Dying in Older Age
reflections and experiences from
an older person’s perspective

Help the Aged
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Edited by Tom Owen

Help the Aged
2005
**Acknowledgements**

Sincere thanks go to all the older people that have contributed in some way to this project. These include Pat McWeeney, who has advised and helped shape my thinking throughout the year, and Audrey Cloet, Zelda Curtis, Jo Bellini and Faizullah Khan for their considered thoughts. Thanks also to Anne O’Daly, Ros Levenson, Iliff Simey, and everyone on the research team at the University of Sheffield.

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1. The University of Sheffield, Palliative and End of Life Care Research Group, School of Nursing and Midwifery, Bartolomé House, Winter Street, Sheffield S3 7ND  
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None of us likes to consider our own death. Perhaps it is part of our normal psychological functioning to push thoughts of our own mortality as far from our minds as possible. We tend to view death as something separate from ourselves rather than embracing it as a natural part of our lives. For many of us, death and dying are taboo subjects.

Those professionals responsible for our health and well-being at the end of our lives often struggle to engage in discussion with patients around the choices available to them. Even in the informal context of close family and friends initiating a conversation about one’s own impending death can be problematic. This is the sort of conditioning we have: that death is something terrible that shouldn’t be discussed.

But is such denial helpful to those people who with increasing age and frailty may be becoming ever more conscious that they are nearing the end of their lives? Dying can be frightening, but without people to share your worries or offer advice, does it not become even more frightening?

At Help the Aged we spoke to older people who certainly felt that the needs of older people who are dying are often ignored. They noted how the shift of government rhetoric to focus upon promoting independence and ‘successful ageing’ – for example, within the (English) Government’s National Service Framework for Older People – diverts attention from the problems and needs of those older people who are unable to conform to this model of ageing, and who simply struggle to cope day to day as a result of deteriorating health and capacity.

Help the Aged decided to act upon these concerns through a programme of work that sought to bring together evidence relating to the needs and circumstances of older people at the end of their lives and to offer older people a platform on which to discuss their views of dying and death.

Given the taboo surrounding death and dying, Help the Aged was conscious that by initiating discussion with older people on this topic we were moving into uncharted territory. We were aware that some older people would not feel comfortable in talking about dying-related issues. Indeed, a number of older people questioned why we wished them to dwell on dying when there was so much to live for. Talking about dying was considered somehow incompatible with their main priority of ‘living well’ right until the end of life.

The seven articles presented in Part I of this report are the culmination of much of the discussion with older people over the past 12 months. The articles are written by those older people we spoke to who felt able to put their views on death and dying on to paper. The authors, from a variety of backgrounds, include retired academics and individuals who are active in campaigning for the rights of older people; others simply have a story to tell. What they have written is heartfelt and powerful.

Whilst not necessarily reflecting the views of either the older population at large or of Help the Aged, the articles offer real insights into some of the concerns, experiences and reflections that older people have in relation to dying and death. They offer a starting point to stimulate further
debate about the experience of dying among older people and to shape services and support to meet the needs of older people at the end of their lives.

Part II presents an overview of research evidence relating to the experience of dying in older age and provides recommendations for future policy and practice development. The overview has been extracted from a larger report written by Jane Seymour and colleagues at the University of Sheffield on behalf of Help the Aged. The report provides startling evidence to demonstrate that the experience of dying is often harder for older people than for younger people who are dying. Older people who are dying are more likely than younger people to experience multiple medical conditions, repeated hospital admissions, lack of preventative planning, under-recognition of symptoms and physical or mental impairment. They are more likely to experience social isolation and economic hardship. Despite this, they are less likely than younger people to receive support at home, in hospital or in a hospice, or to receive attention from GPs or district nurses during the last year of their lives. Older people are often described as the ‘disadvantaged dying’.

This groundbreaking work owes its success to the older people and researchers who have helped us produce this report. For me, the opportunity to listen, think and spend time with these people has been both enriching and humbling. I hope this comes across to the reader and that this work will provide a starting point from which a public debate on death and dying in older age can take place.

Tom Owen, Policy Research Manager at Help the Aged
Part I

Articles on death and dying written by older people
You ask how I feel, knowing I am definitely in the final years of my relatively long life – do I think about it, talk about it, worry about it?

The reply to the first two is a definite affirmative. Yes, I do think about it quite a lot, but my main thought, or perhaps a better word is feeling, is one of complete disbelief. Surely, I say to myself, my parents must have made a mistake on my birth certificate – it is just not possible that I shall be a hundred in twelve short years (and, boy, how short the years are lately, about as long as a month was during schooldays). But truth prevails; I was born in 1916, so it’s simple arithmetic.

Having accepted this, my next frequent thought is what important things do I still have to do before I quit this mortal coil, or, as slang would term it, ‘pop my clogs’? It is this thinking that makes me very angry. I realise that when one is young one feels there is all the time in the world to do everything you ever want to do (including, of course, changing the world for the better!). When that annoying fact has sunk in, I find myself making lists of what I still have to do, and then having to prioritise them. This tells me that, even if I manage to live a very long life, there are many things I won’t have time for this time around. I say ‘this time around’ because I have, after wondering about what happens after death for most of my life, come to believe in reincarnation as being the one thing which makes sense to my logical and finite brain.

My thinking has led to some action in preparing for my death from the point of view of my two sons, who will probably be left behind. I have therefore:

(a) sorted as much of my belongings as possible and marked paper stuff that can be destroyed as only of interest to me;

(b) given them complete power of attorney in case I become unable to deal with my affairs, so that they can do whatever is needed;

(c) left a list of presents I have already bought to give to people (I buy throughout the year), so that, as inevitably I may die before some are given, they can pass them on;

(d) told them when I have booked tickets for the theatre, etc. in advance, where I have put them, as it is possible I may die before the show date and they can then take someone else, with my best wishes!

As to my actual death, I must admit that the extremely un-logical part of my mind simply cannot conceive of a world which doesn’t contain Jean Buzan. How on earth will they manage without me?! The practical part, however, knows that I am going to die, relatively speaking, fairly soon. So this brings me to the third question – do I worry about it? Well, in a way I suppose the answer is affirmative, but it is also partly negative. I truly am not afraid of being dead; for instance, I don’t believe in purgatory or hell. But I definitely am scared of staying alive in a condition that prevents me from looking after myself – quality of life is far more important to me than quantity. So my fear is really of taking a long, helpless and especially painful time actually to die.

I most certainly do discuss all these things with other people, sometimes friends and also, surprisingly, with mere acquaintances. As a gerontologist who for many years has taught and
worked with older people, I am pretty sure that the majority of ‘end-of-lifers’ are cognisant of this condition, and do think and talk about it.

As I am currently volunteering at a day centre for physically handicapped older people, I have managed to talk with several on this subject, both individually and as a group, and there is certainly no embarrassment or upset in broaching the subject. For some, thinking about death has been an important step in reaching a decision about their lives.

For instance, a 93-year-old lady I know once confided with me that she had a big decision to make. She had been suffering from pain for some time and had finally been told that she needed surgery to eliminate it. However, she told me that the anaesthetist had said to her, in no uncertain terms, that her heart was so weak it would most likely not survive surgery. Therefore, she explained to me, she had to make a choice: would she have the surgery and risk very likely dying, or decide against it and live longer, but with the pain? As she shared this with me she was quite calm, as if discussing which of two places to choose to go on holiday. She went on to say that she was really quite inclined towards having the surgery: ‘I’ve had a good long life, and enjoyed it, and I really don’t feel like living longer in this pain,’ she said. I told her that I think, in her position, I would feel likewise.

A 70-year old woman – who, despite suffering with terrible arthritis in her hands and feet, is always bright and cheerful – had a similar decision to make: ‘I have refused the offers of having replacement joints for knees, ankles, elbows, etc. as I would prefer a shorter, better-quality life than a longer one more full of operations and so on. I am absolutely determined to continue doing everything that I can for myself for as long as I possibly can. When people express surprise at how cheerful I am I just tell them, ‘Well, what is the good of worrying about everything? It doesn’t help make it better. You just have to do the best you can with what you have and make the most of it. It doesn’t worry me that I may not have many years left because I just live from day to day, so either I have another day or I don’t.’

It is interesting that when members of my group die, the attitude is always, ‘Well, it was a happy release for her and we’ll remember her as she was.’ ‘Release’ is a word often used about death.

Another extremely bright lady, in her nineties, has told me she feels (and I think almost hopes) that she has had her last birthday. Because she is becoming increasingly physically frail and cannot do most of the things which used to fill her life, she feels it would be a good time to go now when she has lived a long and happy life and has so many happy memories.

In contrast, a gentleman recently turned 100 was certainly not afraid of death, nor did he dwell upon it. He actually feels he would live a lot longer and had a lot more to do, though resenting his lack of mobility and poor hearing. He just simply was unable to understand why on earth people think being 100 is so important, or means anything at all, and hated all the fuss made about it!

Jean Buzan, 87, is a retired gerontologist living in Marlow, Buckinghamshire
The prospect of being near the end of my life is something that I have been conscious of since I was a young man. It is therefore not something that has simply emerged as a result of getting older.

In 1955 I was told I had three weeks to live. I had lived with heart disease throughout my childhood. The pain and fainting and dizziness had become a part of my everyday existence. At the age of 19 I was told I was dying.

I am now 69 years of age. I have spent major periods of my life waiting to hear whether the latest operation I have been through or treatment I have received has been successful in extending my future. I know that life may only offer me another five years but I am not dying – I am living, as I have always done. I am living a very rich and fulfilled life.

In 1967 I married a beautiful woman who I had grown up with, called Audrey. Some years later we discovered that Audrey had multiple sclerosis. We had always been strong together, and this would continue, but initially the only support we received was from each other. No one ever approached either of us to find out how we felt about living with her disease. It seemed that no one cared about what our fears were or how we were coping or how we could better deal with this change in our lives. Most importantly, the care we received was purely medical and supporting us in how we planned to approach the future was never considered. We just needed someone to talk with us and address the enormity of what was happening to our lives.

In April 2001 Audrey died. A huge emptiness consumed me. The love of my life had slipped away from my arms. I will never stop talking about her or remembering her. It is only when you let yourself grieve, when you are honest about how sad you feel, when life begins again. Slowly the pain eases and the gap slowly begins to fill.

It was during this time of bereavement that my experience of doctors and hospitals and indeed the prospect of my life being at an end became the most daunting. I had spent my life in the care of doctors and nurses who at times seemed to hold my life in their hands and then, suddenly, by the sheer nature of the way doctors spoke to me and supported me, I felt scared and alone and very pressured.

I was admitted to my local Coronary Care Unit. I was a very ill man and was immediately asked if on falling unconscious I would like to be resuscitated or not. This was a question which had never been put to me in the past. Why was a doctor asking me if I wanted to be brought back to life again if I died as if he was asking if I wanted milk in my tea? Why was this something that had never been opened up as something I may have to consider in the future?

I am close to my family and I am not scared of dying but this wasn’t something I wanted to talk about with them at this time. It had been put to me more pointedly than ever that this could be the end of my life. I wanted to enjoy the time I had left with my friends and family and not taint what seemed so precious with making such huge and scary decisions. I’m not saying I didn’t need to talk or need someone to listen but this had to be someone independent – also someone who could allow me to make informed choices. Having choice can only be token if you don’t even know what your options are.
By chance, I became friendly with a nurse who supported me in making a decision, which thankfully for me never had to be used. Fortunately since this time life has been so rich and I have enjoyed many new experiences. To think that a doctor wanted a decision made there and then as to whether or not I would choose to live if I needed to be resuscitated! To think that my life was reduced to being pressured into making such a snap decision!

I accept that I will reach the end of my life but when I do I want to be prepared. I want to have made all the choices and decisions I need to in a measured way with the support that I need. Accepting and coping with dying is all down to being ready to move on, to leave this life behind and go to the next stage.

On reflection, being prepared for this experience would have alleviated the fear and pressure I felt at this time. Why wasn’t it something that was always open for discussion with the various players in my network of care?

Everybody dies alone. It is addressing all the fears and making choices and putting your affairs in order that you need to do with other people before you go.

George Fullwood, 69, retired engineer, Sheffield
3 Dorothy Runnicles

During my adolescence and young adulthood I experienced the impact of deaths of people I knew and loved through bombing and war service activity. Only the church workers faced up to the reality of death itself and attempted to give comfort, emotional and spiritual help to those who were known to be dying and helped with the needs of those left bereaved.

Now that there are less church workers and fewer people who are helped by this route, I think we face a yawning gap – both for those who recognise that they are dying and for those experiencing the emotional and practical impacts of sharing that journey with them and the subsequent bereavement. We talk about the factors that make up the quality of life in older age. We also need to talk about the quality of dying. I am sure it is a hidden worry in many older persons’ minds.

For me, with age comes more frequent contact with death and the bereaved. I think there are three important ingredients necessary for those going through the dying process. Firstly, the ingredient of Tender Loving Care and not dying alone; secondly, the availability of effective pain killers; and thirdly, support to encourage and enable people to talk about one’s own dying process, faiths and wishes and being helped to face up to the hidden fears. These fears affect people going through the process and those journeying alongside them who will be left behind, as well as those not yet clear how and when this final stage will start.

While services which provide such ingredients are out there, my experience of both the death of my mother and that of a brother within days of each other seem to suggest that the type and level of support that one receives is greatly dependent upon the circumstances in which you are dying and, in particular, whether you have been formally diagnosed as being terminally ill.

At 74, my brother was attacked by cancer which, over three months, changed him from being an active, sports-loving man into an obviously dying person. Because of his formal diagnosis of cancer, my brother’s experience of the dying process was greatly enhanced by the Macmillan nurses who both assisted his wife in providing all possible TLC and the physical support, at home, from the nearby hospice where he chose to go for the last stage of his dying process. All his family members were encouraged and enabled to be with him in the hospice, including a son who was brought from another hospital to see his father. The medical and social work staff were committed to making the quality of his death as good as possible. It helped us all.

My mother’s death, at 100, was different. It was a gradual but prolonged affair expressing itself in a general deterioration of her physical and mental capacities. At first, in her 70s, her full functioning was assured by my intermittent help and the help of a home help. Gradually, moving into her 80s and 90s, she needed increasing support with personal care, her finances and transport. In the last year she lost her ability to feed herself, walk and talk.

To its credit, the care home where she spent these final two years offered a daily social programme arranged by a separate worker, including outings, walks, indoor activities, discussions, bingo, pub lunches – in which she was pleased to participate. She was visited by family and friends at least two to three times per week, which also meant more outings. Her gradual mental and physical losses did not mean that she lost out on maximising what was possible.
I was called by the staff just before her hundredth birthday, when they found her unwell one morning. I asked that the doctor be called as I made my way to the home. Later in the afternoon when I arrived I could see that although my mother was not conscious she was writhing in pain. I asked for the GP to be called in again. She agreed that my mother needed painkillers for her palliative care and prescribed morphine patches for me to obtain from the chemist. It was 6.30pm. Fortunately I had a driver friend with me and we spent three and a half hours touring across London for a late-night chemist that could provide the correct prescription. My mother’s obvious pain continued throughout this time, and although the sparse care staff did their best I sensed their distress and the pressure of the work.

At 10.30pm I was able to administer the patches and my mother was immediately free of pain. She died peacefully at midnight. I felt angry and disappointed at the difficulty in getting sensitive palliative arrangements for her and wondered how the staff would have managed with other deaths in the absence of any relatives’ contribution.

These two experiences illustrate the enormous difference in the level and quality of emotional support from the professionals to the person dying and the family members involved. It seems that the care and support offered depends on your medical status. As a cancer patient the doors are open to services that help you through the process. However, if you are simply dying of old age there seems to be an assumption that such sensitive support is unnecessary, for you or the loved ones involved.

**What would make a difference?**

The quality of hospice care should be available for all who need it. This includes those older people facing death living alone in the community and those who are living in the lonely confines of care-homes. It appeared to me that the staffing level in care homes is not sufficient to ensure that older people receive the attention they need. Care assistants in residential homes and staff in hospitals need appropriate training in palliative care. GPs and community nurses need to be involved more closely with the residential care sector. Choices should be available to people known to be dying. They should be consulted on their preferences. For those journeying alongside the dying the services for bereavement counselling, e.g. Cruse, should be linked into those involved with older people’s deaths.

It was necessary to break down taboos relating to childbirth in my lifetime. Now we must address the other great area of non-communication. Wider discussion is needed amongst older people to remove the taboos around dying and death.

During my mother’s many years in the dying process, I never felt able to discuss her wishes, awareness, faith and fears about death. Together we maximised her quality of living throughout these years but failed to provide a good quality of dying.

_Dorothy Runnicles, 79, lives in Cambridge and is an activist and advocate for the rights of older people_
I was born in England but both my parents came from Northern Ireland, and I went over there every year until the start of World War II. I was therefore introduced to religion via the Non-Subscribing Presbyterians, the most moderate and forward-looking of the Protestant churches there.

My mother died when I was four in the ‘flu epidemic of 1918 and my father married again in 1921, his second wife being a Church of England communicant – so from then on I was introduced to their Sunday School, Brownies and Guides. As a consequence, my faith was instilled by two different church dogmas, one based on there being one God, the other on the Trinity of the Father, the Son and the Holy Ghost. I have therefore become tolerant of the teachings of different faiths, and selective in what I accept from the teachings; yet while my ‘belief’ in a God has remained strong, my acceptance of a particular religious teaching is not.

I still say that I am a Christian, even though I can’t be a member of a specific church. If I am distressed, this is never a problem, I can still walk into a church and gain comfort from the air of peace within it. I know something beyond us will help me carry on.

As far as dying is concerned, is faith of help to older people? Of the deaths that I have witnessed faith does often seem to play an important role in making dying a peaceful process. My sister, who unlike me did have a particular faith, received help from the rector of the church. On the other hand my father also died peacefully and although he was not a member of any church his inner belief helped him.

Now I am within weeks of being 90 years old and would appreciate some discussion on how to prepare for death. I do not feel I can approach any clergyman as I do not attend church regularly and, more importantly, I am unsure whether I can ask him how I can prepare for dying when I cannot accept some concepts in the Church’s teaching. Nor do I, at my time in life, wish to be ‘fobbed off’ with scripture readings.

In any case, what is the Church’s thinking on how one should prepare for death? And why do I feel it would be embarrassing to ask for its view on this question? Is it because these questions are never asked and therefore never faced, or because they do not know how to answer it? It seems to me that, on the whole, church professionals teach us how to live, but do not fundamentally prepare us for dying.

The same seems to be true of health and social services professionals, upon whom we are likely to depend in later life to do their best to keep us alive. My stepmother died of an angina attack shortly after being discharged from hospital. She was afraid of dying and admitted it: she did not feel as safe out of the hospital. Where was the spiritual help to ease her fears? Neither the Church nor the hospital had prepared her. Again, they seem afraid to talk about death and dying.

I do not feel that I can discuss my worries with health professionals. I cannot think I am much different from the others in that I have wondered how much longer I shall be here. It is seen as morbid to talk about dying: My doctor plainly found it difficult when I said I wanted it made clear in my notes that at my age I did not want invasive surgery to take place should I not be able to
make that decision for myself, and that I had already told my family this. Why the apparent embarrassment? Doctors are used to death, and if they can talk to relatives about organ donation with sensitivity, why cannot we discuss dying with them and what we would like to happen to us, or not?

Similarly, at the Primary Care Trust Strategy Board of which I am a member, the whole emphasis is on providing for the living, which is absolutely right, but we never talk about those who are dying and how they can be helped. Should I ask how they administer the morgues in the hospitals? How they prepare people who are dying to face the fact? Do they have staff trained in this ‘discipline’, or should they, and what the cost would be (and also would it be ‘best value’)?

In fact, probably the only society which talks about death in any depth is the Voluntary Euthanasia Society – a sobering thought. My understanding, however, is that those who argue for euthanasia concentrate on the fear of old age, pain and decrepitude and, it seems to me, the loss of their ‘self’: I believe in the right of choice to be able to say to people who care for me, that I prefer death and so do not want intervention to keep me alive. Voluntary euthanasia, however, is different: for me, it is not appropriate. I would not be able to deal with the transfer of guilt to others. I would have made the choice to die but they might wonder why I made that choice when they could still help me. Moreover, I do not believe at present that I could go through the process and planning of euthanasia. There is a sort of horror about the actual process of killing oneself or getting someone else to kill you. I do not want to determine the date or way of death. My philosophy of life is that things die in their own good time, that one has a span of time and while unforeseen circumstances can take you away, this is not your decision. Perhaps this feeling is linked to my belief.

Coming back to myself, I have found myself shredding old files, extraneous and committee papers and then realised that I was probably ‘clearing the decks’. One day I realised I was regularly reading the ‘Obit’ page in the Guardian paper, and that I was particularly noticing how many people older than me had died. I’m glad I saw the funny side of it, because I now seem to be one of a gradually diminishing circle. I wonder whether or not we do subconsciously prepare for death in this way.

I am fortunate that I have been able to talk to my daughter about my funeral, and to the clergyman of the church where my ashes will lie. I finally realised I was indeed preparing for my death when I went over to Northern Ireland this year and attended the church my ancestors have worshipped at for 270 years. I asked the Reverend’s permission to have my ashes scattered in that church, and before giving it he discussed it with me and what my executors would have to do. I really appreciated that, and felt an inner peace that I have prepared as far as I can and that I shall rest finally where I want to be. Perhaps the fact that I have asked a priest in the Church of England to take my funeral service, and that I shall finally rest in a Northern Ireland Protestant church underlies my submission that I do not have a Faith, but I do have a Belief.

Joan Rowley, 89, is a Life Member of the Open University Students’ Association and an active campaigner for the rights of older people.
In the early ‘80s, as the Community Care Manager for the London Borough of Bexley, I visited a large number of old people nearing the end of their lives. What I saw then was ancient, deteriorating bodies, and people who seemed to take no pleasure in life, but were just waiting to die. I did not want that for myself. I started to look for ways to escape such a grisly fate. As I became old, the possibility of these horrors drew nearer, and I started searching for information about more comfortable ways to die.

There were two powerful influences on me.

At one meeting I attended a very old lady told us a gruesome story. She had a group of friends who arranged a tea party whenever one of them wished to die. The one to die had saved up her sleeping pills for such an occasion. She took the pills and when she became unconscious one of her friends put a plastic bag over her head; they had specially decorated her bag. Sadly, what those ladies did was legally murder, and up until that time I had no idea that, unless you had a doctor’s help, there seems to be no alternative. Taking an overdose seems comparatively easy to me but the plastic bag is not something I could ask anyone else to do or do myself. The issue is not moral but emotional – a compound of fear and revulsion. I knew as I listened that this could never be an option for me. I am not interested in sanctioning such acts of murder – but I am interested in the idea of doctor-assisted suicide, whereby a doctor or nurse provides a prescription or medication in fatal dose to someone nearing the end of their life who wishes to die.

Later, at a seminar organised by the Voluntary Euthanasia Society (VES), I heard a doctor from the Northern Territories in Australia speak about people who came to him for help to die. I recognised in myself the same motivation behind the reasons those people had given to him. They were people who had always been in control of their lives and wanted to be in control of their deaths. Pain was not the key issue; it was autonomy. That was what I wanted.

Little did I know how difficult this would be.

There is a common belief amongst many older people that ‘my doctor will see that I do not suffer’. Many people do not understand that there are clear legal limits to what their doctor could do, and the doctor’s ability to use their discretion at the end of life is not what it used to be – for most people the only option is an increasing dose of diamorphine which may eventually lead to death. And depending on the courage of your particular doctor and the strength of your constitution, this may mean you lie in bed doped, incontinent and without dignity, at the mercy of others for possibly many weeks, having suffered a great deal before diamorphine can even be considered. A hospice may offer a more sophisticated drug regime and better staff, but too often the same helplessness and indignity has to be endured – and often pain as well. Not only do you suffer, but your family have to suffer while watching your long-drawn-out demise. What is the point of that?

There has been a great deal in the press and on television about an organisation called Dignitas. This organisation enables people who wish to die in comfort [to do so] with the aid of a doctor. It is based in Switzerland because, in that country, assisted suicide is decriminalised. Unless the law in the UK is changed to allow doctor-assisted suicide here, the only way to die in comfort at a time of the patient’s choosing is to join Dignitas and go to Switzerland. This is what I shall do.
From this point, I have been running into a succession of obstacles. For example, if I am incapacitated and unable to take myself to Switzerland or even write a cheque, anyone helping me is liable to prosecution. I asked my solicitor whether he would release funds for an air ambulance should the need arise, and if he had a financial power of attorney. He said this would put him in a difficult position because it might be against the law.

One thing I am absolutely determined about and that is not to involve my children in my death. The guilt that they would inevitably feel if they had anything to do with the process is to be avoided at all costs. They know what I intend to do and they respect my wishes.

The reality of old age and decrepitude is something few people think about. I believe this is because our legislators and others who influence policies are not near enough to death to have started to think about what old age and death involve. Understandably they are concerned that old people should not be killed off by grasping relatives. However, doctor-assisted suicide and/or voluntary euthanasia has been legalised in the Netherlands, Belgium and the state of Oregon in the USA for some years [as well as] Switzerland. In Britain, polls have suggested that as many as 80 per cent of people favour some change in our law in this area.

I have been interested in ageing for many years and I have known many old people for whom life is a misery and they pray to God ‘to take me’. I am certainly not going to wait around for God. I have arthritis now and many relatives with dementia, so that means that I have a good chance of getting dementia and my arthritis will certainly get worse. I also have a strong constitution, no heart problems, low blood pressure, low cholesterol (none of the killer diseases) and healthy, long-lived parents; so the actuarial tables say I am likely to live till 103. I am determined that I am not going to end up demented and with every movement agony, dragging on for year after miserable year till 103. Let us look clearly at what is in store for us. For some it comes early, for some later, but most of us face decreasing powers and increasing pain. The lucky ones have a killer heart attack. I have had a good life and at 78 it is still good, possibly the best time of my life, but gradually or possibly suddenly it will not be good. Life will no longer be fun, and at that point I want to be in control and say, ‘Enough is enough. Goodbye.’ The law must be changed so that those who wish to can end their lives when they want to do so in comfort.

Nan Maitland, 78, is a retired community care manager living in London
Gaining insight into older Chinese people’s feelings on their own death or plans for the end of their lives is not something I have been able to do, so all I talk from is my own personal perspective and experiences.

In the Chinese community funeral ceremonies and burials are conducted in various ways depending on whether people follow Christianity, Buddhism or Taoism. Though the procedures for celebrating someone’s life after death vary between faiths within the Chinese community, across all faiths there is a shared belief and attitude that talking about your own or someone else’s death before the event has happened brings very bad luck and carries a bad omen.

Even from a young age, death was not something unusual or alien to me: my father was a well respected elder within our community in Burma and was often approached to help plan funerals or advise on how ceremonies should be conducted.

My father’s involvement came only after the person had died. Death for Chinese people is something that is dealt with after it has happened. Any planning for their care or end of life is done at the time of it being needed by their families and friends.

I have also witnessed the death of my mother and father, sister, brother-in-law, close friends, and my own son. I have taken on the responsibility of planning and arranging their care at the end of their lives and also their funerals (be they arranged by funeral parlours, as with my own son, or crematoriums, as with my sister, or buried at the top of a mountain, as with my father).

I think it is my close and recurrent experience of death and tragedy which shaped my thinking on this matter. I have concluded that death is not something we have control over or that we can necessarily divert. When my parents were dying I realised there was nothing I could do to change the situation and so continued with life and taking on the responsibilities that the death of both my parents left me with.

This is the same attitude I now take to my own death. While we are alive we ought to lead a healthy and meaningful life, to do the things that we like, so that when we die we will feel fulfilled and satisfied. There is nothing we can do to prevent our death. It happens to us all, and focusing on the fear or worries surrounding it cannot make it an easier experience. The only fear I have ever had of death was of someone else’s and not of my own. Even then this was not a fear of dying itself but anticipation of a lingering death due to disabilities or dementia. Death is perhaps something we should embrace as it will never be avoidable. This is one of the reasons why I have prepared a living will.

My experience of planning care and funeral arrangements for others has made me more able to talk freely of my own death with my children in order that they are not burdened with such arrangements. They know where I want to live if I become more dependent and the type of funeral I would like to have.

Furthermore, for me death is not something that is final. It is simply another stage in a very long journey. We cannot possibly have learnt or experienced all we are going to in this vast world in one life. Moving on from this, the way we live our lives now can only prepare us for the next stage in our journey.
I have always known that I must approach the end of my life without worry or regret. I have prepared myself for this by trying to give as much as I can to my family and community in return for the kindness and dedication others have shown me throughout my life.

My early life in Burma and relocation to the UK carried with it much hardship and tragedy but my strength and determination got me to where I am now, at peace. This would never be possible without the love and support of the people in my life I call my guardian angels, who gave unconditionally and whose devotion carried me through the poverty and the pain.

Very importantly, I have also learnt that having forgiveness makes for contentment. For those who stood in my way and treated me so cruelly I have only forgiveness.

It is with that security I will leave this life. I am happy that I will go without any hurt or pain in my heart, ready to receive what is waiting for me at the next stage. Somehow I know I'll be back but how or where I do not know.

Shu Pao Lim, MBE, 81, is chair of the Camden Chinese Community Centre and the Great Wall Society
What’s it like to be 97 and in the last phase of life? After a lot of cogitating – cogitating is a very suitable occupation of the ageing – I have come to the conclusion that I simply don’t know. I can only reply, as I have done on every birthday since time began, that I feel no different. I’m still the same me that I have always been, the same me that I was yesterday and will be tomorrow.

Nevertheless, I have to accept that decrepitude creeps relentlessly on. I cannot, like King Canute when the incoming tide lapped about his ankles, gird my skirts about me and make a run for it. I may feel that I am the same me, but the circumstances of my life have changed and show every likelihood of changing even more every day I live.

What does it feel like to find myself in these circumstances? I have become acutely aware of the fact that my life has disintegrated into two distinct parts. There is the one that I have always regarded as the real me, the outgoing sociable person with a wide range of interests and contacts. The other is the part of my life that is responsible for the management of my daily personal affairs. I flippantly dub this other woman the ‘Old Cow’ in an attempt to lighten the load. All my life I have struggled to strike a balance between the two. As a woman, a mother, this feminine dilemma has been the pattern of my whole life.

Recently however I have realised that I can no longer manage this juggling act. The one I call the Old Cow has with the onward creep of physical decrepitude become more and more demanding, her needs more varied – so much so that she almost takes on an existence of her own.

This rather vague grasp of my situation was abruptly brought home to me when, a couple of years ago, I tripped over a faulty pavement and had to have a hip replacement. Since then, one mishap after another has so reduced me that I am now virtually housebound. How are the mighty fallen – quite literally!

I used to be on the side of the providers of social care, I knew my way around, what to do and who to see. I could suggest to those in need how they could tackle their particular predicaments. What a transformation! All my life committed to building up social services – now I must call on them. But now I no longer have the information, advice and reports that were available to me previously. Without that grasp of what is going on in the changing world of social care I am maddeningly frustrated.

Various assessors now arrive to determine my needs. One and all have worked through their list of tick-boxes. They decided that I did not qualify for care. All I ended up with was a commode that I didn’t need. When I enquired who would empty it, the universal reply was ‘we don’t do that’.

Exasperated, I decided to play them at their own game by drawing up a tick-box of the list of what I expected from them:

1. Take, for example, my need for help getting in and out of my old-fashioned bath, once a week as a minimum. Answer: there is a two-year waiting list for bath attendants owing to cuts in the social services budget. No tick in that box.
2. As an alternative, social services kindly arranged for me to go instead by ambulance to a nearby day centre for a weekly bath. That worked quite well till a sharp-eyed bureaucrat intervened to say that I was just making use of the centre for baths when it was intended for full-time day care. End of baths for me. No tick in that box.

3. I asked for help in trying to find some private aid to assist with bathing. They sent a short list of care agencies but not coherent guidance: ‘We don’t do that.’ I felt like asking them, ‘What do you do?’ But that seemed needlessly rude.

4. The next box relates to my problem of being hard of hearing. After needless arguing I have succeeded in getting two digital hearing aids, one for each ear. These are a bit tricky to fit but the hearing aid centre insists that they cannot afford to organise a home visit to help me (‘We don’t do that’). Why do I have to go to their citadel like a beggar for help? I tot up the costs, in terms of hard cash, of getting me to hospital for what will possibly be a ten-minute interview, to say nothing of the indirect costs to me of tussling to get transport organised and the physical after-effects of the long day of waiting, and they are surely more costly than a home visit.

5. And finally, a source of constant frustration to me, the lack of co-ordination on the part of those who provide the services. They are rigidly organised on a demarcation basis, according to which Trust and which specialism. I am sick of being handed round like a parcel from specialism to specialism. What it boils down to is that I am the sole co-ordinator of all that is provided: a heavy burden for an old woman and one unable to hear. The choice is yours, they assure me, but I’m too old and far too ill-informed to carry such a burden.

So the essence of all this is the appalling feeling of isolation and the terrible sense of insecurity that it all brings, [together with] the expectation on me to keep up appearances, of responding brightly that I feel fine when actually I feel lousy. I tire of the struggle to keep up an interest in all that goes on about me when I am offered no place in the society in which to live my life, no part to play, no justification for my continued existence and, in the cold economic climate in which we live, no value.

I can’t stand the crushing boredom of the life I now lead, busy though it keeps me. When all the days are the same, it is no wonder that I can’t remember what day of the week it is, let alone what month. I weary of being grateful for the gift of a bunch of bananas or a custard tart when I am starving for something to think about. I live on the brink of not being able to manage and life is one excruciating balancing act between being able to manage and the hideous lack of trust in welfare. And if I fall over the brink and can no longer manage, is there anybody there to rescue me? The answer, I suspect, will be ‘We don’t do that’.

Margaret Simey, 97, died in 2004. Having served an apprenticeship under Eleanor Rathbone, she became a life-long campaigner for social justice, focusing in later life on the rights of older people. She was a councillor in Toxteth for 23 years.
Part II

Evidence and discussion
1 Messages from research

This summary is taken from a more detailed report, End-of-life Care, on the circumstances and experiences of older people who are dying written by Seymour et al and published by The Policy Press in association with Help the Aged. Details of the report can be found at the back of this publication.

Jack died in the end of a lung infection. But what in fact killed him was a combination of Parkinson’s disease, severe arthritis, enlarged prostate and a damaged heart. During the year and a half of his final illness, he was treated by three sets of specialists for these different ailments and was shunted back and forth between three different hospitals as each in turn was attended to. As a result his notes were frequently lost or delayed or sent to the wrong hospital; he often spent days, even weeks, without being treated at all, while the hospital he was in worked out what to do with him; and, most serious of all, he invariably lost out on the care of the ailments that weren’t that particular hospital’s speciality. The problem was that while there were lots of people in charge of different parts of Jack’s body, none was in charge of Jack.¹

How do older people die?

In 2002, life expectancy at birth for women born in the UK was 81 years, and 76 years for men. Women aged 65 could expect to live to the age of 84, while men of the same age could expect to live to 81.² Death rates for those reaching 80 years of age have been rapidly declining, with more people surviving past 100. Even for someone reaching their

<table>
<thead>
<tr>
<th>Major cause of death</th>
<th>Men 50–64</th>
<th>Men 65–84</th>
<th>Men 85 and over</th>
<th>Women 50–64</th>
<th>Women 65–84</th>
<th>Women 85 and over</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancers</td>
<td>39</td>
<td>32</td>
<td>18</td>
<td>53</td>
<td>29</td>
<td>12</td>
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<td>Circulatory system</td>
<td>36</td>
<td>42</td>
<td>42</td>
<td>22</td>
<td>40</td>
<td>44</td>
</tr>
<tr>
<td>Digestive system</td>
<td>7</td>
<td>4</td>
<td>6</td>
<td>5</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Respiratory system</td>
<td>7</td>
<td>13</td>
<td>19</td>
<td>8</td>
<td>13</td>
<td>17</td>
</tr>
<tr>
<td>Injury and poisoning</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Nervous system</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Mental and behavioural</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>–</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>5</td>
<td>9</td>
<td>5</td>
<td>7</td>
<td>14</td>
</tr>
</tbody>
</table>

All deaths(=100%)(’000s) 35.6 144.6 53.6 23.0 129.6 116.3

100th birthday, the probability of dying within 12 months is less than one in two.3 Today, 83.5 per cent of deaths occur among people aged over 65,4 and this is likely to rise across the next three decades as the post-war ‘baby boomers’ enter their 80s. Many older people remain in good health well into late old age. However, for some ageing brings with it the experience of chronic life-limiting illness, reduced resources for the retention of independence and fundamental inequalities in health and social care provision.

Older people die from the same diseases as younger people, although the proportions dying of cancer as a primary cause decrease with age and the proportions dying from circulatory and respiratory disease as primary causes increase with age.5 People who die from chronic, degenerative diseases other than cancer tend to be aged over 65 years and to have a prolonged illness trajectory which culminates, in the majority of cases, in death within the confines of the acute hospital.6

With longer life expectancies, more of us are living to advanced old age. Clearly, chronological age is not tied in any direct sense to biological age. Many people in their 90s are much fitter than some of those who are decades younger than them. However, for some the awareness of mortality in late old age may be closely tied to the frustrations of having to live with creeping infirmity and disability, and a sense in which the body becomes an unreliable vessel disconnected from the real ‘self’ within. For many very old people, dying is merely the protracted process of living with multiple losses: loss of social contact, physical fitness and cognition. There is often no definable moment at which ‘dying’ commences among very old people, and the complex factors which lead to death can be understood only retrospectively.7

Chronic illness is unevenly distributed through the older population, with widespread inequality in health status as a result of socio-demographic distinctions such as social class, ethnicity and gender. Income, education, lifestyle, material and social resources all make a difference to the incidence of chronic illness and men and women from lower social classes are more likely to report these. Geographical factors are also important. The chances of living well into late old age depend on all of these factors and the poorer you are, the more likely you are to be ill and die younger.9

For many, the last months and years of life involve ‘living on thin ice’11 with general, non-specific deterioration in health and quality of life interspersed with periods of acute illness. These people face repeated hospital admissions, under-recognition or inadequate control of symptoms, lack of preventive planning and inadequate home support. The experience of dying and death for this group of people and their carers is marked by extreme disadvantage in terms of health and social care provision, particularly specialist palliative care.

The problems that many older people experience in the last year of life are...
therefore ‘those of great age and its troubles as well as those caused by a final illness’.12

Support to older people who are dying
Our tendency as a society to erect barriers against the fact of our own inevitable deaths means that we prefer to minimise the problems facing older people as they reach the end of their lives, since these are dangerous ‘reminders of our mortality’.13 The tendency to attribute deaths to ‘old age’ (some 3 per cent of all deaths in England and Wales) reveals how we tend to assume that such deaths are ‘timely’ or ‘natural’14 and therefore less worthy of our time and concern. Older people are often not considered to be in need of the special care or support given to younger persons facing death.15 In particular there is a ‘lack of responsiveness [among] the medical and nursing services to the needs of older people in the last year of their lives relative to younger people’.16

Older adults with chronic life-limiting illness or who are frail because of advanced old age need help if they are to live at home in some degree of comfort. The availability of a family member or friend who can deliver care and help at home is therefore a key factor in determining how well older people manage at home, and can be a critical factor in eventually enabling death at home. Smaller family sizes, fewer middle-aged women, who have traditionally filled the caring and helping role, and larger numbers of people in full-time employment are all challenges to the provision of informal care. But lack of support for informal care-givers is perhaps an even bigger concern.17

People aged 85 years and older are especially disadvantaged in terms of family support. However, they do not receive more attention from general practitioners or community nurses than younger people and are least likely to be admitted to a hospital or hospice during the last year of their lives.18

It has been estimated that 71,744 people who die from non-malignant disease in England and Wales each year have specialist palliative care needs, and that this group is, on average, from older age groups than those with similar levels of need in the cancer population.19 There is evidence that those who die of non-malignant diseases have as many complex care needs (thus potentially requiring specialist palliative care provision) as those with advanced cancer and yet very few receive specialist care.20 Older people who die from diseases other than cancer tend to suffer longer periods of dependency and illness than cancer sufferers and to receive care which is comparatively poorly co-ordinated. Older people, particularly those with non-cancer palliative care needs, have been found to be ‘relatively neglected in relation to care and research’.21

A study of one hospital has suggested that older adults tend not to be referred by health care staff to specialist palliative care services and that as a result these are predominantly utilised by younger patients.22

Older people with dementia
Approximately 700,000 older people living in the UK have been diagnosed as suffering from dementia. The majority are older adults. The median length of survival from diagnosis of dementia to death is eight years.23

There tends to be a lack of recognition of the terminal nature of the dementia in its advanced stages and a lack of forward planning in considering the needs of dementia patients and their carers. Older people with dementia are less likely than people with other diseases to receive support from GPs or nurses, or to be
admitted to hospital or a hospice in the last year of life. This is despite the fact that the symptoms are similar to those of adults with advanced cancer, but, in dementia, last longer and require higher levels of care. Patients with end-stage dementia tend to have a number of symptoms for which they may not receive effective palliative care. In particular, analgesia is infrequently used. The general difficulty in establishing the wishes of people with dementia means that they are vulnerable to both over- and under-treatment, especially where opportunities have not been taken to discuss prognostic and diagnostic information with the individual and his/her family at an earlier stage. Difficulties in assessing when the dying phase has been entered, or how symptoms (such as pain) should be relieved and managed when communication with the person is no longer possible, add to the uncertainty.

Older people with heart failure
Heart failure is mainly a disease of older people. Its prevalence rises with age from 5.5 per 1,000 for people in their 50s to 47 per 1,000 for those in their 80s. Many people with heart failure have a variety of co-existing conditions, such as chronic obstructive pulmonary disease, arthritis or diabetes. Such individuals have to live with the profound psychological and social effects that chronic illness has on their lives, the side effects of multiple medications and the uncertainty of whether or not they will cope with each new day.

In one study, 60 per cent of patients with heart failure attending an outpatients’ clinic reported that one or more of their problems were inadequately addressed, often because they had concerns which were not directly related to their cardiac condition. In another study, few older patients with heart failure said that they had developed an ongoing relationship with a health professional, and contact with social services or carer support services, e.g. respite, was largely absent. Similarly, information available from cardiac charities such as the British Heart Foundation was little used.

Whilst the Government’s National Service Framework dedicated to heart disease makes explicit reference to the need to take a palliative care perspective, only a tiny number of referrals of patients with heart failure are made to specialist palliative care services (0.3 per cent of domiciliary referrals, 0.4 per cent of inpatient referrals), as compared with 56 per cent of cancer patients receiving some care from specialists.

The views of heart failure patients on how they would prefer to be treated are often not sought.

Most older people die in hospital and yet it is widely reported that this is not the place most people want to die. Indeed only about half of all deaths of older people do not take place in the dying person’s preferred setting. Among people aged over 85, 11 per cent of

<table>
<thead>
<tr>
<th>Setting</th>
<th>Deaths at all ages</th>
<th>Over 65 years</th>
<th>Over 85 years</th>
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<tbody>
<tr>
<td>Home</td>
<td>19%</td>
<td>17%</td>
<td>11%</td>
</tr>
<tr>
<td>NHS hospitals and NHS nursing homes</td>
<td>56%</td>
<td>56%</td>
<td>51%</td>
</tr>
<tr>
<td>Voluntary hospices</td>
<td>4%</td>
<td>4%</td>
<td>1%</td>
</tr>
<tr>
<td>Communal establishments</td>
<td>18%</td>
<td>21%</td>
<td>36%</td>
</tr>
</tbody>
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older people die at home compared to 19 per cent of others in all age groups (see table 2).\(^{34}\)

Home deaths are linked to a number of characteristics, including:

- younger age;
- cancer as a cause of death (because of greater access to specialist palliative care services at home);
- being male (as men tend to die at younger ages than women, they are more likely to have a spouse at home to care for them);
- higher socio-economic status;
- the presence of an informal carer.

Older people with cancer are less likely to die at home than younger people in spite of the acknowledged preference among the majority of older people to remain at home. People aged over 85 years are most likely to die in communal establishments (largely care homes).\(^{35}\) Indeed, only 8.5 per cent of those dying of cancer aged over 85 die in a hospice, compared to 20 per cent of all cancer deaths.

Overall, there is a general trend for the numbers of hospice deaths among older people to decrease as their age increases, while the numbers dying in care homes show a parallel increase.\(^{36}\) Recognition of this trend has given rise to the description of older people as 'the disadvantaged dying'.\(^{37}\)

Another important trend relates to dying older people being moved from their home or care home into hospital immediately before death. This is indicative of a continued shortfall in the quality of local palliative care for many vulnerable older adults living in the community. Most notably, many older adults’ experiences of care in the last year of their lives consist of movement between settings as their condition deteriorates. This has been called the ‘revolving door’ problem\(^{38}\) and is often a result of ‘cost shunting’ between health and social services.

Most research about dying in hospital, with some exceptions, presents a gloomy picture of poor-quality care in busy, noisy and dirty wards, where medical and nursing staff devote little attention to the dying, who are sometimes placed in side rooms away from the central activity of the ward.

Communication with patients and family members is generally inadequate and co-ordination of services slow and ineffective. It has been observed that there is a lack of emotional engagement with patients who are dying, inadequate symptom control, and little clear or open communication about prognosis and treatment with patients and their carers.

Older people risk both over- and under-treatment of their disease and symptoms on entry to the acute hospital, where the picture is rather bleak.\(^{39}\) More positive evidence is associated with the role of community hospitals, which often have the equipment, resources and facilities to care for older people well at the end of life.\(^{40}\)

Approximately 100,000 older people die in care homes each year in England and Wales, but in view of the fact that care-home staff sometimes admit residents to hospital when they are very close to the end of their lives, the number of care-home residents who are dying is much greater.\(^{41}\)

The large majority of homes use a pool of untrained care assistants to provide the bulk of care to their residents. These members of staff may lack core skills such as communication and assessment, and staff turnover is rapid.\(^{42}\)
Confusion and disagreement in relation to the distinction between nursing and personal care have hampered developments aimed at improving and enhancing standards, and relationships between the range of health and social care agencies that intersect with care homes make care planning very complex. Moreover, poorly defined funding for the provision of medical care means that GPs assume such care by default and often reluctantly. Pain management and complex symptom control are sometimes poor as a result, with some evidence of inappropriate medication.  

It should be noted that home deaths are not always viewed favourably by older people, particularly if they fear dying alone, being a burden to others or if they have concerns about pain, suffering, increasing requirements for intimate bodily care and incontinence, or ‘turning one’s home into a hospital’. Among the concerns noted by carers about providing care at home are difficulties with symptom control; nursing care (particularly at night); assistance from social services with transport and bathing; communication; and bereavement support. Carers also cite the importance of continuity of care; access to help and advice; and the problem of Carer’s Allowance being withdrawn after the person’s death, causing financial problems for bereaved carers. 

**The policy and research agenda for older people who are dying**

In general, there is little reference to end-of-life care in policy literature on older people or even in gerontological research. As a consequence the needs of older adults facing death have been neglected. There exists ‘no coherent set of policies relating to death and dying per se [although] policies in several other spheres, including health and social care, shape and influence the circumstances of dying’. 

This may explain why there is a marked absence of older people’s voices in shaping the services provided at the end of life, and also the fact that many older people find that they must fit into service routines, rather than services being flexibly provided to meet individual needs. For older people from minority ethnic groups, who may already be disadvantaged, and whose needs are likely to be particularly diverse, the impact is especially severe.

Accessible information to help inform older people of the services that they should expect at the end of life is generally lacking. Attempts to combat ageism by promoting a positive, healthier and more independent image of old age can also marginalise the needs of vulnerable older people. Indeed, a preoccupation with independence in much of the policy literature obscures any meaningful debate about how to improve the quality of life of older people facing death.

**Older people’s views on issues relating to dying and death**

There is little knowledge of older people’s perceptions about this stage of their lives or their practical, social, spiritual and existential concerns. Despite this lack of knowledge, a consensus has been widely established that, ideally, we should all be able to expect a death where there is privacy, dignity, good-quality care in comfortable surroundings, adequate pain relief and appropriate support in keeping with our preferences.

Some evidence exists to suggest that there is a great deal of heterogeneity in whether and how older people talk about death. For some, death may promise release from the confines and constraints of late old age, and an opportunity to return to the past, or rejoin those they have lost. However, people in late older age may also be concerned about the possibility of creeping indignity, and worried
about the process of dying – particularly of dying alone and in pain. Fear of accidents, or of being forced to move into residential care, were all cited as factors which adversely affect older adults’ sense of dignity.

Like those in other age groups, older people often express ambivalent and contradictory attitudes to death and dying. A quick, painless death may be perceived to be ‘good’ but, equally, a death which gives time for a reunion with family and to settle affairs may be perceived to be preferable. People in very late old age may not fear death *per se*, but rather anticipate this practically and realistically; they may even joke about it with one another.

A death that ends pain and long-term suffering is seen as a release; similarly, the control of pain and other symptoms during dying is seen as essential. The words ‘comfort’, ‘dignity’ and ‘peacefulness’ tend to feature prominently.

Research suggests that older people who have witnessed the death of someone close to them may be dissatisfied with the way that person died. In one study a frequent scenario involved the carer calling for medical help at home when death was close, which inevitably ended up with admission to hospital – which was regretted. However, on the other hand, many spoke of the fears they had had of being alone with the person when they died.49

While older adults may feel it is important to share their thoughts and wishes about death, dying and end-of-life care with their relatives, this is rarely straightforward. It might be assumed that one’s family will not be able to face discussing such subjects when in fact they would welcome the opportunity. Some families will ‘jolly’ their older relatives out of any risky discussion, making it difficult for any sustained exploration of major issues to take place.50 Talking to health professionals, such as nurses, can also be difficult. Nurses entering the profession from training feel unprepared for situations where they are required to discuss or answer questions about death and dying. Talking to peers may be an important way in which older people discuss their thoughts and concerns about death and dying.

It is clear that there is much confusion about the issues relating to control and choice at the end of life, particularly in relationship to concepts of advance care statements and euthanasia. Certainly greater public education in these areas is warranted. Some older people make **advance statements**, a tool for allowing individuals to record their views and values concerning their medical treatment, primarily in terms of their potential to aid self-determination and to help the families of dying people by reducing the perceived ‘burden’ of their decision-making. In discussion with older people, it seems strange that people write their wills or plan their funerals but few give much thought to the care they might want to have at the end of their lives.51

Rather than using advance statements, it might be helpful to think about advance care-planning, a process of discussion and review between clinicians, patients and members of the family.52 More generally, emphasis needs to be placed on the distinction between a desire for information and a wish to assume responsibility for decision-making. They are not one and the same thing.53

*Jane Seymour, Ros Witherspoon, Merryn Gott, Helen Ross, Sheila Payne*
It is perhaps the greatest achievement of medical science that for many people today death occurs at the end of a long life. Yet the event of death itself is only infrequently a topic of conversation during life. Issues surrounding death in older age are often obscured from view by a disproportionate emphasis on the more ‘heroic’ deaths of younger people, and by a tendency for research to neglect death and dying.

It is clear from the work of Help the Aged on this sensitive issue that death is not commonly recognised as an integral part of ageing itself, and that a great number of older people do not feel that they are in a position to articulate their concerns and wishes. Frequently, the opportunity to retain control at the end of life is denied them. It is a tragedy, and a sad reflection on our society, that for many a ‘social death’ occurs long before physical death, with a sense of isolation, disenfranchisement and loss of control too often a common feature of the ageing process and the approach to death.

Services to support older people at the end of their lives are often characterised by inflexibility and limited choice. It is perhaps not surprising that this is the case when older people’s voices so often go unheard in what are, for many, the most important decisions that they will make in their lives.

There can be no one-size-fits-all solution to death and dying. As the articles in this report clearly demonstrate, views on the end of life are individual and personal. But the desire to retain control, autonomy and independence is perhaps as powerful a motivator at the end of life as it is for most people throughout their lives. Returning to older people nearing the end of life the control that many of us take for granted throughout our lives must surely be the guiding principle in improving the care and support in this crucial part of the life journey.

In 2004 there has been increasing public debate on the broad range of issues relating to the end of life, not least in the Health Select Committee’s Inquiry into Palliative Care, which exposed vast inequalities in the provision of good-quality palliative care, or the continuing deliberations about choice and decision-making at the end of life. This debate is playing an important part in breaking down the social taboo which still surrounds death and dying. But even this growing public discussion too often focuses on the event of death itself, rather than the journey and experiences of older people at the end of their lives. The policy and practice agenda needs to reflect that death is not just an event, but a part of the ageing process.

There are four main areas in which Help the Aged would wish to see progress being made.

Firstly, the views and wishes of older people at the end of their lives must be more prominent in determining the care and support that is on offer. Older people should expect to be offered the opportunity to make their views about the end of their lives known, and to have confidence that those views will be respected.

Secondly, it is clear that there are huge inequalities in the way in which care and
support at the end of life is made available to older people. This inequality manifests itself in a variety of ways – in the availability of good-quality palliative care depending on where people happen to live, and in the proportion of older people who do not die in their place of choice.

Thirdly, there can be little doubt that many of the difficulties and barriers faced by older people at the end of their lives are a consequence of inherent age discrimination, which affects the way in which support services at the end of life are often designed without reference to older people’s needs, or the assumptions that are made about older people’s views and wishes at the end of their lives.

Finally, the impact of death on the living is often underestimated. The death of friends and loved ones is a sad reality of life in older age. These events can have a devastating impact on the quality of life of the bereaved, and can often precipitate the loss of independence and increasing frailty. Recognising the impact of grief and bereavement in older age is therefore crucial. It is easy to forget that death also affects the living.

**Recommendations**

**1 For Government**

1.1 Better end-of-life care for older adults should be seen as an urgent public health issue, and must be an integral part of the improvements for older people’s services.

1.2 The Departments of Health should establish a cross-agency collaborative to address the issues of end-of-life care for older adults and to generate and share principles and (good) practice.

1.3 Urgent steps should be taken to improve access to high-quality palliative care for older adults with non-malignant diseases. Consideration should be given to providing specialist palliative care for older adults. The links between specialist palliative care providers and the voluntary sector, and between specialist palliative care providers, primary and geriatric care, should be examined.

1.4 All policy recommendations for older adults should be scrutinised with a view to their implications for end-of-life care.

1.5 Mechanisms must be put in place to ensure that older people are able to fulfil their role as partners in their own care at the end of their lives. Efforts should be made to develop models of user engagement with people facing death: ongoing work at the Universities of Sheffield and Lancaster funded by Macmillan Cancer Relief and St Christopher’s Hospice is of direct relevance in this context.

1.6 Specific policy attention should be directed to the experience of the end of life for older adults who live alone, many of whom will be frail and in late old age.

1.7 Improvements to decision-making in older age, particularly for those without mental capacity, must be implemented in full and without delay.

1.8 Specific policy attention should be directed to the experience of end of life for older adults with dementia and their care-givers.

1.9 Urgent attention should be paid to addressing inequalities in end-of-life
care for older people and specifically to reducing the inequalities in access to high-quality palliative care.

1.10 Attention should be paid to the potential for assistive technologies to help and support frail older people facing death.

2 For regulatory and professional bodies

2.1 End-of-life care should be an integral part of the education and training programmes for all health and social care staff working with older people, and particularly for those care staff working in hospitals, care homes and domiciliary care services.

2.2 Disease-focused practice is outmoded. Co-morbidity and frailty in older age should be recognised as key issues in older adults’ experiences of end of life.

2.3 Palliative medicine and geriatric medicine should be more closely co-ordinated, with shared training posts and joint education initiatives.

2.4 Further steps should be taken to increase the number of professional specialists in palliative care, such as GP facilitators and link nurses.

2.5 Listening to older adults, expressing compassion and concern, and enabling continuity of care through attention to organisational routines should be seen as priorities.

2.6 Examining end-of-life care should be an integral part of the system of inspections undertaken by all health and social care regulatory bodies, with particular reference to the experiences of older adults who live alone.

3 For the NHS and social care agencies

3.1 All health and social care authorities should ensure that the impact of grief and bereavement is an integral part of the assessment of older people’s needs.

3.2 The NHS should assess the provision of palliative care services in hospitals, hospices, care homes and people’s own homes to ensure that they are not unfairly discriminating against older people.

3.3 The assessment and care planning process should include consideration of the support and assistance that the older person may need in planning for the end of life.

3.4 Care professionals should consider the impact of their own practice in providing care and support at the end of life. Training and support to deliver high-quality care at the end of life should be available for all staff working with older people.

3.5 The NHS and social care agencies in England should pay particular attention to the implementation of Standard Two of the National Service Framework for Older People in England (Person-Centred Care) as it relates to dignity at the end of life.

3.6 Older people should have access to independent advocacy services within their communities to ensure that their voices, particularly those of people at risk of exclusion, are heard.

3.7 The NHS and social care agencies should undertake further consultation and dialogue with older people, using a
range of modes of engagement — for example, through a citizens’ jury. Regional discussion and consultation groups should be established, with experienced facilitators.

3.8 Local information and education about end-of-life care needs to be developed. This should include an assessment of older people’s preferences and should address:

- information about caring for dying people;
- matters of end-of-life decision-making, including advance care planning, living wills, consent and communication;
- bereavement and loss;
- spirituality and faith.

3.9 Practical local services and initiatives should be developed to help and support frail adults with severe chronic illnesses.

3.10 The development of a carer outreach scheme, using trained peer educators, should be considered, building on the work of local carer’s initiatives.

4 For the voluntary sector

4.1 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.

4.2 Consideration should be given to the role of the voluntary sector in end-of-life care for older adults, drawing on the experience of the hospice and palliative care movement. For example, day care (provided in consultation with specialist advisers) may be one way of helping and supporting older adults facing death.

5 For research

5.1 The experience of end-of-life for older adults living alone, in late old age and with dementia, needs to be better understood.

5.2 A focused research agenda is needed to look at the situation of older adults facing the end of life with no family care givers.

5.3 The moral and ethical perspectives that older people regard as important in end-of-life care, and their views about what makes a ‘good death’, need to be better understood.

5.4 The life stories and spiritual beliefs of older people, and how these link to their experiences of the end of life and on bereavement, need to be better understood.

5.5 Diversity and cultural issues in end-of-life care for older people need to be better understood.

Jonathan Ellis
Health Policy Manager at Help the Aged

We thank Jane Seymour and colleagues for their considerable assistance in developing these recommendations.
References


15. Lloyd, op.cit.


23. Davies and Higginson, op. cit.


32. Ward, op. cit.

33. Calculated from ONS mortality data (2002).


36. Higginson, op. cit.


43. Froggatt and Henwood, ibid.


45. Ibid.


48. Lloyd, op. cit.


This publication, *Dying in Older Age*, contains a summary of a major report entitled *End-of-life Care*, by Jane Seymour, Ros Witherspoon, Merryn Gott, Helen Ross and Sheila Payne, published by The Policy Press in association with Help the Aged at £14.99 (plus £2.75 p&p) and available from Marston Book Services (tel. 01235 465500 or email direct.orders@marston.co.uk).

**A free booklet** on end-of-life issues, for older people, relatives and carers, is available from Help the Aged. To order a copy, please send 50p (to cover p&p) to Help the Aged Publishing, 207–221 Pentonville Road, London N1 9UZ. For bulk orders please contact Help the Aged Publishing on 020 7239 1946.

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**Encouraging Positive Attitudes to Falls Prevention in Later Life**  
*Professor Lucy Yardley and Professor Chris Todd*

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Presented in a convenient wire-bound flip-over format, this collection of strength and balance exercises can safely be undertaken by older people at home. It was produced by Help the Aged in collaboration with Wandsworth Primary Care Trust and Camden Active Health Team (London Borough of Camden).  
24pp 2003 £4.00 (£1 p&p)

**Nothing Personal: rationing social care for older people**  
*Nuffield Community Care Studies Unit, University of Leicester, for Help the Aged*

Nothing Personal reports on an investigation into the policies and practices of six local authorities across England and Wales in determining how older people can access social care. The study is based on interviews with local authority social services departments, voluntary sector and independent providers of care services, and older people who use the services and their carers.  
112pp 2002 £15.00 (£1 p&p)
What sort of experience can an older person dying in Britain in the early 21st century expect? Dying in Older Age examines the views of older people on dying, the care and support provided towards the end of life, and the issue of control and choice in this most personal of matters – which are so often denied to older people.

Among the recommendations are that dying, so often a taboo topic in life, should be recognised as an integral part of the life course. In that context, we should expect the same concern for quality and fairness as we do other life events.