

Heading into the last days of life



When someone with an advanced illness approaches death, it is usually a gradual and peaceful process, with pain and suffering kept to a minimum.

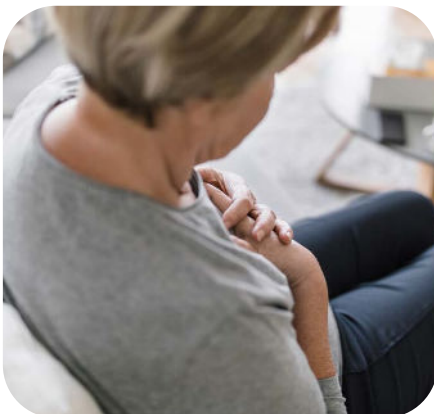
How can you tell when an illness or condition is advancing?

You may notice that the person you are caring for has a change in symptoms and may require more support from you and others.

Perhaps they are beginning to consider end-of-life issues and are feeling anxious, frustrated and helpless, as well as the need to get organised and be prepared.

Psychosocial care needs

As the end-of-life approaches the person you are caring for may begin to reflect on their life, consider their spiritual or religious beliefs, plan where they would like to die, who they would like to have with them and how they would like it to happen.



Spiritual and religious beliefs

Spirituality means different things to different people. It can include religious beliefs or practices, their personal view of the world or a connection to something bigger than ourselves that helps them make meaning of life. With impending death, belief systems often become more important.

Some people seek spiritual support from their priest, elder, minister, rabbi, or imam. Others find comfort in meditation or prayer and the knowledge that others are praying for them.

Others may find their illness or condition has challenged their beliefs and need to talk this through with family, friends or a pastoral care worker. People with no faith or religion may wish to explore this.

Those with a personal philosophy on life may wish to share this through conversation, by writing their thoughts down or recording them in another way.

Intimacy

It is important to recognise that when someone is dying they still experience normal feelings and emotions. Being physically close and touching another human being is a basic need which may become even stronger during the last days of life.

This may include physical intimacy with a partner, but also includes time with children, parents and other loved ones.

When someone is dying, priorities can shift and often relationships and connection become their first priority.

Massage is one form of touch that can facilitate feelings of closeness and connection as well as improve physical comfort. However some people may withdraw from intimacy, touch or social contact. There is no right or wrong way for a person to feel.

Indications of approaching death

It is difficult to predict when someone is about to die, so you may need to prepare yourself for the person you are caring for dying earlier or later than you expected.

Even if you have witnessed death before, it is important to ask questions of the health care professionals involved in care so you feel as informed and supported as possible.

Everyone's death is different. Indications that death is approaching are listed below, but not everybody experiences these changes and they do not occur in any particular order.

Sleeping more and eating less

The person you are caring for may become drowsy and sleep a lot. You can move their position in bed if you think they are uncomfortable, but in the last few hours there is often no need to move them at all.

This inactivity reduces their need for food and fluid, so they may stop eating or drinking altogether. This usually does not cause them any discomfort and is a normal part of the body's preparation for death.

Becoming vague, confused or restless

Sometimes people can become restless in the 24–48 hours before they die. This is not necessarily the result of pain, particularly if they have not experienced any pain prior. Try to reassure them by explaining who you are, speaking calmly, softening lighting and playing their favourite music. Have someone stay beside them as much as possible, holding their hand if this is calming. They may be easily startled if someone enters the room, so use a gentle introduction when someone comes in to indicate their presence. If restlessness is distressing, speak with your visiting nurse or medical service for an assessment in case a cause can be identified.

Changes in vision and hearing

They may experience clouded vision, a faraway look in their eyes, or seem unable to focus on anything or anyone. Although they may not be responsive to conversation, they may find familiar voices calming, as hearing is believed to be the last sense that is affected. Encourage family, friends and other visitors to talk with the person who is dying and one another so the person is aware they have company.

Incontinence

Loss of bladder and bowel control may occur when the person is very near death, but their reduced food and fluid intake means excreta is likely to be minimal. You may need incontinence pads to maintain comfort and hygiene and a draw sheet to protect the bed.

Breathing

When someone is approaching death usually their breathing pattern changes. You may notice gaps in breathing of several seconds or several minutes. This is normal and does not require treatment. Sometimes the dying person may make sounds as they breathe which can be distressing to hear. This is caused by saliva and secretions collecting at the back of their throat, because of their reduced ability to swallow. It is not distressing for the person who is dying. Sometimes elevating or repositioning their head or laying them on their side can reduce these noises, or a doctor may prescribe an injection to reduce the secretions, but this is not always effective.

Changes in colour and temperature

As blood circulation slows, the dying person's arms and legs become cool to the touch and may look mottled and dark. Their face may look pale and their nose may feel cold. Their skin may be clammy and mark easily, bearing the imprint of clothing, bedding or fingers as you provide personal care. Adding a sheet and a couple of warm blankets should be sufficient to make them comfortable, but too much bedding or an electric blanket may make them restless.

It is important for you to take time to talk through these emotions with friends, family, the Palliative Care team or a trusted health care professional such as your GP.

Mixed emotions

As death approaches, you may find that you experience a range of emotions, including being angry that this is happening, scared about what lies ahead, sad at the imminent loss of someone you care for and maybe relieved that soon their suffering will be over. The process may also leave you thinking about your own life and mortality.

You may feel that you just want it all over and done with. Most people in this situation have times when they feel like this, reflecting the strain they are under. It is a very understandable reaction, so it is important to talk so you do not feel guilty about these thoughts.

These responses are all normal and to be expected in such a stressful situation.



Saying goodbye

Caring for someone with a life-limiting illness can allow you time to say goodbye in ways that feel most meaningful to you. This may take the form of an intimate conversation with them, telling them what they mean to you and how you might remember them. You might choose to listen to favourite music together or just hold hands in silence. You might choose to say goodbye in a variety of different ways over a number of days. This is a personal experience so do what feels most appropriate for you.

Preparing your family

As a community, we are generally not comfortable talking about death and dying. It might be useful to start having these conversations with family and friends when the dying person's symptoms change in frequency and severity.

Even if the person who is dying is unable to talk or respond, encourage family to talk to them and tell stories, or explain what they mean to them.

It is important to ensure children are given a choice about visiting the person who is dying, and options for their involvement and interaction.

Some people feel awkward about what to say or do when visiting someone who is dying, so it might help to:

- Focus on listening rather than talking.
- Encourage the dying person to talk about their life, as talking about memories will help reinforce that their life mattered and that they will be remembered.
- Ask gentle questions that maybe encourage sharing e.g. is there something you would like to talk about?
- Try to converse as normally as possible by sharing what is happening in their life.
- Watch television, listen to music, or just sit in comfortable silence; company may be just as soothing as talking.

Crying is a natural way of expressing grief, so reassure visitors that there is no need to be embarrassed about it.

Useful contacts

Australian Indigenous Health InfoNet

- ☎ (08) 9370 6336
- 🖱 healthinfonet.ecu.edu.au/learn/health-system/palliative-care

Cancer Council NSW

- ☎ 13 11 20
- 🖱 cancercouncil.com.au

Carer Gateway

- ☎ 1800 422 737
- 🖱 carergateway.gov.au

Carers NSW

- ☎ (02) 9280 4744
- 🖱 carersnsw.org.au

Caresearch

- ☎ (08) 7221 8233
- 🖱 caresearch.com.au

Centrelink

- ☎ 13 27 17
- 🖱 servicesaustralia.gov.au

Dementia Australia NSW

- ☎ 1800 100 500
- 🖱 dementia.org.au

GriefLine National

- ☎ 1300 845 745
- 🖱 griefline.org.au

Leukaemia Foundation

- ☎ 1800 620 420
- ✉ info@leukaemia.org.au
- 🖱 leukaemia.org.au

Lifeline

- ☎ 13 11 14
- 🖱 lifeline.org.au

My Aged Care

- ☎ 1800 200 422
 - 🖱 myagedcare.gov.au
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My Health Record

- ☎ 1800 723 471
- 🖱 myhealthrecord.gov.au

National Disability Insurance Service (NDIS)

- ☎ 1800 800 110
- 🖱 ndis.gov.au

National Stroke Foundation

- ☎ StrokeLine: 1800 787 653
- 🖱 strokefoundation.org.au

NSW Trustee & Guardian

- ☎ 1300 109 290
- 🖱 tag.nsw.gov.au

Palliative Care NSW

- ☎ (02) 8076 5600
- 🖱 palliativecarensw.org.au

Relationships Australia

- ☎ 1300 364 277
- 🖱 relationships.org.au

Services Australia

- ☎ servicesaustralia.gov.au/individuals/contact-us/phone-us
- 🖱 servicesaustralia.gov.au

The Department of Veteran's Affairs

- ☎ General enquiries: 1800 838 372
- ☎ Counselling Service: 1800 011 046
- 🖱 dva.gov.au

If you require an interpreter, contact the Translating and Interpreting Service (TIS National)

- ☎ 13 14 50
- 🖱 tisnational.gov.au

If you have a hearing or speech impairment, contact the National Relay Service

- ☎ 24 hour relay call numbers
TTY/voice calls: 133 677
Speak and Listen: 1300 555 727
SMS Relay: 0423 677 767
- 🖱 relayservice.gov.au

Caring for someone as they approach the end of their life can be both rewarding and demanding. It is hoped that this book will help to explain what caring involves, so you are better equipped to make informed decisions which reflect your needs and circumstances.

You matter.



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