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What to expect in the last days of life

A leaflet for relatives or carers of Hospice patients being cared for at home

/stpetershospice

Registered Charity No. 269177

St Peter's Hospice
For Patients, Families and Bristol

When a loved one is very unwell, the person and those close to them may think about whether they may be dying or close to death. Many people do not know what to expect and often feel anxious about the unknown. This leaflet describes some of the things that are likely to happen when someone is dying.

We aim to offer individualised care to every patient and support for family and friends, so please let your nurse specialist or another health care professional know what is important to you and your loved one. This includes any spiritual or religious wishes you may have. Healthcare staff will involve your loved one in decisions about their care, if that is what they want, and will check who else they want to include in these discussions. Do speak to a member of the healthcare team if you have any queries or concerns.

Coping with dying

Each person is unique but in most cases we notice some characteristic changes that help us to know that a person is dying. These fall into four main categories:

1) less need for food and drink
2) withdrawal from the world
3) changes in breathing
4) changes that happen just before death

1. Less need for food and drink

When someone is dying, their body no longer has the same need for food and drink as before. Their body slows down and cannot digest food so well or take up its goodness. Your loved one may want to eat or drink but try not to worry if they do not want very much.

Some people may not want to eat or drink at all in the last days of life and swallowing may become difficult as they become more unwell. Although their mouth may look dry, this is not necessarily a sign that they are dehydrated. Gently moistening their mouth with a damp sponge and applying lip salve can give comfort. The District Nurses will be able to help by showing you how to do this safely. A common concern is whether someone should be given fluids through a drip. When someone is dying, a drip often causes more harm than good, for example by causing swelling or fluid to build up on the lungs. For someone who is already at the end of their life, having a drip won't necessarily help them live longer. We therefore take care in deciding whether to give fluid by a drip based on the risks and benefits for each individual patient.

You may find decisions about fluids difficult to understand. Healthcare staff are always happy to listen to your concerns and explain the reasons for our decisions.

2.Withdrawing from the world

For most, this usually happens gradually. The person spends more and more time asleep. When they are awake they are often drowsy and less able to show interest in what is going on around them. This is a natural change, not usually caused by medication. This period often lasts several days but for some it can be longer or shorter.

This is often a difficult time as it can be hard to know what to say to each other. Your loved one may find it comforting for you to read to them or play some of their favourite music. Or they may prefer you simply to sit quietly with them. Try to do whatever you think would give your loved one the most comfort. We encourage you to keep talking to them as they may well be able to hear you, even if they cannot respond.

3.Changes in breathing

When someone is dying, the body becomes less active and their need for oxygen reduces. People who suffer from breathlessness are often concerned that they may die fighting for breath, but in fact breathing usually eases at this time.

The knowledge that someone is close at hand can be a real help in preventing breathlessness caused by anxiety. So, just sitting quietly and holding your loved one's hand can make a difference. Medication can also be used to help relieve these feelings. The District Nurses will be able to help with this.

Oxygen may help some people with breathlessness but usually less so when somebody is dying. The decision to give oxygen is based on each person's individual needs at this time.

Occasionally in the last hours of life, breathing can become noisy. This is caused by secretions in the throat and upper chest, which may build up as someone becomes sleepier and less able to clear them. Medication may be used to reduce these and changes of position may also help. The noisy breathing can sound alarming but this doesn't usually distress the dying person. Again, the District Nurses will be able to help you with this.

4. Changes which occur before death

We want to make sure your loved one is comfortable, so healthcare staff often decide to stop medications and tests which may no longer be helping.

There will be medication provided to help ease pain and any other symptoms if required. Your GP and District Nurse will usually organise 'Just in Case' medications, which can be given as an injection under the skin by the District Nurses. The aim of this medication is to relieve symptoms and not change the natural course of the dying process. If continuous medicines are needed, the District Nurses will start a syringe pump which delivers these continuously through a small plastic needle under the skin.

Some people may become restless or anxious as death gets near. If this is the case, District Nurses will be able to give medication to relieve this and make them feel more relaxed.


A syringe pump

When death is very close (within minutes or hours), your loved one's breathing pattern may change. It can become rapid, shallow or with long pauses between breaths.

Your loved one's skin may become pale, and moist and slightly cool.

Most people do not wake from sleep in the final moments of life but die peacefully and comfortably. Breathing will usually gradually slow and then stop altogether. This may take a long time in some people and it can be difficult to pinpoint the exact moment of death.

Helping to care for your loved one

Professional Carers

Carers will often be arranged to come to the house at regular intervals during the day. They will help with personal care, repositioning and sometimes with meals. Usually the maximum number of carer visits possible is four times a day, usually around mealtimes and at bedtime. Sometimes 'night-carers' will also be arranged to come and sit with the person who is dying 2-3 nights per week and provide care whilst you try and get some rest.

For people who are thought to be in their last weeks of life this package of care is usually available free of charge through 'Continuing Health Care' funding.

Sometimes the St Peter's Hospice at Home team will be arranged to provide care or to support existing professional carers.

District Nurses

District Nurses will visit as needed. If your loved one has a syringe pump they will visit daily. They are also the first contact if you need help out of hours.

General Practitioner/ Family Doctor (GP)

The GP may visit to help ensure the person who is dying is comfortable. They will also help by prescribing medicines as needed.

Palliative Care Specialist Nurse

Your St Peter's Hospice Community Nurse Specialist (CNS) will continue to support you and your loved one in the last few weeks and days of their life. They will be able to give advice regarding symptoms and sources of support and will keep in contact with District Nurses and GPs as needed.

What happens after the person has died

Within the first few hours after death you will need to call the District Nurse or GP to come and confirm the death. If it is your usual GP they might be able to give you the 'Medical Certificate of Cause of Death' or 'Death Certificate' so that you can register the death. If it is an 'out of hours' doctor you will need to contact your GP the next working day to do the certificate. You can then take the certificate to the registrar to register the death.

Once the GP or District Nurse has been you can contact a funeral director. They can usually be contacted 24 hours a day.

How St Peter's Hospice can help

Looking after someone who is dying can be a very difficult time for you. It is really important that you look after yourself and get help.

Often family and friends are willing to help and only need to be asked. Your Hospice CNS will also be able to discuss further sources of support with you.

If you would like further support after the death of your loved one, St Peter's Hospice offers bereavement support. Please ask for an information leaflet about how to make an appointment.

Some of the issues raised in this leaflet can be very difficult, so please don't hesitate to talk them through with a healthcare professional.

Contact	Telephone number
GP	
GP out of hours	111
District Nurses	
District Nurses out of hours	111 or
St Peter's Hospice Advice Line	0117 915 9430
Care agency	
Other	