

## End of life care

This guide is for people who are approaching the end of their life. Some parts of it may also be useful for people who are caring for someone who is dying, or people who want to plan in advance for their end of life care.

It explains what you can expect from end of life care, including palliative care to control pain and other symptoms and to offer psychological, social and spiritual support.

You can also find information about your rights and choices, including refusing treatment, setting down your wishes for your future treatment, and how to give someone the legal right to make decisions for you if you are no longer capable.

This guide also contains information about talking to your family and carers about dying and about your wishes.

### What is end of life care?

This section contains information about what you can expect during end of life care and the things you may want to think about. These include how and where you want to be cared for, as well as financial issues.

Letting your family know about your wishes could help them if they are ever in the situation where they have to make decisions about your care. Knowing that they are acting in accordance with your wishes can remove some of the stress from a very difficult situation.

If you are not approaching the end of your life, you may still want to think about your wishes for your own end of life care. This could include where you would like to be cared for, where you would prefer to die, your wishes for your funeral and who you would like to make decisions about your care if you are not able to decide for yourself.

### What end of life care involves

End of life care is support for people who are approaching death. It helps them to live as well as possible until they die, and to die with dignity. It also includes support for their family or carers.

End of life care includes palliative care. If you have an incurable illness, palliative care will help to make you as comfortable as possible by relieving pain and other distressing symptoms, while providing psychological, social and spiritual support for you and your family or carers. This is called a holistic approach to care, as it deals with the 'whole' person rather than just one aspect of their care.

You may receive palliative care early in the course of your illness together with other therapies to treat your condition, such as chemotherapy or radiotherapy, before you are considered to be nearing the end of your life.

In this end of life care guide, 'end of life care' also covers legal issues, such as creating a lasting power of attorney, so that the person or people of your choice can make decisions about your care if you are no longer able to do so.

Who provides end of life care?

Many healthcare professionals can be involved in providing end of life care, depending on your needs. Hospital doctors and nurses, your DOCTOR, community nurses, hospice staff and counsellors might all be involved, as well as social services, religious ministers, physiotherapists or complementary therapists.

Most hospitals have special palliative care teams who co-ordinate all these services. As a patient, you have the right to choose where you want to receive care and where you want to die. A palliative care team can provide end of life care to patients and their families in hospitals, care homes, hospices and at home.

When does end of life care begin?

When end of life care begins depends on your needs.

The General Medical Council in the UK considers that patients are approaching the end of life when they are likely to die within the next 12 months. This

includes patients who are expected to die within the next few hours or days, and those with advanced incurable conditions. It can also include people who have: general frailty and co-existing conditions that mean they are likely to die within 12 months

existing conditions, if they are at risk of dying from a sudden crisis in their condition

life-threatening acute conditions caused by sudden catastrophic events, such as an accident or a stroke

End of life care may last a few days, or for months or years. End of life care begins when you need it, and will continue for as long as you need it.

This guide also contains information about planning ahead for your future care.

Where you can be cared for

If you are approaching the end of life, you may be offered care in a variety of settings. The palliative care team will organise for you to be cared for according to your wishes.

You can receive end of life care:

at home

in a hospital

in a care home

Hospice care

Care at home

You may not need to move away from home to receive care, as care can be provided at home. Sometimes this is available as a 24-hour service. To find out whether you can receive 24-hour care at home, check with your DOCTOR or community palliative care nurse.

In hospital

In hospitals, there are specialist palliative care teams who work alongside and support the hospital doctors, nurses and other health and social care professionals.

In a care home

You can receive end of life care in a care home if you wish. In a care home, trained staff are available to look after you day and night.

Your DOCTOR can arrange for community palliative care nurses, to come to your home and care for you there. Community palliative care nurses offer specialist care, including:

hands-on nursing

advice on pain and symptom control

practical and emotional support

Care in a care home

You can receive end of life care in a care home if you wish. In a care home, trained staff are available to look after you day and night. They can provide the same kind of care that family members can provide at home, such as help with washing, dressing, and providing meals.

Some care homes provide skilled nursing care to residents when they need it. They are suitable for people who have a disability, a serious long-term condition or very restricted mobility.

Care homes can be run by:

voluntary organisations

private individuals

private companies

## Being cared for in hospital

In hospitals, there are specialist palliative care teams who help hospital staff to care for people nearing the end of their life.

Palliative care teams provide education, training, and specialist advice to hospital doctors, nurses and other health and social care professionals on pain and symptom control. They can help staff with your discharge plan or your transfer to a hospice, community hospital or care home.

Palliative care teams can also provide emotional support and information to you and your family or carers. They can explain to you what is going on, and also make sure you know about your rights and choices about end of life care. If there is anything you want to know, ask your doctor or nurse.

## Planning ahead for the end of life

If you have a terminal illness, or are approaching the end of your life, it may be a good idea to make plans in advance for the future of your care. Planning ahead in this way is sometimes called advance care planning. It involves thinking and talking about your wishes for how you are cared for in the final months of your life.

People usually carry out advance planning because they have a condition that is expected to get worse, which may mean they will not be able to make decisions, or communicate their decisions in the future. However, anyone can plan for their future care, whether they are approaching the end of life, or not. Advance care planning can help you let people know your wishes and feelings while you still can.

These links take you to more information on the following topics:

Why plan ahead

Find out how you and your family, friends and carers can benefit from planning ahead for your future care.

Advance statement

Find out what an advance statement is, and how you can create one to let people know your wishes.

Advance decision to refuse treatment

If you don't want certain kinds of treatment in the future, you can make a legally binding advance decision.

Lasting power of attorney

Find out how to legally appoint someone to make decisions about your care in the future if you become unable to make decisions yourself.

Coping with a terminal illness

Information, sources of support and tips from experts on how to cope with a terminal diagnosis.

Managing pain and other symptoms

Ways to start talking about the fact that you are dying

Talking to your children

If you have children, it may feel very difficult to talk to them, but talking can prevent them from being alone with their worries. Find some suggestions here.