

# Preparing for the end of life



# INTRODUCTION

When someone is approaching the end of their life, it can be a very distressing experience for those close to them. It can help to have information about:

- what to expect from the dying process
- the practical things you need to do once your loved one has died
- where you can get support

This booklet has been produced to provide that information. We hope this can make a very stressful and emotional time a little bit easier for you.

## How this booklet is organised

This booklet has three sections:

### **1 - What happens when someone is nearing the end of their life** (page 2)

Relatives and friends of someone who is nearing the end of life often want to know what the dying process actually looks like. Knowing this can make it less traumatic. In this section we guide you through what normally happens as someone is dying and what you can do to support them.

### **2 - What you need to do once a person has died** (page 5)

When someone you care about dies, it can be very hard to know or focus on what practical things you need to do. In this section we give you a step-by-step guide.

### **3 - Where you can get support** (page 9)

We sometimes need active support to cope with the intense stress of death. In this section we signpost you to sources of support at this extremely difficult time.



# Section 1 – What happens when someone is nearing the end of their life?

People sometimes feel that it would be helpful to know what stage of life their loved one is at, so that they can help prepare themselves and their loved one for what may come. It is also important as many symptoms – physical, psychosocial or spiritual – can be managed with good palliative care.

It is very difficult to predict precisely when someone's life will end. It is also difficult to generalise as not everyone will have the same symptoms at the same time, or at all. However, Marie Curie have produced a very helpful end of life stages timeline. It gives information about what might happen at different stages of the dying process. We have drawn on this and other sources of information, linked in the text, to provide the summary below.

## The last weeks before dying

Changes in the last weeks before dying are often gradual rather than dramatic. The person may:

- Sleep more – they may not want to get out of bed or often be asleep during the day as well as at night
- Eat and drink less – they may only want small amounts of food and drink as appetites decline
- Take less interest in life – they may talk less, usual interests may decline, they may welcome fewer visitors
- Need more help – they may not be as capable of washing, moving or remembering things

## What you can do at this stage

You can support the person by allowing them to take the lead. These changes can come and go over time, so let the person choose if they want to eat or not, if they want to see visitors or not, if they want to be quiet etc. If the dying person is in pain or feels upset or worried about what is happening to them, you can tell a member of their healthcare team who may be able to help.



## The last days and hours before dying

Everyone's death is unique. Some people may die suddenly or earlier than was expected. Some may show none of the signs we discuss below. However, there are some common signs that a person is dying which often occur in the last days and hours before death.

The person may:

- Respond less to your voice or touch – they may drift in and out of consciousness
- Struggle to swallow food and drink – they may cough when trying to do this or the food or drink may go down the wrong way. It is good to seek medical advice if this happens as it may be best for the person to stop eating and drinking at this stage. This is a natural part of the dying process. The body no longer needs fuel to live.
- Struggle to get to the toilet or commode in time – this can be very distressing; reassure them that this is a natural part of the process.
- Become confused or experience hallucinations – sometimes the person can be comforted by hallucinations, sometimes they can be distressed.
- Experience changes in breathing – the person's breathing can change in a variety of ways, becoming shallow, fast, slow, laboured, noisy or irregular.
- Become restless or agitated – sometimes this can indicate pain or unresolved issues or worries.



## What you can do at this stage

The most important thing you can do at this stage is to remain calm and accept what is happening as a normal part of the dying process. If the person is becoming distressed, their healthcare team may be able to help so it is important to let them know what is happening.

You can support the person by continuing to talk with them and touch them. Even if they do not respond, it can be comforting to hear voices they know and love as hearing is the last sense to go. The person may also need quiet and restful times. If they are struggling to eat or drink, an ice cube or lip balm can moisten the mouth or lips.

Your gentle voice and touch can calm someone who is agitated or hallucinating. There is no need to challenge their view of reality at this stage; instead, simply soothe them.

Sometimes the person who is dying can suddenly seem to rally – to be more alert and talkative. This is a good opportunity to share any last thoughts and to be together.

## At the moment of dying

At the moment of dying, the person's breath gets slower and more shallow. There may be long pauses between breaths. Eventually, they may take a long or gasping breath before they stop breathing entirely. Their face may suddenly relax. A few minutes later, their heart will stop beating. They have died.

Dr Kathryn Mannix has produced a short, sensitive video which re-enforces these stages of the dying process. It is available [here](#).



## Section 2 – What you need to do once a person has died

When a person has died, it is normal to feel overwhelmed and unsure of what to do. This can be a very difficult time and it is important to look after yourself.

There is actually no rush to do anything. GOV.UK provide a very helpful [step by step guide](#) to what to do. We have drawn on this and other sources of information, linked in the text, in the summary below. Our guidance is written for the nearest relative of the person who has died – their next of kin. They can of course be supported by others in carrying out these tasks.

The Bereavement Advice Centre also supports and advises people on what they need to do after a death. Further information on each of the steps below can be found on their [website](#).

### Phase 1 – Soon after the person has died (First 0 – 24 hours)

What you need to do soon after someone dies depends on the circumstances of their death. This booklet focuses on what you need to do if the person dies at home and their death is expected. Full details of what to do in other situations are given [here](#).

#### **1. A doctor needs to confirm the death**

When a person dies at home and their death is expected, you need to call their GP practice and their nearest relative, if that is not you. A doctor will come to verify the death by completing a Medical Certificate of Cause of Death (MCCD). This will be sent to a Medical Examiner for review.

#### **2. Notify other family members**

You need to inform other family members and close friends that the person has died.

#### **3. Arrange transportation of the body to its next place of rest**

You need to decide what to do with the body of the person who has died. You can call a funeral director to come to collect the person or you can make alternative arrangements if you want to. You can keep the person at home if you wish. Information on how to care for a body at home is [here](#).



## Phase 2 – Legal Formalities (within the next few days)

### 1. Receive permission from the Medical Examiner to register the death

The Medical Examiner will contact you once they have reviewed the Medical Certificate of Cause of Death, sent to them by the doctor. They will ask if you agree with what is recorded on the certificate and ask if you have any questions. This is voluntary – you do not have to speak to them. You will then be told by the Medical Examiner's office that you can register the death.

### 2. Register the death

You need to register the death within 5 days from when the Medical Examiner's office confirm the cause of death. You make an appointment with your local registry office to do this. Details of your local register office are [here](#). Information about what to take with you to the appointment is [here](#).

### 3. Use the 'Tell Us Once' service to inform organisations of the death

The 'Tell Us Once' government service allows you to report a death to multiple central and local government departments, such as the tax office (HMRC) and the Department for Work and Pensions, at the same time. The registrar will provide you with a unique reference number to use the service online or by phone. The 'Tell Us Once' service does not communicate with private organisations such as banks and utility companies. You need to inform these separately.



## Phase 3 – Make arrangements for the funeral

### 1. Follow the wishes of the person who has died, if possible

The person who has died may have set out what they wish to happen to them after their death. This could be part of an Advance Care Plan or a letter of wishes or they may have talked with you informally. They may have recorded their wishes in a will, if they made one. They may have paid into a funeral plan and made their preferences known. It is important to follow the wishes of the person who has died if you can.

### 2. Decide how to organise the funeral

Many people use a funeral director to organise the funeral for them. You can find a funeral director in your area by using the [Funeral directory](#). Other people organise the funeral themselves. Advice on how to do this can be gained from the [Natural Death Centre](#).

Whatever route you choose, you will need to consider both what would be appropriate and what is practical and affordable. [MoneyHelper](#) has helpful guidance on the essential elements of a funeral and other elements people often include, together with the typical costs.

Decisions can be complex and the raised emotions following a death can lead to family disagreements. You should be assured that these differences are normal, as everyone tries to cope in their own way with their loss.



## Phase 4 – Dealing with ‘the estate’

‘The estate’ is the name given to everything owned by the person who has died. It can be made up of money, property, personal possessions such as a car and so on. There are several steps involved in dealing with the estate.

### 1. Find the will if there is one

The estate is usually passed on to relatives, friends or others, according to instructions the person left in their will. An executor usually deals with the estate of the person who has died. The person who has died will have named their executor in their will. An executor may have to apply for probate. This is a legal document which gives the executor the authority to deal with the estate. If there is no will or in some other special circumstances, an administrator will deal with the estate.

### 2. Decide whether to use a solicitor

Dealing with the financial affairs of someone who has died can be complex. Guidance on the process can be found [here](#).

You do not legally have to use a solicitor to apply for probate. However, you can ask a solicitor to manage the process for you. This is particularly useful if the estate is large or complex or if you wish to reduce your own stress and avoid errors.



## Section 3 – Where you can get support

Hospice UK tell us that many people rely on friends and family to support them through the death of a loved one. However, it is not always possible to find the right kind of support from those who may also be grieving. They may themselves not know the information you need.

Hospice UK gives guidance on when and how to get support outside of family and friends. The list below also gives details of different types of support you can access. There are many different sources, from information about how to organise a funeral, group counselling or one-to-one counselling over the telephone and so on. Availability varies by local area, but the information below is a good starting point.

- CRUSE bereavement support – gives information about the grieving process
- Good Grief – a library of resources and directory of support organisations
- MIND – advice on mental health
- National Bereavement Service – advice on how grief can be managed
- NHS advice on grief, bereavement and loss – ideas of what you can do to help with grief
- The Good Grief Trust – run by the bereaved to give support to others
- Sue Ryder's Grief Guide – to help people understand and cope with grief and bereavement.
- What is grief? – a 6-minute video by Julia Samuel exploring the personal nature of grief and how to be self-compassionate and seek support where needed.
- Widowed and Young – a peer-to-peer support network for anyone aged 50 or under when their partner died.

The following organisations provide someone to talk to about grief:

- AtaLoss – provides a list of bereavement support services, articles and resources. They also offer a live chat with a counsellor for urgent needs.
- The Marie Curie helpline – provides ongoing support over the phone.
- Sue Ryder Online Bereavement Support – provides various kinds of bereavement support.
- Hospice UK – details how to gain support from your local hospice.



We hope this booklet provides you with some of the information and support you need at this present time. We also hope it encourages you to talk openly with professionals and the ones you love about life, death and grief.

“Of course, saying goodbye to people we love is sad, but knowing what to expect takes away a lot of the fear. I’ve met so many bereaved people who wish they had talked about dying more. I’ve never met a person who regretted having those important conversations. We need to talk about it, because talking about death will help us to live together better.”

Kathryn Mannix, Dying for beginners.

