



# WHAT TO EXPECT WHEN SOMEONE IMPORTANT TO YOU IS DYING

*Information for families, friends and carers*



**'always there to care'**

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## How this booklet can support you

The aim of this booklet is to help you to understand what is happening in the final days and weeks of someone's life, to help you feel more prepared for what to expect and less worried.

Sometimes this information can be difficult to take in, particularly at a time when you may be experiencing a range of emotions. This booklet is a way of offering you information which you can read in your own time, or share with family and friends who were not part of conversations around these issues with staff.

When someone important to you is dying, we understand you may have questions, concerns or feel that extra information would help you understand what is happening at this difficult time.

You are welcome to ask the care team questions at any time, or express any fears or worries you may have—we are always here to listen and answer your questions.

You and the person we are caring for can expect to be treated with respect and compassion by all members of the Lindsey Lodge Hospice team at all times. It is important that you feel able to talk to us about your needs and how we can meet them and offer the support which is right for you.

## Recognising the possibility that someone is in the last days or weeks of life

There are no precise ways of telling accurately when someone is approaching the last weeks and days of life, so it can sometimes be difficult to recognise when someone is dying.

The nurses and doctors look for a number of changes in the person's condition such as increasing weakness and sleepiness, a reduction in eating and drinking and difficulty taking medication.

They will take into account how quickly these changes are happening and whether there is any other reason for them. Whilst many people deteriorate at the same steady pace, for others change can happen suddenly and unpredictably.

## What to expect when someone is in the last days of life

Symptoms in the last days of life are often similar no matter what the underlying illness, whether it is cancer or a chronic condition like heart failure.

### Changes to medication

If it is felt that someone may be in the last days of life, we will review their medication and treatment to ensure that the focus of their care is on comfort, safety and dignity. If the person we are caring for is able to discuss what is important to them— for example being awake as much as possible, or having no pain— then we will talk this through with them, and the team will carefully consider what treatment is going to provide the most benefits for that person.

Some medication may help symptoms and will be continued as long as possible. Others may no longer be helpful, or may cause unwanted side effects, in which case they will be stopped. Medications that become too difficult to swallow will be stopped or given in a different way. Many medications that are helpful in controlling symptoms can be continued in an injectable form using a small battery driven pump called a syringe driver.

A syringe driver delivers a steady continuous amount of the medication required under the skin. The medication is absorbed from there into the body in the same way that medication from a tablet is absorbed from the gut into the rest of the body. Various medications can be put in a syringe driver and the dose changed as needed.

The doctor will prescribe medication to be available to relieve pain, sickness, breathlessness or anxiety, if they occur. These can be given either orally or by a small injection under the skin (subcutaneous injection).

If multiple doses are needed to control a symptom then we will give the medication regularly to try and stop the symptom from recurring. Small doses of medication are used to start with, and doses are altered according to the person's needs or any side effects.

### Sleeping

The biggest change that you will notice is that the person will sleep for longer and longer periods, during the day and night, as they approach the end of life, until they are sleeping most of the time.

This sleep will eventually deepen until they may not always respond to you and the person may become completely unconscious. This can be for a short period or several days. This is part of the natural dying process, rather than being caused by medications.

Despite not opening their eyes, the person may still be able to hear you, or sense you being close to them. It may be reassuring for them to hear your voice just by talking or reading to them, smell familiar scents or hear music, or television programmes they like. Sometimes families feel that the person would simply want peace and quiet.

### **Eating and drinking**

As a person becomes weaker and approaches the end of their life their appetite for food and drink usually steadily decreases. This is normal, but can be difficult emotionally, as we often want to give the people food to help them feel better. Sadly, when someone is dying food does not make them feel better.

When someone does want to eat it may help to try smaller amounts, have foods that are softer and easier to swallow, or melt, like ice lollies or ice cream. When we are caring for someone, we will offer them food and drinks regularly as long as desired by the person and as long as this is safe for them to swallow. As time goes on, their appetite will normally disappear.

We do not often give fluids artificially through a 'drip' when people are in the last days of their life, as it does not normally help symptoms, including mouth dryness, or prolong life. We will ensure they are as comfortable as possible by regularly moistening their lips and mouth and regular teeth cleansing.

This is something that friends, family and carers can help with if they wish. If you would like to do so, please ask a member of the nursing team and they will show you what to do. If you have any concerns about your relative/friend not eating or drinking, please don't hesitate to speak to a member of the nursing or medical team.

### **Restlessness**

Sometimes people in the last days of live can experience episodes of restlessness or agitation.

If this happens we will look for a cause, such as pain, anxiety, the need to change position or pass urine and will address that cause. If no cause is found and the person does not settle, we may give a small dose of sedative medication. Other things can help, like familiar people being with them, keeping surroundings calm and well lit, providing reassurance as often as needed and not correcting the person if they make statements.

## What to expect when someone is in the last days of life

### **Changes in breathing**

Occasionally in the last days of life there can be a wet noise when the person breathes in and out. This is due to a build-up of mucus or saliva at the back of the throat, which they are no longer able to cough up or swallow. Whilst this noisy breathing can sometimes be upsetting to hear, it usually does not distress the person themselves. Changing the person's position can help and sometimes medication may be used if the noise is distressing.

There may also be changes to their breathing pattern. It can become very fast, slow or irregular. Sometimes there may be long pauses between breaths.

As their friend, relative or carer, you may find some of the changes to the sound or pattern of their breathing worrying, but these changes usually don't cause any discomfort to the person. They are a sign that time is getting shorter. If you feel there is distress, please let us know and we will review this together along with their comfort and medication.

## Things to consider

The experience of someone dying is different for everyone, and everyone approaches it in a different way.

### **Being there**

Some people talk to their families and friends about whether they would like people with them when they die, and who that is, or some feel they want to be alone. If this has not been discussed, then you can think about what feels right to you.

It is okay to want to be with the person all the time, and it is okay not to want to be with them. If someone is unconscious, some people wish to be with the person, and some feel there is no value in this; again, this is a personal choice with no right or wrong approach.

If it is important to the person, or to you, to be with them at the point that they die, or not to be with them at this point, please let the team know so we can get this right for you.

If you would like to stay overnight, either with them or in a separate room, please speak to a member of the nursing team so they can make arrangements for this.

Usually, when people are dying they undergo steady physical changes, in the way they look, their skin tone and breathing pattern. However, sometimes people can die suddenly. If they had wanted you to be there (or you wanted to be there) at this point but if this doesn't happen, please don't blame yourself. You will have tried as hard as you possibly could. If you would find it helpful to talk to a member of our team about the emotions you are experiencing, we are happy to support you.

### **Talking to us about the things that are important to your relative/friend and to you at this time**

This might be around spiritual or religious needs that we can help facilitate. It may be about the person's interests and their preferences for things such as their appearance, sleeping position and bed covers, music or lighting. If there are things you feel are important, no matter how small, then they are important to us too.

Please feel free to bring in photographs, music, favourite things, even pets. If it is important to have quiet together time, or for you to be physically closer to the person then please let us know and we will do our best to make it happen.

You may have been involved with physically caring for the person until this point. If you would like to stay involved, or step back, please talk to us about it so you are involved as much as you want to be.

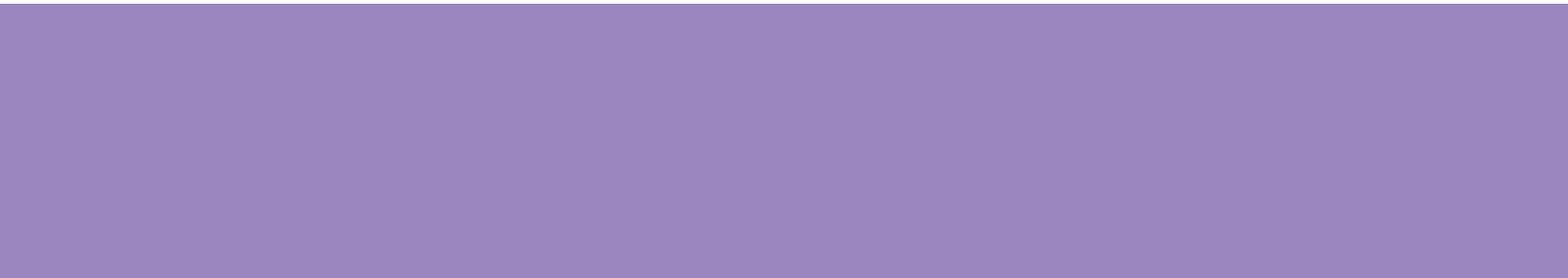


## **Tissue donation**

We recognise it may be difficult for many people to think or talk about tissue donation, particularly at this time. However, if the person has already arranged this, it is important we know about it before they die so we can work with you to make it happen.

Although people with a terminal illness are not usually eligible to donate life-saving organs like kidneys, corneal donation is often possible, which can restore a person's sight, or tissue donation for medical research, sometimes related to the disease that affected them.

If you feel your relative/friend would have like to donate tissues, or wish to know more about this, please speak with a member of our team.



## When the person dies

### **The final moments**

In the last few minutes the person's face muscles may relax, including their jaw and their colour may go pale. Occasionally the face muscles momentarily contract before relaxing again and this may happen more than once.

Sometimes it is obvious when someone is taking their last breath and sometimes there can be a few last breaths that are like small gasps for a minute or two. The person's breathing will eventually stop and then often their body relaxes.

This is a deeply emotional moment, even when death has been expected for a while, and people feel and react in very different ways. It may feel right to sit there and be with the person, or leave the room. There is no need to let the nursing team know until the time is right for you. For some this is immediately before or after death, for others this is some time afterwards. You can be with the person in the room after they have died for as long as feels right for you.

### **How you may feel**

Whether or not they have a religious faith, some people feel that the soul, or spirit of the person remains in the room or nearby for a period after their body has died. Everyone reacts to grief/bereavement differently, and it is normal to experience a variety of emotions or none at all.

When someone close to you dies, you might experience shock, disbelief, numbness, sadness, anger, loneliness or a sense of relief.

As there is no 'normal' way to react, don't feel pressure from yourself or others to act in a certain way, or expect anything of yourself, other than to express what you are feeling.

You might experience shock physically and/or emotionally. For example, you may feel dizzy, nauseous, dazed, numb or empty. As part of feeling shocked, you may not believe the news is real. All these are common ways to react.

Shock may cause some people to react in an unexpected way when they first hear the news of a death. For example, some people laugh hysterically, particularly children. However you react is okay.

You may feel nothing. As a way of coping with the news of a death your feelings may become numb. This may mean you feel like you are dreaming, or the event seems unreal. Sometimes this can make it hard to cry or feel any sort of sadness—that is okay too.

## **Practical information**

If you have cultural or religious traditions or things that were important to the person who has died, or to you that you would like to occur after the person has died, the nursing team can help you with these for example cleansing the person's hands and face, holding mementoes, wearing clothes etc.

Normally the nursing team cleanse the person's body at some point after death and if you wish to do this, or be part of this, then please just let us know.

After the person has died, at an appropriate time within that day or occasionally the following morning, the nursing team will ask you which undertaker you would like to use.

Our staff liaise with them on your behalf, and arrange for them to collect the person's body from the hospice after they have died. You are welcome to come back to the hospice while they are still with us to see or spend time any time you wish with the person who has died.

You will also be asked whether the person will be buried or cremated, as there are additional forms that the doctors must complete if someone is cremated.

A member of the medical team will provide you with a death certificate, which will state the cause of death. Usually we ask that the next of kin collects this the next day, but if this is not convenient please let us know.

Occasionally, for example, if the cause of death is not clear, we need to involve the coroner, which can delay issuing the certificate. If this is the case, we will keep you fully informed.

You will also be given an information pack by the nursing team, which includes information on how to register a death, and how to access bereavement support, should you wish.

From here the undertaker will then help to guide you through the funeral planning process. Some people wish to leave practical matters such as planning the funeral, until after the person has died, while others find completing practical tasks beforehand, with the opportunity to take the person's views into account, can help them to feel more prepared.

## **Bereavement Support**

If you feel that you, a family member or a friend may need additional support to come to terms with the bereavement, please speak to a member of the team about how our Bereavement Service could help.

The service supports adults to express and understand their grief in a safe and confidential space.

Adults can refer themselves to the service at any time, whether directly after an important person's death, or weeks, months or years later.

Our Bereavement Service can be contacted by telephone on: (01724) 270835.

**We hope you found this booklet helpful, and encourage you to share your thoughts and feedback with us, so we can continue to improve the support we offer.**



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Date of issue: November 2021

Revision: 2 years

Review period: November 2023

Author: K Andrew

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