# What to expect in the last days of life

**Many people find death and dying hard to talk about. While it's something we'll all face one day, it can be difficult to know what to expect. This leaflet aims to ease some of the anxiety associated with death and dying, by explaining the changes that often happen as someone nears the end of their life. It also answers common questions and encourages you to speak to the care team if anything is worrying you.**

For most people, dying is rarely sudden, it's usually a gradual and peaceful process, marked by a natural slowing down of the body and mind. Although the process is unique to each person, there are common signs that indicate someone is nearing death. These changes can be hard to witness, but spending time with your loved one, sharing memories and simply being present can offer great comfort.

## Fatigue and drowsiness

As an illness progresses, the body naturally begins to slow down. A person may become very weak, sleep more often, and seem less aware of their surroundings. They may be awake only for short periods and appear drowsy or distant. This is a natural part of the dying process and is often peaceful, accompanied by a sense of calm and tranquillity.

At the very end of life, a person may become unresponsive, but they may still be able to hear you and sense your presence. We encourage you to continue speaking to them and offering gentle touch, while also being mindful not to say anything you wouldn't want them to hear.

## Breathing

Towards the end of life, breathing usually becomes much slower and more irregular as the body needs less oxygen. People often worry about breathlessness at the end of life, but in most cases, breathing becomes easier.

Nearer to death, breathing may change again – with longer pauses, or the tummy rising and falling instead of the chest. Breathing may appear laboured, but it's important to remember that these changes are normal and not usually distressing for the person.

When a person takes their final breath, they may make an unusual facial expression or movement – this is normal and does not mean they are in pain or distress.

You may notice a "rattle" caused by a build-up of mucus. Though this can sound distressing, the person is generally unaware of it. Medication or changing position may help. Simply being there - holding a hand or sitting quietly - can reduce anxiety-related breathlessness.

## Eating and drinking

As someone approaches the end of life, it's natural for the body to slow down, and with that, the need for food and drink lessens. You may notice that their appetite decreases gradually, even for their favourite foods. While it can be hard to witness, it's best not to encourage or pressure them to eat or drink, as this can be uncomfortable for them and emotionally difficult for you.

When a person stops drinking, their mouth may appear dry - but this doesn't necessarily mean they are dehydrated. Gentle mouth care, such as using a damp sponge or applying lip balm, can help keep them comfortable. The care team can show you how to do this.

Towards the end of life, the body becomes less able to process fluids. Giving fluids through a drip is not always beneficial, as it can place extra strain on the body's natural fluid balance and may cause swelling or noisy breathing. The care team will carefully consider whether this is appropriate, based on the person's individual needs.

## Toileting

Sometimes people are unable to control their bowel and bladder, which may be distressing. Staff will do everything they can to keep the person as clean, dry and comfortable as possible, maintaining their dignity at all times. This may involve the need to use pads or the insertion of a catheter to prevent their skin from becoming sore. You may notice urine becoming darker and more concentrated and decreasing in amount - this is normal when someone drinks less.

## Skin changes

The person may feel hot or cold due to their internal thermostat not working as well. When a person is hot, fans or cool wet flannels can be used. If the person is still able to swallow, paracetamol may help.

If the person is cold, blankets can be used but it's important to ensure that they do not become overheated.

People's hands and feet may feel cold and clammy, their limbs may swell, or you may notice their skin turning pale or purple in colour. This is because the blood is not being pumped around the body as well as it has been, this is normal.

## Pain

It's important to remember that most people die without experiencing pain. If pain does occur, the care team will closely monitor and adjust pain relief to ensure the person remains as comfortable as possible.

## Medication

When caring for a person who is dying, the aim of giving any medication is to keep them comfortable and settled. These medications do not slow down or hasten death.

You may be provided with injectable medications to keep at home, in case the person becomes uncomfortable, distressed, or in pain and is unable to take tablets or syrups.

If swallowing tablets or syrups becomes difficult, the care team will ensure essential medicines are given by injection or via a syringe pump. A syringe pump is a small device that delivers medication gradually through a tiny needle placed just under the skin, reducing the need for frequent injections.

## Agitation

As someone nears the end of life, they may become confused, disoriented, or agitated. This can happen for many reasons, including changes in the body, medications, or underlying illness. You might notice your loved one saying things that don't make sense, seeing people or things that aren't there, or becoming restless - pulling at bedclothes, clothing, or reaching into the air.

These behaviours may be signs of delirium, a common and temporary state of confusion that can occur in the final days. Delirium can be distressing to witness, but it doesn't always mean the person is suffering. Often, they are unaware of their actions or surroundings.

Please speak to a member of the care team, as there are ways we can help to calm and reassure someone who is feeling unsettled.

Familiar photos, favourite music, and the presence of loved ones can sometimes help to soothe and reassure someone. In some cases, medication may also be used to help them feel calm and relaxed.

Emotions at this time can be intense - ranging from deep sadness to disbelief or even numbness. Gently encouraging your loved one to share memories or talk about how they're feeling can be a powerful source of comfort and connection.

That said, it's perfectly okay if you need a break or don't feel able to offer support in that moment. Please speak to a member of staff - we're here to help. Looking after your own wellbeing is just as important while you're caring for someone else.

## End of life reflections

As a person nears the end of life, they may begin to reflect on their experiences and express a desire to complete any unfinished business, such as:

- **Resolving any problems with personal relationships**
- **Visiting meaningful places**
- **Sort out personal belongings**
- **Giving gifts or special things away to family and friends**
- **Organise their Will or finances**
- **See a religious or spiritual leader**

As death approaches, the person may speak less, become less aware of their surroundings, and appear more peaceful. Simply being present and letting them know you're there can be deeply reassuring. Gentle, compassionate care at this time can help someone feel that their life has had meaning and that they will be remembered with love.

This is also likely to be a painful and emotional time for you, as you face the loss of someone you love or have cared for. You might feel unsure of what to say, how to help, or what to do - and that's completely natural. Please know that we are here for you. If anything is on your mind, we're ready to listen and offer support.

If you're finding it difficult to talk to children or other family members about what's happening, please speak to a member of staff - we can help with this. Family support is available both in the home and, if your loved one is being cared for in the hospice, children and family members are warmly welcome to visit.

## When someone dies at home

When someone is being cared for at home there are a few things it might be helpful to know. When the person has died, you don't need to do anything immediately and you do not need to call an ambulance. You may want to stay with your relative or friend for a little while.

If the person dies during your GP practice's regular hours, please contact them to inform them of the death. If the surgery is closed, call NHS 111 instead—an out-of-hours doctor may visit to verify the death. Please be aware it may take some time for the doctor to arrive.

Once the doctor has verified the death, you are free to contact a funeral director of your choice. They will arrange to collect your loved one and transfer them to their chapel of rest.

If the death occurs during the night, there is no need to rush contacting a funeral director unless you wish to. Not all funeral directors operate 24 hours, so you can call them the following day.

You may also want to inform your Farleigh Hospice team. They can offer support, and if appropriate, provide care for your relative or friend after death.

On the next working day (Monday to Friday), the GP will issue a death certificate confirming the cause of death. Contact your GP surgery for guidance on obtaining the certificate and how to arrange an appointment to register the death.

## Support after death

Farleigh Hospice offers a bereavement service to support you and your loved ones during this difficult time. We normally suggest people take around three months to process their feelings and allow the normal process of grieving for someone you love.

The Farleigh Hospice website offers a range of helpful information and resources to support you during the early days of bereavement. If you're feeling overwhelmed by grief or have any concerns, our bereavement team is here to provide guidance and support.

You might find it beneficial to attend one of our support groups or speak with a support worker or specialist counsellor. Please let your care team know if you would like a referral - they will be happy to process this for you.

## Comments

We are always pleased to hear any comments about the services we are providing. Your feedback helps us to maintain a high standard of service and we are really keen to hear from you. You can also complete our feedback survey via our website. Please visit: **www.farleighhospice.org/feedback**

**If you need advice about any issues relating to end of life care, call the Clinical Advice Line on 01245 455478 between 08.00 and 20.00 hours, 7 days a week.**

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