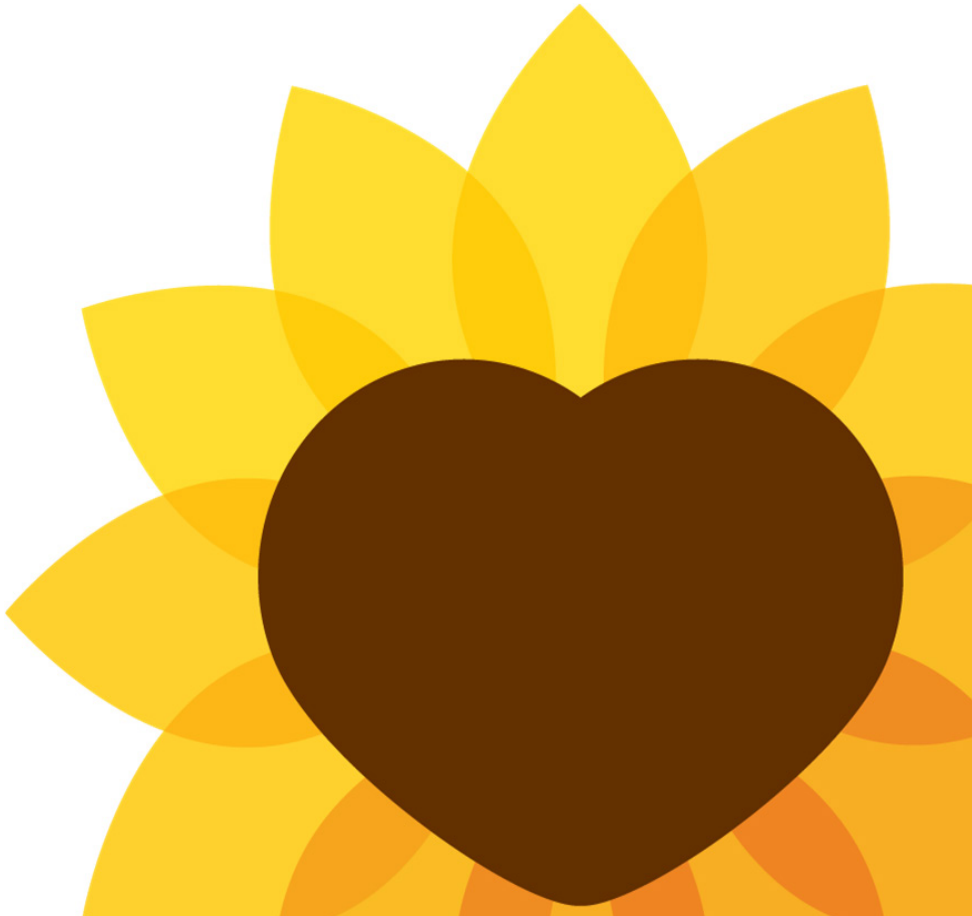




East Cheshire
Hospice

What to expect in the last days of life

Information for patients, families
and carers



Introduction

This can be confusing and emotionally challenging time for patients and their families. Although end of life is natural, this doesn't make the process less daunting. We all understand that end of life means the final phase in life but, often we don't know what this phase entails.

Please know that support is available for you at this difficult time. We will do our best to help guide you through this process and most importantly, ensure that you are able to spend their remaining time peacefully and comfortably.

We hope this leaflet will provide you with useful information to help you understand what is happening at this time.

Planning and care communication

We aim to provide high quality compassionate care which is responsive to the individual needs of our patients and those closest to them. Support will be offered to ensure that preferences, dignity and respect are maintained at all times. You are encouraged to participate in any discussions regarding care provision, and ask questions so that you understand the reasons behind decisions made. If you have any concerns, or if there is anything you do not understand, please tell us.



Signs and symptoms of an approaching death

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. Knowing certain signs and symptoms may help you better prepare both emotionally and practically

Please feel free to discuss any concerns or questions you may have about the dying process.

Below is a general overview of signs that a person may be entering the final weeks to days of life:

- Increasing weakness and/or exhaustion.
- Increasing need to sleep, having to spend the large majority of the day in bed/resting.
- Significant decrease in appetite or no appetite.
- Difficulty eating or swallowing fluids.
- A decrease in ability to communicate and/or concentrate.
- A general lack of interest in things that used to interest them; a strong feeling of apathy.
- A desire to only have a small number of certain people close by and limiting time with visitors.
- Slowed breathing, often times with longer pauses between each breath.
- Noisy/congested breathing – this can be accompanied by a gurgling or rattling sound caused by a person's inability to clear any fluids from the throat. Although this symptom may distress those present, it is important to remember that your loved one is often unaware and not distressed by this.
- Skin becomes cool and sometimes takes on a bluish tone, more noticeably in the hands and feet.

- General dryness of the mouth and lips.
- A decrease in the amount of urine produced.
- A loss of control of the bladder and bowels.
- Involuntary movements that can be repetitive or give the illusion of restlessness.
- Strong feeling of confusion regarding the time, place, and identity of people.
- Hallucinations – the person expressing that they can see and/or hear people or things that are not there. These hallucinations are common and often follow themes such as traveling/preparing to travel or being greeted or welcomed by other individuals that have already died.
- Becoming less responsive to touch or sound; more frequently alternating in and out of consciousness.

It is important to remember that this phase will be different for each individual. Which symptoms occur, severity of symptoms and the order of the symptoms may vary. We aim to provide the best care that we are able when these signs and symptoms are occurring during the final weeks and days of life.

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 clinical team will do everything they can to ensure that you and your loved one is as comfortable as possible.

Even when a person is thought to be in this phase of their illness, depending on their illness, effects on the body and other medical conditions, a sudden acute or catastrophic event can take us all by surprise. We will do our best to prepare you for this, but these events are often unpredictable.

Medications

Medication which is of no benefit at this time will be discontinued. This may include medicines for other health conditions.

Administration of medicines to manage symptoms of illness and dying will be a priority. Clinical staff will be able to advise you what is prescribed. A range of medicines information leaflets are available – please ask clinical staff if you require further information.

Care and comfort

Dying is a natural process that will occur on its own timeline. However, there are some steps that we can take to make the experience as positive as possible. Clinical staff will not wish to interrupt your time with your loved one, but will try to ensure that as far as possible all needs are met.

You can support in care provision in a number of ways:

- Assist with positional changes (seek advice from nursing team if you would like to be involved in this).
- Assist regularly to meet hygiene needs (please let us know if you wish to be involved in this).
- When communicating, use a clear and calm voice. Providing reminders on the date, time, place, and people who are present may ease any confusion. It should be noted that these reminders may not benefit all patients.
- If a patient becomes completely withdrawn, voice supportive reinforcements that do not require any response. Calming phrases will help to create a calm and peaceful ambience.
- Help to keep the lips and mouth moist by offering small sips of liquid using a straw or spoon. There are certain swabs and lip balms that can also be used to combat dryness in the mouth and lips.
- Helping to ease loneliness is a priceless comfort. Simply sitting and gently touching the patient may help to put them more at ease.

Spiritual needs

We are happy to discuss any spiritual or religious needs you or your loved one may have. Please let us know as soon as possible should you wish to access support.

Pain management

It will be very difficult for a patient to remain peaceful and calm if they are experiencing severe pain. Effective pain management is essential for all patients suffering from illness, and we will take all reasonable measures needed to provide a patient with relief from pain.

When to ask for help

When caring for a dying person it is important to know when to seek help. Open communication with the patient, loved ones and our clinical team will allow the patient to receive the best care possible. We have a selection of medicines available as well as non-pharmacological techniques to assist with pain management.

The person's appetite is likely to be reduced

They may no longer wish to eat or drink anything. This is because people who are dying do not need as much energy from food and drink, and because they may find the effort of eating or drinking to be too much.

Eventually, the person will stop eating and drinking, and will not be able to swallow tablets.

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 small mouthful. 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 nursing staff may be able to make suggestions to help them.

Should I be worried?

There is often no need to worry when oral intake ceases.

The mouth may look dry, but this does not always mean the person is dehydrated. Hydration will be considered by the medical team – however in most cases artificial hydration will not be considered appropriate, as it can be a burden and place unnecessary strain on the body during the dying phase, adding to troublesome symptoms.

Is there anything I can do to help?

If the person is conscious and they want something to eat or drink, you can offer sips, provided they can still swallow.

You can give some comfort to a person with a dry mouth by:

- Offering a drink through a straw (or from a teaspoon)
- Moistening the mouth with a damp sponge - special kinds of sponge are available for this purpose (the person may bite on this at first, but keep holding it, as they will let go)
- Placing ice chips in the mouth
- Applying lip balm

The person's breathing may change

As a person's body becomes less active in the final stages of life, they need less oxygen, and their breathing may become shallower. There may be long pauses between breaths.

The breathing can become noisy and make a rattly or bubbly sound. This is because of a build-up of fluid at the back of the throat, which the patient is not able to re-absorb, swallow or cough. Although this can be distressing to hear, it does not usually cause any discomfort or distress to the patient. Sometimes repositioning may help the fluid to drain away.

In the very last moments of life, the person's breathing pattern may change. Breaths may become much slower and quieter before they stop altogether.

Should I be worried?

A change in the breathing pattern is a normal part of the dying process. If the person is anxious, their breath rate may increase a little.

The person does not usually need extra oxygen at this stage.

Is there anything I can do to help?

If the person is anxious, sitting with them so that they know you are there may help to reduce their anxiety. Breathlessness can be frightening - a small fan and an open window can help.

If the breathing is very rattly, it may be helpful to change the person's position so that they are on their side if they agree or do not seem too disturbed by being moved. You can ask to be shown the best way to move the person - ask about sliding sheets.

A medication which may help to reduce the fluids in their chest or throat will be prescribed. This is not always needed, and it does not always make a difference.

The person may become much sleepier

People who are dying may become drowsy and sleep 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 such as music or favourite TV shows. You can provide care and reassurance by continuing to talk to them, holding their hand, and telling them when you enter or leave their room. People who are nearing the end of their life may be asleep or semi-conscious in this way for several days.

Should I be worried?

It is normal for a dying person to sleep more. They may generally become less interested in what is going on around them, and have less energy to take part in conversation or activity.

Is there anything I can do to help?

It is important to remember that, even when the person is or appears to be sleeping or resting, they may still be able to hear you. Do not feel that you need to stop communicating with the

person.

You might want to carry on speaking quietly and calmly to them. You could also try letting them know you are there in other ways – for instance: holding their hand, reading to them, or playing their favourite music.

The person may become more restless or agitated

This may happen in the last few days of life, though the person may become more peaceful again before they die.

Sometimes they may appear confused and may not recognise familiar faces. They may hallucinate and see or hear people or things that are not actually there - for instance, they may see pets or people who have died.

Should I be worried?

Restlessness and agitation can be caused by many things. It may be manageable by quiet reassurance and the comfort of people like you who are close to the person, though it may still be distressing for you to see.

Agitation could also be caused by physical problems, like constipation or difficulty passing urine - ask the clinical staff if you are concerned about this.

If the dying person does not recognise you, this may be distressing for you but it is not a sign that they feel differently about you. More likely, it is that they are unable to clearly distinguish between what is real and what is not - especially if they are a bit sleepy and drifting in and out of consciousness.

Is there anything I can do to help?

Simply sitting with the person may often help to calm them down. Keeping things as normal as possible may help comfort the person.

You can also talk to the clinical staff, as they can check if there is any treatable reason for this or may be able to offer medication to

help settle the person's anxiety.

You can help by:

- Speaking clearly to the person
- Reminding them who you are (and being prepared to do so repeatedly)
- Keeping their surroundings calm with minimal changes in noise level
- Trying not to correct them if they say something wrong, or insist on them getting things accurate, as this may be upsetting for you and for them.

The person's skin may feel cold and change colour

The person's hands, feet, ears and nose may feel cold to the touch (this is due to a reduced circulation). Occasionally, a person's hands or other body parts may swell a little.

Their skin may also become mottled and blue, or patchy and uneven in colour.

Should I be worried?

These changes are all normal parts of the dying process. If the person's hands swell, please be assured that swelling is not usually painful or uncomfortable.

Is there anything I can do to help?

It may be comforting to put gloves or socks on the person. You do not need to warm them up - but doing so may help you to feel more comfortable.

Gentle massage may help - the nurses may show you how.

The person may lose control of their bladder or bowels

This happens because the muscles in these areas relax and don't work as they did. The person may also have fewer bowel

movements as they eat less, and their urine may get darker as they drink less.

Should I be worried?

This may be distressing to see, and you may worry that the person may feel embarrassed. We will do all we can to minimise distress, maintain dignity and personal hygiene.

The person's eyes are closed

It is important to know that in these final stages, the person may close their eyes often. At some point, they may not open them again. If their eyes are open, eye drops may be appropriate to relieve the discomfort of dryness.

Is there anything I can do to help?

As they may still be able to hear you, take the opportunity to say the things that are important to you both.

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, as they don't have the energy to sustain that level of engagement or activity.

How long does it 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 to 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.

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 our care and you want to be there, the nurses will do their best to make sure you can be there and to look after you whilst you are with them.

What happens immediately following death?

When death does occur, the patient's muscles will relax, their breathing will completely stop, their heart will stop beating, and they will have no pulse.

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. It is both common and normal to feel a sense of shock or numbness, 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.

A natural death is not considered an emergency. This means that if you wish to, you may spend some time with the patient.

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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.

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, a doctor must complete the Medical Certificate.

There is more information about what to do next in our booklet 'Help and Care in your Loss'.

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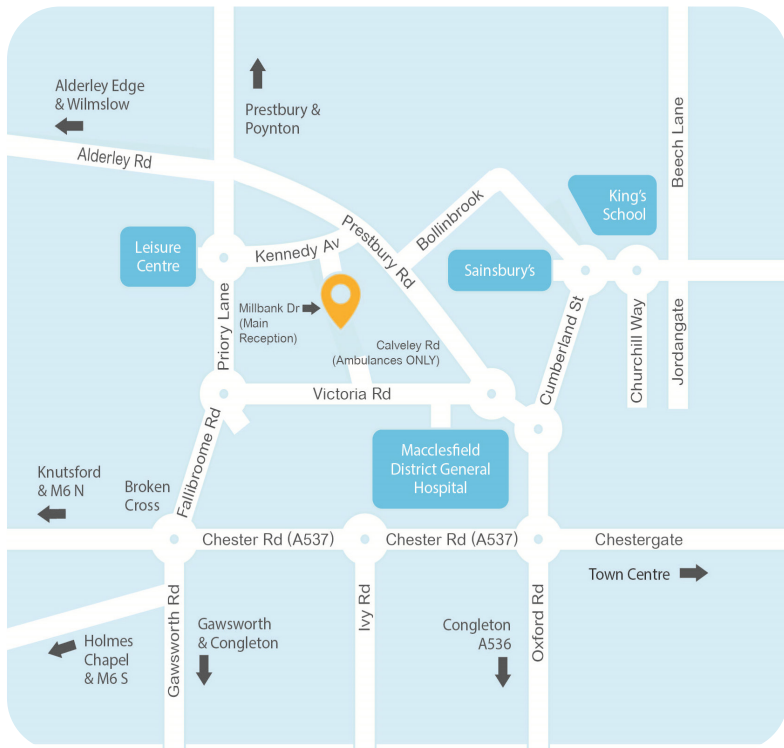
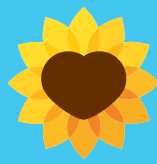
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