

This publication was funded by the Department of Health as part of the Health and Care Voluntary Sector Strategic Partner Programme, enabling voluntary and community sector organisations to work in equal partnership with the Department of Health, NHS England and Public Health England.

June 2017
© Age UK



Foreword

As chair of Age UK and the Malnutrition Task Force I'm delighted to have been asked to write the foreword of this book.

We all seem to find it difficult to have conversations about dying and death. It's an intergenerational thing. We know this because of our social research, which gave us some surprising insights – it seems that we can all talk to our peers but not to our families.

This book is designed for everyone; to help us start to talk to our family and friends, grown up children, and our grandchildren.

Coping with death is an intergenerational challenge – this book provides a narrative that matches the illustrations and can be used in various ways – perhaps as a picture book to discuss with young children using your own words and explanations or as a tool for young people and whole families.

This book is designed to start conversations to help everyone to feel empowered and positive to talk about death, to be confident to question each other and thereby being sure that all our loved ones worries about dying and death are acknowledged. This will support us all to have the knowledge and ability to challenge systems and organisations to ensure that everyone has the best death possible.

We have also made a film as a companion for our book. It can be found on the Age UK and MTF websites www.ageuk.org.uk and www.malnutritiontaskforce.org.uk

With grateful thanks to the department of Health Strategic Partners Fund and NHSE end of life team.

This resource is available to all – we would very much like to hear how you have used it. Do email Lesley.Carter@ageuk.org.uk with your experiences.

Dianne Jeffrey

CBE DL (Chairman of Age UK and Malnutrition Task Force)

Why is it we find it so difficult to talk to each other, our older relatives, our grown up children, young people, children and our grandchildren about what worries we all have about dying? Or about others dying and what may happen to those left behind?

Having conversations with people you love about dying and death is difficult. It brings up many uncomfortable emotions so we tend to shy away from it.

This booklet is designed to help start those conversations. To help everyone to feel empowered and confident to talk about death, to ask questions of each other, to listen, to be sure what all of our loved ones would like to happen when death comes. And have the knowledge and ability to ask the right questions to understand and challenge systems, organisations and health care professionals about the care and support of a loved one who is dying.

We have illustrated this book to allow you to use this, as a device to open up and guide conversations about death and dying for all age groups. Coping with death is an intergenerational challenge.



Why is it important to talk?

Having this kind of conversation early on will ensure that everyone feels they have been able to be part of a discussion and they know what is going on.



Talking about dying, before you need to, can help you and the people you love to be able to accept and have an unpressured conversation about fears and wishes connected with dying. Being able to talk gives us all the opportunity to share openly about any worries, fears or wishes that we have. We can discuss in our own time and in ways that we know they will understand about dying, our own death, their death, being with someone when they die, asking what they want and knowing what to expect and what to do.

Conversations give the opportunity to prompt so that wills are prepared and finances are settled and other wishes can be discussed, for example, around life support machines, organ donation, cremation, burial or about what kind of send-off we would like.

Some organised people buy funeral plans so everything is arranged and families don't have to worry financially or that they are forgetting an important part.

Having these conversations early on will sometimes help smooth family dynamics that can become problematic as families live far and wide and are made up of many complicated parts. This is particularly helpful when thinking about any care that could be needed.

This is because everyone has the chance to know what to expect and that families have had the opportunity to talk and make informed choices together. Everyone knows what that person wants around care needs and support, pain relief, nutrition and hydration and families can learn together what to expect at death, for example about physical changes that happens to our body and why.

What about the children and grandchildren?

We should remember to include children in any conversations as they are very much a part of the loss but are often overlooked.

Grandparents often have a special relationship with their grandchildren. Often grandparents would like to talk to the grandchildren but the parents don't feel comfortable and discourage it. Grandparents talking to their grandchildren when they are very close can be beneficial – they can talk about death in an everyday manner.

Sometimes adults hesitate to bring children into the conversation. They think they are protecting them when, in fact, they might be protecting themselves, and, sensing this, children may not ask the questions that are important to them.

The truth is usually less scary than a child's imagination. Think about how to let children express their feelings. Don't let them feel excluded.



Barriers to having conversations about death

We know from our research that older people are more able to have conversations about death and dying with their peers than they are with their younger friends and relatives.

Younger adults don't want to start conversations – even about wills. Sometimes they worry that they may be seen as money-grabbing. They are also more likely to shut down conversations with their older friends and relatives who are trying to bring up the subject.

'Oh don't talk like that you will be around for years yet'

can be a conversation stopper – it's quite hard for an older person to continue.

We also know that people generally don't think about death until it touches them – before they may have fleetingly thought about the emotional side of losing someone close to them.

We hear from people who have had an experience of a death that they wish that they had been more prepared for, particularly in conversations around what to expect physically when someone dies, what to ask health care professionals and how to challenge and navigate the health care system.

People are worried about starting conversations that they may upset or offend others. We become frightened about what we may hear and become anxious that we may not be able to handle emotionally the conversation about fears and feelings and feel very awkward about mentioning important personal issues such as toilets and keeping clean.



Preparing to talk

You will have an idea of why you want to start the conversation – because it is something you feel needs to happen because of a personal need, arising family issues or family misunderstandings. It could be in response to a terminal diagnosis where support is often provided by the hospital or that death is front of mind because of a bereavement of someone near.

It could be that the opportunity just arises, for example:

'I will miss Madge my walking partner. I was very sad to see how distressed her daughter Sally was when she died – Sally had found it very difficult, it was quite unexpected and she was only ill for a few weeks and died in hospital. I know that Sally feels she could have done more – she didn't feel that she understood the process of care in the hospital and didn't really know what her mum would have wanted.'

You might find the right moment comes unexpectedly, maybe when out for a walk, or over a meal, or a glass of wine. Or you may just need to guide it to happen or you may need to plan the place and time and make arrangements and plan what you want to say – it will always be different.

In a planned conversation thinking about what you wish to achieve in advance can help to control the apprehension and stress that you may feel and gives you the confidence to keep the conversation going even if the other person seems to want to close it down.





What might you want to talk about?

There are lots of questions to think about.

How will everyone cope without me?

How will I cope without them?

What about my cat, my grandchild?

I need to talk about my guilt or shame about something that happened in the past.

Why can't my daughter accept that I am dying?

I want to stop treatment, how can I tell my family?

How could I make the decision to turn off life support machines if I don't know what you think?

If you are thinking about these issues, it's very probable that others are too.

Sometimes when we think about death we worry that we may be tired or cold, thirsty or hungry, in pain, wonder how we will go to the toilet or maintain our personal hygiene? What if I need a hug or my hand held and no one knows? Sometimes we become afraid of a hospital admission or living in a care home because of the negative stories in the media. We wonder will I be able to speak up for myself? Who will speak for me and how will they know what I need?

Dignity and hygiene are very important and a difficult subject to navigate – going to the loo and keeping clean when dependent on others. Who would you feel comfortable helping with personal hygiene and who would you not?

There are uncertainties and fears about the effect medication, illness and pain has on what we say and sometimes this means we might make comments that are hurtful or unkind to the people we love. We may worry that the person left behind will always be hurt by our words. Recognising this in a conversation beforehand could save a lot of heartache.

We all have concerns about being brave pretending all is ok when it's not. We often worry about how our own feelings will behave. We might have concerns that we won't be able to say the final goodbye, or that people watching on feel that they may cry or become angry when their loved one is dying.

Not doing the right thing and not knowing what to expect, not understanding the care, not being able to speak up if they are worried. All these feelings are very normal and are good to share.



How to say it

There are no right or wrong ways - the conversation will be different for all of us.

Leading questions can help and you will intuitively know what would be the best line for you and your family.

'Have you thought about making a will, who would you want to have that lace tablecloth that was made by your grandmother it's so beautiful.'

'Have you thought about what kind of service you would like at your funeral? Would you like it to be like Uncle Percy's – all of us joining in with I did it my way?'

'I have been thinking recently, if you become very ill, would you like me/us to sit with you and chat or listen to music, to hold your hand. Do you have any worries about how we could look after you at home or if you needed to go into hospital how that would be for you? If there ever comes a time when you want to talk about something if you feel frightened, please do tell me.'

'Do you think your dad will be there waiting for me when I die – did you know dad and me used to talk about that. I'd like it if he was there.'

'Molly (granddaughter) and me are very close – what can we start to tell her to help her understand about me dying?'

'I worry about how you will manage when I die... You have been a good daughter and I am proud of you.'

Often in situations we find difficult we tend to search for the right or clever thing to say, or make a joke of it. Such reactions are very understandable – and you will know if it works for you and yours. Humour has an important place too, even in death.

Dying is a profound process that just needs us to be there, we don't have to talk just to be.





Everyone is unique and will die differently.

The next part of this booklet covers some useful information that we hope will provide answers about anxieties and worries. These are some of the issues that were highlighted by the participants who took part in our research and will help you guide intergenerational conversations about death.

Personal care, physical and psychological needs, pain relief, food and drink are often matters that cause the most fear, upset and conflict among families with someone dying at home in care-homes and hospitals. This is often caused by lack of understanding, knowledge and communication between family members and healthcare professionals.

Eating and drinking

It is normal for people nearing death to have a decrease in appetite and thirst, wanting little or no food or fluid. This is because the body will begin to conserve energy.

When a person wants little or no fluid or food, good mouth care and keeping mouth and lips moist will be enough to keep them comfortable.

Sometimes people visiting or around the bedside find this hard to accept and feel that they are not getting the care they need unless they are on a drip. Often with anxieties running high, relatives and friends appear rude and staff can be perceived as uncaring and matter of fact.

Sometimes staff do not share the care plan that they have for the patient in a way that the upset and anxious family can understand. It will be helpful to have a clear conversation with staff so that everyone understands what is going to happen, what to expect, what would be best to keep their loved one pain free and calm.



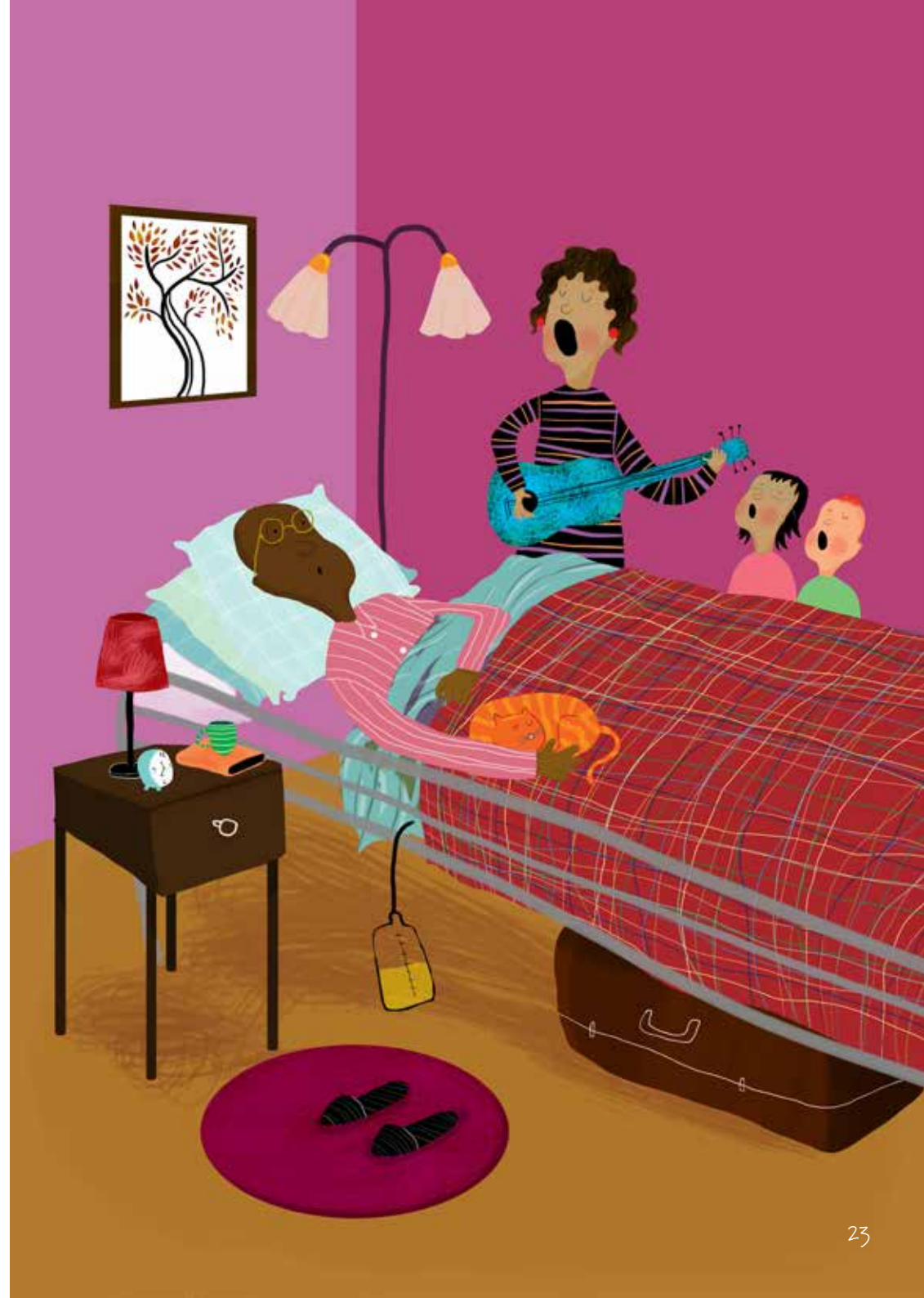
Physical changes

Sometimes when we don't know what to expect a situation can become harder and more frightening. If we understand the physical changes that can happen to a body when a person dies it might take away some of the fear.

As people come to the end of their life their bodily functions slow up and start to gradually close down. It will be different for everyone.

Here are some of the ways that the body prepares its self for the final stages of life:

- Your loved one may spend an increasing amount of time sleeping, and appear to be unresponsive and may be difficult to rouse. This is because of changes in the metabolism of the body.
- Never assume the person cannot hear; hearing is the last of the senses to be lost.
- They may make restless and repetitive motions such as pulling at bed linen or clothing. This often happens and is due in part to the decrease in oxygen circulation to the brain and to metabolism changes.
- In moments of waking they may seem confused about the time, where they are, and identity of people around them – this sometimes could be their nearest and dearest.
- Gently remind them who they are, if they remain confused just go along with it.





You may notice...

- The person's colour of skin may change. Their hands, arms and feet might feel cool to the touch, this is because the circulation of blood is decreasing to the body's extremities and being reserved for the most vital organs.
- It is normal for people nearing death to have a decrease in appetite and thirst, wanting little or no food or fluid. This is because the body will begin to conserve energy, which is expended on these tasks.
- The person's urine output normally decreases. This is due to the decreased fluid intake as well. Sometimes a urinary catheter is used to keep the person comfortable.

You may hear...

- Regular breathing patterns change. They may develop a different breathing pace. These patterns are normal and indicate a decrease in circulation in the internal organs.
- Sometimes you may hear gurgling sounds coming from their chest and these sounds may become loud. This change is due to an inability to cough up normal secretions.
- The sound of the congestion does not indicate the onset of severe or new pain.
- The sound of the noisy breathing is like snoring. It doesn't disturb the person, more those around them.
- The person may become unresponsive and withdrawn. Since hearing remains all the way to the end, speak to your loved one in your normal tone of voice, identifying yourself by name when you speak, hold his or her hand, and say whatever you need to say that will help the person let go.

Coming to the end

They may tell you...

The person may speak or tell you they have to have spoken to friends or family who have already died; they may tell you they have seen places not visible to you. Often the person will feel quite reassured by this.

This does not indicate a hallucination or a drug reaction. This is very common, the person is beginning to detach from this life and preparing for the transition.

Let them go...

Giving permission to your loved one to let go, without guilt for leaving you, can be difficult. Saying good-bye is your final gift of love to the person you love. It achieves closure and makes the final release possible.

We can help the final release – in your own words, it could be:

...Just be holding their hand telling them that you love them.

...Describing favourite places and memories that you have shared.

...Thank them for being them.

...You may have other things that you need to say about past times.

Tears are ok and do not need to be hidden. Tears are a part of saying goodbye. Tears express your love and help you to let go.



How will we know they have died?

Breathing will stop, there will be no heartbeat and there will be no responses.

Eyelids will be slightly open and the pupils enlarged and the eyes will be fixed on a certain point with no blinking.

The jaw will be relaxed and mouth slightly open.

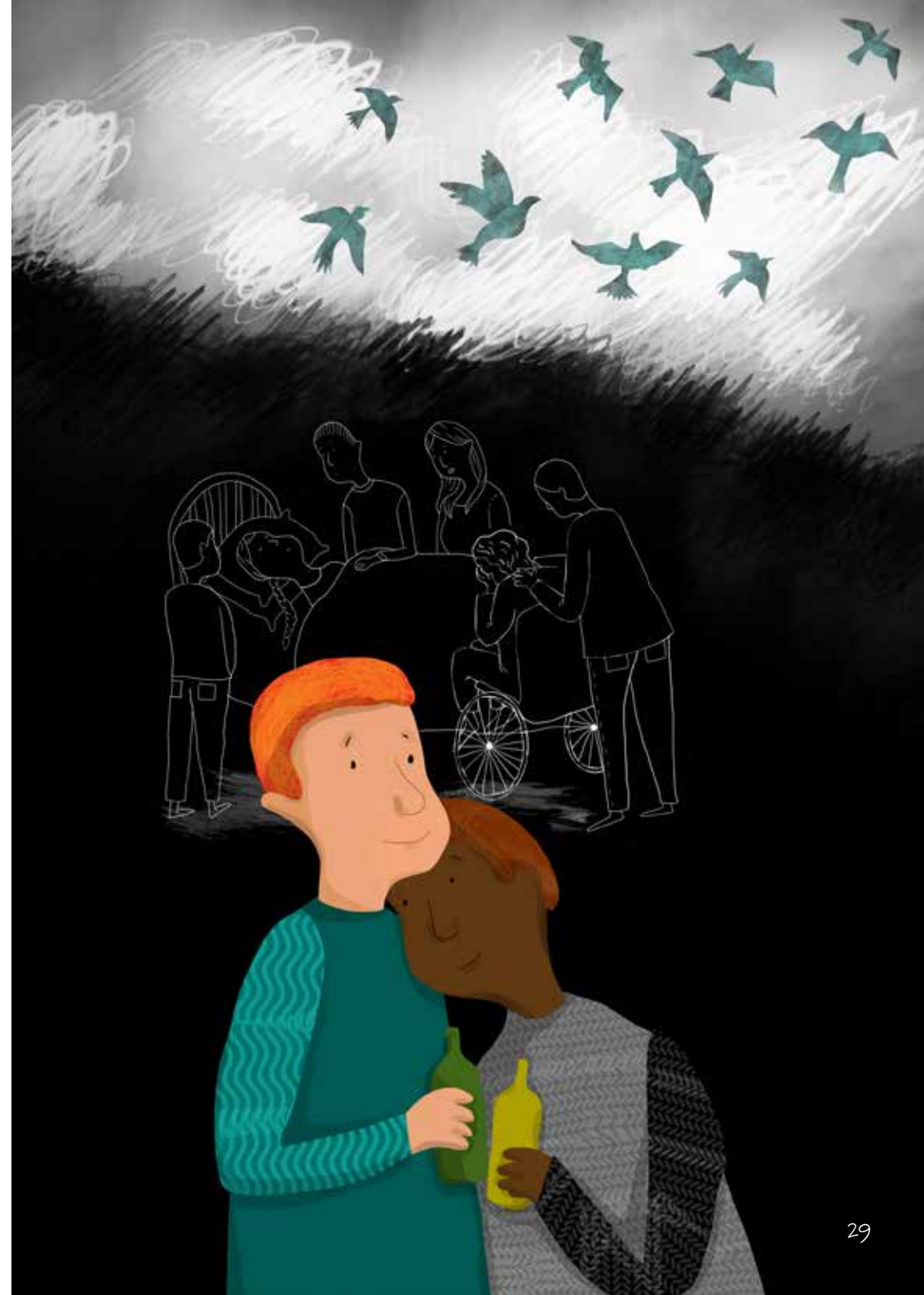
Sometimes there will be a discharge of the contents of the bowel and bladder.

What's next?

The expected death of a loved one is not an emergency. Nothing must be done immediately.

Take some time; come together if there are several people around the bed. Give everyone the opportunity to do what feels right for them.

We will all act independently and sometimes individual's reactions can be unexpected away from the norm. Try not to judge – we will all have our own way of grieving.



Death at home

When you are ready call the GP or the Palliative Care Team who has been supporting you.

If the death was expected, the doctor will give you a medical certificate showing the cause of death. (They'll also arrange for a formal notice to be collected explaining they've signed the medical certificate and telling you how to register the death.)

Call the funeral directors. They run a 24 hour service and will come out at any time.

Some people like to wash and change their loved ones before they are moved from their home. You might want to do this yourself but it isn't necessary. The funeral directors will do this and they will discuss their role when they visit.


In a hospital or nursing home

If your loved one dies in a hospital the Hospital Doctor will certify the death. In a Nursing Home it will be a GP or Registered Nurse. The staff will usually wash and lay out the body – you may help if you wish. The body will be taken to the mortuary until you arrange for collection by the funeral directors and taken to the chapel of rest.

What to do after they are gone

If someone dies unexpectedly, or the family doctor hasn't seen them in the last 14 days, the death is reported to a coroner. A coroner is a doctor or lawyer responsible for investigating unexpected deaths. They may call for a post-mortem or inquest. This may take some time, so the funeral may need to be delayed.



An illustration of a diverse group of people of various ages and ethnicities looking up at a starry night sky. The sky is filled with numerous small, bright stars and larger, glowing golden-yellow spots. The people are standing on a dark, textured ground, and their silhouettes are highlighted against the bright background. One person in the foreground is seated in a wheelchair.

The practical jobs after someone has died

There are usually a lot of administrative jobs that have to be done after someone has died.

It can be hard to know what needs to be done. There is a lot of information on the Age UK website about the order things need to be done as well as the timescales.

www.ageuk.org.uk/money-matters/legal-issues/what-to-do-when-someone-dies2/

Age UK also has a lot of practical information available about registering the death, funeral planning, Wills and how to handle an estate. Have a look at the website or call the Age UK Advice Line **0800 169 2081**.