

At the End

There are things that can help us to prepare as someone approaches the last few weeks and days of life. Having information can help to make choices.

People vary in what they know, understand and believe about death and dying. They also differ in what they want to know. Each individual should choose how informed about death and dying they want to be.



Place of care, place of death

You may prefer to be cared for and die at home. You may want to be cared for at home but to spend your final days in a hospice or hospital. If you find that you are in a hospital or hospice, you may want to go home to die.

Home can have different meanings. For older people, an aged care facility may be their home. Some Aboriginal and Torres Strait Islander people want to go home 'to country'. Being at home may not be as important for you as being able to be with family or friends.

Sometimes though, people can die unexpectedly and not where they planned. Your preferences and choices can change over time. There may need to be continuing discussions about what is the best place for care. This will often depend on what care is available in any place, and where symptom control and comfort can be best provided.

Sometimes a change in the place of care is unavoidable. If this happens, everyone

needs to be aware of your condition and your wishes. They also need to know what your carer wants or needs. Ask questions if things seem to be changing, or if arrangements are not clear.

Preparing for the end

You can make decisions about how you want to be cared for as you move towards the end of your life.

You may have already written this in an advance care directive or advance care plan. Or you may have discussed your wishes with your carer or family.

Where possible, play a part in making decisions about your care, treatments, or medications. Ask questions such as:

- Are treatments and medications still helping?
- Is it time to stop some treatments that are no longer adding to comfort?
- Does your carer need more help?

Information for carers:

Caring at the end

Over time as an illness progresses, you may need to provide more care. Being free of symptoms like pain and nausea is important. They may need changes in medications. Doctors and nurses can help you in managing any change in symptoms such as frequency and severity.

Ability to move will change over time. It might take more effort for the person to walk or stand up from a chair or the toilet. An occupational therapist or physiotherapist can guide you in how to manage these changes. It is important to ask for help.

Changes at the time of death: As a person is dying, they will experience changes. They may become:

- Drowsier
- Detached from reality
- Unaware of what is happening around them
- Less interested in eating and drinking.

You or the person you are caring for may want to know what happens as death approaches. There are common changes that most people will go through. This can be a change in skin colour, in circulation or breathing patterns. However, each person's death is individual, just as their life is.

Immediately after death

The time immediately after a death might be a peaceful time. You might also find it very distressing. You may also feel very tired, physically and emotionally tired. This is normal too. At home there are things that you will need to organise.

It may help if you have a written plan of action prepared in advance. This could be a list of things to do, with names and phone numbers. Consider which family and friends you will need to phone.

An expected death is not an emergency. You don't need to call for the police or for an ambulance. You may want to call a friend or family member to be with you. Ring the community nurse or the doctor to let them know what has happened. A doctor will need to come and certify the death. If the person was expected to die this is not urgent.

A doctor may have seen the person recently. If so, and they die at home during the night, it is possible to wait until morning to call the doctor. You may want to spend quiet time with the person who has died before you ring anyone.

CareSearch is a website that has been developed to provide trustworthy information about palliative care. For more information on this topic visit www.caresearch.com.au