

# My Home Life



## Quality of life in care homes

# My Home Life

## Quality of life in care homes

**Edited by Tom Owen and NCHRDF**

Jackie Bridges, City University

Christine Brown-Wilson, University of Sheffield

Susan Davies, University of Sheffield

Belinda Dewar, Care Commission

Jenny Dudman, City University

Hazel Heath, independent consultant

Julienne Meyer, City University

Caroline Nicholson, City University

Fiona O'May, Queen Margaret University

Jan Reed, University of Northumbria

This report is published by Help the Aged in partnership with the National Care Forum and the National Care Homes Research and Development Forum.

It accompanies an evidence report entitled *A Review of Evidence on Quality of Life in Care Homes* produced for the My Home Life programme, which provides supplementary evidence to this report and will be published online as a PDF in September 2006 at [www.helptheaged.org.uk](http://www.helptheaged.org.uk)

## Contributors to the My Home Life initiative

**Help the Aged**, an international charity fighting to free disadvantaged older people from poverty, isolation and neglect. Help the Aged campaigns for change in government policy, undertakes research into the needs of older people and provides local services in communities across the UK and overseas.

**National Care Forum**, established in 2003 to represent the interests of not-for-profit health and social care providers in the UK. The organisation, building on ten years' experience as the Care Forum, is a leading voice in its sector, representing the views and concerns both of carers and cared-for. It promotes the benefits of the not-for-profit model of care services provision to local and national government, as well as to consumers and other healthcare bodies.

**The National Care Homes Research and Development Forum**, established in 2003 to facilitate contact between researchers and practitioners involved in care-home work. It focuses on a common theme in members' individual work: the desire to make a difference to experiences of those who are living and working in care homes, to which end its 59 members have voluntarily shared their knowledge and expertise to inform this report. These contributions include articles, reports and databases of reference material, authorship of sections and critical reading of draft material by an expert panel.

Copy-edited by Terry Philpot and Gill Rowley

Photography: Crispin Hughes

Copyright © Help the Aged 2006

ISBN 1-84598-002-6

Help the Aged  
207–221 Pentonville Road  
London  
N1 9UZ

## Steering group

Des Kelly (Chair)	National Care Forum: Director
Alex Thompson	Care-home resident
Annie Stevenson	Help the Aged: Senior Policy Adviser, Health & Social Care
Belinda Dewar	Care Commission: Nurse Consultant, Queen Margaret University: Development and Research Manager
Clive Bowman	BUPA Care Services: Medical Director
Gillian Dalley	Residents and Relatives Association: Chief Executive
Jo Edler	Help the Aged: Policy Assistant, Health & Social Care
Julienne Meyer	City University: Professor of Nursing, Care for Older People
Marian Harrington	Westminster Council: Head of Commissioning for Elderly and Disabled Services
Martin Green	ECCA (English Community Care Association): Chief Executive
Pat Duff	Independent adviser specialising in older people's issues, Vice Chair of the Residents and Relatives Association
Rosemary Hurtley	Independent OT consultant
Sharon Blackburn	Heart of England Housing and Care Ltd: Executive Director
Sylvie Silver	NAPA (National Association for Providers of Activities for Older People): Strategic Director
Janet Crampton	Care Services Improvement Partnership: Commissioning Lead for National Older People's Programme

Sue Corrigan	Commission for Social Care Inspection: Policy Manager, Quality Performance and Methods Directorate
Tom Owen	Help the Aged: Research Manager

## Other contributors

### Care-home residents

Twenty-four residents or former residents of care homes contributed to this document, along with three older people who supported residents to write. Some contributors wish to remain anonymous.

Others are listed below.

Estaline Banfield	Helen Biggins
Tom Hamilton	John Linton
Ann Macfarlane	Rosemary McDonald
Helen Middleton	Jessie Mitchell
Janet Nelson	Marjorie Randall
Margaret Regan	James Roemele
Maggie Smith	Betty Titmus
Mary Wycherley	Margaret Laurenson

### Care practitioners

Tracy Paine	CLS Care Services
Roger Fulcher	Care South
Hilary Cox	Abbeyfield
Mark Lloyd	KCHT
Ann Jackson	Orders of St John Care Trust
Douglas Webb	Cornwall Care
Ann Paget	SAGE
Angela Barton	Care-home manager
Amanda Westbrook	Balkerne Gardens Trust
Carol Dimon	Registered nurse, teacher, writer
David Schofield	Care-home manager/owner
Dawn Higley	Care-home manager

---

## Researchers

Nick Allcock	University of Nottingham	Jo Hockley	University of Edinburgh
Charlotte Ashburner	Homerton Foundation Hospital	Cheryl Holman	City University
Frances Badger	University of Birmingham	Khim Horton	University of Surrey
Ruth Bartlett	University of Bradford	Deborah Humphrey	Oxford Brookes University
Liz Begg	Dundee Voluntary Action	Rosemary Hurlley	Independent consultant
Duncan Boldy	Curtin University	Jeanne Katz	Open University
Cathy Butterworth	SHARP Care Planning Systems	Susan Kerrison	University College London
Garuth Chalfont	University of Sheffield	Angela Kydd	University of Paisley
Amanda Clarke	University of Sheffield	Helen Leslie	HRL Training
Mary Clay	Kensington and Chelsea PCT	Jill Manthorpe	King's College, London
Jeanette Clelland	Primary Care Division of NHS Greater Glasgow	Anne Mason	University of Stirling
Collette Clifford	University of Birmingham	Brendan McCormack	Royal Victoria Hospital
Glenda Cook	University of Northumbria at Newcastle	Lynn Meehan	North East London Strategic Health Authority
Angela Cotter	Independent consultant	Alisoun Milne	University of Kent
Gillian Crosby	Centre for Policy on Ageing	Ann-Marie Muncer	University of Kent
Sue Davies	University College London	Lorraine Murray	University of Hertfordshire
Jan Dewing	Independent consultant	Mike Nolan	University of Sheffield
Donna Doherty	University of Sheffield	Julie O'Callaghan	City University
Murna Downs	University of Bradford	Sheila Peace	Open University
Catherine Evans	King's College, London	Judith Phillips	University of Wales
Mark Faulkner	University of Sheffield	Cath Sackley	University of Birmingham
Tina Fear	University of West of England	Pat Schofield	University of Sheffield
Liz Forbat	Older People Researching Social Issues	Karen Spilsbury	University of York
Pauline Ford	Royal College of Nursing	David Stanley	Northumbria University
Denise Forte	Kingston University	Sandra Stark	Northgate and Prudhoe NHS
Katherine Froggat	University of Sheffield	Deborah Sturdy	Department of Health
Sheila Furness	University of Bradford	Judith Torrington	University of Sheffield
Claire Goodman	University of Hertfordshire	Diane Wells	Kingston University
		Jacquetta Williams	University of Kent
		Gillian Wilson	Alzheimer Scotland

---

## Contents

My Home Life: the challenge	6	References	57
Introduction	8	Appendix I	
The testimonies	9	Selected useful resources	65
Betty Titmus		Appendix II	
Janet Nelson		The state of play:	
Maggie Smith		care homes in the UK today	67
Alfred Hudson		Appendix III	
John Cobett		The six senses in the	
Jessie Mitchell		context of caring relationships	70
Alex Thompson			
Estaline Banfield			
It's quality that counts: what we know about quality of life in care homes	34		
Moving to a care home	35		
A sense of identity	37		
From 'home' to 'community'	40		
Creating opportunities for meaningful activity	43		
All in it together: shared decision-making in care homes	46		
A healthy outlook: health and care responses	47		
Care at the end of life	49		
Making improvements: creating a positive culture	51		
Where to now? Next steps in improving the quality of life in care homes	54		



Annie Stevenson

## My Home Life: the challenge

**‘Our homes are our castles.’ This belief runs through our culture: it is about status, ownership, privacy, and who we are. Why is it, then, that when people move into a care home, which itself is a major change in their lives, such considerations no longer apply?**

**Why should care-home residents be excluded from all that those of us in our ‘castle’ take for granted? The opportunities to love, dream, laugh, learn, connect with others, direct our own lives and be noticed are so often, perhaps inadvertently, denied to residents.**

However, such opportunities do exist for many old people in care homes whose staff are in tune with what older people think and feel. But, equally, for far too many residents, those opportunities are not there. This report challenges certain fixed beliefs about how care is provided and what we mean by ‘care’: from patronage to engagement. In addition, the report takes issue with the way care homes are too often perceived as places which tend to be excluded and how, as a consequence, those who live and work in them are devalued and disempowered.

As a society, we are ambivalent about old age and death at a time when people are living longer, the number of older people is increasing, and society has the means to prolong life. The majority of people fear both old age and death, which leads to denial, contempt and dehumanisation – the enemies of dignity. We must not underestimate the challenge of trying to change this as these attitudes and fears lie deep in our collective unconscious.

This report is a starting point for a movement among all those who believe that people’s value and individuality should not diminish as they reach the end of their lives. The vision is about ensuring that people’s higher human needs for enrichment, fulfilment and recognition are met in care homes. It is giving opportunities for care-home residents to have lives which have meaning and purpose, if they wish, or simply to have peace of mind. This is the antithesis of the kind of care which is so often provided without regard to individuals’ needs, wants, tastes and preferences.

Equally, it is important to recognise and value those that work closest with older people. Help the Aged believes that the only way to realise the vision is through positive action, involvement, partnership and seeing care homes as being a positive choice for many older people.

Critical to this is our explicit belief, which we discuss in some detail, that the care home needs to become a community of those who live there, those who work in it and those who have relatives who are residents. Each of these people

has a vested interest in the life of the home, and while the home must be built around the needs of the residents, active participation and a sense of belonging on the part of staff and relatives are critical to making that happen.

Help the Aged has joined with the National Care Forum, a group of not-for-profit care-home providers, to create a foundation for this movement for fundamental change. Our care services need to be fit for the 21st century and older people need to be regarded and treated as citizens, and accorded the rights and dignity of the citizen.

Given the right attention and with a fundamental change in the culture of many of them, we believe that care homes can and must play a crucial part in realising the Government's vision for health and social care outlined in the White Paper *Our Health, Our Care, Our Say*. Now is the time for care homes to be brought in from the cold and their potential harnessed.

I hope that you will be inspired and challenged by what you read and will want to join the movement to change attitudes. I dedicate the report to the 400,000 people whose home life is in a care home, where there should be every reason to get up in the morning; also to those who help them do it, by giving the personal and intimate care, tackling the gruelling and rewarding tasks... and still going the extra mile, as one human to another, by remembering the small things that matter. You have never been more needed.

*Annie Stevenson, Senior Policy Adviser,  
Help the Aged, on behalf of the steering group*





## Introduction

**The *My Home Life* report has been produced as part of an exciting new programme of the same name. Both are part of a concerted drive to increase the quality of life of older people in care homes by creating support for practitioners and accessible tools and information resources to care-home managers, staff and commissioners which they can use in their daily work.**

This report is a result of collaboration between Help the Aged, the National Care Homes Research and Development Forum, older people, and representatives from the care-home sector. It summarises an initial review of evidence, based on both research and the experiences of service users, about what quality of life means to older people living in care homes and what specific practices, behaviour and attitudes impact on the quality of life of older people. The full review, which includes

more examples of good practice and references to further information, is published separately (see copyright page). The report focuses on positive messages and celebrating the good practice that exists in many care homes.

This report comprises three parts:

- articles written by residents of care homes about the quality of life they experience
- a summary of a review of evidence on practices that improve quality of life, as identified by the research community, care-sector practitioners and older people themselves. The review builds on previous research work undertaken by Sue Davies, Mike Nolan and colleagues at the University of Sheffield
- a discussion of the context in which care homes currently operate in the UK.

A conference, drawing together those with a shared interest in the field, was held in London to bring forward recommendations for the care-home sector, government, regulatory bodies, professional bodies, NHS and social care agencies, voluntary organisations and educationalists in research and teaching.

---

## The testimonies

**In some ways perhaps the most important part of this report is the testimonies of those who live in care homes. Their views are not necessarily representative of all residents, of course, but they do give an indication of the range of issues that older people living in care homes face and the practice that they appreciate. Twenty-five pieces were received from care-home residents but only eight are published here.**

Some of those who wrote these pieces are skilled writers with, for example, journalistic experience. Others have received support from Rosemary Hurtley, John Killick, Jo Edler, SAGE (an advocacy group in Scotland), and the Royal Bank of Scotland Centre for the Older Person's Agenda, Queen Margaret University, to express their views.

We have also included three articles from a care-home resident's relative, a care assistant and a care manager. Again, these have been provided to illustrate the perspectives and issues that these groups have in relation to their workplace and the quality of life of residents with whom they engage.

With regard to the testimonies of older people themselves, it is common in reports of this kind, whatever aspect of health or social care they address, to quote the words of service users within a text written by others, very often to illustrate a particular point. We have used such quotations throughout the report for just this purpose. They indicate both the pleasures and the problems experienced by care-home residents, and also illustrate good practice. But had we left it at that we could have fallen into the trap, no matter how unintentionally, of marginalising or seeming to give less importance to the experience of the residents themselves.

We therefore decided that they should be able to speak for themselves at length without the intermediary of either editor or writer (except for basic editing).

To add to the overall interest of the report we have placed these testimonies throughout the text to directly or indirectly illustrate the points being made, the general flow of the argument and the emergent themes. We believe that this both symbolises and serves to reflect our wish that residents should continue to contribute to the work of the programme.

To this end, too, we want to make clear that while the final section contains a list of recommendations, these are not set in stone. Given that one way to improve quality of care is to involve residents, relatives and staff, it is fitting that this report should not be the last word. Indeed, it may be that as expectations of services and care change over time, along with our knowledge of human potential, even among those of advanced age, there can never be a final word.



## Betty Titmus

**I was a campaigning journalist for most of my working life, for everything from refuges for battered women to pedestrian crossings for schoolchildren. If I were still campaigning, there's a good chance it would be for a closer understanding that in the phrase 'old people' the second word is more important than the first. I am a person first. After that, I happen to be old.**

At school I was good at English and had always wanted to be a journalist. But I did not set out to be one. I went to work on the reception desk at a bank in London and later became a clerk.

It was then, when I was 17, that the most important thing in my life happened, which was meeting my future husband. He was a journalist. More importantly, we both liked dancing. And, more importantly still, we fell in love. We stayed that way for the next 60 years or so, until he died in 1994. During that time we worked for local and national newspapers, TV and radio, together if we could, separately if we couldn't.

My husband was 83 when he died, and I went on living at our flat for some time until I eventually had to leave because arthritis made it impossible for me to do the necessary housework. And my memory was not what it was, to such an extent that I began to fear – wrongly as it turned out – that I had Alzheimer's.

A charity offered me a place in their purpose-built residential care home just a few yards away, and I took it. But it was a very hard move and I had to accept a major blow to my independence. Now, I was moving into a residential home to be looked after by nurses, like a child going back to boarding school. My children helped me adapt and supported me as best they could, but that did not lessen the impact of this move, as I saw it, away from dignified self-determination and towards the grave. The matron was a fine nurse, dedicated to her job: a woman of complete integrity. But she was also matronly almost in the caricature sense of Hattie Jacques in *Carry On, Nurse*, or so it seemed to me.

One side of it was that no effort was spared to make me feel at home. Within reason I could furnish my room as I liked, bring my collection of videos and family photos. The nurses were courteous, friendly, respectful, attentive and behaved like good friends.

The other side was that the routines were fairly rigid, with very definite mealtimes and distinct but unstated rules of behaviour. Behind it there was a feeling that now someone else knew best and my life would be run not by me, but for me.

They were trying their hardest not to institutionalise me, but I was being institutionalised, in the nicest possible way. And all the time my memory was going. Now, I was beginning to hallucinate, to have delusions. It seemed like the end, and not a very good end.

The matron left eventually, and was replaced by her deputy. She was a much younger woman who maintained a similar, slightly rigid approach to the running of the place. She, too, was a very good nurse indeed – and she saved my life. For it was she who realised what no one else had – that I was suffering from undiagnosed diabetes. It was easily put right, with minor changes in diet and no sugar at all. After World War II and a couple of decades of food rationing, it felt quite like old times and was no problem for me.

The hallucinations stopped, and my brain, slowly, came back. Frailer, yes, and still plagued by short-term memory loss. Following news and world events wasn't as easy, and writing, which I still tried to keep up with varying degrees of success, was much, much harder. But at least I wasn't, any longer, going mad.

Now, however, a new and uncertain cloud was on the horizon. The home, now 30 years old, was no longer state-of-the-art. New regulations meant all rooms had to be en suite. It was no advantage for me, since having to make the effort to walk down the corridor, even with reduced mobility on a couple of walking sticks, probably kept me mobile and stopped me getting lazy. But that was the new law. And though the deadline for all this was eventually relaxed, it was clear that the

charity would have to knock the place down and rebuild it. It would do this, it thought, in two phases, while everyone continued to live there.

In the meantime, the charity began to run down the intake of residents to reduce the impact of rebuilding. My companions were not getting any younger, any more than I was. Age took them, one by one, until barely more than half a dozen were left. With staff numbers kept at a very adequate level, that meant incredibly high standards of individual and thoughtful care.

A new matron took over – young, very efficient indeed, and very caring. She went out of her way to relax the routines, personalise them where she could, and, most important, increase the number and range of events and activities.

Then, and with very little warning, there was a serious shock. The charity realised its plan to rebuild the place would not work while the residents were still there. All of us, including the staff, were given a little over a month's notice to find somewhere else to go.

The charity softened the blow as much as it could, paying for any alternative chosen and covering all removal expenses. Even so, the shock was considerable, not just for me, but for my fellow residents too, I think. One or two were visibly very upset. When it happens at short notice, that can literally be a killer. In the event, one person did die within days of moving, though I had the impression in this case that the impact of the move did little to hasten the effects of age and infirmity.

We settled on an Edwardian house conversion where the only available room for me was fairly small, and most of the residents were so elderly they were beyond being stimulating company. And because this home was full, there were lots of other residents to dilute the personal attention I had become used to. By now, I was using a frame to get around – and as in most converted buildings, that could be awkward in corridors and over doorsteps that were built for the able-bodied.

So why do I like the new place? Well, the gardens are beautiful to walk in and to look at. From my small ground-floor room, I can see visitors going to and fro, and that makes me feel as if I'm still alive. Huge efforts are made to organise regular activities and outings – and even if I'm not always interested, they are there if I want them.

Most important though, and the real reason my family and I chose this place, is the people who run it and staff it. The matron is a relaxed sort with a sense of humour which disguises the care with which she runs the place.

The staff are amazingly conscientious, and if one or two of them sometimes don't understand something or are out of their depth, they tend to put it right pretty quickly. The initial tendency to talk straight past me when I get visitors ('Does she want a cup of tea?') is reducing as they get to know me and realise that I can still speak for myself.

If there is one thing that I would like to see changed, it would be the tendency to short evenings. Supper appears at a breathtakingly early hour, and fellow residents tend to start going to bed at about 7pm – even though some may prefer to stay up a little longer. Or so it appears to me.

But some things you can do nothing about. As we live longer, nursing home residents are becoming noticeably more decrepit, which does not do much for suppertime conversation in any home nowadays. The ageing effect of this alone is, for me, very hard to fight against.

I believe it must be hard for the staff to deal with this, too. Even with the best intentions, if most of the residents have difficulty expressing their own preferences, it can't be easy to remember that, like me, they still have a voice.

But behind all this, I believe, is a deeper cultural question. I am told that in some developing cultures (for instance, in parts of Africa) the old are objects of respect for their greater knowledge and experience of life.

Hundreds of years ago it was a little like that here, with several generations living in the same house. Even though we live longer, people begin to be written off at a younger age.

We do not expect the elderly to have anything to contribute. We want to be civilised and put them out to grass to retire and relax. We think that the best way to make them feel wanted is to smile nicely and give them en suite lavatories.

But, in reality, the best way to feel wanted is to feel needed. I have spent most of my life being needed, one way or another – needed in partnership with my husband, needed to bring up my children, to run a household, to hold down a job and to try to make a difference in the world. In a nursing home, we should all need each other, care workers and those who are cared for, giving each other company and co-operation and mutual support, just as most people do for most of their lives.

Better facilities and state-of-the-art homes are obviously a good idea, but in themselves they do little to encourage a feeling of community, and sometimes they can do the opposite. The smartest hotels can be the loneliest places in the world – yet, very often, the cultural tendency seems to demand that nursing homes be more hotel than home.

If nursing homes are to lose the perception that often they are just living graveyards for people at the end of the line, this sense of community and co-operation needs to be highlighted. But I think that that in itself has to be a co-operative effort. It involves everyone from political decision-makers to staff and, yes, to residents themselves. They (and I include myself) have as much of a responsibility to help each other as anyone else in this developing relationship.

The sad thing is that the people who look after me make heroic efforts to reverse the existing cultural tendency and to make me feel wanted. In doing so, I think they are some of the most valuable people in the country. But I don't notice them being paid accordingly.

That, however, is a whole discussion in its own right. My own aspiration is a simple one – to return to my former home when it's been rebuilt. If I'm still alive to see it, that is. But that's not because it will have opulent purpose-built accommodation. It's because many of the people who used to work there will also return. And above everything else, it's the quality of the people who run the home that matters most.



## Janet Nelson

**I was born and married in Edinburgh but divorced when my son died. Marriage certainly wasn't boring. I had six children. I was pregnant for the seventh time and they said that it would have been my life or the bairn's life, so I went through with the hysterectomy. I now have 14 grandchildren and six great-grandchildren and one more on the way. Most of them live in Edinburgh and I am very proud of them.**

I have been in this home for five years. I had depression for two years. I was ill and I kept taking pills and they were making me worse. I put in for a sheltered house but refused the two offered to me. I am a nervous person and I didn't think I could cope on my own. I ended up taking an overdose and ended up at the hospital. They didn't expect me to survive. Life's hard but you've just got to keep on with it.

I lived with my son for a while before I moved here. I remember when I moved, after crying on the phone to him, I felt just glad to get a place, to have somewhere to go. The staff here are right helpful, but I miss my son, particularly the night-times when we used to watch the telly together.

What happens one day happens another here. I go to bed at half ten at night with a sleeping tablet and then am up normally at 6am. The others get up at breakfast time: 9am. I just sit about in my room. I very seldom go downstairs to be with others, apart from [when] I go and watch the telly down there. After breakfast I will normally watch the television. Then we have our lunch at quarter to one. Afternoon is much the same as the morning – just sit and watch the telly. So there is not much really going on at all. Days are different because the telly's different.

They do have activities every night. You get dominoes, sometimes a film, a quiz and they open the bar every night. I don't go to the bar at night because I don't drink. They also have people coming in to entertain us: there's a woman who plays the piano and her brother sings. But I'm into *Emmerdale*, *EastEnders* and

*Coronation Street* and if we are having a singer in downstairs I put my soap in front of it.

Sometimes they have karaoke. They have the mikes – the carers do that. I say, 'What's that? It is like a cat squealing.' They have good fun down there but the staff are inclined to take down the people that are senile. A fair few are senile. I am friendly with them but there aren't many residents like me, who aren't senile, I don't think. There is one I used to speak to – she is even more senile now. I had to get a key fitted to protect my room because one of the other residents is bad, I think it is 'old-timers' [Alzheimer's] with her. I was sitting writing a letter this morning when my door opened. It was her. She took a heavy cardigan out of the wardrobe and laid it on the bed.

I love sewing and stitching. I used to work at a furrier and costumier. I wasn't trained but did a lot of the work at home. I still do sewing. One of the staff has taught me a lot – I have made oven gloves, bean bags . . . There's also a scarf that I am knitting and a hat, which is a wee bit difficult. You get everything done for you here, but I think it is inclined to make you lazy. You see them cleaning out the toilets and Hoovering. I would love to be working. I would rather cook for myself but you are not allowed in the kitchen, and you are not allowed in the laundry either.

We have our own bubble bath and things, shampoos and that, which we buy from the pocket money we get. I get £20.05. It's not much. The secretary, she puts £10 worth of £1 pieces so that I can get the phone cards. See, all my daughters have got mobiles and they are expensive to phone. I can't afford Christmas presents off that either. I save £10 on to next week so I can get my hair permed for Christmas.





## Maggie Smith

**I am 88 years old and originally came from Surrey, where I married and lived for 57 years. I came to this residential home after my husband died six years ago. I have one son in Scotland and a daughter who lives nearby. I am going to be a great-grandmother next year.**

I previously worked as a shorthand typist and bookkeeper. I enjoyed playing tennis, taking the children to the coast and I am quite keen on gardening. We had a very big garden. I came from a rural farming family and was used to outdoor living and seeing the scenery and flowers. I like doing things on my own as much as I can, but now have to be very careful due to my osteoporosis as my bones break very easily – without me even falling necessarily – and I have had a lot of fractures.

I came into this home after my back went, due to the osteoporosis, and I was unable to manage the stairs and my daughter was not able to look after me. She made the decision for me to come in here and I was not happy with it at first. Unfortunately, my osteoporosis prevents me from standing for any length of time. I can still get into a car and enjoy going out with my daughter every month.

It is quite free and easy here, which I like, and I get on well with the owner and her husband. I am quite happy in one sense, but I would really like to be able to do everything myself – but my condition prevents this. Ideally, I would like to go out more and be more independent than what I am. I am that type of person. I would love to go away on a holiday and visit my son in Scotland. I would love to find a companion to go with. I need to have someone with me now as I would need a wheelchair.

I did all my own cooking and this is the most difficult thing. Also I am very house-proud and I will never change, especially as I have high standards. However, I do try and help and often change my bed linen and try to do as much as I can; I even sew my nametapes in my pants, but now get tired very easily. I still like to dust my room, apart from the high shelves. I used to love making jam and marmalade, freezing and even made my own bread. There are activities here but I can't keep moving around because of my condition. I watch the snooker, the tennis and bowls and am quite happy to pass the time on my own. I do get miserable at times, but you have to pull yourself out of it.

I get the support I need and cannot complain. I get on well with the carers and always have a laugh and joke, and some of them even shop for me.

I knew I had to come into a place like this, and in one sense I am relieved to be in here, but it is not what I would have wished for. But I am making the best of it. Considering my difficulties, I know it is best for me.



## Alfred Hudson

**As an 80-year-old widower I was admitted to an NHS hospital men's ward with a fractured vertebra and osteoporosis. Fairly soon I was fit to be discharged but as I still needed care I opted to go into a nursing home.**

I was a bit apprehensive before the move but the decision was entirely mine. I wanted to learn to walk again with the aid of a stick; recover my sense of balance, strengthen my back and reduce my stoop.

The nursing home's care standards were very high but fairly soon little holes appeared in the system. My pain-relieving patches ran out one Saturday evening and could not be replaced until Monday; in error, my other painkiller had been prescribed as 'once daily' instead of 'as required' and there was no authority to use this as back-up. My patches had to be changed every three days but this was achieved only because I provided a reminder. Last, my requests for self-help exercises were ignored by the GP.

I left for another care home and it soon became clear that this new family-run home had a very positive approach to each resident.

I was first told that their GP had approved my exercises and they asked to participate in the planning of my future care activities. Happily, this process of consultation continued throughout my stay.

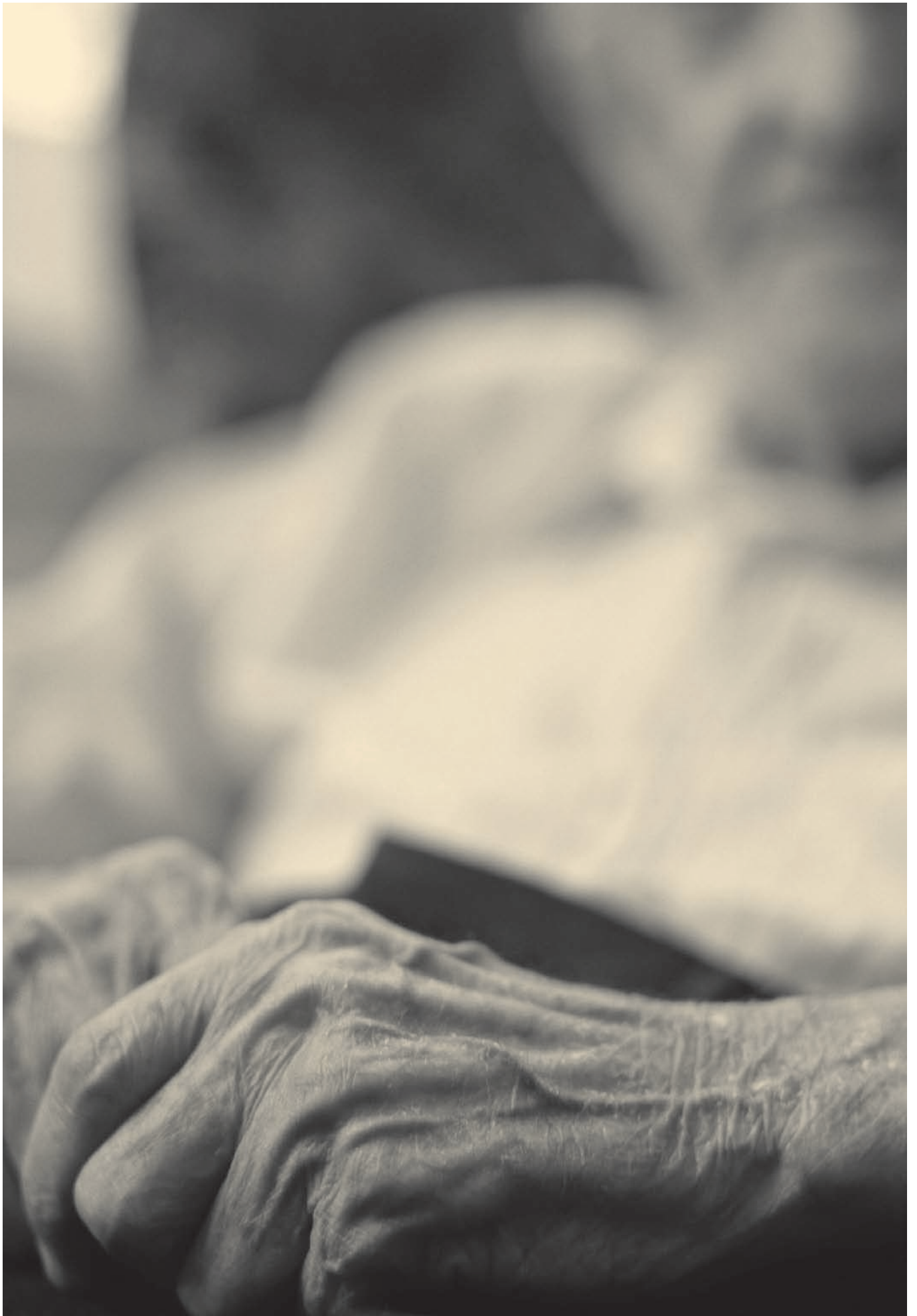
My involvement was further extended when I became a member of an advisory group which met to explore ways in which life could be improved for everyone in the home. It comprised management, staff, residents and families. Because standards were already high it was difficult to make suggestions but jointly we were able to fine-tune some aspects of the system.

There were many well-planned pastimes available to me, both indoors and outdoors, visiting entertainers, as well as evening activities to which families and friends were invited. Fortunately I had many other interests which kept me busy, and although my days were usually 7am to 11pm I was always occupied. One activity which I enjoyed was the computer, which a member of staff taught me to use. I also appreciated chats with the nurses and carers. They always had a smile and made me feel as if I was important.

As exercises improved my mobility I first was able to regularly walk in the grounds, then go unchaperoned to nearby towns until I finally became active enough to return to the community.

After 21 months of excellent care, at the age of 83, I moved into sheltered accommodation where I am able to do everything for myself. The move was right for me but I do miss everyone in the nursing home who helped me to live such a full life. If necessary I would be more than happy to go back.

*(This contributor's name has been changed to protect anonymity.)*



## John Cobett

### **It is difficult for me to tell my story consecutively as I keep losing the thread of what I want to say.**

I was born in 1912, so I am 94 years of age, and left school at 14. I grew up during the period when life was very hard and a struggle for my parents. I married and we had four children and five grandchildren. In my late 70s I moved to sheltered accommodation. Some years later I suffered several strokes and after struggling to manage with daily activities, I decided it was time to accept help and move into a nursing home.

One of the things I found difficult was being treated like a child; it threatened my sense of independence. We were always told things would be nice for us. Some of the other residents felt rebellious: we didn't want things that would be 'nice' for us but things that would be a bit of a challenge sometimes. Most of us were in our 80s and liked to be able to think for ourselves. I don't want to be told where I am going for an outing. Most of these people had been in responsible positions and had experienced an active retirement before needing a nursing home. They were used to making decisions for themselves.

The one-size-fits-all approach to the trip to Worthing (it was always bloomin' Worthing because it 'would be good for us') was not what several of us wanted. Why the heck couldn't we go somewhere else? We would have liked something different (and cheaper), like a trip to some woods to see the bluebells. There was a rather unimaginative, institutional approach which could have been avoided if we had only been asked. The staff were not aware that we felt as we did and we never told them. I sometimes think that my generation is too polite for our own good.

The other example of not having control over our environment was when we were asked if we would like some new chairs. We were very pleased about this but were never given a chance to try out or discuss possible options or see if we liked them, yet we would be spending hours sitting in them. But chairs just arrived one day and they were most

uncomfortable and we didn't like them. This made residents resentful. People began to look for other small grievances because of this incident.

The organisation itself was very good and well run, with well-meaning people. But this required more listening to the residents, to find out what we wanted. Some people will passively accept what is on offer but it is not my style. I think it is important for people to realise that what may seem a small matter to the management of the organisation is of great importance to some of the people's experience of living in a place. Everyone has different standards and tastes, but knowing the individual and their ways is helpful.

Seemingly small things can matter tremendously. Choice of entertainment is another example of this somewhat patronising approach. One or two of the visiting entertainers have been excellent but others have insulted our intelligence – but we were all too polite to say so. I think staff and managers need to be aware of people's feelings and emotions because residents are spending the rest of their lives here.

Another problem is that some of the young girls are not mature enough to deal with the needs of older people. Some of this might be down to their training. Being called 'darling' and 'luvvie' is not really appreciated by a lot of older people. Some may like it but others resent it deeply. There is a poem about how people are addressed as they go through life. It goes through various phases and in the end you are spoken to like a child. Staff should use our proper names. They need to realise that it causes resentment when it is not appreciated how people prefer to be addressed.

I have seen a lot of what I like in this home, such as the generally caring attitude of the staff. In my experience, most of them are kind and considerate and mean well. The thing that would make the biggest difference is if everyone tried to imagine how they might feel when they are my age. They might understand how frustrating it is living in the body of a 93-year-old.

*(This contributor's name has been changed to protect anonymity.)*



## Jessie Mitchell

**Before I moved here I lived on the outskirts of Edinburgh, so at first this place was new to me. I have five children and seven grandchildren. Some live locally.**

I was 68 when I moved here and I have lived here for six years. At first it took me a while to come to terms with it. The social worker said I would have to come here. They didn't tell me what was going on. They said, 'You're going,' and I said, 'Going where?' She said, 'You are going to another place.' I said, 'But why?'

I got no answer. Social workers – I don't have them any more because I just don't like them at all. They are not very good. They gave me no information about anything. They just said, 'You're going to a home.' I said, 'I know that – I am not senile. Why?' She said, 'Don't ask me why. I am just telling you!' I was very angry, but she says, 'You've got to go to a home.'

But with the help of staff I began to do things that I didn't think I could, and I used to help the staff to set tables and wash dishes – things like that. And I enjoyed it. Now I can't. I am not too great now, but I am keeping up as best I can. I like it here very much; they have been very supportive. And since I can't help them now, I feel as if I have let them down. I can't do what I want to do and I get frustrated. They are short-staffed and I get so frustrated because I like to help them. They are not able to do so much because they are too busy to understand what you are asking for. They don't have the time to sit with you now. If we had more staff, they would do something; if we had more staff we could do more activities.

The advocacy organisation have done very well for me. They got these people to come and take me to the library once a fortnight. They have listened and helped me come to terms with things. I used to go to the drama. The drama has helped me to understand what is going on and I really did like it. If they did drama here then that would be grand. I would love that because I miss it.

I love doing my paintings, I really do. I like it very much because I am allowed to do what I want to do. It takes my mind off my own thoughts. There are plenty of activities here. There's a band and we get other people coming. We have children coming.

But I can't do everything just now because I took a bad turn and I can't come to terms with that. I would like to but I just can't. If I could only have another pair of legs. I used to go to exercises all the time but since I took that last stroke it seems to have slowed me down so much. I used to do exercises in the day centre and then they changed it to the afternoon because day care needed the room. And why is it I can't do it? I will have to start again because I am getting lazy.

We can't live on what they give us and I am not going to ask my girls for help. They give us only a few pence and I am not happy. If I had more money I would be able to buy things for my grandchildren – which I can't now and they know that. It is not fair that [they] take everything.

There was a lady that was with me all the time and she died. I can't remember her name. She was with me all the time and I was so cut-up. I knew she wasn't well but I had no idea she was going to die. She took a stroke. She was very nice. I really miss her.





## Alex Thompson

**I'd known for years that I would need to go into a care home but held on until I was unable to manage. I don't think it's good to go on expecting family and friends and neighbours to do things for you forever. They're going to get tired of doing it and have other pressures in their lives.**

This was the only place I looked at because I knew them by their reputation. I phoned the manager and she said: 'Don't ask me questions now – come for the day, ask the residents the questions and then we'll talk at the end of the day.' I thought that was good because it gave me the freedom to ask who I liked and they could tell me all about the place.

I think this care home is very good: there's no comparison really about how the place looks, how it feels, how it smells (which it doesn't). The reception of the staff is very, very good by comparison with other places. Everyone is on a first-name basis from the top down. I am very happy with that because it doesn't seem to affect respect. I think it's much nicer: the manager is the same as everybody else.

Several staff have been here for a very long time, even past retiring age. They're incredible. They are rare people who see it as a life job really worth doing. It's extraordinary to be able to do it as long as that.

There are very few rules and regulations. Nobody has to go to bed at any particular time and while you usually have a day and rough time that's offered for a bath, if you've got another appointment they are always flexible. Sometimes they pop in and say: 'I've got half an hour. Would you like a shower? I know you like a shower.'

Things are offered to you but you don't have to take advantage of them. There's a knitting group that's very active: we knit for a village in Africa. There's a sort of church service once a fortnight, initiated by the residents, which is much appreciated as a lot of people have been churchgoers but are too far away from their

own parish for someone to come and take them and bring them back regularly. We've got what we call an activities organiser, and she arranges carpet bowls, beauty sessions and outings. There's not much input into the activities from residents though, and some of it is old-fashioned and clapped out.

On the whole you don't hear much unkindness or rudeness between residents. It is really a friendly place. People get put at a table of four for dining when you come, and that's where you stay. You don't move about, so that you get to know those four people. That may be disastrous and it may be very nice. We can offer each other support. One person who has been sitting at the same table as me ever since I came is now very confused and unhappy. I can help her a lot with the confusion because I very often have a faint idea of what she's talking about – it makes sense to me, and she calms down when she doesn't [have to] try to explain it and can't get the words out.

There is a lot of expertise among the residents but the skills that they have developed in their lives are completely wasted here. There are several residents who have been first-class cooks and gardeners who could input into the home. There are a lot of things that we could share if given an opportunity but the running of the place is not shared with us, which is a shame. Things just get settled, although on one occasion when we wanted to have blinds outside the window, we said to the manager: 'You are so busy, why not leave that up to us?' They agreed that would be useful, and we put a lot of time and thought into it, and we were able to have our say.

Many of the problems revolve around the communication between staff and residents. They don't actually say, 'Don't make close friends with other residents', but it isn't encouraged. I know one staff member that got sacked because she got too involved with residents.

Residents often experience losses, but if anything goes wrong with your life, like losing a relative, no one takes much notice, and I think

that can be very hurtful. When my sister died I was in a bad way: you need someone to sit beside you to help talk about it. Hardly anyone said: 'I heard your sister's gone, would it help to talk about it?' I don't think that's right. The same is true if you're not well or have an accident. I've had some bad falls, and they'll come and pick you up, but then, afterwards, it's rare if staff ask 'How is it?' and how you are.

Communication about death and dying is another problem. Residents need very badly to express sorrow and grief when somebody dies, and that is actively discouraged. I had a very deep relationship with an old man after I'd been here a little while and people found that really intolerable. The staff found it very difficult. I knew he was dying, and so did he. He was terrified of death and dying and we would talk about it frequently in his last two months. I had a real battle with the staff to tell me when he was really going to die.

Death is such a taboo subject. It's a big problem because all of us are so near to death. By 90 you can't get much nearer without knowing that it is around the corner, and we need to be able to express that sometimes if we want to.

Overall, this place is very good. We are very lucky. It's the little things that matter more and more the older you are, and it's those little things that relatives find it very difficult to maintain and where staff in a care home can really make a difference.

*(This contributor's name has been changed to protect anonymity.)*

## Estaline Banfield

**I was 35 in 1962 when I came to England. My husband sent for me by plane. He was working at the hospital where I took a job as ward orderly. We had family here and we came to join them. There were lots of jobs available. I stayed in the job for 24 years and then retired. My husband died two years ago.**

After an amputation due to diabetes, I came in here about a year ago. I lived in a big prefab flat in Deptford. It was a lovely little flat and I cried when I had to leave it. After this happened, I decided I would move into a home. I did not want to be dependent on my stepdaughter. I did not want 'care in the community' as they said they would send somebody sometimes, and I said, 'That won't do. I would feel worried waiting for whoever was going to come.'

My family worried so much about me being alone, so it was much better all round for me to have someone to look after me.

It was very hard adapting at first, but I had to do something. My family helped me to come to terms with it. I like to be with other people. I have made some new friends in here. When I was not well one day, a lot of residents came up to see me as they missed me and visited me. It has helped. It is the other residents and staff together – everybody. I have more friends here, as at home they'd no sooner looked at me than they were gone, so it is better here. I have made the right choice, I would not go back, no. My life is now different. But I am OK.

I like to have some Caribbean food, but I don't get it now. In the hospital they used to send for Caribbean food for me, rice and peas or pork with nice gravy.

I am waiting for prosthesis for my stump; I hope it will be soon. I will feel much better then; it will give me more independence and I shall be able to do more. I don't want to be too dependent on the staff for my daily care needs. That is what is most important to me now.



**Lillian**  
**(surname unknown,**  
**died 1997)**

I would tell you the tale of my life, sir,  
But I don't want my tea to get cold

The things far back are not misery things.  
But it's a far fetch this remembering  
The events of my life. If I was  
In my own surroundings I might begin to piece  
it together

As a small child what gave me  
The greatest pleasure was to see  
Mother and father walking together  
Up the field as far as the canal  
And then along the road to the church

It's a different country here.  
I don't like it, and they don't speak the language  
properly either

I'm suffering from monkey puzzle.  
The monkey puzzle is this place.  
The puzzle is how to cope with the monkeys

If you said to me right now  
'Would you like to give an account  
of your present-day life?'  
I wouldn't know how to begin.  
I'm here. I'm comfortable. But who  
Put me here I wouldn't know. I know  
I never intended to be here  
Yet the place is familiar enough.  
And here's me whining away at it  
Like some silly petted baby.  
Surely I must have been kidnapped to end up  
here so long past my bedtime?

I think I have not done with grieving.  
Nearly 70 years since his death  
And I got over the first shock  
Then on with my life. Now I  
Feel the need to become reconciled  
With the memory of my father  
In some practical way.  
I shall go there and buy  
A posy of flowers to place on his grave.  
Can you understand how I cannot  
Rest until I have made this peace?

It's so foolish getting in a knot,  
Or grieving about getting in a knot.  
I want to get to the point  
Where it's a case of a matter of course  
After all, what is this lump  
Of matter if you can't make sense of it?

My sister definitely said to me,  
'Don't let them get to you!'  
Well, I reckon they got to me.  
Talk about a monkey puzzle!

It's a rum do, this growing ancient:  
The brilliance of my brain  
Has slipped away  
When I wasn't looking.

*Extracted with permission from John Killick and Kate Allan from Communication and the Care of People with Dementia, Open University Press, 2001*



## Rebekah Luff, care assistant

**Care staff are the most important factor in the quality of life of older residents. They are the ones that spend the most time with residents and are involved in most aspects of their daily living as well as in times of illness or distress. Care assistants should be the asset of every home, the thing that makes people decide to live there or see the benefits for loved ones to live there. However, much of the time they are not seen like this but rather as unskilled workers, people that couldn't do better in life, a necessary part of a new life that must be endured.**

I have worked as a care assistant on and off for the past nine years, starting when I was 16. I was paid £2.50 an hour, a wage somewhat lower than my friends were earning in shops, but on the whole I enjoyed the work. The home had a friendly and intimate atmosphere and the residents and families were well known to all the staff. I felt that I made a positive difference. We were able to spend time with residents, chatting, doing activities and having a joke together.

The residents in this home were very frail or suffering from the later stages of dementia. However, because of the attention that staff were able to give, they knew if a resident was not themselves and how best to provide individual care. For the residents, life must have been frequently hard because of their physical and mental decline.

However, this home gave them the most for the last years or months of their lives, and reduced the suffering of the most frail. I remember that when one resident was very close to dying the manager sat up all night with her.

I left the home because I wanted to earn more. Aged 18, I started working full-time as an agency care worker in a larger care home of about 50 beds. I was one of the few agency staff who regularly worked at the home. Most lasted about a month before finding an easier home. Residents met new staff almost every day. They didn't know until the shift started who would be caring for them. Although I didn't feel that I was often able to make a positive difference at this home, as I was frequently too busy to spend much individual time with residents, in retrospect I think that I benefited the residents by being a person they knew and recognised. As there was only one person on each unit, anything requiring two people would either have to wait while you hunted for other staff or staff would just do it themselves.

I would often go home worried that I'd not been able to do something or that the next staff [member] would forget to do something for a particular resident. I had a very negative view of my skills as a carer. Again, looking back, it was the fact that I did worry about these things and the smaller details that made me a good carer. For those residents that relied on staff for human contact and some kind of friendship their experience in this home must have been one of loneliness much of the time. Some residents spent much of their time in a constant state of unease, not knowing who would be caring for them next.

My more recent experiences of working in a care home have been much more positive and I feel the quality of life of the residents in the home is, on the whole, very good. It's not perfect – no large organisation is – and the residents are not a homogeneous group who all agree on how they would like things to be, but individual choice is given where possible.

The home environment is pleasant and relatively personal. Residents get to know the staff, and new faces are something to be welcomed rather than a cause of worry.

Of course, it is still hard for many residents to adjust and they feel a sense of loss for their former homes and lives. Some residents do not thrive in the home, either because of their own rapid physical or mental decline or because the situation is just too much for them however much staff and their family try. Some people are not suited to sharing living space with others or have become withdrawn and detached after living alone for a long time. It is hard to know sometimes what would be best for these people, but on the other side are those that have immensely benefited from having much more company,

I still think there is more that can be done to improve all care homes, even the good ones like the one I currently work in. Homes still need to do more to attract and then keep good-quality and reliable care staff in order to provide a caring environment for residents and to give them a sense of security. First, I think that role models are so important for staff training. Watching someone who is a brilliant and experienced carer provide good individual care would set a high standard for new care assistants. Good role models are also those staff that work well with other staff, support their colleagues, and check they are OK after a stressful day.

In recent years there has been a huge increase in the numbers of overseas care staff in many parts of Britain. These carers provide a great service as there is such a staff shortage and some of them are qualified nurses or are still training. However, I also feel that many of the overseas staff need different support and training to those that are British. We don't assume that overseas or ethnic minority residents should all be treated the same, so why should the staff? More focus needs to be on communication as sometimes it is hard to understand different accents or dialects.

All staff should also be encouraged to spend time discussing the culture and also the past of older British people, and also to think about what it must be like to receive personal care or to be helped in the bath. Many staff are already very skilled in meeting the emotional care needs of residents. However, others need to be trained and encouraged as it is easy to start to see residents as different to the rest of us and so to stop empathising with their situation.

I believe that further improvements in care homes will not be made until staff are properly trained, respected and cared for. Happy and supported staff will provide better care than stressed and degraded staff. I believe that much more can be done and the key to improvement is to spend more time, and ultimately money, on staff recruitment and training.

### **Alfred Marker, relative of resident**

**I am the youngest son of three children, and always regarded my mother and father as friends at least as much as parents. We shared common interests and attitudes and, most important, had a similar sense of humour.**

So when my father died on my 45th birthday, the link of mutual support between my mother and me was more or less automatic. Their marriage was a lifelong partnership, and now she reasserted a Blitz spirit and reinforced it with a wry humour which I understood and shared.

In the ten years or so since then, as she has grown older and moved into a nursing home, I have often wondered how much more difficult it must be for people whose parents are relatives they may love, but don't much like. Not everyone enjoys the company of their parents.

For a while after my father's death all went as well as could be expected. My mother, bereft but determined to adjust, tried to continue writing as she had for so many years. But now there were no deadlines and no imperative, and my father had gone.

He had been a workaholic. He had often said that when he stopped working he would be 'dead in six months'. He had seen too many people retire and put their feet up, only to die from a sense of uselessness and no longer being needed. In the event, it wasn't six months – he worked until six weeks before he died.

By contrast, my mother had worked all her life to support him, or her children, or anyone who needed help and support. She was a determined and energetic writer on her own behalf. But without being needed she felt a little lost and her writing slowly tailed off. When her mobility and general frailty worsened to the point where she had to move to a care home, the process continued – and now, there were plenty of people around who needed her company and friendship as much as she needed theirs. That remains the case.

I have watched the development of care homes with personal and some professional interest for the last decade or so, and overall I think the direction they are taking is positive. They are, at least, in a state of flux, and that can be positive. A swathe of over-zealous new regulations has brought closures that were sometimes unnecessary and often disastrous for the people involved, as well as causing huge shortages of places at a time when the need for them is increasing.

On the other hand, as new homes are built, I have heard a lot of thinking is going into moving away from the prescriptive approach that has, albeit with good intentions, done a lot to give nursing homes their 'next-stop-the-cemetery' image. I see much more of listening and questioning within care homes. It is leading at least some in the care-home area to realise that a standardised idea of dignified but passive retirement is not always the answer.

Often people sometimes do need to be needed. It's what keeps them alive, as opposed to merely continuing to function. A room in a care home may be the resident's own territory, within reason, but too often, once outside that room in a communal area, the prescriptive regime takes

over, with its precisely timed meals and silently crowded lounges with a TV buzzing in the corner.

Increasingly, some are realising that making a home from home means loosening the routine to something like that of a real household – and it might even be easier to run. And if it felt more like home, it might encourage people to talk to and support each other more easily – and that is the essence of what they need to do.

For the relatives, this loosening of the regime can only be helpful. The role of relatives is often underplayed by nursing homes. They tend to think of the resident as Someone Who Gets Visitors.

But when someone moves into a care home, it's like a stone in a pond, with the ripples moving out to include a lot of people in active roles. Unsung and unacknowledged, they have to do everything from looking after the resident's letters and finances (my own nephew does precisely that for his grandmother), to urging them into action in a bid to keep their interest in life awake and alive.

A real home, which includes everyone and is built on the needs of those who live in there, would be much more than a place where visitors get a cup of tea and a biscuit. It could be somewhere where they want to take part and help.

*(This contributor's name has been changed to protect anonymity.)*



## Lorna Ainsworth, care-home manager

**Working with older people and their relatives has been an enjoyable experience that I am unlikely to forget. Their charm and vulnerability, as they in the main struggled with the fear and pain of old age and dementia, challenged me as a carer. There were many happy moments and many frustrations.**

Care of older people is a speciality which is not afforded the same kudos as working in other areas of nursing. This has the inevitable consequence of problems with recruitment of staff. The result is that any trained nurse is seen as good enough to do the job as employers struggle to fill vacancies. We have few job applications from the indigenous population, who clearly are not attracted to this sector, no doubt put off by the low wages and almost total lack of employment perks such as pensions and sick pay. Those who do work in the sector are given scandalous wages and conditions of employment and inadequate preparation for their role.

It was Florence Nightingale herself who declared that not everyone could care for the sick and dying. The 'elements' of nursing, she declared, were yet unknown. And, sadly, this is still the case. It is not acceptable to take people off the streets as a substitute for adequately trained staff in an environment where there is increasing frailty and complexity. Caring is a complex and challenging role and we do need to address the issue of delivering the highest standard of care to our elderly population, using accepted methodology for measuring need and dependency, rather than being too heavily influenced by costs.

The first anomaly that confronted me when I became involved in the care of older people was the assumption that we still refer to 'residential care' as it was known in the 1960s and 1970s. Residential care was then used by a considerably more able group of (mostly) older

women who opted to live in a care home much earlier in life and so were physically and mentally more independent.

The residents of present-day residential establishments are usually older people with early or medium-stage dementia or those who are so ill that they require supervision and care. Such residents require greater expertise in caring for their needs, which is not being addressed by commissioners and regulators and is not adequately budgeted for. The concern is that care homes are almost exclusively staffed by healthcare assistants who have limited medical training and social skills. Nursing is therefore supplied by visiting district nurses. The idea of person-centred holistic care is inevitably lost in this arrangement. It is time to be honest about the nature of much residential care in terms of training and appropriate provision of the health component within social care.

Colleagues suggest that the National Minimum Standards do not support the individuality of residents. They complain of a balancing act to meet regulatory requirements, and that their professional judgement is ignored. They see the trend as designed to prove to regulators that present standards are being met rather than care focused on the residents that celebrates their individuality. Care staff constantly have to balance paperwork and practical care, much of which is not best use of their time.

Regulation is of major importance but bureaucratic regulation and form-filling is not the answer to improving standards. It would be useful to have greater partnership with regulators. Relatives, residents and advocates need to be involved more in an honest and open way in quality improvement. Too little time is given to really observing and understanding the experiences of the residents, staff and relatives from their different perspectives. The skill is to produce a system which allows the unique and individual character of residents to be given due consideration in the planning and development of this sector.

Although in some areas there is access to care-home support teams, it can take many weeks to make available the expertise of dietitians, occupational therapists and physiotherapists, and speech and language therapists, and sometimes it is not forthcoming at all. Therefore, older people with complex needs outside the acute sector get a second-rate service. The issue of inadequate equipment in nursing homes is also a factor.

We need to assess the time spent on paperwork as opposed to direct care. The thorny issue of standards and the competence of current staff to create truly person-centred care needs to be addressed. Training and development need to be given high priority, with staff recruited who have a genuine interest in caring for older people. Staffing levels and skill mix need to be reviewed as a matter of urgency to reflect the needs of residents, with key workers having the necessary skills and qualifications to ensure research-based care.

Learning care homes and specialist 'gold star' centres of care will inevitably raise standards and attract research funding. The lack of research of any significance to aid real progress in caring for older people in residential settings is a real cause for concern. The integration of health and social care is welcomed, as we need the best possible specialist facilities to meet the challenges we are now facing, where best practice can be disseminated. Mediocrity and inferior standards may then become a thing of the past.

## It's quality that counts: what we know about quality of life in care homes

Quality of life is notoriously difficult to define, as it pervades a range of aspects of everyday life in significant and complex ways. It derives from what makes life meaningful, enjoyable and worth living. If we seek to enhance quality of life we must first discuss individual ideas about what it is, what contributes to it, ways in which it could be supported, and individual priorities.

For staff, this may mean suspending personal assumptions and stereotypical notions of what older people want, and paying attention to what they are saying rather than what others say they need. It would mean looking at what older people living in care homes think will improve or maintain their quality of life. These preferences may not be achievable within the resource constraints of the care home, but stimulating debate by exploring preferences will generate ideas about what could be possible.

*'How life here at St David's could be made any better? By enlarging the staff so that residents and carers are given time together . . . I don't think there is any point in asking about quality of life as I don't think it is going to happen.'*  
Dennis Hearle

Quality of life is often confused with quality of care, which is the way in which care is delivered and the standards that it meets. Separating quality of life from quality of care is difficult, especially as the two are not completely distinct. If care is of a high standard, it can support and promote quality of life, but it is not necessarily the key contributor to quality of life.

*'That's an awful thing – to be in a place and you're ignored – if you ask me. There's never anything like that here, I can safely say that. Because I've got a buzzer, and when I buzz they come to see what it is I want. And maybe it's just a simple thing but important enough for me to buzz.'* Helen Middleton

We also need to understand the connections between the different physical and psychological or emotional dimensions of quality of life and how they interact with each other. As health professionals, for example, we might think of quality of life solely in terms of health, whereas some other issue, such as money or living environment, may be more or just as important.

This involves moving away from a view based on needs to one founded on preferences: in other words, paying attention to what people say they want, rather than what they (or others) say they need. This may mean relinquishing models of quality of life based on needs as defined by professionals. While these may have a sound basis in research or experience, if they are imposed on older people, and driven by professional concerns or constraints, they may not reflect older people's preferences.

*'The one thing I don't like is having to share a loo – there's several of us here and there's two toilets. We have to share them with the men and I would like if we had a toilet for ladies only. One man gets confused and sometimes . . . it is a bit messy in our toilets.'* Margaret Laurenson

To change our perspective on quality of life we need to talk to older people directly to find out what their preferences are: in other words, what they think will improve or maintain their quality of life.

---

## Moving to a care home

The move from one's own home to a care home is a major life change, and often the last move we will ever make. It will probably mean the loss of relationships as well as of an environment in which many emotions and memories are invested (Forte, Cotter and Wells, 2006; Chaudhury, 2003; Tester et al, 2003; McKee et al, 2005). For many the move may be necessitated by a decline in physical and mental health, a reduction in, or even the end of, independence, or the death of a partner. Moving to a care home can therefore have extremely negative connotations. However, with planning and support, crisis-driven admissions can turn into a transition which brings improved quality of life.

Davies and Nolan (2003; 2004) have developed a framework for ensuring the best possible outcome from a move. These are its recommendations.

- Older people should not be put under undue pressure to make decisions on care homes.
- Older people and their relatives need relevant information to enable them to make an informed choice. (The Office of Fair Trading reported in 2005 that 71 per cent of residents surveyed did not remember seeing any booklets or leaflets giving information about care homes.) The 'try it and see' approach, whereby potential residents are able to visit care homes and stay for a period of a few hours, or even a few days, is a useful way in which residents can start to make an informed choice (Kellaher, 2000).
- The decision on the care home should preferably be made jointly between the older person and relatives and carers, with involvement of, and contribution from, health and social care professionals and care-home staff, unless the potential resident or their carer does not want such involvement.

- Older people should be allowed control over decision-making. The Office of Fair Trading (2005) reported that in the majority of cases family were involved in the decision-making process, either solely (37 per cent) or jointly (33 per cent) with the potential resident; only 18 per cent of residents made the decision alone.

*'When I moved into a care home environment I initially experienced confusion, apprehension and upheaval and suffered a complete lack of confidence and, let it be said, a considerable degree of fear – a fear of the unknown, a fear of not knowing what the future will hold, and, quite frankly, of not having any real knowledge about the tenure or, indeed, the rules and requirements of the home.'* James Roemele

Older people and their carers need to feel supported in managing any feelings of guilt, sorrow, loss, grief or anger associated with the change. Relatives are sometimes asked to stay away for the first week or so to allow the person to settle in. This is not good practice (Alzheimer Scotland, 2005), as it denies the important role that the relative plays, with the resident and staff members, during this crucial time. Staff can be inclined to adopt a position of authority, albeit in a very well-meaning way, which can convey to relatives at this highly sensitive time that their services are no longer required. In fact, a relative may require help in redefining his or her relationship with a partner when the partner moves into a care home (Clarke and Bright, 2006).

Overall, the process of entering a care home should be considered as much an opportunity to realise new opportunities and challenges as it is a result of some form of loss of independence or health status.

*'Now that I have spent a year in this home I feel very settled and consider it is a refuge from disturbance in this town and around the world. . . It is easy to converse with a lot of the residents and staff here. My motto now is "just enjoy life."'*  
John Linton

*'I have lived in this residential home for two years . . . I have now rebuilt my life, thanks to the proprietor and staff. I now want to put the past behind me and live in the present and live as active a life as possible.'* Albert Cooper

*'Finally the day came to move [to the care home]. I was ready for the social worker, who was due to come at ten o'clock. But he didn't arrive. I phoned the home and they said they thought there was some mix-up, that I wasn't going to get moved and I said, "What?" I said, "I am all packed." I was in an awful way. My carer had gone and I didn't know what was going on. Finally he [the social worker] arrived at half past one. The social worker came to see me [again]*

### Information resources for transition to a care home

- Help the Aged produces a regularly updated free advice leaflet entitled *Care Homes* which outlines how to find and what to look for in a care home, and discusses care-home fees
- Care home inspection reports
- Elderly Accommodation Counsel's *Care Options Directory* provides a tool to help people seeking care to establish their own priorities, a database of factual information about each UK home, and new qualitative descriptors to help people judge the likely suitability of those homes that are available to them (<http://www.housingcare.org>)
- Alzheimer Scotland (2003) has drawn up an extensive checklist to assist with the process of choosing a home for a person with dementia; it focuses primarily on the practical but also covers personal and cultural aspects.
- A report by Alzheimer Scotland (2005) offers ideas for assisting residents to acclimatise to living in a care home. Guidelines were developed by Oleson and Shadick (1993) cited in Davies (2001, p. 82)
- *Moving to Quality* (Counsel and Care, 1999) provides guidance on what to ask residents when they come into a home.

*shortly after I moved in. He said he would take me up to my house to collect all my stuff. Well, that is the last I have heard or seen of him. The whole thing was very stressful. If things had been explained to me, if they had only phoned to tell me what was what, it would have made all the difference. I could have gone on from there rather than being kept hanging on and making me feel very frustrated.'*  
Margaret Laurenson

## A sense of identity

**Maintaining one's sense of identity is closely linked to self-esteem and perceptions of quality of life in old age (Davies, 2001; Tester et al, 2003; McKee et al, 2005). Living in a care home can serve to undermine people's sense of identity or of self in a number of ways. As Chaudhury (2003) notes: 'The majority of long-term care facilities are "non-places" that afford few links with one's personal or cultural past.'**

In addition, loss of health and cognitive ability may restrict independence and self-realisation. The relative absence of private physical space in which to undertake intimate activities and the provision of communal facilities such as lounges and institutional routines may be in conflict with one's identity.

Person-centred care is one of the national standards set out in the National Service Framework for Older People (Department of Health, 2001). This approach, advocated to overcome the threats to a person's identity associated with living in a care home, encompasses four elements:

- valuing people and those who care for them;
- treating people as individuals;
- looking at the world from the perspective of the individual; and
- providing a positive social environment in which the person can experience relative well-being (Brooker, 2004).

*'An abiding memory is of a woman who cried out each morning for her grapefruit spoon.*

*It was her one possession from her own home and invariably it was missing from the breakfast trolley.' Ann Macfarlane*

Understanding what matters to the individual, including his or her values and wishes (Wells, 2005), is key to person-centred care. The value of biographical work (described below) could be therapeutic for the individual resident while at the same time enabling staff to get to know individuals well and to work with them to tailor the care provided.

Provided staff are given the necessary time, skills and training to carry it out, reminiscence activity has been shown to play a powerful part in maintaining identity in older people, as well as allowing a relationship to develop between residents and staff. In addition, everyday talk about the past benefits each generation, while enabling older people to preserve their identity (McKee et al 2005, p. 121). A biographical approach is also about involving the resident and their family in the process of gathering and reviewing information about their needs and wishes in the care home, and in negotiating how care is to be delivered to ensure it is helpful and appropriate (Davies, 2001; Wells, 2005).

## Examples of approaches adopted in care homes to help residents maintain their identity

- Actively seeking out individual ambitions and exploring how best to meet them is essential but not always straightforward. A dialogue can be developed with residents through listening, observing non-verbal signs, using other aids such as Talking Mats,<sup>TM</sup> gathering information over time, using cues such as photographs, personal objects, and having visitors to develop conversation and interactions (Wells, 2005; Wilson, 2004; Tester et al, 2003).
- Consistent staff assignment has been found to be important in making it more possible for staff and residents to get to know each other (Davies, 2001).

- Involving key people and groups from the local community is of value. In one home, community education workers were invited to meet residents to discuss their interests and to run community education classes in the care home that were open to residents and other members of the community (Lewin, 2002).
- Enabling individual residents to contribute to care-home life and the local community, if they wish, is of benefit. In one example a resident offered to meet new residents as part of their orientation to the home (Lewin, 2002). In the same home, it was proposed that residents should visit local schools to talk about their lives and that the home should produce a leaflet listing interests and topics that participating residents might offer.
- Residents should be enabled to be themselves: to decide how they dress, choose the items they will bring into the home and have control over personal space (Tester et al, 2003).
- It is important to recognise that things, places, animals and ideas can be sources of security, belonging, and self-identity for older people (Cookman, 1996).
- Striking a balance between secure storage of personal possessions (such as jewellery) with residents' wishes to be able to use them when they want to is essential. This does, however, require vigilance from staff and appropriate policies need to be in place.
- Participation in meaningful activities (McKee et al, 2005) is of great value. What counts as meaningful activity can range from engaging in the daily routine of the home, looking at the view from the window, taking up hobbies, religious observance, singing or playing music. In the case of organised activities, it is worth remembering that having the choice to opt out of them is just as important as the activities themselves (Tester et al, 2003).

*'Staff do knock on your door, but some of them knock and then they are in before you know what has happened. I have just had to get used to that. There have been occasions when I have been on the toilet, which isn't good really. It would be more respectful if they waited until you asked them in.'* Tom Hamilton

### Talking to residents about their ambitions and needs

In a project that used a 'wishing tree', wishes ranged from access to audio books to visits to the Highland Show (Lewin, 2002). In another project, a training programme for staff resulted in staff identifying and helping a resident who had always wanted to learn to play the piano, together with others who wanted to learn new things, such as how to use a computer (Wilson, 2004).

Other ways in which residents' hopes can be realised include:

- **establishing a forum for residents and their families** An evaluation of such a forum found that outcomes included the setting-up of new services such as chiropody; environmental improvements, including an improved door entry system; a relocated activities room and the designation of a new smoking area; and a number of initiatives to improve the quality of food and the range of social activities (Ashburner, 2005).
- **recognising ethnic and cultural needs** Doing this may generate pointers to improved care for individual residents. It could involve recruiting staff from different ethnic groups to reflect the local population; staff training on cultural diversity; the availability of translation services; the provision of washing and toilet facilities for particular purposes; potential for segregation of male and female quarters; areas



*'I compare my experience of living (existing?) in a care home to being like a library book, placed on a shelf and forgotten and then once in a while taken down, dusted and put back for another year to rot and decay. . . It does not allow you to express yourself as an individual.'*  
James Roemele

for prayer and meditation; and requirements relating to food storage, preparation and cooking (Mold et al, 2005a, 2005b; Centre for Policy on Ageing, 1996, Institute for Jewish Policy Research, 2002).

- **recognising spiritual needs** Doing this could mean providing places for prayer and meditation; arranging for clergy and others from different religious institutions to visit; enabling residents to attend places of worship or religious events outside the care home; staff training on spirituality; or meeting more general spiritual needs by means of, for

example, reading, expressive arts, music, walking or gardening – activities that can provide 'opportunities for creative meaning, gaining a sense of control and nourishing the soul' (Centre for Policy on Ageing, 1996; Orchard and Clark, 2001; Sapp, 2004; Johnson, 2005; Rose, 1999, cited in Johnston and Mayers, 2005).

- **offering couples space for intimacy and privacy** and using skilled observation and emotional literacy to understand their needs will help residents feel they have the right to express their sexual identity (Forte et al, 2006; Heymanson 2003; Springfield 2002). Special consideration may need to be given to some residents: for instance, those with dementia. A sensitive and respectful approach will be needed from staff to ensure that one person's need for sexual expression does not lead to coercion of vulnerable others.

Communication with residents can be resource-intensive. The use of external advocacy schemes to supplement the time provided by care-home staff can be beneficial.



## From 'home' to 'community'

**The loss of ties to the communities that an older person has been part of can be hard to bear. Creating a sense of community within a care home is therefore a goal to which residents, their families and staff can all aspire and contribute.**

*'What makes a good home is the friendship and the good management and a caring team as back-up, who are friendly and make you feel like part of a family and keep you well looked-after and make sure you are not lonely.'*  
Albert Cooper

## Creating community in care homes

The characteristics associated with 'home', such as family, shared memories, comfortable familiarities, autonomy and a sense of security, are difficult to replicate even within the smallest of care homes (Stafford, 2003; Peace and Holland, 2001; Savishinsky, 1991). Rather than trying to make care homes more home-like, the alternative objective of creating care homes as 'communities' may offer a useful way forward, although it is worth noting that community life is not always easy or straightforward, and is likely to mirror the complicated relations existing in any environment where people live or work with each other (Reed and Payton, 1996).

Gubrium (1993) has a very telling quotation from a resident:

*No place, no hospital, no nursing home is like your own home, not to me . . . Peace of mind, I think, at home makes you different. You run your home.*

*These people here run the nursing home. At home, you're the overseer. You take care of everything, and I think that makes you more like a whole being. Here, you're just a part. When you're home, you're whole. You're a whole person. You're taking care of everything, and everything comes to you by your means, and it makes you feel more at home.*

This statement reveals the importance of ensuring that residents feel that they do have a say in 'running the home' as well as enabling residents to feel that they are part of a whole: the care-home community.

The extent to which members of the care-home community feel that they are able to make a contribution to these relationships and to the care-home community as a whole is crucial to quality of life. Reciprocity in relationships is essential to well-being, and a number of studies have found this to be important for residents of care homes (Ghusn et al, 1996; Roe et al, 2001, Davies 2001).

## Relationships with staff

Relationships with others are a key determinant in developing a sense of community. There is clear evidence that the quality of the relationship with staff members is often the most important aspect of quality of care for residents (Grau, 1995), while the quality of the relationship with residents is for staff the most important reason for staying in the job (Parsons et al, 2003). Reduced attachment of staff to residents has been identified as a strong predictor of staff burnout and turnover (Sumaya-Smith, 1995).

*'I did not know that they had such nice places like here. On television they say many places like this don't treat the patient well. . . But I get very good care here and any time I ask anyone for something there is always someone available who comes when I need them.'*  
Clyde Lambert

Residents highlight the importance to relationships of continuity of staff, adequate communication, staff responsiveness, dependability and trust, and a degree of personal control (Rantz et al, 1999; Bowers et al, 2001; Edwards et al, 2003). In many homes different staff are assigned to residents by rota, which means there is no consistency of individual staff members working with individual residents (Stafford, 2003). However, with consistent staff assignment, relationships can flourish and lead to improved quality of care and lower staff turnover (McGilton et al, 2003; Rantz et al, 2003; Teresi et al, 1993; Burgio et al, 2004).

*'But this is the best place. I am so happy to be here... The nurses and staff treat me so well. . . I have a friend here who I visit on the same floor. One of the staff told me about him and suggested that I might like to visit him. I visit him regularly.'* Clyde Lambert

## Relationships between residents

Older people often want to have a social relationship with fellow residents but find that opportunities are limited in a care home (Mattiasson and Andersson, 1997). Sensory impairments can prevent older people from identifying the usual cues and nuances in conversation. Staff can play a crucial role in ensuring that such interaction does take place – by, for example, holding social events and having places for residents to meet that are easily available to them. One home described how staff supported regular pre-dinner drinks as a way of encouraging low-level friendships among residents.



## Relationships with relatives and friends

Contrary to popular supposition, most family members are keen, often desperate, to maintain their relationship with a relative who goes into a care home (Sandberg et al, 2001; Kellett, 2000). Studies have demonstrated that family members can make a vital contribution, personalising and humanising the life of a resident (Nolan and Dellasega, 1999; Davies and Nolan, 2005; Sandberg et al, 2001; Rowles and High, 2003) and re-engaging residents in familiar aspects of their lives and the world outside.

Nurturing such relationships may need much time and work. Families who feel secure in their relationships with staff may be more likely to become involved. The provision of protected times for staff to speak with relatives has been shown to lead to improvements in communication and a positive difference to residents' experiences of care (Nolan and Dellasega, 1999; Davies 2001; Dewar et al, 2003; Pillemer et al, 2003).

Aveyard and Davies (2006) found that encouraging relatives to contribute to wider decisions about the home by having an action group helped relationships to develop and, as a consequence, staff became more aware of the contribution that relatives made to care.

*'I usually go out on a Tuesday with my neighbour, who takes me out in her car, and I've two neighbours there that take me out. And we go for lunch or go for a cup of tea or a cup of coffee or something. It's very nice and they are really good friends. That's neighbours.'*  
Helen Middleton

Similarly, sustaining relationships with friends, to whom residents have previously acted as confidants, sources of knowledge or been appreciated for their humorous comments, may be important in maintaining quality of life. Maintaining these existing relationships may mean that care homes have to be welcoming and hospitable for visitors, and respond to their needs as well as those of the resident. Adequate facilities and support with transport for visitors too frail to use private or public transport, or provision of telephones to which residents have easy access, or help with writing cards or letters to maintain contact, are therefore vital.

The potential for resident 'adoption' programmes involving local volunteers should be explored so that residents who do not have regular visitors are not disadvantaged.

### **Best practice example: maintaining relationships**

At Bradbury Centre, Shepperton, London, the manager and activity co-ordinator regularly organise 'couples evenings' for residents whose partner still lives at home (i.e. at the resident's former home). Pre-dinner drinks are served in the lounge, followed by a three-course candlelit dinner accompanied by soft music. Many of these residents have advanced dementia and can no longer communicate easily with their spouses. A meal with other people ensures that the conversation flows and that couples can spend an enjoyable evening in the company of others.

Crucial to all this is an environment that is sufficiently spacious to allow residents to receive visitors in private, which helps residents, particularly those whose partner is not living in the care home, to maintain relationships.



## Creating opportunities for meaningful activity

*'You get a wee bit bored, that's the only thing.'*

Margaret Regan



**Recreation, social and community activities and personal development are essential to quality of life for people of all ages and the benefits to health and well-being among older people, even in advanced frailty, have been demonstrated (Richards, 2005; Zimmerman et al, 2005; Baum, 1995; Ballard et al, 2001; Kiely and Flacker, 2003). However, studies suggest that almost 50 per cent of care-home residents' time is spent asleep, socially withdrawn or inactive, with only 3 per cent spent on constructive activity (Ballard et al, 2001).**

The increasing frailty of residents does limit what they might do and staff need to be creative in helping residents. This does not mean, however, that activities need to be highly structured and revolve around groups. One-to-one activities for a short period of time may be more appropriate and beneficial.

A number of studies have highlighted residents' need to 'feel useful' (Mold et al, 2005). This means that residents need to do something that has some meaning for them rather than just a

few hours of programmed activities. They need regular opportunities to take part in housekeeping jobs such as assisting at mealtimes and folding laundry (Brooker, 2001).

*'I have a computer at home. I used it for keeping track of things, addresses for the Christmas cards etc., and I got internet just for curiosity. They have computers in the home but they are difficult to access and the internet connection is difficult.'* Tom Hamilton

There is a growing recognition of the need to link the community within a care home to the world beyond – members of the public, including local community groups, who may wish to volunteer their services, and NHS and social services (Rowles and High, 2003; Rowles et al, 1996). One example is a care home that provides a meeting room for a local Alzheimer's group.

There can be social opportunities through, for example, contact with other residents or pets coming to the home with visitors (Baun and McCabe, 2000), holding regular cocktail hours (Klein and Jess, 2002), and providing music tailored to individual tastes via personal and portable music players and headphones (Burack et al, 2002).

Access to the outdoors is an important part of residents' quality of life as it offers sensory stimulation, opportunities to engage with neighbourhood and community, contact with wildlife, fresh air, physical exercise, and stimulates conversation and reminiscence. Having access to local services and shops and a space for family gatherings are therefore important.

Fletcher (2000), reflecting on his experience of being a nursing-home resident, suggests that staff need to permit greater resident participation in the home. He writes:

*Many people entering care homes still have an ability to make some contribution to their environment and this should be encouraged wherever possible. For one thing, if they are given a purpose in life, through participating in the affairs of the home, this can boost their morale, which can subsequently have tremendous effects on their health. Moreover, their expertise will contribute to the well-being and reputation of the home. Indeed, they can also serve as an early warning system to management if things start to go wrong. (p. 116)*

In achieving this, residents, staff and relatives must appreciate the fine balance between rights and risks that will continually have to be negotiated in places which centre on the resident. However, there is evidence that doing everything possible to eliminate risk can act against quality of life (Parker et al, 2004).

*'I have a range of activities that I enjoy both inside and outside the home. I go out and play bridge twice a week, go swimming and attend a day centre once a week and attend a local Baptist church. I get lifts to some things from my friends. Here there is a regular games, exercise and music afternoon which I try not to miss.'*  
*Albert Cooper*

Activities need to maintain, expand or respond to areas of interest, such as new or existing hobbies. This means that staff need to be aware of what residents do and like to do and think about how these can be maintained. For example, this could be about organising transport to venues, or acquiring equipment that helps a resident, or adapting something that they already have so they can make use of it.

Providing opportunities for learning can improve health, reduce dependency (Dench and Regan, 2000) and also help older people, wherever they live, to take more control over their own lives. Care homes should be encouraged to

provide facilities for learning that are regularly available, appropriate and identifiable (Soulsby, 2004). The Fourth Age Learning Report (NIACE, 2000) suggests that inter-agency collaboration is needed to assist the development of learning opportunities in care homes.

What staff need to do may be as simple as making sure that the radio is tuned to a resident's preferred station for favourite programmes. At other times it may mean thinking about residents as active rather than passive people, with a life full of possibility and potential and encouraging them to talk about what they want to do.

Hutchinson and Marshall (2001) highlight the importance of ensuring that activities are tailored to the individual needs and preferences of residents. Cultural sensitivity is also an important component of planning activities (Mold et al, 2005; Laird, 1979).

Although there is a strong correlation between declining health and self-esteem, many older people define themselves by living a life full of activities, stressing the importance of hobbies, interests, social participation and a daily living routine. With dementia being a primary reason for entering a care home, and being increasingly understood as more of a behavioural syndrome than an illness, it is important to acknowledge the capacity for continued development within people who have dementia (Colman, O'Hanlon, 2004).

Understanding the importance of stimulation through purposeful activity and continuing to make use of one's abilities contributes to self-esteem, a sense of control and well-being, as long as the activities provided are appropriate for an individual (Perrin and May, 2000).

Making sure that what residents do is what residents want to do is only possible if there is a true partnership between staff, residents and their relatives (Eales et al, 2001). Only then can there be a true fit between individual values and preferred activities.



The feelings of helplessness and powerlessness associated with chronic disability affect motivation levels and are compounded if there is a lack of structure and meaning to the day. These feelings can be alleviated by a motivating and challenging environment with opportunities to socialise and become involved in meaningful activity. This is closely linked to autonomy (Mee and Sumison, 2001). When staff are sensitive to what individuals need and want, this can be achieved (Colman, 2004).

For this to happen it is crucial that residents are able to feel they are continuing to contribute to day-to-day life. Reciprocity between staff and residents, allowing residents to offer thanks and appropriate gifts to staff, in return for their help, should not be discouraged.

Engagement with the outside world is important in order to ensure residents still feel part of the wider community. Care homes are sometimes involved in projects whereby schoolchildren come and talk to residents as part of history lessons and residents are invited to school

activities. Similarly, volunteering has been encouraged by having a friends (of the home) organisation or a resident support group.

*'Some of them downstairs just sit back in the chair, you know, looking at each other. Sometimes they get taken out, but very little really. Ivy, on the fourth floor, has got very poor eyesight and she is a bit deaf too; she sits in her room a lot and finds her day hangs. The problem is they are short-staffed. If they had more carers they could spend more time with each individual. We could do with more of. . . having someone coming round and listening to them. It cheers them up because someone is listening to them.'* Margaret Laurenson

## All in it together: shared decision-making in care homes

Ensuring that residents of care homes are helped to exercise choice as much as is practicable is increasingly accepted as essential for quality of life (Kane et al, 1997; Boyle, 2004). The desire to be involved in decisions, both at a personal level and more widely, is likely to vary between individuals (Crain, 2001). In many cases, it will fall to staff members to identify the extent to which a resident or a family member wishes to participate and at what level. This poses a challenge if there is no formal framework for involving residents, their families and staff.

Residents with any degree of cognitive impairment may find it difficult to express their wishes; they are particularly at risk if care routines become inflexible and fail to respond to individual needs and preferences. In order to create opportunities for shared decision-making, staff need to make this a priority and regard it as a positive component of their work.

There are numerous opportunities for negotiation and shared decision-making in the minutiae of daily interactions between residents and their carers. Although examples have been identified in research where such interaction is not evident, some studies have documented how skilled staff have developed sensitive practices which enable the older person to retain as much control as possible.

Risk assessment must be a part of decision-making within the home. Counsel and Care has produced a publication, *The Right to Take Risks*, which helps to explore this issue (Counsel and Care, 2001).

### Example

Cook (2005) has described how a resident set up a system of pulleys and levers to perform tasks such as opening windows and doors, and how this enhanced her comfort levels in the environment. This strategy, however, was developed by the resident without being initiated by the care-home staff.

Getting residents', staff members' and relatives' views and making them part of any changes which are made should be a priority and a requirement of registration. Gathering the views of cognitively frail older people is a special challenge that requires time and skilled communication (Tester et al, 2004).

*'We have residents' meetings which are supposed to be every three months, I believe, and when I took it up with the manager here, she said, "Sorry, we can't always fit it in with staff arrangements." So it works out at every six months.'* John Linton

Something like a regular newsletter to all members of the care-home community can allow everyone to feel involved and to feel that they have a responsibility to find solutions to problems.

In one care home residents are encouraged to show staff applicants around (or even take part in the recruitment process), which both allows residents to contribute and shows prospective staff that the home has a culture of reciprocity.

*'They are all very helpful here but it is not the way I would choose to live. But I could not have gone back home. The thing about home is that you can do what you want when you want to.'* Marjorie Randall

## A healthy outlook: health and care responses

**Health is integral to quality of life and ill-health or disability can compromise its achievement. Bowman et al (2004) found that in 90 per cent of cases medical morbidity and associated disability had been the reason why older people had entered a care home rather than general frailty and social needs. Despite this, there is growing evidence that the contribution of doctors, other professionals and specialist services for older people is limited in care homes.**

For example:

- 21 per cent of homes have no regular visits from a GP;
- a significant proportion of older people do not receive adequate pain treatment, including effective interventions for chronic pain;
- only 5 per cent of homes had direct contact with a geriatrician and 12 per cent with a psycho-geriatrician;
- less than 1 per cent of residents receive hands-on care from a district nurse during any given year;
- contributions from occupational therapists and physiotherapists are particularly sparse despite the fact that they can make an enormous difference to older people's everyday functioning and quality of life;
- speech and language therapy is virtually non-existent in most homes;
- only a third of those who have had strokes and who live in care homes received treatment for secondary stroke prevention (Quilliam and Lapane, 2001); six months after the stroke, care-home residents are less likely

to receive physiotherapy or occupational therapy compared with similarly disabled stroke survivors who have been in hospital;

- although many care homes aim to promote health, external support in respect of nutrition and weight control, exercise, adequate sleep, stress management, safety and drug management is largely absent (O'Dea et al, 2000, 2001; Sackley et al, 2004; Sackley and Dewey, 2001; Glendinning et al, 2002; Baradowa et al, 2001; Challis et al, 2000; Noone et al, 2001; Chow, 2003);

As the Royal College of Physicians, Royal College of Nursing and British Geriatric Society taskforce (2000) has emphasised:

*Care-home residents have often become the medically dispossessed in spite of their complex health care needs . . . it is a paradox that older people with the greatest needs for consistent, creative and effective care now live in care homes denied the traditional essence of interdisciplinary geriatric care.*

Furthermore, a survey by the Royal College of Nursing (2004) recommended that there should be the staff ratio and skill mix to promote achievable independence and that older people should be partners in assessing and planning their health and social needs.

It is disturbing to see evidence that some older care-home residents are paying for services that are provided free of charge under the NHS to those who receive care in other sectors. For example, 8 per cent of homes pay local GPs for their services to residents (Glendinning et al, 2002). Additional costs to homes in the form of GP fees or retainers are commonly passed on to residents. Two-thirds of homes using private physiotherapy levy an extra charge on residents.

The House of Commons Select Committee (2004) recommended, along with regular GP medication reviews, encouraging consultants with an interest in older people to develop services in care homes and that 'the practice of payment of retainer fee [should be] abolished' (paragraph 187).





The findings concluded that what GPs offer to older people in care homes should not be seen in isolation from other lifestyle factors.

This means that a more holistic view of an individual's wishes should be taken rather than the currently prevailing clinically focused perspective, which tends to intensify as people age and become more infirm. It also requires co-operative relationships between the GP, the practice and the home management staff. The importance of the contribution of staff and families should also be addressed, and should acknowledge the rich diversity of older people, who should not be pigeon-holed (ACO, 2005).

There appears to be enormous potential for developing new roles and new ways of working in order to offer a range of multi-professional healthcare services to care homes. There is evidence of such local initiatives developing (details of which are provided in the full report: see copyright page). They could contribute significantly to helping older people to maintain their health, functioning, potential for enjoyment and, ultimately, their quality of life.

*'What would help the quality of life is access to a doctor when there is a medical need. It was useful to have access to a physiotherapist or occupational therapist when I needed it, to help me with my mobility, to enable me to be independent and to keep my confidence.'*  
Frank Campbell

---

## Care at the end of life

**The quality of a person's dying is, in many ways, as important as their quality of life. However, the nature of multiple, often chronic, health problems, such as many older people experience over a period of time, makes it difficult to define when someone can actually be said to be dying (Froggat, 2001; Henwood, 2001). The uncertainty about this can lead to impersonal, reactive and inadequate care (Sidell and Komaromy, 2003; Kristjanson et al, 2005). Existing standards relating to care homes can be vague about the kind of care required when someone is dying (Social Care Institute for Excellence, 2004), which may perhaps reflect a wider reluctance within society to face mortality.**

Literature has tended to move away from trying to define a point of dying to making dying something which is integral and normal within the life of a care home, while also doing everything to enhance the quality of care for those who are not in this position (Nolan et al, 2003). There is consensus that a culture of care should be developed which values older people's dying just as much as their living.

Good care at the end of life requires an awareness of and openness to the likelihood that residents are nearing the end of their lives. Many of the practical approaches to enhancing someone's sense of self and dignity may offer a way of encouraging more openness about dying. When a person with dementia is dying this may create special difficulties: a small but growing amount of research is available on this subject.

A number of national initiatives are being used to improve the experience of dying in care homes: the Gold Standard Framework (Thomas, 2003), the Integrated Pathway for the Dying

(Ellershaw et al, 2003) and the Preferred Place of Care Initiative (Storey, Pemberton et al, 2003). They have received clinical and government support but their effectiveness in care homes is yet to be demonstrated. Various other resources and training materials have been developed specifically for care homes.

## Support for residents in their last few days

Death and dying can be hidden and denied by the culture of the home (Reed et al, 2002; Sidell 2003; Hanson and Seymour, 2003). Support and facilitation of care managers are vital if care at that time is to be of the highest quality (Komaromy et al, 2000; Katz and Peace, 2003).

The specific areas of good practice are:

- staff understanding and being aware of their own attitude to death and dying, and how that may influence decisions about care;
- recognising and valuing the principles of palliative care and a good death;
- an ability and willingness to involve outside support: what are the local support services? how does the care home get access?
- making sure that communication is open and sensitive; accepting that death is coming, yet recognising that some residents and family may not want to talk openly about what is happening; family members may be reluctant to face the imminent death of their relative and can create problems for staff and resident alike;
- making sure that those relatives who may wish to be with a dying family member in the last few days are given the support they need: this means not only emotional support from staff but practical arrangements such as providing refreshments or a comfortable chair.



- recognising the importance of not leaving the dying person alone and ensuring that, for example, enough staff are on shift at such a time for someone to sit with the person or using volunteers for this purpose, either with or in place of a family member;
- supporting other residents when someone is dying: it is valuable to recognise formally that someone has died and offer bereavement support to residents and family members;
- supporting staff: often there is a difficult tension between the professional and the personal in care homes, where staff often feel like 'family' to the resident;
- offering family and friends the opportunity to gather at the home after a funeral, which makes it easier for residents to join them for the occasion if they wish to do so;

- holding an annual service of thanksgiving, to which relatives are invited, to remember all who have died in the past year.

What cannot be over-emphasised is that, as was said at the beginning of this section, the process of dying is a significant one for all of us and the quality of care afforded at this time needs to be as high as for that afforded to the living. Dying is a part of life and the care given at different times of life may be different but it is part of a continuum.

## Making improvements: creating a positive culture

**There is clear evidence to suggest that the culture of a care home directly affects the quality of life of those who live and work there (Reed et al, 1997). A positive culture is characterised as one where the ethos of care becomes and remains centred on the individual, is based on evidence of what makes for good care and is continually effective within a changing health and social care context (Manley et al, 2004). The Six Senses framework developed by Nolan et al (2001) summarises the key principles of 'relationship-centred care' that suggest how the culture of the care home can be improved. This refers to care that recognises and aims to meet the needs of residents, their families, friends and staff who care for them.**

The importance of effective leadership, management and the availability of expert advice to achieve a positive care-home community are paramount. However, access to sufficient resources, particularly staff time, is also essential. The availability of trained and well-motivated staff to meet the needs of residents in care homes is an important aspect of the culture. Team performance will impact on quality of life of residents. Hurtley (2003) highlights the importance of emotional health in the workplace and the interdependence of resident and staff well-being. Ensuring a creative learning environment for staff and residents is necessary to promote person-centred care and the best possible well-being for both staff and residents.

Ronch (2004) believes that we need to change the way we think about older people. The prevalent model in care emphasises the debilitating effects of ageing, which predispose the care staff to take



on the role of custodian – one of 'doing to' the residents. Ronch believes that this devalues staff as much as the residents. She argues the case for adopting a life-span development model whereby both staff and residents' personal growth is valued and there is a shared commitment to ideas, values, goals and management practices by all residents, families and staff.

There is a strong focus in this way of working on the importance of relationships, valuing different perspectives and fostering creativity, learning and innovation. It is posited on a different level of learning within organisations, one which challenges beliefs, as opposed to simply imparting facts or rules.

### Supporting the workforce

Research exploring the relationship between staffing and quality of care has typically suggested a linear relationship. For example, as staffing increases, resident outcomes improve, but 'levels of staffing, expressed as bodies per resident, may not tell the whole story', according to Kane (2004, p. 253). Rather, it is

training and practice development that is key to improvements in the culture of the care home and where there is clearly a link with improved quality of life.

Evidence shows that after undergoing training staff report increased competence, greater self-confidence, enhanced job satisfaction, higher morale, better teamwork, and there is a reduction in the incidence of injury, sickness and absenteeism (Nolan and Keady, 1996).

Evers (2003) contends that overlooking the contribution of carers could be detrimental to the quality of life of residents as the skills staff use ultimately influence the experience of the residents, particularly with the increasing health challenges seen in care homes. She argues that the constraints of a care system built on traditional ways of working and functional tasks, rather than person-centred care, should be questioned.

There is a need for a better-trained and more respected workforce. Evers argues that staff need adequate time to offer care that is based on a sound knowledge and understanding of residents' medical conditions.

Training benefits residents in many ways: it reduces the use of sedation and restraint and is likely to generate more individualised care and enhanced relationships between staff and residents. Overall, knowledge has been seen to improve after training (Deakin and Littley, 2001), which in turn improves practice and makes a difference to resident care (Kenny, 2002).

**Emerging evidence seems to indicate that education and training should be about how staff relate to residents. Both staff registered with the General Social Care Council and its equivalents in Scotland, Wales and Northern Ireland, as well as those not yet registered, need to be educated and trained together so that learning can be a force for change. This is preferable to individual staff members being sent for short courses which are concerned only with specific aspects of their work and which are aimed at qualification.**

Central to this is the principle that residents, relatives and staff should be able to share their experiences of quality of life in care homes, when living and working together, and identifying training needs together with explicit support from management. Closer working relationships are needed between care homes, the local community and institutions of higher and further education to improve quality of life in care homes. We need to recognise that potential has been lost for care homes to be good learning environments for staff. Greater investment in education and training is needed to improve the situation.

Given resource constraints and the difficulty of releasing staff to go for training outside the home, a number of creative learning initiatives have been developed for care homes which are designed either to be delivered in the workplace or as part of a community development initiative.

Brown (2006) demonstrates that offering high-quality experiences for student nurses learning to care for older people nurtures positive perceptions of such work, thus making it a more attractive career option. A good learning environment for students is seen to be one that fosters relationship-centred care based on an understanding of the Six Senses Framework (Nolan et al, 2001: see appendix).

Research into job satisfaction and motivation for care-home staff stresses the interdependence of staff and residents' well-being. It recognises the importance of a management which listens and asks the right questions, and it shows that the development of a learning environment for both staff and residents is necessary to person-centred care and the best possible well-being for both. Furthermore, key values, roles, knowledge and skills must not be assumed. A listening, proactive style of management will encourage open relationships and empower staff to be creative (Hurtley, 2003).



Person-centred care is different from task-orientated care (in itself a defence against emotional involvement). It puts greater emphasis on emotional care, which is particularly needed for those working with people who have dementia, and allows connection, involvement and the promotion of emotional well-being.

**Research shows that good managers:**

- **show an interest in staff and residents;**
- **are approachable;**
- **nurture, care, and conciliate and collaborate;**
- **are unbureaucratic;**
- **show an interest in people's personal lives;**
- **offer people their time;**
- **communicate effectively;**
- **develop a collegiate culture to promote well-being in the workplace.**

*(Ross-Smith, 2005)*

## Other support for staff

In addition to training, other forms of support may also be needed. Care that is not person-centred can result from individual and organisational psychological defences to protect staff from the pain and anxiety associated, as Menzies (1977) has shown, with emotionally traumatic nursing work. We know that the role of care-home staff has become more demanding and complex, particularly if they are working therapeutically rather than simply acting as custodians.

Providing space for reflection and recognition offers staff ways of dealing with the difficulties they encounter (Cotter, 1998; Zagier Roberts, 1994; Halton, 1994). In one example of help given by practitioners a local chaplain supported staff through the more emotional aspects of the work.

Staff need clarity about the goals of care for individual residents and the skills and opportunities to assess whether these goals are achieved. Staff also need to feel that they are appreciated by residents and their families (Campbell, 2003) and by their managers and other staff (Wickes et al, 2004; Perry et al, 2003). Having their work recognised and feeling a sense of achievement are important motivators for care assistants (Pennington et al, 2003; Cronin et al, 1999). Staff have been found to place high value on simple acts such as others saying to them informally that what they did was valued, as well as recognition from colleagues, residents and families (Atkin, 2005).



## Where to now? Next steps in improving the quality of life in care homes

- 1 Debates about quality of life may be complex, but the crux of the matter is that everyone has their own definition of it. This will derive from what, for each of us, makes life meaningful, enjoyable and worth living. Any process seeking to enhance quality of life therefore begins with discussion of individual ideas about quality of life, what contributes to this, ways in which it could be supported, and the individual's priorities within these. For staff, this will mean suspending their personal assumptions about what older people want and paying attention to what they are saying.
- 2 Quality of care needs to be considered within the context of quality of life. Residents must be able to make informed choices about their care and while risk assessments can offer appropriate protection, the outcome of such assessments must not compromise the quality of life of older people living in care homes.

Consequently, the philosophies, strategies, everyday ways of working and methods of evaluation must be capable of reflecting the priorities of each individual service user. In evaluating quality of care we should also acknowledge that different people with an interest in the home – resident, staff member, relative – bring their own insights. New, more positive approaches to quality of care, its provision and its evaluation are emerging which promise better service provision in the future.

- 3 For an older person to move from his or her own home, where they are in control of their surroundings, to a care home can trigger feelings of loss, decline in autonomy and concerns about the future. This review has highlighted how a culture of communication and shared information can be created so that all stakeholders can be involved in decision-making at the earliest stage possible prior to moving to a care home. The National Minimum Standards state that care homes should provide a philosophy of care and offer trial visits to help older people decide which care home to choose. These standards could be extended upon to develop a framework to help smooth the transition into care homes.

- 4** The starting point for helping residents maintain their identity is getting to know them as individuals, and their families, and understanding their lives. It is just as important for managers to be adequately supported to meet the needs of residents, their families, friends and staff. The challenge of providing good-quality, person-centred care, while potentially immensely rewarding, can provoke anxiety and discomfort as staff come to terms with the emotional nature of their work. More research is needed to inform the development, implementation and evaluation of initiatives aimed at preserving the identities of care-home residents. This will add to the growing evidence base for improving the overall quality of life in care homes.
- 5** It is increasingly recognised that each care home develops a distinctive culture, which determines the degree to which individual expectations are met. However, the dominant culture commonly reflects a particular pattern and set of values. Breaking down the barriers between the residents, staff and relatives in care homes can help to create more of a community and improve the quality of life of older people in care homes. Staff and residents have stressed the importance of having adequate time to spend with each other. The care home as community model currently offers most promise for ensuring that the needs of everyone – residents, their families and staff – are reconciled and met as fully as possible. This model requires attention to five essential processes: understanding and respecting the significance of relationships within care homes; recognising roles, rights and responsibilities; creating opportunities for giving and receiving; creating opportunities for meaningful activity; and building an environment that supports community. Care-home policies should be user- and family-friendly and every opportunity should be taken to engage relatives and members of the local community in the life of the home.



- 6** In order for care homes to function as true communities where everyone's contribution is recognised and valued, all those with an interest need to have the opportunity, as expert partners, to be involved in the decisions that affect them, to the extent that they wish to be involved. Care staff should ensure that residents and relatives are provided with opportunities to express their concerns and anxieties at the time of admission and at regular intervals. Shared decision-making requires regular, planned reviews involving the home manager, named nurse, key worker, resident and family members or advocates. Creative methods for disseminating information to all members of the care-home community, such as a regular newsletter, have the potential to ensure that everyone feels involved and allows them to feel a responsibility to identify problems and seek solutions.
- 7** Older people living in care homes clearly have substantial healthcare needs, yet mainstream NHS multi-professional services are not universally available to them. In addition, some residents are being charged for services that are provided under the NHS to users in all other sectors. Primary care trusts should develop systems to make appropriate reimbursement to homes for services which should be provided under the NHS, such as general medical services and physiotherapy. They should also be encouraged to develop new roles and multi-professional teams who



can provide specialist expertise to older care-home residents and also ensure they have access to the full range of services available locally. These teams could also support staff, residents and relatives in order that they develop their skills and knowledge – for example, in the management of medication, rehabilitation and health promotion. This review has highlighted a range of ways in which multi-professional support to care homes can be enhanced, and a variety of projects which demonstrate how this can be achieved. Such initiatives contribute significantly to helping older people to maintain their health, functioning, potential for enjoyment and, ultimately, their quality of life.

- 8** Care homes are complex systems where people are both living and dying, and there is a need to develop a culture of care which values both. Relationship-based care, with the emphasis on personal need and dignity, can facilitate this. Encouraging an open approach to the awareness of dying is a key cultural shift, not just in care homes but in wider social attitudes toward ageing. Many older people need to be given the opportunity to acknowledge death and dying. Palliative care practices for those who are dying are helpful in supporting care homes but more evaluative work needs to be done. Further research is needed on the process of dying, encompassing its emotional and social, as well as physical, elements, and into decisions resulting in residents being admitted to hospital during their last days of life. More evaluative studies



on end-of-life interventions are also necessary, along with a broader debate on how to blend palliative care and care-home practices.

- 9** In order to ensure that the country has a care-home workforce fit for purpose in the future, research needs to track the education and training needs of staff and to share the lessons learned from attempts to improve practice through education: for instance, action-research. Successful creative learning initiatives need to be strategically developed and supported to become part of mainstream practice. Education and training should be about ensuring that the whole workforce learn together at their place of work as part of an initiative to improve quality, rather than simply sending individuals on external courses designed to deliver a qualification and geared to specific areas of work. Working relationships between care homes, the local community and institutions of higher and further education need to be developed. Care homes have lost potential as a good learning environment for staff owing to poor investment in education and training: however, this is the ideal they could be working towards.
- 10** Relationship-centred care should be encouraged by supporting those living, visiting and working in care homes (residents, relatives and staff) to achieve a sense of security, belonging, continuity, purpose, achievement and significance. Quality of life for residents depends greatly upon how the care-home sector is valued by society in general. Working in care homes is often poorly remunerated and seen as low-status. This review has alluded to the blame for poor care often placed on care-home staff, a responsibility that needs to be shouldered by the wider society for the pervasive ageist attitudes that still exist. Care homes should be celebrated for the vital public role that they provide. Care homes should be recognised as a valuable resource to the local community.

## References

- Alzheimer Scotland (2003), *A Positive Choice: choosing long-stay care for a person with dementia*. Alzheimer Scotland, Edinburgh
- Alzheimer Scotland (2005), *Letting Go without Giving Up: continuing to care for the person with dementia*. Alzheimer Scotland, Edinburgh
- Ashburner, C.H. (2005), *Person-centred Care using Systemic Psychodynamically Informed Action Research*. Doctoral thesis. City University, London
- Ashburner, C.H. (2005), *Person-centred Care: change through action research*. Unpublished doctoral thesis. City University, London
- Association of Charity Officers, *General Practice – Special Practice: GP healthcare for older people in care and sheltered accommodation managed by charitable organisations*. ACO, Hertfordshire
- Atkin, M. (2005), *Factors Influencing Staff Turnover in Long-term Care*. Report to Anchor Housing, University of Sheffield
- Aveyard, B. and Davies, S. (2006), Moving forward together: evaluation of an action group involving staff and relatives within a nursing home for older people with dementia. *International Journal of Older People Nursing*. 1: 95–104
- Bajekal, M. (2002), *Health survey for England 2000: Care Homes and Their Residents*. The Stationery Office, London
- Ballard, C., O'Brien, J., James, I. et al (2001), Quality of life for people with dementia living in residential and nursing home care: the impact of performance on activities of daily living, behavioral and psychological symptoms, language skills, and psychotropic drugs. *International Psychogeriatrics*. 13(1): 93–106
- Baradowa et al (2001), A survey of physiotherapy and occupational therapy provision in UK nursing homes. Vol. 15(6). *Clinical Rehabilitation*. Hodder Arnold Journals
- Baum, C.M. (1995), The contribution of occupation to function in persons with Alzheimer's disease. *Journal of Occupational Science*, Australia. 2(2): 59–67
- Baun, M.M. and McCabe, B.W. (2000), The role animals play in enhancing quality of life for the elderly. In A.H. Fine (ed.), *Handbook on Animal-assisted Therapy: theoretical foundations and guidelines for practice*, pp. 237–50. Academic Press, San Diego
- Bebbington, A., Darton, R. and Netten, A. (2001), *Care Homes for Older People. Vol. 2: Admissions, Needs and Outcomes*. PSSRU, Canterbury
- Bowers, B.J., Fibich, B., Jacobson, N. (2001), Care-as-service, care-as-relating, care-as-comfort: understanding nursing home residents' definitions of quality. *The Gerontologist*. 41(4): 539–45
- Bowman et al (2004), A national census of care home residents. Vol. 33. *Age and Ageing*. Oxford University Press
- Boyle, G. (2004), Facilitating choice and control for older people in long-term care. *Health and Social Care in the Community*. 12(3): 212–20
- Brooker, D. (2001), Therapeutic activity. In Cantley C. (ed.), *A Handbook of Dementia Care*, pp.146–59. Open University Press Buckingham.
- Brooker, D. (2004), What is person-centred care in dementia? *Reviews in Clinical Gerontology*. 13: 215–22
- Brown, J. (2006), *Student Nurses' Experience of Learning to Care for Older People in Enriched Environments: a constructivist inquiry*. Unpublished PhD thesis. University of Sheffield
- Burack, O.R., Jefferson, P., and Libow, L.S. (2002), Individualized music: a route to improving the quality of life for long-term care residents. *Activities, Adaptation and Aging*. 27(1): 63–76
- Burgio, LD., Fisher, S.E., Fairchild, J.K., Scilley, K. Hardin, J.M. (2004), Quality of care in the nursing home: effects of staff assignment and work shift. *Gerontologist*. 44(3): 368–77

Burton Jones, J. (2001), *Involving relatives and friends: a good practice guide for homes for older people*. Relatives and Residents Association, London

Campbell, S.L. (2003), Empowering nursing staff and residents in long-term care. *Geriatric Nursing*. 24(3): 170–5

Centre for Policy on Ageing (1996), *A Better Home Life: a code of good practice for residential and nursing home care*, CPA, London

Centre for Policy on Ageing (2001), CPA briefings: Residential care and older people. [http://www.cpa.org.uk/policy/briefings/residential\\_care\\_and\\_older\\_people.pdf](http://www.cpa.org.uk/policy/briefings/residential_care_and_older_people.pdf)

Challis, D. (2000), Dependency in older people recently admitted to care homes. *Age and Ageing*. 29: 255–60

Chaudhury, H. (2003), Quality of life and place-therapy. *Journal of Housing for the Elderly*. 17(1/2): 85–103

Chow, E. (2003), Long-term care: a health promotion challenge. *Perspectives Canada*. 27(2): 16–21

Clarke, A. and Bright, L. (2006), *Relatives and Residents Association*, London

Clelland, J., Scott, D., and McKenzie, D. (2005), An analysis of allied health professional training in care homes for older people in Glasgow. *Quality in Ageing – policy, practice and research*. 6(3): 24–36

Cole, A. and Williams, H. (2004), Life story work as an aid to well-being. *Signpost*. 9(2): 14–18

Cook, G. (2005), *Living with Care Rather Than as an Object of Care: a hermeneutic inquiry of life as a care home resident*. Forthcoming PhD thesis. Northumbria University

Cookman, C.A. (1996), Older people and attachment to things, places, pets, and ideas. *Image: Journal of Nursing Scholarship*. 28(3): 227–31

Cotter, A. (1998), A new lease of life. *Nursing Times*. 94(20), 58–9

Counsel and Care Moving to Quality (1999), *Building on the success of 'Home in on Quality', this pack sets out to help staff in homes achieve high standards in care*. Counsel and Care, London

Counsel and Care (2001), *Residents Taking Risks: minimising the use of restraint – a guide for care homes*. Counsel and Care, London

Crain, M. (2001), Control beliefs of the frail elderly. *Care Management Journals*. 3(1): 42–6

Cronin, A., Fee, L., Simmons, R. & Choudry, S. (1999), *Assessing Older People's Health and Social Needs*. Health Education Authority, London

Dalley, G. et al (2004), *How Do We Care? The availability of registered care homes and children's homes in England and their performance against National Minimum Standards 2002–2003*.

National Care Standards Commission, The Stationery Office, London

Dalley, G. and Denniss, M. (2001), *Trained to Care? Investigating the skills and competencies of care assistants in homes for older people*. Centre for Policy on Ageing, London

Davies, S. (2001a), *Relatives' Experiences of Nursing Home Entry: a constructivist inquiry*. Unpublished PhD thesis. University of Sheffield

Davies, S. (2001b), The care needs of older people and family caregivers in continuing care settings. In Nolan, M., Davies, S., Grant, G. *Working with Older People and their Families: key issues in policy and practice*, pp. 75–98. Open University Press, Buckingham

Davies, S., Darlington, E., Powell, A. and Aveyard, B. (2003), Developing partnerships at 67 Birch Avenue Nursing Home: the support 67 Action Group. *Quality in Ageing: policy, practice and research*. 4(4): 32–7

Davies, S. (2003), Creating community: the basis for caring partnerships in nursing homes. In Nolan, M., Grant, G., Keady, J., and Lundh, U. (eds.), *Partnerships in Family Care*, pp. 218–37. Open University Press, Maidenhead

- Davies, S. (2003), Creating community: the basis of caring partnerships in nursing homes. In M. Nolan, S. Davies, G. Grant (eds.), *Working with Older People and their Families: key issues in policy and practice*. Open University Press, Buckingham
- Davies, S. and Nolan, M. (2003), 'Making the best of things': relatives' experiences of decision about care-home entry. *Ageing and Society*. 23: 429–50
- Davies, S. and Nolan, M. (2004), 'Making the move': relatives' experiences of the transition to a care home. *Health and Social Care in the Community*. 12(6): 517–26
- Davies, S. and Nolan, M. R. (2006), 'Making it better': self-perceived roles of family caregivers of older people living in care homes; a qualitative study. *International Journal of Nursing Studies*. 43(2): 281–91
- Deakin, T.A. and Littley, M.D. (2001), Diabetes care in residential homes: staff training makes a difference. *Journal of Human Nutrition and Dietetics*. 14: 443–7
- Dench, S. and Regan, J. (2000), *Learning in Later Life: motivation and impact*. Department for Education and Employment Research Report RR183
- Department of Health (2002b), The residential care and nursing home sector for older people: an analysis of past trends, current and future demand. <http://www.dh.gov.uk/assetRoot/04/05/94/83/04059483.pdf>
- Department of Health (2001), *National Service Framework for Older People*. Department of Health, London
- Dewar, B., Tocher, R., Watson, W. (2003), Enhancing partnerships with relatives in care settings. *Nursing Standard*. 17(40): 33–9
- Eales, J. et al (2001), Seniors' Experiences of client-centred residential care. *Ageing and Society*. 21(3): 279–96
- Eborall, C. (2005), *The State of the Social Care Workforce 2004*. Second Skills Research & Intelligence annual report. Skills for Care, Leeds
- Edwards, H., Courtney M. and Spencer L. (2003), Consumer expectations of residential aged care: reflections on the literature. *International Journal of Nursing Practice*. 9(2): 70–7
- Ellershaw, J., Wilkinson, S. (2003), *Care of the Dying: a pathway to excellence*. Oxford University Press
- Eyers, I. (2003), *Meeting the Needs of Older People? A comparative study of care home staff in England and Germany*. University of Surrey PhD
- Fletcher, J. (2000), The role of the resident: a personal view. *Nursing and Residential Care*. 2(3): 114–16
- Forte, D., Cotter, A. and Wells, D. (2006), Sexuality and relationships in later life. In S.J. Redfern and F.M. Ross (eds.), *Nursing Care of Older People*, pp. 437–55. Elsevier Churchill Livingstone, Edinburgh
- Froggatt, K. (2001), Palliative care and nursing homes: where next? *Palliative Medicine*. 15: 42–8
- Ghusn, H.F., Hyde, D., Stevens, E.S., Hyde, M., Teasdale, T.A. (1996), Enhancing satisfaction in later life: what makes a difference for nursing home residents? *Journal of Gerontological Social Work*. 26(1/2): 24–47
- Glendinning, C., Jacobs, S., Alborz, A., Hann, M. (2002), A survey of access to medical services in nursing and residential homes in England. *British Journal of General Practice*. 52, 545–8
- Goldsmith, M. (1996), *Hearing the Voices of People with Dementia: opportunities and obstacles*. Jessica Kingsley, London
- Grau, L., Chandler, B., Saunders, C. (1995), Nursing home residents' perceptions of the quality of their care. *Journal of Psychosocial Nursing and Mental Health Services*. 33(5): 34–43
- Gubrium, J. (1993), *Speaking of Life: horizons of meaning for nursing home residents*, pp. 128–9. Aldine de Grueter, New York
- Halton, W. (1994), Some unconscious aspects of organizational life: contributions from psychoanalysis. In A. Obholzer and V. Zagier Roberts (eds.), *The Unconscious at Work: individual and organizational stress in the human services*,

pp. 11–18. Routledge, London

Hanson, J., Kellaher, L., Rowlands, M., Percival, J., Marcoux, J. and Zako, R. (2003), *Profiling the housing stock for older people from domesticity to caring*.

[http://www.bartlett.ucl.ac.uk/research/space/housingfutures/2-EQUAL/UCL\\_EQUAL.pdf](http://www.bartlett.ucl.ac.uk/research/space/housingfutures/2-EQUAL/UCL_EQUAL.pdf)

Help the Aged (2005), *Care Homes: helping you to help yourself*. Help the Aged, London

Henwood, M. (2001), *Future Imperfect: report of the King's Fund care and support worker inquiry*. King's Fund, London

Heymanson, C. (2003), Sexuality and intimacy in care homes. *Journal of Dementia Care*. 11(5): 10–11

Hockley, J., Dewar, B. and Watson, J. (2005), Promoting end-of-life-care in nursing homes using an 'integrated care pathway for the last days of life'. *Journal of Research in Nursing*. 10(2): 135–52

House of Commons Health Committee (2005), Select Committee on Health: Sixth Report. <http://www.publications.parliament.uk/pa/cm200405/cmselect/cmhealth/399/39902.htm>

Hurtley, R. (2003), *Job Satisfaction and Motivation for Staff in Long-term Care*. University of Surrey MSc

Institute for Jewish Policy Research (2002), *Facing the Future: the provision of long-term care facilities for older Jewish people in the United Kingdom* [http://www.jpr.org.uk/Reports/PJC\\_Reports/no\\_1\\_2002/main2.htm](http://www.jpr.org.uk/Reports/PJC_Reports/no_1_2002/main2.htm) Accessed 2/11/2005

Johnston, D. and Mayers, C. (2005), Spirituality: a review of how occupational therapists acknowledge, assess and meet spiritual needs. *British Journal of Occupational Therapy*. 68(9): 386–92

Kane, R. (2004), Commentary: nursing home staffing – more is necessary but not necessarily sufficient. *Health Services Research*. Vol. 39, p. 251

Kane, R.A., Caplan, A.L., Urv-Wong, E.K., Freeman, I.C., Aroskar, M.A., Finch, M. (1997), Everyday matters in the lives of nursing home residents: wish for and perception of choice and control. *Journal of the American Geriatrics Society*. 45(9): 1086–93

Katz, J. (2003), Managing dying residents. *End of Life in Care Homes: a palliative care approach*. Katz and S. Peace (eds.). Oxford University Press

Kellaher, L. (2000), *A Choice Well Made: mutuality as a governing principle in residential care*. Centre for Policy on Ageing/Methodist Homes, London

Kellett, U.M. (2000), Bound within the limits: facing constraints to family caring in nursing homes. *International Journal of Nursing Practice*. 6: 317–23

Kenny, C. (2002), Care home staff denied training. *Nursing Times*. 98(40)

Kiely, D., Flacker, J. (2003), The protective effect of social engagement on 1-year mortality in a long-stay nursing home population. *Journal of Clinical Epidemiology*. 56: 472–8

King's Fund (2004), *Care Services Inquiry Factsheet*. King's Fund, London

Klein, W.C. and Jess, C. (2002), One last pleasure? Alcohol use among elderly people in nursing homes. *Health and Social Work*. 27(3): 193–203

Komaromy, C., Sidell, M. and Katz, J.T. (2000), The quality of terminal care in residential and nursing homes. *International Journal of Palliative Nursing*. 6(4): 192–200

Kristjanson, L. et al (2005), The experience of supporting a dying relative: reflections of caregivers. *Progress in Palliative Care*. Vol. 13, no. 6, December 2005, pp. 319–25(7)

Laing and Buisson (2004a), *Laing's Healthcare Market Review 2004–2005, incorporating the Fitzhugh directory of independent healthcare financial information*. 17th edn. Laing and Buisson, London

- Laing and Buisson (2004b), Long-term care. <http://www.laingbuisson.co.uk/longtermcare.htm>
- Laird, C. (1982), *Limbo: a memoir of life in a nursing home by a survivor*.
- Lewin, M. (2002), 'What I want is a double bed': person-centred planning and the development of community links in a residential home for older people. The City of Edinburgh Council, Edinburgh
- Manley, K., et al (2004), *Changing Patients' Worlds through Nursing Practice Expertise*. Royal College of Nursing Institute, London
- Marshall, M.J., Hutchinson, S.A. (2001), A critique of research on the use of activities with persons with Alzheimer's disease: a systematic review. *Journal of Advanced Nursing*. 35(4): 488–96
- Mattiasson, A. and Andersson, L. (1997), Quality of nursing home care assessed by competent nursing home patients. *Journal of Advanced Nursing*. 26(6): 1117–24
- McGilton, K., O'Brien-Pallas, L., Darlington, G., Evans, M., Wynn, F. and Pringle, D. (2003), Effects of a relationship-enhancing programme of care on outcomes. *Journal of Nursing Scholarship*. 35(2): 151–6
- McKee, K., Downs, M., Gilhooly, M., Gilhooly, K., Tester, S. and Wilson, F. (2005), Frailty, identity and the quality of later life. In *Understanding Quality of Life in Older Age*, A. Walker (ed.), pp. 117–29. Open University Press, Maidenhead
- Mee, J. and Sumison, T. (2001), Mental health clients confirm the motivating power of occupation. *British Journal of Occupational Therapy*. 64(3): 121–8
- Menzies, I.E.P. (1977), *The Functioning of Social Systems as a Defence against Anxiety*. Tavistock Institute of Human Relations, London
- Meyer, J., Lowe, E., and O'Callaghan, J. (2006), *Partnership with Care Homes Project*. Unpublished interim report. City University, London
- Mold, F., Fitzpatrick, J.M. and Roberts, J.D. (2005a), Minority ethnic elders in care homes: a review of the literature. *Age and Ageing*. 34(2): 107–13
- Mold, F., Fitzpatrick, J.M. Roberts, J.D. (2005b), Caring for minority ethnic older people in nursing care homes. *British Journal of Nursing*. 41(11): 601–6
- Netten, A., Bebbington, A., Darton, R. and Forder, J. (2001), *Care Homes for Older People*. Vol. 1. *Facilities, Residents and Costs*. PSSRU, Canterbury
- Netten, A., Darton, R. and Williams, J. (2003a), Nursing home closures: effects on capacity and reasons for closure. *Age and Ageing*. 32(3): 332–7
- Netten, A., Darton, R. and Williams, J. (2003b). Roles, quality and cost of care homes. *PSSRU Bulletin 14*. 20–1
- NIACE (2000), *Learning in the Fourth Age: fourth age learning report*, DfEE, London
- Nolan, M., Dellasega, C. (1999), 'It's not the same as him being at home': creating caring partnerships following nursing home placement. *Journal of Clinical Nursing*. 8(6): 723–30
- Nolan, M.R. and Keady, J. (1996), Training in long-term care: the road to better quality, *Reviews in Clinical Gerontology*. 6: 333–42
- Nolan, M., Davies, S., Grant, G. (2001), *Working with Older People and their Families: key issues in policy and practice*. Open University Press, Buckingham
- Noone, I., Fan, C.W., Tarrant, H. (2001), What happens to stroke patients after hospital discharge? *Irish Medical Journal*. 94: 151–2
- O'Dea, G., Kerrison, S.H., Pollock, A.M. (2000), Access to health care in nursing homes: a survey in one English health authority. *Health and Social Care in the Community* 8(3): 180–5

O'Dea, G. et al (2001), Regulating nursing homes: caring for older people in the private sector in England. *British Medical Journal*. 323(7312): 566–9.

Office of Fair Trading (2005), *Care Homes for Older People in the UK*. A market study. Office of Fair Trading, London

Office of Fair Trading (2005), *Survey of Older People in Care Homes. Annexe F*. Office of Fair Trading, London

Oleson, M. and Shadick, K.M. (1993), Application of Moos and Schaefer's (1986) model to nursing care of elderly persons relocating to a nursing home. *Journal of Advanced Nursing*. 18: 479–85

Orchard, H., Clark, D. (2001), Tending the soul as well as the body: spiritual care in nursing residential homes. *International Journal of Palliative Nursing*. 7: 541–6

Parker, C., Barnes, S., McKee, K., Morgan, K., Torrington, J., Tregenza, P. (2004), Quality of life and building design in residential and nursing homes for older people. *Ageing and Society*. 24: 941–62

Parsons, S., Simmons, W., Penn K., Furlough, M. (2003), Determinants of satisfaction and turnover among nursing assistants: the results of a statewide survey. *Journal of Gerontological Nursing*. 29(3): 51–8

Peace, S. and Holland, C. (2001), *Inclusive Housing in an Ageing Society: innovative approaches*. The Policy Press, Bristol

Peace, S., Kellaheer, L. and Willcocks, D. (1997), *Re-evaluating Residential Care*. Open University Press, Buckingham

Pennington et al (2003), The role of certified nursing assistants in nursing homes. *Journal of Nursing Administration*. 33(11): 578–84

Perrin, T. and May, H., (2000), Developmental model of practice for dementia care. In *Well-being in Dementia*. Churchill Livingstone, London

Perry, M., Carpenter, I., Challis, D., Hope, K. (2003), Understanding the roles of registered nurses and care assistants in UK nursing homes. *Journal of Advanced Nursing*. 42(5): 497–505

Pillemer, K., Suito, J., Henderson, C. et al (2003), A co-operative communication intervention for nursing home staff and family members of residents. *The Gerontologist*. 43 Special Issue II, 96–106

Quilliam, B.J., Lapane, K.L. (2001), Clinical correlates and drug treatment of residents with stroke in long-term care. *Stroke*. 32: 1385–93

Rantz, M.J., Zwygart-Stauffacher, M., Popejoy, L., Grando, V.T., Mehr, D.R., Hicks, L.L., Conn, V.S., Wipke-Tevis, D., Porter, R., Bostick, J. and Maas, M.M. (1999), Nursing home care quality: a multidimensional theoretical model integrating the views of consumers and providers. *Journal of Nursing Care Quality*. 14(1): 16–37

Rantz, M.J., Grando, V., Conn, V., Zwygart-Stauffacher, M., Hicks, L., Flesner, M., Scott, J., Manion, P., Minner, D., Porter, R., Maas, M. (2003), Innovations in long-term care. Getting the basics right: care delivery in nursing homes. *Journal of Gerontological Nursing*. 29(11): 15–25

Reed, J. et al (2002), Going home from hospital – an appreciative inquiry study. *Health and Social Care in the Community*. 10(1): 35–45

Reed, J. and Payton, V. R. (1996), Constructing familiarity and managing the self: ways of adapting to life in nursing and residential homes for older people. *Ageing and Society*. 16(5): 543–60

Reed, J., Payton, V. (1997), Understanding the dynamics of life in care homes for older people. Implications for de-institutionalising practice. *Health and Social Care in the Community*. 5(4): 261–8

Richards, K.C., Beck, C., O'Sullivan, P.S., Shue, V. (2005), Effect of Individualized Social Activity on Sleep in Nursing Home Residents with Dementia. *Journal of the American Geriatrics Society*. 53(9): 1510–17

- Richards, K.C., Beck, C., O'Sullivan, P.S., Shue, V. (2005), Effect of Individualized Social Activity on Sleep in Nursing Home Residents with Dementia. *Journal of the American Geriatrics Society*. 53(9): 1510–17
- Roe, B., Whattam, M., Young, H., Dimond, M. (2001), Elders' perceptions of formal and informal care: aspects of getting and receiving help for their activities of daily living. *Journal of Clinical Nursing*. 10(3): 398–405
- Ronch, J.L. (2004), Changing Institutional Culture: can we re-value the nursing home? *Journal of Gerontological Social Work*. 43(1): 61–82
- Ross-Smith, Chesterman C., Peters, M. (2005), 'Watch out, here comes feeling!' Women executives and emotion work. *International Journal of Work Organisation and Emotion*. Vol 1, no 1, pp. 48–66
- Rowles, G.D., High, D.M. (2003), Family involvement in nursing home facilities: a decision-making perspective. In Stafford, P.B. (ed.) *Gray Matters: ethnographic encounters with nursing home culture*. School of American Research Press, Santa Fe, pp.173–201
- Rowles et al (1996), Individualizing care: Family roles in nursing home decision-making, *Journal of Gerontological Nursing*. 22: 20–5
- Royal College of Nursing (2004), *The Future Nurse: evidence of the impact of registered nurses 2004*. Royal College of Nursing, London
- Royal College of Physicians, Royal College of Nursing, British Geriatrics Society (2000), *The Health and Care of Older People in Care Homes: a comprehensive interdisciplinary approach: a report of a joint working party*. Royal College of Physicians, London
- Sackey, C.M., Dewey, M.E. (2001), Recovery from severely disabling stroke. *Clinical Rehabilitation*. 15, 4, 455
- Sackley, C.M., Copley Atkinson, J., Walker, M.F. (2004), Occupational therapy in nursing and residential care settings: a description of a randomised controlled trial intervention. *British Journal of Occupational Therapy*. 67, 3, 104–10
- Sandberg, J., Lundh, U. and Nolan, M.R. (2001), Placing a spouse in a care home: the importance of keeping *Journal of Clinical Nursing*. 10, 406–16
- Sapp, S. (2004), Well-being in older people: the role and importance of religion and spirituality. *Signpost*. 9(2): 9–14
- Savishinsky, J. S. (1991), *The Ends of Time: life and work in a nursing home*. Bergin and Garvey, New York
- Seymour, J.E., Hanson L. (2001), Palliative care for older people. In M. Nolan, S. Davies and G. Grant, *Working with Older People and Their Families*. Open University Press, Buckingham
- Sidell, M. (2003), The training needs of carers. In Katz, J.S., Peace, S.M. (eds.), *End of Life in Care Homes: a palliative care approach*. Oxford University Press
- Sidell, M. and Komaromy, C. (2003), Who dies in care homes for older people? In Katz, J.S., Peace, S.M. (eds.), *End-of-life Care in Care Homes: a palliative care approach*. Oxford University Press
- Social Care Institute for Excellence (2004), *Terminal Care in Care Homes*, Report 10. [www.scie.org.uk/publications/briefings/briefing10/](http://www.scie.org.uk/publications/briefings/briefing10/)
- Soulsby, Jim Malin, Eirwen, and Griffiths, John (2004), *Mapping Learning Opportunities for Older People: guidelines and a toolkit for mapping learning opportunities*. NIACE Dysgu Cymru, Cardiff
- SPAIN (2005), *What Price Care in Old Age? Three years on from SPAIN's 'Underfunding of social care' paper, what has changed?* Help the Aged, London
- Springfield, F. (2002), Lesbians, gays and transsexuals in care homes. *Nursing and Residential Care*. 4(12): 586–8
- Stafford, P.B. (2003), Homebodies: voices of place in a North American community. In Stafford, P.B. (ed.), *Gray Matters: ethnographic encounters with nursing home culture*, School of American Research Press, Santa Fe, pp. 121–52



Stone, R.I., Reinhard, S.C., Bowers, B., Zimmerman, D., Phillips, C.D., Hawes, C., Fielding, J.A. and Jacobson, N. (2002), *Evaluation of the Wellspring Model for Improving Nursing Home Quality*. The Commonwealth Fund [www.cmwf.org](http://www.cmwf.org)

Storey, L., Pemberton, C. and O'Donnell, L. (2003), Place of death: Hobson's choice or patient choice? *Cancer Nursing Practice*. 2(4): 33–8

Sumaya-Smith, I. (1995), Caregiver/resident relationships: surrogate family bonds and surrogate grieving in a skilled nursing facility. *Journal of Advanced Nursing*. 21(3): 447–51

Teresi, J., Holmes, D., Benenson, E., Monaco, C. Barrett, V., Ramirez, M., Koren, M.J. (1993), A primary care nursing model in long-term care facilities: evaluation of impact on affect, behavior, and socialization. *Gerontologist*. 33(5): 667–74

Tester, S., Hubbard, G., Downs M. et al (2003), Perceptions of quality of life of frail older people in care homes. *Unsettling the Ordinary: changing ideas about ageing*. The 32nd annual conference of the British Society of Gerontology, Newcastle upon Tyne, 4–6 September 2003

Tester, S., Hubbard, G. Downs, M., MacDonald, C., Murphy, J. (2004), What does quality of life mean for frail residents? *Nursing and Residential Care*. 6(2): 89–92

Thomas, K. (2003), *Caring for the Dying at Home*. Radcliffe Medical Press, Abingdon

Wagner Committee (1988), *Residential Care: a positive choice*. A report of an independent review of residential care, HMSO, London

Wells, D. (2005), Biographical and developmental approaches. In H. Heath and R. Watson (eds.), *Older people: assessment for health and social care*. Age Concern, Glasgow

Wicke, D., Coppin, R., Payne, S. (2004), Teamworking in nursing homes. *Journal of Advanced Nursing*. 45(2): 197–204

Wilson, H. (2004), *Thinking Outside the Tickboxes: a report of a programme of training in person-centred practice within services for older people*. Unpublished report

Zagier Roberts, V. (1994), Till death do us part: caring and uncaring in work with the elderly. In A. Obholzer and V. Zagier Roberts (eds.), *The Unconscious at Work: individual and organizational stress in the human services*. Routledge, London, pp. 75–83

Zimmerman, S., Sloane, P.D., Williams, C.S., Reed, P.S., Preisser, J.S., Eckert, J.K., Boustani, M., Dobbs, D. (2005), Dementia care and quality of life in assisted living and nursing homes. *The Gerontologist*. Special Issue No.1, 133–46

[www.ageconcern.org.uk/bookshop](http://www.ageconcern.org.uk/bookshop)

[www.napa-activities.net](http://www.napa-activities.net)

<http://www.agecare.org.uk/>

<http://www.jcn.co.uk>

# Appendix I

## Selected useful resources

A more extensive list of resources is provided within the PDF report *A Review of Evidence on Quality of Life in Care Homes*, produced for the My Home Life Programme and available via [www.helptheaged.org.uk](http://www.helptheaged.org.uk).

### Activity

- The National Association of Providers of Activities for Older People exists to put activity at the heart of care and to increase the status of activity providers. It provides training, research and publications, regional groups, sharing days and a newsletter for members. [www.napa-activities.net](http://www.napa-activities.net)
- A range of training and resources is available, including a leadership development certificate in Providing Therapeutic Activities for Older People (City and Guilds 6977 [www.city-and-guilds.co.uk](http://www.city-and-guilds.co.uk)) Level 3 NVQ and, for all engaged in providing meaningful activities, Provision of Activities in a Care Setting (Network Training [www.enquiries@network-publishing.co.uk](mailto:www.enquiries@network-publishing.co.uk)) Level 2 NVQ
- *The Successful Activity Co-ordinator*, a learning resource providing information and ideas for developing an ability-focused 'active care home', is available via [www.ageconcern.org.uk/bookshop](http://www.ageconcern.org.uk/bookshop).

### Community

- Burton-Jones (2001) provides some excellent ideas for ways in which staff can involve relatives and friends in the life of the home.

## Access to health services

- A project in Flintshire has successfully developed multi-disciplinary working to offer regular health reviews with residents, which not only improved the health and well-being of people resident in nursing homes but also delivered financial benefits resulting from savings following medication reviews. <http://www.jcn.co.uk>

### End-of-life care

- Macmillan Cancer Relief Foundations in Palliative Care. A programme for facilitated learning for care homes ([www.macmillan.org.uk](http://www.macmillan.org.uk))
- *Gold Standard Framework* (Thomas 2003)
- *Preferred Place of Care Initiative* (Storey, Pemberton et al, 2003)
- *The Bridges Project: individual care pathways for care homes* (Hockley et al, 2005).

### Culture change

- *The Wellspring Model*: Stone et al (2002)
- *An action-research study in a nursing home that aimed to promote a positive culture of care in a care home for people with dementia*. Davies et al (2003)
- Quality of end-of-life care was the focus of improvement in eight nursing homes in Scotland using an integrated care pathway. Hockley et al (2005).

### Identity

- Cole and Williams (2004): Guidance on compiling life diaries with people with dementia is provided in the booklet *Why Make a Life Diary?*
- An approach that featured 'place' as a theme for reminiscence work used residents' photographs taken at their homes together with their own stories. This was successful in triggering memories in care-home residents with dementia (Chaudhury, 2003)
- Mold et al (2005a) reviewed best-practice guidelines in relation to minority ethnic older people in care homes.

### Training and development

- The Care Homes Training Collaborative is a work-based model of training offering diagnostic Skills for Life assessment together with a personal development/individual action plan
- Care Homes Learning Networks, developed in partnership with the University of the West of England, offer a network for care homes to improve and enhance the quality of care, develop their workforces, introduce research, and support student placements
- Allied Health Professional Input: Clelland et al (2005) report an interesting initiative through which an Allied Health Professional Care Homes training team in Glasgow provided 648 care staff with training
- Teaching packages on mental health: 23 care homes in Gloucestershire provide training tailored to educational needs based on pre-training assessment
- Agecare Awards Programme covers the entire range of the sector's staff, from core skills training for care assistants and ancillary staff, through supervisory and specialist levels, to a 'higher practice' grade for physicians and senior managers. The programme has been recognised through numerous awards.  
<http://www.agecare.org.uk/>

## Appendix II

### The state of play: care homes in the UK today

**It is estimated that there are about 486,000 places in care homes across the UK (Laing and Buisson, 2004a). Over the past 20 years the balance between the different types of providers has changed. The number of homes owned by local authorities has fallen drastically (Dalley et al, 2004) and the private sector is now the major provider (Bebbington et al, 2001).**

Not-for-profit organisations continue to run a significant minority of homes. Within the private sector, while the proportion of beds supplied by the major providers has increased over the past 10 years, from 6 per cent to more than 22 per cent, 54 per cent of homes are still single-home businesses and 8 per cent of small businesses run only two or more homes (Office of Fair Trading, 2005).

The average care home in the UK has about 30 places. Some 89 per cent of beds in local authority and voluntary residential homes are in single rooms. In other types of home this falls to about 65–69 per cent (Netten et al, 2001). Residents' rooms can be as small as 10 square metres in size, which is notably smaller than a typical student room or a prison cell (Hanson et al, 2003).

#### Demand

Until 1993 there was a rapid expansion in the number of care homes. This was fuelled both by an ageing population and by open-ended income support funding. Since then, capacity has fallen by 15.5 per cent from its peak in 1996. Demand has also fallen by 12.4 per cent during the same period (Office of Fair Trading, 2005). However, it is believed that over the next 50 years the

number of places would need to expand by about 150 per cent to meet the demand of our increasingly ageing population. Clearly, this is heavily influenced by government policy, which at present is placing the emphasis on providing alternative forms of care in people's own homes (Office of Fair Trading, 2005).

The availability of care homes varies across the country. For example, London has only two-thirds of the places which it might be expected to have for the proportion of older people in its population. A number of organisations have highlighted a serious shortage of services for those with mental health problems, including dementia and depression (King's Fund, 2004; SPAIN, 2005).

Nationally, care homes have an occupancy rate of over 92 per cent (Laing and Buisson, 2004b). The Social Policy on Ageing Information Network (2005) argues that that the actual occupancy rate should be lower so that 'spare places' could offer choice for prospective residents, short-term respite placements and discharges from the NHS or intermediate care.

#### The circumstances of residents in care homes

The proportion of older people who live in long-term care is only 4 per cent (Bajekal, 2002). Older people admitted to homes are typically over 80 years old, female, unmarried, living alone, and live in a house rented from the local authority or housing association. They are in receipt of Income Support and Housing Benefit, and Attendance Allowance, and live in a poorer neighbourhood.

Among the many reasons why people enter residential care are functional disablement (42 per cent); carer stress (38 per cent); abuse (2 per cent); loneliness (2 per cent); and homelessness (1 per cent) (Office of Fair Trading, 2005). Illnesses associated with admission include dementia (38 per cent), arthritis (32 per cent) and cardiovascular disease/stroke (20 per cent). Other illnesses and

disabilities include respiratory disease, deafness, depression, fractures and blindness.

According to Bowman et al (2004):

- over 50 per cent of residents have dementia, stroke or other neuro-degenerative illnesses or diseases;
- 76 per cent require assistance with mobility or are immobile; and
- 71 per cent are incontinent.

There is also evidence that people admitted to care homes are increasingly older (aged 80 and over) and considerably more dependent than was the case a decade ago (Netten, 2001).

Very little is known about the extent to which existing services are used by people from black and minority ethnic groups. In one survey, only 1.2 per cent of residents were from an ethnic minority group. In general, BME service users are more likely to be younger; male; living with their family prior to admission; have a higher incidence of cognitive impairment, dementia and incontinence; and be generally more dependent. They are also more likely to be admitted for a mental health problem, or problems with their housing or carers, rather than for a physical health problem (Bebbington et al, 2001).

### Staffing and skill mix

According to Eborall (2005), the social care workforce in care homes is predominantly female (over 95 per cent); part-time working is common (50 per cent); and settings for older people tend to employ older workers. The lowest-paid care workers earn similar amounts to retail-sector cashiers and check-out operators. While the great majority of staff provide humane and empathetic care, inevitably the lack of training they receive often results in technical, attitudinal and coping deficiencies (Henwood, 2001).

Recruitment and retention of care-home staff, both qualified and unqualified, is a major issue, especially in areas where the cost of living is high (King's Fund, 2004). Netten et al (2003a) found that a lack of qualified nursing staff was

the factor most frequently cited for care-home closures, arguing that unless there are marked increases in care staff wages, something that care homes can ill afford at present, recruitment and retention will continue to be a problem.

Little is known about current levels of training for care assistants. Netten et al (2001) found that two-thirds of homes in their survey had staff with NVQs or BTEC awards, while many other members of staff were working towards such qualifications. Another survey, by Dalley and Denniss (2001), found that at least 20 per cent of all care assistants had some form of additional training qualification – for example, at NVQ level.

There was also a requirement that by 2005 a minimum of 50 per cent of care staff should be trained to a minimum of NVQ level 2 or equivalent, and for all homes to demonstrate staff training and development. However, by 2004 only 22 per cent of private and voluntary care homes in England had achieved this target, while progress among the remainder is variable (Laing and Buisson, 2004a).

### Funding

The cost of residential and nursing-home care is divided between the state and the individual, with the amount each has to pay determined by means-testing. One of the most recent government policies to impact on care-home fees has been the decision, in the case of England and Wales, to make nursing care free to everyone, but not 'personal' care. In Scotland the decision was taken that both personal and nursing care would be funded by the state. However, 'hotel' costs still have to be met by the resident.

The latest review by Laing and Buisson (2004a) found that in April 2004 61 per cent of independent care-home residents were having their fees paid by local authorities and 33 per cent were financing themselves.

If the baseline fees paid by the local authority do not cover the entire cost of the fees charged by the care home, it is possible for a third party, often a family member, to pay a top-up fee. The Office of Fair Trading (2005) estimates that about 35 per cent of those receiving state funding are also being topped up by a third party.

The average fees across the UK in 2002–3 are £496 a week for nursing homes and £345 a week for residential homes, although charges in London and the South-East are significantly higher (Dalley et al, 2004). It has also been found that those paying their own fees are often charged up to £50 to £100 more (Laing and Buisson, 2004a). This suggests that a number of providers are subsidising the inadequate levels of funding they receive from local authorities by increasing the fees of those who fund themselves.

Funding is a continual problem, with local authorities claiming that central government funding has been inadequate over a long period of time, yet ministers have maintained that councils are provided with sufficient funds to enable them to carry out their duties. SPAIN (2005) believes that this problem stems from the insufficient money transferred from the Department of Health and Social Security to local authorities at the time of the Community Care Act 1990. While local authorities have received increased allocations, it remains open to debate whether these increases have been sufficient to cover the additional pressures of demand, wage costs and inflation (Laing and Buisson, 2004a; SPAIN, 2005).

## The closure of care homes

Between December 2001 and April 2003 745 care homes in the independent sector closed. Closure is usually precipitated by a number of factors. These include low levels of fees for residents funded by local authorities; the cost implications of the National Minimum Standards; disillusionment with the long-term care sector; retirement; increases in running costs such as

wages; the expectation that future local authority fees would not cover costs; and problems with recruitment and retention of staff (Netten et al, 2003b; Department of Health, 2002b).

Unless the effect of market forces, such as the cost of meeting the minimum standards, high land and building costs and the problems of recruiting staff, begin to be tackled – through, for example, improvements in fees paid by local authorities – the likelihood is that, for the time being, care homes, especially the smaller ones, will continue to close (Netten et al, 2003b; SPAIN, 2005).

With sufficient political commitment none of these factors ought to present insuperable problems, even though they are tough challenges. In part, they rely on the willingness to commit greater resources to the sector. But they also demand a vast cultural change. Residential care has never enjoyed high public esteem or even much public or political interest. It may cater for only a tiny percentage of the older population, but that 4 per cent represents over 400,000 individuals. Standing behind them is a very significant part of the social care workforce – largely unqualified and certainly underpaid, yet, perhaps against the odds, providing high-quality care for what has become an increasingly vulnerable, frail and dependent group of people.

Eighteen years ago, the Wagner committee (*Residential Care: a positive choice*, 1988) said that residential care should and could be ‘a positive choice’. The landscape of the sector has changed vastly since then but such a choice should still be available both for those who live in care homes and those who work in them.

## Appendix III

### The six senses in the context of caring relationships

<b>A sense of security</b>	
For older people	Attention to essential physiological and psychological needs to help feel safe and free from threat, harm, pain and discomfort. To receive competent and sensitive care.
For staff	To feel free from physical threat, rebuke or censure. To have secure conditions of employment. To have the emotional demands of work recognised and to work within a supportive but challenging culture.
For family carers	To feel confident in the knowledge and ability to provide good care without detriment to personal well-being. To give adequate support networks and timely help when required. To be able to relinquish care when appropriate.
<b>A sense of continuity</b>	
For older people	Recognition and value of personal biography. Skilful use of knowledge of the past to help contextualise the present and future. Seamless, consistent care delivered within an established relationship by known people.
For staff	Positive experience of work with older people from an early stage of career, exposure to good role models and environments of care. Expectations and standards of care communicated clearly and consistently.
For family carers	To maintain shared pleasures and pursuits with the person in the care home. To be able to provide competent standards of care, whether delivered by self or others. To ensure that personal standards of care are maintained by others. To maintain involvement in care across care environments as desired or appropriate.
<b>A sense of belonging</b>	
For older people	Opportunities to maintain and/or form meaningful reciprocal relationships. To feel part of a community or group as desired.
For staff	To feel part of a team with a recognised and valued contribution. To belong to a peer group, a community of those who work with older people.
For family carers	To be able to maintain and improve valued relationships. To be able to confide in trusted individuals in order not to feel isolated.

<b>A sense of purpose</b>	
For older people	Opportunities to engage in purposeful activity to make constructive use of time. To be able to identify and pursue goals and challenges. To exercise choice.
For staff	To have a sense of what therapeutic care is expected to achieve, and a clear set of goals to which to aspire.
For family carers	To maintain the dignity and integrity, well-being and sense of self of the resident. To provide constructive care (Nolan et al, 1996).
<b>A sense of achievement</b>	
For older people	Opportunities to meet meaningful and valued goals, to feel satisfied with one's efforts, to make a recognised and valued contribution. To make progress towards therapeutic goals as appropriate.
For staff	To be able to provide good care, to feel satisfied with one's efforts, to contribute towards therapeutic goals as appropriate, to use skills and ability to the full.
For family carers	To feel that one has provided the best possible care, to know one has done one's best. To meet challenges successfully. To develop new skills and abilities.
<b>A sense of significance</b>	
For older people	To feel recognised and valued as a person of worth, to know that one's actions and existence are of importance, and that one matters.
For staff	To feel that work with older people is valued and important, and that one's work and efforts matter.
For family carers	To feel that one's caring efforts are valued and appreciated. To experience an enhanced sense of self.

*Slightly adapted from Nolan et al (2001), table 9.2 on p.175, and reproduced with permission from the authors.*



## **New titles from Help the Aged**

### **Spotlight on Older People**

What is life really like for disadvantaged older people living in the UK today? This report reveals how people dependent on a state pension try to cope with daily living costs; it looks at isolation, mobility and access to essential services; quality of life; at the scarcity of employment and learning opportunities; and at how our society tacitly supports the institutionalised ageism within our health and social care systems. The voices of older people provide a vivid commentary throughout this report, in which Help the Aged calls for an end to the injustice that remains entrenched in our society.

£5.00 ISBN 1-84598-007-7 July 2006

### **Listening to Older People: opening the door for older people to explore end-of-life issues**

Few older people get the chance to discuss issues relating to death and dying, but when Help the Aged held a series of 'listening events' to facilitate such discussions the participants welcomed the opportunity. They talked about care and treatment options, spiritual and emotional needs, coping with bereavement and how to communicate wishes to close family. This report, with a foreword by Professor Ian Philp, National Director for Older People's Services, captures the conversations and makes recommendations for practitioners and policy-makers.

£8.00 ISBN 1-84598-004-2 April 2006

### **Planning for Choice in End-of-life Care**

Developed from a series of 'listening events' held by Help the Aged to facilitate discussion among older people of death and dying issues, this booklet explores options for care and treatment at the end of life, and especially the issue of advance statements, or 'living wills'.

£2.00 ISBN 1-84598-002-6 April 2006

### **Working with Hospital Patients with Dementia or Confusion**

As part of its Dignity on the Ward campaign, Help the Aged commissioned this pocket guide from the Royal College of Nursing Gerontological Nursing Programme to provide hospital staff with practical information on working with patients who have dementia or confusion on acute wards.

£1.00 ISBN 1-84598-005-0 March 2006

### **Older People, Decent Homes and Fuel Poverty: an analysis based on the English House Conditions Survey**

Every winter over 20,000 older people die as a result of the cold. One reason for the shocking levels of these 'excess' winter deaths is the number of cold, damp homes around the country. This issue, together with fuel poverty and energy efficiency, is examined in this report, jointly commissioned by Help the Aged and the British Gas Help the Aged Partnership.

£10.00 ISBN 1-904528-99-6 June 2006

### **Housing Choice for Older People**

This report by Joe Oldman looks at the diversity of housing needs among older people and the often limited housing options available to them. It includes a comprehensive range of policy and practice recommendations to help improve the situation and ensure that our older citizens need not live in poorly heated, sub-standard accommodation.

'An excellent publication – far superior to most information produced in this area in recent years.'  
Foundations (National Co-ordinating Body for Home Improvement Agencies)

£10.00 ISBN 1-84598-006-9 2006 also pdf via [www.helptheaged.org.uk](http://www.helptheaged.org.uk)

### **Moving On: the meaning of activity for older homeless people**

This report for Help the Aged by Kim Willcock shows that meaningful activities can help to build the confidence and skills that are necessary for successful resettlement and re-integration into the community.

June 2006 pdf via [www.helptheaged.org.uk](http://www.helptheaged.org.uk)

### **Live Choices: supporting older homeless people to engage in meaningful occupation in the community**

As Kim Willcock shows in this report for Help the Aged, the Live Choices project in East London demonstrated that homeless and formerly homeless older people (aged 50 or over) can, with support, develop new interests, establish new social relationships and engage in regular meaningful occupation in the community.

June 2006 pdf via [www.helptheaged.org.uk](http://www.helptheaged.org.uk)

How can we ensure that care-home residents enjoy good quality of life? This extensive report, produced by Help the Aged in partnership with the National Care Forum and the National Care Homes Research and Development Forum, presents direct testimony from residents, relatives and staff on the highs and lows of living in a care home today. It urges a new, patient-centred rather than process-driven approach, focusing on meaningful activity and shared decision-making, in order that the care home can become a community of those who live there, those who work in it and those whose relatives are residents.

£10.00

ISBN 1-84598-002-6

Fighting for disadvantaged older people in the UK and overseas,

## WE WILL:

**COMBAT POVERTY** wherever older people's lives are blighted by lack of money, and cut the number of preventable deaths from hunger, cold and disease

**REDUCE ISOLATION** so that older people no longer feel confined to their own home, forgotten or cut off from society

**CHALLENGE NEGLECT** to ensure that older people do not suffer inadequate health and social care, or the threat of abuse

**DEFEAT AGEISM** to ensure that older people are not ignored or denied the dignity and equality that are theirs by right

**PREVENT FUTURE DEPRIVATION** by improving prospects for employment, health and well-being so that dependence in later life is reduced

Help the Aged, 207–221 Pentonville Road, London N1 9UZ

T 020 7278 1114 F 020 7278 1116

E [info@helptheaged.org.uk](mailto:info@helptheaged.org.uk) [www.helptheaged.org.uk](http://www.helptheaged.org.uk)

**HELPTHEAGED** WE WILL<sup>R</sup>