

Listening to Older People



**Opening the door for
older people to explore
end-of-life issues**

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Foreword

For far too long the issues of ‘death’ and ‘dying’ have been taboo in our society, but with an increasing array of possibilities and choices open to people at the end of their lives, it will become ever more important for people to have the opportunity to think through and discuss their preferences and likely needs towards the end of life.

As this report shows, there is a real appetite amongst older people for an opportunity to discuss death and dying, to share experiences and consider options. I very much welcome Help the Aged’s initiative in taking forward this project, and hope that this report will prove helpful to everyone involved in planning for the end of life – whether they be policy maker, or practitioner, family member, friend, carer or individual.

As well as highlighting the value, in itself, of creating a forum for discussion about issues of death and dying, the report also brings out some key areas for improvement around the end of life experience.

We need to ensure people have a range of options open to them to discuss end of life decisions. Some people want to have these important discussions with friends, others with families, and others prefer to discuss these matters with professionals. We need to ensure that older people have the opportunity, and where necessary are supported, to consider their care and treatment options and make fully informed choices about important issues such as resuscitation. We need to ensure that people’s spiritual and emotional needs are catered for at the end of life. And we also need to think about the continuing needs of the bereaved, following a death.

We need to do more to make sure older people are treated with dignity and respect in their interactions with health and social care professionals at the end of life; and that professionals in health and social care are equipped to support people who are dying. I



hope that as we take forward the plans laid out in *Your Health, Your Care, Your Say* we can take on board these important points, and ensure that services are in place which are supportive of and responsive to the needs and wishes of older people who are dying.

I also hope that all of us who read this report will be prompted to consider these important issues from our own personal perspectives – whether for ourselves, or as family members, friends or carers.

Professor Ian Philp
National Director for Older People’s Services

Introduction



This report describes findings from a collaborative venture between Help the Aged and a team of researchers from the Universities of Sheffield and Nottingham to run four listening events around the UK. These aimed to offer older people the opportunity to express their views about the end of life, while also supporting them with advice and information to help meet their concerns. Seventy-four people from diverse communities attended these events, which took place between October 2005 and January 2006.

The listening events reported here form part of the Help the Aged programme of work on dying and end-of-life issues. This programme was initiated from a literature review on end-of-life care for older people commissioned by Help the Aged and carried out by Jane Seymour and colleagues at the University of Sheffield (Seymour et al 2005). One of the key conclusions of this review was that there was little public communication on end-of-life issues and that older people's views were neglected in relation to policy and practice in this area. The review also suggested that compared to younger people who are dying, older people are:

- less likely to die in their place of preference
- less likely to receive specialist care
- more likely to experience multiple health conditions
- less likely to have social support networks
- more likely to experience financial hardship
- often not fully involved in discussions concerning the options available to them at the end of life.

(Seymour et al 2005)

In response to these issues, Seymour and colleagues carried out a project (funded by the Health Foundation) to develop and evaluate a peer education programme. Training was provided to a group of five older volunteer peer educators to assist in running two workshops where information and advice about treatment and care options at the end of life was offered to older people and community representatives in Sheffield.

The peer educators also helped compile an educational guide for use within these sessions (*Planning for Choice in End-of-life Care*). Both the workshops and the guide were evaluated extremely positively and feedback suggested that the project should be disseminated more widely

to other groups. To this end, Help the Aged, the peer educators and the research team collaborated to deliver four additional listening events across the UK, following the model developed in the peer education programme.

This report summarises the discussions that took place at the four listening events. The phrase ‘opening the door’ in the title of the report refers to a comment made by one participant in the listening events – a retired care-home manager:

We prepare for everything except the one thing that comes to all of us. People used to say when someone in the care home was dying, ‘We’ve got to shut the door.’ But I encouraged people to keep the door open and people would sit with the dying person. Later, [the dying person] told me, ‘Thank you for that. It’s taken away the fear.’ You see, it opened the way for them to talk and to expose their fears.

It is our intention that these findings will further open up discussion about death and dying. We want the concerns older people have about end-of-life issues to be more widely known. Fundamentally, we want to bring these concerns to the attention of policy makers and practitioners.

Scope of ‘listening events’

Aim

To increase understanding of the concerns older people may have about end-of-life issues and, where possible, to provide them with advice and information to address their concerns.

Objectives

- To work in a facilitated and safe environment with small groups of older people to explore end-of-life issues.
- To further test and refine the peer education guide previously piloted in Sheffield which aimed to enable older people to obtain information about treatment and care options at the end of life.

- To gather information for use within Help the Aged campaigning and to increase understanding of how the organisation’s programme of work on death and dying needs to move forward.
- To further increase public awareness of the issues that older people face at the end of their lives.

Management of events

Although the management of the events was the responsibility of the team of researchers at the Universities of Sheffield and Nottingham, the involvement of Help the Aged was crucial to the success of the events in terms of forging links with local communities and using their own contacts to target potential participants. The team from Help the Aged arranged and set up appropriate venues and were represented by Tom Owen and other staff at the events.

Design and methods

Four events were held in:

- North England (23 participants)
- South England (15 participants)
- Scotland (11 participants)
- Wales (25 participants).

Each event took place over the course of several hours, with breaks for refreshments and lunch. In the morning ‘open discussion’ in the small groups gave participants the opportunity to raise some of their own concerns and anxieties about the end of life. In the afternoon ‘guided discussion’ centred on the educational guide. Further detail about ethical considerations, design and methods may be found in the appendix.

Recruiting participants

Help the Aged devised a range of recruitment methods. These included advertisements in the local press and community group magazines, letters and emails to representatives of older people groups, and personal contacts. Groups

targeted included independent forums for older people (such as Better Government for Older People and '50-plus' groups). While it was people aged over 60 who comprised the majority of attendees, some younger people who had a particular interest or involvement in end-of-life care also attended. A total of 74 people took part.

The following groups participated in the events:

- general population of over-70s
- older carers
- community groups in deprived areas
- Chinese elders
- spokespersons and members of older people's groups.

The study was subject to an ethical review by the University of Sheffield's Research Ethics Committee but, due to time restraints, we were unable to apply for the necessary ethical approvals required to invite older people living in continuing care or in hospital/hospices to the events. We acknowledge that our sample under-represents very frail and/or disabled older people and elders from black and minority communities, with the exception of elders from the Chinese community (n=4).

Locating this project in the context of a broader programme of work means that some of these shortcomings have been at least partially addressed (for example, Payne et al, 2005). Although we did not ask people to provide private information about themselves, we are aware that the age range of those who attended the events was broad, ranging from people in their early 60s to others in their late 80s.

It was inappropriate to record participants' discussions on tape; rather, data was collected by written notes taken by observers in each of the small groups. The quotes we include below are therefore impressionistic rather than verbatim. Notes were recorded on the main issues and concerns people had about the end of life and care at that time, as well as the questions/issues raised in response to the guide.

Although it is not possible to make widely applicable generalisations from our sample of 74 people, we are confident that we have collected a very wide range of views from older adults living in different localities and with different socio-demographic and cultural backgrounds. Each person's story of loss is unique and the stories reported here are very diverse, but it is the ordinary, everyday things that connect us with each other. As Margaret Forster observes in her family memoir, *Hidden Lives*, among all the stories told by our parents and grandparents 'sometimes their story is the story of thousands' (1995:13).

Findings



Many people saw the event as an opportunity to share their experiences of loss. Numerous people commented that this was the first time they had spoken about their experiences in a public arena and this was the first event examining this topic that they had attended. Although tears were sometimes shed by those relating their stories, participants expressed the desire to continue to share their experiences during the events. One woman, who related an emotional story about her sister's assisted death (outside the UK), said that she was grateful that she could tell this story and felt the small group provided a safe and comfortable place in which to relate her experiences. Two people needed to take time out from the discussions, supported by members of the team.

The following section contains a descriptive account of participants' views¹ on end-of-life issues, presented under six themes:

- (1) perspectives on talking about the end of life
- (2) raising concerns about death and dying with family members
- (3) the importance of spirituality
- (4) after death: bereavement; funerals

- (5) care at the end of life, with emphasis on perceptions and experiences of, or lack of, person-centred care, communication, information, dignity, essential care; making complaints; reasons for poor care; cost of care; good care
- (6) concerns about death and dying: place of care; dying alone; being in pain; euthanasia; living wills; and resuscitation.

We have attempted to utilise a variety of participants' voices rather than rely on a few individuals, both between and across the different events. It should be noted that participants did not always state when their experiences occurred or whether their comments were based on perceptions, expectations or experiences, although we report when this was made clear.

¹ Pseudonyms have been used to protect people's identities.

1 Perspectives on talking about the end of life

Talking about the end of life: a peer educator's perspective

Frankly speaking, working alongside professionals on issues of care for older people approaching the end of life has brought a new dimension to my life, particularly because I have never concerned myself about these issues before. The realisation has been almost a shock – and rather surprising. Now that I have accepted that I, too, am nearing the end, the issues are more real and demand serious thought. For me, this is just the beginning of a long process of helping people to prepare for what for some is inevitable as they get older and nearer to the end of life. Everyone needs to be prepared, especially those engaged in the caring professions, since no one knows what lies in the future.

Carmen Franklin

A few participants said they had initially been 'deterred' from attending the event because of the words 'end-of-life' [care] in its title. Some felt that use of the words 'death and dying' might have accounted for the difficulties in recruiting attendees for the events in some areas. Others – for example, the four Chinese participants – disagreed, preferring 'frank' or 'bold' terminology. Although they said it was 'bad luck' to talk about death in Chinese culture, any fears that they had about this were overridden by their desire to know more about the subject.

While people openly stated that they found it a hard and often emotional topic to discuss, all said that this had not deterred them from attending:

I came here today – I don't know how to talk about these things, about death.

All who took part recognised death and dying as important topics. Most said they attended to gain more information and because they had concerns about the end of life. One woman said:

I wish there was a discussion like this thirty years ago when I lost my husband.

Some people attended the events as representatives of local groups/organisations and wished to disseminate the information. The Chinese participants all said that had come 'to give and to receive', to find out more about choices at the end of life, and to pass on the information to their communities. For the majority of participants, it seemed safer to discuss such concerns in a group:

I can't cope with hearing about dying. It feels like giving up on life. But I do need help to face up to it.

The attendees of one event comprised, in the main, members of a local pensioners' group; it was clear that they were a close-knit community of friends who respected each other, worked together, and shared the joyful and the sad times. For this group, end-of-life issues were accepted as part of their shared experiences. Similarly, one person at a different event said:

It's important to talk and share experiences. You can't understand these issues by reading a book or reading about it on the internet.

It was suggested that older people might prefer to talk to their peers about end-of-life concerns since they were more likely to empathise with those concerns:

A friend didn't feel safe talking about dying with people other than those of her own age. She felt that she might be patronised.

Many felt that similar events should be 'made available to everyone', including younger people. One participant said:

This is the first time I've seen anyone talk about dying or end of life. It's an issue that really needs to be opened up and the spotlight put on it.

Some participants reflected that people in Western societies are generally reluctant to talk about the end of life, whereas in other cultures 'there is no mystification' surrounding death. Others, however, felt that this reluctance to talk about death was changing and that, generally, people were becoming more open to discussing such issues. One woman expressed surprise that

death and dying was a topic that was not much talked about:

I have a husband who's ill. Most people are afraid of physical pain and anguish, but I'm surprised it's not talked about more.

For others, it was the death of those close to them that had caused them to consider the subject. One participant said that several of his contemporaries had died the year before and this had suddenly made him realise that he should make some arrangements for his own death. A woman commented:

[My family] thought that we were all immortal, until my husband's death.

Although some participants said they preferred not to talk about end-of-life issues or had not thought about them in depth, they did not deny death but accepted its inevitability.

Views about dying:

- *I'm not afraid of dying – it's like turning off a light.*
- *Dying must be seen as a part of life.*
- *I'm scared of dying.*
- *There is nothing more personal than dying.*
- *It's a bit like what Woody Allen said about death: 'I'm not afraid, I just don't want to be there when it happens.'*
- *[Someone said to a friend on his 90th birthday that] he wouldn't want to live till 90, and he said, 'Wait till you're 89 and then you'll want to.'*
- *Older people do want to talk about death.*
- *I'm quite philosophical about dying.*
- *I find it easy to talk about.*
- *When people are younger, they don't want to talk about death.*
- *Older people are not preoccupied with death.*

2 Raising concerns about the end of life with family members

Participants' views varied about discussing end-of-life issues with their relatives. Some said that even if they had initiated the discussion, their families were unwilling to talk about it. For others, talking about death and dying with their families presented no problems.

Talking to families about end-of-life issues

- *We feel able to talk to our family: we can laugh about it sometimes.*
- *I'm very emotional. If something's wrong with one of my family, I'll look after them, but I don't want to know what's wrong. I don't want to talk to them about it.*
- *They say talking about it [death] is being morbid. But it's not, it's realistic.*
- *My family joke about it, but no more than that.*
- *They [the family] don't want to talk about it – children tend to see their mothers as indestructible.*
- *I have no trouble talking to my daughter about it – she's a nurse.*
- *My family will not raise it. They think I'm worried about them accessing my money.*

Often, it was the death of one family member which had prompted discussion within families:

I lost my dad two years ago so I feel able to discuss things with my mum now.

Sometimes the desire to plan their funeral (see also section below) had given rise to conversation:

The response from my family when I told them my funeral arrangements was, 'Oh, Mum, what have you done that for?' And I said, 'I've done it, I've got a package deal.'

Some participants had talked to their families about what they wanted should they ever be unable to care for themselves in the future:

I've told them not to bother coming to see me if I don't know they're there... Women get hair on their faces as they get older, they get left whilst men get shaved... I said to my husband, 'If I've grown a moustache and I'm unconscious, don't you dare bring anyone into see me.'

Others felt that it was important to write down their wishes since 'sometimes, families can get it wrong':

My son does not want to know, hear or listen, so we need to write it down. Husbands don't always want to discuss it and I'm not going to be here to make sure it happens.

Family members' reluctance to discuss end-of-life issues was given as one reason to write a living will (see pages 27–8).

3 The importance of spirituality



Although relatively few comments were recorded about spirituality, it was clear that for those participants who raised the issue the spiritual aspects of death and dying were very important. Some people reported that having a faith and/or belief in an after-life was a source of comfort when reflecting on the end of life. One woman said that she was unworried about dying since she did not think death was the end: 'The soul is important and goes to God.' Another commented:

I believe this is not the only life I have. I'm 72 now and I can't take seriously the thought of death – there's more!

It was suggested that even people without faith earlier in their lives 'often look to religion at the end'. One man said, 'I knew of an atheist who wanted to see a priest before they died.' Many said that they had found the clergy (of all faiths) very supportive, both at the end of life and in planning and conducting funeral services. However, most participants felt that healthcare professionals, such as nurses, needed to pay greater respect to the spiritual and religious needs of all patients:

We live in a secular society. In hospital, death is very clinical. My friend was on a ventilator and when I ask about chaplaincy services I was considered a loony. The spiritual side is neglected.

Some groups discussed the importance of considering the needs of people of all faiths, to reflect today's multi-faith, multi-cultural society.

Having a faith was felt also to be helpful in opening up discussion with family members; for example, one participant said that he could talk about the end of life with his grandchildren, who had attended Sunday school when they were younger.

4 After death

A personal experience of bereavement: a peer educator reflects

Over the last few years, with my growing interest and involvement in end-of-life issues and seminars, the subject of 'bereavement' has been referred to frequently. At the listening events people have voiced their problems, having suffered a bereavement, sometimes recently.

An analysis of the various aspects of bereavement reveals the diversity of circumstances surrounding the subject and people's reactions to it. Whilst all people react differently, there are often characteristics common to most cases. In thinking about people's reactions to bereavement, I am greatly influenced by my own response when I suffered the closest bereavement ten years ago.

At a time of loss I believe that the bereaved suffer from shock – often delayed – having concentrated on caring, followed by funeral arrangements. Then, quite suddenly, the activity has gone and the inactivity almost produces a vacuum. The carer then requires the care. It is in this state that a bereaved person can actually be unwell, without knowing the reason or even realising that they are unwell.

Advice from well-wishers can sometimes be totally inappropriate, with comments such as 'snap out of it' or 'time will heal'. A bereaved person can't 'snap out of it' to order and, whilst time will heal, the healing process can be long and private. Bereavement and grief are, to some extent, synonymous. Some well-intentioned advice can actually be counter-productive and perpetuate the grief. Mental and physical activities are often the most effective way of filling the void of loss. Certainly, voluntary work provides a useful purpose and, simultaneously, can benefit others.

Don Thompson

*(See also educational guide
Planning for Choice in End-of-life Care)*

Many stories were told on the themes of grief and loss. Those reported here show how different people's experiences and perceptions are, and that there is no one way to grieve, as Don Thompson, one of the peer educators, describes above. Although people often cried as they told their stories, and were supported by other group members, they were keen to continue, which indicates that the act of telling is cathartic in itself:

I think that a little cry helps – even when it is totally out of the blue.

Bereavement

Opinions varied concerning what helped people to grieve: some preferred to 'keep going' with everyday tasks; others needed time to reflect upon and remember the person who had died; a few chose to be alone; and many wanted the support of professionals, family or friends (which was not always forthcoming). Most people talked about feelings of loneliness and guilt, although they recognised that they had nothing to feel guilty about.

Following the death of a loved one, some participants said that they had needed help with practical tasks:

I needed somebody to do my thinking for me [immediately after the death], someone to take over, co-ordinate, do all the ringing around, the arranging and the forms. If only someone had been there . . .

It was suggested that social workers or home carers should offer support to the bereaved person in order to help settle their affairs; however, continuity and familiarity of care was important:

If there had been a number to call for help with such matters, I wouldn't have called. It needs to be someone who has seen you through the care, a familiar face.

Concentrating on practical tasks following bereavement helped some people to get through the first days, weeks or months. Those

who had cared for a family member over a long time said that they needed particular support:

Grieving is hardest when you have been caring for your wife for a long time, and when they die, people shouldn't leave you alone. I felt so guilty after my wife died, [thinking] 'Have I done enough?'

This feeling of guilt was common to many:

I felt so guilty, no counselling, no having someone to talk to... a friend slept with her husband's ashes on her pillow and wept all night. You need to talk to someone who has gone through it themselves. I still have this guilty feeling even though I know there was nothing that I could do.

Although many people described the 'awful loneliness' following bereavement, not everyone said that they wanted to talk about it in the early days. This included some of the younger participants:

I did not want to talk about my dad dying, maybe because I never got to say goodbye. Not everyone wants to talk at the time of bereavement...

One participant said that the funeral was particularly hard:

The funeral is supposed to make you come to terms with death, but for me it was a trial, I wanted to get it over with.

Many participants said that other people seemed to avoid them following their bereavement:

After the funeral everyone stays away. They're frightened.

Remembering the past

In the past, many participants felt that there was 'more of a sense of community': people 'rallied round' to help if someone was dying or after a death. Some attendees from Scotland discussed their childhood in the tenements and recalled the way death had been accepted as a natural part of life there. Although poor, neighbours helped each other out at times of childbirth and death: 'In the old days we worked and lived for each other.'

One man described the death of his son, in his thirties, many years before, which was still very vivid to him: 'I've never got over it.' He had experienced this and many other deaths, and said that although he could accept the reality of death, he tried not to think about it.

Thoughts on bereavement

- *After you have lost somebody, it takes so much courage to get yourself back to your old self.*
- *We all need time and space to consider things following a death.*
- *We are expected to move on too quickly.*
- *I didn't cope at all well after the death of my dog.*
- *I still get reminders for my wife's hospital appointment, letters from the chiroprapist and the like: they are a constant reminder of my grief.*
- *Sometimes I find myself crying and laughing at the same time: crying because he has gone, laughing when I remember being with him...*

Moving on

A widow in her seventies shared poems she had written with the group which, she believed, had helped her to talk about her husband's death. At home, she drew comfort from looking at a red camellia in her garden, planted when her husband had been living. She said that the bush, especially when it was in bloom, was a constant reminder of her late husband and of the importance of 'getting on with life'.

Funerals

Talking about funerals – the ones they had attended in the past and plans for their own funerals – was common to most groups. Some people were concerned about how their funeral would be paid for; others were already contributing to a payment plan or had already paid for their funeral in advance. Strong views were expressed about the cost of funerals.

Death 'more visible' in the past

There was a great deal of discussion in some groups about the way funerals were conducted in the past. Generally it was agreed that death was less of a taboo since it was a more 'visible' process.

Remembering funerals in the past

- *A man would come round to the house to collect funeral payments.*
- *The dead were laid in the front room. We stood the coffin up in the corner of the room.*
- *Life was different. Everyone turned out when the body came home.*
- *In the olden days [Chinese] people prepared for death: they wore special clothes [this reflected their status in the next life]. From the age of 35, the coffin and clothes were ready at hand and couples were buried next to each other.*
- *It used to be part of the ritual, having time to reflect after someone has died – closing the curtains, the wake – but the ritual is disappearing. There's a sense that you have to go on as usual now.*

Financial considerations

The cost of funerals was a great concern for some participants. For example, one woman was extremely anxious about how her mother's funeral would be paid for: her mother lived in a nursing home and she worried all her remaining savings were being spent on the fees. One man was concerned about the service provided by undertakers and had been campaigning for a change for ten years:

The funeral service is a disgrace. People are cheated. It's a rip-off.

A retired clergyman replied that the local clergy know the cheapest undertakers in their own communities and will recommend them. Nevertheless, worries about the cost of funerals affected some people's plans:

There's not much money, but I've arranged my own funeral.

Some people had already paid for their funerals:

That way [if you pre-pay] they don't up the bill.

Personalising the funeral

Many participants had considered and planned their own funerals. Sometimes this was initiated after attending 'impersonal' funerals that 'had no relevance to the person who has died'.

Reflecting upon the person's life was important for the bereaved and some had recorded in advance what they wished to be said at their funerals.

It was pointed out that some families could not be relied upon to know what the deceased would want:

Family never do the right things at funerals. They choose the wrong hymns and sometimes they leave it to the reverend, who knows nothing about the deceased.

Others disagreed:

I think a lot of it is the family and if you attend church. I've been to funerals where the vicar has spoken about the person and has known them. It's completely different than where the vicar didn't know the person.

One person indicated that it didn't worry him at all what his funeral would be like:

My sister and brother are often on to me about whether I want to be cremated or buried. I haven't made up my mind yet. I keep saying, 'Chuck me over the wall.'

Some participants had considered plans for their funeral in detail, recording their wishes or telling their families what they wanted.

Thinking about the details

The coffin	Music	Clothes	Reasons for planning
I've picked out my coffin – pink inside.	I've written down all the songs I want. I want a jazz band.	I don't want people to wear black.	It makes me feel in control.
I've ordered a cardboard coffin.	I've specified that I want Mozart.	It's a celebration.	It's the last thing I can do for myself.
I'd like to put personal things in my coffin.	We want 'Wish me luck as you wave me goodbye.'	People must respect what you want them to wear.	It's settling it for your family.
I want my ashes scattered in the sea.	I'm having Daniel O'Donnell singing 'Going'.	I want to wear special clothes when I'm buried <i>[Chinese participant].</i>	It's essential to let people know what you want – it's to do with your values.

Two stories vividly illustrate the importance people placed upon a funeral reflecting the wishes and personality of the person who has died:

I'm a non-believer, so I won't have clergyman. I'll have one of my sons or my husband. Lots of my friend think the same... talking about what a wonderful gardener or inspirational teacher they are, because that's what's important. A vicar wouldn't be able to do that. The sadness of a funeral I went to was because they didn't mention the fact that he was a wonderful gardener, not because he'd died. He was old and had had a wonderful life...

5 Care at the end of life



Defining end-of-life care

All patients with a chronic, progressive and generally fatal illness, or an advanced or irreversible disease, need high-quality well organised end-of-life care. This group... includes patients with organ failure such as heart disease and chronic obstructive pulmonary disease, stroke, general frailty, dementia and other neurological conditions, as well as people with cancer.

(The NHS Confederation, November 2005)

[End-of-life care] requires an active, compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life-threatening conditions. Such care is sensitive to personal, cultural, and spiritual values, beliefs and practices, and encompasses support for families and friends up to and including the period of bereavement.

(Ross and Fisher, 2000, page 9)
See also Seymour et al (2005)

Health and social care at the end of life were overwhelmingly the biggest concerns to participants in terms of how much time they spent talking about these issues in the small

groups. Arguably, the events might have attracted people who had experienced poor care and took the opportunity to raise their concerns.

Topics discussed under the theme of health care were numerous and included: lack of person-centred care; poor communication; inadequate information; neglect of dignity and essential care; the difficulty of making complaints; and reasons for poor care and experiences of good care. We will describe each in turn.

Lack of person-centred care

Many participants expressed the view that people in NHS hospitals were not treated as individuals. It should be noted, however, that it was unclear whether this was a perception or based on personal, recent experiences.

These comments were typical:

- *In the big hospitals, you're a number.*
- *Hospitals are like factories.*
- *People [dying] in hospital are often treated as insignificant pieces of flotsam.*
- *Staff need to engage with patients as human beings with individual values.*

Some participants were particularly concerned about the way older people seemed to be treated as a group, rather than as persons with individual needs:

They put all older people in geriatric wards because of their age, but it should be by condition, not age.

In one case, lack of individualised care was illustrated by the unimportance attributed to giving the correct name to a patient:

I went into hospital with pneumonia recently. I noticed after a few days they had put the wrong name above my bed. I asked them and they said, 'Oh, don't fuss. Old ladies fuss more than old men.'

It was apparent that some of the problems experienced by participants and their relatives were caused by poor communication.

Poor communication

Examples of poor communication were numerous and appeared related to people's personal experience with individual doctors, nurses and, in one case, a GP's receptionist.

Comments about poor communication

Residential carers:

They don't know how to address [older] people: they say 'luvvie' or 'ducky'.

GPs:

Doctors address you from the back of their necks whilst talking to their computers.

GP's receptionist:

You are lucky to get past the receptionist – however urgent the appointment.

Hospital doctors:

When people see my [disabled] husband, I say, 'Don't talk to me – talk to my husband.' But doctors talk down to him: 'No use talking to you, you won't understand.' He feels degraded.

Hospital nurses:

They speak to you as if you're mentally deficient. That really annoys me.

In an attempt to help improve medical staff's communications with older people, one man described how the 50-plus group he belonged to had arranged an awayday for GP practices about attitudes to older people, but no doctors had attended.

One woman, who had cared for her ill husband at home for many years, described how she felt left out of her husband's care when he was admitted to hospital. She wanted to continue to be involved in his care, but the nurses did not listen to her:

Why couldn't I help out in the hospital? Why wouldn't they let me? They said, 'That's our job.' In the end, I knew the nurses were meant to reflect on their practice, so I asked one to reflect on what it would be like for her if it were her husband...

She felt that the staff continued to disregard her wishes:

In the end, I asked to take him home. But I had to battle and involve the social worker. Many people want to come home [at the end of their lives]. They do better. But I had to battle. Why is it so hard?

At times, participants felt that poor communication between health care professionals was lacking. One person gave an account of an aunt who had suffered cancer followed by a stroke, but practitioners from the two specialties had not met together to discuss her care: they seemed unaware of her wider, holistic needs.

Other people described a lack of co-ordination and planning amongst health care staff:

- *My neighbour was in hospital for weeks and was sent home, but there was no one there. They forgot to arrange for someone to come in. I phoned the hospital and they apologised, they should have made arrangements.*
- *On the day my grandmother was supposed to go to the nursing home, they said that they had not done the financial assessment and so she couldn't go for another week – though she had prepared herself for the move. It was all messed up.*

- *She had senile dementia – no relatives – and social services, due to financial constraints, couldn't place her in a nursing home and gave her home helps instead. There was no one with the expertise to help. She died a few weeks later.*

Some participants discussed who they felt was the most appropriate health professional to talk to about end-of-life concerns. Their feelings reflected their personal experiences of care.

Views about who should give advice and support on end-of-life issues

- *GPs don't have the time. I don't feel they have the bedside manner that they used to – they don't even visit. Going to a GP is like going to the post office. Tell them what's wrong and they write a prescription, then send you on your way.*
- *You get more attention from nurses. The nurse knows more about where to go.*
- *Macmillan nurses are great. They go through the process, my mother [had cancer] and was told without being patronising, sympathetic without being maudlin, 'This is the process, this is what will happen.' My mother said, 'Well, I know now.' It made her much more prepared for what was to come.*
- *Hospices look after the family as well as the patient. They give advice and support.*
- *Having a familiar face to give support is important.*

It was suggested that for those who do not have a terminal illness, such as cancer, but are simply deteriorating due to older age, it is harder to ask for outside advice about the future. Such individuals have to rely on friends and family to help them cope with impending end of life.

Lack of information

Many participants felt that they were given insufficient information about their own or their

relatives' prognosis at the end of life. Some people went further and felt that medical staff sometimes deliberately hid information from them. This had an effect on their ability to challenge decisions and to make informed choices. For others, this lack of information meant they felt unprepared for their relative's death. A variety of reasons, including ageism, were offered for medical staff's reluctance to share information.

Reasons given for lack of information

Wrong assumptions:

They [health professionals] assume they know the level of information that you can absorb about your condition [in hospital]. In the old days, we would never question the doctor, but you are entitled to know as much as possible.

Arrogance:

When you speak to doctors, they judge your intelligence – i.e. you wouldn't understand – a type of arrogance presuming we don't understand.

Feeling threatened:

There was this young GP, he was horrified at programmes on TV about health as it meant people questioning more – he felt threatened. They are serving us and we are entitled to know.

Lack of time:

They haven't time. They never get back to you when you ask a question.

Ageism:

I want the dignity of being able to decide these things for myself – not to be treated like a baby.

Some participants felt that medical staff sometimes hid 'the truth'. One woman described her mother's death in hospital. The night before she was going to be discharged, her mother had apparently fallen when getting out of bed to go to the toilet. It seemed that the bed's brakes were off and she slipped. The call buttons were

faulty and no one came as she fell, gashing her head. Her mother was found later, lying in a pool of blood. It was particularly upsetting because her mother's death certificate recorded the cause of death as 'pneumonia'. However, the daughter felt that medical staff were hiding what really happened – that she died of blood loss as a result of her fall.

Perceptions about the lack of adequate information about methicillin-resistant staphylococcus aureus (MRSA) were expressed by participants at the London event:

They [doctors] keep saying 'pneumonia, pneumonia – poor man's friend'. No matter what they die from, it's pneumonia. But it's MRSA.

The local pensioners' action group had organised a protest march to the local hospital in protest about what they saw as a 'cover-up':

We're ashamed and frightened to go into hospital because you don't come out.

In general, people felt that they had insufficient information concerning what was available at the end of life to challenge decisions made by professionals. This restricted their ability to make informed choices. Some participants reflected that they would have made different choices about their care, or that of their relatives, if they had been told what to expect. For example, one woman commented:

I had weeks of chemotherapy and radiotherapy; every person was wonderful, but I couldn't go through it again [radiotherapy] if I had known it was a back-up system. Wouldn't have done it. I did it to please the doctors. They don't tell you how long diarrhoea etc. lasts. You lose weight and then gain it all again...

Many people recalled how, as the relative of a dying person (often their husband or wife), they felt they were given insufficient information. Consequently, they felt unprepared for the person's death.

Feeling unprepared

- *It's all the time you spend sitting in hospital. No one came near or by when my husband was dying. He was in an agitated state. I don't mean they have to overdo it, just no one cares. Actual words they said to me was 'He's poorly' – poorly means poorly. I had no idea he was going to die. If they'd told me it was crucial, I could have held his hand...*
- *No one told me that it [the cancer] was aggressive. If I'd known the severity I could have prepared myself better. I only found out when they agreed to show me the [medical] notes.*
- *I was totally unprepared. My husband's experiences of dying were appalling. It took 18 weeks for a cancer diagnosis. We were then introduced to a Macmillan nurse who we never saw again... The cancer specialist only said four words to me, to say that he was incurable. In the end, I was unable to say goodbye. Everything that happened convinced me there was ageism in the Health Service.*

The Chinese participants felt they experienced particular difficulty in knowing where to get help and information that was relevant to their community.

Some participants felt that older people – by virtue of their age and experience – should not only be given more information but also consulted more about their condition and care:

You've lived with your body for 70 years, so they should listen to what you say. You know when it's not working.

A few participants had heard of the government's 'expert patient' initiative and thought that this was a good idea. One man commented:

Consultants should be trained that they are not superior to the patients and that patients are part of the team.



Lack of dignity

Participants raised many issues concerning the importance of dignity in care, including the importance of upholding dignity at the end of life. Most people felt dignity was crucial to policy planning and provision of care. As one man said:

We need to be pushing on the dignity aspect. In the consultation document on the Commissioner for Older People in Wales the word 'dignity' had been removed. This needs to be put back in.

Some comments around dignity pointed to the need for basic good manners amongst

Suggestions to improve dignity

- *Staff should call you by your surname until you say that you want to be called by your first name.*
- *Simply by asking people what they want, asking their permission to do something; for example, the consultant's ward round at the bottom of your bed...it's as if you're not there.*
- *Listen to older people about life.*
- *Having more respectful attitudes.*
- *Not patronising us.*

healthcare staff, such as asking permission to call people by their first names or before undertaking care. Other comments revealed that people sometimes felt they were treated with a lack of respect because of their age.

One man described his wife's death in hospital; he had been appalled at the care he had witnessed, which he considered 'callous'. He had felt so strongly and been so emotionally upset that he had taken the matter up with 'the authorities'. He said that while he could not undo the situation, he had protested in an attempt to spare others having to go through his unpleasant experience and memories. He concluded, 'There was a total lack of dignity in the whole [dying] process.'

Similarly, a woman described her husband's care when he was seriously ill:

He had lost his dignity in the hospital – he turned his face to the wall. When he came home, he had hope and a better quality of life.

Lack of essential care

Most of the examples of lack of dignity at the end of life were linked to what some participants saw as the low priority given to essential care amongst healthcare staff. This included lack of

help with eating and drinking, poor moving and handling techniques and lack of attention to patients' personal care. There were numerous illustrations about lack of essential care which seemed to suggest to participants that professionals simply did not care:

Care in hospital – the care is going out the window.

Experiences of poor care

Lack of assistance with eating and drinking:

They [nurses] do not feed them. If you haven't got a family, you don't get fed.

[Nurses] had no idea how to deal with people with Alzheimer's. They just brought the food into the room and left it near the door. I said, 'She's over here and the food's over there. She's no chance of getting it.'

Moving and handling:

My wife was dragged on and off the commode. It caused abrasions – we couldn't work out what had caused them at first.

Personal care:

They don't do the basics. They don't wash patients any more. When my father was dying, I went to see him one day and his hair was out here – dishevelled. From that day on, my father was dead. He had no dignity at all.

Poor hygiene:

My partner had a heart attack. We had to clean all round the bed and supply pillows. I'm only small and I had to bathe him and had to wash the bath first.

Lack of respect:

There is a terrific lack of respect for older people amongst doctors and other staff. One woman, who was blind, was offered a television repeatedly. There was a terrible smell, but when I pointed out the bin to a nurse, she said, 'It's not full yet.' When I complained, one doctor said, 'What do you want me to do – wave a magic wand?' and I said, 'It would be nice if you did something.'

Making complaints

A few people had made complaints when they, or their relatives, had experienced poor care and were keen to acknowledge that these complaints had been acted upon. Many, however, said that they found it difficult to complain – they didn't know how, or were worried that it would have a negative impact on the care the patient received.

One man described the poor treatment of a relative aged in his seventies:

He was incontinent and was in a nursing home. He fell and broke his hip and had to be hospitalised. His wife went to see him and there was vomit on the floor from the previous day. The physiotherapist wasn't told he had dementia... His wife complained and things improved. Now this case is used as a model for older people with dementia.

In general, however, it was agreed that it was not always easy to complain:

Complaints procedures are not accessible enough. There should be more education about how to complain. There's no point grousing if you haven't followed the procedure. Some don't like to complain. People are afraid it will be taken out on the patient.

One woman felt that the reluctance to complain was 'very British':

I'm not from Britain. I'm very surprised that people here don't speak up for themselves. Where I come from, we think, 'We have paid for this service.' Here, people just don't speak up.

Others felt that the reluctance to complain was to do with being older:

They [older people] are proud to be independent; they don't want to disturb the doctor. The old school idea that 'I'm all right', even if they aren't. They'll try one medicine, then another, but never go to the doctor.

Many participants said that some older people needed a family member to speak up for them:

People without family and friends find their voices are not listened to, they don't have a push from

behind. When you get to a certain age, you're a 'non-person'.

A similar view was clearly articulated by one woman's story:

My mother-in-law died recently. She was in hospital for several days after having a heart attack. When it was known that she was going to die, they removed everything – drip, antibiotics. Okay, her heart was going to kill her, but why should she die dehydrated and gasping for breath? The whole family was at the hospital. The staff didn't like that and were rude to us. Good job we were there – we insisted she was put back on the drip and oxygen. If you're alone, you have no one to fight your corner.

Reasons given for poor care

Participants discussed a variety of reasons for poor care including staff shortages, poor pay, the closing down of small hospitals and the loss of the matron's role. However, inadequate training and education for medical staff and nurses were felt to be the main areas for improvement. Many felt that staff lacked the necessary skills to care for older and dying people.

Some people felt that lack of training for doctors and nurses was to blame for poor care:

I worry about lack of caring around NHS. Those in the caring profession seem to live in bubble, not aware of what it's like – more awareness in training of individual's needs – do unto others as you would be done by.

Shortages of staff and poor pay were discussed, but were not an excuse for poor care:

[Nurses] busy, but busy doing nothing.

Many participants believed that health care staff needed further training.

Changes in organisation and structure were another reason given for poor care, particularly in London. Participants cited the fact that smaller hospitals had been shut down and the 'good ones' closed. Many participants felt that the

Suggestions for education of health and social care staff

Basic skills:

- *More practical nursing skills.*
- *Hands-on experience for nurses.*
- *Care home staff need to be trained to look after older people and also paid better.*
- *Doctors should be given tips on how to deal with people.*

Specialist skills:

- *Those in the nursing profession should be asked whether they want to specialise in – paediatric, geriatric etc., then they would know how to look after older people.*
- *Need to learn how to care for people with Alzheimer's.*

Care of the dying:

- *More sensitivity is needed and more constant care.*
- *You might be dying, but you still need that care and doctors need to know what they are doing.*
- *In private homes, only a small percentage of staff are trained sufficiently; often very young people without maturity/experience to deal with older people, dying and death.*
- *Care homes – look after older people until near the end, but then people get admitted to hospital to die. This is wrong.*

problems with the NHS started when the role of the matron was lost. This comment was typical:

They've taken away overall supervision. Matrons used to come and inspect – so bring back matrons. You never see the new matrons.

Cost of care

People pointed out that being ill or incapacitated in some way was difficult enough without having to worry about the financial implications of needing care. Some perceived that there were inequalities in care according to where people lived and what they could afford to pay.

Participants in England and Wales raised what they saw as the injustice of paying for long-term care.

One man said:

Those who are wealthy will get the best care.

Another felt that the government was more concerned about cost than quality of life:

It's like the cost of prescriptions for Alzheimer's. The government evaluates things too much on cost/benefit analysis and does not focus on quality of life. NICE do not evaluate things properly before making a decision.

Many people talked about the injustice of people having to sell their homes to fund care:

You pay taxes all your life and save to make life better for your children and then they take it all off you.

Some could see the government's problem:

With the population going down and all of us living longer somebody has to pay for it.

One participant felt that more older people now had to live with their children because they could not afford to live on their own. Others were anxious about the future because they were childless:

I don't have children, so does anyone want to adopt me?

It was suggested that choice and quality of care depended on where people lived and that older people were given low priority:

There are no real support services in the community for the elderly – it's a lottery.

As a result of these concerns, it was felt that more advice was needed with regard to financial matters:

We need guidance to arrange things. Don't always like talking about finances – it's an inherent fear – but solid, sound advice is needed at an individual level.

Good care

Although there were many illustrations of poor care, some participants pointed out that they

had witnessed or received good care in hospital and in the community. Others were anxious to make clear that generalisations about care should not be made and that many had experienced good care from individual doctors, nurses and other care staff.

These comments were typical:

You can't tar all staff with the same brush.

Hospitals and care homes are so different. Quality of staff needs to improve in care homes. Some very good – some not.

Personal experiences of good care

In the community:

- *Nobody can complain about our district nurses. They keep people alive.*
- *There are some very good examples of care, like the Macmillan and Admiral nurses and so on...*
- *My GP is marvellous. [One evening] the phone went. He had phoned me at eight o'clock at night. I had seen him in the morning and was a bit quiet and he phoned to check that I was all right.*

In hospital:

- *My mother and mother-in-law died in hospital – couldn't be better treated. I held their hands, it was like going to sleep. If something like that [dying] could be lovely, then it was.*
- *I couldn't have had any better treatment. All the people during the twenty weeks I was in hospital were lovely.*
- *My husband had Alzheimer's and the care was absolutely wonderful.*

In continuing care:

- *My mother-in-law is in sheltered accommodation now. It's well run. She feels a lot more secure. She has people around her in her own age group. She chose the house herself and wouldn't go anywhere else.*
- *My brother has good care with memory loss – so there is good care around. Vast majority of staff are wonderful.*



Caring for older people as individuals seemed to make the difference, as the three comments below illustrate:

Examples of individualised care

- *When my husband went into hospital, they asked me to make a diary of his life. Things he liked, things he didn't. Pictures of important people. And all the nurses looked at it and said, 'Oh, hasn't he had an interesting life?'*
- *I was given humanitarian encouragement in hospital by compassionate medical staff. Nothing can replace personal discussion and the opportunity to express and share anxieties.*
- *My mother-in-law is in care, with dementia. I agree with the concerns about pay and also staff turnover. But all the clients in her establishment are addressed by name, all have a 'memory box' and there is a potted history of everyone for new staff. There are entertainment facilitators, they are taken out, but I wouldn't know what my mother-in-law would have liked to do. Quality of life is important.*

6 Concerns about death and dying

Participants raised most of the following issues during the first open group discussions. Other topics discussed, including living wills, euthanasia and resuscitation, emerged mainly in response to the subsequent guided discussions in which the educational guide *Planning for Choice in End-of-life Care* was used.

Some people mentioned that they were not afraid of death but were afraid about the process of dying and, in particular, where they were cared for at the end of life and by whom, dying alone and being in pain.

A personal view from a retired nurse: a peer educator reflects

I was a nurse on a ward in a general hospital where the majority of the patients had some form of dementia, and I often witnessed end-of-life medical care that was distressing for all concerned. I felt that it should be possible for folk to have more of a say in how and where they died, so was interested to see what information was available regarding this.

Margaret Cock

Place of care at the end of life

Some participants worried about being a burden on their families should they become unable to care for themselves. This concern clearly influenced where they wanted to be cared for at the end of life, as the comments below reveal.

Preferences for care at the end of life

In hospital:

I don't want to become a burden to my family. I don't want to cause problems.

At home:

I want to die in my own home, but depends if I can cope. Need to look at the burden on others, the wife etc...

A hospice:

We are fortunate that we have a hospice here. I'd like to go there.

Not by children:

I'm caring for my wife now but who will care for me? I wouldn't want my children to have to provide all that care.

Uncertain:

I'm worried about being on my own, but equally concerned at the thought of going into care or inflicting on my children – they have their own children and responsibilities.

No choice:

Do you have a choice? My uncle had a stroke and went into a community hospital and then a residential hospital. But he didn't like it in there. He wanted to go home, but he couldn't.

A few participants felt it was their family's responsibility to care for them:

If you've lived long enough and your kids have been a problem to you, just make sure you live long enough to take a vengeance and be a problem to them [laughs].

Unsurprisingly, many participants expressed the desire to die in their sleep. This was precipitated by a fear of dying in a care home or a 'geriatric ward' or being a burden:

Quite frankly I'm looking forward to the end of my days. My brother, father and mother died in their sleep. I hope I do the same. I hope I don't have to sit in a care home.

Most of us want to die in our sleep, but worry it won't happen. I worry I will go into a geriatric ward. Care differs in the NHS. Fear that I won't die in sleep, will be put in geriatric ward and then you're left there...

I'd like to duck the burden and go out like that [clicks fingers].

Not everyone feared dying in hospital and some had witnessed peaceful deaths in this setting, as well as at home:

Two members of my family died at hospital and two at home – so peaceful – just closed their eyes. Please God I go the same way.

Dying alone

Some people expressed concern about being left on their own at the end of life. Couples worried about one dying before the other and many hoped that their families would be with them when they died. Carers worried about what would happen to the person they cared for if they died first, as illustrated by the following story.

A family carer's story

One woman, who had been married for 60 years, described how she was the main carer for her husband, who was very ill. She said that she was devoted to her husband and hoped, quite selflessly, that she would be the one to be left on her own eventually. Nevertheless, she had a dread of ultimately being on her own – being agoraphobic added to her concerns – and she did not want to inconvenience her family. She said that they were both dreading anything happening to either of them and were 'just living a day at a time'. She prayed for the ideal solution – that they would die together or within a very short time of each other.

Other people worried that they might become ill and die alone:

I have moved to a flat and there's nobody in the block. I worry about dying alone and suffering a stroke, etc. If I took ill – what would happen? It's the indignity of dying alone.

This man felt that it was media reports that 'triggered worrying about these things', although he had personal experience of such an incident: 'I attend a reading group and one member had been dead for five days before anyone found them.' His fears resonated with others in the group:

I have one fear – I have a wonderful family – if I was on my own and they couldn't get to me. People can be dead for days.

Participants talked about their desire to have their families around them when they died:

The comfort of knowing that a loved one is with you, holding your hand.

The importance of having their children present was stressed by the Chinese participants. They described how 'bonding' between parents and children was very important in Chinese culture and said that not having their children present (especially the eldest son) when ill or dying would be 'devastating'.

Being in pain

Participants' decisions about whether they would want to continue with treatment if they became seriously ill or incapacitated at the end of life seemed shaped by whether they thought they would be in pain and whether this could be relieved. Some thought that pain could be kept under control:

Maintaining our dignity is the most important thing. You can get medication now – nobody needs to die in pain.

Others were worried about being in pain and wanted to die if this was the case:

When you're curled up in the foetal position in pain, turn off the machine.

Interestingly, no stories were recorded about people actually experiencing others dying in pain. However, eyebrows were raised in one group when a former nurse said pain could be controlled, as if participants were sceptical about whether this could be achieved. No one mentioned, prior to the introduction of the education guide, the concept of palliative care, in which pain and symptom control is one major goal.

Euthanasia

The thought of being in pain or incapacitated led some people to overtly state that they agreed with euthanasia:

I agree with euthanasia if the quality of life isn't there. There shouldn't be suffering.

One participant (who had lived abroad where euthanasia was allowed in law) had personal experience of euthanasia which she describes below.

One woman's personal experience and view of euthanasia

No one's asking older people what they think about euthanasia. Nobody can decide except the person who is in that situation. My sister became very ill with cancer and she was allowed to go home. She couldn't eat – she decided to have euthanasia. My other two sisters were very against it and it became very difficult between us. It is the person themselves who matters. We all gathered round her bed and she had a peaceful death. Every person has the right to a dignified death. We need to ask people, not just have young people legislating for them.

Some people pointed out that they had not discussed euthanasia with others before and welcomed the chance to express their views. The Chinese participants said that they wanted the opportunity to talk more about assisted dying and to have their views listened to and respected. One Chinese woman said that she wanted to 'end the misery' of her mother when she was in hospital. Her mother was unable to eat or drink and was artificially fed. Her mother had pulled out the tubes feeding her and her daughter asked, 'What if she couldn't have pulled them out? No one asked her if she wanted to be kept alive.'

Comments suggested that some people were confused about the definition of euthanasia:

Morphine is given to hasten death and no reasons why – isn't that euthanasia?

Definition of euthanasia

Euthanasia has been defined in the UK as 'a deliberate intervention undertaken with the express intention of ending a life to relieve intractable suffering'.

(House of Lords 1993/4: 10)

Currently in the UK it is now recognised that where death is inevitable, then *life-prolonging* treatments such as resuscitation, artificial ventilation, dialysis or artificial feeding may be withdrawn or withheld.

In such cases the goal of medicine becomes the relief of symptoms. The provision of 'basic care' and comfort *must* be provided and can never be withheld. **Removing life-prolonging treatments is not euthanasia.**

It is acknowledged that sometimes giving adequate symptom control or withholding or withdrawing life-prolonging treatments may hasten a death that is already expected. **This is not euthanasia.**

*(See also educational guide
Planning for Choice in End-of-life Care)*

Some participants stated that they were against euthanasia:

I'm against it [euthanasia] on religious grounds and because I don't think it's fair on the doctor, but having made that decision on a dogmatic basis I would want to go quickly and can see the appeal.

Others felt it could be used as an excuse to get rid of older people:

Euthanasia is one stop closer to assumptions that the 'whingeing wrinklies' can be gotten rid of.

Such concerns had prompted some people to record their wishes in the event that they were unable to express their desires for themselves in the future.

Mental Capacity Act

In April 2005 a new Mental Capacity Act was passed. The main principles are that someone taking substitute decisions must act in the **best interests** of the person concerned and choose the options which are **least restrictive** of their rights and freedoms.

The Act allows for the following factors to be part of the decision-making process for people who lack capacity:

- a written advance statement/directive refusing certain medical treatment
- a lasting power of attorney (LPA): a person can make a LPA while he or she has mental capacity, giving the power to make decisions on their behalf to a specified person

- a decision by the Court of Protection
- the Appointment by the Court of Protection of a deputy to make decisions
- the advisory input of an 'independent consultee', appointed by social services.

(from <http://www.mind.org.uk>)

(See also educational guide *Planning for Choice in End-of-life Care*)

Living wills

Mostly prompted by the discussion using stories in the guide *Planning for Choice in End-of-life Care*, a few of the group participants shared the information that they had made a living will.

Living will

A 'living will' is a shorthand term for a document which records an 'advance statement' about future medical treatment and care. It is used to place on record a person's views and values.

Advance statements are usually associated with a person's views about their end-of-life care – for example, on resuscitation – but they can be used to outline views and preferences about other things that are important for everyday life.

It has been suggested that advance statements *may* have a useful role to play in safeguarding patients' choices, or in helping health professionals and families to make treatment decisions. This is because they are made *before* someone becomes incapacitated by serious illness.

(See also educational guide *Planning for Choice in End-of-life Care*)

Some people described how they had gone about making a living will.

Views on how to make a living will

- *I got it from the Humanist Society. I've got a file at home where I keep all my gas bills etc. My doctor knows and my son has a copy.*

- *I have made a living will; it wasn't a difficult process. My friend has done it... I kept meaning to do it and then I had pneumonia... so I did it. I didn't have a solicitor but I had witnesses.*
- *I have done one and given it to a friend and copied it to my GP. It's annually revised, so they can't say, 'You've changed your mind.'*
- *It's important that you tell the family where the documents are. You can't assume they'll know. They might not even know that you've got a solicitor, let alone who it is.*

Reasons for writing a living will

- *I do not want to be resuscitated if I am terminally ill.*
- *I want to make sure that I make the decisions now, when I have all my senses.*
- *Without one, who says our families will adhere to our wishes?*
- *It helps avoid family disagreements with person's wishes.*

The Chinese participants agreed that living wills were a good idea but said that they would not necessarily want to formalise their wishes in written form. One woman pointed out that older people in the Chinese community might be illiterate, so would be unable to sign their names. They would prefer to discuss their hopes and concerns with their families:

There is a Chinese saying which says that if someone is very ill for a very long time, their family will run away from them. But an advance statement would make it easier for the family to know what to do at the end of life. It would be simpler and easier to discuss.

One Chinese participant described how she had told her son what she wanted at the end of life – no resuscitation. She said it was crucial to act on the dying person's wishes because these are so individual. Other participants also said that they preferred to discuss their wishes rather than record them:

I haven't done, but perhaps I'm naïve; I trust my children. Resuscitation has been mentioned and I trust they know that I wouldn't want to be.

Writing a living will: a peer educator reflects

I have now put in writing the treatment I would like if the time ever comes when decisions have to be made on my behalf. This is my living will signed by me with witness signatures of two friends – at no cost – and one given to each of my family to keep. I now feel confident to carry on with my life – even at the age of 81 I can still look to the future. It took time to think and plan ahead but now I can carry on with my life. Each day is a new day – a new challenge!

Ivy Sharpe

Many people said that they had not heard of living wills before and some had concerns about recording their wishes in this way:

One of the things that's bothered me, I wouldn't know how to draw up a living will. You hear about people starving to death and it's supposed to be painful and surely that's not what people meant... I'm thinking you don't always realise the consequences of your decisions.

Again, this shows that there is some confusion about what is allowed in law; the provision of 'basic care' and comfort must be provided and can never be withheld.

Concern about writing a living will

My mother is nearly 90 and she had a stroke. She was kept on a hospital trolley for three days, she was incontinent, couldn't speak or walk. But her condition then improved. She now enjoys life. She watches TV, visits family and has a good quality of life. In those first few days, you wouldn't have given her any hope and I feel this highlights the need for safeguards in living wills.

Other participants felt that writing a living will was something they would now consider. One couple cared for their disabled daughter, aged in her forties. Their primary concern was for her continued care should they die before her. Another man had suffered a heart attack and felt that the 'time was right' to make his wishes known. He was keen to do this for himself since he did not want his wife or anyone else making decisions for him.

The educational guide *Planning for Choice in End-of-life Care* sets out some of the risks and benefits of advance statements ('living wills') for readers to consider.

Some people wanted to ensure that small things they valued in everyday life would continue to be a part of their life if they became seriously ill or incapacitated.

Things to remember about me

- *I need aqueous cream for my face. It is painful without it. This is the thing that is really important to me, that would need to be remembered.*
- *I would ask for the hospital window to be left open so that I could hear the sounds of nature, children playing, birds singing.*
- *I always like to have the last word.*
- *I like to listen to jazz bands.*
- *I really don't want to have a moustache if I am in care.*
- *I would want a cat on my bed.*
- *I would want to be sure that I was absolutely clean – this is really important to me.*

*(See also educational guide
Planning for Choice in End-of-life Care)*

Resuscitation

A few discussions addressed the issue of resuscitation, again often in response to the stories in the guide *Planning for Choice in End-of-life Care*.



Resuscitation and other life-prolonging treatments

These treatments include, for example, cardio-pulmonary resuscitation (heart and lungs), artificial feeding and hydration (administration by a tube which enters the body), ventilation (breathing by a machine) and intravenous medicine (by drip or injection).

Basic care

This includes nursing care, pain relief and relief of other symptoms and the offer of food and drink by mouth (perhaps with a spoon, straw or cup).

The code of practice produced by the British Medical Association states that patients can refuse life-prolonging medical treatment, but they cannot refuse basic care.

(See also educational guide Planning for Choice in End-of-life Care)

Some participants' experiences of caring for their relatives who had died had led them to reflect on the issue of resuscitation:

I've been involved in quite a lot of deaths. I'm particularly interested in the issue of 'no

resuscitation'. I went through it with my husband. That's what I asked for [not to resuscitate him] and I knew that's what he would've wanted.

Observing or experiencing poor care had sometimes led people to the view that they did not want to be resuscitated:

I am someone who has been in and out of hospital all my life. I have concerns about what will happen to me when I can no longer do things for myself. My wife died three years ago. The treatment she got was not good. I had promised her she wouldn't go into hospital but eventually she had to be admitted – she was in a coma by this stage. Even the experience of physically getting my wife out of the flat on a stretcher was upsetting. My experiences have led me to advising the family that I wouldn't want to be resuscitated.

Others felt upset that the issue had been raised by medical staff, but recognised that health professionals were in a difficult position:

I went to visit my aunt. The doctor asked if we wanted her to be resuscitated. She was only in for observation! It's a terrible responsibility on the medical staff to decide.

Despite acknowledging that death and dying are important topics to discuss, many participants said that it was important to 'live for today'.

Conclusion and recommendations

This report has described findings from four listening events around the UK. Our aim was to offer older people the opportunity to express their views about the end of life while supporting them with appropriate advice and information on the key concerns. The findings illustrate the heterogeneity of older people's views, experiences and concerns.

Generally, the end of life was perceived as a sensitive and emotive subject. However, people's apprehension about discussing the topic frequently was overridden by their desire to know more about the decisions and choices available to them at this time. Many had not been given the opportunity to discuss the subject before – with their families or friends, with health professionals or in a public forum.

People attended the events out of curiosity, to gain more information and to share information with their colleagues and peers. The variety of stories told about grief and loss illustrated how much people's responses and needs vary, but also revealed shared reactions and experiences. For example, some people attached importance to thinking about their spiritual/religious needs at the end of life, while others emphasised practical issues, such as paying for and planning their funerals.

Health and social care at the end of life appeared to be at the forefront of participants' concerns. Participants' comments show that there is still much to be achieved, particularly in the areas of communication, information and essential care. Although some people were keen to point out that they had received good care and that generalisations about care and about staff should not be made, descriptions of poor care were numerous.

Some felt that ageism was responsible for the disrespectful and sometimes patronising way older people in need of care are treated and had themselves experienced negative attitudes or witnessed undignified practices. Particular concern was voiced about the care of vulnerable older people who had no family to speak up for them and people with dementia. It was acknowledged that inadequate resources were a

factor in poor care, but many felt doctors, nurses and other care staff often lacked the necessary motivation or skills to care for older and dying people.

While it is easy to focus on negative experiences and perceptions of poor care, participants also articulated their expectations in terms of good care. People wanted to be treated as individuals, not primarily as patients or as *older* people; they wanted to be treated with respect and to be involved in decisions relating to their treatment and care; they wanted health and social care professionals to talk to each other, so that care might be planned appropriately; and they wanted decisions relating to treatment and care at the end of life to be equitable, rather than based on postcode, ability to pay or the ability of the individual, or the individual's family, to articulate need.

Continuity and familiarity in care, as well as time to discuss end-of-life issues, were seen as important. Participants wanted to talk to health professionals who were already involved in their own or their relatives' care, and who were willing to spend time listening to their concerns. Without sufficient and accurate information, people ended up unaware of the choices available to them and were unable to challenge decisions made on their behalf; thus, their ability to make informed choices was undermined. Some people said they felt unprepared for their relative's death, due to a lack of transparency in discussing prognosis, decision-making, treatment and care. This sometimes added to the bereaved person's sense of guilt and loss.

Many participants were anxious about the process of dying, place of care and who would look after them. The ideal scenario for them was to die in their sleep, at home, surrounded by their families. Once more, people perceived that they had little control over such issues. Some feared dying in pain, dying in a care home or a 'geriatric' ward, or dying alone.

People's anxieties about death and dying seemed to shape their views and decisions about the end of life. Some had written down their wishes in the form of a living will in case they became

unable to express their desires for themselves in the future. Many, however, had not heard of living wills before participating in the events or were uncertain about what they involved. For some, living wills seemed a good idea, whilst others expressed misgivings about recording their views in this way. For a few participants, the desire not to be a burden, the fear of being in pain or being incapacitated, had led them to consider refusing life-prolonging treatments such as resuscitation or artificial feeding, or to request euthanasia. Others pointed out that if euthanasia were legalised, older people might feel a duty to choose death to relieve the burden on family, friends and the taxpayer.

The need for greater awareness of what life-prolonging treatments might involve, together with more information about the ethical and legal issues, was illustrated by people's confusion about these issues: for example, when treatment can be withdrawn and what constitutes euthanasia in law. There was a general consensus on the need for more honesty and openness in discussions about advance care planning and, in particular, euthanasia. It was clear that participants were glad of the opportunity to talk about such issues in an unthreatening and non-judgemental environment.

The educational guide *Planning for Choice in End-of-life Care* was welcomed as one step toward supplying understandable information about this difficult area. We acknowledge that the issues we address in the guide are subject to rapid change: this should be borne in mind in referring to it.

Recommendations

Our recommendations build on those previously set out in a report commissioned by Help the Aged (Seymour et al, 2005). We have highlighted issues to which participants in the listening events drew particular attention.

A programme of information and education about end-of-life care needs to be developed. This is important for health and social care professionals and also for users, carers and the general public. Little attention has been paid to public education on issues relating to end-of-life

care, which is an anomaly in the context of the current emphasis on the importance of choice, autonomy and information. Any public education initiative should address:

- information about caring for dying people and for people with life limiting illnesses, such as dementia
- end-of-life decision-making; including funeral planning, advance care planning, resuscitation, living wills, euthanasia, consent and communication
- bereavement and loss
- spirituality and faith
- financial considerations.

Also:

- An oral history archive of older people's stories and experiences of end-of-life care and bereavement should be collected, with a view to making these available for the education, help and support of older people and health and social care professionals.
- Palliative medicine and geriatric medicine should move towards greater co-ordination, with shared training posts and joint education initiatives.
- Education and practice relating to end-of-life care should encourage a critical perspective on the idea that choice and control are always the most important factors in good care. While many people will wish to play an active part in decision-making relating to their treatment and care, some will find this daunting, or may prefer to delegate decision-making responsibility to a family member or a clinician. There is a difference between desire for information and desire to assume responsibility for decision-making. The notion of 'entrusting' one's care to others may be a useful concept to consider in this context.
- Listening to older adults, expressing compassion and concern, and enabling continuity and familiarity of care should be seen as priorities. These are basic tenets of good practice in health and social care, but are neither given the priority they deserve in



the training and education of professionals nor nurtured adequately in the pressurised environments in which health and social care professionals work.

- The care of older people dying in acute hospitals and care homes needs to improve. It is still the case that the ‘good death’ is hard to achieve in these settings, owing to a complex range of factors including physical environment, availability of basic equipment and the support and appropriate training of professional staff. Until the care of the dying is afforded a higher priority, many older adults will suffer the experience of either under- or over-treatment at the end of life and will fail to be provided with the good standards of comfort and symptom control that we should all be able to expect.
- Attendees at the listening events voiced particular concerns about the lack of essential care given to dying older people, especially those without families to speak up for them and people with dementia.

- At a policy level, recognising better end-of-life care for older adults is an urgent public health issue, in keeping with the stance of the World Health Organization towards palliative care. A helpful step would be to map out the variety of service provision, resources and models of care that are relevant to the end-of-life care of older adults, and to facilitate dialogue about how best to mobilise scarce resources in pursuit of better end-of-life care for us all.

A peer educator’s view

The listening events were very interesting, as so many people wanted to talk about end-of-life planning but felt that it was a hard subject to speak about. I feel they needed someone just to listen and to help them make their own minds up if they should ever be left alone or even need to make a choice with regard to the future care.

Ivy Sharpe

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Planning for End-of-life Care

The educational guide *Planning for Choice in End-of-life Care*, by the Peer Education Project Group that produced this report and frequently referred to within it, is available at www.helptheaged.org.uk. It is also available in slightly shorter form, or guidance for facilitators of group discussions, as a printed booklet, from Help the Aged Publishing (tel. 020 7239 1946 or email publications@helptheaged.org.uk). The booklet is free of charge, but we charge 50p towards p&p.

Appendix: research methods

Ethical approval

The study was subject to an ethical review by the University of Sheffield's Research Ethics Committee. Invitations to the events were co-ordinated by local Help the Aged groups, to ensure that potential attendees had a good prior understanding of the aims and objectives of the project; they were all provided with an information leaflet. Participants at the events were asked to read and sign a consent form, including consent to be photographed and to use their anonymised comments in subsequent reports. Due to the topic's sensitivity, we were guided by feedback from peer educators and attendees at the event.

Design and methods

Each event took place over the course of several hours, with breaks for refreshments and lunch. Following a brief talk about the background and aims of the events, we invited people to join small discussion groups. Whole-group discussions had not evaluated well in the earlier Sheffield workshops. The day was divided into morning and afternoon sessions.

In the morning open discussion in the small groups gave participants the opportunity to raise some of their own concerns and anxieties about the end of life.

In the afternoon 'guided discussion' centred on the booklet *Planning for Choice in End-of-life Care* developed by the team in the earlier project funded by the Health Foundation. The guide was developed around realistic stories as a means of introducing participants to care planning and communication at the end of life. This method has been used successfully to address sensitive subjects before and evaluated well in the workshops held in Sheffield.

We used the principles of focus group conduct (Morgan 1988; Kitziinger 1995) to run the events. Each group comprised a researcher, one or two members of the Help the Aged team and one or two peer educators, depending on availability. Our experience in running similar events in Sheffield showed that two peer educators per

group could provide support for each other. Given the sensitive nature of the topic, the events needed to provide a 'safe' environment in which all participants not only felt able to express their views and concerns, but also to maintain their privacy if they chose (see below – 'Guide for small-group discussions'). We drew on our experiences of the workshops held in Sheffield, together with a Help the Aged guide (*Essential Steps*) to running conferences, for this process. In order to enable people to feel comfortable discussing their concerns about the end of life, only a small number of participants (maximum n=30) were invited to the events.

Analysis

Members of the research team and peer educators made notes during the small-group discussions and these were compared and added to those recorded by staff from Help the Aged. The qualitative data from the completed questionnaires was also included in this analysis. One member of the research team (AC) read and re-read the recorded notes before applying the framework approach developed by Ritchie and Spencer (1994) to analyse data. Framework analysis uses a thematic framework to classify and organise data according to key themes, concepts and emergent categories.

The first stage of analysis involved familiarisation with the data and identification of emerging issues to inform the development of a thematic framework which was then applied to all the group data. This comprised a variety of emergent topic headings, whereby data from each group was summarised. Members of the research team and the peer educators were asked to read and comment on the initial analysis, adding to and amending the themes until an agreed framework of themes was developed. Our aim was to build-up a comprehensive picture of older people's views about the end of life.

Some observations about design and methods

Small-group discussions

One of the disadvantages of running small groups is that discussion may be dominated by one or two people, which may cause passive participants to be influenced or inhibited by more verbal participants. In addition, some people may be polite and wish to fit within the norm. Often it is difficult to achieve a balance between participants feeling that they have had adequate opportunity to speak about matters that are important to them (which may deviate from the topics under discussion) and of ensuring that everyone in the group feels able to have their say. We tried to avoid this as far as possible, by explaining that all opinions should be listened to and respected and that any one view or statement was not more desirable than another. If one person's views dominated, the group facilitator reminded participants of the original ground rules of respect for individuals and their views, keeping to the topics discussed, not criticising others – even if they disagreed with their opinions – and not interrupting when someone was speaking. This is particularly pertinent for discussions of a sensitive nature which may raise powerful emotions.

Many people saw the event as a forum for sharing their experiences of loss. This was illustrated by the fact that two members of the Help the Aged team asked if they could share their own experiences of the death of a parent. Many people commented that this was the first time they had spoken about their experiences in a public arena and this was the first event examining this topic that they had attended. Although tears were sometimes shed by those relating their stories, participants expressed the desire to continue to share their experiences during the events. One woman who described an emotional story about her sister's assisted death (outside the UK) said that she was grateful that she could tell this story and felt the small group provided a safe and comfortable place in which to relate her experiences. Two people needed to take time out from the discussions, supported by members of the team.

It needs to be noted that participants did not always state when their experiences occurred or whether their comments were based on perceptions, expectations or experiences, although we report when this was made clear.

Sample

Due to time restraints, we were unable to apply for the necessary ethical approvals required to invite older people living in continuing care or in hospital/hospices to the events. We acknowledge that our sample under represents very frail and/or disabled older people and elders from black and minority communities, with the exception of elders from the Chinese community (n=4). Locating this project in the context of a broader programme of work means that some of these shortcomings have been at least partially addressed (for example, Payne et al, 2005). Although we did not ask people to provide private information about themselves, we are aware that the age range of those who attended the events was broad, ranging from those aged in their early 60s to late 80s.

Although it is not possible to make widely applicable generalisations from our sample of 74 people, we are confident that we have collected a very wide range of views from older adults living in different localities and with different socio-demographic and cultural circumstances. Each person's story of loss is unique and the stories reported here are very diverse, but it is the ordinary, everyday things that connect us with each other. As Margaret Forster observes in her family memoir, *Hidden Lives*, amongst all the stories told by our parents and grandparents 'sometimes their story is the story of thousands' (1995:13).

Evaluation

To evaluate the impact of engaging in the listening events, we asked participants to complete a questionnaire about the day and, if they wished, to comment further on the *Planning for Choice in End-of-life Care* guide. Rather than asking people to complete the questionnaire at the event, we provided a stamped addressed envelope to allow people time to digest and

comment on the guide before returning the questionnaire. The questionnaire contained space for qualitative comments and was anonymous.

Views on the listening events and educational guide

From 74 participants, 45 questionnaires were returned: almost all participants were overwhelmingly positive about all aspects of the event and educational guide: All who returned a questionnaire strongly agreed/agreed that the event was worthwhile and the majority (97 per cent) strongly agreed/agreed that the content of the day was relevant to their needs/needs of their organisation. It needs to be noted, however, that one person was deeply unhappy that an issue of particular importance to him personally was not the sole focus of the event he attended. On reflection, we acknowledge that the sheer lack of opportunities to express strongly held views about end-of-life care means that this was always going to be a risk.

Educational guide *Planning for Choice in End-of-life Care*

- *Gave me food for thought. I had already planned and paid for my own funeral to save the expense falling on my family, but I had not given much thought to the events leading up to it. I now have a better idea how my end of life should be, for which I thank you.*
- *A very interesting booklet. Indeed, I think all pensioners should have one.*
- *I'll pass the information on to friends and colleagues. The book also contains some things that I had thought about but did not know how to pursue, so it has been a great help to me and will be to others that I know, thank you.*
- *Well constructed and covers all aspects. It is difficult to know how one would cope when faced with terminal issues – there are no practice runs – but in general terms, you have covered all eventualities.*

Small-group discussions

- *I found it easy to participate and easy to understand all that went on in the groups.*
- *Everyone listened to everyone else. A very relaxed and informative day.*
- *The facilitators were very caring. I was full of apprehension but I was put at ease by their relaxed guidance and was able to express my own feelings with the group.*
- *Group workshops were of the right structure and enabled people to share and contribute their experiences. Also insights into many problems which one could take away and discuss with one's peer groups.*

Some helpful and constructively critical comments about details in the educational guide were noted and incorporated as appropriate in the revised guide. Some examples of these are listed below.

Possible improvements to booklet

- *The booklet is easily understood and readable. Perhaps there could have been a few more examples of how people of different faiths deal with these issues.*
- *The spiritual side should not be neglected, but best integrated into the whole document.*
- *It is in danger of becoming too large and unwieldy; at least some parts could be slimmed down. Too much to read can be off-putting. It is a good starting point for discussion and finding answers.*
- *It would be useful to have an example of what others have written on things to remember me by.*

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