Universal Declaration of Human Rights, (UN), 1948), because we have the ability to make autonomous choices based on reason. It is from this objective aspect of human dignity that the concept of equal human rights and the right to respect for autonomy emerge and it is the duty of everyone to respect these rights in others. For older people, it is this type of dignity, which they refer to when they suggest that dignity concerns equal treatment and the right to make their own decisions and exercise control over their lives.

The subjective aspects of dignity include three 'types of dignity'. The dignity of moral stature, the dignity of merit and the dignity of personal identity. The dignity of moral stature refers to the individual's moral autonomy or integrity and suggests that a person has dignity if they are able to live according to their own moral principles. While not directly relevant to older people in healthcare (although in Chapter 6 some older people comment on aspects of their behaviour in an attempt to maintain their dignity), this type of dignity is particularly relevant to professionals. It is this type of dignity that is infringed when the systems in which they work, impact on their sense of dignity as a health professional. This experience often engenders feelings of frustration about the lack of resources necessary to fulfil the moral demands of humane and decent care for many older people.

The dignity of merit, refers to the fact that dignity may be ascribed to people due to their role in society. A common theme within the Dignity and Older Europeans study was the dignity ascribed to older people which failed to recognise their wisdom, their experience and the contributions they have made to society, all of which result in an obligation on others to treat them with respect.

The dignity of personal identity refers to the individual's capacity to construct a meaningful life narrative for him or herself, suggesting that the dignified person is someone who can provide a positive account of their life, either as in individual, or as a member of a group. If the person lacks the necessary cultural resources to tell this story, they can be in danger of being excluded or isolated from society. This type of dignity is particularly relevant to older participants most significantly insofar as they recognised the effect of ageist stereotypes and the lack of social worth, which they often experience. Negative impacts on older people reinforce feelings of marginalisation and impute lower social worth. This inhibits recognition of their true diversity and competence. Furthermore, it is this type of dignity which is most likely to be violated as a result of illness or frailty when the individual can no longer take care of themselves and must rely on others for the most intimate aspects of daily life. The absence of this type of dignity is often experienced as humiliation, degradation or embarrassment.

### **Dignified Care**

Evidence from the Dignity and Older Europeans study and those of many other authors (Jacelon, 2003; 2004; Matiti and Trorey, 2008; Baillie, 2008) have all identified the components of dignified care as comprising of the following aspects, which are confirmed in this study:-

- Respectful communication.
- Respects privacy.
- Promotes autonomy and a sense of control.
- Addresses basic human needs such as nutrition elimination and personal hygiene/appearance in a respective and sensitive manner.
- Inclusive and encourages participation.
- Promotes identity.
- Focuses on the individual.
- Recognises human rights such as equality, respect and autonomy.

Similarly, undignified care consists of care that:-

- Renders the individual invisible.
- Depersonalises or objectifies the individual.
- Is abusive and humiliating.
- Is narrowly focused.
- Disempowers the individual.

### The Credibility of the Findings

Ensuring the credibility of findings is also essential. In presenting the findings, a spread of data from participants, the Trusts and wards has been used to demonstrate that the findings and therefore the recommendations are based on an analysis of all of the data, rather than on a few well chosen examples. In this way, the validity of the conclusions drawn can be assured. This practice also adds to the transferability of the findings in that they form a broad picture of the collective experiences of older people and those working on acute wards, which can logically be said to 'represent' similar settings within the UK (Popay and Williams, 1998). For similar reasons, dramatic accounts, especially of negative examples of care, have been avoided as where these occurred they were the exception rather than the rule.

In addition, the study methods have incorporated:-

- Data triangulation from a range of sources including older people, their carers, Trust managers and ward staff.
- Source triangulation by in-depth study of 16 wards in four different Trusts over an extended period of time.
- An unstructured approach to data gathering, allowing key features to evolve through ongoing analysis.

Each of these factors add to the credibility of the findings.

PART TWO

# **Introduction to the Findings**

As is appropriate for an ethnographic study, the findings are discussed alongside their presentation in the following three chapters. The first two chapters, 4 and 5, discuss the systemic barriers to dignified care and therefore may appear excessively negative in their presentation. This is not the intention, instead the findings are intended to highlight for the reader the complexities of delivering dignified care, many of which are the result of decisions and factors beyond the influence of those involved in direct patient care. If dignified care is to become a reality for all older people, these barriers need to be enunciated and understood before they can be addressed. Failure to do this can result in the responsibility for providing care resting solely on the shoulders of individual staff or one occupational group when, in reality, the situation is more complex.

In Chapter 6, the personal experiences of dignity by older people, their relatives and the ward staff and the practicalities of delivering dignified care are explored at the level of the individuals involved.

In Part 3, Chapter 7 then considers all of the findings, identifying both the barriers to and enhancers of dignified care.

Before presenting the findings, a number of additional points should be emphasised.

Throughout the study, the majority of older people and their relatives participating in the interviews expressed views of the overall standards of care received, although as shown in the following chapters, their expectations of care were not high. They were generally complimentary about nursing staff who they felt work very hard.

Similarly, the majority of staff wish to deliver the highest standards of care possible and many of those who were interviewed expressed regret that this is not always possible. Circumstances are often difficult with staff shortages and bed pressures being a daily reality. Despite such sincere intentions, the fieldwork clearly demonstrates that the care provided to patients is variable. Nowhere was the care on any ward either totally 'dignified' or totally 'undignified', instead, the randomness of the quality reflected something of a lottery. This variability occurred from ward to ward, sometimes in the same ward when different staff are on duty or at different times of the day. For many older people, this inconsistency was something which they had to come to terms with. Comments such as, '....the day staff were very nice,... had a wonderful attitude with some patients. It was a different story on night time .... I was horrified by some of the night staff' highlight the unpredictable standards. For others, the inconsistency resulted in uncertainty about what would happen or what was expected of them, leading to even greater apprehension.

The difference between what people say they do and what they actually do, mentioned in Chapter 3, was also evident throughout the study. In ward staff interviews, for example, when asked about what was involved in promoting dignified care, the majority of staff mentioned ascertaining how people wished to be addressed and using that preferred name. In practice and from the interview accounts with older people, this did not happen. Similarly, with regard to the provision of choice and information and respecting privacy, many staff members highlighted these aspects within interviews, but in practice many older people and their relatives criticised the lack of information and choice and highlighted issues surrounding privacy.

In presenting these findings, a spread of data from all of the Trusts and wards has been used to demonstrate that the findings and therefore the recommendations are based on the analysis of all of the data, rather than on a few well chosen examples, ensuring that the conclusions drawn are valid.

Finally, the findings from this study concerning the meaning of dignity identified no new dimensions of dignity from those identified within the Dignity and Older Europeans and other studies previously cited. These include notions of identity, respect, recognition, independence, control and participation in decision making as being essential components of dignity and are discussed in more detail in Chapter 7.

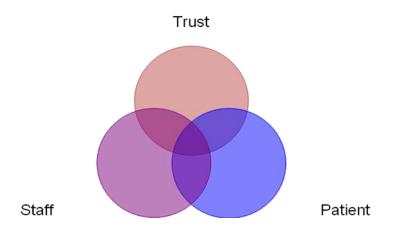
# **Chapter 4: Whose Interests Matter?**

'A patient is the most important person in our hospital. He is not an interruption to our work; he is the purpose of it. He is not an outsider in our hospital; he is a part of it. We are not doing a favour by serving him; he is doing us a favour by giving us an opportunity to do so.'

(Bombay Hospital motto adapted from a quotation by Mahatma Gandhi)

## Introduction

This chapter presents the findings concerning the systemic and organisational factors that influence the delivery of dignified care to older people in acute hospital Trusts. The title of the chapter has been chosen to reflect the multiple and at times, competing interests of NHS Trusts at the organisational, ward and individual levels. One of the central foci of this study has been to identify the occupational, organisational and cultural factors that impact on dignified care. It is recognised from the outset that individual staff practices cannot be abstracted from the habits, routines and values of the institution in which they work. Consequently, the approach is not only to focus on care practices, but also to explore the organisational cultures in which these practices are always embedded. Understanding the contexts of care is essential to reaching an informed and sustainable approach to changing practice. In paying attention to the contexts of care, it is clear that the interests of patients (and their relatives) at times conflict with those of acute Trusts, Trust managers and staff working on acute wards. By recognising these conflicts of interests, it is possible to identify some of the fundamental barriers to dignified care for older people.



### Figure 3: A Meeting of Interests or Conflict of Interests?

The chapter draws on all data sources and the examples exemplify how the competing concerns and priorities of acute Trusts as organisations and the subsequent ambiguity over the objectives of staff responsible for delivering care, create significant challenges to the realisation of dignified care. In exploring points at which interests intersect and conflict, this chapter necessarily identifies and highlights barriers to the provision of dignified care for

older people and thus may appear negatively skewed. In Chapter 7, the findings are drawn together across the themes and this balance is redressed by identifying aspects of the structure and organisation, as well as aspects of individual practice, that enhance older people's dignity.

The findings are discussed under the following headings:

- What matters is what is measured.
- The problem of risk and unintended consequences.
- Working the system and unintended consequences.
- Trust, blame and the culture of defensiveness.
- Protocols of care.
- Caring roles and the division of labour.
- Seeing the task.
- Staffing levels and continuity of care.

### What Matters Is What Is Measured

"Not everything that can be counted counts and not everything that counts can be counted."

### (Albert Einstein)

Einstein's maxim encapsulates the difficulties inherent in judging and measuring performance within an institution. This is especially problematic in UK acute Trusts where over the past decade there has been a drive towards regimes of clinical governance that assess performance based on measurable indicators. This move towards making clinical work more transparent and clinicians more accountable has partly been in response to a crisis in confidence in the medical profession generated by a number of high profile scandals during the 90s, including the high death rates in an infant cardiac surgery department in Bristol and children's organs being removed and retained during post-mortem examinations without parental consent in Liverpool (see Checkland et al, 2004).

With reference to the data, some of the consequences for the care of older people that result from relying solely on quantifiable indicators to judge current standards of care or ways in which to improve care in the future are discussed.

Fundamentally, there are huge difficulties in measuring 'quality' in healthcare. Making choices as to what to reward and what to value becomes a significant bureaucratic exercise. Due to the subjective qualities of both the subjects and the object of clinical work, trade-offs can occur between efficiency, safety and/or the quality of patient experience. There is an inherent inability within these measures to adequately account for the wider aspects of patient experience, such as the promotion of dignified care. Going back to Einstein's quote, the immeasurability of the patient's experiences in any quantifiable way, make it inevitable that regimes of regulation are unable to either reward or audit all of the things that matter:

"Aspects which are immeasurable, but are nonetheless exceedingly important to patient experience, are neglected." (Brown & Calnan, 2009: 15)

What is 'measured' can only ever be an indicator of the elements of care provision that occur in an acute service. Quantifiable measures can never provide a complete picture due to the complexity of illness and the subjective human experience of it. The problem arises, when indicators are turned into targets, as they [indicators] become the standard by which the whole service is judged. This means that a small, measurable element of a single aspect of care comes to represent the whole. As a consequence, the experiences of care that surround these measures are lost.

To take one example; a key concern of each of the Trusts is patient safety, particularly infection control. This has resulted in many audit practices and measures to manage the risk of infection effectively. Focusing only on what these measures can show, results in the older person's experience of care being neglected. For instance, processes put in place to control and manage infections such as being nursed in a side room engender increased feelings of isolation. Similarly, older people being moved around or between wards to ensure people with infections are nursed separately can result in disorientation, apprehension and confusion. The impact on older people's experiences of care are likely to be ignored as they are not part of what is measured in managing infection. Many older people interviewed and observed, experience isolation when separated into side rooms with limited contact with others, feelings exaggerated by restricted visiting hours, which is also intended to reduce the risk of infection. This older person explains the feelings of loneliness and isolation from being barrier nursed in a side room:

"You wouldn't want to be in a little room on my [sic] own because you felt lonely, on your own. You're not feeling well. If there's something going on around you that you can watch it takes your mind off it. But that's the only time I've cried in hospital, being in a little room on my own. No, I didn't like it."

(Interview with a 68 year old woman, Carnation Ward, Downlands Trust)

From observations on the same ward, this woman's experience was confirmed as it was apparent how people in side rooms are often neglected and have less opportunity for engagement with staff and other patients:

The side rooms are difficult to manage as they are rather isolated and tend to get left. Nobody seems to check the side rooms unless they call.

(Observation: Carnation Ward, Downlands Trust, Night Duty)

One ward sister believed that the patients' needs are secondary to the focus on infection control:

She showed the researcher around the bays and pointed out that there were no lockers anymore as they had been told to remove them as part of the 'de-cluttering' drive. She said she tried to keep everything on their table, which becomes very cluttered or in the cupboard in the wall, which they cannot reach. There is a real problem with things getting lost, particularly hearing aids, which are expensive

(Observation: Marigold Ward, Downlands Trust).

In summary, concentrating on measures to increase confidence in performance has dysfunctional consequences. The most obvious of these is the potential for the distortion that occurs when particular performance targets, such as infection control, are privileged above all else. As Strathern (2000) makes clear, the technology embedded in audit is not a good means of understanding how organisations 'really' work, because it 'gobbles up' one kind of information, in this case rates of infection, but cannot get to the real essence of overall quality, namely the increased isolation and lack of human recognition. What can happen as a result is that aspects of practice that are not being measured are given less priority. Given that experiences of care and of dignified care are impossible to measure, or at least not in any quantifiable way, this poses serious challenges to the provision of dignified care.

## The Problem of Risk and Unintended Consequences

For the 4 Trusts in this study, managing risk is central to the organisation of acute care. This is not only evident at the level of Trust board policy and strategy it is present at every level of care provision. The most visible of these risks concern patient infections, managed through infection control policies and procedures. The risk of patient falls is another concern for older patients and with other untoward incidents on the wards, prevention of these is also central to the practices of care. The priority given to managing these risks is not in itself problematic as safety and prevention of harm are as much a concern of patients and their families as they are of Trust boards. However, following the crisis of confidence in the medical profession discussed earlier, there has been a significant shift in attitude that has demanded that internal strategies to regulate risk in clinical practice, be brought into public scrutiny with the publication of hospital 'league tables', rather than being left to managers to deal with in appropriate ways.

The response to the need for further regulation of clinical practice has resulted in the management of risk being subjected to audit and transparent practice. It is this approach to the regulation of risk that alters the ways in which staff approach care delivery and subsequently poses a threat to older people's dignity. In all areas of healthcare there are inherent uncertainties regarding both clinical outcome and the patients' experience of care. NHS policy over the past decade has attempted to eradicate these uncertainties through regulatory systems in the form of clinical governance. This approach aims to manage risk through calculability. The premise being that by eradicating the variable nature of clinical practice that relies on the particular expertise of clinical teams within a locality, it will be possible to achieve a more standardised, homogenous practice by following protocols,

monitoring and audit, target and performance measures (Checkland et al, 2004; Brown and Calnan, 2009).

These internal systems of control seek to 'operationalise' the management of what Power (2004) describes as societal risks, such as accidental harm done to patients in the course of clinical treatment or care, so that they become, instead, 'system risks'. The consequence of this is that the risk of harm to patients has become part of the regulatory regime of healthcare and therefore a matter for healthcare organisations rather than clinicians. Managing the risks posed to older people's care both in terms of clinical outcome and the experience of care has become a 'systems risk' and as such the societal risk, namely the risk to older people, is neglected in favour of safeguarding the system itself. Trusts as institutions are consequently more concerned with managing the 'secondary risks' described by Power (2004) as risks to the organisation rather than being concerned about the wellbeing of the individuals that the organisation serves. Such secondary risks include litigation, failure to meet targets and the accompanying punitive financial repercussions or the reputational risk to the Trust. By managing institutional risk, which always focuses on the political and financial capital that surrounds issues such as infection control, falls or waiting times, rather than on minimising the risk to individual older people, the opportunities for dignified care may well be exacerbated.

As highlighted above, the prioritisation of infection control as a Trust priority can have unintended consequences on the quality of the patient experience. Similarly, the priority given to managing risks related to patient safety, particularly when these risks are altered from being societal to 'system risks', also has unintended effects as the opportunity to balance risks to ensure the overall quality of care for an older person is diminished. Due to concerns of potential risks to the system, of falls and other untoward incidents, the culture of acute care practice encourages patients to remain in their chairs and use bedpans or commodes rather than being helped to a toilet. Staff are also more likely to adopt habits of using bed rails when perhaps they are not necessary.

"I think that staff are very safety conscious and if bedrails are on beds, they think they need to pull them up and if they leave them down that could be being neglectful, even though that actually might be the right decision for that patient and there might still be risks, it's about balancing them."

(Interview with a Consultant Nurse, Westway Trust)

The scenario described above was evident throughout our observations on the acute wards, where concerns for patient safety, particularly for confused patients or those with dementia, means that staff spend a great deal of time preventing patients from moving out of their chairs. The fear of people falling or of them handling technical equipment that may pose risks to others was evident on many of the observed wards:

Phillip is standing up and is trying to walk. Both the SN and the SSN rush to him and take him gently back to his chair, saying, 'There's a cup of tea coming round in a minute.' (I later discover Phillip is described as a 'wanderer' and has had a number of falls). Phillip has got up again; he says he is going next door. The HCA says, 'I need you

to sit down, will you sit down for me? Stay there for a bit, stay there for me'. (Observation: Marigold Ward, Downlands Trust, Afternoon) These constant attempts to control confused patients and make them sit down in one place sometimes leads to increased agitation (Marshall and Allen, 2006).

The examples illustrate how clinical governance systems work to 'operationalise' risks which, as Power (2004) describes, means that they are rendered 'calculable' and monitored for the danger they pose to the organisation. As a result, they become less about the individual who is at risk, in this case the older person, and more about managing responsibility, blame and the possible repercussions of this risk to the system at large. Below are some examples that illustrate how staff manage risks in ways that can detract from patients' dignity:

Annie calls out again and Amy goes to her.

'Can I go to the toilet please?'

'You've got a pad on.'

'Can I have help to the toilet please?'

*'If you... (she sighs with frustration) you've got low pressure, when you stand up your blood pressure drops and you'll be falling'* 

(Observation: Wellington Ward, Westway Trust, Night Duty)

This example on a general medical ward raises an important question: when are risks worth taking when balanced with a patient's experience of care and their sense of dignity? Annie's risk of falling in this case is not balanced against the indignity of being told to soil herself and the feelings of degradation that must naturally follow. Instead, what we see is that care practices tend to be risk averse and do not balance the possibilities of harm to the person's sense of worth, their identity and fundamentally their dignity. An alternative and less forgiving account of this observation might be that the nurses are busy trying to settle patients for the night and there are insufficient staff available to take Annie to the toilet. However, the widespread use of justifications such as the one above (the risk of falls) was observed in many wards throughout the study, at times when staff were less pressured. On this basis, the conclusion is that such actions stem from the desire to avoid risk.

The focus on risk avoidance can, in some cases, override an appreciation of a person's dignity and sense of worth, as Dorothy's experience described below exemplifies:

I hear Dorothy saying she would like to go to the toilet and the HCA calls for the SN to come and help her. I hear a disagreement commence – the patient says she has a pad and she has definitely 'gone.' The HCA seems to be disputing this saying, 'there's nothing there' and 'hold on to the frame.' The patient says again, 'No, I've just gone again, look, I'm doing it see.' The HCA then says, 'I'm more concerned with you holding on to the frame.' The nurse has come out to look for wet wipes and the HCA then tells Dorothy to sit down while she goes to look for the nurse. They return together and both enter the curtains from opposite ends without knocking. They tell her they are going to put her on to the bed and to reach back to hold it. I hear Dorothy saying, *'I'm sorry about that.'* I hear no response from the Staff.

(Observation: Carnation Ward, Downlands Trust, Afternoon)

This example is particularly poignant in illustrating the sometimes extreme compromises to older people's dignity that staff are willing to make in ensuring that risks are being managed. Dorothy is extremely concerned about being able to maintain her self-respect by avoiding the situation she finds herself in, whereas the staff accept this situation as a consequence of avoiding Dorothy falling. Dorothy's plea to use the toilet is ignored by the staff, partly due to their attention being focused on her 'holding on to the frame' beyond anything else. This takes away her control, disconnecting Dorothy from her own body, something that can leave people feeling violated as the boundaries to the self are unable to be preserved (Waskul and Reit, 2002).

The centrality of risk in the culture of these acute Trusts and the practices of care that this generates, mean that control, often over fundamental aspects of older people's bodies and selves, are taken from them as this next example illustrates:

Respondent:	'Well they wheeled me into a room waiting for the x-ray you see and he plonked me there and said I'll be back for you in a quarter of an hour and the fellow came out and called my name and I just got out of the wheelchair and walked'
Wife:	'Walked over.'
Respondent:	'People were looking, thinking, wondering what's going on?'
Wife:	'I haven't really thought about this because you're quite right because there wasn't particularly probably any real reason for you to be in the wheelchair apart from some sort of control thing that they like to know where you are.'
Respondent:	'Yeah. Absolutely, yes.'
Interviewer:	and that you stay there and that they know when you're going.
Respondent:	'You are our responsibility and therefore we will Escort you to this place, you don't go on your own.'
Interviewer:	Yes, but it does have an effect on how you feel, doesn't it, and yourhow powerful you feel. And as you say, just getting up and walking across the

the room probably made you feel quite powerful really that you could just do that.

Respondent: 'Yes, indeed'

(Interview with 79 year old man and his wife, Daffodil Ward, Downlands Trust)

This man describes how he was put in a wheelchair, regardless of his ability to walk, wheeled along a hospital corridor and told to wait in the chair for his scan. The decision of staff to automatically use a wheelchair to transport this man who still has his mobility intact, left him with a reduced sense of control and placed the connection between his body and his selfimage in jeopardy, which is an integral part of maintaining one's identity and sense of dignity. The decision to use a wheelchair highlights both the culture of risk aversion across acute Trusts and the time pressures. In talking to staff and observing on the wards, it is clear that 'busyness' is also a central feature of the acute Trust culture. Transporting an older person in a wheelchair is seen as a quicker and easier option than helping them to walk. This has repercussions for how older people experience being patients on acute wards, something that is developed in the following two chapters.

## Working the System and Unintended Consequences

The ways in which staff interpret clinical governance requirements and the target driven priorities of waiting times, patient safety and particularly infection control has many unintended consequences on daily practice. As demonstrated above, this can mean that staff become risk averse, often protecting themselves and the Trust against 'secondary risks' posed to the institution.

In one Trust, this tendency was recognised and steps to address the issues were being taken through additional training. As the quote below shows, the lack of power experienced by frontline staff was clearly recognised:

"No, it's about leadership and it's about a culture and it's equally about everybody owning that and I think, you know, we're running a programme which we've developed, which we've called 'Valuing Patients, Valuing Staff' and we're taking frontline staff and their Supervisors because what you find is for whatever reason the staff are feeling slightly disempowered, so they know what needs to be done, and quite often that takes no money...[Hmm]... it doesn't actually take any time, just takes a bit of thought and a little bit of effort, but they – they would argue they can't do it because nobody's told them they can or because it doesn't fit the Trust policy or, because they want to do something and the supervisor comes along and says, "Well actually you can't do that". So, we're trying to instil a culture where you know service improvement belongs to everybody and it isn't about a central team jettisoned in to do, it's about you understanding your service, your ward, your department and the needs of your patients and making a difference. The smallest difference an make a huge difference to the patients. So, it's very much about the culture and that comes from leadership. Leadership sets the culture, it's okay

to do, it's okay to take a risk, it's okay to have a try and if it doesn't go well, then we'll learn from that and we'll try something else."

(Interview with Director of Learning and Development, Meadowfield Trust)

Staff can also become involved in what Smith (1998) has termed as 'gaming', whereby they engage in games in an attempt to 'beat' the system. Examples of this include the moving of patients around wards and the hospital to meet the maximum four hour wait target in Accident and Emergency departments, or to meet waiting list targets.

In this study, 'gaming' occurred most often as a response to the policy across all of the acute Trusts of maintaining a high level of bed occupancy to increase efficiency, service rationalisation and the specialisation of services on particular hospital sites and wards within them. The policy of high bed occupancy leaves no slack in the system for emergency admissions and means that staff are under immense pressure to make beds available, as this example illustrates:

There is some discussion about a new patient who is being sent up from theatre but they haven't got a bed. They mention that Sharon had been asked to go to ward 15 as the most independent patient on the ward but has refused. They are not sure who else they can move. In the end, a SN says, 'Going to have to ring theatre and ask them to hold on to her until we've got a bed sorted.'

(Observation: Carnation Ward, Downlands Trust, Lunchtime)

The meeting of Trust priorities, especially bed occupancy targets can work against the organisation by increasing other risks, especially that of hospital acquired infection as this Trust manager recognises:

'Whenever we have a death or a colectomy as a result of the C-Diff infection or we do a root cause analysis if we get an MRSA bacteraemia, then we always look at movement and often particularly with C-Diff patients you will find that they've had multiple moves. Now whether there's a relationship between those two things, we haven't quite worked out, but yeah, so that's something that we do look at.'

(Interview with a Nurse Director, Downlands Trust)

Moving patients around the hospital to meet bed occupancy targets can also increase the length of stay of some patients, result in poorer outcomes and have other negative impacts, including the prioritisation of patients for treatment being based on organisational, rather than clinical grounds, often, with a reduction in the overall quality of care, which patients receive:

An HCA had been with Ellen behind curtains in bed 28. Her son has been waiting in the corridor. A SN passing stops and tells him that the plan is to move Ellen to ward 10, 'a rehabilitation ward' – she tells him she will come and talk to them later and help them pack up. This she does but as they are doing it another SN comes down the corridor saying, 'Don't send her to ward 10, the matron has just rung up to say they have had to give the bed to someone else'. The son stands by in amazement then starts to unpack her things again.

(Observation: Thames Ward, Uphill Trust, Afternoon)

I move round to the nurses' station. There is a discussion going on about who to admit next. It has been agreed to take a patient from ward 10 (to swap with Ellen) but one of the junior doctors says tactfully, 'Do you know these are the ones the consultants want up' (pointing to a list of names on the white board). Then the rather more pushy senior house officer (SHO) says that a particular patient Mr X must come as he is on a treatment that they can't manage on his current ward. The SN then has to go and stop the first transfer and arrange for Mr X to come. A little later the phone goes and it is the ward where Mr X is currently – they say they can't send him as he needs a single room.

(Observation: Wye Ward, Uphill Trust, Afternoon)

Such pressure on beds, alongside the requirement to maintain single sex bays within wards, means that patients are continually moved within wards, between wards or even between hospital sites. Older people tend to fall victim to this more than most, as their clinical needs often do not fit easily into a single specialism. Older people whose acute illness is complicated by confusion or dementia are most likely to be moved as their needs are often seen as 'inappropriate' in the specialist acute ward, as this nurse describes:-

She immediately tells me she knows what is wrong – she says it is having dementia patients on acute wards. She tells me of the difficulties nursing aggressive dementia patients on bays with other patients. She says dementia patients can be moved round the hospital three or four times during their stay and this increases their confusion and aggression.

(Observation: Severn Ward, Uphill Trust, Night Duty)

This pressure on beds requiring the movement of patients, impacts on the quality of care older people receive. Older people receive less attention on the wards as they are seen as being in the 'wrong' place (an issue discussed in detail in Chapter 5). When patients are moved in the middle of the night, as often occurs, levels of confusion increase, as do cases of missing property. This unintended consequence is a drain on Trust resources as is the cost of dealing with the complaints from patients about the possessions lost during the moves:

"He lost part of his property in that move because it happened in the middle of the night and that's not supposed to happen. There is a cut off point for transfers, so I believe you're not supposed to be transferred after 8pm. And that's certainly something we see, there's a lot of claims for lost hearing aids, glasses and false teeth. It's a massive amount of money this Trust pays out for that." (Interview with Complaints/PALS Manager, Downlands Trust A further example of the unintended consequence of Trust priorities is the costs in staff time spent packing patients' belongings, transporting them, giving handovers to other clinical teams and cleaning vacated beds and bed areas for the next incomer. This time and the resources spent on these activities could be spent delivering dignified care:-

"Well, I mean it wouldn't even bother me if I had to say I'm really, really sorry, you've got to go, take the brunt of whatever I was going to take and take it, we take it every day so, you know, that wouldn't be an issue to me. But the actual packing up, ringing the porters, handing over the patient like to wherever they're going, making sure all medications go up with them. Making sure that all the discharge management stuff is all sorted to go up with them. All the notes are ready to go up with them and that you've documented that you're transferring them elsewhere and then ringing the relatives to tell them that they're not actually on this ward. Just to transfer one patient. Now sometimes you can have six of them."

(Interview with a Staff Nurse, Ash Ward, Meadowfield Trust)

This time and energy involved in moving patients is also demoralising for staff who feel this should not be the primary focus of their role, as this member of staff describes:

"I didn't come into nursing care to ship patients to different wards; I came into nursing to nurse in care, you know, and all the nurses are the same"

(Interview with a Staff Nurse, Elm Ward, Meadowfield Trust)

More importantly, however, it gives an impression to older people and their relatives that they are of little value and don't matter much:

'Anyway we went back on...From Brown ward where we'd been taken we then went back to Red ward. We were put in the first bay and you were shown the bed and we were just left. I felt that I shouldn't actually leave. I wasn't happy about leaving. I think it was about 9.45/10.00 at night when I left and I thought it doesn't feel right to actually leave. I don't trust the people because they haven't made sure that everything is in order, that Dad's comfortable.'

(Interview with the daughter of a 78 year old man, Daffodil Ward, Downlands Trust)

The 'gaming' practices mentioned above can also manifest in ways that use the system, or interpret Trust priorities, to continue and legitimate ward working practices. In the example below, the healthcare assistant (HCA) refuses to allow an older man to wear his glasses to see his nails on the grounds of potential harm:-

#### 'Can I have a nail brush?'

*Yes, I'm doing your hands now. We haven't got a nail brush but we've got these wipes. Oh, your nails need cutting. Oh, here we go okay?'* 

'What are you doing?'

'It's okay, your nails are thick so they're bending a bit, but you're okay'

'Oh, stop it'

'You're okay, they're just thick, I promise. See, that's it now'

'They're bleeding'

'No, they're fine, look. Okay?'

'Where are my spectacles?'

'On the side, nice and safe'

'Where?'

'Here' (She picks them up and shows them to him)

'Can I put them on?'

'If you put them on, you might roll on to them and hurt your face in the night, okay?'

(Observation: Wellington Ward, Westway Trust, Night Duty)

The risk posed to this man is one that can be easily managed, therefore the decision the healthcare assistant makes in not allowing him to wear his glasses is less to do with the risk of harm to the patient and more to do with the working practices on the ward, especially completing tasks quickly and moving on to the next patient, something explored in more detail in Chapter 6. Despite feeling some sympathy for the healthcare assistant who is trying to settle patients for the night, the impact on this man's sense of dignity is that he is patronised and treated as one might a child, showing him the glasses but not allowing him to put them on. Rather than reorganising working practices to fit the Trust priority of managing risk, staff instead use Trust priorities to legitimate cultural aspects of the ward that values getting jobs done in a timely fashion.

There are other examples where staff draw upon Trust policies to legitimate the particular cultures of care amongst the ward team. For instance, different wards had different attitudes towards relationships with relatives. On some wards they were seen as an irritation and a distraction and their enquiries were a nuisance, as the observation below illustrates:

helps the staff; if the relatives help to care for their loved ones. 'Not really. Not many of them are here for the right reasons, they tend to just interfere. If they are here to help out of concern that's great, but when you've got medicines to administer you don't have time to answer their twenty questions.'

(Observation: Wellington Ward, Westway Trust, Evening)

This attitude towards relatives and/or carers reflects a certain distrust of 'outsiders' on the wards who may be critical of the approach adopted. On other wards, relatives appear to be supported and valued almost as much as the patients:

When Nancy's husband arrived on the ward, outside of visiting hours (something normally frowned upon) the staff were extremely pleased to see him. Particularly Beryl, who told him how much better Nancy is when he is around, 'She is not aggressive, she doesn't wander off and she seems much happier in herself.'

(Observation: Nelson Ward, Westway Trust, Afternoon)

In the previous example, the relative is recognised for his expertise in caring for his wife. On wards where relatives are viewed as a nuisance, the staff explain the ward's limited visiting hours or restrictions on relatives' access by referring to Trust policies to promote patient safety, by reducing infection. Some staff also used the patient's right to dignity by suggesting that relatives could not be present when they were providing intimate care, even when those relatives had a direct caring role outside of the hospital:

"I think, you know, visiting times is a major compromise on patients' dignity sometimes and I don't think that people see the broader picture."

(Interview with the Deputy Ward Manager, Drake Ward, Westway Trust)

This deputy ward manager continues by explaining that visitors often intrude upon aspects of care, particularly when they are used to caring at home, in ways that aren't appropriate within a hospital environment. This problem is also identified by Allen (2000) who describes the problematic role of the 'expert carer' on hospital wards and the power struggles that can arise between relatives/carers and ward staff.

What is evident from this study is the tremendous work involved in negotiating and maintaining positive relationships between relatives and staff. Staff can feel challenged by relatives, viewing them as a threat as the ward is where nurses have control over the organisation and process of care and in many instances, define the care standards. The challenge of defining care standards is one of the strongest themes across all of the Trusts in the study. This involves staff reflecting on what they believe to be unrealistic expectations of care by relatives and patients, as this quote illustrates:

"I think sometimes families have unrealistic expectations and patients have unrealistic expectations of what goes on and they sort of assume that you're the one person looking after their family and that doesn't, it obviously doesn't work like that all, um, and, you know, 'Oh why weren't you here to do that?' It's like, 'Well, I'm sorry I was somewhere else.'"

(Interview with a Specialist Registrar, Ash Ward, Meadowfield Trust)

What this notion of 'working the system' brings to light in particular are the ways in which staff participate in negotiations, through recourse to Trust policies, priorities and targets to legitimate particular approaches to the care of older people and to assert their authority in setting care standards that may differ from those of relatives/carers or even the patient.

## Trust, Blame and the Culture of Defensiveness

The centrality of governance procedures, as well as a more general societal trend towards complaints and litigation (Nettleton et al, 2008), results in increased decisiveness in the relations between patients (and their relatives/carers) and the staff. This is driven in part by a culture of defensiveness amongst Trust staff, which is echoed in the account by a Trust manager:

"I think we're quite defensive about the services that we provide and we don't like to take onboard that we are doing things wrong."

(Interview with Complaints Manager, Downlands Trust)

Increased surveillance and control through clinical governance processes, designed to enhance confidence in acute care, neglect the importance of building trust at the point of care. As Tsoukas (1997) explains, the more information on the inner workings of an organisation, the less inclination there is to trust its practitioners. In other words, the increase in regulatory regimes can reduce the opportunities for trust between patients and practitioners. For Checkland et al (2004), attempting to build confidence in systems through rules is misguided and they suggest that more attention should be paid to sharing information and communication between individual health professionals and their patients.

If we return to Power's (2004) idea of 'system risk', the tendency amongst staff is one of selfprotection, which contributes to the broader systems approach of managing the 'secondary risks' of blame, reputation and punitive financial sanctions to the organisation. As such, the culture is one in which mistakes are not permitted, or at least that is the perception of many of the staff participating in the interviews. One of the consequences of this culture of defensiveness is that staff come to view patients as an enemy to defend themselves against as Jim, one of the staff nurses, describes, '*It's turned into a big game of them and us.*'

Two members of staff I hadn't seen before came up to the nurses' station and ask Jim (a staff nurse) about the man who'd had a fall. He tells them that the man said he's fallen, '*but he was back in bed and given how much he struggles in and out of bed I don't know how he would've got himself back into bed.*' They nodded and headed down to the bay. Jackie (a HCA) tells me, '*This man says he had a fall out of the bed onto the floor right, but he never could've got off the floor if that'd happened.*' Jim: 'He did say this morning that he almost fell.'

Jackie: 'That's why no-one will see to him on their own now.'

Jim: 'It's turned into a big game of them and us.'

(Observation: Wellington Ward, Westway Trust, Morning)

This defensive practice can also mean a lack of engagement amongst staff or between staff and patients and their relatives about problems that arise on the wards. Interviews with relatives and patients highlight how, when they approach staff about a particular problem, which they are willing to resolve with the staff involved, are instead handed a form about the complaints procedure as the following interview with a Trust manager exemplifies:

"And quite often also a thing that's come through from patients, just while I remember it and relatives is when they have approached staff saying, I'm not very happy about it and they're given a complaints leaflet or a PALS leaflet."

(Interview with a Complaints Manager, Downlands Trust)

This is also reflected in the way staff respond to concerns on the wards. Below is an extract from a relative's interview where she describes trying to talk to a member of staff about concerns she had about her mother's care:

"I mean there was one time I tried to speak to one of them and she said, 'Yes?' and leant against the wall and looked at me and I said, 'I'm sorry, I'm not going to speak to anybody like that, leaning against the wall and so on, I'd prefer to go somewhere private, can we go to....' And she said – she said – I don't know what she thought I was going to say, she said, 'Well, yes, I suppose so, but I'll have to have a witness.' And she went off and got someone else and fair enough and we're sitting, you know, like this. Now I don't know whether she thought I was going to hit her, verbally abuse her or what, but I think, I suppose I felt they were on the defensive which is a shame."

(Interview with the relative of an 84 year old woman with dementia, Oak Ward, Meadowfield Trust)

This example highlights some of the ramifications of attempting to build confidence through rules and regimes at the system level rather than building trust at the point of care.

In exploring the impact of this, Smith (2001) makes a helpful distinction between 'confidence' and 'trust'. Confidence, as she explains, governs everyday interactions where we assume relative certainty provided by abstract systems such as role expectations, commonly shared norms, expert knowledge, systems of regulation and law for example. Trust on the other hand is necessary where there is vulnerability or uncertainty and it arises

between individuals rather than between individuals and systems. NHS policy has concentrated on founding organisational and professional practice on confidence rather than trust. The problem in doing this is that confidence obscures the uncertainty associated with much clinical care, as well as the complex personal interrelationships involved in maintaining positive experiences of care. Mistakes then become unacceptable, as a number of interviews with ward staff highlighted and was observed in the defensive practices that occur when problems arise.

The processing and handling of complaints within Trusts provides another example of the self-protective practices meant to eradicate risks posed to the institution by mistakes being made. Handling complaints is an administrative process that is not necessarily responsive to the issues raised. Complaints are taken and responded to within a certain number of days with a standard letter. The process is highly bureaucratic and can be demoralising for those staff working within the system:

"Within the complaints team I feel the function is basically to take the complaint. The complaint is processed and it's sent to complaints coordinators who then request whoever is appropriate to investigate and give a response and then the response is sort of coordinated and cut and pasted into different sort of templates. I think that people don't want it to be like that but I just think that the nature of the work sort of makes it turn out that way."

(Interview with the Complaints/PALS Manager, Uphill Trust)

Attempting to build confidence through system processes diminishes the opportunity for trust to develop between practitioners and patients. Issues raised are frequently and quickly positioned within the regimes of regulation, such as the formal complaints procedure. Many issues would be better dealt with directly by the person involved and the failure to adopt such an approach poses difficulties for patients and relatives who are met with a bureaucratic response to a problem, which often has emotional undertones. Such responses also diminish the moral motivation of clinical staff by shifting accountability away from the relationship between the practitioner and patient, to those with powers of sanction, on the basis of rules and measures that may not fit with the staff member's internal moral motivation.

## **Protocols of Care**

Clinical governance has attempted to regulate the practitioner-patient encounter in an effort to develop an evidence-based standardised approach to providing care and treatment. Harrison (2002) has termed this 'scientific bureaucratic medicine' consisting of set protocols and care pathways for the treatment and care of particular disease categories. One of the difficulties with such an approach is the large number of anomalous situations, particularly in acute care, that require a creative, reflective approach for which a protocol is insufficient. This is particularly true when caring for older people whose multiple needs often cut across disease categories and are often accompanied with complex social situations that further complicate strategies for care. Furthermore, this kind of approach to healthcare reduces the possibility to build more meaningful relationships between practitioner and patient.

Such approaches can also result in the loss of a broader understanding of patients as people. This not only limits possibilities for recognising diagnostically significant signs and symptoms that exist outside of formal set protocols for assessment, but also discounts aspects of the person's social circumstances, thoughts and feelings, which may impinge upon clinical assessment, clinical outcomes and the person's experience of care.

The nurse in the extract below explains the importance of recognising what she describes as the 'little issues' in providing dignified care to older people:

"I mean, as a mentor, as a nursing mentor, you have the opportunity to sit down with students and explain to them what is going on with the patients and the little issues that aren't related to the illness at all. Seeing the validity of that is, is an issue and quite difficult for a lot of students."

(Interview with a Senior Staff Nurse, Churchill Ward, Westway Trust)

These 'little issues' that help staff to provide dignified care come not from checklists or tick box evaluations, but from the staff member's expertise in establishing a relationship with people and getting to know their needs. Such expertise is built on an accumulation of handson experience of providing patient care that is responsive to them as people, as well as patients with conditions.

The extract below describes an example of the ways in which the recording of information can take precedence over the more embodied process of interacting with people to read and assess their needs:

William says he doesn't want any [food]. The HCA tries to persuade him to have some soup and the domestic shouts out that he didn't eat anything the night before nor for breakfast. The HCA says, 'I think he needs to be referred to the dietician and we need to set up a food chart.'

(Observation: Severn Ward, Uphill Trust, Lunchtime)

In this example, a patient who is not eating or drinking enough is put on a food and fluids chart and perhaps referred to a dietician. However, the people recording what he has had to eat or drink that day do not talk to him about his appetite, how he is feeling in himself, or if there is any physical problem that may be preventing him from eating. The process of recording is not seen as an opportunity to engage with the person, as staff tend to ask each other about what the person has eaten, ensure it is recorded and leave the patient's bedside without any interaction with the person at all:

"I think the main problem is when, because we have to document everything we do and if we're sat at the desk writing they think we're not doing anything. If we keep answering the bells and keep going to patients then we end up not going home until sort of half an hour after our shift's finished and you don't mind it now and again but when it comes to all the time it's just not..."

(Interview with a Staff Nurse, Daffodil Ward, Downlands Trust)

As the above quote describes, every aspect of care must be recorded and often recorded two or three times in different formats. Many staff members suggested that the prevailing view was that: *'If it isn't written down it hasn't been done'*, which supports the argument above about practices designed to manage responsibility and blame ('secondary risks'). Of course, the assumption implied by this mantra is that if it is written down it has 'been done' but the earlier example about food and fluid charts illustrates this is not necessarily the case.

Although the literature on increased governance and regulation of clinical practice has mainly focused on doctors and medicine (Nettleton et al, 2008; Harrison, 2002; Flynn, 2004 for example), increased regulation over the assessment, treatment and care of patients in the form of tick box evaluations, audit, standardised assessments, protocols and set patient pathways, as evidenced above, has spread throughout all areas of healthcare practice including nursing, healthcare assistants and therapists. The focus of these assessments is often to ensure that information is recorded and it is the recording of the information, rather than its quality or how well it reflects a person's needs, which takes precedence.

The reliance and focus on adhering to checklists for day-to-day assessment and observation of patients, detracts from the staff's ability to draw on broader experiences in assessing patients. The tools for assessment are not in themselves problematic, the problems arise when these aids to assessment become the assessment itself. Nettleton et al (2008) suggest that due to the increased attempts to regulate and standardise aspects of healthcare work, the essential embodied knowledge and practices of practitioners are diminished.

Medicine is often referred to as an art rather than a science because making a clinical diagnosis requires tacit knowledge derived from an accumulation of hands-on experience (Polanyi, 1966). This tacit knowledge and embodied practice, is essential to all areas of healthcare to ensure staff are able to assess and respond to patients as people rather than as a fixed type of patient who requires a standard pathway and an accompanying set of assessment protocols.

Flynn (2004) suggests that the codified knowledge underpinning the culmination of evidence-based practice and increased audit and regulation, represents a 'machine bureaucracy' that attempts to minimise the use of tacit knowledge and correct mistakes through performance monitoring. This is particularly problematic in the provision of dignified care, as the process of assessing and caring for patients is fundamentally an embodied practice and one that requires trust, intuition and instinct, as well as checklists, protocols and pathways based on evidence.

Working in an organisational culture where the avoidance of risk forms a central part of all guidelines and where procedures and protocols govern the provision of care can reduce opportunities to instil broader experiential knowledge of caring for older people. This is particularly true for those training or recently qualified who work on acute wards and who

often gain limited hands-on experience with older patients, as in the case of this newly qualified occupational therapist:-

She has just qualified and is on rotation currently working with the rheumatology patients. She doesn't feel she has enough to do but the OT on the ward won't let her work with the other patients. She has come to see Margaret in bed 14 and she comments that she doesn't look too good today. She has a short chat with her and then leaves.

(Observation: Severn Ward, Uphill Trust, Morning)

The culture across these acute Trusts of ensuring quality through setting standards and regulatory mechanisms to monitor them can result in a reliance on formal procedures, even when a degree of discretion would be more appropriate. Reflecting the culture of self-protection across the acute Trusts, individual members of staff would often seek safety in the system by following a protocol, as this account of a daughter who wanted to take her father's body home illustrates:-

John had died the previous night. Evidently he went in his sleep; his relatives weren't with him and were quite upset. The staff tell me about the difficulties in deciding who should tell his brother, Arthur, who is also on the ward and in the end leave it to the daughter. They also had a problem because the daughter wanted to take the body straight away but they couldn't let it go 'as there were procedures to go through' and there was no-one to contact over the weekend.

(Observation: Severn Ward, Uphill Trust, Night Duty)

Acting outside of formal procedures or using discretion to deal with more sensitive situations was something that staff seemed reluctant to do across all the Trusts as the following extract from a Trust manager describes:

"And you know you ask them the question, 'Well who said you can't do that?' and they don't know who said they can't do it. 'Cause [sic] actually nobody said they couldn't, they can do it, they just think they can't do it."

(Interview with Director of Learning, Meadowfield Trust)

In each of the Trusts, staff tended to act within the rules or at least the rules as they understood them. The few exceptions to this tended to be people in positions of authority who felt confident that they were supported in their actions.

# Caring Roles and the Division of Labour

Findings presented so far have reflected the Trust level systems and structures that impinge upon the provision of dignified care for older people. Those reflecting local ward cultures will be discussed to demonstrate the significant role they play in influencing the quality of care. These cultures are in part embedded within the wider Trust systems and structures but they also reflect the routines and habits that develop within particular ward teams.

Observations of care and interviews with staff highlighted how the physical tasks of washing patients, making them comfortable, providing personal care and assisting with eating and drinking take time and are delegated to the least qualified staff who have the lowest status in the hierarchy. This is also identified within the literature (Firth-Cozens and Cornwell, 2009), as a development exacerbated by policies to reduce labour costs whilst achieving higher quality (Allen 1997).

Observations of care showed that the tasks involved in intimate care tended to be undertaken by healthcare assistants. The process of spending time with patients as part of providing care appeared to be devalued and nurses claimed that spending time with patients was something that was only possible to do once the 'more important' things such as distributing medications and doing paperwork had been completed:

The staff nurse arrived in the bay with the medications trolley. Emily asked if she could go to the toilet. The staff nurse said she would have to wait as she had to complete the medications. She then locked the trolley and left the ward. After a few minutes she returned with one of the male HCA's who took Emily to the toilet, whilst she continued to give out the medications. [It struck me that in the time it took to find the HCA she could have taken Emily to the toilet herself.]

(Observation: Elm Ward, Meadowfield Trust, Evening)

Observations such as this are reflected across the 16 wards that took part in this study, although to varying degrees. As well as being echoed by some older nurses that this is a problem of 'nurses today' who have distanced themselves from aspects seen to be mundane or unskilled, it was also noted by some patients:

"I think that's where nursing is going wrong, is that some of these nurses now don't want to do the mundane tasks that the old, you know, nurses in the 40s and 50s had to do. They think to themselves we've got a degree. We've got a degree now, we don't do things like that you know, I think."

(Interview with a 70 year old man, Wye Ward, Uphill Trust)

The demarcation of roles in the nursing of patients on acute wards can pose problems for both teamwork and valuing the comprehensive tasks and activities that contribute to providing patient care as this example illustrates: I meet up with the two HCAs who are checking backs at the other end of the ward. One in particular gives me a long moan about the morale of the HCAs, 'We are the ones who do all the work – we do everything, since the nurses have had their pay rise they think they are above it – even the ones that were good aren't anymore...' The other HCA seems to agree but doesn't say much. [The HCAs do seem to be the ones who are expected to respond to buzzers and the staff nurses only respond if they have to. Although I have seen this happen quite often, some staff nurses willingly help HCAs if asked and sometimes without being asked. However, the staff nurses do spend a lot of time either with the medication trolley, the computer or doing paperwork at the desk].

(Observation: Severn Ward, Uphill Trust, Night Duty)

The problem raised here is not so much the extent to which nurses contribute to 'hands on care', which differs from ward to ward, but the feeling amongst staff of this work not being seen as of importance or value, as the healthcare assistants suggest that the nurses think 'they are above it'.

Daykin and Clarke (2000) also recognise the relationship problems resulting from changes in the organisation and the nature of nursing work and the central caring role of HCAs. This demarcation of roles also impacts older people's care, as this next extract shows:

A buzzer has been going for some time on the North side. It is coming from the male toilet. The ward sister has been standing in the corridor during all this time with the medication trolley. After about 10 minutes an HCA comes past and shouts, *'I'm coming Gerry'* – she goes and does something in the day room. She then comes back and goes and gets Gerald from the WC.

(Observation: Severn Ward, Uphill Trust, Morning)

Here, the ward sister ignores the buzzer and continues distributing medications. As a result, the patient is left for over ten minutes in a toilet. An alternative interpretation is that the ward sister is confronted by a conflict of priorities – continue with medications as nursing staff are not supposed to interrupt medication rounds or deal with a patient who needs attention. However, in observations many qualified staff did lock and leave the medicine trolley to fulfil other duties. In the following example, the ward sister demonstrates different priorities:

When I arrive on the ward, the deputy ward manager is doing the medications. She is in the female nine-bed bay. She does make a point of lowering her voice to ask, 'Anything for your bowels?' One of the patients asks, 'I need the toilet' when she arrives at her bed. She stops doing the medications and helps take the woman to the toilet. She looks at me as she passes and says, 'You can never do one thing at a time.'

### (Observation: Wellington Ward, Westway Trust, Morning)

How care work is allocated, appears to be a function of the ward culture and the example set by the ward leader and as shown above, this can impact on team work and staff satisfaction as demonstrated by the events cited on Severn ward above.

The difficulties posed by the narrow focus of caring roles are not limited to nurses and healthcare assistants but includes therapists and doctors. On many occasions, the specific interest or focus of one practitioner would come in to conflict with those of another, without anyone reflecting on the impact on the patient's overall care. The extract below during a period of observation on a stroke ward exemplifies the ways in which staff can work against each other due to a focus on their particular role:

Tim is waiting for his lunch while the other patients are being washed and changed ready for their food. In-between HCAs are helping George with his food as he keeps losing where things are on his table. The dietician comes over to Tim's bed and looks around. Jenny (one of the HCAs) asks her what she needs and she replies, '*I'm just wondering why he's not eating that's all'* – as she leaves the bay she rolls her eyes at me as if to say why is no-one giving this man his food. Each member of staff is very focused on their tasks whether it is nutrition (dietician) or personal care (HCAs) so they are often pulling against each other rather than working together.

(Observation: Churchill Ward, Westway Trust, Lunchtime)

Task allocation results in a greater potential for patients to be neglected in the delivery of basic care, as this example from a relative's interview describes:

"He was flat on his back, I went out to see him and his wife made a point of coming every day at 11.45 or else he would have had nothing to eat. She's a doctor actually so she's a very busy woman but I met her just by accident in the corridor and she said, 'Oh, I'm going to see him as well or else he won't have anything to eat', because he couldn't eat, he was flat on his back."

(Interview with relative of a 78 year old man, Carnation Ward, Downlands Trust) Seeing the Task

Despite the current policy and strategy focus on person-centred care and the patient experience, observations in the wards suggest that care remains task orientated and delivered in a way that best suits the ward routines and practices and team members rather than being responsive to patient need:

It takes quite a while before they go back to Enid who has been waiting on the commode. I hear Enid say something that I can't hear from behind the curtain and the staff nurse responds, saying: 'Would a catheter be better?' 'Yeah, it would really' What's the best way to pop it in, get you on the bed?' 'No, not really' 'What do you normally do then?' I normally hold on to my chest of drawers and...' 'The chest of drawers aren't here' [laughs]. 'Shall we get you on the bed then?'

(Observation: Wellington Ward, Westway Trust, Evening)

Enid is used to performing self-catheterisation at home. On this occasion instead of responding to Enid's preferred method or offering her the possibility of inserting her own catheter, the staff appear to ignore her comments and get Enid onto the bed. This makes the task quicker and easier for them as performing a catheterisation with someone standing would be difficult. Performing the task for Enid in this way would probably be quicker than allowing Enid to catheterise herself. An alternative interpretation resulted from discussion of this case at one of the stakeholder workshops, where a senior nurse suggested the decision to get Enid 'up on the bed' could also be to do with concerns over safety, adhering to protocol and fear of litigation. What is notable is that regardless of the motivation, in this instance, the staff, having asked Enid's opinion, fail to explain their decision and the reasons behind it. In doing so, they ignore Enid's suggestion, or worse by laughing at it, humiliate Enid even further.

The problem with falling into routines, particularly when tasks involve sensitive, intimate aspects of care, is that staff can become less responsive to the person and their preferences. This is further complicated when patients' preferences are difficult to read, as is often the case for older, frail patients. Staff should be attuned to patients' verbal and non-verbal responses to their approaches to providing intimate care, something that habit, routine and orientation to the task do not always allow. This was identified by Eraut: 'Routines tend to become increasingly dysfunctional over time: not only do they fail to adjust to new circumstances but 'shortcuts' gradually intrude, some of which only help professionals to cope with pressure at the expense of helping their clients' (Eraut, 1994: 112).

Despite being busy, some staff managed to complete tasks in ways which took account of patient preferences and allayed their anxieties about being a nuisance or causing nurses additional work. Such actions convey to patients the sense that they are important, a sense of being valued, rather than the receiver of a series of tasks to tick off a list:

The HCA was with a woman in the bed to the right helping her to wash. The curtain was drawn and I heard the patient ask, 'Are you struggling for time? I don't want to be a nuisance' and the HCA responded: 'No, don't be silly. If you want to soak your feet that's fine.' The woman said, 'It's just that they're so difficult to reach, sorry to be a nuisance.' 'You're not a nuisance at all, that's what we're here for.' The HCA comes out from behind the curtain and goes to the sink to fill up a bowl with water and then calls to the patient to ask if it is okay if she comes back in. She then opens the curtains and tells the woman, 'There you go now call if you need anything and let us know when you're finished and we'll come and sort you out okay?'

(Observation: Nelson Ward, Westway Trust, Morning)

# **Staffing Levels and Continuity of Care**

One of the complex issues in relation to providing dignified care is building relationships between staff and patients. The numbers of dependent older patients with co-morbidities who occupy acute medical beds have risen considerably over the last 10 years, while staffing levels have stayed much the same. This was the view of many ward sisters and other clinical staff who described the difficulties they experienced in managing workloads with current staffing levels and the implications that has on the time and ability of staff to provide high quality care:

Interviewer:	Yeah. Is there anything that stops you doing that? Are there any times when you're not able to do what you would like to do really?
Respondent:	'It's time constraints really. I mean you could Sometimes, you know, a patient is laid in a wet bed and that you don't actually have time to go and clear them up and that's awful because'
Interviewer:	That's terrible, yes
Respondent:	'They're looking at you and it's obviously uncomfortable and obviously not nice but …'
Interviewer:	And does that often happen would you say?
Respondent:	'Not so much on the early shift but on the late shifts it can quite happen, yes.'
Interviewer:	'Because there's less staff?'
Respondent:	'Yeah. And it's like they're trying You've got the HCAs trying to do dinner and there's only two of them. We're trying to do the drug round which is very important because otherwise the late staffthe night staff can't do their drugs on time and it is very difficult.'

(Interview with a newly qualified Staff Nurse, Daffodil Ward, Downlands Trust)

Inadequate staffing levels have a major impact on delivering both dignified care and care of an acceptable standard as the example above demonstrates. The impact is further intensified when added to reduced bed numbers, high bed occupancy rates and frequent movement of patients in an effort to improve productivity and patient flow. Together these factors make it more difficult for staff to get to know patients and appreciate their needs so © Queen's Printer and Controller of HMSO 2011. This work was produced by Tadd *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. Project 08/1819/218 that the continuity of care suffers. Also, staff too are often peripatetic and so are less likely to feel supported or part of the ward team. This was also reflected in patients' and relatives' experiences:

While in the corridor, the relatives look at the board with the pictures and names of all the members of ward staff. The son turns to his mum and says, 'I don't recognise half of them' and then says, 'They all do different shifts I suppose.'

(Observation: Churchill Ward, Westway Trust, Evening)

To try and resolve this problem and ensure patients are adequately informed, some wards operate a 'named nurse' system where patients are allocated to a specific nurse who has responsibility for overseeing their care and providing information. However, this strategy is not implemented consistently or effectively. This is partly due to the short length of stay of many patients, together with the introduction of 12 or even 14 hour shifts. This means that the 'named nurse' might be present on the day of admission but not on duty again until after discharge.

The significance of ensuring continuity of care in maintaining older people's dignity was seen during observations. Patients develop relationships with particular members of staff and these are fundamental to them feeling comfortable about receiving intimate care. These relationships are often disrupted by staff shift patterns, the movement of staff between different ward teams, as well as the movement of patients themselves. Below is an example of one relationship between one of the patients Laura and Rose, a healthcare assistant:

Betty:	'Can I sit in my chair, I'm really uncomfortable in bed?'
Rose:	'Yeah, give me 2 minutes and I'll come back and help you into your chair okay? Morning Laura. How are you? Did you have a shower yesterday?'
Laura:	'No.'
Rose:	'No. You gonna [sic] have one this morning?'
Laura:	'I was waiting for you.'
Rose:	'Yeah, but I'm working on the other side this morning – make sure you ask for a shower.'

[Laura doesn't ask another member of staff for a shower]

(Observation: Oak Ward, Meadowfield Trust, Morning)

The introduction of 14 hour shifts in some wards were used by ward managers to offer their staff more flexibility and a better work/life balance, particularly those caring for young children or older relatives. From the patients' point of view, the debate is whether it is

better to have continuity of care throughout a day, with the same member of staff caring for you from when you wake up until you go to sleep, or to have continuity over many days so that you are cared for by the 'named nurse' from arrival on the ward to discharge. During the observations, it was noted staff working 12 or 14 hours were exhausted by the end of their shift and this also had an impact on the quality of care delivery. In reality, patients experienced a lack of continuity in their care, with some describing situations in which it was rare to see the same member of staff more than once:

Interviewer:	Did you get the impression whether the staff were
	agency staff or were they permanently on that ward
	or didn't you know really?

Respondent: 'I think there was agency staff but I think the main members of staff were probably permanently on there. Because of course they change on shifts don't they? I only saw one nurse on two occasions. The rest of the time it was all change so I wouldn't actually know whether they were or not to be truthful.'

(Interview with a 68 year old woman, Carnation Ward, Downlands Trust)

# Care Quality, Trade Offs and the Balancing of Interests

Fundamentally, Trust initiatives, priorities and targets exist in a world of competing concerns and therefore when prioritising aspects of care through measures and performance targets, there will always be a trade off in which aspects of care quality – particularly those that are difficult to measure – are neglected. In the following example, a Trust board member describes some of the trade-offs between achieving shorter waiting times and the reduction in the quality of older people's care, which she describes as being like a conveyor belt:

"So, in a sense targets are a good thing [she spoke about reduced waiting times as an example] but everything has a price and the price is relentless pressure on the wards to shift people through as quickly as possible. I think it's too easy to lose sight of the fact that patients are human beings too and they need to be treated carefully and with respect. It is a genuine tension between the conveyor belt 'maximum throughput, minimum length of stay', 'get them out', 'get them through the system', 'next one please'. We do it at a price and that needs to be understood."

(Interview with a Trust Board Member, Downlands Trust)

# Summary

As the examples explored in this chapter have shown, the 'nothing' that, in the Trust board member's opinion, is lacking in patient care can be an older person's dignity. Focusing solely on what is measurable can also have a profound effect on those delivering care who may

come to feel that their work as care-givers is devalued because it is difficult to measure (Firth-Cozens and Cornwell, 2009).

What has driven the organisation of health services over the past 10 years has been a concern with the processes of clinical work which has taken precedence over the patients' interests. The finding above show how the mechanisms for regulating healthcare are themselves often the means by which patients' interests are undermined. Even where practitioners are able to resist complete compliance through 'gaming' practices or through subverting Trust priorities to legitimate their own practice, there is still a need to adhere, at least superficially, to organisational restrictions and protocols, not least for self-protection. The potential to divert attention from the patients' interests may therefore be even greater, as the regulatory procedures set the conditions within which practitioners are able to work.

The tensions and conflict of interest are deeply embedded in the demands placed on hospital staff. These cannot be overcome by individuals, but they can be reduced or reinforced by different models of regulation. A culture of trust, built through open communication at the level of practitioner and patient (and relative), together with the sharing of information may provide an alternative means of ensuring the quality of care in ways that would build on, rather than diminish, the moral motivations of the staff providing care.

The current forms of regulation do not correspond with the values and moral motivations or the social structures that exist amongst professionals and ward teams. As a result, these forms of regulation cannot facilitate change in the quality of care (Davies, 2002). Instead, staff participate in 'gaming' while continuing to adhere to the informal structures of Trust and ward cultures. As previous commentators have suggested, (Davies et al, 2000), organisational culture is not uniform or coherent. This was identified in the 4 acute Trusts where some cultural attributes were seen to be prominent only in one section of the organisation, such as a particular ward team or professional group. Perhaps a focus on changing cultures of care, rather than formal structures of regulation would offer a more appropriate means of impacting on and improving the quality of older people's care in acute Trusts.

Initiating such a change is immensely difficult, as organisational culture change involves complex social phenomena that are not readily amenable to external controls. However, there are some attributes or organisations that aid the process of culture change, including the ability to re-learn and re-educate staff to think differently. This together with positive leadership to promote new approaches, are examples of such attributes (Meek, 1988; Mannion et al, 2010).

Many of the unintended consequences of Trust priorities discussed in this chapter have adverse effects not only in terms of conflict with patients' (and relatives') interests, but also with the interests of clinical staff, Trust managers and Trusts as organisations.

The findings suggest that the interests of staff, Trusts and patients (and relatives) do not necessarily have to conflict. By paying attention to the quality of care for older people, Trusts can more readily ensure dignified care, reduce the risk of infection, reduce unnecessary drains on Trust resources and improve staff morale.

Overwhelmingly, individuals working in the 4 NHS Trusts, as managers and frontline staff, are motivated to represent patients' interests but their individual motivations are frequently compromised by a number of systemic and organisational factors that this chapter has tried to address. These include: setting acute Trust priorities on the basis of measurable performance indicators; the culture of blame and the management of 'secondary risks'; the organisation of service provision, particularly the high bed occupancy rate; increased specialisation; and rationalisation of wards and hospital sites. Finally, local ward cultures that have developed in the context of untenable staffing levels, the focus on the task and a strictly demarcated and hierarchical division of labour result in a struggle to provide continuity of care.

To end this chapter, a quote from a Trust manager highlights the huge challenges facing staff at all levels in promoting the patient's interests as being those that matter the most:-

'Nothing – nothing gets equal weighting to targets and finance regardless of what people say to you about the NHS. At the end of the day that is what drives people because it's about sustainability. What is an organisation supposed to do but concentrate on survival? Will it ever be survival to us around the quality of care that people get? If you look at Mid Staffs who were struggling to survive with their finances and their four hour targets, and dignity and respect get lost. I always feel that that's my responsibility, at the Board, is about bringing people back to the primary focus of our existence – what about the patient in this?

(Interview with a Nurse Director, Meadowfield Trust)

# **Chapter 5: Right Place – Wrong Patient**

*'When we talk about providing care for inpatients, we are in effect talking about care of the elderly.'* 

(Director of Operations, Westway Trust)

# Introduction

In this chapter a key message echoed by staff at all levels in the organisations involved in this study was that the acute hospital is not the 'right place' for older people is explored. The chapter examines how the prevalence of this view has resulted in the physical environment, staff skills and education and organisational processes acting as barriers to delivering dignified care to older people.

Environmental barriers include:

- the disempowering nature of acute wards, which add to, the disorientation experienced by many older people on admission to hospital.
- the concern engendered in many older people by being in close proximity to patients of the opposite gender.
- the boredom and dejection resulting from the loss of communal spaces and activities.
- the environmental hazards that the acute ward presents especially for older people whose acute illness is compounded by dementia, confusion and/or delirium.
- the lack of information about the personnel and ward routines.

Barriers to dignified care due to deficiencies in the knowledge and experience of ward staff include:

- a lack of attention paid to the care needs of older people in educational programmes.
- a lack of knowledge of the needs of people with dementia.
- the impact of increasing specialisation.
- the lack of training in relation to the provision of dignified care.

In terms of organisational processes the main barriers are:

- the perpetual movement of older people within and between hospital wards.
- the view that these patients should not be there anyway.

In describing these barriers, these findings necessarily describe the negative impacts on dignity and dignified care. However, in Chapter 7, this balance will be redressed when possible solutions and strategies to enhance dignified care are discussed.

As described in Chapter 1, the majority of beds in acute hospitals are occupied by older people who are likely to be very old (Oliver, 2010; Parker et al, 2006), yet the quotation above was a solitary voice amongst those we spoke to.

The Director of Operations cited above also described a recent survey carried out in the Trust:-

"One of our doctors recently did a survey on our medical wards, it was about 200 beds on – on this site and the average age of the patients in the beds when he did the census was 82, that was – and ten percent of the patients were over 92."

(Interview with a Director of Operations, Westway Trust)

As previously discussed, these older people are also likely to be confused, either acutely due to a change of environment, infection, stroke or their treatment or due to some form of dementia and they will probably have more than one ongoing medical condition as well as the acute condition that brought them into the hospital (Wanless, 2006; Parker et al, 2006).

The typical patient arriving on an acute ward is therefore old, possibly confused and with more than two long-term conditions. However the prevalent view expressed in each of the four sites within this study is that acute wards are the wrong place for older people.

One member of the ward staff commented during one of the interviews:

*"It's just not the right place for them."* 

(Interview with a Staff Nurse, Ouse Ward, Uphill Trust)

This sentiment was echoed by many ward staff and Trust managers. Sometimes the reference was to old people in general, but often it referred to older people who were confused or had a number of chronic conditions in addition to the condition for which they were ostensibly admitted.

This chapter will explore what lies behind this view that the acute hospital is not the 'right place' for older people. It draws on the analysis of the data to highlight features of the physical environment, staff skills and the ward culture, which impact on the acute care of the older person and the extent to which these are compatible with dignified care.

# **Disempowering Spaces**

The impact of the physical environment on a person's sense of wellbeing is not a new concept (Davies, 2000a; Haak, 2009), indeed the effect of the hospital on a patient's health and recovery was highlighted by Florence Nightingale who observed that, 'a variety of form and brilliance of colour in the objects presented to patients are an actual means of recovery' (Nightingale, 1859). There is a growing body of literature that describes the kinds of environment that can promote health and wellbeing through the use of colour, lighting, layout and signage as these aspects can maximise an individual's sense of control whilst minimising the impact of confusion or dementia (Day et al, 2000; Dalke et al, 2005; Marquardt and Schmeig, 2009).

Although each Trust, and many wards within each Trust, are different in their physical design, there are a number of common features across these areas concerning layout, use of space and equipment, which have a direct effect on the experience of older people, and © Queen's Printer and Controller of HMSO 2011. This work was produced by Tadd *et al.* under the terms of a 116 Project 08/1819/218

which influence the way staff work and therefore affect the provision of dignified care (Aitkin, 2008).

#### **Designed to Disorientate**

The hospitals in this study, like most in the UK, are confusing places. There are often identical corridors painted in the same colours and a lack of distinguishing features as shown in the images below:



Illustration 1: Showing the Almost Identical Nature of Two Different Hospital Corridors

Similarly, the wards and the bays within them often look identical, despite them sometimes being on different levels.

As one man who had experienced six moves commented:

"One ward looked very much the same as another. If they'd moved me when I was asleep, I simply would not have known I'd been moved. It was like that."

(Interview with 79 year old man, Oak Ward, Meadowfield Trust)

The difficulties this causes are demonstrated below when a patient was returned following a scan. The porters thought they were on the wrong ward and the patient agreed. Just as they were about to wheel him off again, a passing nurse recognised the patient and saved him from a long trawl around the hospital:

Two porters arrive with Mr Denton (bed 10). They ask him if he knows his bed number, which he doesn't – no-one asked seems to be able to help and the Porters say, 'They've given us the wrong ward again haven't they?' Mr Denton starts to say it's the wrong ward too (all the wards look very similar). Then the staff nurse comes out from behind the supper trolley and says, 'Oh yes, he's mine – bed 10' and they wheel him in. (Observation: Wye Ward, Uphill Trust, Afternoon)

Given the confusing design of many of the hospitals to the visitor, there is often little help for someone trying to navigate their way, especially if they feel vulnerable or are confused. Inside many wards it is rare to find signage or directions to toilets and washing facilities or even to the exit. Many doors have no signs at all and some bathing and toilet facilities have changeable signs according to the gender of the patients in the adjacent bays. There are usually few other clues to help people orient themselves in time and place and when clocks are present, they are often stopped or show the wrong time:

He [a patient] asks what time it is and I look over at the clock and say well that one's stopped at 3.15 but I think it's actually around 12 or quarter past.

(Observation: Oak Ward, Meadowfield Trust, Afternoon)

Nor are there date boards or signs showing the name of the hospital or ward. It is easy for patients who are frequently moved from ward to ward to lose track of where they are and the monotony of daily experience means that even those who are not cognitively impaired tend to lose track of time and day:

As the male healthcare assistant (MCHA) is leaving the ward, Alan asks, 'Is it Saturday 23<sup>rd</sup> May?' The MHCA confirms this and Alan says, 'It's hard to know what day it is – they are all the same.'

(Observation: Carnation Ward, Downlands Trust, Morning)

The notice boards in evidence are often covered in A4 sheets of small type-face writing, with inadequate or out of date information about the ward's performance in various audits which would be fairly meaningless to most patients or their relatives. On some wards, other notice boards display various documents from the DH's Dignity in Care campaign.

One ward, which is specifically for older people with dementia who are acutely ill, is the exception to this general rule about signage. Here there are more signs and pictures on the doors to indicate bedrooms, bathrooms, toilets and such like. However, even on this ward, the only notice board in the corridor is the ubiquitous plastic covered 'Ward Performance' board. The ward manager commented that they did have a pin board with photographs of the staff showing their different uniforms but it had to be removed as part of the infection control measures.

The net result of such poorly designed areas is a sense of disempowerment as the patient (or visitor) is forced to seek help to negotiate the immediate environment. This sense of a lack of control together with the forced dependence upon their carers is well documented in much of the literature on promoting the older person's dignity. It results in damage to the individual's sense of self as a competent individual therefore negatively impacting upon their self-respect as well as their identity (Davies, 2000; Baillie, 2007; Baillie 2008; Gallagher et al, 2008; Matiti and Trorey, 2008; Webster and Bryan, 2009).

#### **Designed to Dismay**

The Commission for Healthcare Audit and Inspection (2007a) states that 'Being in single sex accommodation and having access to single sex bathing, washing and toilet facilities is one of the most important considerations for older patients in maintaining their privacy and dignity'. It also notes that in the 2006 NHS Inpatient Survey (CHAI, 2007b) almost a quarter of older patients said they had to share a room or bay with members of the opposite sex during their hospital stay and that this was sometimes for the convenience of 'the system' rather than the patient. The 'single sex' wards observed in this study covered a range of configurations from completely segregated accommodation to barely separated bays for each sex alongside shared bathrooms and toilets. In this study all except two wards accommodate both male and female patients in single sex bays.

Many of the toilet and washing facilities are unisex which means older people have to walk in their nightwear past, or sometimes through, bays with people of the opposite sex. Many of the bays look similar which causes difficulty for confused patients and increases the potential for embarrassment and uncomfortable situations as described by this member of the ward staff:

"Then you've got, you know, 'the wanderer', the lady, you know, and she was wandering in and out of the men's bays. The same thing, you know, when you've got gentlemen in there, you know, they're confused as well and they'll 'wander' and you've got nothing, they've got nothing on the bottom, you know."

(Interview with a Ward Receptionist, Daffodil Ward, Downlands Trust)

In 2007, the Chief Nursing Officer in England published a report on mixed sex accommodation in NHS hospitals following a blaze of publicity highlighting the issues (DH, 2007). Despite distributing guidance to Trusts, this issue continues to both plague the NHS and deny many patients dignity.

All of the patients and many of their carers spoke about the embarrassment and humiliation they experience in relation to mixed sex facilities, which they feel are an affront to their privacy and dignity.

"Well certainly mixed sex wards I find that very undignified, for not just the women, for men as well. One would go in – you'd go in there [the toilet] and as you're coming out a gentleman's going in. I mean I was okay because I had you [her husband] with me or Julia [her daughter]. But if you were on your own and worrying about whether the toilet door's shut or the bathroom door, that's very undignified."

(Interview with a 76 year old woman, Drake Ward, Westway Trust)

Part of this problem is definitional in that Trusts argue that as long as patients are not sharing sleeping accommodation, they are not mixed sex wards, whereas for older people, men and women in the same overall area in various states of undress constitutes a mixed sex ward.

In August of this year, the coalition government announced their decision to end mixed sex accommodation other than ITU and Accident and Emergency Units by December 2010 ()www.bbc.co.uk) and from January 2011 any breaches would be publicly reported and the Trusts fined as they currently are. Under these arrangements, sleeping, bathroom and toilet facilities will only be shared with people of the same sex, however, mixed wards in which men and women are separated in bays or rooms would remain.

The matter of bodily privacy in relation to mixed sex facilities is one of the key issues that older people and their carers reported in this study. Where embarrassment had occurred this was deeply felt. Some of the worst situations are to be found in the medical and surgical admission units where patients often have to share mixed bays. Some patients stay in these areas for three days or more before being admitted to a ward and the impact on their sense of dignity is immense.

### **Designed to Deject**

The importance of having a place where patients can go away from their bed area has been highlighted in a number of studies (Davies, 2000 a, b, c, d and e). As well as the motivational stimulus of a change in environment and the opportunity to socialise with other patients and visitors, a number of studies demonstrate the positive impact on physical recovery when patients can move around the ward (Graf, 2006: Brown et al, 2009; de Morton et al, 2009) and engage in activities (BMA, 2011). There are also nutritional benefits of being able to eat together in a separate room (Wright et al, 2006). However, in each of the 4 Trusts the acute ward is very focused on caring for the patient around the bed space. Brown et al (2009) found that on average hospitalised patients aged over 65 spend most of their time lying in bed, despite being able to walk independently.

On most of the observation wards, 'day rooms' used for their original purpose were rare. Instead they are used for a range of purposes such as additional bed provision; as staff or meeting rooms; for storage or as a physiotherapy gym. Consequently, there is nowhere for people to go – other than in or on their bed or beside their bed in a chair. Both ward staff and patients recognise that this is detrimental to physical and psychological recovery:

The staff comment on the lack of a day room on the ward. They say people have nowhere to go, they are often on the ward for a long time and they get depressed and go downhill

(Observation: Marigold Ward, Downlands Trust, Afternoon)

"I think they'd benefit from having a day room for the patients because like those that are recovering from hip operations and that and learning to walk again...it's just something for them all to do and somewhere to go, albeit if it's not to watch telly, you know, get together and talk."

(Interview with 60 year old woman, Thames Ward, Uphill Trust)

On many occasions, patients were observed loitering at the nurses' station rather than staying at their bedside:

Later I notice John and William from Bay 3 who have come out of their bay and are sitting talking by the nurses' station as there is nowhere else for them to go.

(Observation: Marigold Ward, Downlands Trust, Evening)

This has implications for patient privacy and confidentiality, as there are many conversations about other patients both face to face with other professionals and on the telephone to relatives, which can easily be overhead by anyone nearby.

One Trust manager commented:

"We've eroded all the day rooms, or not, yeah, we've probably eroded all the day rooms and using them as meeting rooms or expanded bed capacity without considering the, the impact on – on I say the environment of care."

(Interview with a Specialist Advisor, Westway Trust)

Another member of ward staff describes some of the problems that the lack of a day room has resulted in:

"So their theory was to take the males onto the other side 'cause [sic] they've got 36 beds over there because they did away with the day room, and bring us over here, so we actually dropped a six-bedder, um, so that gave them the extra – the extra beds you see. Yeah, oh there's no doubt about it, yeah. They see, um, beds and they see numbers, but what happens from that patient coming in to going out, nobody seems to really get genned up on, hmm. So she's opening her bowels while you're trying to eat your dinner, which is awful. I mean there was a lot to be said when they got rid of the day rooms. You could sit at the table and interact with the patient with....you know, on your table and have conversations and they used to do activities and use the day rooms for activities, interaction. I do miss those I must admit."

(Interview with a Staff Nurse, Elm Ward, Meadowfield Trust)

Even the relatively mobile patients appear remarkably inactive, sitting in silence in or by their beds for many hours with little interaction, merely staring into space. The 'Patient Line', the individual telephone and TV system over each bed has a small screen and fiddly controls so that it is rare to see an older person use them. Many older patients also complain that they are too expensive. Diversionary activity is not encouraged in many settings as it is seen as inappropriate in an acute setting where the drive is to 'move people on' as quickly as possible.

As this ward manager points out:

"You know, there's none of that because, because hospitals are no longer a place for that to happen and I can understand that but where do they go?"

(Interview with Ward Manager, Daffodil Ward, Downlands Trust)

Both staff and patients commented that this leads to depression, boredom and a lack of motivation in patients who consequently take longer to recover (see also Hershkovitz et al, 2007).

The confused patients who tend to stay longer on acute wards as access to rehabilitation wards is often denied, fare even worse in such environments as they are the people who most need stimulation (Perrin, 1997). As this senior nurse points out:

"Just trying to occupy them sometimes and not just....not just expecting them to sit there, you know, in a vegetative state sort of thing, you know, like a lot of...a lot places do."

(Interview with a Matron, Uphill Trust)

Indeed, on the rare occasion where some form of activity takes place on the ward, staff recognise the positive impact it has on patients' wellbeing and behaviour:

I can hear music on my way down to the ward and when I arrive, there are two male violinists in the day room. A few of the staff were dancing with Betty and another patient to the music (they looked awkward as it wasn't the most appropriate dancing music) but Betty seemed to be the ringleader, trying to get everybody up. There was a group of staff standing by the entrance where I was observing and they were saying how great it is to see some of the patients be so calm and fully engaged in something. *'Take John, I've never seen him sit still for so long'*. I noticed Joan sat silently with her eyes closed listening, she'd told me before that she used to play the violin and how much she loved it. The difference seeing Betty the night before, distressed and agitated, to how she was this morning, having fun and dancing.

(Observation: Drake Ward, Westway Trust, Morning)

The virtual absence of planned, purposeful activity for patients is recognised in other studies and it is suggested that if the quality of care older patients receive is to improve, nursing staff must see the provision of activity as an integral part of their role and function (Nolan et al, 1995)

The isolation resulting from restricted visiting hours, which was discussed in Chapter 4, adds to this sense of despondency and boredom and as described in the previous chapter for those patients nursed in cubicles, this sense of isolation is even more heightened. Thus, on many wards, the patients are sat around the walls of their bay like characters from a Beckett

play. The sense of isolation and separateness impacts on the individual's dignity as their sense of purpose and fulfilment is lost.

### Designed for Danger

Another aspect of the physical environment observed on most of the acute wards is the presence of a large amount of technical equipment, not only by individual patient's beds but also in corridors and bays as, large computer trolleys and other equipment need to be stored and recharged. These take up valuable space and are difficult for the less mobile to negotiate safely.

Another danger identified by staff is the tendency of confused patients to meddle with equipment either being used at their own bedside or at that of other patients. One member of staff describes this problem:

She tells us about one of their older patients who should have been moved from the ward as she needs constant nurse observation as she keeps playing with the acute patients' equipment but that there is nowhere for her to go. Sister tells us how this is not the right environment for her [the older person].

(Observation: Nelson Ward, Westway Trust, Afternoon)

The dangers within the hospital environment are clearly identified by Healey and Scobie (2007) in the National Patient Safety Agency report, 'Slips, Trips and Falls in Hospital' which states 'Many aspects of the hospital environment may have an impact on the risk of falls or injury' including 'furniture and medical devices, including beds, trolleys mattresses, chairs, commodes and wheelchairs' (p.47). They go on to say that 'poor storage of equipment and supplies can increase the risk of patients falling' (p.47).

For older people who may feel unsure and lack confidence in their mobility generally, having to navigate an array of equipment, often with trailing wires, again reduces their sense of competence and control, which impacts on their self-image as they perceive themselves as helpless and dependent.

The experience of people with dementia and/or confusion will be discussed later in this chapter however the result of staff worried about patients tampering with or falling over equipment (Happ, 2000) is that they spend much of their time trying to confine patients in the chairs by their beds where much of the care is delivered.

### **Survival Information**

There are many different groups of staff who come into contact with older patients on the acute wards. On a busy morning, there are often doctors, nurses, healthcare assistants, physiotherapists, occupational therapists, speech therapists, dieticians, radiographers, domestic staff, porters and more.

The number of different personnel is difficult for some of the older people to deal with particularly when it is not made clear who the various people are. A few wards in this study

have boards showing how to identify staff from their different uniforms and one has a laminated patient information leaflet by each bed. However, clear and concise information about staff was rare. This can be disconcerting for patients as shown in the field note below:

Two men arrive at Valerie's bed, dressed in T-shirts and shorts. They say 'Hello, how are you?' She looks a bit mystified (they do look a little disreputable) and says, 'Better than I was and who have I got the pleasure of speaking to?' 'Physios.'

(Observation: Carnation Ward, Downlands Trust, Morning)

From both the field work and the interviews, it is clear that some staff introduce themselves and explain their role and if the patient is mobile, give information about where to find the toilet and bathroom. If the patient is immobile, some staff hand people their buzzers and show them how to operate the bed. Others, however, do not bother with any of these courtesies so that patients are left to discover essential information for themselves. This inconsistency or variability was discussed in the introduction to Part 2 and where information is lacking it impacts negatively on the older person's dignity as it renders them dependent. When it is shared it has a very positive effect as demonstrated below:

"Well, I think a sense of security by being explained, having things explained. It's information. Information, to be given a sense of security and from that would come being made to feel special I think."

(Interview with a 78 year old man, Marigold Ward, Downlands Trust)

*"I've forgotten her name, anyway she was a Filipino and she told me where the bathroom was and everything else. Their manners and helpfulness were tip-top."* 

(Interview with 80 year old woman, Nelson Ward, Westway Trust)

This section has demonstrated how acute hospital and ward environments often fail to meet the needs of their largest group of users, older people. The environment has a negative impact on the older person and many of the physical factors serve to disempower older patients, leaving them even more dependent and vulnerable. They do this through poor design, which does not distinguish areas making them difficult to navigate. The environments fail to orientate people in time or place and for those who are already confused, this can cause further deterioration. Older people are also disempowered when they are placed into embarrassing or humiliating positions such as those found in mixed sex wards.

The lack of stimulation in wards is also a cause for concern as there is little to motivate patients to move away from their beds or distract them from their illness. Not only is there a general lack of communal areas to promote engagement and social interaction, but visiting is restricted in many wards and the individual televisions in so many Trusts are inappropriate for older people as the small controls are difficult to manipulate. Many patients become bored and disinterested, some become depressed. A sense of purpose and fulfilment is

important to the experience of dignity (Bayer et al, 2005) as well as to physical outcomes and wellbeing.

The lack of storage and level of equipment needed hinders patient movement and increases dependence, as they need assistance to negotiate the area.

Bearing in mind the multitude of staff who arrive on wards on a daily basis, the lack of information about who they are and their various roles confuses many older patients and their relatives. Similarly, admission procedures and information about the environment are inconsistent and depend on the approach of individual staff. Thus patients are again disempowered as some lack even the basic information 'to survive' competently on the ward. In such environments, people lack control, lose their self-esteem and are made to feel more dependent. This older person echoes the views of many others about what is important to maintaining her dignity:

"I kept my dignity. I didn't have to keep asking to be helped."

(Interview with a 76 year old woman, Drake Ward, Westway Trust)

The following section will explore the skills and expertise of the staff and their impact on delivering dignified care.

# Staff Skills and Expertise

As emphasised throughout this report, the vast majority of inpatients in NHS acute Trusts are older people and yet few frontline staff receive specific or specialised training in relation to this client group. One reason put forward for this is that working with older people is traditionally seen as routine and relatively undemanding, requiring only basic training. One argument is that this is not simply a reflection of a lack of understanding of the complex needs of older people, but instead demonstrates a more deeply ingrained negative and dismissive view of elderly people. That is, it is an example of ageism, dehumanisation and a denial of dignity for the older person (Thompson, 1995).

The introductory pages of the National Service Framework for Older People (NSFOP) (DH 2001a) identified that 'Staff do not necessarily intend to behave in a discriminatory fashion, but lack of skills and lack of confidence in working with older people can lead to behaviour which is perceived as discriminatory' (p.21). Addressing the needs of older people in hospital, Standard 4 of the NSF declares that '[O]Ider people's care in hospital is delivered through appropriate specialist care and hospital staff who have the right set of skills to meet their needs (DH, 2001a). The review of progress of the NSF undertaken by CHAI (2006), still found that staff were ill-prepared to meet the needs of older people.

The findings suggest that little has changed in the past four years:

"In university sort of dignity and that was always – particularly in the NMC it's always there but they never sort of described it but at university we did a lot, you know, respect the patients and things. But, in terms of dealing with say dementia patients or anything, you only sort of cover that if you're in mental health, it's sort of missed in adult nursing. So, actually we are getting a lot more patients that, you know, dementias but, you know, really unless you were lucky enough to go on the ward as a student with dementia, it's not – you're not sort of...no, you don't really, you don't cover it at university because it's classed as mental health but then if you're on the mental health branch that you be it, you know, but seeing as a lot of elderly patients on the ward do have it, they're not in a mental health hospital, you do – we do really. I think it should be incorporated at university and studying to like deal with people dementia because you don't know the best way to deal with them."

(Interview with a Staff Nurse, Churchill Ward, Westway Trust)

The lack of expertise amongst many nursing staff in acute hospitals in working with older patients in general and particularly with people who are confused or demented has been recognised for some time (Dewing, 2001; McCloskey, 2004). More recently, the Commission for Healthcare Audit and Inspection (CHAI) report into dignity and acute Trusts (2007a) states that: 'There are huge gaps in the knowledge of nursing staff regarding issues such as care for patients with dementia, cultural issues and practical aspects of dignity. This may affect their ability to recognise individual needs and the associated risks and could inadvertently cause compromise in dignity' (p.40).

# The Skills Gap

### **Older People's Care**

In this study there was an acceptance amongst staff that there is a skills gap in relation to older people's care – as this comment shows:

"I don't think we do focus on it as much as we should do really, no. And I would like to see it being a lot more focused on older persons and dementia care because it is a bigger part and it's growing. It's increasing day by day, year by year is the older population. But no, I don't think we focus on it as much as we should do to be quite truthful."

(Interview with a Ward Manager, Severn Ward, Uphill Trust)

Some ward staff working on wards specifically for care of older people, are concerned about the lack of skills for meeting the needs of older people. Very few have specific training for working with older people, or with people who are confused – as exemplified in this nurse's account:

"Obviously when you train to be a nurse you go through so many different placements every year and they normally do throw in a healthcare of the elderly placement. So that's all the real training you get is whether you pick it up while you're training as a nurse."

(Interview with a Staff Nurse, Severn Ward, Uphill Trust)

If nurses get little specific training about the care of older people, healthcare assistants appear to get even less:

"They're new...you know, completely new, they come in, they do the basic Trust induction, which is nothing to do with being an HCA. They'll then come to a ward and we'll try to allocate them to a nurse to look after them. They're supernumerary for a week, eight days....And then they're out there. They then do an HCA induction but that happens very often about eight weeks or more after they've been in the job."

(Interview with a Ward Manager, Marigold Ward, Downlands Trust)

The lack of training devoted to older people within the medical profession has also been well documented. 'Geriatric medicine does not feature prominently in the curricula of many medical schools. Conventional medical education emphasises 'textbook' presentations of single conditions from lucid patients, which are amenable to curative treatment' (Oliver 2008, p.169)

Oliver (2008) also refers to the negative image of geriatric medicine; 'Despite a growing emphasis on holistic care, communication and team-working, there is still a bias in the values of medical training towards the high-tech, the novel and the rare – and of course, the well-remunerated' (p.70). He goes on to describe a Norwegian study in which medical professionals and students ranked 33 diagnoses and geriatric problems along with mental illness were ranked bottom. He concludes that: 'The care of older people is therefore seen as unattractive and low status by many, compounded by the lack of potential for private practice income' (ibid).

Similar views are expressed by a number of participants:

"This has always been a culture within nursing staff in this hospital. If you're very acute and you've got high-tech equipment, you're a better nurse than the ones dealing with confused patients."

(Interview with a Healthcare Assistant, Marigold Ward, Downlands Trust)

"I don't think it's that people don't want to do care of the elderly work but I think it's not as exciting for some of the nursing staff. And maybe we just don't understand enough about working with people with dementias or, you know, those sorts of deteriorating conditions."

(Interview with Complaints/PALS Manager, Downlands Trust)

"It has got a reputation of just being sort of old people who need social sort outs who are in hospital for months on end and there's not really anything wrong with them, you're just sort of looking after them like you would in the nursing home really. I think that's...Yeah. That's all. I mean it doesn't take that much skill to nurse someone really but to do sort of the acute nursing bit does. So I think that's the reason why care of the elderly has got a bad reputation." (Interview with a Staff Nurse, Ouse Ward, Uphill Trust) The Nursing and Midwifery Council (NMC) produced 'Guidance for the Care of Older People' in 2009. However, this guidance is of a very general nature, encouraging qualities such as competence, empathy, assertiveness and skills in relation to fundamental care, all of which apply to every person with whom a nurse may come into contact. The complex care needs of older people are not addressed. In relation to nurse education, despite older people being the largest users of healthcare there is no programme of specialist education or post-qualifying course relating to ageing or nursing older people.

In one Trust where reconfiguration of services is high on the agenda, nurses think that plans in relation to older people are doomed to fail:

She says that the Newlodge hospital will end up – 'a dumping ground for older patients with dementia that Brightside hospital don't want'. She mentions that they don't call wards 'Care of the Elderly' anymore because they can't get the staff if they do.

(Observation: Carnation Ward, Downlands Trust, Morning)

Such attitudes are well documented in nursing, (Courtney and Tong, 2001; Tadd and Bayer, 2006; Higgins et al, 2007) and medicine (Kee and Rippingale, 2009) however, there are some staff who understand the skills involved in caring for older patients:

"You know, elderly care to me is unique you know 'cause [sic] we have multi pathology, multi, you know, multi pharmacy, multi, you know, multi everything, it's – it's magnified, plus the – the challenges of their social problems."

(Interview with a Ward Manager, Drake Ward, Westway Trust)

And there are staff who, coming from a background of working with older people recognise the value of these skills:

"And a lot of the Tiptree hospital staff that come over here, you know, didn't have those acute skills and stuff. We've all learnt that now and, but we've still got those skills on how to deal with somebody who's elderly, frail, in pain, not eating, nobody's getting to grips on what's going on."

(Interview with a Ward Manager, Marigold Ward, Downhill Trust)

There are also senior managers who recognise the value of such skills as well as the need to promote them:

*"It's about being a positive role model in working with older people, and the skills that are required and, you know, and recognising and celebrating those skills as well."* 

(Interview with a Nurse Consultant, Westway Trust)

The reasons for such views will be discussed further below, but before that a second and important skill deficit is the ability to care for the person with dementia.

### Dementia Care

The second skill-gap identified concerns the specific skills in caring for the 25 percent of older people whose acute illness is complicated by dementia, not to mention those with confusion, delirium or other mental health problems such as depression, whose needs are also poorly addressed:

"A lot of the problems are fear, they don't' know how to engage with the patient who has got mental health problems, they don't know what sort of terminology they need to use, how they can, use distraction techniques to sort of change people's behaviour and things and we can't expect them to if they haven't had the training or the input to do it, and if they don't see other people with those skills either then..."

(Interview with a Practice Development Matron, Meadowfield Trust)

According to Dewing (2008), approaches to the care of older people with dementia adopted by nurses working in acute areas, commonly consist of ignoring the patient or relying on a few restricted strategies which reflect an overall ignorance regarding their needs. This seems a harsh assessment and rather than indicating a poor attitude towards such patients, highlights a lack of education and the anxiety experienced when having to care for these patients:

"There is a great gap 'cause [sic] being a general nurse we don't specifically have the training that the mental health nurses have and I have advocated for years, we need a specified, we need something that, you know, for – for all levels of staff that says, 'This is what you....' You know, '....and this is why they're like this' because if you can understand why somebody is like it you can then start to deal with it. But when you've told somebody the fiftieth time no they can't go home and they can't catch the bus and you end up lying to them, like we do don't we?"

(Interview with an Assistant Ward Manager, Drake Ward, Westway Trust)

It also goes some way to explaining why so many nursing staff see acute wards as the wrong place for people with dementia, regardless of their acute needs. Indeed, as a Trust manager in this study points out:

"Nobody goes into healthcare and public service to be nasty to anybody, elderly or otherwise. But I do think our awareness of what the issues are for the elderly is still not as good as it could be."

(Interview with a Medical Director, Downlands Trust)

In a recent study, 97 percent of staff in acute hospitals said they always or sometimes cared for patients with dementia (Alzheimer's Society, 2009) and so it is surprising that the skills

required are not seen as essential for all staff. The gap in training is not confined to nursing staff as one member of the ward staff commented during the field work:

The ward sister expresses concern about the care of older people with dementia who she feels get a raw deal when it comes to rehabilitation. The rehabilitation ward won't take people with dementia so they have to be rehabilitated on the ward - sometimes they stay on the ward for weeks. But she thinks the physiotherapists tend to leave them if they don't cooperate immediately. She has known physiotherapists to give up saying the patient won't do anything and then the ward staff have got them walking to the toilet. She says it is often the ward staff who end up doing the rehabilitation work and thinks there should be physiotherapists who specialise in treating older people with dementia.

(Observation: Carnation Ward, Downlands Trust, Night Duty)

This can be contrasted with the approach this occupational therapist (OT) who has experience of working with older people and people with dementia adopts. She arrives on the ward to assess a patient's walking and does not take her initial refusal as an answer but instead uses engagement and persistence to achieve her aim:

The OT is with Fiona talking to her about her home and how she manages. She asks her to walk with her frame but Florence refuses. She talks to her a bit more about going home and then asks her if she will walk for her again and this time she agrees. She gets up and walks with the frame and the OT out and down the corridor quite cheerfully.

(Observation: Rose Ward, Downlands Trust, Morning)

As demonstrated above, with little specific training most staff deal with people as they think best on a day to day basis, often relying on their own personal experience without any particular guidance:

"I suppose it depends on what – what you've done in the past 'cause I worked in a Nursing Home for years, so I've worked with elderly, with dementia, I worked in like an EMI unit, so I've done them, so I probably know how to deal with them where the likes of like Catherine she's just fresh out of University, not very old herself, so she probably hasn't got that much experience in it. You know, where I've had years of it, so and like worked at the Hospital for years as a Team Assistant as well, and because I looked after like, I've had elderly relatives, you know, like my mother-in-law, I looked after her for like a few years, now I'm looking after my mum, so it's - it's quite, I'm quite used to just doing it."

(Interview with newly qualified Staff Nurse, Oak Ward, Meadowfield Trust)

This 'common sense' approach based on experience is typified by the comments of this nurse:

She said you have to deal with people with confusion differently – 'Some people you can jolly out of it, others you have to be firm with and others you have to just go along with – you have to be flexible' she also said 'We've got a really nice lot of men at the moment.'

(Observation: Daffodil Ward, Downlands Trust, Night Duty)

This, no doubt, is another reason for the great variability in care that is experienced and observed, with the result that sometimes the same patient can be managed in different ways by different staff at different times. An example comes from observing the way staff cared for a confused woman:

There are different approaches to looking after Betty. There are those who go along with Betty and simply accompany her, whether it's to look for a bag or check where her friends are and there are those who try to reorientate her to the hospital ward and tell her that she is not allowed to go into other's rooms rather than simply trying to distract her with a cup of tea for example.

(Observation: Drake Ward, Westway Trust, Afternoon)

Staff on a number of wards faced many difficulties in trying to deal with people with dementia who need to be 'occupied'. Sometimes confused patients are brought to sit at the nurses' station as a means of distracting them whilst the staff are getting on with paperwork.

Jane from bed 11 has been brought to sit at the nurses' station – she is very restless and keeps asking to be taken to the WC. She sits in her chair at the nurses' station for a bit and the staff nurse who is writing her notes talks to her saying she can be nurse McDonald and they will go to her with their problems. The staff nurse says she can talk to the visitors for her.

(Observation: Thames Ward, Uphill Trust, Afternoon)

Even patients commented that staff experienced difficulties in caring for such patients:

"All they needed was somebody to sit and talk and explain and OK within five minutes they might forget and they would have to have it explained to them again but that's what you do isn't it? You know, that's just life when people are confused."

(Interview with a 78 year old man, Daffodil Ward, Downlands Trust)

CHAI, in their report (2007a) found that in most of the Trusts they inspected, staff find it difficult to engage with patients with dementia as they do not have adequate knowledge of their condition.

Only one Trust in this study had a ward that specialises in the acute care of people with dementia, which considering that 25 percent of the acute inpatient population suffers from

this condition is surprising. The specialist knowledge and skills of staff working on this ward impacts on care as one member of staff points out:

"We don't harass them as much here. You have to on a medical ward because it's dangerous, you know, and they can interfere with drips and all sorts. And that's the worst thing you can do to a demented person is to keep harassing them and nagging them, you know, because it gets on their nerves."

(Interview with a Male Healthcare Assistant, Rose Ward, Downlands Trust)

These concerns raise an important question as to whether or not we should view the skills required for older people generally and those with dementia specifically, as core skills or specialist skills. The tendency toward specialist approaches is tempting, however as older people are the greatest users of inpatient services and those with dementia constitute a considerable proportion of the inpatient population, there is a powerful argument that the skills required to deliver care should be seen as, 'core'.

### Core Skill or Specialism

If the emphasis continues to be placed on specialisation in both service delivery and education, then older people with multiple conditions are in danger of falling between these specialisms, as no one person takes an overview (Oliver, 2008). This is described so well by this Trust manager:

"We have forgotten the generalised humanity that we have to deal with. We want to partition everybody into their own 'ism' or their 'ology'. What I'm trying to convey is that there are some aspects of patient need that we're almost in denial about because somebody else specialises in it – but whoever it is, it ain't [sic] me."

(Interview with Trust Board Member, Uphill Trust)

The emphasis on specialisation can also mean that what are seen as 'core' skills are devalued:

"A nurse, a good nurse, has a good set of core skills. What we actually do sometimes, we do the reverse, you know? We actually de-skill them because we make them specialised and we actually take something away from them."

(Interview with Trust Board Director, Uphill Trust)

Oliver (2008) gets to the nub of the issue when he states that: 'Education, training and received values in medicine need to change to reflect the reality of modern medical practice. The core business of hospitals in the NHS and throughout the developed world is in patients with illnesses, which are long-term and common and in treatments, which are low-tech and palliative or disease-modifying. Yet professional values and training still overly prioritise the acute, the rare, the high-tech and the curative' (p.168).

If this is accepted, then the skills required for older people's care should be seen as core skills in which all staff are trained. Maben et al (2007) argue that 'the educational direction of nursing is disconnected from the pressing realities nurses in practice face, with a curriculum that often fails to identify the actual focus of the registered nurses' work and the challenges of the practice environment' (p.110).

In other words, staff are not trained for the realities of everyday practice and the result of this is that they are disillusioned, burnt-out and dissatisfied.

In concluding this section, the attitude of staff towards the care of older people is probably influenced by wider and deep-rooted negative social attitudes to ageing, which have been recognised by the CHAI (2007a): 'While staff are introduced to the nursing of older people as part of their basic training, this area is still considered less attractive to pursue as a career. This may be due to deep-seated ageist beliefs and stereotypes, which lead to an unhelpful attitude when staff are required to nurse older people' (p.37).

In this context, the importance of training, in all its forms and making it available for all staff to raise awareness and promote a positive attitude towards the care of older people cannot be over-emphasised. If the NHS is to counteract the development of 'institutional ageism' the recognised gap in training needs to be bridged as one Trust manager highlighted:

"Older people are mainstream in healthcare. So we've got to influence positively from the outset."

(Interview with Nurse Director, Westway Trust)

Dahlk and Phinney (2008) make a similar point when they argue that to improve the care of older people, the older population must be acknowledged and nurses must possess the knowledge and resources to meet this population's unique need.

### **Training on Dignity**

Given the emphasis in recent years on the importance of receiving and delivering dignified care, all staff were asked about specific training opportunities in relation to dignity. Although students all emphasised that this was important in their education and they would fail if they 'did not state that patients were treated with respect'. How to do this was not always specified.

The following quotes show how the availability of training or education on dignity depends on the individual universities or Trusts but continuing education on dignity and dignified care was rare:

- Respondent: 'I trained in 1970-73 so it was very much old school then. I mean you learnt on the wards. You didn't have as much...well certainly no university training. You just had general, you know, training about diseases and medications and general nursing type...medical stuff'
- Interviewer: Yeah. And have you had anything since then? Have there been any sort of in-service training sessions on dignity?
- Respondent: 'Not on dignity. No'

(Interviewer with Senior Staff Nurse, Nelson Ward, Westway Trust)

- Interviewer: Did you have anything specifically about dignity in your training?
- Respondent: 'No. No'
- Interviewer: And have you had anything since? Since you've been in the job?
- Respondent: 'Not really. It's all sort of self learning and reading articles and stuff and there's a lot in the papers and the journals now about, you know, maintaining patients' privacy and maintaining dignity and the whole, you know, not calling them friendly names and so on'

(Interview with a Staff Nurse, Malvern Ward, Downlands Trust)

"When we first started 'uni', like in my first year, we did loads of stuff, we had to feed each other, um, brush each other's teeth, um, and then we had to feed each other blindfolded to see what it would be like from a blind person's point of view. We had to wash each other's feet and dry them. We did all sorts of things like that so we knew what it was like and it was horr – funnily enough, it was horrible, like I didn't want nobody to do that to me, we were all dead embarrassed, so we do stuff like that and then, um, throughout the course we do odd things. I've just done a concept analysis which is basically picking apart a concept of dignity, like of dignity, um, so we do – it's covered all the way through, you don't just learn it and it stops, every – Yeah, if I write an assignment, it's got to be in there. If it's not, you've got to think about that, it's like key things you've got to include, dignity and respect, all of them are in everything we do, it's taught in everything and so they taught us to do examinations, 'Don't forget....' they'll say, 'Don't forget your dignified care, remember to introduce yourself to the patient, ask them if it's alright, give consent, pull your curtains round, privacy.' So, it's not just – we're not just taught it once, it's everything you do, we're taught it over and over and over. It's like it's

drummed into us a lot [laugh] and then when you come to the wards, well it's all different."

(Interview with a Nursing Student, Beech Ward, Meadowfield Trust)

Most participants had very naïve perceptions of what is entailed in treating an older person with dignity. Most spoke about the importance they placed on treating people with dignity, however, they found it difficult to explain how they did this, beyond general statements about 'ensuring privacy' and 'treating people with respect by asking how they would like to be addressed'.

This is a classic example of how what staff say they do does not coincide with what is observed in practice. For example, most patients interviewed were not asked how they wished to be addressed. Instead, it was assumed they would not object to being addressed by their first name and in reality, the majority did not object to this approach. However, a significant minority whose first name was not the one by which they were routinely addressed were frustrated by staff ignoring their preference.

Despite the policies in each of the Trusts about dignity and the provision of dignified care, for many staff, the reality of practice and the tension experienced in the 'call to dignity' had become rhetorical, the latest 'buzzword' to which they should subscribe, but which bore little relationship to the situation in which 'care' was delivered.

This section has highlighted the skills gap experienced by health professionals and workers. It seems that despite older people being the 'core business' of the NHS, frontline staff are not adequately prepared to meet their needs.

# The Older Person's Experience on an Acute Ward

During the field work, the researchers tried to gain an understanding of what the 'place' might feel like for an older person, lying in their bed or sitting in their chair on an acute ward. The difficulties imposed by the physical environment and the skills of the staff had a direct impact on the patients but they also influenced the way staff worked and the general atmosphere of the ward.

The first impression is often of immense 'busyness' amongst the staff, particularly in the mornings when there might be many different staff on the ward: doctors' rounds (with large retinues), physiotherapists, occupational therapists, dieticians, cleaners as well as nurses and healthcare assistants. The activity can be frenetic with staff very obviously walking quickly, not making eye contract and keeping engagement with the patients to a minimum whilst carrying out their tasks. The consequence of this is that many older people feel unable to call staff as they don't like to bother the nurses who seem so busy, as this person said:

"They seemed awfully rushed and so they didn't really have time, I don't think, to look at you, and to take the time to see if you was [sic] okay."

(Interview with a 63 year old man, Malvern Ward, Downlands Trust)

During observations, there were a number of occasions when patients or relatives were hovering at the nurses' station trying to catch someone's eye in order to speak to them, only to give up and return to the bedside as staff rushed to and fro, ignoring them.

This sense of pressured activity is in stark contrast to the inactivity of the majority of patients who found it hard to break the monotony as this woman commented to another patient:

'Oh dear, these days are a week long.'

(Observation: Oak Ward, Meadowfield Trust)

If staff did have any spare moments, these were rarely spent engaging with patients but would instead be spent finding something else to do or invariably, gathering at the nurses' station for a chat:

"When I got in there, and I had to go and find them, they were all gossiping, just standing round talking."

(Interview with a 72 year old Carer, Elm Ward, Meadowfield Trust)

# Change the Ward or Change the Patient?

The findings from the observations and interviews in this study, suggests that there is a mismatch between the needs of the majority of patients being admitted to acute hospitals and the place that acute hospitals have become. In recognition of this fact, many ward staff and Trust managers came to the conclusion that it is the older patient who is in the wrong place.

# The Wrong Place

Some staff expressed the view that there were patients who shouldn't have come into hospital in the first place and that they were 'handed off' to Accident & Emergency by GPs and NHS Direct as a simple solution when alternative care might be better:

"Because there are clearly a number of conditions that people will come in with that perhaps there could be other opportunities for care."

(Interview with Medical Director, Westway Trust)

The SN comes back to me with 'a solution'. She says most of the dementia patients come into hospital from EMI homes (often with dehydration). 'They have trained nurses there – why can't they be treated in the nursing home – the doctors could go out to them.'

(Observation: Severn Ward, Uphill Trust, Night Duty)

Other staff highlighted the problem of delayed transfers of care which resulted in patients staying too long in acute wards:

"We will have patients in this hospital and we have a high number of patients in this hospital, who are no longer medically ill, they're medically stable, they might be well because they do need some ongoing care, but it might only be social care and they need to go to some sort of nursing home, but they want to go to a particular nursing home and that frustrates the hell out of me because they're occupying a bed that they shouldn't."

(Interview with Director of Finance, Westway Trust)

Whilst this is a serious issue and one might have some sympathy for the Trust managers who have to manage acute services, the fault does not lie at the feet of the older people concerned, but with the system itself, which is not only failing the older person but also those who are acutely ill and waiting to be admitted.

Other staff, however, just believe that the acute ward is the 'wrong place' for 'them' and there must be 'another place' that would be better. This nurse highlights the difficulties posed by what are termed 'outliers' [patients who are moved to wards where their consultant does not have beds] and raises questions about the quality of their care as they are not regularly followed-up by the admitting team and nurses do not feel competent to provide care:

"The lady was very confused. She should have been in a different ward really because some of the busier wards here, you know, there is too much coming and going and I think she was an outlier so I think that was the issue, she wasn't under her speciality and so with regards to that you don't get as much regularity or follow up from your team and perhaps the nurses don't feel maybe as qualified to look after those patients."

(Interview with Complaints/PALS Manager, Downlands Trust)

In the following quote, the staff member appears to be suggesting that staff in acute hospitals lack awareness of people's needs:

"In a busy acute hospital because with the best will in the world it, they do need to be somewhere where the staff have some awareness of the needs of people."

(Interview with Safeguarding Co-ordinator, Downlands Trust)

The interpretation, however, is that the needs of older people on acute wards are those that the ward staff should be concerned with. Oliver's (2008) comments about 'socials' and 'acopias' again spring to mind as the older person is seen as needing some other sort of care delivered somewhere other than the acute ward.

The idea of 'another place' for older people with dementia is highlighted by this member of staff:

I talked to one of the staff nurses at the desk. She immediately tells me she knows what is wrong – she says it is having dementia patients on acute wards. She says it is difficult to get extra staff to help and she would like to see a separate ward.

(Observation: Severn Ward, Uphill Trust, Morning)

#### **Perpetual Motion**

The actual picture on the wards within the four Trusts is one of the constant movement of patients both into and out of individual wards and between beds and bays within the wards. People are moved frequently, day and night, and below is a typical conversation between the staff involved about how to move everyone round:

She suggests moving someone from Bay 2 into Bay 3, so that there is a spare bed for an admission. The other staff nurse suggests Mary could go back to Bay 1.

[Mary has recently been moved from Bay 1 to Bay 2]

(Observation: Daffodil Ward, Downlands Trust, Morning)

The constant movement of patients is recognised as a problem by managers:

"I don't believe that it's the right thing to do, to move patients from ward to ward unless their care pathway, unless it's part of their planned care pathway and there's a clinical reason. However we do it and we have a patient movement policy but at times, you know, of extreme bed pressures it goes out of the window and we move people into areas if they're going home the next day and, you know, things like that. And people often have multiple moves and I think that affects length of stay in the long term, it affects patient experience, sometimes."

(Interview with a Director of Nursing, Downlands Trust)

The reasons given for this were the need to achieve a high level of bed occupancy as described in Chapter 4, as well as the need to have acute patients on the right specialist ward. Also, the need to have patients in single sex bays and the need to have particular patients in 'observation' beds or barrier nursed in single rooms. Beds cannot be left empty so everyone has to move round regularly in the attempt to get the 'right patients' into the 'right place' without leaving empty beds. As one manager pointed out:

"Our bed occupancy, we're presently running with our bed occupancy at the moment about 95 percent, which is way too high, it should be about 85 percent, so that when we do get a busy period we've got the ability to flex our capacity upwards to cope with, with those surges."

(Interview with Chief Executive, Westway Trust)

"This hospital in particular is a regional speciality for, in a number of areas and because of that we quite often have a lot of bed pressures and I see as a consequence of that people get moved quite a bit. And even to the point where, you know, I've recently had a 93 year old who was due for discharge the following day that got moved the night before onto the critical decision unit just because they needed the bed."

(Interview with Trust Board Member, Downlands Trust)

This member of the ward team also recognised the problem that specialist wards result in:

"But the pressure is to find a bed for people. That's the problem with having speciality wards you see, if they need to be on that ward you've got to create room."

(Interview with a Service Assistant, Severn Ward, Uphill Trust)

The result is a 'conveyor belt approach' which, even if it works smoothly, involves perpetual motion and unfortunately it is often the older person with multiple chronic conditions who does not fit neatly into any one specialist setting who gets moved most.

The interview with the ward sister below describes the situation for older people who are seen as unwelcome in most wards as they may be there for lengthy periods. The use of terminology like 'bounced around' conjures images of unwanted parcels being passed on as quickly as possible:

"I feel that the elderly people that are here that are not stroke are, they're lower priority because perhaps they're not so unwell so if they're washed, dressed, sat in a chair and comfortable then that's fine, let's go and sort out now our acute patients that have got no airway maintenance or are fitting or need a scan or MG or IV antibiotics or IV fluids, and I really do feel for those patients are being bounced around in here and back out again. They're moved out at short notice to make a bed for another stroke so they could be moved anywhere in this Trust within medicine. The wards don't want them because there's no discharge date. Well, no there isn't because they're complex, they're unwell, they're just not ready for discharge. Well there's no discharge.... And they just ... they just get bounced around."

(Interview: Ward Sister, Daffodil Ward, Downlands Trust)

Many Trust staff found such trends of great concern:

"I often worry about the older person being in that system because often they – they've got more needs, are more vulnerable and I do worry in a system where we're encouraged to sort of move people on, are we moving them on to the right place?"

(Interview with a Senior Nurse Manager, (Surgery), Meadowfield Trust)

This leads us to ask, is there a 'right place' and if so, where is it?

### The 'Right' Place

There was a view amongst some Trust managers that in the perfect world every patient would be in the 'right' place.

"I hold dear the principle that you should be put in the right place, making sure that patients are cared for in the right place at the right time, so in the right ward with people with the right skills."

(Interview with a Nurse Director, Downlands Trust)

This view is supported by a number of evaluations of various dedicated units for frail older people, which all suggest benefits in functional outcome and subsequent mortality when such people are cared for in dedicated units (Parker et al, 2006). However, as one interviewee pointed out, the 'sheer numbers argument' suggests that to have special wards for *all* older and possibly confused patients, that is two thirds of the hospital population, does not seem feasible:

"They've opened up an EMI ward, but that will soon be full and what will happen then when that's full, there'll be just the same back up situation. It's because our population is getting older and older and older and, as patients get older, sometimes their mental health will decline and they'll get more of these problems."

(Interview with a Ward Manager, Nelson Ward, Westway Trust)

# Summary – 'Lining Up the Ducks a Bit Different'

Acute hospital and ward environments fail to meet the needs of many of their largest group of users, namely older people.

In summary, this chapter has provided evidence that the acute ward is frequently 'unfit for purpose' as a place to treat older people with dignity. The physical environment is often confusing and inaccessible to older people. The majority of staff, although doing their best, are often ill equipped in terms of their knowledge and skills to deal with the patients they are required to care for. The atmosphere on the wards could be characterised as one of the constant movement with fast throughput and little opportunity for engagement with the person who has a range of human needs, both medical and emotional.

The fact that many interviewees recognised these issues but concluded that it was the older patient who was in the 'wrong' place seems strange when the majority of patients on acute wards are in this older age group. The assumption that there must be a better place for 'them' to be, but where it is, 'it ain't here', is suggestive of an underlying institutional ageism. The more obvious response would be to accept that it is the wards and the service that need to adapt to the needs of the majority of patients so that the ethos is one of being the 'Right place for each patient'. The alternative to moving (or not admitting) the patient who is seen

as the problem, is to change the place they come into, or as one Trust manager put it, 'Line up the ducks a bit different.'

This particular manager went on to talk about how all wards could be made more accessible to older people, drawing a comparison with the work that has been undertaken to ensure public places are accessible to disabled people:

"I've got to work out, and the Department of Health have got to work out, some ideas that might be equivalent to how we started all those years ago when what we started with was a disabled toilet which was just a big toilet. And what we've done over the years, we've designed them haven't we through feedback from patients, feedback from that client group."

(Interview with a Director of Facilities, Uphill Trust)

There is now plenty of advice and guidance about how to design areas that are 'dementia friendly' for instance, (Health Facilities Scotland, 2007). Some measures such as the effective use of colour, signs, layout, safe floors and safe walking spaces, can be cost neutral if incorporated when refurbishments are undertaken and these can benefit all patients, not just those who are old and confused.

A ward manager in the study also talked about how some of the good practice that takes place on some wards specialising in dementia care or rehabilitation could be replicated on all acute wards so that the patient was not the one who had to move:

"That's what we need to capture on the other wards, and not move them around the hospital. Just take them to where they're going to be and welcome them."

(Interview with a Matron, Care of the Elderly, Uphill Trust)

This 'good practice' could include awareness amongst staff of how to engage positively with older people and those who are confused and an acknowledgement that in some cases, diversionary activities can promote speedy recovery rather than being seen as an encouragement for people to stay in hospital longer than necessary. The driver of this kind of change of emphasis could be through training and national directives as recognised in the Department of Health overview of research to support the National Service Framework for Older People, 'As long as some service providers continue to see older people in nihilistic or stereotyped ways, it may take more professional education or national policy directives (such as NHS-funded nursing care) to improve the situation for older people' (DH, 2008b).

Although the Department of Health's recent publication of a revised implementation plan for 'Living Well with Dementia – A National Dementia Strategy' (DH, 2009b) does not imply a speedy nor coherent national response to the skills gap: 'Skills for Care and Skills for Health' have commissioned a scoping study which maps the workforce working with people with dementia and their education and training needs. A second report also maps the existing accredited education and training available and the gaps in that provision. The Department has established (2010) a new Workforce Advisory Group, chaired by the National Clinical Director for Dementia. The Advisory Group will take forward the findings and

recommendations from the initial scoping study and gap analysis in a way which supports local autonomy. There will be a move away from a top down management model led by the Department to support greater local accountability for decisions affecting workforce supply and demand' (DH, 2010d).

It has been suggested that the modern acute hospital may contribute to adverse outcomes for older people (Parker et al, 2006). However, there is also evidence that acute hospitals *can* become places that meet the needs of older patients if they have the right environmental modifications and staff who are knowledgeable and positive about working with older people and who have the right training and support (Moyle et al, 2008; Haak 2009; Davies, 2000a, b, c, d, e). This requires the recognition at all levels that older people are, and will remain, the main users of inpatient care in NHS acute hospitals and as such can reasonably expect a service that is accessible to them rather than one that fits the needs and aspirations of the system, the organisation and its staff. Or, as Borbasi et al (2006) put it, 'A *whole organisation shift in thinking away from what conveniently suits the institution to thinking that is person-centred and dementia-friendly.*'

For as one Trust manager in the study said:

"But actually usually it's something that we're not doing, not that they're [older people] not doing, you know. If they don't fit my model somehow it's their bloody fault and that really, I'm sorry, but that angers me."

(Interview with a Chief Executive, Downlands Trust)

# **Chapter 6: Seeing the Person**

"You're spoken to as a human being, not as a patient."

(86 Year old woman, Nelson Ward, Westway Trust)

### Introduction

In this chapter the findings related to the impact of individual interactions on dignified care are discussed under the following headings:

- Participants' overall view of care.
- Respectful communication.
  - Forms of address.
  - Patronising older people.
  - Referred to as a task or number.
  - Being ignored.
- Power in place.
  - Fundamental care.
    - Privacy.
    - Nutrition.
    - Using the toilet.
    - Washing and dressing.
    - Being informed.
- The views of relatives.
- Approaches to care.
- Staff dignity.

Every encounter between individuals has the possibility to enhance dignity or to violate it and nowhere more so than in health and social care settings, not least because the various actors are usually in an unequal relationship in terms of knowledge, power, familiarity, wellbeing and dependence. As described in Chapter 2, there is no shortage of analyses of the concept of dignity and although these differ, as each may emphasise particular aspects of 'dignity', it is generally agreed that there are objective and subjective aspects attached to the concept (Nordenfelt, 2004). The objective aspect, has been referred to as human dignity (Spiegelberg, 1970) or 'Menschenwürde' (Nordenfelt, 2004) and refers to the fundamental worth of each human being, as expressed in the United Nations Declaration of Human Rights (1948).

The subjective aspect of dignity has also been variously referred to: dignity in general (Spiegelberg, 1970); relational dignity (Pleschberger, 2007); social dignity (Jacobson, 2007); and dignities of identity, merit and moral stature (Nordenfelt, 2004). Moody alludes to these issues when he highlights that as a moral term, dignity is used to judge or evaluate both an individual's own behaviour and actions directed towards them and refers to these as the 'self-regarding' and 'other-regarding' aspects, both of which involve the notion of 'showing respect', be this self-respect or treating others with respect.

The importance of these aspects to the present study is that how others behave towards a person can impact upon the way in which they 'regard' or 'respect' themselves. For example, if an adult person is treated like a child by someone, then the person sees themselves as reduced or less worthy, through humiliation or embarrassment. Similarly, if an adult behaves as a child might, for instance by being incontinent, then this impacts negatively on the way in which they see themselves. As Szawarski (1986) states, '[A] human being's dignity is based on respecting and persevering his or her own moral identity... My sense of self-respect is seriously imperilled when somebody or something forces me to act against my ideal self and thereby lose my self-respect' (p.200).

This notion of the importance of 'seeing', be it ourselves or others, echoes the words of Iris Murdoch, the philosopher and novelist who died of Alzheimer's Disease in 1999. Murdoch claims that how we act in the world mirrors what we see. She writes, "I can only choose within the world I can see, in the moral sense of 'see', which implies that clear vision is a result of moral imagination and moral effort" (Murdoch, 1970:37). In other words, paying attention and the willingness to pay attention, are moral qualities. Murdoch also recognised that the most important and most difficult realities for us to 'see' are other people. Thus, cultivating one's vision to see beyond ourselves to others is, according to Murdoch, a true moral activity and one which is essential for dignified care.

Thus, how one 'sees' the person, be it oneself or another as an individual, is what matters and is crucial to the experience of dignity. Any situation that detracts from this has the potential to damage one's sense of dignity and self-respect by engendering feelings of worthlessness, embarrassment, humiliation and such like.

The ability to deliver dignified care requires the carer to look with a 'moral eye' and see the person who is the subject of care as someone deserving of that attention and care.

This chapter will focus largely on the impact of the encounters that take place within the acute setting and the influence these have on the experience of dignity.

# **Dignity and Care**

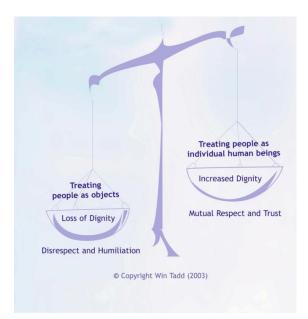
As discussed in Chapter 1, concerns about standards of care for older people in acute hospitals have been raised in many quarters and raising the quality of care has become a major goal of the NHS (DH, 2008b). Sir Michael Parkinson in his report 'My Year as National Dignity Ambassador' stated, 'I think that is the thing we really need to address, the fact that we treat old people as unworthy of our time and consideration. If we treated young people the way we treat older people there would be an outcry, quite rightly so. We don't complain enough about the way our older people are treated' (2010, p.4).

Any talk of 'care' be it 'good care' or 'poor care', faces a difficulty in that 'care' is a contested concept and therefore it is difficult to define. However, one systematic review (Paterson et al, 2001) found that patients characterised nurses as follows:

Table 12:	Patients' View	vs of Caring and	Uncaring Nurses
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Characteristics of Caring Nurses	Characteristics of Uncaring Nurses
<ul> <li>perceptive about patient needs</li> <li>returned to patients without being called</li> <li>listened carefully to patients</li> <li>behaved in ways that engendered feelings of value and worth</li> <li>treated patients as human beings</li> <li>made eye contact in conversation</li> <li>engaged in general conversation</li> </ul>	<ul> <li>were always in a hurry</li> <li>showed a lack of interest in patients as individuals</li> <li>didn't listen</li> <li>rarely had time to talk</li> <li>were very efficient</li> <li>were distant</li> <li>adhered to rules</li> <li>avoided eye-contact</li> <li>were unavailable for long periods of time</li> <li>interactions were experienced as scolding, or 'superior'</li> </ul>

Claims that 'care' itself is lacking are heard with increasing frequency in both nursing (Ray 1981; Reverby, 1987; Kelly, 1988; Corbin, 2008) and medicine (Dieppe, 2000; Teale, 2007; Reed, 2008). A number of reasons for this have been put forward including stress, burnout, lack of recognition, increased specialisation, poor attitudes, changes to educational programmes, increasing professionalisation, increased technology, managerialism and neoliberal economic cultures in which the co-modification of care has resulted in people being treated as objects to do things to (Lown, 2007). From this position it is a small step to treating them without respect or dignity. This is illustrated by the dignity balance (Fig. 4) developed as part of Dignity and Older Europeans study (Tadd, 2003).



### Figure 4: The Dignity Balance

So how did older participants and their relatives view the care that they receive?

# Participants' Overall Views of Their Care

The majority of older people who participated in this study expressed content with their care, and some experienced excellent care. However, many had low expectations of what care should be like. When asked, 'Were you treated with dignity during your stay in hospital?' most participants tended to reply, 'Yes, we couldn't fault it'. On probing about various aspects of care, many participants recounted how particular aspects of care were not particularly dignified.

This gentleman for instance on being asked if everyone was treated with dignity replied:

"Oh yes, I wasn't made any exception, everybody had the same care, the old fellow with Alzheimer's, he wanted to use the toilet, so he rung his bell and they came and they said, 'Oh, we'll bring you a commode.' And they brought the commode and he said, 'Oh...' he said '... I can't use that, I want to go to the toilet.' They said, 'Well, you know, this is a toilet, it's just that you know that, we're not allowed to transport you on a commode to the toilet and we don't have any means of getting you there.' And he said, 'Well, I'm not using it' and the nurse said, 'That's fine, you go in the bed...' she said, '... and we'll come back later and we'll change it.' And about ten minutes later they came back and they washed him, cleaned his bed, fresh bedding on there and put him back to bed. So, I thought that was really good."

(Interview with a 65 year old man, Drake Ward, Westway Trust)

This person didn't seem to appreciate that being instructed to soil oneself constitutes a dreadful indignity or that the reason for not taking the man to the toilet may well have been an excuse, for the nurse's convenience, as all wards have chairs on which to transfer people to the toilet.

It is important, therefore, when asking people about their experience of care to ask questions about specific aspects of care rather than broad, all encompassing ones. This problem was also identified by Goodrich and Cornwell (2008) as one of the major issues with relying on patient satisfaction surveys to estimate the quality of care.

Further evidence of older people's low expectations and their gratitude for the care they received, can be found in this man's account:

"Well, yes, I suppose you like to be treated in the proper manner and civilly that's where dignity comes into that, but, well everyone is entitled to be treated by the [laughs] well young the same as the old, but older people more, as they can't fend for themselves so much when, well I'm pretty good on the whole but some people can't do a lot for themselves can they? If that's the meaning of dignity, I don't know, but it obviously comes into it doesn't it? I don't think they were so bad about me, I mean the last time I was only in there – it's about a month ago, I say two and a half days [laughs] not very long. And the time before that, it was about last July I think, I was in there a week then but, well they weren't too bad to me. I suppose I was brought up in the days when, in the 30s, when there wasn't much money and the depression and you weren't, you just took life and whatever came along and the normal refinements, well, you wouldn't know of course, you weren't born, but I mean there was no money about, my father was out of work a lot and well I suppose my mother and father struggled to make ends meet. It's got me that way, I'm not a fussy person, it made me not a fussy person; I mean that's not sort of finicky, if you know what I mean. I don't like complaining about pain, I suppose we all get it, you can't worry about every little thing [laughs]. I've survived up until now, up to 82 years of age, so it can't be so bad. Well I suppose being able to, conform to the rules a bit being in hospital, but I suppose I do as much as I can, I don't make a scene, I put up with things, I have done up to now, I don't – I'm not one for making a scene, I don't think I make a scene, I take whatever comes along more or less."

(Interview with an 82 year old man, Nelson Ward, Westway Trust)

This participant is saying that he thinks he was treated okay, but as he was brought up in the depression when there was *'little about, you just got on with things and didn't expect too much.'* He says words to the effect that he never had too much, *'l'm not a fussy person.'* 

He then goes on to comment about, 'not complaining' and 'not making a scene', being his approach, although the following excerpt suggests that he had little attention:

Interviewer:	Tell me about the attitude of the staff treating you, did		
	you find them approachable and polite and did they have		
	time to chat to you?		

Respondent: 'Well sometimes you wouldn't get, always get any or too much response from them, but perhaps that's because I wasn't like an urgent case or something, I don't know but... I didn't have much cause to ask them for anything. But I suppose they may have been busy sometimes, but they've got to attend to the most ill haven't they?'

(Interview with an 82 year old man, Nelson Ward, Westway Trust)

Older people frequently describe a reluctance to complain. For example, this man implies that dignity or being dignified involves behaving appropriately, even though later in the interview he speaks of the 'massive' problems he experienced with privacy:

Respondent: 'Well, dignity in my opinion is, has been, for me is to keep quiet and keep out of things and so, you know, that's it really and that way you – you don't get involved and – and they respect you because you're quieter or ....' it?

Respondent: 'Well I had as much as anybody else, I suppose, I couldn't expect more but that – that was a massive thing'

(Interview with an 86 year old man, Wellington Ward, Westway Trust)

Similarly, this 87 year old woman expressed analogous views especially about being seen as a 'good patient':

Interviewer:	When you were in the hospital was there anything that you did for yourself to maintain your dignity while you were there? Do you remember doing anything in particular?
Respondent:	'Well always trying to be polite and do as I was told'
Interviewer:	Do you think that was important to sort of keep on the right side of the staff?
Respondent:	'Oh yes. Yeah, you're not rude to them'

(Interview with an 87 year old woman, Carnation Ward, Downlands Trust)

This reflects the findings in the Dignity and Older Europeans study where many older people expressed the view that behaving with 'decorum', by not complaining or reacting to poor treatment, was one of the ways in which they maintained their own dignity. This reluctance to complain, together with the low expectation of care, is important when such emphasis is placed on surveys of inpatient care as a measure of quality, as without detailed questioning or the use of observation as an adjunct, they are likely to present too positive a picture.

Older people are also reluctant to criticise the NHS, which many believe is a marvellous institution. This 82 year old man who experienced very poor care was initially worried that taking part in the study would in some way jeopardise the NHS:

"I was worried in case I said something that would cut the National Health Service and I don't wish to do that, ever. They have been perfect, I mean that, but when I went to that hospital, I thought, other people have got to go into hospital after me, so they need a whistleblower, I've got to do something, I must do it, I must say what happened."

(Interview with an 82 year old man, Elm Ward, Meadowfield Trust)

In the following example, this woman had tried to convey important information about her mother's allergy to penicillin, only to find that she was dealt with in a dismissive manner and her knowledge disregarded:

Interviewer: How did that make you feel?

Respondent: 'Very frustrated'

Interviewer: Yes

Respondent: 'And unimportant'

Interviewer: Yes

Respondent: 'And it's as if what you...your experiences or how...how... how involved you are with the person in the Hospital is just insignificant'.

Interviewer: It's irrelevant. Yes.

Respondent: 'Irrelevant. Doesn't matter. And we're talking about somebody's life here. I mean I understand that some families aren't that involved with the care of their elderly parents but I had the knowledge'

Interviewer: Yes. Yes, exactly.

Respondent: 'And I did feel that we were just...just'

Interviewer: It's very upsetting isn't it?

Respondent: 'They're very busy as well I think and they haven't got the time'

(Interview with 55 year old female relative, Carnation Ward, Downlands Trust)

Despite her treatment, what is interesting is that she makes excuses for the staff saying, 'They're very busy as well I think and they haven't got the time', when there is no excuse that justifies the type of treatment, which renders people powerless.

## **Respectful Communication**

One of the most immediate ways in which a person is acknowledged as a human being of some worth is through communication.

#### Forms of Address

A number of studies have shown that forms of address are important to older people (Baillie, 2008; Tadd, 2006; Woolhead et al, 2006; Jacelon 2003; Matiti, 2002). This was not generally confirmed in this study as the majority of older people interviewed had no objection to being referred to by their first name. Only a minority objected and saw this as an insult to their identity:

Respondent: 'People came in to see me and they obviously had a ...you know, they had a joke with, you know, and ... as if they've known you all your life almost and called you John and I called them Myrtle or whatever it was and we... the men would always shout, 'Oh here comes Myrtle...' So all in all it was a very pleasant experience on one side and having a stroke it...it wasn't exactly a painful experience, you know. Well straightaway they called you by your Christian name'

- Interviewer: Did they ask you whether you wanted to be called that?
- Respondent: 'No. They just did it, you accepted it and they...you called them by their Christian name so that there was that link there. No problems.'

(Interview with a 78 year old man, Daffodil Ward, Downlands Trust)

#### Similarly:

Respondent:	'And I – what I liked about it all, if my name was stuck up, it was always Arthur, not Mr Weston, and I felt all of us by our first name and that puts you at ease'
Interviewer:	And did they ask you when you first arrived, you know, how you'd like to be addressed?
Respondent:	'No, they didn't but they called me by my first name, they do all of them [patients] like.'

(Interview with an 82 year old man, Nelson Ward, Westway Trust)

For other participants, failure to address them by their chosen name was a serious oversight:

- Respondent: 'But my main complaints were the...Or the main one was the identity. You were asked how do you wish to be named?'
- Interviewer: Oh right. Yes. And what did they say?

Respondent: 'Mrs or by your first or second name? Well my name is Ann Jane but I'm always called Jane. And I just said well Jane. I'm not fussed about being addressed as Mrs but, they always used Ann'

- Interviewer: Could they get it right?
- Respondent: 'No, never...because they get your old notes. Ann! Please can I be known as Jane? It didn't happen. The same thing happened at the other hospital. How would you like to be known? By Jane please. Also known as Ann. I gave up. Leslie said, 'Well it's your own fault, you should have insisted.' I said, 'What's the point?'

Interviewer: So, when people came...when the nurses came did they introduce themselves...

- Respondent: 'I was Ann, yes'
- Interviewer: *Oh, you were always Ann*
- Respondent: 'Yes. Yes. And of course people would phone up...And my niece phoned from Canada of all places, 'How is Mrs Jane Davies?' 'We don't have anybody of that name on the ward!''

(Interview with an 87 year old woman, Carnation Ward, Downlands Trust)

#### And:

- Respondent 2: 'Why did some of them call you "James" did they?'
- Respondent 1: 'Yeah, well, they were just reading the names off the end of the bed you see'
- Interviewer: *Right. So have you do you tend to go by "Jim" and they were calling you "James"*?
- Respondent 1: *I I'm just always known as "Jim" but they knew me as "James"*

(Interview with an 87 year old man and his wife, Wellington Ward, Downlands Trust)

As well as using first names, there is a common practice of using pet names as in the following example:

One of the occupational therapists comes by to say goodbye to Enid 'Alright cupcake, just thought I'd come and say cheerio.' Enid puts her cheek out for a kiss and he leans down and kisses her cheek.

(Observation: Churchill Ward, Westway Trust, Morning)

This example is particularly disturbing as not only does the male occupational therapist refer to the woman as 'cupcake', he kisses her on the cheek. Although innocent in its intent, it is not appropriate behaviour for a professional and could easily be misconstrued, especially by a visitor or someone who is confused.

In the following example, the patient replies using the same term of endearment in a somewhat scathing tone:

The gum chewing healthcare assistant gets Linda from the WC and walks back to bed with her. When they get there he sees her lunch tray is still there. '*Have you finished with this darling?*' he says. '*Yes darling*' she replies.

(Observation: Ouse Ward, Uphill Trust, Afternoon)

Amanda, the staff nurse, comes in shouting, '*Right ladies, medicines again.*' She continues in the use of pet names calling Suzanne, who must be at least 75, '*Babe*'. She goes round giving everyone their medication calling them '*Hon*' or '*Darling*'.

(Observation: Elm Ward, Meadowfield Trust, Afternoon)

During the interviews with Trust staff, most participants mentioned how important it was to ascertain how older people wished to be addressed and not use terms of endearment. The quotes below from one Trust show how, although senior Trust staff emphasise the importance of addressing people respectfully, views of frontline staff may be different:

"Well, I've read the sort of European research and things like that and a lot of the stuff I read seemed to be quite hospital focused actually rather than community focused. And so I think there...there is a lot about individuality and, you know, I always hear about names...people being called by the name they want to be called by and just because someone is older, you don't automatically assume you can call them by their first name or by some sort of diminutive name for them."

(Interview with a Safeguarding Coordinator, Downlands Trust)

"Communicating with the patient in a way that the patient can understand and for example asking somebody what they want to be known as and not assuming that you're gonna [sic] call them by their forename or even worse, you know, 'lovely' or 'darling' or...so communication."

(Interview with a Nurse Director, Downlands Trust).

One staff member, however, could see nothing wrong with calling patients by their first names or by using 'pet' names:

"I think as long as a patient is comfortable with it and I think if a patient wasn't, most of them may say, well may not, but as long as it's not offensive and it's not...in any way would be derogatory, I don't really see the problem. Because I do it...I don't even think about doing it and I'm like "Are you alright sweetie?" And I don't realise I'm doing it. But, it's just like...it's a term of endearment because you see these people quite a lot and you want them to be okay and...Yeah, I don't do it in a derogatory...I don't mean it to be in a derogatory way and I don't think...No-one's ever picked me up on it, if that makes sense, and said can you just not...I think as long as....I think it's judging a person as well and knowing if it's appropriate, what kind of personality and temperament they have. Definitely. Yeah. As long as you don't overstep the mark." (Interview with a Student Nurse, Daffodil Ward, Downlands Trust)

This nursing student misses the point that, simply because she has no intention of being offensive or derogatory, this does not mean that an older person will not perceive this as such. As the following excerpt shows, such approaches can be seen as offensive and patronising:

"It was just that tone of voice. And then Io and behold when I went on the ward one of the junior doctors, 'Sweetie...come on sweetie...ah bless.' It's time you altered your...You're meant to be professional and you can't get away with keep talking to people like that. That....That was one of the things that really annoyed me."

(Interview with a 65 year old woman, Wye Ward, Uphill Trust)

Rarely were new patients asked how they would like to be addressed and almost everyone used terms of endearment. Different people may have very different ideas as to how they should be addressed, which reflects the subjective aspects of providing dignified care and staff should demonstrate respect by always asking how people prefer to be addressed and ensuring this information is conveyed to all involved in their care. Failing to do this can violate a person's dignity when it is seen as patronising and akin to treating an adult like a child.

The choice of language when talking about patients is also important. Some examples in previous chapters have included, 'Oh yes, he's mine – bed 10', 'move them on as quickly as possible' and 'make a bed for another stroke'. When staff refer to the people they care for in these terms, depicting them as passive objects, it demonstrates a lack of respect and reflects what Irurita (1999) termed as 'rough-hand care'.

Although the medical staff tended not to refer to patient's using first names or terms of endearment (although as cited above, one patient was referred to as 'sweetie' by a junior doctor) their communication skills were not perfect. Some could be quite brusque and offhand with patients, while others were extremely courteous as in the following example:

Behind the screens the doctors are very courteous. They call the man 'Sir' explaining everything to him, and asking if he has any questions. They speak softly so that others can't hear. One doctor asks permission to listen to the man's chest. She leaves him comfortable, opens the curtains and offers him his cup of tea, which has just been brought to him and thanks him for his time.

(Observation: Oak Ward, Meadowfield Trust, Evening)

#### **Patronising Older People**

Some staff spoke to older patients in a condescending or patronising manner as in the following example:

I then move to room 4, one of the female 6-bed bays. One of the healthcare assistants comes and calls round, 'Any of you girls need the toilet before lunch? Anyone? Oh, was that a yes I heard?' One of the women nods and asks, 'Can I have the chair?' The healthcare assistant replies: 'Let's try and walk a bit first. Okay, push off the chair, nice and tall like a solider. Chest out. Bum in.' The woman starts to walk out of the bay with her frame.

(Observation: Beech Ward, Meadowfield Trust, Lunchtime)

The healthcare assistant refers to the patients as 'girls', 'was that a yes I heard?', 'Let's try and walk' after the woman has asked for a wheelchair, and 'nice and tall like a soldier. Chest out. Bum in' are all examples of what is commonly termed as 'elderspeak', (Williams and Kemper 2004; Williams, 2009). Elderspeak consists of using various ways in which speech is accommodated or adjusted when speaking to an older person. Typically, these adjustments include using sing-song tone, exaggerating and prolonging words or syllables, speaking more slowly than is necessary, limiting vocabulary, repeating statements over and over again, making statements sound like questions, and using diminutives like 'dear' and 'sweetie'.

The studies cited above have shown that such patterns of communication, as well as having an impact on dignity and damaging self-esteem, may also be harmful to outcomes of care. Elderspeak can cause older listeners to see themselves as cognitively impaired or incompetent. It can lead to more negative images of ageing and older people who have more negative images of ageing have worse functional health over time, including lower rates of survival (Langer, 2009; Langer and Rodin, 1976). When used with people with dementia, elderspeak results in the person being less cooperative and receptive to care and more aggressive (Williams, 2009).

Another way in which older people are patronised is when staff treated them as though they are incompetent. In the following example an agency staff nurse is doing a medication round:

Without any greeting or smile, Audrey the staff nurse tells Nelly to take her blue inhaler. *'What now?'* says Nellie. *'Yes'* says Audrey. *'I want to see your technique.*' Nellie takes her inhaler and Audrey says, *'Well done that was very good.*' Nellie looks offended and says, *'So it should be, I've been doing it for years.'* 

(Observation: Oak Ward, Meadowfield Trust, Afternoon)

In wards that are exclusively for older patients, many staff automatically raise their voices when addressing older people as though they are deaf, as one of the researchers reflects in their field notes:

I wonder why the nurses raise their voices when they speak to the patients. It's patronising and even if the patients were deaf, shouting is not a helpful way to communicate, especially when they never seem to get down to the person's eye level.

(Field notes following a morning observing on a medical ward for older people)

#### Referred to as a Task or as a Number

Other aspects of communication are also disrespectful. In some instances, patients are referred to as elements of their care as the following citation shows:

Sam described many of the patients as 'double handlers' which means you need two people to help move and change them.

(Observation: Churchill Ward, Westway Trust, Night Duty)

This reduces people to the tasks associated with their care. Worse than this, however, on a number of wards staff refer to patients by their bed numbers, albeit not directly to the person, but by calling out to other staff members down corridors or from bay to bay. Apart from appearing unprofessional, it is not difficult to imagine the impact on the individual of being referred to as a number. This is not isolated to one Trust or to a few wards, but is a widespread practice. When asked why they did this, a commonly stated 'reason' was for confidentiality, although as patients' names are clearly above their beds, this seems implausible:

A healthcare assistant, Jackie comes into the bay with a tray with two meals on. She looks at an empty made bed and calls out loudly to those in the previous bay,

'Where's 9B, is he in the toilet?'

'Who?' (they call back) '9B'

'I don't know, probably'.

'Oh don't worry'.

(Observation: Oak Ward, Meadowfield Trust, Evening)

The use of bed numbers is chronic – '11B's done, 5A's on the commode' or '2Bs self-caring'. Or even, 'Who's that shouting?' '2B, who else?'

(Field notes following observation on an orthopaedic ward)

As the staff nurse in charge passes the nurses' station, she says to the other staff nurse, 'Why is bed 30 still here?' (This is Mrs Sharma, the young Asian woman who was moved out of the single room and has remained behind her curtains). 'Move her to the discharge lounge.'

(Observation: Ouse Ward, Uphill Trust, Afternoon)

The nurse leaves and Meggie is still waiting to go to the toilet. She waits another 10 minutes and a healthcare assistant comes in. She also raises her voice and says, 'What is it Maggie?' Meggie (whose name is above her bed) says she wants to go to the toilet. The healthcare assistant goes to the doorway and shouts, 'Help with a transfer for 8c'. A staff nurse comes in to assist. 'Maggie needs to go to the toilet.' The staff nurse says, 'It's Meggie' to which the healthcare assistant says, 'Maggie, Meggie, I never remember.'

(Observation: Oak Ward, Meadowfield Trust, Morning)

This notion that people are routinely objectified is important. In Chapter 4 and above, for instance, we reported how older people were told to soil themselves in the incontinence pad they were wearing. This is much easier to do when an individual is viewed as an object, different from us, different from people like us. In a way, it is a form of the 'slippery slope' argument as it enables unpleasant outcomes to become acceptable norms and therefore is something to be avoided all costs.

Dignity is also violated when staff scold older people as in this example where a patient, Sadie, has been ringing the bell repeatedly as she needs the toilet and is either ignored or told to wait. In the end Sadie can wait no longer and soils herself:

The bay smells of faeces. A domestic is polishing the floors and a young volunteer is helping people complete their menu cards. Sadie, a very old woman is ringing for the nurse. After a few minutes Diane, a staff nurse comes in and rebukes her saying, *'What are you ringing for? There's no point in ringing, there's only me – Don't ring again.'* 

(Observation: Elm Ward, Meadowfield Trust, Afternoon)

One can only imagine the humiliation and shame that this woman must feel, being reduced both in her eyes and those of others, because not only has she soiled her bed but she is then left to lie in it and is also reprimanded.

One of the most serious ways in which people are rendered invisible and their personhood disregarded is by being ignored.

### Being Ignored

This is a common occurrence encountered in a range of situations. For example, in staff handovers patients are routinely ignored:

One patient (Maureen in bed 3) is awake and aware that they are talking about her but cannot hear what they are saying. She apologises and says she is sorry but she cannot hear, they just say it doesn't matter and move on. There is clearly no intention of involving patients in these handovers although the ones who are aware seem uncomfortable about this and unsure of their role.

(Observation: Carnation Ward, Downlands Trust, Morning)

Medical staff can also be guilty of excluding patients from discussions and decisions about their care. Of course it may be that the person could have contributed little to a clinical discussion but this could have been explained:

The doctors arrive at bed 5 (house doctor, consultant and one other). The house doctor addresses the patient, 'Alright Mr Burns? We have just come to see how you are getting on.' The consultant then says, 'Hello Mr Burns' and the house doctor then talks to the consultant, telling him that Mr Burns is doing very well, he has had some oedema, etc. The doctors continue to talk among themselves – they do not address Mr Burns again until the consultant turns to him and says, 'Alright sir' and they leave.

(Observation: Carnation Ward, Downlands Trust, Morning)

In the following example, the patient challenges the young doctor who excludes her from the conversation. However, this is a rare occurrence:

Respondent 1:	'He'd stand by my bed talking about me but not to me. He was probably mid twenties'
Respondent 2:	'You should have just said "Hello" [laughs]
Respondent 1:	'I did interrupt actually, I said, "This is not on, full stop.'

(Interview with a 74 year old man and his wife, Nelson Ward, Westway Trust)

Instances of older people being ignored during personal care are also a common occurrence.

Rather than using the delivery of personal care as an opportunity to engage with people, many staff simply ignore the older person, or choose to catch up with colleagues.

The evening meal arrives and from the corridor I hear the nurses talking together while they distribute the meals to the patients. No-one talks to the patients.

(Observation: Wellington Ward, Westway Trust, Evening)

I have noticed that the staff don't engage with patients about their lives and any spare time is spent chatting together at the nurses' station, leaving patients to stare into space for hours on end as there is little to distract them.

Most staff talk together when making beds.

(Observation: Oak Ward, Meadowfield Trust, Evening)

Sometimes the differences between staff who acknowledge patients as people and those who do not is stark as the observation notes taken in the same bay on the same morning show:

I arrived onto the ward and went to Bay 7, which is a four-bedded female bay. There are four patients. An agency member of staff comes in and proceeds to make up an empty bed. She doesn't greet anyone or smile at them. Rita, the healthcare assistant, takes Mary for a shower and when she is gone, the agency nurse comes in and strips her bed. Again, she looks quite formidable and doesn't smile or speak to anyone.

(Observation: Oak Ward, Meadowfield Trust, Morning)

Rita and another healthcare assistant return to bath Jennifer, a woman with Huntingdon's. They smile and speak to her very gently and quietly, asking about her brother who is apparently very handsome. When they are finished and open the curtains, Jennifer looks very comfortable and calm, her hair nicely brushed and she is wearing clean nightwear. Then Rita and her colleague bed bath Pamela, an elderly, frail looking woman. Again, they close the curtains and they speak quietly to her whilst washing her and changing her bed. When they are finished they open the curtains and Pamela is sitting out of bed, looking comfortable, however, her hair is uncombed.

(Observation: Oak Ward, Meadowfield Trust, Morning)

When staff genuinely engage with people, this is very noticeable and has a powerful and positive effect on individuals. This extract from an older person's interview demonstrates the impact that being treated as a human being has on her:

Interviewer:	And when you went on to the orthopaedic ward what		
	would you say was different about the way you were		
	looked after there?		

Respondent: 'It was me. All of a sudden I was someone! And I mean I must have looked a complete freak because as I said they'd had to take all these stitches out and re-do them. And although I was clean, which was lovely, washed it all off I was... 'Oh my dear, you've been in the wars' and found me a bed and made a fuss and everything. I mean I couldn't obviously have a cup of tea or anything like that but you felt...you know, it was like, 'Are you alright now?' You know, 'If you want to go to the toilet just press your buzzer and...' and so on. Completely and utterly different ...They actually came to see whether I'd settled in alright. 'Can I put stuff away...help you put stuff in your locker?' In fact I don't know what a green uniform...she was a lovely lady, she had a green uniform. I think she's like a helper isn't she? She eventually came up and said, 'Do you need us to ring anyone and tell them you've changed wards?' Well, I thought that was lovely. Nobody's spoken to me for four days and this lovely lady came up and said, 'Do you want us to let anyone know?' And I thought that was superb. And that was what was totally and utterly lacking in the other ward. I keep saying downstairs, I don't think it was.

(Interview with a 68 year old woman, Carnation Ward, Downlands Trust)

In the next example, the healthcare assistant engages the patient about her love of gardening and relates that to the business in hand of feeding her. She demonstrates that she knows about her as a person, her interests and hobbies and gives a sense that she is important as an individual in her own right:

Another younger healthcare assistant was feeding another patient, Ethel, who was a little more able to communicate, she certainly seemed to understand what was being said to her and what was going on around her even though she wasn't able to say very much herself. The healthcare assistant feeding her was asking her if she liked the food and whether she grew some of the vegetables that they had in her garden. Ethel responded enthusiastically, nodding and smiling. She seemed to be enjoying the food and the company of the healthcare assistant who also seemed to be enjoying their time together. It made me think that, if taken as an opportunity to talk with patients, feeding patients could be a real way of building more meaningful relationships where the patients become more than patients but people, with interests and experiences. The healthcare assistant was interested in Ethel's vegetable garden and was asking about the biggest turnip she had ever managed to grow and Ethel was laughing and making a gesture with her hands to show how big it had been. The healthcare assistant laughed with her and said to her colleague that Ethel has a wicked sense of humour.

(Observation: Drake Ward, Westway Trust, Lunchtime)

This is in direct contrast to the following example where the staff completely ignore the person they are caring for:

Back on the ward a nurse and healthcare assistant are washing, changing and dressing a female patient, Irene, who is completely bed bound behind a curtain. I can hear most of their conversation, which seems to be focusing on their own families at home. There doesn't seem to be any involvement with the patient, either talking to her about her life or involving her in the conversation about theirs. Every so often you would here more loudly 'Roll to me Irene....well done.'

(Observation: Churchill Ward, Westway Trust, Morning)

The sensitive manner in which staff demonstrate how they understand what the woman in the next scenario is feeling is commendable; they connect with her and try to dispel the inevitable humiliation and embarrassment by diverting her attention to the photograph of her family:

After lunch, Elsie rings her buzzer, she's crying and looks really distressed. Ian, a healthcare assistant, and Rob, a staff nurse, come in and close the curtains around Elsie. She says she's afraid she has disgraced herself by soiling the bed. She says the smell is dreadful and she hates having to have intimate care from two young men. Rob explains very gently that she mustn't worry, they don't mind and that they are there to care for her. They wash her and change her bed. They speak kindly and distract her from the embarrassing nature of their task by asking about the photographs of her family

(Observation: Ash Ward, Meadowfield Trust, Afternoon)

Being ignored or treated as an object to be moved and manipulated by staff can result in older people feeling invisible and this experience can be heightened by the behaviour of some staff as shown in the following example:

The patients are all eating quietly. At one point, a healthcare assistant comes to bed 6 and starts looking at the notes, resting them on the bed whilst the patient is in the bed eating her meal. The nurse doesn't speak to the patient. Eventually she leaves without saying anything to the patient.

(Observation: Carnation Ward, Downlands Trust, Lunchtime)

Clearly, there are issues about common courtesy in this example, however, what is striking is that the nurse feels she can just utilise the bed space without seeking permission or even acknowledging the person. This raises the question of where the power lies in the relationship of older people and healthcare staff as, in this example, there appears no indication that the staff member considers the bed space as belonging to the person who temporarily inhabits it.

### **Power in Place**

Being in control of one's environment and possessions, especially when one might have limited control over one's body and what happens to it, is critical to experiencing a sense of dignity (Walsh and Kowanko, 2002; Woolhead et al, 2006; Agich, 2007; Baillie, 2009). Some ward staff recognise this and a number refer to the importance of empowering older people.

However, this assumes that the person who is 'being empowered' already lacks power. How much better to consider that the person possesses agency and then act on that belief:

"Acknowledging and respecting the agency of the individual places the individual at the heart of the care process. Every individual must be recognised as having power – the agency – to construct, direct and manage the care they receive..... Agency implies an integral relationship with the care team in which a care recipient is an active agent in care and functions as a subject – not an object – of care" (Ferguson et al, 2009, p.4)

Some patients either temporarily or permanently will lack a measure of agency, but then staff should take whatever steps are necessary to ensure the person experiences even a small degree of control and security.

The feeling of worthlessness and disempowerment resulting from being ignored is emphasised by the fact that the immediate environment of the ward and bed spaces are seen as the staff's territory, rather than the patients. The lack of respect shown to the person's space and sometimes their property can again assault their sense of self-worth. This criticism can be levelled at all staff groups, nursing, medical, therapy, portering and housekeeping. During the empirical work, we had no sense that patients were in control of their bed space as the following shows:

I have noticed on many wards how the pharmacists enter a bay and, without acknowledging the patients, go to their lockers, unlock the medication divide and check on the contents. For an older or confused person this can be alarming.

(Observation: Beech Ward, Meadowfield Trust, Morning)

In another example, this woman who is paraplegic describes how, without consultation, the nurses would 'tidy' her things from her bed and then leave her with no means of retrieving them:

"They used to take all my things off the bed, like books and magazines, plonk them on the windowsill and be quite put out when I rang the bell and said, can I have my stuff back [laughs]. That is really, really annoying in hospital, especially when you can't get out of bed yourself and move it. If you take my wheelchair away I'm hopeless, I can't get out. I mean I couldn't get of bed without any help."

(Interview with a 71 year old woman, Wellington Ward, Westway Trust)

Trust managers were aware of this apparent lack of care of people's possessions as this is often identified in patient surveys and complaints, yet they were less forthcoming about how the issue is addressed:

"Sometimes it's personal belongings not looked after properly, which is a form of respect for personal belongings."

(Interview with Trust Chair, Downlands Trust)

The following example of losing someone's teeth can impact greatly on the person's dignity causing embarrassment, as well as leaving them unable to speak or eat correctly:

"She was admitted on the Saturday, by the Monday, when I visited, they'd lost her false teeth. She's never had her teeth back, they never found them. And they said, 'Well, she's confused, she's put them somewhere.' Now she couldn't move beyond her bed to her chair, that's all she could do, so she didn't lose them, they went and they've never been found, she's never had any teeth since."

(Interview with the daughter of a 90 year old woman, Oak Ward, Meadowfield Trust)

The 'cavalier' attitude with which patients' belongings are treated is something that annoys many people, as in this man's account:

"Eventually they sort of came and said would I get out of – get up because they wanted to make my bed for the next client coming in. I had to get up and get myself dressed. So I got up and went to my sort of locker and nothing in there. 'What have you done with my clothes?' They found they were in a locker by another bed, they'd sort of put my clothes in one bed and me in another bed."

(Interview with an 82 year old man and his wife, Elm Ward, Meadowfield Trust)

Clearly, it is careless misplacing the man's belongings, but the whole encounter demonstrates how staff view the environment as their space and not even temporarily the domain of the patient. This patient went on to comment that it was almost as if, 'You have had your attention, now it's someone else's turn and that's all that matters.'

There is nothing to suggest that the staff see the person or the things he owns of any worth in their own right and this is another way in which dignity is denied.

## **Fundamental Care**

For many of the older people and their families that we spoke to, the most important aspects of their care involved fundamental elements of personal care such as elimination, eating and drinking, washing and dressing and gaining information. This man expresses this when he is asked about what dignified care means to him:

"Being fed when you can't feed yourself but being fed hot food. That, to me is desperately important. Being cleaned up quickly if you have had an accident instead of just being left to lay in it while they say, well, I've got to finish this but when I've done that I'll come back. Well that could be half an hour or three quarters. I can't honestly say that happened to me but then I don't have that problem. And I sometimes think it's the casual way staff speak to the patients, you know, the casual way they treat them and - and yet I can't put my finger on any one of them. It's just this general attitude, well, you know, they're patients, they're the old things so we'll look after them and they do their best for us, well in their own way but you're not important to them, you're not. You don't want to be important to them, that's not the word I want, but everything is sort of done as they think it should be done. They don't say, would you like it this way or are you more comfortable that way, they just say well, you usually lay on your side so lay on your side. Sorry, but there again, you see, I do think dignity comes into it."

(Interview with an 82 year old woman, Wellington Ward, Westway Trust)

Many patients believe that fundamental care should be delivered with sensitivity and when necessary in private.

### Privacy

Ensuring both bodily privacy and the protection of personal information are important aspects of maintaining dignity and of recognising the centrality of the person. Yet on many occasions both of these constituents of fundamental care were ignored. One example of this was the lack of use of privacy notices when intimate care was being undertaken behind the curtains. This was despite there being notice boards on many wards devoted to 'Dignity in Care', encouraging staff to take the 'dignity challenge' and drawing attention to the privacy notices that are to be used on curtains. In observations, these were rarely seen with the result that staff members repeatedly walked into closed curtains, regardless of what was happening behind them:

The curtains are around Olive in bed 3. A healthcare assistant and a staff nurse arrive and enter without knocking or calling out. The house doctor speaks through the curtain about Winnie, 'I wonder if Mrs C could go to Ward 30.' The healthcare assistant comes out and says she thinks she has already been referred. Another doctor comes and looks in through the curtains asking about his colleague. I hear the healthcare assistant saying, 'I'm just covering you up.' Then a third doctor arrives and all go in – no-one knocks or announces their presence. I hear the healthcare assistant say, 'The doctor is just going to look at your wound.' I hear the doctor say 'That's okay,' and they leave. There seems to be no conversation with the patient.

(Observation: Carnation Ward, Downlands Trust, Morning)

When I leave Bay 1, Iris asks me if I can get a nurse as she needs a bedpan. When I go back about 10 minutes later Iris is still behind curtains, presumably on her bedpan, surrounded by other people's visitors. (She is in a middle bed of three). Two healthcare assistants arrive and enter the curtain without 'knocking'. I hear (and presumably everyone else hears) 'You alright Iris? We're just going to get you off this or it's going to go all over. Right, you alright to get off? You do some of the work as well – it's not just us.'

(Observation: Ouse Ward, Uphill Trust, Afternoon)

No matter how routine it is for staff to see patients in varying states of undress or in compromising situations such as on bedpans or commodes, it is not routine for patients. For them, it is out of the ordinary to be seen in such circumstances and is a source of acute embarrassment. A number of authors (Jacelon, 2003; Ennes, 2003; Matiti and Trorey, 2008) have described how people continually re-adjust their ideas of dignity to enable them to cope with situations such as these when their dignity may be threatened. The following examples demonstrate how patients reconcile this and modify their notion of dignity and indignity:

Respondent:	'Well as you get older and more and more helpless you don't care much'
Interviewer:	What don't you care about?
Respondent:	'Nudity. I mean, I've got a lift for the bath as well but I'm not allowed to do it on my own. You press a button and it goes up and down And somebody has to be there with me. That's fine and I try and wash my hair under the shower at the same time. But you're naked and you have to have someone come in with you and turn the shower on or off or whatever – so what?'
Interviewer:	Yes, and it doesn't bother you?
Respondent:	'Not now. It did initially'
Interviewer:	It would have done, yeah, when you were younger perhaps?
Respondent:	'No, in the last year or so'
Interviewer:	Yeah, right. So why do you think it doesn't bother you so much now?
Respondent:	'Well you need…you realise you need help'
(Interview wit	h an 87 year old woman, Carnation Ward, Downlands Trust)

'That [using a commode] did frighten me a bit, yes, but, um, once I was able to go to the bathroom I knew was out of that bed. Um, that was the main thing because I'd only been able to use a commode and, er, it's not degrading because, I must be fair, they covered the curtains round, you know, and they couldn't do enough for you because they knew that you weren't able to do it...and I think that's a long way to go to keep your dignity.'

(Interview with a 78 year old woman, Drake Ward, Westway Trust)

This woman could deny that using a commode in the vicinity of others was undignified because she was afforded privacy and because people understood that she was unable to do otherwise and that made the situation acceptable.

In the following example, the patient does not have the opportunity to protect his dignity in this way as the nurse carelessly allows others to observe what is now an undignified, albeit necessary procedure:

I move to sit in the nine-bed bay. The man who'd had all the trouble with his catheter, John, was still there. One of the male healthcare assistants I hadn't seen before comes over and pulls the curtains round, but there is a big gap in the curtains so that both the patient I am sat next to and I can see everything that is happening through the curtain. *'I'm just going to check your pad, yeah, I'm just going to change that for you.'* When he comes back with the pad, the gap in the curtain is still there and I make a conscious effort to look away as does the patient in the bed next to me, who looks embarrassed. *'Okay John, if you could turn away from me for a minute please.'* As he turns he catches the eye of the other patient and they both look away.

(Observation: Wellington Ward, Westway Trust, Evening)

Bodily privacy is important to all of us, and particularly so in public spaces such as hospital wards. The hospital gowns available in three of the Trusts we visited, were also a source of embarrassment as they rarely closed down the back:

As I am about to leave the bay, I see a patient in the corridor, sitting in a chair - he asks a healthcare assistant for some help, she says she is a bit busy. A bit later, I see someone help him off the chair – he is wearing a gown, naked down the back with an incontinence pad hanging off.

(Observation: Marigold Ward, Downlands Trust, Morning)

Many patients commented on the unsuitability of hospital gowns and how they afforded little dignity:

A student brings Albert out of his bay – he is wearing a short theatre gown over his rather large frame. As he climbs on to the trolley I hear him say, *'Not very dignified this'*. The student puts a blanket over him and he lies back.

(Observation: Ouse Ward, Uphill Trust, Afternoon)

Although many staff often failed to act when patients were exposing themselves in pubic, some were more aware and took efforts to ensure that patients' bodily privacy was maintained. Often, it was patients who were confused who exposed themselves and in the following examples, staff act to maintain the person's modesty:

The healthcare assistant says she will walk her back there but as she gets up June's gown gapes at the back. The staff nurse jumps up and covers her up saying, 'You're flashing again, good thing there are no men here'

The healthcare assistant and June then set off down the ward.

(Observation: Thames Ward, Uphill Trust, Night Duty)

Later, when Jean keeps pulling her gown off, a healthcare assistant puts another one on the other way round which keeps her covered.

(Observation: Severn Ward, Uphill Trust, Afternoon)

In only one Trust were appropriate gowns provided for patients:

She helps Margery to walk to the toilet. Margery is wearing a hospital gown which is one of the best I have seen as the patient is completely covered and although there is a slit, it overlaps with an inner layer, completely maintaining the patient's modesty.

(Observation: Elm Ward, Meadowfield Trust, Morning)

A second aspect of privacy concerns confidentiality of patient information and many staff are frequently careless in relation to this. Often they speak loudly at the nurses' station about patients and their treatment with little regard for the sensitive nature of some of the information.

There is a doctor at the nurses' station talking to a relative of a patient who he thinks may have had a stroke. He is speaking quite loudly and using the person's name. The relative is speaking more quietly but seems concerned at the way her relative is behaving. The doctor says, 'She is 91 - some elderly people go like that – you just have to remember it is her illness and her age – it's not her.' He was trying to be helpful but it seemed a bit dehumanising. He then talks to another patient about another patient on the ward and the diagnosis and treatment plan – again quite loudly.

There is little recognition that certain discussions such as those concerning bodily fluids or processes may be embarrassing for patients:

The patient from bed 11 comes out to the nurses' station and rather tentatively looks round for a nurse. In the end, she finds the ward manager and asks, 'Do you still want to monitor my water?' The ward manager says 'Yes' and rushes off to get a pan and puts it in the toilet for her. When the patient comes out of the WC there are lots of people around the nurses' station – she looks round for someone to tell but then gives up and goes back to her chair – presumably having left the pan in the WC. This was a difficult situation for the patient who clearly didn't want to have to break into the group at the nurses' station to tell them about 'her water'

(Observation: Wye Ward, Uphill Trust, Morning)

#### Nutrition

As demonstrated above, many staff take time over feeding, engaging the person and finding out their likes and dislikes. Others fail to ensure patients have adequate nutrition as the following example shows:

A housekeeper brings a meal for Mildred who has severe visual impairment and is in bed. Mildred is slipping over to one side making it impossible for her to eat, and she says, 'I need to get someone to sit you up.' I hear the nurse who is giving out the lunches call to Abby to sit Mildred up. Abby comes in and moves Mildred so she is sitting straight in the bed. Mildred says, 'I can't see the food' and Abby replies, 'Yes you can, you saw the tablets I gave you earlier' and walks out. Mildred tries to eat her meal, a vegetable lasagne, with her fork but the food keeps falling off. She only manages to pick a few morsels in about 10 minutes so that the food is cold. Sometimes the food falls of the fork onto Mildred and she picks it up with her fingers. Eventually, she gives up but she had not had more than two forks full of food.

Mildred finds her dessert (rhubarb crumble and custard) and tries to eat it but soon realises as she spills the custard that this isn't going to work. She replaces the spoon and leaves it. With the back of her hand, she feels for her tea, but when she realises it is a cup rather than a lidded beaker she doesn't attempt to drink it. A different housekeeper comes in to collect the trays and says, *'What's wrong Mildred, aren't you hungry today?'* as she clears her table.

(Observation: Elm Ward, Meadowfield Trust, Lunchtime)

Both Age UK (2010) and the Patients' Association (2010) have recently highlighted the persistent issues surrounding nutrition in acute wards and the poor outcomes that result from neglecting patient nutrition. In the above example, the researcher was faced with an ethical dilemma as to whether or not to intervene immediately. She decided not to but to

observe what happened. Immediately after the food was taken away she spoke to the ward manager and a meal was brought, an apology given and Mildred was helped to eat it.

On other occasions, helping patients to eat is clearly seen as a chore to be accomplished as quickly as possible:

The suppers arrive and a staff nurse, Audrey, brings Bella her meal and begins to feed her. Audrey speaks in a very loud voice, 'Open your mouth' 'Lovely mashed potato and oh I'm not sure what that is.' Every now and again she asks (in a loud voice) 'Have you had enough, do you want any more to eat?' and looks somewhat disappointed when Bella smiles and nods her head. The 'open your mouth routine' goes on and on until Bella is finished.

(Observation: Oak Ward, Meadowfield Trust, Evening)

### Using the Toilet

The accounts of patients being told to soil themselves highlight the degradation and denial of human rights that some patients endure. The violation of dignity also includes intimate care being undertaken without due regard to privacy or sensitivity.

Although some staff members display a deep understanding of what it must be like to perform the most basic human functions in the presence of others and they make every effort to ameliorate the impact on dignity, others show less compassion in delivering fundamental care.

Staff can also be slow in responding to buzzers. This is often because they are engaged with other patients but it is a common occurrence on all of the wards where buzzers ring and ring. On one occasion, a patient waiting in a toilet rings the bell for so long that she falls when attempting to return to her bed unaided and on another occasion, a buzzer rings for 18 minutes before someone comes to take the patient to the toilet. On a number of occasions, the researchers had to find staff, as patients were almost in tears either needing pain relief or needing the toilet. At other times, patients were in danger of falling.

In the following account, which was played out for over one and a half hours, the staff fail to recognise the signs that a patient needs the toilet:

The frail lady next to me rings the bell – she looks very uncomfortable and is fiddling with her nightdress, pushing down the bedclothes as if she needs the toilet. She rings the bell again. After another five minutes the healthcare assistant comes in. 'You wanna [sic] go down?' The woman, who has had a severe stroke, has difficulty speaking but indicates, 'no'. The healthcare assistant then says, 'You wanna [sic] go up?' And raises the bed before walking out of the ward. She doesn't ask the woman if that's better or anything.

As she gets to the door, she calls down the ward to another nurse about what the patient wanted. At 5.15pm, a staff nurse enters with the

medicine trolley. Without washing her hands, she opens a 500ml bag of saline and draws up to 50mls and tries to unblock the frail lady's naso-gastric tube without speaking to her. The tube is blocked and she can't unblock it. Without washing her hands, she moves down to the chart and writes on it. The woman is pushing down her bedclothes again exposing her underwear. The nurse assumes the woman is hot and throws the counterpane and a knitted throw down onto the woman's feet. The patient is immediately uncomfortable and struggles to pull up the counterpane while fidgeting with her underwear. She looks most uncomfortable. No-one asks if she is in pain. A junior doctor arrives and he and the staff nurse discuss the blocked naso-gastric tube. He says it's not worth re-siting it as she's going to theatre for a peg tube the following morning but the nurse points out the woman's had nothing since 10.00am that morning, so the doctor inserts an intravenous line.

The doctor leaves and returns with a venflon in his hand and inserts this into the woman's left hand (I wonder when the infusion will be put up as this woman must be dehydrated by now). Suppers are brought in and throughout the meal the lady next to me has continued to fidget with her clothes and ring her bell but no-one seems to get the message that she may need the toilet. Her pillows look incredible uncomfortable and I really want to rearrange them properly. One nurse walks in and quickly shuffles the pillows but doesn't address the continued fidgeting. Although when not in the bay, the nurses and ward sister seem to be just chatting at the nurses' station, no-one takes the time to find out what is wrong. Everything is reactive and the focus is on doing the jobs that are part of the routine.

The woman again rings the bell and tries to speak but the healthcare assistant doesn't seem to understand that she is trying to say, 'bedpan'. I ask her if she thinks the woman needs a bedpan. 'No' she says and walks out, still leaving the woman without a solution.

The woman continues to ring the bell. I hear the assistant say, 'It's Mary again.' She comes in and announces very loudly to the ward, 'Do you want a bed pan?' The woman nods, looking very relieved.

The healthcare assistant returns with a bedpan and closes the curtains. Loudly, she asks the woman to, 'Lift yer[sic] bum up' saying again, 'Lift up darling I have a bad back.' She leaves the woman and after five minutes comes back asking, 'Are you finished darling?' The nurse opens the curtains and takes the bedpan away.

The woman is left too flat and her pillows look lumpy. I go to her and raise her bed and shake and turn her pillow. As she smiles, I notice her mouth looks dry and dirty. I don't know how long she has been nil by mouth as she has had a severe stroke and a naso-gastric tube. But no-one has cleaned her mouth all evening. There is no mouth tray or sponges on her locker. Soon after, I leave the ward feeling quite despondent. I have seen little evidence of 'care' – the tasks are completed and people aren't treated cruelly or anything like that but something – care, compassion, empathy, dignity, interest even in the patients is lacking.

(Observation: Wellington Ward, Westway Trust, Evening)

In this example, the healthcare assistant is coming to the end of a 14 hour shift, which she prefers to work as this means she enjoys a longer time off duty. These long days can impact negatively on patient care as staff appear too tired to bother by the end of their shift.

In April 2006, the British Geriatrics Society (BGS) launched their 'Behind Closed Doors' campaign, which contains much useful information (www.bgs.org.uk) on how to promote dignity during elimination. Shanahan et al (2008) undertook an audit on an older person's rehabilitation unit based on the campaign material and found that of the nine instances of bedside toileting observed, only three people were offered a choice of using a bedpan/commode or going to the toilet; although curtains were closed in every case, in one third someone entered the curtains without permission and hand-washing facilities were only offered to two of the nine people.

These findings reflect our own observations of toileting practices. Many patients who are able to walk to the toilet with help have their dignity threatened by being brought commodes to the bedside and few privacy notices are used. Rarely are patients offered hand-washing facilities after using a bedpan or commode, and although behind the curtains they may be offered wipes, such invitations were never overheard and wipes were not seen.

Another aspect of care that can infringe upon patients' dignity is in relation to personal hygiene.

#### Washing and Dressing

Some staff try to use the bed bath as an opportunity to engage with patients and ensure it offers a pleasant experience as the following example shows:-

Emily, a staff nurse, and Jenny, a healthcare assistant, have finished washing Maureen and she is sitting in a chair. Emily explains that they will put her back to bed to eat lunch and then sit her up again a little later today. She explains it's important for Maureen's recovery to sit out each day so that she will get stronger. They continue making the beds, before screening Lillian and giving her a bed bath. When the curtains are opened, Lillian is wearing fresh pyjamas and her hair is combed. She looks refreshed and is sitting in a chair.

(Observation: Elm Ward, Meadowfield Trust, Morning)

For some patients, however, a bed bath is a humiliating ordeal. The 78 year old woman below describes the embarrassment she felt when a male nurse did her bath every day:

- Respondent: 'He was, I think he might have been Polish but I felt, I didn't want to – to say anything because I didn't want people to think I was against foreign people. But I suppose I could have treated it different and some people did but, I felt uncomfortable with him....So he did – and, there was lots in the Westway, we had lots of male nurses. I know they're nurses and they're male but, they have, quite a few....'
- Interviewer: So did you feel that was undignified, being treated...sort of very personal care issues being treated by a male nurse?
- Respondent: 'Yes, I did really. Some people didn't seem to mind but I just didn't feel comfortable with it. I mean, some of them are alright, some of the males, they're quite different somehow in some ways to others. He was quite young, but, I, you know, other times when men are sometimes kinder men [laughs] but, I don't know.'

(Interview with an 88 year old woman, Wellington Ward, Westway Trust)

This woman was deeply distressed by having intimate care delivered by a young man on a daily basis. During the interview she spoke of how she came to dread the daily wash because every day this young man washed her chest and how she felt unable to complain in case people thought her racist. People also walked in and out despite curtains being drawn and regardless of what was happening to the patient.

One ward manager suggested the privacy notices were not used as they were dangerous:

"No, we don't use them as we bang our heads on them [bulldog clips] They're dangerous."

(Interview with a Ward Manager, Drake Ward, Westway Trust)

### **Being Informed**

Having the necessary information is essential to exercise one's agency and make decisions about one's own life. This is another unpredictable aspect of care. Some patients are given information about all aspects of their care whilst others complain that they find it difficult to ascertain information. Many patients are dissatisfied with discharge arrangements or information about investigations:

Interviewer:	How did you feel about how they communicated with you?		
Respondent 1:	'Brilliant, they was good, they were good.'		
Respondent 2:	Yeah. Then again, you know, if you needed any		

information about your illness or what they were doing...'

Respondent 1:	'You had to ask.'
Respondent 2:	'You had to ask, they wouldn't just come up to you and say, oh well, your scan istomorrow afternoon at three o'clock, you know.'
Respondent 1:	'No, we had to askWell I kept asking about that because I waited a few days, didn't it [sic]?'
Respondent 2:	'For this brain scan that Joan was having we had absolutely no idea when it was going to be done.'
Respondent 1:	'I had to keep asking. And that was – although they came in the morning and said your scan's at whatever time, the morning I was having it and they said oh they're fetching you at such and such a time so as soon as they knew on the ward they were waiting for information from the department.'

(Interview with a 69 year old woman and her husband, Nelson ward, Westway Trust)

# The Views of Relatives

Although some carers are grateful for the way that their loved ones are cared for and returned to better health, a number did raise serious complaints.

There is a growing literature concerning the difficulties that carers face when engaging with health and social services and the professionals within them. Livingston et al. writing in the British Medical Journal identified that:

- Professionals do not recognise emerging problems (fobbing off carers' concerns) which can result in delayed diagnoses.
- Poor quality of information available to carers in terms of timing and quantity.
- Confidentiality and data protection so staff are reluctant to discuss the person's needs or treatment with the carer.
- Bureaucracy and rigidity as staff insist on sticking to protocols (Livingston et al., 2010).

Lindhart et al. (2008), in a study of nurses' collaboration with relatives, found that although the overall organisation of care can cause staff difficulties in engaging with relatives, many of the factors are individual, such as the nurse's attitude and actions and the way in which they view relatives as a 'demanding resource'. This results in a flight or fight response where nurses either completely avoid relatives or are dismissive of them, as highlighted in Chapter 4. In a systematic review of older people's and relatives' experience of acute care, Bridges et al. (2010) claim that relationship-based care is central to a positive experience. They highlight three essential aspects of this:

- Connection that is creating a reciprocal relationship.
- Maintaining identity which requires that each person is seen in all of their complexity.
- Involvement which highlights the importance of equity and power differentials in decision-making about care and treatment.

The following example of a carer's experience support these research findings:

Mr H in bed 9 is wheeled off for a CT scan. His wife who has been visiting him thinks she might as well go home - she asks a housekeeper how long the scan is likely to take and is told anything from 20 minutes to an hour. Mrs H decides to go home anyway but on the way out she asks a staff nurse about her husband. The staff nurse says he is not one of her patients but the nurse who is looking after him is in handover. She suggests she should wait by the bed but there is no bed as it went with the patient. Mrs H looks doubtful, so the staff nurse says she will go and tell the other nurse and Mrs H waits in the corridor. A little later the nurse arrives and confirms that Mr H has gone for a scan (which his wife knows). She wants to know if it is a full scan or just his head - he has been very confused and she wants to know if it is secondaries in his brain or an infection. They talk about the options for going home and whether she will cope as she is worried about him wandering at night - she has had no sleep. All this discussion takes place in the corridor and is audible to anyone around. Mrs H asks if her husband is on steroids and the nurse replies, 'I don't know without looking at the notes sweetheart.' Then she says, 'When we know the results we'll take it from there – it's about us all working together. If you want to know anything just grab one of us. Okay sweetheart, take care.'

[It seemed to me that's what she tried to do on this occasion and actually got no further information].

(Observation: Wye Ward, Uphill Trust, Afternoon)

The next account is from a man who felt let down by the system. His mother had been in hospital over three months. She had been moved from an acute ward to a dementia ward in a psychiatric hospital. Every appointment arranged to discuss his mother's case had been cancelled and his mother had no identified social worker:

"I can't say they were impatient, but I – I don't think they – they weren't really geared up to coping with someone like my mother and they didn't have they didn't appear to make sufficient time to actually see her. Sometimes I'd go in, there'd be a number of them sort of in the little office bit, and they were there and I often felt, well it would be nice if they, someone could've have made a bit more time to talk to my mum. But there again, I don't know what their particular roles were. So, I don't want to criticise them too much, but I was...you can imagine if you're driving from here to the hospital and you're going to see your mother and your mother's walking around naked in a cubicle with all the blinds down and she thinks she's living there full-time, you know, that – that that was pretty awful. In all the - the time my mum first went in on 19<sup>th</sup> December, she hasn't been outside at all in – in all that time and for someone who liked seeing gardens and, you know, flowers, that seems like being a prisoner. Because the – the two meetings I should have had by now have both been cancelled, one at that hospital and one at the new one. So I don't think that's really right. You know, I can appreciate people cancelling meetings and so on, but you'd have thought in almost three and a half months I could have seen someone formally by now. Right, so I'm finding I'm having to sort of try and look at things on the internet to find out what sort of things can be done but I felt left out and unfortunately this is what you hear about old people who have sort of mental problems, that they are left and this isn't very good."

(Interview with the son of an 84 year old woman, Nelson Ward, Westway Trust)

Although staff like the nurse in the following example did recognise that relatives are stressed and anxious about their loved ones, the tendency to mistrust remains:

"I know it's just because they're [relatives], worried and stressed and...and things aren't being done in their eyes because they can watch us be busy but they don't...if we're not helping their relative they can see that well you're not doing anything."

(Interview with a newly qualified Staff Nurse, Daffodil Ward, Downlands Trust)

This healthcare assistant who is very experienced has a different view of the situation and admits that some staff avoid relatives due to the 'flight from fright' effect mentioned above:

Respondent	'Some staff really	i aron't koon	on interaction	with relatives'
Respondent.	Some stujj reuny	i uren t keen	on meraction	with relatives

Interviewer: Why do you think that is?

Respondent: 'Typically, I think it's because in most cases when a relative comes to the reception area looking for a member of staff they're looking for answers, they're looking for conclusions and resolutions to their worries.'

(Interview with a Healthcare Assistant, Daffodil Ward, Downlands Trust)

Staff need to acknowledge that relatives have cared for the people who are now patients, sometimes for many, many years and it seems important for them to remember that although the status might have changed from carer to relative, or older person to patient, the feelings of love and responsibility are the same.

# Approach to Care

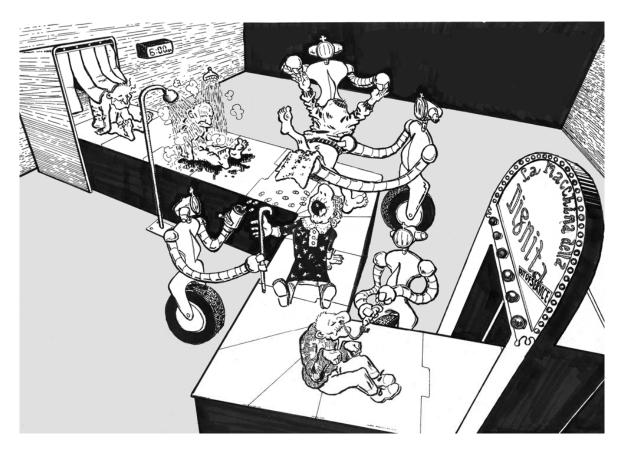


Illustration 2: Task Centred Care © Toni Boix-Ferrer 2004 reproduced with permission

Despite the current focus on patient-centred care, (Goodrich and Cornwell, 2008; Dr Foster, 2010) there is little evidence of this within the participating Trusts. This is not because staff are averse to the idea. Indeed, many staff express disappointment that they are unable to deliver such care. Many staff, especially nurses, spoke in interviews about the ideals and values such as individualised care, or patient-centred care being emphasised in their education and how this is central to treating people with dignity, yet there are few examples where this is seen.

Care **is** task based on acute wards, with someone doing the washes, someone else doing the observations and another person doing medications, which for the individual patients may feel like being upon a conveyor belt. This isn't because staff chose to deliver care in this way, but it is all that can be done with the staff mix available. This state of affairs has important consequences for staff who frequently feel dissatisfied with the care they are able to give. They leave work late, are often in tears and many are looking for other jobs.

In interviews, a number of staff said how they found that there is a mismatch between the ideals promoted in their educational programme and the realities they face in practice. Maben et al. (2007) term these individuals 'crushed idealists' who are 'unprepared for the differences between the way they were taught and the realities of practice' (Maben et al, 2007, p.109). These authors go on to state, 'This disconnection leads to disillusionment and for some a desire to leave the profession. In consequence, a greater gap than ever before now exists between the ideals and values adopted by students during their education and those evident in the practice setting' (p.110).

Rather than individual patients being seen as the focus of staff attention, care is frequently fragmented and patients are reduced to the tasks to be completed, which reflects in the language in use such as, 'you're done'.

After the visitors leave, the staff begin to go round and check patients and start getting them ready for bed before the night shift arrive. One of the healthcare assistants is in one of bays talking to one of the nurses, '9B and 9D are done, me and Alison did them' and the nurse looks around the bay and says, 'Right, that's you four done.'

(Observation: Oak Ward, Meadowfield Trust, Evening)

There are other approaches to care delivery that are more proactive, such as rounding (Castledine G et al, 2005; Meade et al, 2006). These proactive approaches have been shown to offer a number of benefits such as reduced use of call bells, reduced falls, a reduction in the distance nurses walk in the day (sometimes up to 1 mile) and increases in patient satisfaction (Meade et al, 2006). This strategy has been successfully introduced in a small number of UK hospitals such as Whipp's Cross, the Royal Free and Betsi Cadwaladr University health board and is one way to ensure that care is proactive rather than reactive.

Although no examples of nurse rounding were observed in this study, excellent examples of proactive care were observed by staff on one ward in particular. This care involved anticipating patient needs and attempting to explain what would happen next:

Brenda (a middle aged woman) in the bed next to Pauline returns from theatre. She is wide awake. Carol, a staff nurse, is with her, checking her observations, asking if she has any pain. Again, the curtains are closed, Carol speaks in a quiet voice simply explaining what she is doing, what will happen next and when she can have a drink.

(Observation: Elm Ward, Meadowfield Trust, Afternoon)

A young doctor returns to Gloria. He is pleasant and polite and squats down so that he is on the same level as her. He speaks quietly, drawing a diagram to explain what will happen and answers her questions. He spends a considerable time with her. When he leaves, Gloria tells everyone that she will be going to theatre that evening and hopefully they will divide the adhesions.

(Observation: Elm Ward, Meadowfield Trust, Morning)

When the staff have completed Lillian's bed bath Jenny, the healthcare assistant tidies the ward, ensuring the correct instructions are above the bed, she offers people a cold drink and asks if everyone has their buzzers at hand before leaving the ward.

(Observation: Elm Ward, Meadowfield Trust, Morning)

What is clear from the observations (and perhaps not surprising) is that when staff feel appreciated, supported and competent, care is better than on those wards where staff feel overworked and pressurised, or that their efforts are taken for granted. Similar negative feelings are engendered when staff feel their concerns are not listened to, or that they do not have the skills to adequately fulfil their role. This is particularly the case in relation to caring for people with dementia and/or delirium and it is these patients whose care raises most concerns. The vast majority of staff want to give better care and many are deeply concerned that they cannot achieve this goal. This impacts on the staff's dignity as well as that of patients and relatives.

# **Staff Dignity**

Since 2003, NHS staff surveys have provided direct feedback on employment, working experience, attitudes and behaviours. The aim of these surveys is to help NHS Trusts to identify areas for improvement. Analysis of the surveys demonstrates a correlation between staff and patient experience so that patient satisfaction is higher in institutions where staff are satisfied and negative staff experience is reflected in poorer patient experience. According to Raleigh et al (2009), managerial support, working extra hours and work-related stress, suggest that the working conditions and morale of staff impacts on the patient experience.

In two Trusts involved in this study 'Support from immediate managers' was in the worst 20 percent of all Trusts. In one Trust 'Suffering work-related stress in last 12 months' was in the worst 20 percent and in two Trusts, 'Work pressure felt by staff' was worse than average. In the remaining Trust, this score was in the worst 20 percent. In two Trusts, 'Staff job satisfaction' was in the worst 20 percent and, in one Trust, 'Feeling satisfied with the quality of work and patient care they are able to deliver' was in the worst 20 percent. In a second Trust, this factor was rated worse than average (CQC, 2010c).

In the Dignity and Older Europeans study, staff reported the inability to deliver care of an adequate standard impacts negatively on their own experience of dignity as they do not feel valued by either their colleagues or managers (Arino-Blasco et al, 2005).

In some wards, there is little evidence of teamwork and on occasions there are signs of friction between staff. Sometimes staff are publicly reprimanded, as in the following situation involving two people with dementia:

Pat starts folding blankets and Elsie helps her – they continue to 'make beds' for some time. A healthcare assistant comes out of the bay a little later saying, 'They're making beds in there, well at least they're not fighting, they're friends' then calls out, 'You alright you two?' The nurse in charge comes out of the handover room where she has been taking a break. She sees Pat and Elsie in Bay 1, 'What are they doing in there?'. The healthcare assistant answers, 'They're making beds,' 'Well stop them.' The male staff nurse says lightly/jokingly to the nurse in charge, 'What's the problem, have you got a problem with your patients?' She responds, 'Oh okay I suppose it's okay.' Meanwhile another healthcare assistant has been in to see Joyce in a side ward who has asked to go to the toilet. The nurse in charge sees the healthcare assistant and asks her across the hallway why she is not in Bay 1 settling Margaret. She tries to explain but the nurse in charge doesn't seem to understand so she ends up having to shout across that she is taking Joyce to the toilet.

(Observation: Daffodil Ward, Downlands Trust, Evening)

From conversations between the nurse in charge (the deputy ward manager) and the doctor and other nurses, there seems to be some animosity between her and the ward manager. I also got the impression from others on the ward that they did not always agree with the decisions that the ward manager makes or asks them to make.

(Observation: Drake Ward, Westway Trust, Night Duty)

Patients also sensed when staff relationships were strained:

- Interviewer: So did you get a sense of leadership on the ward you were on?
- Respondent: 'No. There seemed to be a culture of fear there. Staff would immediately defend themselves and each other'

(Interview with a 66 year old man, Nelson Ward, Westway Trust)

Staff also express their dissatisfaction when they cannot give care of an adequate standard:

"This morning when I came in there were three patients in beds around the nurses' station, one of them with her head sticking into the bathroom, as they had fallen in the night and it was the only way the staff could keep an eye on them safely. The night staff were distraught and didn't feel they were providing dignified care. There is also a lack of nightwear and sheets and I have found patients naked in bed as there are no nightdresses."

(Interview with a Ward Sister, Marigold Ward, Downlands Trust)

On some wards there was also a 'pecking order', which was picked up by patients as demonstrated in the following example:

"I thought....it's so difficult, everything happens in the morning. The tea comes around, porridge or whatever and then sometimes consultants with a small entourage came at the same time as everything else is happening including the cleaning lady. And you felt so sorry for the poor cleaning lady because there's no way she could do it. She's the bottom of the list and she sort of tried to remember to come back. But that all happened so somehow that could be improved. All that happening together, she should have come later or...it all was happening; morning cup of tea, trolleys for this, perhaps the medication trolley, I can't remember. But everything together including maybe the surgeon or doctor and they're given priority and then the cleaning takes a lower order doesn't it? And that's not right. And that happened all the time. I do think they should...the timing is wrong. She needs space. She is very important. But she wasn't. She's the bottom of the list and she shouldn't be."

(Interview with a 78 year old woman, Carnation Ward, Downlands Trust)

When asked if her own dignity was ever compromised, one staff nurse replied:

Respondent: 'Definitely. I would never tell anybody of the public...I would never tell anybody where I worked'

Interviewer: *Really?* 

Respondent: 'Mmm, so I think that might be a loss of dignity. I would I used to be very, very proud to be a nurse, but I wouldn't say that I was very proud to be a nurse, because I think you get a lot of negative feedback in the press, I think you get a lot of negative feedback...I'm not saying a lot from patient's experiences on here, but you do get some of that, and yeah they're right. Not all the time, but I would say probably six out of ten of them, they're very right in what they say'

(Interview with a Staff Nurse, Elm Ward, Meadowfield Trust)

Another view commonly expressed is that staff do not feel valued by their senior managers, as this senior staff nurse comments:

Respondent: 'Not really no. Just the senior nurses that are ward nurses the same as myself, no. And to be quite honest, I don't think I would feel happy approaching them anyway, because I don't really know who they are. They don't know me, which is another thing I think is sad, you know. They don't know who is working for them. So when they do come down, it's all spot checks and you feel like you're being, you're not doing your job well enough or you've got to pretend that everything is all hunky dory for their benefit and sometimes it isn't always hunky dory.

Interviewer: So you don't feel valued?

Respondent: 'No, and I don't think that there's - I do feel valued from

my bosses within the team very much so, very much so and like I say this, the ward itself, I love it. Like I say, I left and I came back. I loved it and I love being busy. Like I say I left to come back to being busy. I wouldn't want to be just sat around when there's always something you could be doing. Even if it's just talking to a patient or giving them a hug, which is a valid part of your job. You know... They [senior managers] don't respect the skills and they don't respect the staff.'

(Interview with a Service Assistant, Wye Ward, Uphill Trust)

Sometimes patients failed to treat staff well, by being ungrateful or rude:

The staff nurse answers the buzzer but when she comes back she says, 'Oh that man in bed 10 is very arrogant, he called me a stupid girl – it's not what you want at 3.30 in the morning. I felt like saying, 'Don't speak to me like that' but you can't.'

(Observation: Wye Ward, Uphill Trust, Night Duty)

As described in Chapter 4, most staff had not had training about delivering dignified care or care for people with dementia. There is little opportunity for clinical supervision or reflective practice and in only one Trust is the patient experience being included in staff appraisal.

If staff do not recognise dignity, if they feel taken for granted, if their self-esteem is dented, then it becomes more difficult for them to deliver dignified care. This is where ward leaders as well as Trust managers have a key role to play in ensuring that the voices of their staff are heard, that they are supported and appreciated as the 'strongest driver of staff engagement in the NHS is a sense of being valued and involved' (Ellins and Ham, 2009, p.23).

#### Summary

This chapter has focused on how the personal encounters that occur on acute wards influence the experience of dignity for patients, their relatives and the staff themselves.

Dignity **is** important as demonstrated by Valentine et al (2008) in a World Health Organisation survey undertaken in 41 countries. In this survey, dignity is shown to be the second most important non-clinical aspect of quality of care for patients. Similar findings have been shown by Ipsos MORI, who in one survey undertaken in April 2004 found that in terms of keeping patients satisfied, there is a very strong correlation between the extent to which patients feel they are treated with dignity and respect and their overall perception of the hospital. A second Ipsos MORI report, (28 June 2004), titled 'Frontiers of Performance in the NHS' highlights the main factors that determine overall patient perceptions. They conclude that being treated with dignity and respect is key. In a follow up Frontiers survey (2008), MORI argue that 'treating people with dignity and respect, in particular, emerges as a critical factor in how patients view services.' In terms of patient outcomes, there is evidence that positive health and social outcomes result when people feel valued and respected; are involved in care decisions; maintain a positive self-regard; and can exercise direction over their lives (Kenny 1990; Bensink et al, 1992; Brillhart and Johnson, 1997, Ranzin et al, 1998; Tadd, Dieppe and Bayer, 2002; Walsh and Kowanko, 2002). Patients who experience dignified care are more likely to comply with treatment and report a higher satisfaction with care (Beach et al, 2005; Glendinning et al, 2006).

If dignity had been at the forefront of organisations described as 'failing', and perhaps most notably in Mid-Staffordshire, things might not have gone so far wrong, as Sir Stephen Moss and Antony Sumara writing in the intelligent Board Report (Dr Foster, 2010) state: 'The human impact of what we do as a Board is at the heart of our responsibilities. The Board focuses on what it means to patients and families when our actions cause problems....Our Board has learned that a patient's experience is influenced predominantly by how well we meet their fundamental needs. We need to be aware how long it is taking for nurses to respond to call bells, and how well we are assessing a patients' nutritional state and acting on it' (p. 14-15). The need to connect with staff has also been recognised: 'We have set up a buddying system in which newly registered nurses are linked to a Board member ... to encourage a better two-way understanding of how we are each contributing to patient care' (p.15).

Both in the accounts of older people and those of their relatives, and in the 617 hours of observations, the care provision on these acute wards is very variable. Nowhere is care either totally 'dignified' or totally 'undignified'. This variability occurred from ward to ward, sometimes in the same ward when different staff were on-duty or at different times of day. For many participants, as seen in Chapters 4 and 5, inconsistency was something with which they had to come to terms and for some this led to uncertainty about what will happen or what is expected of them, leading to even greater apprehension.

Respectful communication is at the core of dignified care, together with elements of fundamental care including ensuring privacy, addressing nutrition, elimination and personal hygiene needs. Because care is task based and reactive to patient's requesting assistance, the individual's sense of dignity is further undermined as the individual is reduced to a state of dependence. Dignified care could be much enhanced if strategies to meet patients' needs in a proactive manner were to be implemented.

Fundamental to experiencing dignity is the sense of being in control, especially of one's immediate environment and what is happening. The lack of information mentioned by many older people and their carers, impacts negatively on this sense of control not only resulting in heightened anxiety, but also reducing independence and fostering dependence.

Finally, staff need to feel valued and be treated with respect by their colleagues, managers, patients and carers and the role of the ward manager in promoting a respectful working environment is key. The ability to deliver care of an appropriate standard is also essential for staff to experience a sense of dignity as being in a position of having to deliver inferior care results in staff feeling demoralised.

This relative sums up why 'seeing the person' is crucial to delivering dignity – regardless of who the person is:

'To treat them as you'd want to be treated. I think if you can look everyone in the eye, and I mean everyone in the eye, I mean the man who's selling the Big Issue, I mean the man who's sitting down on the pavement playing an accordion or whatever. To recognise people, to look them in the eye, to be able to come to **where** they are and speak to **them** because they are human beings, and I think if I was there, I would like people to do that to me....so I think as long as you respect one another and treat them exactly the same.'

(Interview with the wife of a 74 year old man, Nelson Ward, Westway Trust)

# **PART THREE**

## **Chapter 7: Influences on Dignified Care**

'Being addressed the way I want to be addressed. Being asked, not told. Having people working with me. Respecting my choices, my decisions. And if I'm able to control my situation and being allowed to do that without being judged and being seen as difficult – that is dignity.'

(Interview with an 82 year old man, Beech Ward, Meadowfield Trust)

## Introduction

This chapter summarises the main findings from the study addressed in the preceding three chapters. By bringing these together, it is possible to identify the key factors that influence dignified care for older people on acute wards. The chapter reflects upon what this study has shown to be the most significant barriers to the provision of dignified care before highlighting the enablers of dignified care. It is these that have informed the recommendations for change. First, however, the chapter begins with a discussion of dignity and dignified care.

## Dignity and Dignified Care

As discussed in Chapter 3, it is not possible to set aside 'a priori' knowledge, and the view of dignity which informed much of our thinking is that which was developed in the Dignity and Older Europeans study. Four types of dignity were highlighted in that study, human dignity or Menschenwürde, the dignity of moral stature, the dignity of merit and the dignity of personal identity, which are described in Chapter 3. Although this model is not fully accepted by all authors, many aspects are shared with other accounts of dignity as shown in Chapter 6 and the account features prominently on SCIE Dignity in Care website. Primarily, dignity is concerned with viewing people as important in themselves, viewing them as equals and as having value and worth. Of utmost importance is recognising that people have identities and personal histories that make them who they are and that the ways in which others act towards them affects the way that they see themselves in profound ways.

#### **Dignified Care**

Evidence from the Dignity and Older Europeans study and those of many other authors (Jacelon, 2003, 2004; Matiti and Trorey, 2008; Baillie, 2008) have all identified the components of dignified care as comprising of the following aspects, which are confirmed in this study:

- Respectful communication.
- Respects privacy.
- Promotes autonomy and a sense of control.
- Addresses basic human needs such as nutrition elimination and personal hygiene/appearance in a respectful and sensitive manner.
- Inclusive and encourages participation.
- Promotes identity.
- Focuses on the individual.

• Recognises human rights such as equality, respect and autonomy.

Similarly, undignified care consists of care that:

- Renders the individual invisible.
- Depersonalises or objectifies the individual.
- Is abusive and humiliating.
- Is narrowly focused.
- Disempowers the individual.

Rather naively, the authors planned this study with the objective of establishing guidelines for the provision of dignified care. The observation that the provision of dignified care is 'not rocket science' is one that is frequently made and at the level of individual interactions or personal care this may well be true. For instance, people should be treated courteously, bodily privacy should be maintained, patients should where necessary be assisted to eat and drink, and so on. However, the reasons why this does not always happen are complex and multi-layered and they cannot be addressed by imploring one occupational group, to care more. Instead, it requires action at all levels of the NHS and by every member of staff, from the chief executive to the porter. Another set of guidelines or 'dos and don'ts' will do little to rectify the situation as these already exist in abundance. However, some tensions are worth emphasising in relation to dignity and dignified care.

As seen from the interview comments from older people, part of the difficulty for health professionals in relation to delivering dignified care is that this may or may not result in a sense of dignity. As we have seen from the interviews with participants, dignity is necessarily subjective and the experience of dignity may differ from individual to individual.

An example may help to illuminate these issues. Imagine a frail older person who is doubly incontinent because of their acute illness. The person opens their bowels in a six-bedded bay and feels humiliated and embarrassed. The nurse responds immediately to the call bell and is kind and courteous, reassuring the person that it is not their fault that this happened. She then calmly cleans and changes the person with a minimum of fuss, respecting their privacy and leaving them comfortable. Although the nurse has treated the person in an exemplary manner, delivering care that is dignified and respectful while conveying to the person that they are valued and worthy of such attention, the person may still feel undignified and experience a sense of shame and humiliation.

Many aspects of illness and ageing can result in an individual experiencing a sense of indignity and such feelings may well be beyond the control of the individual health professional. However, what the health professional or staff member must be able to do is guarantee that the experience of indignity is not due to their actions which should serve to ameliorate such feelings.

Second, because of its subjective nature, a first step in delivering dignified care must be to ascertain from individual patients, and especially those who are prone to a loss of dignity, what dignity means to them.

## The 'Problem' of Older People in Acute Care

Rockwood and Hubbard (2004) state that 'if you set up a service for people who have only one thing wrong at once (a diabetic clinic, for example, or a coronary artery bypass graft service) but people with many things wrong turn out to be its major users, the fault lies not with the users, but with the service and its design. In modern health care however this appears to be a minority view, and one which is trumped by the notion that the people with many things wrong at once are at fault – that they are 'inappropriate' (p.429).

The most powerful message from this study is the perception amongst staff at all levels that acute hospital wards are the wrong place for older people. This widespread perception has grown in part from a legitimate concern over failures in the primary care system that can result in older people, whose interests may be better served in the community, entering the acute hospital. The evidence highlighted in Chapters 1 and 5 suggests that for the majority of older people who access acute services, they do so on the basis of acute clinical need. That is not to say that these acute needs are not accompanied by multiple chronic conditions and, for some, either dementia or delirium, but the acute clinical need still remains. Therefore, what began as a legitimate concern over the inappropriate admission to acute care of a minority of older people, is now receiving a disproportionate level of concern and attention, with some Trust managers highlighting it as *the* problem facing the acute sector.

"I think that one has to make a very clear distinction between the acute medical care of the elderly and the care of the elderly, and I don't think that we do that remotely like well enough...They [older people] require a degree of care and attention that isn't dependent upon high levels of medical intervention, but requires a more informed level of general care around their clinical conditions and we simply haven't made these distinctions appropriately enough in policy."

(Interview with Trust Board Chair, Meadowfield Trust)

This Trust manager spoke in depth about the problem of what he described as non-acute older people, particularly those with dementia, occupying acute hospital beds. He concedes that *'there may have been cause to believe'* that they had some medical condition, but reflects that really, their needs are not those that require *'high levels of medical intervention'* but, *'general care'* that is not appropriate to the acute sector and this distinction should be better reflected in policy towards primary and community care provision.

The call for more and better community based care may be well founded. However, the disproportionate degree to which those responsible for providing and delivering acute care focus on this issue means that their attention is deflected away from the growing numbers of older people with complex co-morbidities, who require and deserve acute care. These people currently occupy 70 percent of hospital bed days in acute hospital wards This perception of the 'problem' of older people in the acute sector has also spread throughout the acute Trust culture so that for the staff working at the frontline, older people have become synonymous with 'socials' or 'acopias', regardless of their acute clinical needs (Oliver, 2008, see Chapter 1). What the examples from this study have shown are the

multiple ways in which this perception and the actions that stem from them impact negatively on older people's experience of care and fundamentally their dignity.

The mismatch in acute Trusts between the kinds of patients deemed appropriate to admit – those with single, acute conditions amendable to curative treatment – and the majority of patients who enter the acute care system, namely older people with complex physical and mental co-morbidities, permeate the strategic planning of acute care. This results in many acute hospital wards being 'unfit for purpose' in relation to the provision of dignified care of older people. The lack of recognition for the 'bread and butter' work means that the planning and delivery of acute care can be ineffective for the majority of patients being treated. It can also create a demoralising working environment for staff who feel they spend most of their time treating people who 'shouldn't be there'.

The evidence in this study has highlighted the ways in which acute Trusts fail to treat the majority of acute patients - older people - with dignity and respect. Many staff suggest that it is the patient who is in the wrong place. But the argument put forward is that the environment, the skills and expertise of the staff, the organisation of the acute sector and its strategic policies should be modified to better meet the needs of the majority of acute patients – the old, the frail and those who are confused.

Below is a summary of the main concerns about each of these key areas and their implications for dignified care provision for older people. The discussion of the issues includes an exploration of these aspects of care provision; Trust initiatives; and the beliefs and views of some staff, that help redress the current imbalance between the needs of the acutely ill older person and the organisation and delivery of acute care.



#### Figure 6: Influences of Dignified Care

## **The Environment**

One of the ways in which the mismatch manifests itself is in the physical and social environment of the acute ward. The acute ward can and sometimes does disorientate, disempower, embarrass and disengage older people. However, it is important to highlight some of the examples from the study of the ways in which older people's dignity was and could be enhanced through the physical and social environment of the acute hospital ward.

#### **Disabling/Enabling Spaces**

As shown (see Chapter 5), the acute ward can become a disabling physical space for the older person who may easily become confused and disorientated due to the lack of differentiation between both the wards and the bays within them. Clues and signage to orientate older people or help them navigate their surroundings were lacking or poorly executed, resulting in older people becoming more dependent on staff. Some simple and relatively low cost signs and colour coding can be used to great effect. Boards displaying the date and the name of the ward; information about staff; clocks in full working order and the use of colour such as red toilet seats rather than completely white bathrooms are some examples of inexpensive actions that can be taken to make spaces more enabling. These changes can have a major impact on older people who enjoy increased independence and control as a result. Only one ward of the 16 in this study, had attempted to make these small but significant changes and this was an acute medical ward for people with dementia. In contrast, in the majority of acute wards, the design did not consider the frail older person who requires orientation and stimulation. Instead design was focused on the needs of people requiring highly specialised, clinical and technical care.

#### **Communal Spaces**

The loss of communal areas on acute hospital wards is in part a symptom of the 'get them in, get them out' mentality which staff spoke of [see Chapter 4] that has resulted from many of the drivers to Trust activity. As many of the Trust managers described, the focus on reducing length of stay, of 'moving people on' has become central to the activities and the priorities of acute NHS Trusts.

"So reducing the length of stay of the patients, discharging them in a timely manner, driving that discharge forward so preventing delays with the patient's discharge because things can drift a few days and that makes a big, has a big impact on your length of stay."

(Interview with a Trust Matron, Downlands Trust)

An orientation such as the one above, results in communal spaces that may improve patients' wellbeing, rehabilitation and recovery not being seen as key components of the acute ward environment. Instead, engagement and stimulation are aspects of care, which should happen elsewhere, once the patient had been discharged from the acute ward. As one Trust manager suggested, 'We don't want to do anything that might encourage people to stay.'

However, the research evidence suggests that the inclusion of communal activities and social engagement, can increase rates of recovery and benefit both patient's psychological wellbeing and their clinical recovery (BMA, 2011; Fredman et al, 2006; Mumford et al, 1982 – see Chapters 1, 2 and 5). In this study, where social engagement was encouraged and diversionary activity took place, it had enormous benefits for older people and promoted their recovery. The activities also benefited staff in enabling them to find more appropriate ways to engage with patients and care for them, particularly those who were confused:

I can hear music on my way down to the ward and when I arrive, there are two male violinists in the day room. A few of the staff were dancing with Betty and another patient to the music (they looked awkward as it wasn't the most appropriate dancing music) but Betty seemed to be the ringleader, trying to get everybody up. There was a group of staff standing by the entrance where I was observing and they were saying how great it is to see some of the patients be so calm and fully engaged in something. *'Take John, I've never seen him sit still for so long'*. I noticed Joan sat silently with her eyes closed listening, she'd told me before that she used to play the violin and how much she loved it. The difference seeing Betty the night before, distressed and agitated, to how she was this morning, having fun and dancing.

(Observation: Drake Ward, Westway Trust, Morning)

#### **Mixed Sex Wards**

The embarrassment that older people face when sharing wards with members of the opposite sex is explored in Chapter 5. However, the need to better define what is meant by single sex wards deserves discussion. The separation of male and female sleeping accommodation is a commitment within all acute Trusts. In England, failure to meet these formal targets results in financial sanctions, but the experience of sharing toilet and shower facilities or, even having to walk past a male or female bay in one's nightwear, can also cause significant embarrassment and humiliation for older people.

The need for greater privacy (see Chapter 5) is part of the reason why many acute hospitals are moving towards a greater proportion of single rooms. However, these are not universally welcomed by patients or staff. Some staff believe this will offer the best solution to the problems of promoting dignity and privacy, whereas others see single rooms as isolating and depressing and suggest that patients in single rooms are more easily ignored by staff. The observations in the wards indicated that single rooms could impact on staff behaviour as the space becomes the patient's and the power dynamic (see Chapter 6) of the interaction changes:

"I think it will change, whose room is it then? Is it the patient's room? Whereas at the moment the Nightingale ward belongs to us if you see what I mean...I think that changes the whole dynamic between the patient lying in the bed and the staff coming into their room and what do you think you can demand of them and ask of them and the information you're expecting."

(Interview with Trust Chief Executive, Downlands Trust)

This view is not shared by all. Many staff commented on the isolation older people experience in side-rooms, a factor that was also borne out in the field work. Nurses in particular commented on the difficulties of observing a greater number of patients in single rooms, especially with existing staffing levels. In some Trusts, steps to introduce a physical space that promotes the social interaction some patients experience in communal bays and the greater privacy provided by single rooms have been created. These are bays with fewer beds that offer increased space around the beds, with suitable partitions and en-suite facilities. Patients then have direct access to washing and toilet facilities without having to leave their bays and at the same time avoid the isolation and disengagement that can occur from being nursed in a single room.

## **Staff Skills and Expertise**

Another mismatch between the needs of the majority of acutely ill older patients in the strategic planning of acute services is exemplified in the level of skills and expertise of staff. As shown in Chapter 5, many staff tend to specialise in particular clinical areas but lack the skills needed to treat older people, particularly those who are confused or have dementia. Due to the overriding perception amongst staff that older people are in the 'wrong' place, training in certain aspects of older people's care is seen as appropriate only for those working on specialist medical wards for older people or elderly mentally infirm (EMI) wards, rather than being seen as core skills needed for all staff across all adult areas of acute care. This is despite these inadequacies in training being highlighted in both the National Service Framework for Older People (DH, 2001a) and the National Dementia Strategy (DH, 2009b). The following quote by a chief executive describes what is needed:

"The logical answer would be is that everybody is trained to recognise that there is dementia amongst other presenting factors when the patient comes in but we don't make it as the determining factor on how we handle everything else with the patient. We tend still to regard them as the... I don't know say the leg ulcer or the DVT or whatever it happens to be and I hate discussing patients' conditions. But we rarely regard them as the older person who is also dementing. And I think that we fail them for that reason because it's almost as if we...you just used the term elephant in the room and I would say yes, we go along, we just put the blinker up so actually we're going to....all the way round this patient and we're going to talk about everything except the fact that he or she is patently disconnected."

(Interview with a Trust Chief Executive, Uphill Trust)

Expertise, skills and knowledge about how to care for and work with older people is crucial for all staff working on acute wards, be they doctors, nurses, care assistants, professions allied to medicine, domestic staff or porters.

Examples of reflective practice or continuing education on promoting dignity; on caring for people with dementia; or care of older people offered as a core skill, were not in evidence in any Trust. Post registration/continuing education and training courses on promoting dignity, caring for older people and caring for people with delirium or dementia were sometimes available in some Trusts but the reality was that staff could not be released to attend. Almost © Queen's Printer and Controller of HMSO 2011. This work was produced by Tadd *et al.* under the terms of a 193 Project 08/1819/218

none of the staff spoken to had had specific training in either promoting dignity or in caring for older people, even on care of the elderly or dementia wards. This reflects the need to prioritise and value the knowledge and skills needed to care for older people, rather than prioritising knowledge and skills that are increasingly specialised around narrow clinical conditions that one Trust manager described as 'vanishingly specialist'.

## **Organisation of Acute Trusts and Policy Strategy**

The organisation of acute services has developed in line with the historical developments of medicine as a profession that separates clinical work into distinct areas and the politics of service rationalisation. Particularly over the past 30 years with the advent of neoliberal economics in health and welfare provision, (Osborne 1993) the strategy for acute care services is to train and develop expert clinical staff, to deliver care in increasingly specialised units located in specific hospital sites and finally to focus on achieving faster throughput and shorter lengths of stay. Together with current increases in bed occupancy rates and the idea that each patient should be in the 'right' place, this problem has intensified. People are constantly being moved around or even between acute hospitals in order to try and create beds and, as described in previous chapters, older people experience this the most often. This is not simply a problem for the quality of care that older people receive, but it impacts on Trust resources and patient safety as staff are diver ted from direct patient care to move patients and clean bed spaces, and increased movement results in increased rates of infection (See Chapter 4).

### **Seeing the Person**

Approaches to care provision that recognise older patients as people with their own life experiences and personal biographies are central to ensuring dignified care. In the main, staff tended to focus on tasks, on getting the jobs of washing, dressing and toileting done, rather than seeing the person who needs care as the central focus (see Chapter 6). Some staff identified the performance of tasks as opportunities to engage with patients, not only about their acute care and treatment but about aspects of their personal lives that make up who they are – thus helping them to maintain a sense of identity. Where staff engage with patients in this way, the benefit for older people is obvious:

I arrive on the male nine-bed bay and one of the male nurses I'd not met before, Jim, was with a patient doing some observations – I later discovered that they were a little worried about the man's blood sugar and his fluid levels. He sat on the bed filling in the chart, talking to the man who was a former teacher and asks him, 'So what did you use to teach then?' They talk while he finishes filling in the forms in the file. He then asks, 'How was your walk with the physios?' The man sighs and shakes his head. 'Oh like that was it?' Jim says and they both laugh. As I'm waiting for Jim who has agreed to do an interview with me, I observe him with the patients. He takes his time with the patients when he does things like observations or giving medications. While doing observations, he sits and has a long conversation with one of the older men on the bay about poetry and music. (Observation: Wellington Ward, Westway Trust, Morning)

Another way to ensure patients are treated as people, rather than objects to be 'done to' is when staff try to anticipate their care needs. Rather than waiting for patients to ask for help or use their bells to call for staff, taking the time to ask patients if they need anything can increase patients' sense of control and confidence as staff appear to know what they are doing and avoid problems before they emerge, as the following exemplifies:

One of the other patients asks her, 'Can you turn this off?' (Nebulizer)

'Have you had enough?'

'It's time.'

'There you go, do you want your telly?'

'No.'

'You gonna [sic] have a nap? Okay. You alright apart from that?'

'Well, I can't hear. I think the battery's gone on my hearing aid.'

'Oh well, we can sort that out for you. Not sure when the next hearing aid clinic is, but I'm sure we can get you a new battery. Have you got it there and I'll send it down for you?'

She gives the nurse the battery.

(Observation: Ash Ward, Meadowfield Trust, Afternoon)

Had this member of staff not asked if the patient was okay and simply dealt with the immediate task of turning off her nebulizer, she may never have raised the issue of her hearing aid. Staff that acted in this way (see Chapter 6) not only pre-empt patients' needs but make patients feel as though they are valued and looked after, rather than feeling that they or their needs are a nuisance to staff, something that many patients expressed during interviews when describing how they felt using their bells or calling out to staff who they perceived as 'busy'.

Evidence suggests that proactive care, such as performing 'rounding' to anticipate care needs such as helping patients to use the toilet or helping them in or out of bed for example, actually reduces risks to patients, increases patient satisfaction and reduces calls for staff by patients (Meade et al, 2006). This enables staff to manage their work more effectively while ensuring that the quality of care is maintained, however no examples of this were observed. What was seen were some staff who routinely before leaving a bay asked every patient if they needed a drink, any assistance and whether they had their call bells.

Ward managers have a challenging but significant role in ensuring that all members of the team approach patients in ways that recognise them as people. Many ward managers

described the difficulties they faced due to continual staff changes, but also the inability to get their entire ward team together at any one time.

However, we did observe ward leaders who were able to set standards that all staff members were aware of and worked towards. In these areas, poorly performing staff were challenged when acting in ways that were not appropriate. Some ward leaders also seemed adept at creating a culture of professionalism amongst their staff that informed the ways in which they spoke to each other and to patients. For example, on one ward, staff would always introduce themselves to patients if they were not already known to them. This included all staff on the wards from the HCAs to the consultants as these two examples taken from this one ward demonstrate:

The staff nurse goes over to one of the patients and says, 'Hello Oriel, my name's Sharon. I'll be looking after you this afternoon.'

The consultant goes to the woman closest to where I'm sitting and introduces himself, 'Hello Mrs Foster, I'm Dr Jones.'

(Observation: Beech Ward, Meadowfield Trust, Afternoon)

This kind of professionalism, as well as being respectful in terms of communication, also engendered confidence in the patients:

"I had one who was, I would say, definitely okay and one who definitely was very superior. Oh she, she – I think she, she exuded calm competence really."

(Interview with a 73 year old man, Elm Ward, Meadowfield Trust)

The influence of a ward manager that was most potent was when they were physically present on the ward and this impacted on both the staff and the ward atmosphere:

The ward seems to have settled a little after the morning chaos under the influence of Audrey, the deputy sister who has a calming influence and quietly goes around catching up and tidying the ward. A nurse rings in to say she is ill, despite the staff shortages Audrey is very calm and shows her first concern is for the nurse who she advises to go to A&E.

(Observation: Drake Ward, Westway Trust, Morning)

Interestingly, the observations brought to light a significant difference between wards that provided care exclusively for older people and those which were for all adults regardless of their age. On designated wards for older people, many staff would automatically raise their voices when talking to the patients. Often, this developed into a habit of shouting, not only when talking to the patients but also when communicating with each other. This is perhaps unsurprising in that it reflects both an institutional ageism, whereby older people are stereotyped and their care is given little value within acute Trusts (see Chapters 4 and 5) but also a broader societal ageism, whereby older people are patronised and infantilised (see Chapter 6).

What must be recognised in highlighting the role of the ward manager is that unless they act as positive role models, they can have a negative effect on the ward and care practices, which was something that was also observed. Strong leadership is an important way of instilling a positive ward culture and ensuring care practices are focused on treating and caring for older people rather on than completing tasks:

"Leadership I – I think it's got to be in you, you've got...you're that type of person who wants to go that extra mile, I think you've got to have that in you. But then I think that can be enhanced through strong leadership and setting an example on how to speak to people, you know, how you would deal with a patient, etc. I'm sure what people see in their leaders, the good qualities, people think, you know, I want to be part of that so, yes, leadership's certainly important in that."

(Interview with a Facilities Manager, Meadowfield Trust)

Many of the ward managers who participated in interviews described the challenges they face in trying to ensure care quality, often with little support from their managers and little autonomy to make decisions that directly influence the quality of care, such as staff recruitment. It is important therefore that ward managers are given the support they need to be good leaders, as well as the opportunity to develop leadership skills, as this Trust manager describes:

"Some things we've been involved in, like the Beacon Ward Project, which was taking ward leaders and developing their leadership skills or giving them permission around leadership skills, but very much in line with how patients viewed things, you know, so making changes to the way wards work in line with patients' views. I think there's reasonable access to training, you know, and sort of professional development."

(Interview with Safeguarding Consultant, Downlands Trust)

It is also critical for dignified care that ward managers are willing and feel competent to challenge inappropriate behaviour and practices as this Trust manager describes:

"And I think we've got some very strong ward leaders as well who will, you know, have really strong ideas about how people should be treated and how they will....you know, they won't tolerate anything else on their wards."

(Interview with Nurse Director, Meadowfield Trust)

This was evidenced on some wards for example, when one ward sister on hearing a nurse tell someone they could observe an admission as 'We've got one coming in' immediately checked her by saying, 'What do you mean 'one'?' By doing this, leaders are able to set the tone or the standards that are expected on their ward and this starts with the type of language staff use, particularly when referring to patients. Dignified care, tended to be lacking on those wards where patients were referred to as bed numbers, for example, and this may be a useful indicator.

Teamwork and collective responsibility were also central components in delivering dignified care to older people. The relationships between ward teams and the various professionals within those teams were often fraught. As already described in Chapters, 4 and 6, this can be due to changes in working roles and the perceived value of hands on caring tasks, especially amongst nurses and healthcare assistants. At other times, this is due to poor communication between different professional groups who are focused on their specific area of concern such as diet or the person's observations or mobility. The difficulty posed is that these teams fail to take a collective responsibility for ensuring dignified care that brings together all of the different elements of that patient's management. The wards where there was evidence of this kind of teamwork were those where everyone on the ward was willing to 'pitch in' when needed, regardless of their job title, in order to ensure the best care for the patient.

### Barriers to and Enablers of Dignified Care in the Acute Care System?

Clinical governance's focus on quantitative measures to ensure quality together with the preoccupation with monitoring and avoiding risk (particularly infection control) has unintended consequences on care delivery that impact negatively upon older people's experience of care. It needs to be acknowledged that qualitative approaches could supply powerful evidence about how patients, their families and staff experience care delivery.

Acute Trusts can be divisive places where the building of trust at the point of care between patients, their relatives and professionals is at risk of being diminished. Relations tend to be mediated by systems, protocols and procedures that exist in part to protect staff and the institution (see Chapter 4). This manifests itself most significantly in the following ways:

Staff tend to be risk averse and are less able to make judgements that balance risks with patients' overall experience of care.

Some staff become involved in 'gaming' either through continually moving patients around the acute hospital to ensure high bed occupancy or through drawing upon Trust priorities/policies to legitimate ward practices.

Complaints and problems arising on the wards tend to be formalised and bureaucratised rather than addressing the particular concern informally.

Many staff feel unsupported, as mistakes are perceived as being unacceptable.

So what can Trusts as organisations do to ensure that older people are treated with dignity on acute wards?

First, they must prioritise patient experience above all other competing concerns. As discussed previously, there are many competing priorities in every Trust and keeping patient experience at or near the top of the list is not easy. One Trust manager describes what he thinks needs to be done:

"First of all, you set it out in writing in your recruitment literature, in your mission statement, on the wall of the staff rooms and everywhere else, this is what we state. So first of all, I think you've got to enunciate your culture, © Queen's Printer and Controller of HMSO 2011. This work was produced by Tadd *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. Project 08/1819/218 not just assume that people absorb it. Second, when you recruit you make it clear that's your expectation and to the extent that you can you look for those sorts of qualities in the people applying, difficult thought that is in the interview or what other setting. And your senior staff, clearly it's an important part of their job and their appraisal and their targets and their job objectives, to ensure that this sort of culture is lived day in, day out. And of course senior management in particular have to set the example. And it's very hard work."

(Interview with Trust Chair, Downlands Trust)

Central to prioritising patient experience is an understanding that people must come before numbers, as Robert Francis QC stated in the Mid Staffordshire NHS Trust Enquiry: *'Statistics, benchmarks and action plans are tools, not ends in themselves. They should not come before patients and their experiences'* (Dr Foster, 2010).

More attention is being paid to understanding and prioritising the patient experience, and ensuring that fundamental care and care quality are seen to be as important as finance, clinical effectiveness and patient safety for Trust boards (Kings Fund 2009; 2010). This is something that this study re-emphasises in order to ensure that older people receive dignified or decent care.

Some Trusts involved in this study adopted the following strategies to ensure that the patient experience remains a central concern. One Trust included a vignette of a patient's actual experience at the beginning of every board meeting, before discussing finance or targets. This focuses attention on what matters most. In another Trust, the staff magazine was used to describe incidents that lead to complaints, ensuring that mistakes are understood and used as an opportunity for learning.

Part of prioritising the patient experience is ensuring that resources that impact upon dignified care are given due prominence and this includes items such as linen, appropriate gowns and clothing being available and in a good state of repair. There are many occasions where staff struggle to ensure patients are in clean beds, have towels or are in clean, appropriate dress, simply because of a lack of resources.

While Ian is changing the beds he tells me, 'We never have enough linen, they always send 50 at a time but if you think they change 41 beds maybe twice – how's 50 gonna [sic] be enough?

(Observation: Ash Ward, Meadowfield Trust, Morning)

The HCA calls the next ward to borrow some sheets – the lack of linen seems to be a perennial problem, particularly at night. HCA1 starts tidying the nurses' station till the second HCA arrives back and HCA1 then goes off to collect the sheets. (Later in the shift) chairs as we have no bed linen – it's not right, it's early (6.15am) and makes a long day for them – they should deliver the linen at night'

(Observation: Carnation Ward, Uphill Trust, Night Duty)

As this Trust manager explains, it's about balancing the resources you have while keeping patient care as the focal point:

"We've got a limited amount of resource, so therefore you can't go out and buy all the staff that you would like. You can't build and buy all the facilities you would like because the money just won't fit. So therefore it's about working through well, what is the best way of using your resource to ensure that we don't compromise patient care."

(Interview with Director of Finance, Westway Trust)

Appropriate staffing levels and skill mix are also essential, although in all Trusts financial constraints had meant a virtual freeze on recruitment. In one Trust however volunteers were being used to assist with errands, take round drinks and such like. Volunteers could also be used to great effect to reduce the social isolation and boredom of many older people on acute wards.

Another difficulty encountered was the defensive practices that can become habitual on the wards and one way of breaking these down is by building better relationships and communications between frontline staff and their managers. A common complaint amongst staff is that they felt unsupported, not listened to, or that managers had no appreciation of what they are faced with on a daily basis.

Many Trusts had measures in place to try and combat this issue, such as staff feedback forms that would provide them with the opportunity to voice their concerns although some staff tended not to complete them as they saw no evidence that action was ever taken. Building better avenues of communication is important for staff morale, but also for building a culture in which staff themselves are treated with dignity, their professionalism is recognised and where they are encouraged to make judgements on the basis of their professional experience (see Chapter 6).

Building stronger relationships between the ward and the board is not simply about communication, but about understanding. Those at board level must communicate their messages and explain the policy imperatives to frontline staff, and listen to their concerns. Senior managers also need to spend time on the wards, acquiring a real sense of what staff face when performing their duties. In one Trust, it was described how senior staff were on the wards:

"I think like the heads of nursing are visible on the wards. The matrons are on the wards all the time, all the time."

(Interview with Board Director, Downlands Trust)

However, whether board members themselves spent time in clinical areas was not so clear.

Some ward staff described nurse managers who had previously worked shifts on the wards with them:

"Our old senior nurse, not our present one now, but every month she would do a shift on every single ward and, I mean, she had a rotten time because she'd come on the wards and like people would give her [laughs] like the worst patients and everything like that. She'd be absolutely knackered by the time she finished her shift [laughs]"

(Interview with Deputy Ward Manager, Nelson Ward, Westway Trust)

This staff member felt that he and his team had a much better relationship with this nurse director as they felt she not only listened to their concerns but understood them at first hand.

Managing and monitoring the quality of care on the wards is central to ensuring the quality of clinical work and patient protection. However, the current focus on formal audits at the point of care detracts from the staff's ability to draw on their own professional competence and experience to make judgements in the patient's best interests (see Chapter 4).

An additional approach to monitoring clinical work to ensure quality is through the staff appraisals system. One of the Trusts has introduced patient experience as a key component of staff appraisals alongside clinical competence. This provides the opportunity for reflective practice without creating more checklists or audits to be completed during the clinical encounter itself. This approach may also help build a culture in which staff are supported to learn from mistakes and reduce the defensive practices that currently dominate acute wards. Similarly, the practice of staff from various levels simply 'observing' care for a period of time, initially on one's own ward, but also on other wards, can help staff 'see' where change may be needed as well as where good examples of care are evident, which should then be praised, shared and encouraged.

## Summary

In drawing out the key influences on dignified care for older people, this chapter provides the first step towards making recommendations for change. Trust activity following the Department of Health 'Dignity in Care' Campaign has tended to focus on the individual behaviour and attitude of nurses, especially with the advent of dignity champions. This study shows that the situation is much more complex than this. The actions of all staff, both clinical and managerial, impacts upon the provision of dignified care as do wider policy and Trust drivers.

The study reiterates the need for a shift in perception and, for some a change of attitude, towards caring for older people, to ensure that they are recognised as people and that their identity is maintained. The study has also shown how the attitudes and behaviours of clinical staff exist within a complex set of organisations cultures with competing priorities and that

these competing priorities impact upon staff approaches to the care and the treatment of older people.

Finally, the central message from this study is that aspects of the acute care system that influence dignified care most significantly are driven by the definition of what an acute ward is and should be – and the strategic planning and implementation of care that follows from this. By talking to older people and their relatives, spending time on acute wards and talking to acute Trust staff, we have been continually faced with, what seems to us, to be a blindingly obvious mismatch between the patients who the acute sector is currently set up to care for and the needs of the majority of actual patients who are admitted to the acute care system, namely the old, frail and those with dementia.

There is an urgent need for change in the culture of acute care so that it is inclusive of older people who have chronic co-morbidities and confusion *as well as* acute clinical needs. This will only happen once there is a recognition and acceptance that the majority of patients are not in the wrong place, but that the place and the system itself is deficient and must change to accommodate the majority of patients admitted.

## **Chapter 8: Conclusions and Recommendations**

"What do old people want? But I never can hear what old people want because of the uproar made by people telling me what old people want. Most old people take what they can get because they have no choice about it. It is we who make the moulds and pour old people into them."

(Isaacs 1976: 171)

#### Introduction

The following discussion and recommendations are based on the evidence reported in this study together with evidence from other research studies referred to, government and independent reports on dignified care for older people which together result in a compelling body of evidence. The findings suggest that the provision of dignified care to older people in acute NHS Trusts is variable and unpredictable. This unpredictability occurs on the same ward, at different times, when different staff are present, as well as across different wards. Policy development and those responsible for the institutions themselves, have not acknowledged that the current structure and organisation of acute hospitals has failed to keep pace with the changing demographic and characteristics of their main users. This has resulted in many acute Trust wards failing to adequately meet the need for dignified care of their largest group of users, namely older people.

Healthcare has changed considerably since the advent of the NHS 60 years ago, with advances in health technology, pharmacological treatments and surgical procedures and, elimination or reduction of major causes of morbidity and mortality. But the organisation of acute Trusts has remarkably, remained much the same as when they were 'general hospitals'. The focus is on medical specialisms – wards for neurology patients, cardiology patients, patients undergoing gastric surgery, vascular surgery, orthopaedic surgery and so on – whilst most patients admitted to acute hospitals are now over 65 and have complex, chronic, multiple co-morbidities which 'complicate' their acute illness.

Added to this, a number of other factors have resulted in tensions and pressures that have had a dramatic impact on the culture and standards of care. These include:

- reductions in bed numbers and increased bed occupancy.
- the removal of long-stay care of the elderly wards.
- ever increasing sub-specialisation, rationalisation and relocation.
- the largely artificial separation of health and social care.
- the introduction of neoliberal economic cultures.

Some commentators claim that the impact of these changes has reached the point of crisis in today's health system:

"Health care is facing a major crisis that I call 'peak-medicine' – the moment when accelerating health care demand, consequent on proliferating technology, ever increasing specialisation and rising consumer expectations, overwhelms the resources available to care for a rapidly ageing population." (Youngson, 2010, p.1)

#### **The Key Findings**

The main findings are described under four overarching themes: 'Whose Interests Matter?'; 'Right Place – Wrong Patient'; 'Seeing the Person'; and 'Influences on Dignified Care'.

**Whose Interests Matter?** explores the conflict of interests between the priorities of the Trust, those of the staff and of the patients.

Although many of the Trust priorities and policies are in place to safeguard the wellbeing of patients, the unthinking pursuit of them can expose patients to violations of dignity. The rise in clinical governance has resulted in audits of practice and risk management strategies to reduce infections, falls and such like and ensure the quality of clinical care. Yet these well-intentioned activities can result in older people being isolated in side wards, visiting being restricted to two hours per day, people being nursed in bed or in the area immediately adjacent to it, so that movement is restricted, all of which impact on older people especially those with dementia.

The fear of making mistakes or being held accountable should a patient fall, results in staff being both risk averse and defensive as they perceive that if things go wrong they will be blamed. Common dignity violations resulting from these consequences include people being told to soil incontinence pads or being made to use commodes and bedpans, rather than being taken to the toilet. Older people who need assistance are most in danger of having their dignity violated as a consequence of such practices.

This defensiveness also impacts on patients and relatives who try to raise legitimate concerns, which are often met with hostility and suspicion and a reluctance to deal with issues locally. This increases the need to investigate complaints centrally, which has cost implications, but more importantly, results in a loss of trust in the service as a whole. Bureaucratic procedures can rarely deal with the emotional fallout involved when patient experience falls below expected standards.

Targets for bed occupancy and waiting times, specialisation and single sex accommodation all result in patients (invariably older patients) being moved around the ward and/or hospital. This can lead to increasing confusion and dependence, extended lengths of stay and adversely affect long term outcomes. A recurring theme in all staff surveys has been the failure of Trust boards to ensure staff understand the policy directives and Trust messages about their own policies. Classic examples include the target for four hour waits in Accident and Emergency or the 18 week elective admission target. Of course, it is good that emergency admissions are treated quickly and that people do not wait inordinate amounts of time for treatment. However, the pressure this places on staff is considerable and needs to be appreciated by both Trust boards and policy makers. Nor is the pursuit of these targets cost neutral.

The resource involved in continually moving patients (usually older people as they are less likely to fit neatly into one specialism) around the hospital is considerable and needs to be addressed. The negative outcomes mentioned above are also costly in terms of resources. Staff view this continual movement of patients as an additional burden, which takes them © Queen's Printer and Controller of HMSO 2011. This work was produced by Tadd *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. Project 08/1819/218

away from delivering care, which the vast majority are motivated to do. More importantly, such practices give an impression to older people and their relatives that they are of little value and do not matter much in the system.

The introduction of standard protocols to improve outcomes, can also have unintended consequences as they cannot take account of human complexities. They also discount aspects of the person's social circumstances, thoughts and feelings, which may impinge upon clinical assessment, clinical outcomes and their experience of care. For older people, protocols can be particularly problematic as the existence of co-morbidities means that these patients rarely 'fit' the standard protocol. The reliance and focus on adhering to checklists for the day-to-day assessment and care of patients detracts from the staff's ability to draw on broader experiences in assessing patients. The tools for assessment are not in themselves problematic, the problems arise when these aids to assessment become the assessment itself. For example, people with a poor appetite are not asked about the possible reasons why they are not eating, such as a sore mouth, nausea, pain and such like. Instead, they are placed on a food chart and may be referred to a dietician. The recording becomes the focal point, rather than the possible reasons for the person's poor appetite and appropriate solutions to remedy it. Even the recording becomes mechanistic, something to be completed at certain times of day, often by asking other staff what has been eaten, rather than the person involved.

The focus on recording care rather than on its delivery is a result of the dramatic increase in quantitative audits, where what is audited is the record of care rather than the actual care. This, together with standardised protocols, can de-skill staff as they become reluctant to use professional judgement to identify creative solutions to patient problems.

To address these issues, it must be acknowledged that the unthinking acceptance of targets and monitoring regimes can work against Trusts if the substantial costs of the unintended consequences are not taken into account and therefore impact not only the quality of care and patient experience, but also on the efficiency and effectiveness of the Trusts as a whole. It might be cheaper to breach a four hour wait, than run to the expense of the staff involved in moving patients or risking hospital acquired infection such as C Difficile (and subsequent treatment costs). It may be that a five hour wait could reduce the need for movement without adding too much of an additional burden for the person waiting. Thus, there is a need for ongoing and intelligent dialogue between those who set policy directives, those who commission services and those who deliver, so that the effects of suggested targets, drivers, strategies and service changes are fully worked through before their wholesale implementation. In this way, real costs and consequences can be foreseen and steps taken to avoid the most negative of them.

Increased drives for efficiency and balancing the books has resulted in staff shortages overall and reductions in the numbers of qualified staff in particular. The effect of this is that care has become task-centred to ensure that the 'jobs' are done. Observations of care and interviews with staff highlight how this results in the fragmentation of care as the physical tasks of washing patients, making them comfortable, providing personal care and assisting with eating and drinking, take time and are delegated to the least qualified staff who have the lowest status in the hierarchy. The result is that this care is itself denoted as being of low value, rendering it unimportant as it can be done by anyone. This can affect team working, resulting in negative cultures, which again impact on patient care as resentment among different staff groups reduces cooperation.

Inadequate staffing levels also affect the continuity and quality of care as often bank or agency nurses are used to cover shifts. This is despite compelling empirical evidence that US Magnet Hospitals with high qualified to unqualified staff ratios produce better patient and staff outcomes (Haven and Aiken, 1991). Similarly, the impact of increasing numbers of staff choosing to work long days of 12 or 14 hours has an impact, both on quality and overall continuity of care. The use of volunteers, whilst in no way compensating for experienced staff can help to improve patient dignity, by ensuring people's calls for assistance do not go unanswered, ensuring patients are served promptly, running errands and providing companionship and social engagement, especially for older people.

The use of patient experience criteria in staff appointment and appraisal systems can encourage reflection on actions and practices, engendering confidence in professional judgement and avoiding the checklist mentality that is so evident. Holding staff accountable for their actions in a fair, consistent and continuous manner and for delivering care of an appropriate quality is also necessary if the patients' experience of care is to be improved. Ward sisters in particular, need to be supported and investment made in their development as leaders. Their role is key to the ability of Trusts to deliver dignified care, yet often patients do not know who is the ward leader and ward sisters are not always aware of the practices taking place on their wards. Some are reluctant to challenge staff when they see poor practice, so that this is perpetuated and becomes the norm.

**Right Place – Wrong Patient** explores the message echoed by staff at all levels, in each of the four Trusts, that the acute hospital is not the 'right place' for older people, despite older people being the most frequent users of acute services. This has resulted in older people's concerns and needs not being routinely considered at an organisational level. The environment of the acute hospital and the individual wards, constitute disempowering spaces for older people.

A lack of signage, discriminating colour, notice boards, accessible information all serve to make hospitals and wards difficult to negotiate and increase patient dependence as people must then seek help. The lack of space and complex equipment can pose a risk, especially to confused patients. Similarly, the lack of both communal spaces and stimulating activities can result in patients becoming demotivated, disinterested and depressed (BMA, 2011). Added to this, the close proximity of patients of the opposite gender is a cause of concern for many older people. Clear statements of what is meant by single and mixed sex wards should be provided to all patients to allay anxieties and where possible, prepare older people for their experiences in hospital.

In part, these issues result from the widespread attitude that older people do not belong on acute hospital wards and should 'go somewhere where they can be cared for'. This attitude must be changed. If all hospitals were designed and operated to meet the needs of frail older people, then they would also meet the needs of other users. The interests of older patients are not reflected in the design, organisation and culture of the hospitals that serve them. In order for acute hospitals to become fit for purpose, they must become places that can meet the needs of the older population who require acute services. In terms of design, there is little evidence that patients and/or their relatives are routinely consulted about

improving the environment of care, despite evidence of the effectives of strategies, such as experience-based design (EBD) (Bate and Robert, 2006). The positive impact on dignity of addressing environmental issues is also evidenced in the work of Davies (2000a, b, c, d and e) and Haak (2009).

The failure to accept and act on the fact that older people with complex clinical needs are the greatest users of acute services has implications for the initial and continuing training and education of staff. This has resulted in a significant skills gap that adversely affects the quality of care and level of dignity afforded to older people. Many of the patients also suffer from mental health problems such as dementia, depression, or delirium. The evidence from staff and Trust manager interviews suggests that the extent to which staff are prepared to meet the needs of older people is variable. Few have any specific training on the needs of older people, on caring for someone with dementia or, on delivering dignified care. Rather, it is assumed that everyone understands about dignity, that older people need only 'basic care' and that people with mental health problems, especially those with dementia should be 'elsewhere'. Staff need to understand that failure to deliver sensitive care that promotes dignity has important negative clinical outcomes (Beach et al, 2005).

To assist in combating this skills gap, where older people with complex needs are admitted, then expert staff should be on hand to assist ward staff deliver comprehensive care. For instance, a frail older person with a fracture complicating other co-morbidities should be seen by a geriatrician to oversee all aspects of care other than the actual surgery required for the fracture. Similarly, the rise in the number of patients with dementia admitted because of an acute illness should be addressed by providing psycho-geriatric or dementia liaison services, to oversee aspects of dementia care and advise staff on managing behaviour.

The impact on staff of this general failure to recognise what is the core business of acute Trusts is another important consideration. Interest in staff experience as a marker for quality of care is growing, as correlations between staff and patient experience are well documented. The belief that the people one is caring for 'shouldn't be there' together with a lack of knowledge of the importance of addressing older people's needs, means that all staff are at risk of being socialised into ways and practices that 'get the jobs done' but 'lose sight of the individual and their needs'. As a result, staff can become demoralised which further impacts on the quality of care delivered to patients.

That many interviewees across all 4 NHS Trusts recognise these issues but conclude that it is the older person who is in the 'wrong place', together with the assumption that there must be a better place for 'them' to be, may suggest an underlying and widespread ageism. One can only conclude that the view that older people should not be on acute wards is a significant barrier to the delivery of dignified care. To address these issues, a clear message needs to be delivered throughout the NHS to counteract the view that the admission of older people to acute wards is inappropriate.

**Seeing the Person** focuses on the impact of individual encounters that take place within the acute setting and the influence of these on the experience of dignity for patients, their relatives and staff. Every single encounter which takes place in acute Trusts has the potential to enhance or deny dignity.

Generally, older people viewed their care positively, but probing specific aspects revealed many examples of undignified practices. Also, older people generally had low expectations in terms of care standards. Many remarked on trying to be 'good patients' and not demanding a great deal from staff.

As shown in many other studies, respectful communication is essential for the delivery of dignified care. Whereas other studies have emphasised that forms of address are important to older people, the majority interviewed in this study did not mind being called by their first names, even when their preferences were not sought. Some participants, however, complained about staff addressing them by the 'wrong' first name as this impacts negatively on their sense of dignity.

Disrespectful communication practices are widespread, with 'elderspeak' which humiliates and infantilises older people being observed frequently. Similarly, older people are often referred to as tasks such as a 'double handler', or by their bed numbers, both of which objectify people and deny their humanity. Dignity is also infringed when older people are ignored such as when staff fail to respond to requests for help or fail to engage with them while performing other tasks.

The wards and even bed spaces were very much the 'professionals' spaces, as little regard was paid to patients or their property. This constitutes an infringement of dignity as patients are disempowered and made to feel that they lack control.

As expected, fundamental care such as feeding, elimination, washing, dressing, being given information, all afforded opportunities for dignity to be promoted or denied. This is reinforced in much of the literature cited in Chapter 2. Maintenance of privacy is essential in many of these aspects of care and the lack of suitable curtains, ill-fitting hospital gowns that impact on patients' modesty and places where confidentiality can be maintained are of major concern. The lack of basic items such as clean bed linen is a daily concern for many ward staff. In relation to toileting there were examples on many wards where patients were told to soil their pads when they requested to be taken to the toilet. Like referring to people by a task or bed number this practice may well be an indicator of a general lack of dignified care in that area. Trusts should take firm action to end the unacceptable practice of patients being told to soil themselves as some practices should never be condoned.

When staff promote dignity while delivering fundamental care, the positive effect on patients and their sense of dignity is almost palpable. Chochinov (2009) suggests a simple yet effective way in which staff can be reminded of the importance of seeing patients as persons. This is to ask every patient on admission, 'What do I need to know about you as a person to give you the best care possible?' This also serves to instil a sense of value and ensure that the patient knows that they will be treated as an individual who matters to staff.

Approaches to care delivery are important. When patients are seen as individuals in their own right, with a history and preferences, dignified care is much more likely to exist. However, organisational factors such as those described above, often result in care that is largely reactive, focusing on a series of tasks rather than promoting proactive management that anticipates a patient's needs in a coherent and consistent way. Task orientation is also a result of inadequate skill mix, with a high proportion of unqualified support staff, as care

then becomes akin to a series of tasks being done to patients, rather like being on a conveyor belt.

Without appropriate staff support, it is unlikely that high quality care that emphasises the need for qualities such as dignity, individuality and compassion will be achieved. This will only happen if the message that dignified care is the standard to be expected is transmitted throughout the organisation. This may be promoted for instance by ensuring that national policy is translated into meaningful messages for 'frontline' staff. Trust board members, senior managerial and clinical staff must accept responsibility for the quality of care and these staff must show a genuine interest in the experiences of all patients as well as delivering clear messages about what will and will not be tolerated.

The inclusion of patient stories at board meetings and acting upon them is another way that Trust managers can demonstrate their genuine interest in patient experience, especially if they are used to foster organisational learning. An open learning culture that respects staff and patients equally and appreciates their contributions is essential in promoting dignified care. Thus, the role of leaders at all levels of the organisation is critical, as it is they who reinforce standards and appropriate attitudes and behaviours.

To do this, however, such leaders have to be visible, be they Trust board directors or members, senior clinicians and managers or ward/team leaders. To be credible, leaders must understand the difficulties encountered by staff. Visible leaders engender trust and cohesiveness as they are seen as credible and understanding of the difficulties encountered by staff. Staff are unlikely to treat patients with dignity and respect if they are not treated in this way by their leaders.

Clear processes are needed to facilitate two-way communication between ward staff and senior managers. However, it is of no use encouraging staff to send feedback to the board if no action is ever taken. Encouraging staff at all levels of the organisation to use observation of care to 'measure' its quality, can enhance the quality of service provision by identifying and reporting both examples of best practice and deficiencies in service. This is essential for the delivery of high-quality health services (CHAI, 2007, Dixon-Woods, 2003).

**Influences on Dignified Care** - reflecting on each of the above themes, this section highlights the most significant barriers to providing dignified care and the strategies and actions that enable dignified care which have informed our recommendations for change. Many of these have been identified above and will not be reiterated.

It is however worthwhile emphasising that from both the findings from this study and those from the empirical literature cited in Chapter 2, dignified care involves:

- Respectful communication.
- Respect for privacy.
- Promotion of autonomy and a sense of control.
- Addressing basic human needs such as nutrition elimination and personal hygiene/appearance in a respectful and sensitive manner.
- Inclusivity and encouraging participation.
- Promoting identity.

- Focusing on the individual.
- Recognising human rights such as fairness, equality, respect, dignity and autonomy.

Similarly, undignified care consists of care that:

- Renders the individual invisible.
- Depersonalises or objectifies the individual.
- Is abusive and humiliating.
- Is narrowly focused.
- Disempowers the individual.

Already a proliferation of guidelines (see SCIE website at www.scie.org) are in existence and additional ones are unnecessary. What is required is a sincere and sustained effort to implement these in all areas of acute NHS Trusts. To do this requires an acknowledgement of the complexity involved as the lack of dignity experienced by many older people is not simply due to the inappropriate actions of individual staff members. Indeed, the vast majority of staff wish to deliver care of a high quality. Instead, it is due to a multiplicity of systemic factors that result in acute NHS Trusts frequently failing to deliver dignified care to frail older people. Not least amongst these is the mistaken view that older people should not be in acute wards. They are there, mainly due to acute illnesses, complicated by other chronic conditions. They deserve to be there.

Rather than, 'Right Place –Wrong Patient', the wards as they are currently, are the 'Wrong place for the Right Patients'. A concerted effort is needed to ensure that in future acute wards become the 'Right Place for the Right People'.

## Conclusion

The numerous reports, research studies and media campaigns cited in this report have drawn the same conclusions as this study that acute services are failing to deliver appropriate care for older people. For example, Dr Foster highlighted 12 failing NHS Trusts (www.timesonline.co.uk, 2010) whilst the Care Quality Commission (CQC identified that 42 out of 167 Trusts were breaching the standards required for registration (www.guardian.co.uk, 2010). The independent (and now public inquiry) into the Mid-Staffordshire NHS Foundation Trust shows what can happen when the focus shifts from the people Trusts serve to the financial status of the organisation. Most recently, the Health Ombudsman, Ann Abraham has highlighted that the NHS is failing to treat older people with care, compassion, dignity and respect (Parliamentary and Health Service Ombudsman, 2011).

In response to the Mid-Staffordshire affair, NHS Chief Executive, David Nicholson, in a letter to all NHS Trusts stated:

'I do not think that Mid-Staffordshire then is any way typical of the care that you and your staff provide to patients day and day out. Every 36 hours the NHS treats 1 million people, many of whom have their lives saved or improved because of the care they receive from dedicated NHS staff' (2010) The NHS does treat many people successfully every day, of every year and the fact that many people are living longer after acute illness is itself evidence of improved healthcare. However, we should not be complacent. The price that many older people pay is the loss of dignity and the impact of this on individuals and their families is considerable. The cost of such failures does not only affect the individual concerned, however.

The cost of the public inquiry to date has already reached almost £4 million which is a substantial loss to the public purse and does not take into account the costs of the independent inquiry or the many investigations already undertaken.

Sir Stephen Moss, chair of the newly formed Trust board in Mid-Staffordshire, in a presentation at the King's Fund, has warned that 'Any Trust Board that ignores fundamental care does so at their peril' (London, 2010).

Large scale organisational change, such as service reconfigurations, mergers and such like, can have a negative impact on the ability of organisations to deliver high quality care, (CHAI, 2009). The recent White Paper, 'Equity and Excellence: Liberating the NHS' (DH, 2010a) will result in unprecedented change at a time of stringent economic control. This will bring additional pressure as well as raised expectations, with the rallying cry of, 'No decision about me without me' and an increased focus on choice, patient experience and Patient-Reported Outcome Measures (PROMS). These changes will be delivered alongside increasing accountability not least by introducing payment on performance. Thus, the coming months will be extremely challenging and the potential for reduced standards will be very real.

Not least amongst these challenges are the economic constraints in which the NHS will be required to operate. Many will say that the recommendations we are making are too costly to be implemented at this time. Again, it is worthwhile emphasising that while Mid-Staffordshire has proved costly, so too have the measures required by other failing NHS Trusts, who lost sight of patient experience and delivery of fundamental care. Complaints are costly and compensation claims are costly, so a focus on delivering high quality care which places patient experience and the provision of dignified care at the centre of service delivery can make economic sense, especially as the advent of 'social enterprise organisations' will push quality and considerations of dignity higher up the agenda of acute services. Patients and their general practitioners will be customers looking for 'customer care' that recognises their individual worth. Thus, acute NHS Trusts will need to be even more responsive to patients' experiences of care and the central importance of dignity and respect and, they should have robust strategies in place to meet these challenges.

Currently, not all staff groups see the delivery of dignified care as their business. The dignity campaign (DH, 2006b) has largely been enacted by nurses, whilst NHS managers and other clinicians (with some notable exceptions such as the members of the British Geriatrics Society) have failed to engage fully with the initiative. Whilst it is commendable that individuals and organisations such as the Royal College of Nursing promote this campaign and work to make a difference, (for example at the beginning of 2010 there were some 14,000 dignity champions), at best, such strategies can only go so far towards addressing the fundamental change that is needed if the apparent deficits in acute care are to be reversed. A strategic approach is needed at the institutional level to produce the cultural transformation required and to sustain it.

Dignified care is not the preserve of a single occupational group rather it is the responsibility of every person working in the NHS, from the chief executive to the hospital porter. For real and enduring change, lessons must be learned and changes must be made. The observation that the provision of dignified care is 'not rocket science' is one that is frequently made and at the level of individual interactions or personal care this may well be true. For instance, people should be treated courteously, bodily privacy should be maintained, patients should were necessary be assisted to eat and drink, however, the reasons why this does not always happen are as identified in this report, complex and multilayered, making them difficult to separate and address. To assist in this the following enablers of dignified care have been identified:-

Enablers of dignified care include:-

- attention to the physical environment that takes account of the needs of older people including appropriate signage, careful use of colour, information and date boards, safe walking spaces and communal areas to improve social interaction and engagement.
- adequate space between beds to enable privacy especially when using hoists.
- gender specific washing and toilet facilities.
- staff appraisal systems which take account of the patient experience and offer opportunities for reflection on practice.
- appropriate staffing levels to meet the demands of patient care.
- sensitive delivery of fundamental care that takes account of individual patient needs, especially the need for privacy.
- the use of signs to prevent entry to the patient spaces when intimate care is being undertaken.
- courteous and respectful communication practices.
- respectful attitudes of staff to both patients and colleagues.
- social activities and engagement especially on wards that are exclusively for older patients.
- ward managers who have a visible presence on the ward and who foster collaborative team work.
- staff who are confident and competent in their expertise and feel supported by their managers.
- the use of volunteers to assist staff.
- organisational policies and operating procedures that place patient experience at the centre.
- Trust managers who demonstrate genuine involvement in both patient and staff experiences.

We hope this study has gone some way towards unearthing these complexities and that the recommendations we offer for the acute care sector will enable positive and lasting improvements to the care of older people and their families.

The words of this Trust manager provide a fitting note on which to close.

#### "What we can't do is make them any younger and sometimes

sadly we can't make them better but we can make them comfortable and we can embrace them properly with conversation, stimulus, a meal, a clean environment and an environment that makes it easier to co-exist on a ward with others."

(Interview with a Director of Facilities, (Uphill Trust)

Based on the evidence from this study together with the cumulative evidence from the Dignity and Older Europeans study, the research studies and reports cited in this study the following recommendations are suggested to ensure that older people in acute NHS Trusts are treated with dignity.

#### Recommendations

#### 1) Recommendations for the NHS as a System

- 1.1 Older people are the most frequent users of acute hospital services therefore ageist attitudes which result in comments such as '*They shouldn't be here*' are inappropriate. This key message should be clearly understood throughout the organisation.
- 1.2 The NHS should understand the need to design and operate its acute services to explicitly meet the needs of frail, older people. Such services will also meet the needs of other users.
- 1.3 The connection between policy and practice should be made explicit by translating what developments in policy mean in practice for both frontline staff and those responsible for implementation, to ensure that clear unequivocal messages are received.
- 1.4 Dignity and respect are core values that underlie the NHS Constitution, it is essential that all Trust and health boards are reminded by NHS chief executive(s) that they are responsible for all aspects of the quality of care and for ensuring that the values enshrined in the constitution become a practical reality for everyone in the organisation.

#### 2) Recommendations for Royal Colleges and Regulators of Professional Groups

2.1 The education of all healthcare professionals needs to be reassessed to ensure it is in line with the needs of the majority of patients in acute hospital Trusts – older people. This reappraisal must include a better understanding and appreciation of comorbidities, the nature and management of dementia and delirium and the complexity of older people's needs. Changes to professional curricula to better reflect these needs and meet them in a dignified manner would be appropriate (see National Service Framework for Older People, DH 2001a).

#### 3) Recommendations for Commissioners

- 3.1 Commissioners should adopt an outcomes-based approach that includes outcomes relating to dignity and respect.
- 3.2 Commissioners should ensure that all older people with complex needs complicating acute illness are seen by a geriatrician in order to advise colleagues on management.
- 3.3 Commissioners should ensure that liaison services with old age psychiatry (or other specialist services for dementia/delirium) are provided in all acute settings.

#### 4) Recommendations for Trust Boards

- 4.1 Patient movement should be reduced by either: a lower bed occupancy rate which would allow more flexibility when trying to place patients according to specialism or gender or, by altering how the hospital is organised so that there is less emphasis on the spatial separation of specialisms. This could be promoted by:
- i) Shared care approaches and joint responsibility for patients whose conditions span specialisms.
- ii) Consultants and their teams undertaking 'patient rounds' rather than 'ward rounds'.
- 4.2 Trust boards should give attention to environmental design and where possible enable patients to participate in redesign/refurbishment projects. Specifically:
- i) Older people are the main users of acute hospitals. Therefore the NHS should understand the need to design and operate its acute services to explicitly meet the needs of frail older people. Such services will also meet the needs of other users.
- ii) All hospital refurbishments and new builds should incorporate dementia-friendly design as standard for all areas. This should include safe walking spaces and the helpful use of colour, lighting and signage to help orientate those with dementia or delirium.
- iii) The value of communal spaces on acute wards in terms of social engagement and activities should be recognised as a means of preventing deterioration and promoting recovery (BMA, 2011).
- iv) Minimum space requirements around bed areas should allow dignified care while using large hoists and other equipment. Secure, accessible storage space for patients' belongings should be available at all bed spaces.
- v) Clear definitions and information concerning single sex wards should be provided prior to admission to prepare older people for situations where there may be members of the opposite sex in adjacent bays or sharing bathing or toileting facilities.
- 4.3 Trust boards should ensure effective management by developing communication strategies that guarantee the free flow of information from 'board to ward' and 'ward to board'. These strategies should be enhanced by visible and accessible middle managers and board members. The board members should accept responsibility for the day to day quality of patient care and therefore need to ensure that they are well informed about all aspects of the patient experience. Trust board meetings should focus on the experience of patients, both good and bad, and communicate the messages across all staff groups.

- 4.4 Trust boards should ensure effective implementation of policies through an awareness and understanding of the impact of policies and priorities on patient care and practices at the ward level. Resources to ensure privacy and dignity, such as the provision of adequate amounts of clean linen and nightwear must be seen as essential.
- 4.5 In relation to risk management, Trust boards need to balance the impact of risk management strategies against patients' experience. Professional staff must be reassured that they will be supported and enabled to decide when risks are worth taking to promote patient dignity.
- 4.6 Targets and clinical governance directives can create an over-emphasis on checklist based audit and measurement, which may fail to see the person and be detrimental to patient care and experience. Broader approaches to determine the quality of patient care and the experience of patients should be adopted, including regular observation of care by middle and Trust board managers and qualitative interviews with service users and their family members.
- 4.7 Trust boards must ensure a comprehensive and compulsory programme of both induction and continuing training for all staff groups in relation to the provision of dignified care and the needs of older people, especially those with dementia (See National Dementia Strategy, DH, 2009b).
- 4.8 Time must be available for staff to reflect on practice and to question inappropriate practices that have become accepted norms, such as forms of address; respecting people's space and belongings; and task driven activity at the expense of engagement with patients.
- 4.9 Trust boards should adopt human resource policies that embed dignified care in the organisational structure, especially those in relation to recruitment and staff appraisal, so that essential aspects of patient experience such as dignity and respect are included.
- 4.10 Trust boards should invest in leadership programmes for key staff, especially ward sisters/managers.

#### 5) Recommendations for Middle Managers and Clinical Leaders

- 5.1 Middle managers must accept responsibility for promoting dignity and hold teams accountable for delivering high quality, dignified care at all times. They must challenge undignified practices and reward dignified care.
- 5.2 Middle managers should develop ward leaders giving them more autonomy and support to manage their staff.

#### 6) Recommendations for Ward Managers

- 6.1 Ward managers should support staff in the delivery of dignified care and be willing to speak for them to ensure resources are in place to enable the delivery of care of an appropriate standard.
- 6.2 Ward managers must be willing to challenge inappropriate or poor practices and take necessary actions to ensure they do not recur.
- 6.3 Ward managers must foster team approaches to care and facilitate communication between team members, thereby ensuring that all staff are treated with dignity and respect.

#### 7) Recommendations for Staff

- 7.1 All staff must be willing to engage with organisational policies and strategies designed to deliver individualised care and recognise and respect every individual's need to be treated with dignity.
- 7.2 All staff must take account of older people's sensibilities especially in relation to the gender of staff delivering intimate and/or personal care.
- 7.3 All staff must be willing to reflect on the impact of their own actions on patients' experience of dignity.
- 7.4 All staff must be aware that ageism is a societal presence and therefore present in acute Trusts. This awareness should result in an acknowledgement that the 'bread and butter' work of acute hospitals is caring for older people and they should commit to always demonstrating respect and acting to safeguard the older person's dignity.

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### LIST OF ABBREVIATIONS

APPG	All-Party Parliamentary Group
BGS	British Geriatrics Society
ccw	Care Council for Wales
СНАІ	Commission for Healthcare Audit and Inspection
CSCI	Commission for Social Care Inspection.
CQC	Care Quality Commission
CT Scan	Computerised Tomography Scan
DH	Department of Health
EMI Unit	Elderly Mentally Infirm Unit
EU	European Union
FA	Framework Analysis
HAS	Health Advisory Service 2000
HIW	Health Inspectorate Wales
НСА	Healthcare Assistant
НССРА	House of Commons Committee of Public Accounts
IV	Intravenous
JCHR	Joint Committee on Human Rights
LA	Local Authority
МНСА	Male Healthcare Assistant
MAU	Medical Admission Unit
MG	Myelogram
NAO	National Audit Office
NATCEN	National Centre for Social Research

NCEPOD	National Patient Enquiry into Outcome and Death	
NHS	National Health Service	
NMC	Nursing and Midwifery Council	
ОТ	Occupational Therapist	
PEAT	Patient Environment Action Team	
RCN	Royal College of Nursing	
RCP	Royal College of Psychiatrists	
R&D	Research & Development	
SN	Staff Nurse	
SNMAC	Standing Nursing and Midwifery Committee	
SSIW	Social Services Inspectorate in Wales	
MDT	Multi-Disciplinary Team	
υк	United Kingdom	
UN	United Nations	
UA	Unified Assessment Process	
WAG	Welsh Assembly Government	
WTE	Whole time equivalent	

## Addendum to the report

This research document is an output from a research project that was commissioned and funded by the Service Delivery and Organisation (SDO) programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. The management of the project and subsequent editorial review of the final report was undertaken by the Policy Research Programme (PRP) programme based at the Policy Research Programme Central Commissioning Facility (PRP CCF).

The management of the project and subsequent editorial review of the final report was undertaken by the Policy Research Programme (PRP) programme based at the Central Commissioning Facility (CCF) as part of its Preventing Abuse and Neglect in Institutional Care of Older Adults (PANICOA). As the SDO programme had no involvement in the management or editorial review of the project we may not be able to comment on the background of this document. Should you have any queries please contact <u>sdo@southampton.ac.uk</u> or <u>farheen.shafiq@prp-ccf.org.uk</u> (for the PRP).

## **Appendix 1: Ward Observation Schedule**

# Dignity in Practice: An Exploration of the Care of Older Adults in Acute NHS Trusts

# Ward Observation Schedule (Plus Elements from Interview Findings with Older Adults and Their Relatives/Informal Carers)

When observing in clinical areas, the following provides an outline guide for making field notes.

Broad descriptive accounts of care episodes and events should be written.

#### Factual Aspects to be Documented:

- Date and time of observation.
- Ward pseudonym.
- Type of ward.
- Diagram/description of area being observed.
- Number of staff.
- Grades of staff.
- Note any visitors.
- Number of patients and levels of dependency.
- Gender of patients.

#### In Recording Events Pay Attention to:

- Ward environment and culture.
- Ward leadership.
- Translation of existing policies into practice.
- Attitudes to patients.
- Protection of privacy and modesty.
- Protection of confidentiality.
- Communication and interactions between staff, patients and staff and patients.
- Patient involvement and participation in care and care decisions.
- Maintenance of personal identity.
- Mealtime activity.
- Hygiene and toileting.
- Evidence of reflective practice.

# Appendix 2: Dignity Workshop Report

Four stakeholder workshops were held in Bristol, Manchester, Durham and London towards the end of the project. Each of these brought together a range of NHS managers and staff, voluntary organisations interested in or advocating for older people and policy makers (≈150 in total) to discuss the issues emerging from the study and determine how these resonated with their experiences. The research team were also interested to hear what policy and organisational changes participants believed necessary to promote the dignity of older people.

The day consisted of an outline of:

- The study methodology
- The key themes
- Whose interests matter?
- Right place, wrong patient
- Seeing the person
- Influences on dignified care.

These were interspersed with sessions where participants were invited to address some of the following questions:

- Does what you have heard resonate with your experiences?
- What practice and policy changes would have the most positive impact (in the short and in the longer term) on the provision of dignified care?
- How might they be achieved, with no more than a modest increase in resources?

Other questions to consider:

- How can the NHS acute sector become equipped to treat the 'typical' patient who is older, has a number of chronic conditions and may be confused?
- How can a high level of bed occupancy be maintained without the need to move older people around?
- What would be the most effective and efficient way of ensuring that the environment of the acute ward is 'fit for purpose' as far as older people are concerned?
- How can acute Trusts ensure that their organisational priorities and the provision of dignified care do not conflict?
- How can the balance be redressed between a reliance upon standardised procedures and professional judgement.
- How can risk be managed in ways that do not compromise older people's dignity?
- What would enable staff to respond to individual patient's needs rather than those of the service?
- How could we provide a more positive work environment to allow staff to develop their personal resources for delivering dignified and compassionate care?
- What kind of competencies are essential for leaders and managers of health services to support dignified care?
- How should we manage individuals who do not deliver dignified care?

• What factors contribute to the culture of defensiveness amongst NHS staff and how can this be changed?

#### Whose Interests Matter?

Although some participants initially displayed some defensiveness to the messages from this presentation and offered explanations about lack of staff experience and staff burnout, the presentation's key messages were generally well received, especially risk aversive behaviour being problematic with staff becoming blinkered by policies and guidelines.

#### **Right Place, Wrong Patient**

As with 'Whose Interests Matter?' this presentation also provoked some defensiveness in some respondents and some emphasised the need to treat staff with dignity if the NHS was to expect dignified care. The 'Releasing Time to Care' initiative was mentioned as a means of staff spending time with patients, though only one respondent felt that the initiative actually enabled greater communication. Surprise was expressed at some of the terminology being used by the staff in interviews, e.g. 'move them on', feeling that this showed a lack of empathy. The lack of 'joined-up thinking' in relation to the wider healthcare system was also mentioned. This referred to the manner in which some patients were admitted into hospital perhaps unnecessarily and then were difficult to discharge. The integration between nursing homes, care homes and acute wards needed to be more advanced and cooperative.

Training was also seen as a key aspect of providing dignified care for older people. It was felt that many of the skills associated with providing good care were seen as 'basic' when they were highly skilled and needed ongoing training and reinforcement. The presentation was largely well-received and many of the key points – the unnecessary movement of patients, the environment of the wards, etc – were met with great resonance.

#### Solution Group 1

The groups discussed and raised the following points from their deliberations:

- Training and education for everyone as all staff work with older people.
- Leadership and role modelling.
- Maintaining dignity was the responsibility of everyone, not just nurses.
- Communication.
- Recruitment.
- Unnecessary admissions.
- Specialist beds.
- Risk aversion.
- Physical environment.
- Partnerships/Community Integration.
- Dignity Champions Network/Dignity strategy.
- This Is Me and dementia friendly practices/design.
- Cultures and practice.
- Less restrictive visiting hours.

#### **Seeing the Person**

The 'Seeing the Person' presentation was delivered as a 'story' of a day on two wards. It was based on data drawn from the study with one day describing a ward where 'undignified' care was the norm and the other describing a ward where dignified care was delivered.

This approach received a very favourable response with some parts of the stories provoking very powerful responses. The feedback from workshop attendees expressed a great deal of resonance with their own experiences. Many participants at each workshop suggested that putting the stories into DVD format as a constructive and practical training resource for the NHS would be very useful. Additionally, many participants thought this presented valuable evidence that could be presented to Trust boards. Participants believed that chief executives must be required to become more involved in issues of dignity as ultimately, 'the buck stops with them'.

#### **Influences on Dignified Care**

This presentation was also favourably received and the need for excellent and visible leadership at every level was emphasised. The need to monitor and measure patient experience was raised but with no clear suggestion as to how. One workshop believed that discussing patient experience at board meetings would be a step in the right direction. Similarly, the reward and praise of good practice should also be at board level and disseminated down across staff. It was also felt that staff should deal with complaints personally rather than have patients go through the convoluted complaints process. This would allow them to see the effect of their actions on patients and relatives.

#### **Solution Groups 2**

The groups discussed and raised the following points from their deliberations:

- Praise good practice.
- Patient feedback & participation.
- Leadership/training.
- Principle of respect.
- Removal of generic care plans.
- Communication.
- Amalgamate health and social care as the separation is artificial for older people.

# **Appendix 3: Protocol for Researchers - Suspected Abuse or Neglect of Participants**

This protocol relates action to be taken by researchers should they observe abuse, neglect or serious loss of dignity of patients observed by or disclosed to project staff.

Abuse occurs when a person has caused harm, or may be likely to cause harm to the physical, sexual, emotional/psychological, financial or material wellbeing of another (especially a vulnerable adult). The abuser may be a visitor or a staff member.

All project staff will be made aware of the local 'Protection of Vulnerable Adults' procedure which will form part of the induction training.

#### In the event of suspected abuse or neglect:

The researcher observing, suspecting or receiving a disclosure of abuse, neglect or any situation where the researcher feels there has been a serious breach or loss of dignity, should inform the ward manager and principal investigator.

The researcher should record accurately the relevant events and facts and/or the nature of any suspicions. The record must be dated and clearly signed.

#### If the person is in immediate danger:

- Immediate steps must be taken to protect them.
- In life-threatening situations, the police must be contacted.
- The principal investigator must be contacted.
- The ward manager/senior nurse must be contacted in the first instance.

The principal investigator will be responsible for:

- Ensuring the 'Protection of Vulnerable Adults' procedure for the relevant Trust is followed.
- Liaising with the senior staff who will determine what action is required.

#### If the vulnerable adult is NOT in immediate danger:

- The principal investigator must be informed.
- The ward manager must be informed.

The principal investigator will be responsible for:

- Ensuring the Protection of Vulnerable Adults procedure for the relevant Trust is followed.
- Liaising with the senior staff who will determine what action is required.

# **Appendix 4: Dissemination**

The project team have planned a variety of dissemination initiatives.

- 1) Stakeholder workshops held in Durham, Bristol, Manchester and London. A full report of these workshops is given in Appendix 2. However, it is important to note that these workshops were extremely valuable in allowing us to validate and hone our findings and discuss and refine our conclusions.
- 2) Each of the four Trusts have been offered feedback meetings concerning the findings in their own Trusts. In addition, as outlined within the submission, training/education sessions for staff within the four Trusts have been offered as a way of thanking them for their participation and giving of their valuable time. Most Trusts have asked if these can take place after the winter when more staff will be available.
- 3) Once approved, the study report will be available on the SDO website and that of the PANICOA programme, as well as Cardiff and Kent University websites. The study report will be printed and circulated to those participants who have requested a copy.

The report will also be distributed to:

- Academy of Medical Royal Colleges
- Age Cymru
- Age UK
- Baronesses Greengross and Knight
- British Medical Association
- Chair of the CQC
- Chair of the Health Select Committee
- Chief Executives' Forum
- Chief Nursing Officers in England and Wales
- Chris Ham, King's Fund
- Commissioner for Older People in Wales
- Council and Care
- Council for the Regulation of Healthcare Professionals
- Council of Deans of Health
- David Behan, Department of Health
- Deputy Minister for Health and Social Care, Welsh Assembly Government
- Dicken Weir-Hughes, Nursing and Midwifery Council
- Dignity in Care website, SCIE
- Director, RCN Wales
- General Medical Council
- Medical Schools Council
- Nigel Edwards, NHS Confederation
- Paul Burstow, Minister for Care Services
- Paul Cann CEO, Age Concern, Oxford
- Picker Institute Europe

- President of the British Geriatrics Society
- Royal Colleges of Physicians, Psychiatrists, General Practitioners, Surgeons, Emergency Medicine and Nursing
- Royal Society of Medicine
- Skills for Care
- Stroke Association
- The Alzheimer's Society
- The Health Foundation
- The Mental Health Foundation
- The Patients Association
- 4) For presentation at the stakeholder workshops, 'the story' 'Two days Two Wards' was developed from the data. Many participants expressed the view that these would make excellent training materials, especially if made available as a DVD. It is hoped that this possibility can be explored within the PANICOA initiative as a practical, evidence-based output to promote dignified care.
- 5) Research briefs will be prepared for policy makers, voluntary organisations, NHS Trusts and the public.
- 6) Final Project Conference A final project conference is planned. Invitations will be sent to all NHS Acute Trusts, Welsh Local Health Boards and the interested parties listed above.
- 7) Presentations and Publications: The research team have developed a comprehensive publication plan to ensure maximum coverage and this will be enacted in the New Year. The following peer reviewed and professional journals have been identified as potential targets and decisions will be made as to the most appropriate choices to ensure maximum coverage:

Peer Reviewed Journals	Professional Journals
Sociology of Health and Illness	Nursing Times
Health Sociology Review	Nursing Management
Journal of the American Geriatrics Society	Health Services Journal
Age and Ageing	Nursing Management
Journal of Applied Gerontology	British Medical Journal
The Gerontologist	Hospital Doctor
Reviews in Gerontology	BGS Newsletter

#### Journal of Advanced Nursing

Peer Reviewed Journals

**Professional Journals** 

Journal of Nursing Scholarship

Peer Reviewed Journals

International Journal of Nursing Studies

Qualitative Health Research

Nursing Research

Journal of Clinical Nursing

Journal of Nursing Administration

Nursing Science Quarterly

Advances in Nursing Science

Health Care Analysis

#### Peer-reviewed Papers

Tadd, W; Hillman, A; Calnan, S; Calnan, M; Bayer, A; Read, S. Right place - wrong person: dignity in the acute care of older people. Quality in Ageing and Older Adults, 2011; 12(1): 33-43

#### Abstracts Submitted

British Sociological Association Annual Conference, April 2011, 'Socials, a-copias, outliers and boarders: Who is the 'right' acute hospital patient?' Hillman A, Tadd W, Calnan S and Calnan M.

Calnan M, Tadd W, Hillman S, Calnan S, Bayer A and Read S 'Right Place – Wrong Patient': why acute hospitals do not work for older people. Health Policy and Politics Network Conference, September 2011, Oxford.

#### Invited presentations

Tadd W. and Calnan M., (2011) 'Dignity in practice: an exploration of the care of older adults in acute NHS trusts' SDO Network Chief Executives' Forum, May 5<sup>th</sup> London and May 19<sup>th</sup> Nottingham.

Tadd W, Hillman S, Calnan S, Calnan M, Bayer A and Read S., (2011) Keynote presentation 'Dignity in Care: The reality of making it happen in practice' Dignity in Care Conference: Because it matters, hosted by Shrewsbury and Telford Hospital NHS Trust and Staffordshire University, Faculty of Health, Shropshire Education and Conference Centre 12<sup>th</sup> May 2011.

Tadd W, Hillman S, Calnan S, Calnan M, Bayer A and Read S., (2011) 'From right place- wrong person to Right place right person' invited presentation Delivering Better Health Services, 2011 Joint HSRN and SDO Network Annual Conference, 7 and 8 June 2011, Liverpool.

Win Tadd has been invited to give a key note paper at the British Geriatric Society National Meeting May  $16 - 18^{th}$  2012, Llandudno.

#### Presentations

Hillman A, Tadd W, Calnan S and Calnan M W, Embodiment, identity and accomplishing dignity: Caring for older people on acute hospital wards, World Congress of Sociology held in Gothenburg, Sweden, July 11 to 17, 2010.