

Symptoms



The way we feel pain is affected by many other factors in our life such as stress, anxiety, sleep and our past experiences of pain.

Pain

The symptom most feared by people with a life-limiting illness is pain. Although it is a common symptom in some conditions, not everyone with a life-limiting illness experiences pain.

To manage pain effectively, it is important for your Palliative Care team to consider and discuss all the factors that are affecting the pain experienced by the person you are caring for.

A holistic management plan can then be developed, which may involve setting realistic goals, exercise, mobility and positioning aides, hobbies and discussions with a counsellor or social worker.

Taking medications is usually part of the pain management plan.



Medications to manage pain are called analgesics. There are many analgesics, and the doctor will consider the type of pain and its severity when prescribing. Taking the right analgesic in the right dose will assist the person you are caring for to continue doing the things that are important to them.

In general, people with a life-limiting illness will take analgesics at the same times each day in order to manage constant or background pain. Additional doses of medication can be taken when the regular dose is not enough to manage a flare in pain, termed breakthrough pain, which may occur after showering or exercise.

Analgesic medications come in various forms including tablets, syrups, suppositories, injections or skin patches, and may include morphine or similar strong analgesics.

Constipation

Constipation is a common problem in people with a life-limiting illness. It can be caused by reduced physical activity, a changed diet, reduced fluid intake and analgesic medications including morphine.

It is normal to need laxatives to keep the bowel working well. Encourage the person you're caring for to drink plenty of fluids, keep as mobile as possible and take laxatives regularly.

Nausea and vomiting

There are many reasons for nausea and vomiting. Medications can be prescribed to help but you may also consider reducing exposure to various triggers such as strong smells (perfumes or cooking).

Nausea may be reduced by simple measures such as fresh air, adjusting the body position or by sipping cool fluids such as lemonade, sports drinks, juices or cordial. Providing mouth care may also help.

Weight loss and decreased appetite

Loss of appetite in life-limiting illness is common and can be distressing for carers. Attempting to increase food consumption may be difficult and cause unnecessary tension, particularly if the person you are caring for has no appetite. They may want to avoid looking in the mirror if they find the change in their body size upsetting.

Avoiding regular weight checks is also recommended as weight loss can still occur even when eating. Buying new clothes or adapting existing items so they fit may help them feel better. You may also find adding extra padding to the

bed or chairs makes them more comfortable, and that they need more clothing, bedding or heating than normal in order to stay warm.

Fatigue

Fatigue is a debilitating symptom of a life-limiting illness which is often described as an overwhelming feeling of exhaustion. It is normal as the disease progresses for the person to need to spend more time sitting in a chair or more time in bed.

Some people find supplements or vitamins helpful in building their energy levels. Light activity or exercise, if possible, may also help.

Prioritise activities that are most important for the person – this might mean choosing to save energy for family or friend visits by showering every second day.

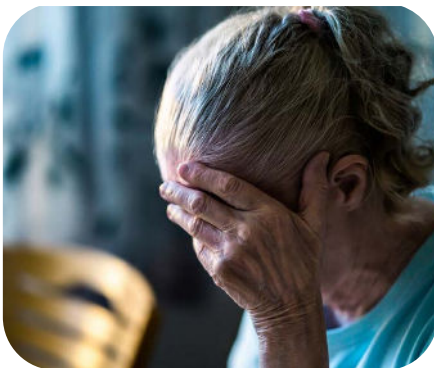
Encourage the person you are caring for to balance periods of activity with periods of rest before they get tired. Offer help and a chair for some activities. Arrange items used daily between waist and shoulder height so they are easy to reach. Allow a little more time to get things done and cut out unnecessary tasks or steps to conserve energy.

Confusion

Confusion or delirium is not uncommon in people with a life-limiting illness. It is not a sign of mental illness or dementia. It may be caused by a number of factors, including medications or medical conditions.

You can help to lessen confusion by keeping to a routine and having familiar things and people around. Try to have the house light during the day and dark at night and have a clock in view. Keep the surroundings quiet and calm.

Consider whether familiar music may be comforting. If they are disorientated they may need to be reminded where they are and supervised when walking. Night-lights in the hallway and toilet may help prevent falls. An assessment by your visiting health professional is recommended for ongoing or severe confusion.



Breathing problems

Difficulty breathing, also called dyspnoea, is a common symptom and often increases as the end of life approaches. It can be very distressing for the person with the condition and for the carer to observe.

It may help to open windows, be outside or have a fan blowing gently near the person's face. Medications are sometimes useful.

Finding ways to relax and reduce anxiety caused by breathlessness can also help. Ask your doctor or Palliative Care team for assistance.

Depression and anxiety

Identifying depression can be difficult due to the changes of advancing disease. However, if the person you are caring for shows signs of persistent low mood, irritability, insomnia, expressing fears and feelings of loss of control, loss of dignity or being a burden and a general pervasive sense of hopelessness and helplessness, they may be suffering from depression and/or anxiety.

It is important to share these concerns with the person you are caring for and seek help from your doctor or Palliative Care team.

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
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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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