



HASCAS

DIGNITY THROUGH ACTION
(Older People)

RESOURCE 5

**OLDER PEOPLES' GUIDE
TO DIGNITY**

Note: the term 'carer' has been used in this Guide to refer to anyone who is responsible for delivering or managing care to older people.

*Health and Social Care Advisory Service (HASCAS),
11-13 Cavendish Square, LONDON, W1G 0AN*

OLDER PERSONS' GUIDE TO DIGNITY

The purpose of this short guide is to provide a description of what you should expect from care with dignity, how to identify undignified treatment and what to do about it.

DIGNITY AND RESPECT

You will hear the terms 'dignity' and 'respect' used a great deal in relation to older people and their care. The terms are used in two common ways:

- **Being treated with Dignity.** Dignity is a quality in the way people are treated and respect is one measure of this quality. Most people expect to be treated with dignity and respect, and have a very finely tuned sense of whether or not they are being treated in a dignified or an undignified way. You should always expect to be treated with dignity and other people should respect your personal civil and political rights, and freedoms. As you will see below you have considerable legal rights to expect to be treated with dignity and respect.
- **Maintaining your personal dignity.** Dignity is also word used to describe how you can appear or behave. This is very much a product of how you feel about yourself (*self-esteem*) and your personal expectations for recognition by others for your history, achievements, position in society, personality, qualities and skills, and how you think you should fit into the world around you. This drives how you respect yourself, look after yourself, keep yourself clean and fit, dress yourself and act towards others. Maintaining your own personal dignity is very much your own responsibility. Many older people seem to be very robust and manage to maintain their personal dignity, whatever happens to them. Whereas, many older peoples' personal dignity can too easily be damaged by: physical mistreatment, illnesses and injuries, effects of drugs, incontinence, frailty, mental competence, need for supervision, carers using harsh or infantile language, humiliating and embarrassing treatment, inability to complete tasks that were once easy, reduced mobility, poor malnutrition, poverty and so on. Unfortunately, many people in society have difficulty seeing past the outward appearance of older people to treat them with dignity and help them maintain their personal dignity. This can lead to the 'slippery slope' into maltreatment and abuse. As you will see below maintenance of your personal dignity should be considered to be an essential part of professional care practice.

BEING TREATED WITH DIGNITY

International Conventions on Human Rights

Following the experiences of World War 2, the United Nations created a **Declaration of Human Rights** in 1948. This was about the adoption of the principles of human rights by the international community. The Declaration said that all human beings, were '**endowed with reason and conscience ... are born free and equal in dignity and rights . . . and should act towards one another in a spirit of brotherhood**'. The ideas about rights and freedoms set out in the United Nations Declaration of Human Rights were included in the European Convention on Human Rights in 1950 by the Council of Europe (*one of the oldest European integration organizations*). All Council of Europe member states are party to the European Convention (*which the UK helped to draft*) and any new members are expected to ratify the convention at the earliest opportunity. The European Convention on Human Rights is enforced by the European Court of Human Rights and sometimes you will see in the press reports about proceedings in this international court.

The idea was that everyone has a moral obligation to treat other human beings with dignity because all human beings have '**nobility**' and '**worth**', and people need to be treated with dignity as part of fulfilling their human lives. This brings with it other ideas such as '**equality**', where people should be treated on an equal basis, whoever they are, whatever their age, whatever their background, how they are behaving or whatever they may be suffering from.

United Kingdom Human Rights Act (1998)

In the United Kingdom your human rights are guaranteed by the Human Rights Act (1998), which provides a basis for human rights legal action in the United Kingdom. UK human rights laws contain the same basic ideas about your civil and political rights as in the United Nations and European Conventions. It covers personal rights and freedoms that should be available to all people regardless of age, sex, nationality or citizenship.

Human Rights are about respecting your rights and freedoms. It covers your civil and political rights as well as your personal freedoms.

- You have the **right to life** and this is protected by law. There are only very limited circumstances where the state may take this right away e.g. defending others from unlawful violence.
- You have the **right not to be subjected to torture or degrading treatment**. This may sound extreme, but it covers any form of inhuman, degrading or humiliating treatment and can include the quality of your living conditions. This is about not only physical or psychological abuse, but includes rough treatment, physical restraint, use of inappropriate medication (*sedatives, tranquillisers*), bullying as well as form of mistreatment by care staff.
- You have the **right to be not held in slavery or servitude**. This may also sound extreme, but you should not be required to perform any form of forced or compulsory labour.
- You have the **right to your liberty and security**. You should not be deprived of your liberty except in accordance with lawful procedures e.g. being arrested or being subject to lawful detention in mental hospitals.
- You have the **right to respect for your private and family life**. This can be restricted by other laws in certain situations. Otherwise under this right you have, for example, freedom to choose your sexual identity, to choose how to look and dress and have freedom from intrusion by the media.
- You have the **right of protection for your property**. You should not be deprived of your personal property except under limited conditions provided for by law e.g. paying taxes.
- You have other **rights and freedoms**. There are normally no restrictions placed on your rights and freedoms. However, because we live in a democratic society you obviously cannot just say nor do what you want. You have to respect other peoples' rights and freedoms. You are also legally constrained by the needs of national security, public safety, public morals, protection of public order and public health, and crime detection and prevention.
 - You have the **right not to be discriminated against**. There should be no discrimination to your rights and freedoms on any ground such as age, sex, race, colour, language, religion, political or other opinion, national or social origin, wealth, birth or other status. However, public authorities can treat people differently, if it can show that it is pursuing a legitimate aim and that the discrimination is proportionate. The Human Rights Act (1998) also includes the **prohibition of abuse of rights** where no group or individual can engage in any activity or perform any act aimed at the destruction of any individual's rights and freedoms.
 - You have the **right to freedom of thought, conscience and religion**. Everyone has the right to freedom of thought, conscience and religion and this right includes freedom to change his religion or belief and freedom, either alone or in community with others and in public or private. You also have the right to profess your religion or belief, in worship, teaching, practice and observance.
 - You have the **right of freedom of expression**. Everyone has the right to freedom of expression. This includes the freedom to hold and express opinions, but you are restricted in what you say or write by the rights of others.

- You have the **freedom of assembly and association**. Everyone has the right to freedom of peaceful assembly and to freedom of association with others, including the right to form and to join trade unions for the protection of their interests.
- There are a number of other rights and statements in the Human Rights Act (1998):
 - You have a **right to a fair trial** everyone is entitled to a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law.
 - You have a **right that you will not receive any punishment outside of the law**, nor shall a heavier penalty be imposed than the one that was applicable at the time the criminal offence was committed.
 - Men and women of marriageable age have the **right to marry** according to constraints of national laws and to have a family
 - You have the **right to free elections** at reasonable intervals by secret ballot.
 - You have the **right to education**.
 - The death penalty is prohibited.

It is important to understand that while the Human Rights Act (1998) protects your rights and your freedoms, the Act also aims to ensure that everyone's rights are properly respected. This means that one person's individual rights will sometimes have to be balanced against another person, often in a court of law. Also your rights have to be balanced against the wider interests of the whole community. The rights of others or the community will sometimes take precedence over your personal rights and freedoms. The UK Ministry of Justice has published a short introduction to human rights called '**Making Sense of Human Rights**' on their Internet Website (*See Note 1 below*).

WHAT TO DO IF YOU BELIEVE YOUR HUMAN RIGHTS HAVE BEEN VIOLATED

In the serious situation where you believe that your human rights are being violated then you should take action because you are the best protector of your human rights. However, it is advisable to approach any possible violation of your human rights (*and any other related laws*) in a calm, careful and graduated way. You will need to confirm that your human rights really have been violated and you are likely to need professional help and guidance to help you do this. You will also need to clear about the outcome you want if you pursue the matter. You can obtain several useful booklets on 'human rights' from the Government website '**direct.gov**' (*See Note 2 below*). You can seek advice from the **Citizens Advice Bureau** (*who will have the information booklets*) and **Community Legal Advice**, which can put you in touch with legal advice providers in your area. There are also a number of Law Centres around the UK, which can also provide advice. Otherwise you may wish to contact a solicitor directly. You may find that it is easier to first use the complaints system of any organization which you believe has violated your human rights. A complaints system will be an important part of any care organization's management process. The organization should want to learn from its mistakes and deal with problems efficiently. If you use the complaints system route than you should expect a relatively quick response, but you may still not achieve the outcome you want.

If you are still dissatisfied, then you may be advised that you ought to take more formal legal action. You are entitled to bring a case before the appropriate court or tribunal in the UK, but there are likely to cost implications. The court or tribunal will consider your case and make a ruling. You should not expect a quick outcome or the necessarily the outcome you want.

Note 1. Internet Address: www.justice.gov.uk/a-z/humanrights.htm.

Note 2. Internet Address: http://www.direct.gov.uk/en/Governmentcitizensandrights/Yourrightsandresponsibilities/DG_4002951

DEVELOPING DIGNIFIED CARE FOR OLDER PEOPLE

Over the last decade the Government introduced several care initiatives such as:

- The **'National Service Framework'** (2001) which initiated improvements through local health and social care providers as well as national programmes covering such subjects as age discrimination, person-centered care, and promotion of health and active life. Despite this, it was still found that the experiences of older people in care remained unacceptable.
- The **'New Ambition for Old Age – Next Steps in Implementing the National Service Framework for Older People'** (2006). This was designed to continue the work of ensuring older people and their families would have confidence that in all care settings older people would be treated with respect for their dignity and their human rights. One of its programmes, **'Dignity in Care'**, was launched by the Government, with the aim to stimulate the national debate around dignity in care for older people. There were two core ideas. Firstly, awareness of dignity as major factor in delivering care to older people would be raised by issuing **'10 dignity challenges'**. Secondly, carers would be encouraged to register as **'Dignity Champions'** and be inspired to take local action to transform care services.
- **The 10 Dignity Challenges.** The Government laid down national expectations from a national service that respects dignity issuing 10 dignity challenges to care service providers, those that commission care and the general public. They were open ended expressions of concern about what people who use care services expect. You can see that not only human rights are important part of these challenges, but your personal needs are also included. The challenges were seen as:
 - **Dignity Challenge 1: Abuse.** There should be zero tolerance of all forms of abuse.
 - **Dignity Challenge 2: Respect.** Older people should be given support people with the same respect you would want for yourself or a member of your family. People should be cared for in a courteous and considerate manner.
 - **Dignity Challenge 3: Person-centered Care.** Older people should be treated as an individual by offering a person-centered care service. Staff should take time to get to know the older person receiving services and agree with them what services they require.
 - **Dignity Challenge 4: Autonomy.** Older people should be helped to maintain the maximum possible level of independence, choice and control.
 - **Dignity Challenge 5: Communication.** Older people should be listened to and supported to express their needs and wants. For those older people with communication difficulties or cognitive impairment, adequate support and advocacy should be supplied.
 - **Dignity Challenge 6: Privacy.** Respect people's right to privacy. Personal space should be available and accessible when needed. Areas of sensitivity which relate to modesty, gender, culture or religion and basic manners should be respected.
 - **Dignity Challenge 7: Complaints.** Ensure people should be able to complain without fear of retribution. Concerns and complaints should be respected and answered in a timely manner.
 - **Dignity Challenge 8: Care Partners.** Care service providers should engage with family members and carers as care partners. Relatives and carers should be kept fully informed and receive timely information. Relatives and carers should be listened to and encouraged to contribute to the benefit of person receiving services.

- **Dignity Challenge 9: Self-esteem.** Older people should be assisted to maintain confidence and a positive self-esteem so as to maintain the self-confidence of the older person receiving services and promote their well-being.
- **Dignity Challenge 10: Loneliness and Isolation.** Care service providers should act to alleviate people's loneliness and isolation.
- **Dignity Champions.** The Dignity in Care Campaign introduced a registration scheme for dignity champions. A dignity champion is someone who believes that being treated with dignity is a basic human right, not an optional extra; where care services must be compassionate and person-centered. The growing number of dignity champions who are bringing a focus to the issues of dignity in care organizations and encourage other staff to change working practices for the better. The Department of Health has an Internet Website for Dignity Champions (*See Note 3*).
- **Assuring the Quality of Care.** Dignity is only one of the qualities of care provision for older people, where care must be seen as part of an overall well planned, resourced and implemented approach. Any consideration of the how well a care service operates with dignity can only be assessed from examining the whole care provision package. The Health and Social Care Act (2008) provides the basis for the Care Quality Commission's Regulations (2009). This detailed guidance covers the standards of quality and safety that people who use health and adult social care services have a right to expect and is based on what people who use services have said about what matters most to them. Dignity, as a measure of quality of care, is interwoven throughout these comprehensive and demanding Guidelines.

HOW DO YOU KNOW IF YOU ARE NOT BEING TREATED WITH DIGNITY OR RESPECT?

Most people expect to be treated with dignity and respect, and have a very finely tuned sense of whether or not they are being treated in a dignified or an undignified way. However, it is a wide subject area and many recent reports have shown a continued lack of dignity and respect in all aspects of the care for older people in hospital, residential and independent living care environments. At the end of this booklet there are some of the questions which should raise your awareness of how dignity and respect in care can be easily damaged. You may find that you are able to identify other questions as well.

WHAT TO DO IF YOU FEEL YOU ARE NOT BEING TREATED WITH DIGNITY AND RESPECT

You have seen the 'Dignity Challenges' listed above and these represent the main areas of concern about dignity and respect in care. You may be in a situation where you (*or perhaps your family and friends*) believe that you not being treated with dignity and respect. You might even witness what you think is the poor treatment of somebody else. So what is to be done?

- Your first action should always be to ask people about why they are behaving in a particular way. Often there is no intention of abuse, neglect or lack of care. Carers may need to be reminded that they may have missed something or they have just fallen into a bad habit. You may wish to be assertive and explain what your expectations are. As part of this you should allow carers to explain why they behaving in a certain way as you may not be aware of all the facts. Being assertive is not easy and you may be uncomfortable doing this. You should always be prepared to talk through dignity and respect issues with your family and friends (*or an advocate*) and seek their advice. They may be better able to represent your concerns to a care organization.
- You might, as an alternative, speak to a supervisor or manager (*perhaps even the local 'dignity champion'*), if this helps avoids embarrassment all round. You might make use the organization's 'suggestions card system', user group meetings or even raise issues through a 'user or client group'.

Note 3. Internet Address: <http://www.dhcarenetworks.org.uk/dignityincare/BecomingADignityChampion/>

Use whatever method suits you or the situation, but if you are unhappy then you (*or perhaps your family and friends*) should always find a way to raise a dignity or respect issue.

- For more serious issues you may wish to make a formal complaint. Making a complaint about carers or their organization about dignity or respect issues requires a bit of effort. You (*or perhaps your family and friends*) need to be clear about:
 - What you think has gone wrong. You should be able to put this in note form. Writing some notes will help you focus on the essential points.
 - What you want to happen as a result of the complaint.
 - How to make the complaint. You need to know who to make the complaint to.
- You can make a complaint directly to a care organization. Every care organization is likely to have a 'complaints system' and you expect a proper response within a reasonable time. You also should expect that the standard of your care should not deteriorate as the result of making a complaint. If you are unhappy with the outcome, then there many avenues open to you. However, you should always involve family, friends, advocates and professional advisors in decisions about what you want to do next. You can seek further advice from the Citizens' Advice Bureau, local social services, a solicitor and national advice agencies some of which are described below.
- For complaints about quality of care, the **Care Quality Commission (CQC)** is a major source of advice and will, where necessary, investigate complaints independently. The CQC Customer Services Team is available during office hours on **03000 616161**. The CQC provides information about making complaints against care homes and services, council social services and independent healthcare services, but not the NHS. The CQC has an Internet Website (*See Note 4*).
- For complaints about NHS services, you might consider contacting:
 - **The Patient Advice and Liaison Services (PALS)**. There is a PALS in every NHS trust. PALS can provide further information and discuss options with you about complaints. Some complaints may be taken up by PALS on your behalf.
 - **The Independent Complaints Advocacy Service (ICAS)**. ICAS is a free, confidential and independent service which can help you make a formal complaint about NHS services. ICAS has a list of regional contacts on their Internet Website (*See Note 5*). You can contact ICAS directly using a website contact form (*See Note 6*).
 - **The Parliamentary and Health Service Ombudsman**. The Ombudsman is located at Millbank Tower, Millbank, London, SW1P 4QP. The Complaints Helpline is available during office hours on 0345 015 4033. The Ombudsman has an Internet Website (*See Note 7*).

There are many other ways of making complaints. Depending on the nature of the complaint you might consider contacting professional bodies such as the Nursing and Midwifery Council (NMC), or perhaps your MP. There are also many other charitable bodies from which you can seek help such as Help the Aged, Age Concern and the Geriatrics Society.

Note 4. Internet Address: <http://www.cqc.org.uk/contactus/howtoraiseaconcernorcomplaint.cfm>

Note 5. Internet Address: http://www.pohwer.net/about_us/contact_us.html

Note 6. Internet Address: http://www.pohwer.net/about_us/contact_form.html

Note 7. Internet Address: http://www.ombudsman.org.uk/contact_us/index.html

DIGNITY AND RESPECT IN CARE: SOME QUESTIONS TO ASK YOURSELF

Some questions about respect

- Do carers treat you with dignity and respect at all times? Have your carers ever explained why you should expect from them about respect and courtesy?
- Do you think your carers treat you with courtesy and respect even when they are under pressure?
- Are your cultural and religious attitudes and beliefs respected by your carers?
- Is your 'quality of life' one of the principle concerns of your carers?
- Did you receive a proper induction and familiarisation to care environment?
- Are your carers 'over familiar' or even rude?
- Do your carers talk about you as if you were not there?
- Do your carers talk to you using silly sounds, impatient or patronising tones or childish language?
- Do your carers respect your individual habits and values?
- Are your carers visible, attentive, well presented and easily identifiable when on duty?
- Do you ever have undignified care experiences or are humiliated?
- Do carers deliver support at your pace not theirs?
- Do carers ever show impatience with you as carry out tasks?
- Do carers ever make you do things you cannot carry out or do not have enough time to carry out?
- Do you have the fluids you want (*and the drinks are left within reach*)?
- If you have to use special equipment (*bibs, special cutlery, special food trays, special diets etc?*) is this done with care and sensitivity?

Some questions about abuse

- If you have reported abuse to carers were you assessed properly?
- If you have reported abuse to carers was the matter pursued?
- Do carers ever refer to you using inappropriate terms?
- Have you ever been discriminated against?
- Have you ever been give medicines to sleep or quieten you, which you do not think have been necessary?
- Have you ever been restrained physically or locked in a room?
- Is your call bell or alarm out of reach or not working?

Some questions about privacy

- Do carers respect your personal privacy?
- Are you ever made to undress or expose yourself in a way that has embarrassed you or left you feeling humiliated?
- Do carers use the privacy equipment correctly and to best *effect (e.g. bedside curtains, privacy signs, cubicles)*?
- Do carers knock on your door before entering their room and only normally enter after waiting for your reply?
- Do carers pull back your bedclothes without asking?
- Do carers protect the security of your personal possessions?
- Do carers ask permission before touching your belongings?
- Do carers maintain confidentiality about you?

Some questions about your autonomy

- Do you think the assessments made by carers about you are more based on assumptions than fact?
- Do carers explain procedures to you and reassure you?
- Do carers always obtain your consent before doing things with you/to you?
- Do carers assess you for mobility regularly and accurately?

Some questions about your care as an Individual

- Do carers respect your cultural and spiritual needs?
- Do carers provide you with your prescribed medication completely and on time (*where they have that responsibility*)?
- Do carers understand your personal food preferences (*e.g. timings, portion size, cooking style, content, and acceptable combinations - including ethnic and religious issues*)?
- Are you concerned that carers do not maintain accurate documentation about you?

Some Questions about maintaining your confidence and self-esteem

- Do carers acknowledge your social standing, status and merits?
- Do carers try to allow you to carry out eating, personal care and hygiene activities as much as possible on your own?
- Do carers help you to look presentable and act respectably (*respecting your personal wishes as far as possible*)?
- Do carers help you with personal hygiene? Do you think you are over supervised?
- Do carers try to ensure you wear your own clothes as much as possible (*where this is relevant*)?
- Do carers allow you enough time to complete tasks within your capability?

- Do carers ever place you in situations where you might fail socially or physically in the presence of others?
- Are carers aware of your anxieties or concerns? Do they ever try to find out?

Some questions about loneliness and isolation

- Are you ever lonely? Do you think your carers could recognise loneliness?
- Do carers ever help you to find enjoyable, stimulating and challenging activities (*leisure and social activities, therapeutic treatments, and paid or voluntary employment*)?
- Do carers help you keep in touch with other older people, relatives and friends?
- Do carers ever stop to sit and spend time to talk to you?
- Do carers recognise when you wish to be on your own and when you do not wish to join in with others?

Some questions about communication

- Do carers ever encourage you to talk to them (*expressing opinions and making choices about your care*) and listen to you in a way that makes you feel valued?
- Do you know who is currently in charge of your care?
- Have you had the arrangements for calling for assistance explained to you?
- Do carers respond to your requests for assistance quickly and with a willing manner (*this includes use of 'call bells' or 'alarms'*).
- Are your carers supported by multi-cultural or religious sources to help understand your needs?

Some questions about making complaints

- Are you concerned that if you or your family or friends were to make a complaint, the nature of your care would change for the worse?
- Do carers or care organisation respond to your complaints quickly and tell you what is happening?

Some questions about family and friends as carers

- Do carers try involving your family and friends as far as possible in your care *(subject to your wishes)*?
- Do your family and friends know who to talk to about your care?