

# **What can happen when someone is dying**

**Information for  
relatives and friends**



## Notes

You may want to use this space to write down important names and numbers, or questions you may want to ask.

# What's happening?

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The doctors and nurses believe that your relative or friend is now dying. We understand that this can be a sad and difficult time. Our main priorities are making your relative or friend as comfortable as possible, maintaining their dignity and supporting you.

Staff will discuss with you any decisions about your relative or friend's care to make sure that you understand the reason(s) for these. Staff will regularly review your relative or friend's condition and if necessary make any changes to keep your relative comfortable.

Please do not hesitate to ask us if you have any questions or concerns. Also, please tell us if you would like to be more involved in your relative or friend's care, for example, washing and mouth care.

## Nearing the end of life

This leaflet may help you understand some of the changes that can happen when a person is dying.

When someone is dying certain changes within the body can happen. Although these changes can be difficult, they are a natural part of the body preparing itself for death as the different body systems slow down. If you have any questions or concerns about these changes please speak to us.

It can be difficult to predict when someone will die as some people

die very quickly without much warning, while others slowly deteriorate over days or weeks. However as death approaches the following may occur:

- Loss of appetite, difficulty swallowing and taking medication
- Extreme tiredness and weakness
- Changes in breathing pattern e.g. noisy breathing or shallow breathing
- Changes in body temperature and skin colour
- Confusion and, or, agitation

There is more information about these symptoms over the page.



## What you might expect

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### Loss of appetite, difficulty swallowing and taking medication.

Your relative or friend may no longer need, or want to eat or drink. At this time mouth care is very important. Therefore, we will give your relative or friend regular mouth care to keep their mouth moist and comfortable.

If your relative or friend can still eat and drink safely, this can continue as long as possible. If you have any concerns about their ability to swallow please ask a nurse or doctor.

They may no longer be able to take medicines by mouth. The doctors will review which medicines they still need and may stop others.

They may also prescribe medications to aid comfort if needed. If your relative or friend is finding it hard to swallow, they may receive their medication through a fine needle placed just under the skin. This will avoid repeated injections. They can also give medicines to control symptoms through a syringe driver.

A syringe driver is a small portable pump usually containing enough medication for 24 hours. The pump delivers a continuous dose of the drugs through a small needle or tube that is inserted under the skin in the arm or tummy.

### Extreme tiredness and weakness

As time passes your relative or friend is likely to sleep much more and, when awake, less able to talk to you. They may seem unconscious for hours or even days at a time.

We believe that although people who are dying may not speak they may still be able to hear. Please speak to your relative or friend as though they can hear.

You may wish to comfort them by holding their hand.



## Other possible symptoms

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### Changes in breathing pattern

You may notice changes in your relative or friend's breathing. It could be slower, shallow or slightly quicker. As people approach the end of life the body is less active and the need for oxygen may be less.

Often their breathing may become irregular or they may appear to "miss" a breath – this is called "apnoea" and can appear alarming but is a normal process for someone who is progressing towards the end of their life.

Sometimes breathing can be noisy. This is often due to a collection of normal secretions in the chest and throat that your relative or friend is too weak to clear by coughing. Sometimes changing their position can help or we may give them medication.

### Changes in body temperature and skin colour

You may notice that your relative or friend's body temperature changes, sometimes they may appear flushed or cool. Their hands and feet may feel cold, or their skin may feel moist.

Their skin may appear to have colour changes, it may be pale or discoloured.

These changes are all normal.

### Confusion and, or agitation

You may find that your relative or friend becomes confused and, or agitated which can be distressing.

Sometimes a quieter environment can help.



There can be many reasons for confusion and, or agitation. The staff will check if there is a reason for this, for example, pain, restlessness, needing a change of position or to pass urine and take appropriate action.

## Support for you

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All these physical changes can be difficult for you to watch and cope with and we understand that this may be a sad and upsetting time. If you are concerned about anything please speak to the nurse or doctor.

Please don't let any concerns about saying or doing the wrong thing, keep you away from your relative or friend at this time. Often saying nothing and simply being present is enough. If you feel you cannot be present, for any reason, then this is fine.

As death approaches you may become anxious or scared, or even experience a sense of relief. This is natural. Talking to someone about your thoughts and feelings and the concerns you have can often help.

Saying goodbye to someone close to you can be very difficult; it can be difficult to know what to say, how to say it or even when to say it. However you may find it helpful.

Saying goodbye can be done in different ways, for example, writing a letter, sitting next to the bed.

Other people may not feel the need to say goodbye. If the death happens when you are not there, it is good to know that you are comfortable with the decisions that you make.

You may feel it is important for you or someone else to be present at all times, but please remember it is also important to take breaks, eat and drink, to sleep and to look after yourself.

During this time, whether in hospital, at home, in a hospice or in a care home you may wish to contact a representative from your faith or belief community for support. We have contact details of local representatives.





## Organ or tissue donation

If you know that your relative or friend wished to be an organ donor, or was on the donor register, please let us know so that we can discuss this.

In some circumstances a member of staff may ask about organ donation.

## Further support when someone dies

If you would like further information and support on what happens following the death of your relative or friend NHS Ayrshire and Arran has produced a booklet "When someone has died.... Local help for you". This leaflet gives information on local funeral directors and advice on arranging a funeral.

Please ask a member of staff for a copy.



## Patient and Family Support Services

At the hospice we have a Patient and Family Support Services team who can offer you support and advice. This includes social work, pastoral care, counselling and bereavement support. The service provides positive and practical ways for families to draw on their own strengths at difficult times. The team offer ongoing support, pre and post bereavement, to ensure that families have continuity of care when help is needed.

If you would like to get in touch with them you can:

- Speak to a member of the hospice team who can make a referral for you
- Email the service [AA-UHB.AyrshireHospiceReferral@nhs.net](mailto:AA-UHB.AyrshireHospiceReferral@nhs.net)
- Visit our website [www.ayrshirehospice.org](http://www.ayrshirehospice.org)

Or call us on **01292 269200** asking for **Carolyn Hall** who will discuss your concerns with you.



This leaflet has been adopted and adapted from an  
NHS Greater Glasgow and Clyde leaflet:  
‘What can happen when someone is dying –  
information for relatives and carers’

Grateful thanks to those organisations and individuals.

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