Planning for Choice in End-of-life Care

Educational guide

The Peer Education Project Group
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Jane Seymour, Sue Ryder Care Professor of Palliative and End-of-Life Studies, University of Nottingham
Dr Caroline Sanders, Research Fellow, University of Manchester
Dr Amanda Clarke, Lecturer, University of Sheffield
Maddie Welton, Nurse Consultant in Cancer Care, Sheffield Teaching Hospital NHS Foundation Trust
Dr Merryn Gott, Senior Lecturer in Gerontology, University of Sheffield

Peer educators

Ivy Sharpe and Don Thompson, Rotherham Pensioners’ Action Group
Muriel Richards and Carmen Franklin, Sheffield and District African-Caribbean Association (Older Women’s Group)
Margaret Cock, Attendee at developmental workshops in Sheffield

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Background

This guide is a result of an 18-month project which was funded by the Health Foundation (grant ref: 577/2766): ‘A peer education service for advance care planning: a development study with older people’ to raise awareness of advance end-of-life care planning among older adults and community groups representing them.

The aim of the project was to develop and evaluate the acceptability and feasibility of a peer education programme for enabling older people to obtain information about treatment and care options at the end of life. This included advice on how to talk about these issues with other individuals, their families and healthcare professionals.

Peer education

Peer education - sharing information with people of a similar age and background - has been found to be a successful means of raising awareness about health issues amongst older people (Bernard and Ivers 1986) and a useful way for older people to discuss issues about planning ahead for end-of-life care.

(Seymour et al, 2002 and 2004)

Training sessions were developed for a small group of volunteer peer educators (n=5) to work with other older people to talk through these issues. The peer educators also helped compile the educational guide.

A peer educator’s reflection on taking part in the project

Like many folk I am not an academic, and often wondered if anything relevant to my way of life comes out of a research study. Almost every day in the media we hear how research has taken place in a variety of topics from garden plants to global warming, so is there anything left to be researched? Are the results of any interest to the ordinary member of the public, especially us older folk?
At Sheffield University it was noted that there was a lack of information regarding advance care planning for end of life and that many older people felt they had little say in their care. Extensive research was undertaken to look into the available literature, and very little was found.

A workshop for older people was arranged and the team presented their findings, and it was suggested that further work was needed with input from older people. I attended that first workshop and I am now a peer educator! Five of us volunteered for training as peer educators, two from a local pensioners’ group, two from an African-Caribbean group and myself, a recently retired nurse. I worked in an acute hospital on a ward mainly caring for people with dementia. During this time I realised how many relatives found it difficult to decide the type of long care etc. their relative would want, care and dying being a subject they had not discussed.

We had three training days, and had sessions on various helpful topics: for example, loss and bereavement, palliative care, legal issues and group dynamics. Alongside this, we spent a great deal of time editing the guide, making sure that it was a readable and acceptable publication. The professional researchers treated us all as equals and this has made for a good team spirit. At the end, we made a video where we - the peer educators - expressed our views about the project.

We thought this would be the end of the project, but then Help the Aged took it up, holding ‘listening events’ around the country. There has certainly been a lot of interest in the subject, not only about advance care planning but in the idea of peer education.

So is this the end or beginning of the research? I think in future years we will all hear a lot more about advance care planning and be encouraged to think about all the issues involved.
Two workshops involving older people and community group representatives were held in Sheffield where older people’s views, experiences and concerns about care planning at the end of life were discussed and the peer education material was piloted. The guide was re-drafted as a result of feedback from participants at the workshops and again, in response to critical readers’ suggestions.

Both the workshops and the guide were evaluated very positively and feedback suggested that the project should be disseminated more widely to other groups (see Sanders et al, in preparation). To this end, Help the Aged and the team of researchers from the Universities of Sheffield and Nottingham collaborated on a small number of listening events held across the UK. These events are described in the companion report *Listening to Older People: opening the door for older people to explore end-of-life issues.*

Following the listening events, the guide was revised in response to participants’ comments and the issues they raised.

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Older people have always been good educators for younger people, but with support we can educate each other on more serious issues. So I hope you can see that this research is relevant and valuable, and as it goes on for publication hopefully many older folk will be able to use the guide amongst themselves. I have learnt a lot and it has been an enjoyable and worthwhile experience.

*Margaret Cock*
Using the guide

The guide has been designed to be read and discussed in small groups; most people who attended the workshops and listening events, where the guide was piloted, indicated a preference for discussing it with their peers. However, you may not have the opportunity to do this or may prefer to read the guide on your own. For those reading it on their own we have provided suggestions for where to go for further support.

In case you would like to use the guide as part of a small-group discussion, we have included ideas for small-group discussion as an appendix to a slightly longer version of the guide, available online at www.helptheaged.org.uk.

Planning for Choice in End-of-life Care is a step towards supplying understandable information about a difficult area. We acknowledge that the issues we address in the guide are subject to rapid change: this should be borne in mind when referring to it.
Introduction

Today, many older people remain in good health well into late old age. However, some may worry about future illness and the end of life, particularly if they know they have a serious illness, have experienced bereavement or live alone and are not sure where to seek help. Lack of knowledge about what is possible in terms of help and support can increase their anxiety.

This guide has been developed to raise awareness about advance care planning amongst older people. Advance care planning means looking ahead at possible future options for health care, particularly at the end of life, and expressing preferences. Individuals will need to discuss the issues with their families and with health professionals.

This guide provides information to help readers to think about what is right for them as individuals. It is intended as a preliminary guide, not the sole information source, and other sources of help are indicated within it.

Please note that the information provided here may be subject to change.

The guide is in three sections:

1 Legal and ethical issues
2 Caring and coping
3 Loss and bereavement.

Our research work has highlighted that some older people want more information about end-of-life care, including how to talk about these issues with family, friends and healthcare professionals.

One issue on which more information is often needed is palliative care. The philosophy behind it is that people who are facing a serious illness, and their nearest and dearest, should be able to expect privacy, dignity, good-quality care in comfortable surroundings, adequate pain relief and appropriate support in keeping with their preferences.
This model of care was spearheaded in part by the development of the modern hospice movement, founded in 1967 by the late Dame Cicely Saunders at St Christopher’s Hospice in London. Dame Cicely’s mission was to convince others that people should not be deserted in the time of their greatest need, but should be cared for in a manner that enables them to live life as fully possible and respects both their wishes and their uniqueness as people. Talking about and planning how one wants to live the last stages of life can contribute to achieving this.

The information provided here is linked to two stories (see boxes on pages 8 and 24). Questions for group discussion or individual thought follow each part of the story. The information is provided to help address these questions, clarify any points of confusion and point out sources of further information. The material is not intended to promote any one form of planning, but to provide enough information for readers to be able to make their own choices.

The content of this guide has been formed from a collaborative literature review and a series of discussion meetings and workshops. We are very grateful for the support of the Health Foundation and Help the Aged, which made this work possible.
1 Legal and ethical issues

This section introduces some of the main legal and ethical issues associated with advance care planning.

There has been a great deal of discussion and debate in the media about the major life-and-death decisions associated with advance care planning. Much of this debate has focused on the use of ‘advance statements’, or ‘living wills’ (see section 1.1) as a means of making advance plans about medical care and treatment. These can also guide families and/or healthcare professionals acting for people who are now unable to make decisions for themselves. However, it is important to understand that advance plans can be made for the more everyday decisions that have a major impact on our lives. Such decisions might include the place where we would want to be looked after if we were to become incapable of looking after ourselves.

Joe’s story (part 1)

Joseph Potter had recently retired from work and lived with his wife Emily in a small village just outside Sheffield. Sadly, Emily’s mother had died recently. This had made Joseph and Emily think about the type of care they would want to receive if they were seriously ill. After hearing a programme on the radio about ‘living wills’ they felt that these were something they would like to know more about.

They had several questions, for example:

- What is a living will? (see section 1.1)
- What are the pros and cons of drawing up a living will? (see section 1.3)
- How could they find out more about living wills? (see section 1.4)
- If they were to make a living will, what should they then do with it? (see section 1.5)

Activity Use the information in sections 1.1–1.7 to help address Joseph and Emily’s questions.
1.1 What is a 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 set 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, resuscitation), but they can be used to outline views and preferences concerning other issues that are important for everyday life. This might include, for example, views about the place in which you would ideally like to be cared for or special instructions to guide your care.

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 recorded before someone becomes incapacitated by serious illness.

An advance statement may be in any of the following forms:

- a signed document or card (if it is an advance refusal of treatment it must be witnessed: see below, and section 1.5);
- a witnessed oral statement;
- a note of a discussion recorded in a patient’s medical file (at the patient’s request).

In England and Wales, advance statements which record preferences to refuse particular types of life-prolonging treatments (see section 1.2) can have legal force. These are known as ‘advance directives’.

For an advance directive to be enforced when required, health professionals must be convinced that the patient had capacity to make the statement (please see section 1.8) and that the patient had accurately predicted their current situation. For example, a person with dementia may decide that they wish to refuse resuscitation if their illness becomes such that they can no longer make their wishes known.
Any advance directive that they draw up will apply only in this particular instance. If something happens meanwhile that they have not foreseen (a car accident or a fall, for example) and they need resuscitation, this must be provided. **Section 1.9 provides a summary of the implications of the Mental Capacity Act for this issue. The Act comes into force in 2007.**

Patients can never refuse what is known as **basic care** (see section 1.2). Nor can they ask doctors to do anything which is illegal or not in keeping with standards of accepted good practice. Sometimes people may wish to set out a request for particular types of treatment. Such requests for types of treatment are not legally binding, but can help doctors to decide how to act in a patient's best interests.

### 1.2 Some important definitions

**Life-prolonging treatments**

These include cardio-pulmonary resuscitation (heart and lung), artificial feeding and hydration (administered 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 or drink by mouth (perhaps with a spoon, straw or cup). This kind of care may also be referred to as **comfort care**.

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.
Artificial feeding
This is the giving of food in a way which does not require ‘eating’ in the normal way by mouth. It involves the delivery of food to the person’s body by a tube or by a drip into the bloodstream.

There is a debate about whether artificial feeding is ‘basic care’ or ‘life-prolonging treatment’. You may have seen some newspaper reports about this.

Palliative care
Palliative care improves the quality of life of individuals (and their families) facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.1

1.3 Things to consider in drawing up an advance statement
It is essential to find out about treatment options before drawing up an advance statement. For example, medical treatments may become more effective as they become more advanced. Also, advances in technology and specialised equipment may allow people more choice in the future. This could alter decisions about where people would like to be cared for when the time comes. It is also important to know that:

● people’s views may change;

● advance statements tend not to address important everyday decisions such as where one might wish to receive care.

Some people may feel that it is more important to ensure that older people have the same access to treatment as younger people.

Other points were raised in discussion with older people about the pros and cons of advance statements.2
1.4 How can you make an advance statement?

You do not necessarily need to have a solicitor in order to make an advance statement or living will. Various books and information pamphlets are available to provide help and advice. Some stationery chain stores also sell ‘do-it-yourself’ packs, and there are many websites that enable you to purchase an advance statement. However, note that:

- you do not need to spend money in order to make an advance statement;

<table>
<thead>
<tr>
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<th>Bad things about advance statements</th>
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<tbody>
<tr>
<td>I want to be asked and this helps me to express my views</td>
<td>I may leave it too late</td>
</tr>
<tr>
<td>As important as wills</td>
<td>I don’t want to be asked</td>
</tr>
<tr>
<td>Helps with control: ‘I want to go my way’</td>
<td>It is difficult to discuss this type of thing with my family</td>
</tr>
<tr>
<td>Stops doctors from playing God</td>
<td>Family might be too shocked when illness comes and won’t remember my instructions</td>
</tr>
<tr>
<td>Helps families speak for older people</td>
<td>But, you might change your mind, and…</td>
</tr>
<tr>
<td></td>
<td>Doctors need to make snap decisions in some cases of sudden illness</td>
</tr>
</tbody>
</table>
your local library may stock some self-help books on this subject, or might even purchase such books for you to borrow.

1.5 Signing an advance statement: dos and don’ts

This information in this section is particularly applicable to the drawing up of an advance statement refusing certain types of life-prolonging medical treatment. This is known as an **advance directive**. As we noted earlier, advance directives can have legal force. Please refer to section 1.9 for information about the impact of the Mental Capacity Act, which comes into force in 2007.

You may wish, however, to take the following steps when drawing up any kind of advance statement.

**What you should do if you are making an advance statement**

- Find two impartial witnesses. The following people would **not** be appropriate: your husband, wife or partner; a relative; anyone who could gain from your death (e.g. by inheriting something from you).
- Sign the document first yourself, using ink, with both witnesses watching (the witnesses do not need to read the document or even know what it is about).
- The witnesses then sign the document with you watching.
- You need to record the date of signing.
- Both you and the witnesses should initial the bottom right-hand corner of each page, except the page on which you sign.

**What you should not do when making an advance statement**

- Don’t cross anything out or make any alterations either before or after signing. This could make your advance statement invalid. If you make a mistake, start again.
Don’t try to add, insert or delete anything after signing. It could cause confusion later. If you want to make any changes or additions, start again.


### 1.6 Storing your advance statement

If you make any kind of advance statement, you may want to think about giving a copy to:

- any doctor who may be involved in your care (e.g. your GP, or a hospital doctor if applicable);
- a lawyer, if you have one;
- a close friend, family member and/or partner.

Having made the statement, you will also want to store it in a place where it is easy to find, and tell those closest to you where it is.

You can also make and carry an advance statement card, similar to a donor card. This would alert people to the fact that you have made an advance statement.
1.7 The role of personal values

**Joe’s story** (part 2)

After searching out more information about living wills, Joseph and Emily felt unsure about completing such a document. Joseph said he did not want to record instructions about specific treatments because he did not feel strongly that he would want to refuse them. It seemed more important to him to leave a record of his values and beliefs that might help his family to decide things for him if he could not make decisions for himself.

A number of things were particularly important to Joseph. For example, he had enjoyed the companionship of his dog Jamie for the previous five years. He wanted to be sure that his dog would be cared for if he or his wife were unable to do this. He also felt that if he needed to receive residential care at some point, Jamie (or any other pet) should be able to visit him. Joseph was very fond of music, too, and found it spiritually comforting.

For Emily, it was her faith that mattered a great deal to her. Emily knew that she would want to receive some spiritual support if she were seriously ill.

It can be difficult to think ahead to the future. Personal values are very important for the process of advance care planning. This is because end-of-life treatment decisions are made in the context of deeply held beliefs and personal views about what contributes to quality of life. Two simple open-ended questions that may help in thinking about this are:

- what makes life worth living now?
- what would make life not worth living in the future?*

Remember that the answers you give to these questions now may change as your situation changes or as you face a final illness.
Some types of advance statement combine a record of personal values with a specific directive about treatment preferences.

Some people may want to ensure that the small things they value in everyday life continue to be a part of their life if they become seriously ill or incapacitated. This may include where you wish to be cared for or what information you would want to receive from the health professionals caring for you. It could also include the type of clothing you do or do not like to wear or the type of music you like to listen to.

These things can be recorded and passed on to a family member or a close friend.

**Things to remember about me:**

**examples from older people’s discussion groups**

- 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.

**Activity: things to remember**

On the page opposite write down some things you would like people to know about you if you were very ill and unable to communicate.
Things to remember about me
Joe’s story (part 3)
There had been a lot of discussion in the newspapers about living wills. Some reports seemed to suggest a link with euthanasia. Joseph still felt uncertain about the law on this issue.

Joseph intended to make his values and preferences clear to his wife and adult children. However, he wondered whether doctors would take into account the views that he and his family had agreed when making decisions about treatment.

Issues to consider

- You may wish to think about your own views regarding Joseph’s concerns.
- Have you read or heard news reports about these issues?

Use sections 1.8–1.12 to find out about the following:

- the law on ‘consent’ in the UK;
- the involvement of patients and their families in care decision-making?
- the meaning of euthanasia;
- guidance about the removal of life-prolonging treatments.

1.8 Consent and capacity

Consent must be sought for all medical treatments. This is very important because giving (or refusing) consent is the means by which people can choose to accept (or refuse) medical treatments. This helps to ensure that people are not subject to any treatment they do not want. To give valid consent people need to be able to access and understand appropriate information relating to the decision they need to make.
It is assumed that adults have the ability (capacity) to make decisions unless this can be proved otherwise. If a person is shown to lack capacity, treatment may be provided to them where doctors think it is in that person’s best interests.

Clinical staff must take all possible steps to maximise the decision-making capacity of individuals. This should include providing simple information in a language that people can understand, or in some audiovisual format if that is more appropriate. Health professionals also need to recognise that a person’s capacity will vary. Decisions with serious consequences require a greater degree of capacity than simpler decisions.

1.9 The 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 comes into operation in April 2007.

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

- **lasting power of attorney (LPA)** A person can make a LPA while he or she has mental capacity, giving the power to make health and welfare decisions on their behalf to a specified person or persons. LPAs can also deal with financial matters and will gradually replace the existing ‘enduring powers of attorney’ that apply to these currently. The person or people appointed to make health and welfare decisions does not have to be the same person or people appointed to make financial decisions. When an LPA is drawn up, a declaration of capacity must be completed by a professional (a doctor or solicitor, for example).
• **independent advocate**  The court can appoint a deputy, or an Independent Mental Capacity Advocate (IMCA). An IMCA is someone appointed to support a person who lacks capacity but has no one to speak for them.

• **advance directives or statements**  The Act makes it clear that people can make advance statements refusing treatment if they should lose capacity in the future. However, it is made clear that no advance decision will apply to any treatment which a doctor considers necessary to sustain life unless the decision is in writing, signed and witnessed. In addition, there must be an express statement that the decision stands ‘even if life is at risk’.

  *(for a summary of the Act see [http://www.dh.gov.uk/PublicationsAndStatistics/Bulletins](http://www.dh.gov.uk/PublicationsAndStatistics/Bulletins))*

In sections 1.5 and 1.6 we give some guidance about signing and storing such instructions.

**1.10 What does ‘euthanasia’ mean and is it likely to become legal in the UK?**

There is a wide spectrum of views about euthanasia and many misunderstandings about it. It 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). It is illegal in the UK.

In Belgium and the Netherlands, euthanasia at the voluntary request of a competent adult is now legal under very tightly defined circumstances. Periodically, there have also been attempts to change the law in the UK. A bill about ‘assisted dying’ is still being considered by Parliament as we go to press. Debate on the subject continues in the media and among politicians and policy-makers.
1.11 Withdrawing and withholding life-prolonging medical treatment

Currently in the UK it is recognised that where death is inevitable 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. ‘Basic care’ and comfort must be provided and can never be withheld. **Removing life-prolonging treatments is not euthanasia** (see also previous sections 1.1 and 1.2).

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.** In most instances, however, giving medical treatment according to accepted best practice – for example, using drugs to relieve pain and other symptoms – does not hasten death.

Despite the legal distinction outlined above, ethical and legal debate about withholding or withdrawing life-prolonging treatments continues on many fronts.

1.12 What if your treatment preferences change?

If you make an advance statement but later change your mind about what you have recorded, you can destroy all copies of the document and write a new one. You can give a copy to your doctor and/or anyone else who received the old one.

Sometimes people worry that they might change their mind after they become seriously ill and when they are unable to communicate their wishes. This is often seen as a disadvantage of advance statements (see section 1.3). For this reason some people say they prefer to rely on discussions with a partner, close family, friends or health professionals in order to make their preferences known.
Alternatively, some people prefer to record their personal values, which may assist loved ones and your doctors to interpret what treatments you might choose or refuse based on those values (see section 1.7). If you have written an advance statement you should make sure that you review what you have recorded periodically. This is best done through a conversation with a doctor or with someone you trust.

**Sources of further information**


http://www.alzheimers.org.uk

http://www.ageconcern.org.uk
When facing serious illness, patients and families may not know what they should do next, or how to talk about their worries.

Caring for someone who is seriously ill may be rewarding but can also present challenges. Assumptions are often made about what is ‘right’ in caring relationships: for example, many people believe that adult children should care for sick parents, even though not all will be able, or want, to take on the role of carer.

In many relationships, ‘choice’ is not an issue but there may be a sense of mutual obligation. However, sometimes potential care-givers are not well enough to give care. Some people who are seriously ill may feel like a burden. They may prefer not to be cared for by their family members. To remain independent they may not ask for help or may reject support when it is offered.

The nature of a relationship may change as a result of giving or receiving care. The closest of relationships are not always between family members, but may be between partners or special friends. All close relationships, of whatever type, can offer valuable support but may create complications. Previous conflicts in a relationship may once again come to the surface when faced with a crisis such as life-threatening illness. Sometimes feelings of guilt and anger associated with care can cause misunderstandings and further conflict. Poor communication, practical problems and lack of information can all contribute to the difficulties faced.

The story overleaf and subsequent sections attempt to address some of these issues.
Issues to consider

Use sections 2.1 to 2.4 to think about the following questions.

- What might make it easier for Rita to communicate with her daughters? *(see section 2.1)*

- What might be important issues to consider as part of planning for future care? *(see sections 2.1 and 2.2)*

- What options might be available for future care? *(see sections 2.2, 2.3 and 2.4)*

- What advice could be given to Rita and her daughters to help them make future plans? *(see sections 2.2, 2.3 and 2.4)*

2.1 Talking about the future

Problems and tensions in care-giving are part of normal life and normal relationships. Many people find it is very difficult talking to their family or close friends about their worries as they face a serious illness.
Sometimes each side tries to protect the other. As a result, although we may think that it is important to talk, this is rarely straightforward.

Sometimes we try to guess what our relatives and friends want. We might think that someone who is ill cannot face discussing the future, when in fact they may welcome the opportunity. The box below offers advice.

**Words to try**

<table>
<thead>
<tr>
<th>When you think you want to say:</th>
<th>Try this instead:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mum, you are going to be fine.</td>
<td>Mum, are there some things that worry you?</td>
</tr>
<tr>
<td>Don’t talk like that! You can fight this!</td>
<td>It must be hard to come to terms with all this.</td>
</tr>
<tr>
<td>I can’t see how anyone can help.</td>
<td>We will be there for you, always.</td>
</tr>
<tr>
<td>I just can’t talk about this.</td>
<td>I am feeling a little overwhelmed right now. Can we take this up later tonight?</td>
</tr>
<tr>
<td>What do the doctors know? You might live forever.</td>
<td>Do you think the doctors are right? How does it seem to you?</td>
</tr>
<tr>
<td>Please don’t give up. I need you here.</td>
<td>We’ll miss you terribly. But we will get through it somehow.</td>
</tr>
<tr>
<td>Don’t be glum. You will get well.</td>
<td>It must be hard. Can I just sit with you for a while?</td>
</tr>
</tbody>
</table>

Sometimes talking is hard. It is OK just to sit in silence and be with the other person, who will know that you are there and will take comfort from your presence. Some things are difficult to put into words. Even small, unfinished conversations can open the door to better understanding.

2.2 Issues to consider

When facing life with a serious illness, many difficult questions can arise. The person who is ill may be worried about physical symptoms or may wonder what will happen as their life draws to a close.

Many of us have little or no recent experience of caring at home for someone with a serious illness. It is important to remember that almost all symptoms can be relieved with modern medical and nursing treatments. For example, good pain relief is nearly always possible throughout the course of illness, without too many side effects and without making the person too sleepy. It is now known that pain can be relieved without any risk of causing addiction.

Everyone agrees that the person who is in pain must be listened to. If you are not confident that you are receiving the best medical care or advice, you may want to consider contacting a health professional or other adviser to talk about these things with you.

2.3 Who can help?

2.3.1 The general practitioner (GP)

The GP has overall responsibility for the healthcare of the person being cared for at home. A GP can:

- prescribe drugs;
organise additional help if you need it: for example, visits from a district nurse or Macmillan or Marie Curie nurse, a physiotherapist or occupational therapist;

- arrange for admission to a hospital or a hospice;
- make arrangements for respite care to give carers a break.

You are entitled to ask your GP about whether these services are suitable for you. You can also ask about free prescriptions and other benefits (see financial help section below) which are available to you if you have ‘a continuing physical disability which prevents you from leaving home without the help of another person’. Ask your GP or hospital doctor about these.

Many people we spoke to in the course of our research were sceptical about the degree to which they could talk easily to their GPs about end-of-life issues. In discussion, ideas were put forward about how to manage this. Here is a selection of these.

- Make an initial appointment to tell your GP that you would like to return to talk about end-of-life issues and outline the particular concerns you may have. This will give your GP a chance to consider these in advance of your next appointment.
- Ask if you can book a ‘double’ appointment so you do not feel rushed.
- Make a list of any questions or concerns you may have and take them to your appointment.
- Take a relative or friend with you for support.

2.3.2 District nurse (or community nurses)

District nurses plan and organise patient care at home. This may include administering injections, changing dressings and giving advice about pain, breathlessness or incontinence. District nurses will refer to the GP if they need advice in helping with these problems. They can
work with social services to arrange for the delivery of any special equipment you need.

You are entitled to contact a district nurse. Your GP surgery can tell you who your local district nurse is and provide contact details.

District nurses may visit up to three times a day. Some areas have night staff too. Sometimes a nursing support worker will help with bathing and washing.

2.3.3 Nurse specialists

Marie Curie nurse

Marie Curie nurses now care for almost half of all cancer patients who die at home. They may work at night and/or during the day to provide one-on-one care for the patient and practical and emotional support for families at what can be an exhausting time.

If you think someone may need help from a Marie Curie nurse, you can contact your district nurse, who is the central point for communication and co-ordination of the patient’s care at home. For more information go to www.mariecurie.org.uk/nursing

Macmillan nurse

Macmillan nurses specialise in cancer and palliative care, providing support and information to patients, families, and friends. While they mainly provide care to cancer patients, they try also to provide care to patients with other illnesses.

Macmillan nurses can help patients make informed decisions about their treatment and guide them through the maze of different services. They also help people to cope with problems such as the symptoms associated with treatment and disease.

Macmillan nurses work both in people’s own homes and in hospitals, and their services are free. Many people are referred to a Macmillan nurse
by their GP, district nurse, consultant or ward sister. Your local primary care trust, GP or hospice will be able to give you information about how to contact a Macmillan nurse. See also www.macmillan.org.uk

Heart failure nurse

In some parts of the country heart failure nurses offer specialist care, advice and information about problems associated with heart failure. They may provide counselling and support for patients who are diagnosed as having heart failure and follow-up care for patients who have been admitted to hospital. They can offer specific advice to patients about drugs, investigations and other treatments.

There are many other specialist nurses providing support for different conditions. For example, community psychiatric nurses provide a great deal of care for people with dementia and their families. You may wish to ask your GP about the availability of such nurses in your area.

2.3.4 Social services

Many kinds of help are available. However, you should always remember that the services that you and the person you care for may be offered will depend on the individual’s circumstances and the outcome of an assessment. The sorts of things that might be available include:

- help with bathing or dressing and other personal care;
- respite care and short breaks from caring;
- adaptations to where you live, and equipment;
- residential and supported accommodation;
- occupational therapy;
- day care;
- lunch clubs and/or provision of meals;
- transport.
How to get help
Usually you will need to go through a process of assessment, although if your needs are especially urgent it may be possible for services to be provided immediately with an assessment being made later. To ask for an assessment of need contact your local social services department.

2.3.5 Financial help – benefits and allowances
If you are ill or disabled, rely on someone else to care for you or are giving care to someone else you may be eligible for various kinds of benefits. Be aware that benefit rates and rules are constantly subject to change. You can ring SeniorLine, the free helpline at Help the Aged, for up-to-date information, or contact your local Citizens Advice Bureau. If you have a dedicated social worker, he or she will be able to help. Some examples of benefits include:

Carer’s Allowance (CA) (formerly Invalid Carer’s Allowance)
This is the only benefit aimed specifically at carers. It is intended to replace the wages you might otherwise earn from a job if you were not caring. In order to get it, you must be over 16 years of age, caring for someone for at least 35 hours per week and not earning more than a specified amount per week from paid employment. The person you care for must be receiving Disability Living Allowance Care Component (Middle or Higher Rate), Attendance Allowance or Constant Attendance Allowance.

Income Support
This benefit is for anyone who is not required to ‘sign on’ as available for work and whose income is below that which the government thinks they need to live on. Either you or the person you care for might therefore be entitled to this benefit. If you claim income support you can also claim Housing Benefit (HB) and Council Tax Benefit (CTB), and you may also be able to get a one-off payment from the Social Fund for help with exceptional expenses.
Disability Living Allowance (DLA)
This benefit is aimed at people aged under 65 who need help with personal care or with getting around. It is tax-free and is not means-tested, so the person you look after can claim it as well as other benefits they are entitled to.

Attendance Allowance
This is a tax-free, non-means-tested benefit which can be claimed by the person you look after if he or she is aged 65 or over and needs help with washing, dressing and other personal care, or needs substantial supervision.

Finding out more and getting advice about benefits
Benefits leaflets and claim forms are available from any Benefits Agency office, and many can also be obtained from post offices and advice centres. Most are available in English, Welsh, Arabic, Bengali, Chinese, Gujarati, Punjabi, Somali, Urdu, Vietnamese and in Braille.

There is also a freephone telephone line run by the Benefits Agency to give benefit advice to people with disabilities and their carers: 0800 882200 (advice is available in various languages in addition to English).

(information kindly provided by Sheffield Carers Centre)

2.3.6 Voluntary support
Most parts of the UK have a vibrant network of voluntary, community and faith (VCF) organisations, providing help and support. The local library or the local Council for Voluntary Services (CVS) will have a list of organisations, and often the local social services department will too.

They can provide or help with:

- ‘good neighbour’ schemes, offering help with shopping and small practical tasks;
- sitting services, such as Crossroads;
carer support groups, through the local carers’ centre, including support when caring comes to an end;

- befriending schemes;

- home improvement grants, home safety and minor adaptations through the local home improvement or StayPut agency;

- advocacy and help with making complaints about services;

- signposting to access information about services;

- information and support to working carers, through carers’ centres, including help with returning to work after caring ends;

- a listening ear and emotional support;

- bereavement support, such as that provided by CRUSE.

2.4 Staying at home or going to a hospital, hospice or care home

Most of us think we would like to be cared for at home, even in a final illness, but we may not want this if it means that our families or friends are placed under too much pressure. Some older people who were interviewed in a study expressed a range of concerns, which are summarised in the box below.

**Concerns about dying at home**

**Dying alone**
*I suppose you want your family and friends with you, wherever you are.*

**Being a burden**
*I have no daughters. I have just sons and my daughters-in-law are fantastic but I wouldn’t want to feel as though I was a burden on them.*
Some of the following questions might be important for you in deciding where you would wish to be cared for if you became ill.

- Are there any simple and affordable changes that could be made to make it easier for me to stay in my own home?
- Whom would I consider as my ‘main’ supporter or carer? Can I talk to them about these issues?
- Do I know anything about hospice or hospital care?
- Would I prefer to go into sheltered housing or a care home? How much would this cost?

**Needing intimate care**

*People of this age want their partner with them; they don’t want their children there because there’s a lot of embarrassing things, and they don’t want their sons and daughters attending to them, if you know what I mean: personal things.*

**Becoming disabled**

*If he was getting increasing pain and… [becoming] increasingly physically disabled, like I’m thinking of incontinence and things like that. If he got to that stage, I think he’d be better off in hospital.*

**Turning home into a hospital**

*I had to make an effort at a time when I didn’t want to talk to anybody. I sort of kept going, welcoming everybody and making them coffee and everything at a time when I wanted to shut the door and be on my own… We reached a stage where this hospice at home took over and they just literally moved in all the equipment that they needed to look after [husband].*
Making changes and adaptations to the home

If people develop an illness or chronic condition that causes them difficulties, changes may be needed to ensure they remain safe and comfortable at home. Checklists may help in assessing safety in the home, and can help you identify potential problems such as inadequate lighting and loose carpets. Working through these may prevent potential problems. Some people may benefit from simple devices to help with small tasks such as opening packages and jars, or picking things up from the floor. Other people may need larger-scale alterations such as a stair-lift or a ‘walk-in’ shower or bath. Medical equipment may even be needed. Some aids and adaptations may be provided by social services, or by the National Health Service. Your GP may offer advice on this and can refer you to an occupational therapist.

Hospice care

Hospices care for both the person who is facing the end of life and their loved ones. Hospices take a holistic approach (caring for the whole person), by aiming to meet physical, emotional, social and spiritual needs. Although hospices are generally known for providing care for people with cancer, they may care for people with other conditions. People can go to a hospice for day care, respite care or to stay for longer periods of time. Nearly half of all people admitted to a hospice return home again. The average length of stay is just 13 days, and all care is free of charge. Many hospice services are community-based nowadays. Many hospices provide services in patients’ homes (such services are often called ‘hospice at home’). However, hospice services remain scarce, so not everyone in need can get this type of care.

Hospices provide a range of services including pain control, symptom relief, skilled nursing care, counselling, complementary therapies, spiritual care and bereavement support.

(for more information see www.helpthehospices.org.uk/)
Care homes

For some people, a residential or nursing care home may seem the best option, especially if they have been struggling alone in their own home, or are unable, for whatever reason, to have care at home. Other people may have concerns about losing independence or privacy. Many carers may feel guilty about admission to a care home, even if this becomes necessary.

The issue of which care home to choose can be bewildering; people may be especially concerned about assessing the quality and standards of care. Social services may provide a list of homes and can sometimes help with the costs, depending on a person’s income. Charities such as Age Concern also provide fact sheets and self-help books on this issue.

Rita’s story (part 2)

Rita had become very weak and was finding it difficult to manage between visits from her daughters and the community nurses. Her daughter Rose suggested that her mother should come to live with her and her family. Her own children were teenagers and one of them had already left home. Rose felt that she would have more space and time to care for her mother than her sister, whose children were still young. Both Camilla and Rose had part-time jobs, but Rose felt she could give up her job to care for her mother. Rita said that she would prefer to live with her daughter rather than move to a nursing home or hospice.

Activity  Use section 2.5 below to address the following question:

- what factors are now important for Rose to consider?
2.5 Care-giving: what are the issues?

Deciding about caring
When making decisions about caring for someone it is important to spend some time thinking about yourself and what you can and cannot offer in terms of help. You need to know that it is OK to decide not to provide care at home. One writer\(^8\) suggests a series of questions that you should ask yourself.

- What are my priorities (e.g. family, employment, leisure)?
- How well do I get on with my relative (who needs to be cared for)?
- How much time do I have?
- What is my own health like?
- What skills and resources do I have (to provide care)?
- What is my financial position?
- How good would I be at day-to-day caring?
- How would my taking on a day-to-day caring role affect my partner and children?
- What would be my reasons for caring for my relative myself?

Views about family care-giving identified in discussion with older people*
(1) Continuity of care is vital, particularly for people with dementia.
(2) Getting help and advice is a fight.
(3) Carers can feel that they have let the person down when it is the services that are at fault. Feelings of guilt make bereavement worse.

* These views were expressed by attendees at a consultation meeting in Sheffield hosted by Help the Aged (2004)
If you decide to care for someone who is ill, you will want very much to try to cope for as long as you can and to give the best care that you possibly can. This can often be difficult. You might find caring easier if you seek out and accept help from local services – both health and social services. Some services may be free, while others need to be paid for.

The use of such support services may make a considerable difference to the quality of life for patients: helping them to maintain some independence and helping their families to care for them over a long period of time. However, the type and amount of support depends on where you live and how the services are organised.

(4) Carers take on the role of caring for a dying person with inadequate preparation: they need help learning to care and to cope.

(5) Carers could learn from one another: listening to the stories that others have to tell would be helpful.

(6) Adapting to life after bereavement when one has been a carer is very difficult: you can feel ‘dropped’ and isolated.

(7) Withdrawal of carer’s allowance after the person’s death causes financial problems for bereaved carers.

(8) It is vital that carers accept offers of help while giving care and keep at least some outside activities or hobbies going. Otherwise bereavement will be much harder later on.
Further sources of information and support

**Carers Information**
Web: www.carersinformation.org.uk
Tel: 01785 606675

**CarersLine:**
Web: www.carersonline.org.uk
Tel: 0808 808 7777

**Princess Royal Trust Carers’ Centres**
Web: www.carers.org

**Age Concern**
Web: www.ageconcern.org.uk
Tel: 0800 009966

**Help the Aged**
Web: www.helptheaged.org.uk
Tel: 020 7278 1114
SeniorLine: 0800 800 6565 (0808 808 7575 in Northern Ireland)

**Counsel and Care**
Web: www.counselandcare.org.uk
Tel: 0845 300 7585

**CancerBACUP**
Web: www.cancerbacup.org.uk
Tel: 0808 800 1234

**Macmillan Cancerline**
Web: www.macmillan.org.uk
Tel: 0808 808 2020
Alzheimer’s Society  
Web: www.alzheimers.org.uk  
Tel: 0845 300 0336

Help the Hospices  
Web: www.helpthehospices.org.uk  
Tel: 020 7520 8200

Caring Decisions  
Web: www.caringmatters.dial.pipex.com

Citizens Advice Bureau  
Web: www.citizensadvice.org.uk

Carers UK  
Web: www.carersuk.org  
Tel: 020 7490 8818

Hospice Information Service  
Web: www.hospiceinformation.info  
Tel: 0870 903 3 903

Marie Curie Cancer Care  
Web: www.mariecurie.org.uk  
Tel: 020 7599 7777
3 Loss and bereavement issues

Facing illness and coping with giving/receiving care often involve facing loss and feelings of grief. These feelings can be very powerful and hard to make sense of. They may be made worse because of thoughts of other losses experienced during one’s life. The ill person may be coming to terms with a limited life span and all the associated fears and anxieties. The person giving care may be facing the probability that they may soon be bereaved, perhaps for the first time.

When care-giving comes to an end after death, carers can feel an acute sense of loss not only in respect of the person who has died but also in terms of their own role and occupation, which can breed insecurity. On the other hand, a sense of emptiness and/or isolation could turn into something more positive, opening up different opportunities for change and personal growth.

Rita’s story (part 3)

Rita did move to live with Rose, who was able to care for her mother with the help of her sister and visiting Macmillan nurses. When Rita died peacefully, Rose was very proud of the role she had played in caring for her. However, afterwards she found it very difficult to cope. She argued with her sister about arrangements for the funeral. During the weeks following the funeral she left the house very little and found it difficult to face people when she did go out. Her family were out of the house much of the time. Rose no longer had work or caring commitments; she found it hard to sleep or to focus on anything else.

Activity Use sections 3.1 to 3.3 to help address the following question:

What advice could be offered to Rose about the way she is feeling, and about things that might help?
3.1 The experience of grief

Everyone is different and will experience grief after bereavement in a unique way.

The individual experience can vary greatly from hour to hour and day to day. Some people may feel relief; others, an overwhelming sense of loss. People who have been bereaved may feel physically ill. Extreme tiredness, nausea, aches and pains are all common and understandable. Tiredness may be made worse sometimes by thoughts of how one will manage in the future. Some people may actually become ill, perhaps catching a bad cold or succumbing to another minor ailment. Feelings of sadness, depression or anxiety are very common and tend to occur in waves, often triggered in an unexpected way. Some people may experience feelings of detachment from what is happening around them: they may feel as if everything is unreal or they find it very hard to join in seemingly ‘normal’ life again. Others may find it hard to concentrate or remember simple things. Irritability or an inability to sit still or sleep might also be experienced. People grieve in many different ways. Some people feel better quickly, others take much longer.

There is no right or wrong way to go through this most universal of all human experiences.

Some of the people we talked to said that they needed some very practical help in the very early days of bereavement and that the lack of such help made their bereavement experience much more difficult than it might have been. This included help with tasks such as registering the death and sorting out funeral arrangements. These mark the social changes that death brings and can be very hard to face alone.

The Citizens Advice Bureau provides helpful information about what to do after a death at www.adviceguide.org.uk; alternatively, telephone your local branch.

The Government also provides information on its website, called ‘Direct Gov’: www.direct.gov.uk/Over50s/EndOfLife/WhatToDoAfterADeath
3.2 What else can help?

When one faces loss, one may experience a sense of need to try to find meaning and comfort. This is not always easy, particularly if you live alone, or do not find it easy to talk about such issues. It also depends on the type of relationship you had with the person who has died. Everyone is different, with different needs and support networks.

In the *Handbook for Mortals* a number of ideas are put forward about how to find comfort. These are listed in the box below. Such activities may be things that are already familiar, although for some they may be completely new.

**You may take comfort in:**

- telling stories about your life
- participating in different forms of creative expression, such as art and music
- keeping a journal
- seeking spiritual or religious guidance and support.

Other things that might help include talking regularly to someone you are close to, physical activity such as walking, or joining a support group (Leming and Dickinson, 2002). The bereavement charity CRUSE suggests that ways of remembering a loved one whom we have lost can be important. Ways to remember could include compiling a memory book or a special box to hold mementoes, planting a tree or a shrub, or making a donation to a favourite charity. Help the Aged also has useful information on this issue.
3.3 Signs of resolution following bereavement

When what can be overwhelming feelings associated with grieving begin to diminish, people may find that they recognise the following signs:

- eating and sleeping well
- showing an interest in reading, TV, news
- talking positively about the future
- talking about the person who has died without getting very distressed
- engaging in new activities and relationships.
Sources of further information

CRUSE Bereavement Care
CRUSE House
126 Sheen Road, Richmond
Surrey YW9 1UR
Tel: 0870 167 1677
Email: help@crusebereavement.org.uk

Foundation for Black Bereaved Families
11 Kingston Square
Salter’s Hill
London SE19 1JE
Tel. 020 8761 7118

Jewish Bereavement Counselling Service
8/10 Forty Avenue
London HA9 8JW
Tel: 020 8385 1874

Lesbian & Gay Bereavement Project
Counselling Department
Lighthouse
West London
111–117 Lancaster Road, London W11 1QT
Tel: 020 7403 5969

The Samaritans
Tel: 08457 90 90 90
Web: www.samaritans.org.uk

Sheffield Carers Centre
Tel: 0114 272 8362
References


Other useful publications


Selected titles from Help the Aged

Dying in Older Age

What sort of experience can an older person dying in Britain in the early 21st century expect? Dying in Older Age examines the views and expectations of older people in the final years, the care and support provided by our public services towards the end of life, and the issue of individual control and choice, so often denied to older people, in the approach to death.

Among the recommendations are that dying, a taboo topic for many of us, 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 in other life events.

ISBN 1-904528-94-5 44pp 2005 £5.00

Planning for the End of Life

Is there such a thing as a ‘good death’? Perhaps there is, if before the time comes we have endeavoured to resolve our difficulties with those we care for, make peace with our god, sort out our affairs and make clear our health-care preferences. This booklet looks at many issues associated with the end of life, discusses the options open to us and provides a useful list of contacts for further help and advice.

ISBN 1-904528-96-1 36pp 2005 £5.00

Best Foot Forward

One in four people aged over 65 needs podiatric care but is not receiving it. Foot care is especially important for older people, because if their feet develop problems their mobility can be affected – and, hence, their independence and their emotional well-being. However, free NHS podiatry care has been greatly reduced. This report looks at
the scale of unmet need among the older population and the likely longer-term outcome of not providing low-level podiatric services. It also suggests some innovative and cost-effective alternatives to traditional service delivery.

ISBN 1-904528-97-X 44pp 2005 £8.00
Information and advice leaflets

Financial leaflets
- Can You Claim It?
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- Fitter Feet
- Healthy Bones
- Healthy Eating
- Keeping Mobile
- Managing Your Medicines
- Shingles
- Staying Steady

Leaflets are free of charge and can be downloaded from www.helptheaged.org.uk. Other titles can be ordered via Help the Aged Publishing, 020 7239 1946, or email publications@helptheaged.org.uk.
Fighting for disadvantaged older people in the UK and overseas,

WE WILL:

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

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

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

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

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