

What to expect in the last few days of life

Sue Ryder

Contents

Introduction.....	3
What are the signs that someone is close to death?	4
How long does death take?.....	6
What can I do to help?	7
Can friends and family be there when the person dies?	7
What happens immediately after someone dies?	8
Confirming that the person has died	8
Caring for their body.....	9
How can I plan for the end?	10
Where can I find support?.....	11

Introduction

People often tell us that they are worried about what will happen when they, or the person they love, is close to death. They ask us what they should expect. Each person's experience is unique, but for most people with a terminal illness, they are peaceful and comfortable when they die. They are not in pain and they are not anxious or distressed.

Although everyone is different, there are some common things that happen as part of the natural process of dying. At this stage, the person who is dying is often unaware of many of these things, but it can help those who care for them to know what to expect. This guide is written with carers in mind.

If your loved one is being cared for at home rather than in a hospice, please speak to a healthcare professional in advance for further information and advice on what to expect immediately after someone dies at home.

"All deaths are different, all families are different, all relationships are different."
Sue Ryder Hospice Ward Manager

What are the signs that someone is close to death?

Just as you and the people you love are unique, so is each person's experience of dying. Some of the things which often happen are:

- wanting to eat and drink less, or not at all
- withdrawing from the world
- sleeping more or being semi-conscious
- changes in breathing
- restlessness and agitation
- cold hands and feet

It can be very difficult to see these changes happening to someone you love, but they do not mean that the person is uncomfortable or in distress. The changes are a natural part of the dying process, and the healthcare team will do everything they can to ensure that you and your relative or friend is as comfortable as possible.

Wanting to eat and drink less

People who are dying do not seem to need as much energy from food and therefore do not need to eat and drink as much as someone who's well. Seeing someone you love stop eating can be very difficult and hard to accept, but this is a natural part of the body slowing down. The best thing to do is to let the person eat and drink as much or as little as they want, even if it is only a teaspoon. It's fine if they don't want anything at all. Sometimes people stop eating days or even a couple of weeks before they die.

Sometimes a person may have trouble eating and swallowing, and if this is the case the healthcare team may be able to make suggestions to help them.

"Dying is completely unique to each person. There are some normal things you see, but everyone is different. I've seen people who don't eat at all for days and one man I cared for was eating full meals up to the end."

Sue Ryder Hospice Ward Manager

Withdrawing from the world

As people become close to death they often seem less in touch with what is going on around them. They may talk less and not be able to concentrate or do things they would normally do, like reading the newspaper.

Sometimes a person can be quiet all day whilst their carer is with them, but brighten up and chat more when someone who is not so close to them comes to visit. This is just a sign that they feel safe and comfortable with the person who is caring for them, but don't have the energy to sustain that level of social engagement.

Sleeping more or being semi-conscious

People who are dying may become drowsy and sleep more and more of the time. Even if they do not seem to be awake, they may still take pleasure from hearing a loved one's voice or the usual sounds of life such as music or favourite TV shows. You can provide care and reassurance by continuing to talk to them, holding their hand when you sit with them, and telling them when you enter or leave their room. This can be a good time to give them permission to let go and to say goodbye. It is also important not to say anything that you wouldn't want them to hear. People who are towards the end of their life may be asleep or semi-conscious in this way for between two and three days, or sometimes longer.

Changes in breathing

Often people's breathing changes quite a bit in the last days and hours of life. It can become more laboured, or their breaths have a pattern where they become more rapid, then slow right down with long seconds when they don't breathe.

Their breathing can become noisy and make a rattly sound. The rattling sound is caused by a build-up of fluid at the back of their throat. Although this can be distressing to hear when you love someone, it does not usually cause any discomfort or distress to the person. Sometimes propping their head up on a pillow and turning it to one side may help the fluid to drain away.

These changes in breathing might start five minutes before someone dies, or can go on for 24 hours or more - everyone is different.

Restlessness and agitation

Sometimes people can become restless or agitated shortly before their death. Their doctor or nurse will make sure they have the medication they need to ensure that they are not in pain, anxious or frightened.

Cold hands and feet

In the final hours, the person's hands or feet may become cool to touch and become paler or bluish in colour. This happens because their circulation is slowing down. They may like a blanket or thick socks that can help to keep their feet warm.

How long does death take?

Dying is a natural process that is unique to each individual and no one can tell you how long a person's final days or hours might be. It can be very hard to see some of the different signs and not know what is happening or when the person might die.

We need to remember that we still can't fully explain what is going on in a person's body and mind as they reach the end of their life. People who care about them can still be a support to the person by letting them know that you are there, talking to them and holding their hand.

What can I do to help?

There are lots of things you can do to make people as comfortable as possible in their final hours.

- Using pillows or cushions to support people, or simply changing the position they are lying in can help people to get more comfortable. Sometimes people are difficult to move and the healthcare team will help with this.
- Sometimes, if people feel achy in a particular part of their body, you can ease the pain using warm or cold pads.
- Simply holding the person's hand can calm and reassure them. Complementary therapists can give tips and teach carers how to do a simple hand massage.
- Often the person can find it calming just to have you there and to know that you are calm and not anxious.
- Carers can give oral medication if needed, so it is important to know and understand the medications the person is taking.

If you are looking after someone at home, the specialist community nurse, district nurses, and the GP can help and advise you on making the person as comfortable as possible.

Can friends and family be there when the person dies?

It is often a big question for people whether friends and family want to be there when the person dies. People often say that they want to be present, but there is no right or wrong answer. Because it is hard to know when someone might die, it can also be hard to make sure that someone who wants to be there can be.

If your friend or relative is in a hospice and you want to be there, the healthcare team will do their best to make sure you can be there and to look after you whilst you are with them.

What happens immediately after someone dies?

Even though you know the person is dying, and you can try to prepare yourself, it is hard to know how you might feel when they actually die. Some people feel shocked or numb, whilst other people might feel overwhelmed with sadness, or even anger. It is also normal, particularly if it has been a long illness, to feel a huge relief. You may find it helps if you have already thought of someone you can call who can be with you and support you at this time.

Although this is likely to be a very emotional time, there are still some formal things that need to happen. The first is confirming that the person has died. This is called verifying the death.

Confirming that the person has died

If your friend or relative dies at home, you need to call the GP or out-of-hours service within two or three hours of the person dying, and a doctor will come as soon as possible to confirm that the person has died. If your friend or relative dies in a hospital or hospice, the staff will organise for the death to be verified (nurses can verify an expected death).

There are some things that need to be done to confirm the death, and some people prefer to leave the room when this is happening. This includes checking the person's pupils for any reaction, checking for breathing and listening for their heart sounds with a stethoscope.

Although nurses can verify someone has died when their death was expected, only a doctor can give you a 'Medical Cause of Death Certificate'. You will need to take this to the registrar in order to register the person's death. You will also be given information about 'Duties of the Informant' which explains all the things that the registrar will ask you.

There's more information about registering the death in our leaflet 'What needs to be done after a loved one dies' (ref. SRC459).

Caring for their body

If you are in a hospice or hospital you can normally spend some time with the person after they have died and you can call your family, or anyone who needs to, to come in. Sometimes people want to be left alone to spend some time with and say their final words to the person. Sometimes they find it comforting to have a member of staff with them.

Once the death has been verified, if there is a mortuary at the hospice or hospital, the person's body may be moved to the mortuary, or, if there is no mortuary on site, the funeral director will collect their body.

If the person has died at home, you may need to follow additional advice given to you by a healthcare professional in advance about caring for their body. You can keep their body at home until the funeral if you choose, or the funeral director can take it to their funeral home. The funeral director can help you to look after the body at home, or if you choose to have their body cared for at the funeral home, you can still visit them there.

If you haven't already arranged a funeral director, the hospice or hospital will have a list of funeral directors you can contact. There's more information about organising the funeral in our leaflet 'What needs to be done after a loved one dies' (ref. SRC459).

"After someone dies, people can find it comforting to stay with them, but they may feel uncomfortable touching their friend or relative's body. Sometimes I sit with them and hold the hand of the person who has died and the hand of their relative or friend, so that I'm connecting them."

Sue Ryder Hospice Ward Manager

How can I plan for the end?

Even though you know your friend or relative is dying, your first reaction when the death occurs is likely to be shock. You may find it hard to think clearly and to work out what you need to do.

The best thing is to have a really clear plan in place for immediately after your friend or relative dies. Think through issues such as who you will ring to come and support you and what you might need to do if you have children at home. If you have made a plan for these things, then initially you can follow it almost as if you are on autopilot.

For more detailed guidance on what happens in the following days, see our leaflet on 'What needs to be done after a loved one dies'.

“It’s comforting to know that you’re not alone”

When someone you care about is dying or has died, it’s comforting to know that help is never far away. Sue Ryder’s Online Community is a safe place to go for free, 24/7 practical and emotional support when you’re coping with the loss of a loved one.

Available from your computer, tablet or mobile and moderated by Sue Ryder, our community is there to support you whenever and wherever you need it.

Join our community at www.sueryder.org/support



Contact us

call: **0808 164 4572**

email: **healthandsocialcare@sueryder.org**

visit: **www.sueryder.org**



/SueRyderNational



@suerydercharity

This document is available in alternative formats on request.

To give feedback on this leaflet,

Please contact **healthandsocialcare@sueryder.org**