



St Catherine's
hospice care

What to expect when someone is approaching the end of their life

Information for family, friends and carers

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When someone is approaching the end of their life, there are common end-of-life stages that they may experience.

Whilst it's not possible to predict which changes they will experience, understanding them may help you to feel less afraid or uncertain at such a difficult time.



Supporting your loved one

When someone is approaching the end of their life, it's important that their care is guided by their wishes.

Advance care planning can support this through discussing their needs and wishes with the doctors and nurses caring for them. Plans may change and that's ok; it's important that they are comfortable and supported throughout.

Talking about dying can be challenging as you may want to 'take their mind off it'. However, being open and reassuring that you are there to listen, or talking about practical matters to ensure their wishes are met, may provide some comfort to you and your loved one.



Places of care

Home

Your partner, relative or friend may wish to remain at home in comforting and familiar surroundings with their family and friends. If they choose to receive care at home, it's important to consider their needs and how these may increase, and how they might impact on their family and those caring for them.

St Catherine's Hospice Clinical Nurse Specialists are able to work with your district nursing team and GP to provide support and help with comfort.

Hospice

The St Catherine's Hospice inpatient unit provides palliative and end-of-life care in a safe, peaceful and comfortable setting. Our specialist team of nurses, doctors and allied health professionals (AHPs), provide care 24 hours a day, seven days a week. We also offer emotional, spiritual and social support to those who require it, including patients' loved ones.



Using syringe drivers at the end of life

Syringe drivers allow the person to receive the medication they need to be comfortable during the final weeks or days of life through administration of medication at a constant rate. For example, sometimes people may no longer be able to swallow medicine, meaning that a syringe driver would be a suitable alternative to ensure medications are still given.

The tube is normally inserted in the arm, leg or abdomen and can hurt very slightly when it's first put under the skin. Once inserted the syringe driver shouldn't cause any pain but will need to be changed every day.

Medication can help to treat pain, breathlessness, agitation, fluid in the throat or lungs, and sickness.

However, it's important to take care of the skin around the tube and ensure that it's dry. Please contact the nurse if the syringe driver is dropped onto the floor or in water, if the tube comes out, if the skin looks irritated, if the machine stops working or the alarm sounds.



Changes in the final months

Physical Changes

As a life-shortening illness progresses, you may notice your loved one loses weight or has a reduced appetite and fluid intake. They may stop doing their normal activities and start to sleep more. This may cause worry for family and friends as they may stop feeling hungry or thirsty, however please be assured that this is normal as the body is beginning to slow down.

Mental and Behavioural Changes

As a person starts to realise and accept that they are dying, they may begin to separate themselves from others. For example, they may not want any visitors, even family, or they may find it hard to interact with people. They may also spend time reflecting on their life, memories and possibly any unfinished business which they may require support with.





Changes in the final weeks and days

Eating and drinking

When someone is in the last few weeks and days of their life, their body will slow down and use less energy. This means they will eat and drink less and may look thin and frail. They may also find it difficult to swallow or have a dry mouth.

Some people don't want to eat or drink or are unable to at this stage, which can be upsetting for family and friends, however this is normal and shouldn't be forced as this can increase discomfort.

Doctors and nurses can provide guidance and support in relation to eating and drinking if your loved one wants to and is able to swallow. If you have concerns about eating and drinking, please discuss with the nurses or doctors involved in your loved one's care.

Sickness

Some people may feel sick at this stage. Their doctor or nurse can support with finding the cause of this and may change their diet, medication or recommend relaxing activities.

Weakness and tiredness

Sometimes people may spend more time in bed or in a chair as they become too tired for everyday activities, meaning they may also sleep more. People can often still hear others when they talk to them gently or feel them when they hold their hand.

Bladder and Bowel

When someone is coming towards the end of their life they may struggle with their bladder and bowel movements and lose some control as their muscles relax. The nurses can support with ensuring they are comfortable and maintain dignity where possible. It's helpful to talk to the doctors and nurses, as well as your loved one themselves, regarding what they need and who can provide the care.

Pain

Not everyone experiences pain; some people may approach death without any pain. However, if they are experiencing pain, talk to the doctor or nurse as this can usually be managed with the correct treatment.

Breathing

Changes in breathing are common when someone is dying. Some may become breathless or their breathing may become loud or noisy. Using a fan or having a window open can increase comfort. In some cases medication may be useful, which you can discuss with a doctor or nurse.

Mental behaviour and emotions

As a person enters the last weeks and days of life, changes to the body can also affect the brain. They may become detached, restless, confused or delirious. This can be very upsetting for family and friends to see their loved one like this. Ensuring calm and quiet surroundings can help, as well as holding their hand and reassuring them. In some cases, medication can be helpful, again, please discuss with your doctor or nurse.



The final hours

As a family member, relative or friend of someone who is in the final hours of life, you may feel uncertain and frightened. It may be of some reassurance to know that for many people suffering a life-shortening illness, the final moments are in fact peaceful.

Loss of consciousness

Towards the end of life, many people lose consciousness but may still be aware of others around them. They can often hear what is being said around them and to them, as well as feel when someone is holding their hand.

Skin

Blood circulation will start to slow down in the final hours meaning the skin may appear blue or mottled (different coloured patches or blotches). Hands, feet and limbs may also feel cold, which is normal.

Breathing

In the final days and hours, breathing may get louder or sound quite noisy. It may cause upset or worry for those around them but please be assured that it's unlikely that your loved one is in distress or any pain. They are likely to be unconscious and unaware of the change to their breathing.

As the moment of death approaches, breathing can slow down and become irregular. It may stop and start, or there may be long pauses between each breath. The duration of this type of breathing can differ before breathing stops.

Moment of death

When a person dies, those around them may notice their face suddenly appears relaxed and peaceful.

If your loved one dies in the hospice, you can tell a health professional who will then be able to support you. If you are at home, call your GP or district nurse who will arrange to visit to confirm the death.

It's important that you take the time you need with your loved one. You don't need to call the GP or district nurse straight away as you may wish to spend some time saying goodbye. Family and friends may also want to sit with the person who has died and say their goodbyes.



Support from St Catherine's

Losing a loved one can be a very distressing time, so getting the right support is important.

It's important to remember that there's no timescale for bereavement or requesting bereavement support, as everyone grieves differently. Please don't hesitate to contact our Support Team if or when you feel ready.

You can contact them via email at supportteam@stcatherines.co.uk or by phoning 01772 629171. More information about bereavement support can be found on our website at www.stcatherines.co.uk.