At the end – dying explained

Summary

- People have different levels of knowledge about dying.
- People may or may not want to know what happens when someone dies.
- There are things you can do to prepare for a person’s death.
- There may be spiritual matters to consider when a person is nearing the end of life.
- There are some common signs when a person is nearing death.

People have differing levels of knowledge about dying. They also have differing views about how much they want to know. Some want to know what to expect; others prefer not to know.

Unlike other big events in life such as birth, a new house or a new job, dying is not often discussed. Talking about dying can be hard. There is no right or wrong way to deal with death and dying. Your beliefs, values, culture, experiences and circumstances will shape your own view.

If this information stirs up emotions for you, ask for support from those around you, or contact your doctor or the palliative care team for further information about support.

The last few weeks of someone’s life

The last few weeks of someone’s life can be full of physical and emotional changes. If you are a carer it will help if you understand what to expect. Your role will change as the person becomes less able to do things for themselves.

As people approach the end of their life, new issues can arise. A new symptom may become apparent or an existing one may get worse. A person approaching the end of life is likely to be less able to do the things that they did before.

Keep in touch with the palliative care nurses and other health professionals to talk about what is happening. This can help you to feel less alone.

With the palliative care team in close contact with you and assisting with issues as they arise, there shouldn’t be any need for the person to be admitted to hospital. By having things in place with the palliative care team, such as after-hours contact numbers, you can avoid the need to call for an ambulance.

You may want to talk about end of life arrangements to ensure they are in order before your relative or friend dies. This could include:

- making sure they have an up-to-date will
- making sure that they have told someone where their important paperwork is
- knowing any particular wishes for their funeral.

This information may have already been documented in an advance care directive. The person may have also already appointed a medical treatment decision maker. There is more information on recording wishes for future care and related matters in the section on advance care plans.

Preparing for the end of someone’s life

You can do things to prepare yourself as someone approaches the last few weeks and days of life. You may want to sit with the dying person, sometimes for hours. This does not mean that you will be there when they die. The person may die when you are out of the room. This happens a lot. You shouldn’t feel guilty about this.

Often there are signs that death is imminent and you can get family and friends together. Sometimes, a person will die quickly without some of the warning signs.
You may have seen someone die before but every death is different and you cannot predict what will happen. You may feel that you just want it all to be over. This doesn’t mean that you wish the person dead. It may mean that you just want them to be relieved of their distress.

Sometimes the person says they are bored or depressed, or are tired of being a burden or just ‘want it to end’. Comments like this can cause concern for others but are very common. Often just acknowledging your relative’s feelings can help. If unsure what to say or do, ask a palliative care team member; they have good skills at dealing with this stage of life.

**Spiritual care at the end of life**

Spiritual care refers to any support related to questions about life’s meaning, depending on the person’s values and beliefs. It is broader than formal religious practices. A person facing death may have more questions about their own mortality or what happens after death.

If the person is not religious, there may be other things about their life’s meaning that provide comfort such as family or friends gathering around, favourite music or pets being present.

If spiritual issues become a concern, seek guidance from the palliative care team or a pastoral care worker. While these matters are usually very personal, palliative care staff regard spiritual issues as a very important part of the care they provide.

You can find more information under ‘Emotional, spiritual and cultural care’.

**Nearing death**

This can be a time when relatives and friends feel they are waiting with a sense of anticipation. You may feel like you’ve ‘had enough’. Thoughts and feelings like this are normal and very common among family members and people providing care.

Sometimes the dying process happens over a few days. This can be distressing for some people. If you are in a hospital or residential care facility, ask what they have available for visitors. Access to tea and coffee or extra chairs can make your time more comfortable.

As someone approaches the end of their life they may become more drowsy. As a person is dying they will have less energy and become easily tired. They are likely to become weaker and may spend more time asleep.

They may become detached from reality, or unaware of what is happening around them. They may be less interested in eating and drinking. They may need changes in medications and visits from health professionals.

No one can give an exact answer of when someone will die. However, the timing of someone dying can be easier to predict the closer the person is to death. Rather than dwelling on how long it might be, this time is best used to express feelings and share cherished moments together.

There are some common indicators that death may be near, within days or weeks. Usually more than half the following signs will be present:

- spending large amounts of the day in bed
- being unable to move from bed to chair without help
- difficulty swallowing solid food
- sleeping for many hours
- not talking very much
- occasional confusion with time, the past and with people
- restlessness
- being unable to ask to go to the toilet
- changes in breathing.

Ask the palliative care team if you want more information or help identifying if death is close. Sometimes death may still occur without much warning, with some or many of these signs not occurring.

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Dying

For many people, dying is peaceful. The person may not always recognise others and may lapse in and out of consciousness. Some people have phases where they wake again and can talk, and then slip back into unconsciousness. There can be a change in colour, in circulation or in breathing patterns as the body begins to ‘let go’ of life.

The person will usually slip slowly into complete unconsciousness. They can’t be woken at all but may still be able to hear and be aware of the people around them. Each person’s death is individual, just as their life is.

For some people, dying may include restlessness. This and any other concerning symptoms can usually be treated. The palliative care team will expect to spend more time with you in these later stages, so ask for help if you are concerned.

You can bring great benefit to a person dying, just by being there, sitting with them, holding their hand or speaking in a calm and reassuring way. These simple things should not be underestimated. Even when the person does not respond, they can probably hear you.

Immediately after a death

Immediately after a death is often a peaceful time. You, family and friends may just want to sit with the person. You may or may not want to be alone. Family and friends can help you during this time, sometimes just by being there.

An expected death is not an emergency. You don’t need to call for the police or an ambulance. A doctor will need to come and certify the death. If the person was expected to die this is not urgent. The palliative care team can give you more guidance on what to do.

At home there are things that you will need to organise. A written plan of action prepared in advance will help. This could be a list of things to do, with names and phone numbers. Consider which family members and friends you would ring.

For more detailed information visit the BHC End of life and palliative care services page, under the ‘What to do after someone dies’ tab.

Where to get help

- For more information about the final weeks, days and hours of life, visit Caresearch.
- Visit Palliative Care Australia for the resource The dying process.
- For more detailed information about caring for someone as they approach the end of life download the booklet Supporting a person who needs palliative care.

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