



# YOUR RIGHTS AT THE END OF LIFE



## Glossary

### **Advance Decision**

This is a legally-binding document available from Compassion in Dying. You can use it to record the kind of medical treatments you would want to refuse or consent to, in specific circumstances, if you lose mental capacity. (See pages 18 to 24).

### **Carers' Allowance**

This is a benefit available to some people who provide care for more than 35 hours per week. (See page 27).

### **Carers' Strategy**

This is a Government strategy which aims to increase recognition of carers and carers' rights, and to provide carers with better support. (See page 26).

### **Disability Living Allowance**

This is a tax-free benefit for children and adults under the age of 65 who need help with personal care. (See page 14).

### **End-of-Life Care Plan**

This is a way of recording your wishes and preferences, for example, where you want to die and the kind of treatment you want or do not want. (See pages 8 to 9).

### **End of Life Care Strategy**

This is a Government strategy which promotes high quality care for all adults at the end of life in England. It aims to provide people with more choice about important issues such as where they would like to die and the specifics of care provided. (See page 6).

### **Lasting Power of Attorney**

This is a legally-binding way of appointing a relative or friend to be able to make decisions on your behalf, should you lose mental capacity or the ability to communicate. (See page 19).

### **Liverpool Care Pathway**

This is a National Health Service tool which gives doctors and nurses guidance to ensure that dying patients (and their relatives and carers) receive a high standard of care in their last days of life. (See page 13).

### **Mental capacity/competence**

Mental capacity, (or being mentally competent) is the ability of a person to make decisions for him or herself. (See pages 18 to 19).

### **NICE**

This is the National Institute for Health and Clinical Excellence, an independent organisation that provides national guidance on promoting good health and treating ill health, including guidance on the use of medicines and treatments within the NHS. (See page 24).

### **Patient Advice and Liaison Service (PALS)**

This is a NHS service that provides support and information to patients while they are using hospitals or other NHS services. There are PALS offices across England. (See page 16).

### **Palliative Care**

Palliative care is the active holistic care of people with advanced progressive illness, and of people approaching the end of life. This care includes the management of pain and other symptoms and the provision of psychological, social and emotional/spiritual support. (See page 8).

### **Preferred Priorities for Care**

This is a document similar to an End-of-Life Care Plan that allows you to record your wishes and preferences for care and treatment. (See page 9).

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## Introduction

### by Sarah Wootton

Preparing for the end of life is something that very few of us want to do when we are healthy. Many people do not start to seriously consider the end of life until the first symptoms of an illness or the death of a loved one, and it can sometimes be difficult to know where to look for answers to questions about the care you can receive or what your rights are.

Compassion in Dying believes that the most qualified person to make the important decisions about your care and treatment at the end of life is you. To do this you need access to expert information about end-of-life options, support to make informed choices and care from a provider that you feel is the most appropriate.

This guide aims to help you to get the information that you need by looking at patients' rights as they exist today in England and Wales. If you are a carer this guide also tells you about your rights and helps

support you through the traumatic days, weeks and months after the death of someone you love.

This guide is designed for people who are planning their own end-of-life care, or are helping a loved one to plan theirs. We hope that this guide will help you to answer any questions you might have around your rights at the end of life and will support you to plan the end-of-life care that is right for you.

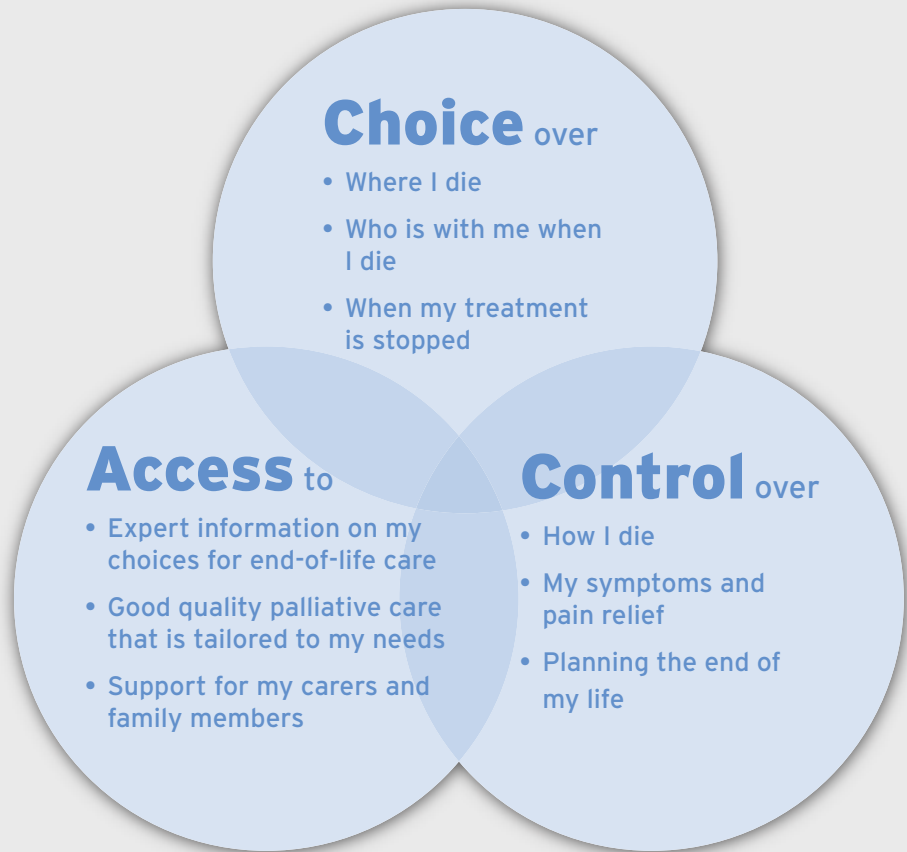
If you would like more information on any of the issues covered in this guide contact Compassion in Dying on 020 7479 7731, email [info@compassionindying.org.uk](mailto:info@compassionindying.org.uk) or visit our website [www.compassionindying.org.uk](http://www.compassionindying.org.uk).



**Sarah Wootton**  
Chief Executive  
Compassion in Dying



## Principles for Dignity at the End of Life



A previous version of this guide was published by Dignity in Dying. Compassion in Dying and Dignity in Dying are partner organisations working for the benefit of people at the end of life. Compassion in Dying conducts research and provides advice and information to people affected by the end-of-life process, including health and social care professionals. Dignity in Dying works to promote patient choice and extend rights at the end of life.

# 1

## End-of-life care

### WHAT THE END OF LIFE CARE STRATEGY MEANS FOR PATIENTS AND CARERS

In July 2008 the Government launched the End of Life Care Strategy. The Strategy marks an important step forward in the way that people approaching the end of life are treated. It is intended to give everyone nearing the end of life access to high quality care whether they are at home, in a care home, in hospital, in a hospice or elsewhere. The Strategy says that patients should have:

- The chance to discuss personal needs and preferences with health and social care professionals and to have your wishes recorded in a care plan (the End-of-Life Care Plan). Your preferences and choices will be taken into account and accommodated wherever possible.
- Coordinated care and support, ensuring that your needs are met, whoever is delivering a service to you.
- Rapid specialist advice and clinical assessment wherever you are.
- High quality care and support during the last days of your life.
- Services which treat you with dignity and respect, both before and after death.
- Appropriate advice and support for your carers at every stage.

The End of Life Care Strategy will not result in legislation and does not provide people with legal rights. The provisions set out in the Strategy are recommendations and action will be needed at many different levels to turn the vision set out in the Strategy into reality.

### Will I be informed?

Being diagnosed with a terminal illness can be a very frightening experience. Sometimes your doctors will give you information that you find difficult to take in. If you want your doctors to repeat information, to explain your condition, treatment options or life expectancy in more depth, or if you have any questions, you should ask.

If you find it difficult to talk to your specialist doctor you could speak to others involved in your care – such as nurses, social workers or another doctor such as your GP. You may want to ask a close friend or family member to be with you for these conversations to give you emotional support, or to help you ask your questions.

We are all different. Some people want to know everything about their condition and life expectancy and others don't. It is important to let your doctors know how much information you would like to have, so that they know what suits you best.

# Your Rights at the End of Life

## **DR RICHARD SCHEFFER, ON INFORMING HIS PATIENTS:**

“Every person is an individual. When facing a life-threatening illness there are of course some similarities in the experience, but the way the individual reacts is always unique. That uniqueness must be respected.

Health professionals have a responsibility to offer clear information to the person about the disease and the treatment options, at a rate that they can take in, and to allow and assist the person to make choices about how their care is managed. Such information is necessary from before diagnosis right through to when the person is dying.

It goes without saying that such conversations should take place in private, with as much time as the individual needs. These discussions may need to be repeated as a person under such stress does not always remember the things said and may think of other questions. The individual should always be offered the opportunity to have someone with them during such conversations.”

Dr Scheffer is a recently retired palliative care consultant and hospice medical director.



## **Did you know...**

**You can ask doctors for more information about your condition and life expectancy, and you can ask them to repeat information.**

Compassion in Dying wants health and social care professionals to have access to training on end-of-life issues including offering emotional, psychological and spiritual support to patients; communication skills and high-quality bereavement skills.

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## End-of-life care

### PALLIATIVE CARE AND END-OF-LIFE CARE

There are many definitions of palliative care. The purpose of palliative care is to enable people with a life-limiting illness to live “as well as possible” until they die.

The definition most generally accepted in the UK is:

“Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.” (National Institute for Health and Clinical Excellence (NICE) Guidance on Palliative and Supportive Care for Adults, 2004)

Unlike palliative care, the term “end-of-life care” has not been formally defined. It is an everyday expression referring to the provision of care during the last phase of life.

### Will I be able to make decisions about the care and treatment I receive?

One of the main themes of the End of Life Care Strategy is the End-of-Life Care Plan. Every person approaching the end of their life should be offered the chance to discuss their wishes and preferences, and have these recorded in an End-of-Life Care Plan.

Your End-of-Life Care Plan could include information on where you want to be cared for and where you want to die, who you want to have with you, the kind of treatment you want or do not want to receive and any other values and wishes that are important to you.

If you would like to refuse life-sustaining treatment at any stage, you can also record this in advance. However, in order to be legally binding, your refusal will have to meet the requirements of the Mental Capacity Act 2005. For more detailed information on the right to refuse treatment, and requests for treatment, see pages 18 to 24.

You can complete an End-of-Life Care Plan by yourself, but we strongly encourage you to discuss the content of your plan with the people who provide your health and social care and the people close to you.



The people who care for you should also give you the opportunity to review and update your plan on a regular basis. They should respect the plan, and your views, as far as they possibly can.

End-of-Life Care Plans are not a new concept - many hospices, GPs practices and other care providers are encouraging patients to discuss their views and values, and have helped them record their wishes, for some time.

The Preferred Priorities for Care (PPC) document (previously called Preferred Place of Care) has been particularly successful in recording people's wishes and preferences at the end of life. The Preferred Priorities for Care (PPC) is a type of End-of-Life Care Plan form that is increasingly being used across the country. Many care providers have also established their own local version.

A Preferred Priorities for Care form is downloadable from [www.endoflifecareforadults.nhs.uk/eolc/ppc.htm](http://www.endoflifecareforadults.nhs.uk/eolc/ppc.htm). When completing the form, you are encouraged to discuss the content with the people close to you and the people involved in your care.

## Did you know...

**An End-of-Life Care Plan enables you to express anything that is important to you and that you believe will give you peace of mind at the end of your life.**

65% of people think they would be more likely to have a dignified death if they could discuss and record their wishes around care and treatment at the end of their lives. Yet 40% of people have never discussed their wishes for care and treatment at the end of their lives with anyone. If you have a serious or terminal illness you can ask your GP or other doctors to provide you with an End-of-Life Care Plan and to help you fill it in.

If you are not given this help, let Compassion in Dying know. We want everyone to have the chance to fill out an End-of-Life Care Plan and to see them respected by health professionals.

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## End-of-life care

### Will I be in pain?

When thinking about dying, a majority of us fear pain the most. In most situations pain can be managed. Pain-relieving medication, such as morphine, may be administered by injection, via a patch, or most often, in a form that can be dissolved under the tongue. Not all pain requires medication though - sometimes pain can be alleviated through treatments such as physiotherapy or occupational therapy.

If you are in pain you should talk to your doctors about this. Usually doctors will be able to give you different medication, or try new treatments that will reduce and control the amount of pain you are experiencing.

Doctors' understanding of pain relief has improved greatly in recent years. However if your usual doctor - your GP or someone else - is having problems controlling your pain, you can ask to be referred to a palliative care specialist.

If you feel uncomfortable receiving certain types of pain-relieving medication, do not be afraid to talk about this to your doctors and the people who care for you.

The people who treat you have a responsibility to involve you in decisions about your pain relief. If you feel you do not get a say in decisions about your pain

relief, do not be afraid to ask your doctor or nurse to be more involved as you have every right to do so.

Occasionally, if a person is in severe pain, the only way to relieve the pain might be to administer pain relieving medication up to a level where that person loses consciousness. This is called sedation. Sedation can only be applied when a person is suffering intolerably and if there

is no other way to relieve their symptoms. If you feel your pain is so great that you need to be sedated, you should ask to speak to a palliative care specialist.

Should you decide to refuse medical treatment in advance, it is important to keep in mind that you cannot refuse basic pain relief. Even if you refuse treatment you can feel assured that you will be kept comfortable.

### Did you know...

**Before starting any investigation or treatment your doctor must ensure that you have been given enough time and information to make an informed decision, and that you have given your consent.** This includes decisions about your pain relief. 89% of the British public consider choice over pain relief an important factor for having a dignified death.

Any risk involved in medical treatments must be discussed with you in clear language. For minor investigations or treatments, it is usually enough for you to give oral or implied consent, which might for example be given by rolling up your sleeve to have an injection or to have your blood pressure taken. In higher risk situations, it is important that your doctor obtains your written consent, after they have given you all the information you need to make an informed decision.

## Where can I be cared for, and where can I die?

The End of Life Care Strategy aims to give people greater choice about where they spend their last weeks and months, and where they die. At present, most people die in hospital but the majority would prefer to die at home.

If you have strong views on where you want to die, you should make sure your family and your medical team are aware of your wishes.

The main options available are:

### Care at home

If you feel very strongly about receiving care at home at the end of your life, we recommend that you set this out in an End-of-Life Care Plan. It is crucial that you discuss your preference for receiving care at home with your primary carer in order to ensure that your carer fully supports your wishes and preferences as set out in your End-of-Life Care Plan. The people who provide health and social care for you should accommodate the wishes set out in your End-of-Life Care Plan as far as they possibly can. In order to avoid an emergency hospital admission, it would be particularly helpful to make it clear in your care plan that you do not wish to be rushed into hospital in your final hours.

At present there is no guarantee that you will be able to receive care at home if this is your wish, due to local variations in the allocation of resources to home care.

If you choose to stay at home, your GP will have overall responsibility for looking after you. He/she will provide you with any medication you need, and can refer you to other professionals if necessary.

A district nurse will also support you, and in some cases a specialist nurse such as a Marie Curie, Macmillan or Hospice at Home nurse, or an outreach worker from your local hospice can care for you at home, free of charge.

These nurses also provide support for your family members. Your GP or district nurse can help organise a nurse from one of these organisations. However, at present there are no guarantees that a specialist nurse will be available to you.

You might also receive support from social services, subject to an assessment. Social services can provide meals, transport and caring equipment, and help you with personal care and hygiene, amongst other things.



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## End-of-life care

### Care in a hospice

Hospices provide a range of services such as pain and symptom relief, complementary therapies, counselling, and bereavement care for your family. Hospice staff will try to address your emotional and social needs, as well as your physical needs.

Some people receive day care at a hospice and return home at night. Others live at the hospice for a short period of time and then return home, and others reside in the hospice until they die. The charity 'Help the Hospices' can help you locate hospice services in your area, but unfortunately these services remain scarce.



However, in recent years the best hospice practices of pain relief and emotional support for dying people have been extended to other settings. The majority of GP practices and hospitals now have special 'pathways' in place for patients nearing the end of life. Patients on these pathways will receive and benefit from hospice care techniques, even though they are not in a hospice.

### Care in a nursing home/care home

If you are not able to stay at home due to illness, but you do not have a place in, or do not wish to go to, a hospice or hospital, you could go to a home. There are different types of homes, and costs vary. Some are privately owned and run for profit, and others are run by charities or religious organisations. They are known as 'private' and 'voluntary' homes respectively. There are also specialist 'EMI' homes (standing for Elderly Mentally Infirm), which care for people suffering with conditions such as dementia.

Your local authority can provide you with a list of homes, and may assist with the cost of your care, subject to an assessment. An assessment will establish how much money you will be expected to contribute yourself to the cost of your fees. If you have particular nursing care needs, these will be assessed by your local Primary Care Trust. Depending on your nursing care needs, you will receive a contribution per week towards the cost of your home fees.

Charities such as Age Concern, Help the Aged and Counsel and Care can provide you with information on choosing a suitable home.

## Care in a hospital

If you receive care in a hospital during the last phase of your illness, you can ask to be seen by a palliative care specialist.

The NHS is also running a programme in hospitals which allows all health professionals to provide high-quality care for dying patients which focuses on the physical, psychological and spiritual comfort of patients and their relatives. This programme is called the Liverpool Care Pathway for the Dying Patient (LCP). When doctors and nurses looking after you believe that you are dying and you only have hours or days to live, they will care for you according to the Liverpool Care Pathway. This should guarantee that you will receive high-quality care at the end of your life, similar to the care you would receive in a hospice.

## Did you know...

**You can record your wish to be cared for at home, in a hospice, hospital or care home.**

Most people would prefer to die at home but only 1 in 5 of us do (Healthcare for London, A Framework for Action, 2007). If you want to be cared for and die at home, you can record this wish in an End-of-Life Care Plan. This will be particularly helpful in order to avoid an emergency hospital admission in your final hours. But not everyone wants to die at home - you can state where you would like to spend your last days in your End-of-Life Care Plan, and talk to your GP and others that care for you about your options.

Traditionally, palliative care has been centred on cancer patients. 72% of people are shocked that palliative care is only routinely available to cancer patients, and not to those with other terminal illnesses. Although there will not always be places available in a hospice, health professionals should be able to provide you with high-quality care in other settings, using tools such as the Liverpool Care Pathway.

Compassion in Dying would like to see more Government investment in palliative care so that everyone has access to these services at the end of life, regardless of where they live or the illness they have. Contact us for more information.

# 1

## End-of-life care

### What financial support is available?

Disability Living Allowance - sometimes referred to as DLA - is a tax-free benefit for children and adults under 65 who need help with personal care.

If you have a progressive disease and you are not expected to live for more than six months there are special rules for claiming to make sure you get your benefit more quickly and easily.

You can also make a claim for someone under the special rules without them knowing or without their permission. If they satisfy the relevant conditions, they will get a letter saying that they have been awarded the allowance, but special rules will not be mentioned.



Disability Living Allowance has two components (parts): a care component and a mobility component, which applies when you can't walk or need help getting around. Depending on your personal needs, you might be entitled to receive just one component or both. If you are terminally ill and you are not expected to live for more than six months, you will immediately get the highest rate of the care component. The highest rate currently amounts to a weekly allowance of £70.35 (as of July 2009).

If you start to get Disability Living Allowance it also might increase the amount of other benefits or credits you're entitled to, such as Income Support, Pension Credit, Housing Benefit, Council Tax Benefit, Working Tax Credit and Child Tax Credit.

You can claim online using the following link:

**[www.dwp.gov.uk/eservice](http://www.dwp.gov.uk/eservice)**

Or you can get a claim pack by phoning the Benefit Enquiry Line, contacting your local Jobcentre Plus office or local social security office, or downloading the claim form from **[www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DisabilityLivingAllowance/DG\\_10011925](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DisabilityLivingAllowance/DG_10011925)**

If you are aged over 65 you can claim a similar benefit to DLA called Attendance Allowance. You can claim online on **[www.dwp.gov.uk/eservice](http://www.dwp.gov.uk/eservice)**

Or you can get a claim pack by phoning the Benefit Enquiry Line or downloading the form directly from **[www.direct.gov.uk/en/DisabledPeople/FinancialSupport/AttendanceAllowance/DG\\_10012442](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/AttendanceAllowance/DG_10012442)**

For more information contact:

The Benefit Enquiry Line  
telephone: 0800 88 22 00

The Disability Living Allowance/Attendance Allowance Helpline  
telephone: 08457 123 456

Your GP should also be able to help you claim these benefits.

## Did you know...

**If you have a progressive disease and are not reasonably expected to live for more than another six months, there are special rules to help you claim benefits more quickly and easily.** You can get the highest rate of Disability Living Allowance (DLA) and Attendance Allowance immediately.

# 1

## End-of-life care

### How do I complain?

It is important to complain if you are not getting the services or support that you need.

#### NHS services

You are entitled to complain if you are receiving NHS services. You can also give a friend or family member permission to complain on your behalf.

If you have a complaint, the first thing to do is to submit your complaint to the organisation providing the service. You can raise any concerns by speaking to a member of staff, for example a doctor or nurse in hospital or the practice manager of a GP surgery. Usually, any problems will be resolved quickly without the need to make a formal complaint.

If you are not satisfied with the response and want to continue with your complaint you can do so by speaking or writing to the primary care practitioner or organisation concerned. If you are complaining to a hospital trust it is usually best to find a contact name for the Complaints Department or address your complaint to the Chief Executive.

If you are still unhappy following the formal response to your complaint, you can take your complaint further. The arrangements for doing this are different in the different countries of the United Kingdom.

In England you should contact the Health Service Ombudsman on 0345 015 4033, email [phso.enquiries@ombudsman.org.uk](mailto:phso.enquiries@ombudsman.org.uk), or you can visit the website [www.ombudsman.org.uk/](http://www.ombudsman.org.uk/). In Wales you should contact the Health Service Ombudsman on 0845 601 0987 or through the website [www.ombudsman-wales.org.uk](http://www.ombudsman-wales.org.uk).

It is also a good idea to speak to your local Patient Advice and Liaison Service (PALS) when you decide you want to make a complaint, and at any stage in the process. PALS will be familiar with the complaints procedure in your area and can support you through the process. You can ask your GP or hospital for contact details for your local PALS, or phone NHS Direct on 0845 46 47, or check on the PALS website: [www.pals.nhs.uk](http://www.pals.nhs.uk).

For more detailed information and guidance on making a complaint contact the Patients Association on 0845 608 4455.

## **Residential care homes and nursing homes**

You are entitled to complain about care received in a residential care or nursing home, or social care that you are receiving in your own home.

You can raise your concerns directly with the care service first, to see if they can be resolved without making a formal complaint.

However, if you are worried about sharing your concerns directly with the care service provider you can make your complaint to the Care Quality Commission. You can contact the Care Quality Commission on 03000 616161 or email [enquiries@cqcc.org.uk](mailto:enquiries@cqcc.org.uk). Or you can visit their website [www.cqc.org.uk/](http://www.cqc.org.uk/). CSCI is the regulator for social care services.

You can contact CSCI on 0845 015 0120 or 0191 233 3323 or email [enquiries@csci.gsi.gov.uk](mailto:enquiries@csci.gsi.gov.uk).



# 2

## Making decisions about care and treatment

### Can I refuse medical treatment?

Yes - under common law, if you are an adult with mental capacity, you can refuse medical treatment even if you will die as a result. If the treatment has already begun, you can instruct your doctor to stop it.

The law says that adults with mental capacity have an absolute legal right to refuse treatment, "notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent."

This means that you do not have to justify your decision to refuse treatment, but you do have to show that you are capable of making the decision, and that you understand the consequences of it.

In addition, the Mental Capacity Act 2005 has given **ADVANCE DECISIONS** to refuse treatment statutory force. This allows you to refuse treatment in advance, should you lose mental capacity or the ability to communicate, through an Advance Decision. The Mental Capacity Act covers England and Wales only.

### Did you know...

**You have the legal right to refuse medical treatment, even if you will die as a result.** You do not have to justify your decision to refuse treatment, but you do have to show that you are capable of making the decision, and that you understand the consequences of it.

### How can I ensure my healthcare wishes will be respected if I lose mental competency in the future?

There are three main options for helping you make sure that your views about medical care will be respected in the future.

#### **Option one: Advance Decisions**

Make an Advance Decision (also known as a living will or an advance directive). An Advance Decision allows you to set out in advance, what medical treatment you would like to refuse, should you lose mental competency or the ability to communicate (for example if you were in a persistent

vegetative state, or if you developed dementia). It is a very good idea to make an Advance Decision if you have strong ideas about the kind of treatment you would want in these situations, particularly in regard to life-sustaining treatment.

If you make an Advance Decision, *Compassion in Dying* recommends that you talk to your doctors about it and give one copy to your GP (and any other specialists that you regularly see) and one copy to your next of kin. Some people also

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request their local hospital to file a copy of their Advance Decision so that the medical staff will be aware of the existence of their Advance Decision if they are admitted to hospital. It is a good idea to discuss your wishes and the contents of your Advance Decision with other family members as well. We strongly recommend that you regularly update your Advance Decision so that it reflects your wishes. Advance Decisions are legally binding, so doctors should respect your wishes as stated in your Advance Decision.

Compassion in Dying provides an Advance Decision that is fully compliant with the Mental Capacity

Act, and easy to use. Some other organisations such as the Alzheimer's Society and the Huntington's Disease Association also provide Advance Decisions. A solicitor could also draw up an Advance Decision for you, but this is likely to be much more expensive than buying, or making a voluntary donation for an Advance Decision from a voluntary sector organisation.

For more information on Advance Decisions contact Compassion in Dying on 020 7479 7731.

## **Option two: Lasting Powers of Attorney**

The other alternative is to appoint one of your relatives or friends your Lasting Power of Attorney (LPA). The Lasting Power of Attorney was established by the Mental Capacity Act, and replaces the Enduring Power of Attorney. This authorises them to make decisions on your behalf should you lose mental competency or the ability to communicate. There are two kinds of Lasting Power of Attorney - financial, and health and welfare.

Each kind of LPA costs £120 to set up and some people are eligible for a reduced charge to set up an LPA. Appointing someone as your LPA will give them complete control over

your financial affairs and/or your health and welfare. Under the health and welfare LPA you can give someone the power to refuse life-sustaining treatment on your behalf. Therefore, if you do decide to appoint an LPA you need to be confident that they will respect your wishes, and act in your best interests.

You can find out more about Lasting Powers of Attorney from the Office of the Public Guardian on 0845 330 2900.

## **Option three: End-of-Life Care Plans**

As explained on pages 8 to 9, End-of-Life Care Plans allow you to record your wishes and preferences for the end of life. These may include specific wishes related to your healthcare. The Mental Capacity Act 2005 states that if you are no longer able to make your wishes clear, the people who make decisions about your healthcare must consider, so far as reasonably possible, your past and present wishes and feelings. They must in particular consider any relevant written statement you made in the past, ie an End-of-Life Care Plan. However, an End-of-Life Care Plan is not legally binding in the way that an Advance Decision is.

# 2

## Making decisions about care and treatment

### **What if I make an Advance Decision and change my mind?**

Compassion in Dying recommends that you regularly read over and witness your Advance Decision, so that doctors know that refusals of treatment set out in it are up-to-date.

If you change your mind about your treatment wishes you can make the change to your Advance Decision, sign and date the section you have changed, and ask someone to witness the change for you.

You can also verbally revoke any decisions set out in your Advance Decision at any time should you change your mind. However, it is best to also make the changes to your Advance Decision in writing if you can.



## TREATMENTS YOU CAN REFUSE

We can tell you about some of the most common end-of-life treatments, but it is important that you speak to your doctor about which ones you are most likely to receive - because this depends on your particular condition.

### **Cardiopulmonary Resuscitation (CPR)**

If your heart stops, your doctor might try to restart it using CPR. This involves him or her repeatedly pressing against your chest in a 'pumping' action, in order to stimulate your heart's natural rhythm. At the same time, air will be pumped into your lungs to replicate breathing.

### **Mechanical or artificial ventilation**

A ventilator machine can help you if you are unable to breathe on

your own. Ventilators are also known as respirators or life-support machines. It involves pumping air into your lungs through a tube, which is inserted into your nose or mouth. In some circumstances, a surgeon might need to create a small hole in your throat and insert the tube directly into it, but this is uncommon.

### **Artificial nutrition and hydration**

If you are unable to eat or drink in the normal way, your doctor might provide you with a liquid solution that contains the hydration or nutrition you need. The liquid can be given to you through a number of routes, depending on your particular condition. The liquid can be given through your veins, via an intravenous drip. Alternatively, you could receive the liquid through a tube that goes through

your nose and into your stomach (a 'nasogastric' tube). These tubes can only be used for a few weeks though; if you need artificial nutrition or hydration for a longer amount of time, a 'PEG' feeding tube might be required. This involves an operation as surgeons will need to put the PEG directly into your stomach.

### **Antibiotics**

At the end of life, when the body is already weak, infections that you would otherwise be able to fight off can be fatal. Medicines that treat these infections - such as antibiotics - could therefore be considered life-sustaining medicines in this context. Antibiotics can be given through your veins (via an intravenous drip), or in a pill, depending on the type of infection and your general condition.

## TREATMENTS YOU CANNOT REFUSE

### **Food and water**

Advance Decisions do not allow you to refuse food and water. Food and water are not a form of medical treatment and therefore you cannot refuse food and water in advance of losing capacity. On the other hand,

artificial nutrition and hydration are considered to be a form of medical treatment and you can refuse this in your Advance Decision.

### **Pain relief**

Advance Decisions do not allow

people to refuse basic care, which includes comfort, personal hygiene and pain relief. The people who care for you will do everything to keep you comfortable and pain-free at the end of your life.

# 2

## Making decisions about care and treatment

### How do I make my wishes known?

The End of Life Care Strategy recommends that patients' wishes and preferences for care, including their Advance Decision (if they have one) are recorded in their care plan. The Strategy also recommends that local registers of people's End-of-Life Care Plans should be set up so that all people involved in a person's care, including out-of-hours and emergency services, have access to their care plan and know what their wishes are.

However, it may take some time for the local registers to be set up. Therefore Compassion in Dying strongly recommends that you give a copy of your Advance Decision to your GP to ensure that it is placed on your medical record. Some people also request their local hospital to file a copy of their Advance Decision so that the medical staff will be aware of the existence of their Advance Decision when they are admitted to hospital.

Becoming a member of MedicAlert could ensure that information about your decisions would be easily available to health professionals. MedicAlert members wear either a bracelet or necklet (known as an Emblem). The MedicAlert

Foundation provides this identification system for individuals with hidden medical conditions, allergies and/or Advance Decisions. The bracelet or necklet is engraved with the wearer's vital details or main medical condition(s), a personal ID number and a 24-hour emergency telephone number so that medical staff can access further details.

You can contact MedicAlert on 0800 581 420.

### Did you know...

**You can refuse treatment in advance should you lose mental competency or the ability to communicate in the future.**

Since the Mental Capacity Act came into force in October 2007, health professionals have a legal duty to comply with your wish to refuse treatment as set out in your Advance Decision.

Compassion in Dying works to raise awareness of Advance Decisions and we are also the leading provider of Advance Decisions in the UK. Contact us for more information about Advance Decisions and your right to refuse treatment.

### Can I demand that medical treatments are given to me?

You do not have a legal right to demand medical treatment. If you do tell your doctor that you want a treatment, he/she will usually try to meet your needs. You can record requests for treatment in your End-of-Life Care Plan. Ultimately though, your doctor does not have to provide any treatments that he/she feels are unnecessary, futile or inappropriate.

### Did you know...

**If you make an Advance Decision you should give a copy to your GP to include in your medical record.**

86% of people believe those suffering from a terminal illness should be able to exercise choice over their care at the time of death and 79% believe it is important not to have their lives prolonged against their wishes. The End of Life Care Strategy states that good PCTs will set up localised end-of-life Care registers including people's End-of-Life Care Plans and Advance Decisions. This process may take some time so we strongly recommend that you give a copy of your Advance Decision to your GP and other health and social care professionals involved in your care.

For advice on how to ensure your treatment wishes are recorded and respected contact Compassion in Dying.



# 2

## Making decisions about care and treatment

### Can I demand to be given specific medication?

In recent years there have been several high profile stories in the news of terminally ill people seeking specific medications that were not available in their local area but were available to people with the same condition in a different part of the country.

This is a very complex area. In brief, there are four main reasons why you may not have been prescribed a particular medication:

- Your doctor does not think it is appropriate for you - in this situation your doctor should be able to clearly explain their decision. However, you can ask for a second opinion from a different doctor.
- Your doctor cannot prescribe the medication for financial reasons - in this situation you can make a complaint to the Chief Executive of the relevant Primary Care Trust (PCT) or Hospital Trust.

- The treatment you are asking for has not yet been approved by the National Council for Health and Clinical Excellence (NICE) - if NICE has not recommended a specific treatment, it is not supposed to be provided on the NHS.
- The NHS is waiting for NICE to issue guidance on the treatment - each PCT will have a policy on what happens in this situation which they should be able to show you.

In some situations you may be able to pay extra for specific medication, whilst continuing to receive the majority of your medication and care from the NHS.

For further advice and information you can contact the Patients Association on 0845 608 4455.

You can also speak to your local Patient Advice and Liaison Service (PALS). They will be familiar with policies and procedures in your area.

### What if my wishes aren't respected?

If you are mentally competent and doctors ignore or go against your stated choice to refuse treatment, you can make a formal complaint to the PCT or Hospital Trust that employs them.

If you have expressed your wish to refuse treatment in an Advance Decision, doctors must respect this. Health professionals can only ignore your Advance Decision to refuse treatment if they have reasonable grounds to believe that your Advance Decision is either not valid, or not applicable to the situation at hand.

If you have an Advance Decision and you are mentally competent, but doctors ignored or rejected your Advance Decision when you were not competent or able to communicate (for example, during an operation), you can make a formal complaint to the PCT or Hospital Trust that employs them, and you could press charges for assault.

We want to empower people to make their wishes known and have them respected. If you find yourself in a situation where your wishes are not respected, we are here to help you. Contact Compassion in Dying on 020 7479 7731 and we will assist you further and provide you with useful legal contacts should you find yourself in these situations.



# 3 Carers' rights

## CARERS

A carer is someone who provides unpaid care by looking after an ill, frail, disabled or dying family member, friend or partner.

### Will I be informed?

The Government's End of Life Care Strategy recognises the extremely important role of family, close friends and informal carers for people approaching the end of life. The Strategy states that carers should be closely involved in decisions about the care and treatment of the person they are caring for. They should also be given information about the likely progress of the condition of the person they care for and about services which are available to them.

Government is currently creating an information service for carers, which will provide full and easy access to information for carers through a single national telephone number and website. Your local authority should also ensure that you receive all the information you are entitled to as a carer - the person you are caring for does not have to be receiving services from the local authority, and neither do you, in order for you to be entitled to this information.

### WHAT DOES THE CARERS' STRATEGY MEAN FOR CARERS?

The Carers' Strategy sets out a vision that by 2018 carers will be recognised and valued as being vital to families and communities. Support for carers will be tailored to meet individuals' needs, enabling carers to have a balance between their caring responsibilities and a life outside caring.

The Strategy will set up:

- A national information helpline (0808 802 0202) and website for carers ([www.nhs.uk/carersdirect/](http://www.nhs.uk/carersdirect/)). Carers will be able to access all the information they need directly, or be referred on to more appropriate support.
- A training programme for carers to inform them of their rights and the services available to them, and help develop their advocacy and networking skills.
- Personal budgets, a term used to describe an upfront clear allocation of a certain amount of money to individuals to help them with their social care needs. For carers, this helps to ensure that the people they care for can buy the services that meet their own needs and those of the carer.
- Additional funding over the coming years to fund more planned breaks for carers.
- An awareness raising campaign about the right to request flexible working, to raise awareness among employers and carers about this right.



## What financial support is available to carers?

Carer's Allowance is a benefit available to some people who provide care for someone who is ill and receiving Disability Living Allowance or one of a range of other selected benefits.

To be eligible for Carer's Allowance you must be at least 16 years old, not enrolled as a full-time student, resident in the UK, not currently receiving other benefits, and you must provide care for a minimum of 35 hours per week.

You cannot claim Carer's Allowance if your weekly income reaches a certain threshold and if

you are in receipt of certain other social security benefits such as State Retirement Pension.

You can claim Carer's Allowance online:  
**[www.dwp.gov.uk/carersallowance](http://www.dwp.gov.uk/carersallowance)**.

Or you can contact the Carer's Allowance Unit on 01253 856 123 and they will send you a claim form.

As a carer you and the person you care for may be eligible for additional benefits such as help with council tax and fuel bills. For more information, enquire at your local social security office or contact:

The Benefit Enquiry Line -  
telephone: 0800 88 22 00

Carers UK -  
telephone: 0808 808 7777

Counsel and Care's advice service supports people over 60, their families and carers when they need advice and information. If you would like to contact Counsel and Care for advice, please call 0845 300 7585 or email [advice@counselandcare.org.uk](mailto:advice@counselandcare.org.uk).

# 3 Carers' rights

## What other support is available to carers?

If you provide a regular and substantial amount of care for someone aged 18 or over, you can ask your local council's social services department for a carer's assessment.

Based on your assessment the social services team will decide if you are entitled to support. This could include giving you a break from caring, making adaptations to your home, or providing emotional or practical support.

For more information contact your local social services department or visit [www.direct.gov.uk/en/CaringForSomeone/CaringAndSupportServices](http://www.direct.gov.uk/en/CaringForSomeone/CaringAndSupportServices).

Combining work and looking after someone is often very difficult. Since April 2007, carers for terminally ill people have a statutory right to ask their employer for flexible working to help them balance their work and caring responsibilities. Under this right, you can ask your employer to change your working pattern, including hours and location of work. You will need to write to your employer and set out the changes you would like and how these changes will affect your job. You can only make one request per year and, if accepted, the changes will mean a permanent change to your

employment contract, so it is important to think carefully before applying. There is a set procedure that all employers must follow and requests can only be refused for specified reasons. If your employer refuses your request, you can appeal their decision.

As a carer you can also qualify for the right to take a 'reasonable' amount of time off work to deal with an emergency involving a dependant. To use this right to time off, you must inform your employer as soon as possible after the emergency has happened. It is at your employer's discretion whether the leave is paid or unpaid.

If you are a parent looking after a child under the age of five, you are entitled to up to 13 weeks of parental leave. If you are a parent looking after a disabled child under the age of 18, you are entitled to up to 18 weeks of parental leave. Parental leave is usually unpaid but your employer can offer to pay you. You must give at least 21 days' notice to your employer to take parental leave.

For more information on support for carers, please contact Carers UK on their CarersLine: 0808 808 7777.

### Did you know...

**You are legally entitled to a carer's assessment when you are a carer. Based on your assessment your social services team will decide if you are entitled to support.**

There are more than half a million carers of terminally ill people in the UK. Compassion in Dying wants these people to receive more support including legal protection against employment discrimination, better access to respite care and access to Carer's Benefit regardless of age.

## **How do I represent a loved one who is not mentally competent?**

If the person you are caring for is not mentally competent and they have not appointed you as their attorney (using the Lasting Power of Attorney - see page 19) then you do not have any formal say over their treatment. However, most doctors will include carers and loved ones in discussions about treatment decisions.

If you strongly disagree with the treatment decisions doctors are making regarding a loved one who is no longer mentally competent, you may need to apply to the Court of Protection. The Court was set up under the Mental Capacity Act to resolve such disputes quickly.

For advice and guidance on this process please contact the Office of the Public Guardian on 0845 330 2900.

## **Can I complain on behalf of a loved one?**

You are entitled to complain if you think a loved one is not receiving the standard of care they need and deserve. For information about making a complaint about health or social care services see pages 16 to 17.



# 4 Rights after death

## Will I be given the information I need?

The End of Life Care Strategy has recognised the need for easy access to reliable information for people who have just lost a loved one. Gaining access to information that is understandable and easy-to-use will help people to cope with the loss of a loved one.

The charity Cruse Bereavement Care aims to promote the well-being of bereaved people and aims to help people come to terms with their grief and cope with their loss. The organisation provides support and offers information, advice, education and training services.

If you would like to obtain information and advice following the loss of a loved one, you can contact Cruse Bereavement Care on their Day-to-Day helpline: 0844 477 9400.



# Your Rights at the End of Life

## What financial support is available?

You may be able to claim Bereavement Payment if your husband, wife or civil partner had:

- paid their National Insurance contributions, or
- their death was caused by their job,

**And** either:

- you were under State Pension age (60 for women, 65 for men) when they died, or

- your partner was not entitled to Category A state Retirement Benefit when they died.

Bereavement Payment consists of a one-off, lump-sum payment of £2,000 and is tax-free.

You may also be able to claim Bereavement Allowance, the taxable weekly benefit paid to you for up to 52 weeks from the date of death of your husband, wife or civil partner.

You are eligible if all of the following conditions apply. You are:

- a widow, widower or surviving civil partner aged 45 or over when your partner died
- not bringing up children
- under State Pension age (currently 60 for women and 65 for men) and your late husband, wife or civil partner paid National Insurance contributions (NICs), or they died as a result of an industrial accident or disease. This weekly benefit will vary depending on your age at the time following your partner's death.

For more information on financial help for the bereaved, please visit [www.direct.gov.uk/en/Governmentcitizensandrights/Death/WhatToDoAfterADeath/DG\\_066810](http://www.direct.gov.uk/en/Governmentcitizensandrights/Death/WhatToDoAfterADeath/DG_066810)

## Did you know...

**You may be able to claim Bereavement Payment or Bereavement Allowance if you have lost your partner and you fulfill certain conditions.**

The loss of a loved one is inevitably a very difficult and distressing time. As well as the grieving process, there are many practical considerations, such as registering the death and arranging the funeral, to be considered.

Following the death of a loved one 89% of us believe that practical support dealing with legal and financial matters is important, and 77% believe that bereavement counselling and emotional support is important. Compassion in Dying wants bereaved people to have easy access to services offering legal and financial advice and referral to counselling services.

# 4 Rights after death

## What other support is available?

You can get practical help from a wide range of people after the loss of a loved one. The health professionals who have cared for your relative, partner or friend might be able to help and you could also consult a funeral director, a solicitor, the social services department and Citizens Advice, amongst others.

When you are bereaved, practical tasks such as registering a death, closing bank accounts and sorting out inheritance may feel like daunting tasks.

In England and Wales, you normally need to register a death within five days. It's best to go to the registry office in the area in which the person died, otherwise it may take longer to get the necessary documents and this could delay the funeral arrangements. Registering the death will take about half an hour; you may need to make an appointment beforehand. Most deaths are registered by a relative. The registrar would normally only allow other people if there are no relatives available.

There is an interactive tool on the internet which gives you all the information you need about who can register a death and how to go about it, including the documentation needed.

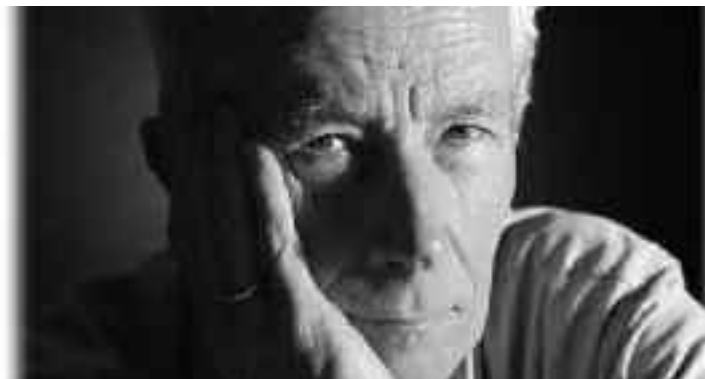
This can be consulted on:

**[www.direct.gov.uk/bereavement\\_radio.dsb?pro=BDT](http://www.direct.gov.uk/bereavement_radio.dsb?pro=BDT)**

A simple checklist of what to do when someone dies can be consulted on:

**[www.direct.gov.uk/en/Governmentcitizensandrights/Death/WhatToDoAfterADeath/DG\\_10029808](http://www.direct.gov.uk/en/Governmentcitizensandrights/Death/WhatToDoAfterADeath/DG_10029808)**





### RIGHTS UNDER THE REVISED CORONERS' SYSTEM

A small proportion of deaths need to be reported to the coroner before they can be registered, for example, if someone dies during an operation or unexpectedly.

The new Coroners and Justice Bill provides a charter for bereaved people who come into contact with a reformed coroner system, which explains the services bereaved people can expect from the coroners' service.

The Charter sets out how the information needs of bereaved people who come into contact with the coroner's service will be met. This information will be tailored to individuals' and

families' wishes, preferences and expectations where possible and people will be advised sensitively.

People will also have the opportunity to ask questions and raise particular concerns throughout the process and the Charter establishes a right of appeal to the Chief Coroner in particular instances.

Coroners will also keep information on the main organisations and support groups which offer help or support to people who have been bereaved and will make this information available to family members.

**Note:** All opinion poll figures quoted in this guide are from ICM poll, commissioned by Dignity in Dying, May 2008, unless stated otherwise.

# Sources of help and advice

**You can contact Compassion in Dying for more information on any of the issues covered in this guide.**

## **Compassion in Dying**

181 Oxford Street  
London  
W1D 2JT

Tel: 0207 479 7731  
Email: [info@compassionindying.org.uk](mailto:info@compassionindying.org.uk)  
[www.compassionindying.org.uk](http://www.compassionindying.org.uk)

The booklet does not discuss the option of assisted dying because this is currently illegal under UK law and is therefore not a right. Our partner organisation Dignity in Dying campaigns for terminally ill, mentally competent adults who are suffering unbearably to be given the option of an assisted death, subject to a range of legal safeguards.

**For information on the law on assisted dying, or to join the campaign contact**

## **Dignity in Dying**

Tel: 020 7479 7730  
[www.dignityindying.org.uk](http://www.dignityindying.org.uk)

## **Hospice, palliative care, and nursing care information:**

### **Help the Hospices**

Tel: 020 7520 8200  
[www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)

### **Hospice Information Service**

Tel: 020 7520 8200  
[www.hospiceinformation.info](http://www.hospiceinformation.info)

### **Hospice at Home**

[www.hospiceathome.org.uk](http://www.hospiceathome.org.uk)

### **Macmillan Cancerline**

Tel: 0808 808 2020  
[www.macmillan.org.uk](http://www.macmillan.org.uk)

### **Marie Curie Cancer Care**

Tel: 020 7599 7777  
[www.mariecurie.org.uk](http://www.mariecurie.org.uk)

### **Sue Ryder Care**

Tel: 0845 050 1953  
[www.suerydercare.org](http://www.suerydercare.org)

## **Patient groups and older people's charities:**

### **Age Concern**

Tel: 0800 009 966  
[www.ageconcern.org.uk](http://www.ageconcern.org.uk)

### **Help the Aged**

Tel: 020 7278 1114  
[www.helptheaged.org.uk](http://www.helptheaged.org.uk)

### **Counsel and Care**

Tel: 0845 300 7585  
[www.counselandcare.org.uk](http://www.counselandcare.org.uk)

### **Patient UK**

[www.patient.co.uk](http://www.patient.co.uk)

### **The Patients Association**

Tel: 0845 608 4455  
[www.patients-association.org.uk](http://www.patients-association.org.uk)

### **Patient Concern**

[www.patientconcern.org.uk](http://www.patientconcern.org.uk)

### **Motor Neurone Disease Association**

Tel: 0845 762 6262  
[www.mndassociation.org](http://www.mndassociation.org)

### **Huntingdon's Disease Association**

Tel: 0151 298 3298  
[www.hda.org.uk](http://www.hda.org.uk)

### **MS Society**

Tel: 0808 800 8000  
[www.mssociety.org.uk](http://www.mssociety.org.uk)

### **Parkinson's Disease Society**

Tel: 0808 800 0303  
[www.parkinsons.org.uk](http://www.parkinsons.org.uk)

### **Terence Higgins Trust**

Tel: 0845 122 1200  
[www.tht.org.uk](http://www.tht.org.uk)

# Your Rights at the End of Life

## Other useful contacts:

### Citizens Advice Bureau

Web: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

### Carers UK

CareresLine 0808 808 7777  
[www.carersuk.org.uk](http://www.carersuk.org.uk)

### Cruse Bereavement Care

Tel: 0844 477 9400  
[www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

### Office of the Public Guardian

Tel: 0845 330 2900  
[www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)

### MedicAlert

Tel: 0800 581 420  
[www.medicalert.org.uk](http://www.medicalert.org.uk)

### The Benefit Enquiry Line

Tel: 0800 88 22 00  
[www.direct.gov.uk](http://www.direct.gov.uk)

### The Disability Living Allowance/Attendance Allowance Helpline

Tel: 08457 123 456  
[www.direct.gov.uk](http://www.direct.gov.uk)

### Carer's Allowance Unit

Tel: 01253 856 123  
[www.direct.gov.uk](http://www.direct.gov.uk)

### Care Quality Commission

Tel: 03000 616161  
[www.cqc.org.uk](http://www.cqc.org.uk)

### Health Service Ombudsman

Tel: 0345 015 4033  
[www.ombudsman.org.uk/](http://www.ombudsman.org.uk/)

### Financial Help for the Bereaved

There is no central telephone number but you can find out more from your local Jobcentre Plus.  
[www.direct.gov.uk/en/Governmentcitizensandrights/Death](http://www.direct.gov.uk/en/Governmentcitizensandrights/Death)

### Natural Death Centre

Tel: 0871 288 2098  
[www.naturaldeath.org.uk](http://www.naturaldeath.org.uk)

### Samaritans

Tel: 08457 909090  
Email: [jo@samaritans.org](mailto:jo@samaritans.org)  
[www.samaritans.org.uk](http://www.samaritans.org.uk)

### Carers Direct

Tel: 0808 802 0202  
[www.nhs.uk/carersdirect/](http://www.nhs.uk/carersdirect/)

### The British Pain Society

Tel: 020 7269 7840  
Email: [info@britishpainsociety.org](mailto:info@britishpainsociety.org)

## Online resources:

### Information about coping with a terminal illness:

[www.terminalillness.co.uk](http://www.terminalillness.co.uk)

### Downloadable Preferred Priorities for Care form:

[www.endoflifecareforadults.nhs.uk/eolc/ppc.htm](http://www.endoflifecareforadults.nhs.uk/eolc/ppc.htm)

### To claim benefits online:

[www.dwp.gov.uk/eservice](http://www.dwp.gov.uk/eservice)

### To download a Disability Living Allowance claim pack:

[www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DisabilityLivingAllowance/DG\\_10011925](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DisabilityLivingAllowance/DG_10011925)

### To download an Attendance Allowance claim pack:

[www.direct.gov.uk/en/DisabledPeople/FinancialSupport/AttendanceAllowance/DG\\_10012442](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/AttendanceAllowance/DG_10012442)

### To claim Carers Allowance online:

[www.dwp.gov.uk/carersallowance](http://www.dwp.gov.uk/carersallowance)

### For help registering a death visit:

[www.direct.gov.uk/bereavement\\_radi.o.dsb?pro=BDT](http://www.direct.gov.uk/bereavement_radi.o.dsb?pro=BDT)

### A checklist of what to do when someone dies is available at:

[www.direct.gov.uk/en/Governmentcitizensandrights/Death/WhatToDoAfterADeath/DG\\_10029808](http://www.direct.gov.uk/en/Governmentcitizensandrights/Death/WhatToDoAfterADeath/DG_10029808)

### Entitled To - a website providing information on benefits and tax credits:

[www.entitledto.co.uk](http://www.entitledto.co.uk)

### Turn2Us - a website providing information on benefits and financial help:

[www.turn2us.org.uk](http://www.turn2us.org.uk)

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181 Oxford Street  
London  
W1D 2JT

Tel: 0207 479 7731

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[www.compassionindying.org.uk](http://www.compassionindying.org.uk)