


What to Expect When Someone Important to you is Dying

answering
your...

questions

Bev - Nursing




preparing you for what to expect

This booklet is designed to help prepare you for what to expect, and what you can do, in the very last days and hours of a person's life.

It is relevant for any expected death, whatever the cause, including, for example, when someone is dying from advanced lung or heart disease, dementia or cancer.

There are likely to be several professionals and carers involved during this time, as well as friends and family. If someone is dying at home or in a care home, the team involved in looking after them will include their general practitioner (GP), working with the community nursing team and with other multi-disciplinary community teams. If the person is in a hospice or hospital, a team of nurses, doctors and other healthcare professionals, led by a medical consultant, will be looking after them.



The healthcare professionals and care teams aim to work closely together with the patient and their family, to make sure that they provide support in ways that meet the needs and wishes of the dying person and are in line with their beliefs and values. We recognise that patients and families are the experts in how they live their lives, and those looking after them need to be advised as to what is important to them, so that everyone involved can work together to provide the most relevant help and care.


We know that each family is different. Many families feel it is very important to be involved in providing care and be with their loved ones, but sometimes this isn't possible or may not be right for that person or family.

We encourage families to talk about their choices and preferences with the care team.

what happens when someone is dying?

This process is unique to each person. It is not always possible to predict exactly when a person will die. However, there are some changes that signify a person is likely to be close to death. It is normal for these signs to come and go over a period of days.

During this period, it can be important for families and carers to take a break from the bedside, to talk to someone, to seek help or support, to sleep or to attend to their own physical needs. It's essential to consider the carer's feelings and needs, as well as those of the person being cared for.



why are they not eating and drinking very much?

In the last days of life, the person may no longer wish to eat or drink very much, or anything at all. We are aware that it can be hard for family and friends to see someone they love stop eating and drinking, but this is a normal part of the dying process. This may be because they find the effort of eating or drinking to be too much for them, or because they have little or no need or desire for food or drink. Eventually, the person will stop eating and drinking completely, and will not be able to swallow tablets or liquid medicines.

The person's mouth may look dry, and can be moistened, but this does not necessarily mean they are thirsty. The healthcare team will regularly monitor the person to check for symptoms or signs of being thirsty or dehydrated and will develop a plan with the person, their family members or those closest to the person about how to manage this. The addition of hydration, by giving them fluids through a drip for example, must be used carefully as it can add more discomfort rather than help.

is there anything I can do to help?

If the person is conscious, check if they want something to eat or drink. You can offer the sort of food they preferred when they were well, and sips of fluid to drink, provided they can still swallow safely.

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

- offering a drink from a teaspoon or syringe
- offering to place crushed ice or sorbet in their mouth
- applying lip balm.

You can also ask one of the nurses to demonstrate how to use a small soft toothbrush to moisten and freshen the mouth if the person is too sleepy to manage sips to drink.

what if they can no longer take their medications?

Most medications can be discontinued towards the end of life; the doctor or nurse will advise on this. If the person needs medication to control any symptoms, this can be given by injection, or a very small tube that is inserted under the skin and is attached to a device called a syringe pump or syringe driver.

is there anything I can do to help?

It's helpful if you can let the doctor or nurse know if you see any changes in the person who is dying, so they can check them and give extra medication if they think it is needed. If you are worried, don't hesitate to ask one of the team.

I am worried that they are sleepier

It is normal for a dying person to be drowsy and sleep more. They become less interested, and have less energy to take part, in what is going on around them. This does not necessarily mean they are no longer hearing what is said to them. They may also drift in and out of consciousness. In these final stages the person may close their eyes, or their eyes can sometimes be half open, although they are not awake.

Some people become completely unconscious for a period of time before they die; this could be for a short time, or for as long as several days.

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. Speaking quietly, calmly saying the things that are important to the person and/or holding their hand, reading to them, or playing their favourite music, can be helpful. Simply being together can be a great comfort.

why does their skin look different?

As a normal part of the dying process, the person's hands, feet and face may feel cold to the touch or may swell a little because the circulation is reduced. The colour may change to mottled, pale or blue. This is not usually uncomfortable. Due to the changes to the body at this time, the person is more likely to develop what is sometimes called a pressure sore.

is there anything I can do to help?

Hands or feet do not need warming up, but an extra blanket or socks may be comforting. A nurse can show you how to give gentle massage. Regular changing of position is important to help reduce the risk of a pressure sore. One of the healthcare team can provide guidance and arrange for a special mattress to be used to aid comfort.

what about toileting?


The person may lose some control of their bladder or bowels. This happens because the body and muscles relax. They may also have fewer bowel movements and their urine may get darker, as they eat and drink less.

is there anything I can do to help?

One of the nurses can advise on equipment that may help, such as incontinence pads or a catheter. They can also show you how to keep the person clean and comfortable.

why could they be restless or agitated?

Often, the dying process is very peaceful and gentle, but sometimes episodes of restlessness and agitation may happen in the last few hours or days of life. Sometimes dying people may appear confused and may not recognise familiar faces.

The top of the page features a teal header with the word "Friends" written in a light, white, sans-serif font, slanted upwards from left to right. The background of the header has a subtle pattern of overlapping circles and lines in a slightly darker shade of teal.

This is not a sign that they feel differently about you. They may not be able to distinguish clearly between what is real and what is not – especially if they are sleepy and drifting in and out of consciousness, rather like what can happen when we are half-awake or half-asleep.

They may hallucinate, and see or hear people or things that are not actually there; for instance, they may see pets or people from their past. Quiet reassurance and the comfort of those who are close to the person may help.

Sometimes agitation can be a sign of some discomfort, such as from constipation or difficulty passing urine, so this is worth considering and reporting to the nurses if you think this is a problem.

is there anything I can do to help?

Sit calmly with the person.

When appropriate, speak clearly and audibly to the person, reminding them who you are.

Keeping things as normal as possible and offering familiar religious, spiritual or cultural support or rituals may provide comfort for them and those with them.

Talk to the doctor or nurse if you feel the person is agitated or in pain, as they can check if there is any treatable reason for this, and they may be able to offer medication to help relieve this symptom.

Keep the surroundings calm, with minimal noise levels.

Try not to correct them if they say something wrong, odd or inaccurate.



will there be any changes to their breathing?

A change in breathing pattern is a normal part of the dying process. Breathing is sometimes shallow, or a little faster, or there may be long pauses between their breaths. Sometimes the breathing becomes noisy; this can occur because their muscles are very relaxed and the normal fluids in their chest or throat can collect there, causing a rattling sound. The rattling sound may be unfamiliar or unsettling for you to hear, but it does not cause distress to the dying person.

is there anything I can do to help?

Sitting with them so that they know you are there may help to reduce any anxiety.

If they are breathless a small fan and an open window can help. The person does not usually need extra oxygen.

It may be helpful to change the person's position if they agree or do not seem too disturbed by being moved. Ask the nurse to show you the best way to move the person.

The doctor or nurse may also suggest medication which may help with this symptom.

the person's final moments

Dying is a natural process that is unique to each person. For most people, the final moments of dying are peaceful. Breathing becomes slower and more irregular with long gaps in between breaths. This might take place over a few minutes, but it can be longer. Eventually they take a breath out and do not take another breath in; they have stopped breathing. Often the person's body will relax completely after this.


what happens after the person has died?

There are some formal things that need to happen. The first is for a healthcare professional to confirm that the person has died. This is called 'verifying the death'.

There are some small checks that need to be done to verify the death. It is ok to leave the room when this is happening or you may wish to stay. This process includes checking the person's pupils for any reaction to light, checking for breathing and listening for their heart sounds with a stethoscope. After the death has been verified, the chosen funeral director can be contacted.

Although some nurses can verify someone who has died when their death was expected, only a doctor can complete a 'Medical Certificate of Cause of Death' (MCCD). The doctor will write the medical certificate giving the cause of death as soon as they are able. This certificate is then discussed with an independent doctor called the medical examiner (ME) who looks through the patient's record and talks to the healthcare professionals who looked after them to check that what is written on the certificate is correct. The ME also talks to the person's family to check that they understand and accept what is on the certificate and that there were no concerns about the care the person received. If everyone is in agreement, the MCCD will be sent electronically to the local Registrar of Deaths.

So at some point fairly soon after the death, the ME will call the nominated family member to talk everything through. If the family accept the proposed causes of death, the ME will then explain how to make a face-to-face appointment with the Registrar to complete the process of registering the person's death. At this



appointment with the Registrar, you will be given the necessary paperwork to allow the Funeral Directors to proceed.

Some cases need to be referred to the coroner, and there are strict rules about this, for example if the person died after a fall or head injury. This can slow the process by a few days.

caring for the patient after death


If at home, the family do not need to do anything straight away. It is ok to stay with the person or come and go from the room, whatever feels right. When ready, you can ask a member of the care team to explain what to do next.

If you are in a hospice or hospital, family can normally spend time with the person after they have died and can call the rest of their family. Sometimes people want to be left alone to spend some time with, and say their final words to, their loved one. Sometimes they find it comforting to have a member of staff with them.

Once the death has been verified, a particular ritual or ceremony may be important to beliefs or culture.

The funeral director can be contacted to collect the patient and take them to the funeral home.

Whether the person dies at home, in a hospice or in a hospital, a decision will need to be made about a funeral director. This may



be something that was talked about with the person before they died as they may have prepared a funeral plan.

It is important for the professionals involved in the care to know whether the person who has died will be buried or cremated, as this determines the paperwork that the doctors must provide.

where can I turn for help if I have any concerns or questions?

We hope this information has been helpful and may work towards you feeling more prepared for what to expect when someone is dying. There are various people who may be able to answer your concerns or questions. Please talk openly to the healthcare professionals involved as they will be able to help you or will direct you to someone who can help.

Phyllis Tuckwell continues to support you as a family after your loved one has died.

We will write to you around nine weeks after the death, to let you know about the services Phyllis Tuckwell provides.

If you wish to access bereavement services before this please make contact with:

Patient & Family Support team

01252 729430

Acknowledgements to: Adapted from National Council for Palliative Care, Hospice UK & Sue Ryder leaflet. 'What to expect when someone important to you is dying'.

***Large print version
available on request.***

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