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## Managing your pain and other symptoms during a life-limiting illness

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### Summary

- Common symptoms at end of life may include pain, nausea, constipation, breathlessness and fatigue.
  - Relieving symptoms is a key aim of palliative care
  - There are effective ways of reducing pain through the use of pain-relieving medicines, and complementary therapies
  - Use a pain diary and medication chart to keep track of symptoms and changes.
  - Most palliative care medication is supported by the Pharmaceutical Benefits Scheme.
  - Ask your doctor questions if there is anything you do not understand.
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Pain management is a key part of end of life and palliative care. If your pain is well managed, you will have a better quality of life. You are likely to sleep better and have more energy during the day. If you feel less pain, you can be more active, which also reduces your risk of complications.

We all feel discomfort in different ways and people experience pain differently. Not all people who need palliative care suffer ongoing pain.

### Managing pain with pain medication

Pain relievers (or analgesics) are used frequently in end of life and palliative care. Always follow the instructions for taking your pain medication. Talk to your doctor or pharmacist if your medicines lose their ability to reduce your pain or are causing side effects. This can occur if you are taking pain relief medications for a long time.

Let your doctor know if you are taking (or are about to take) any over-the-counter medication, herbal remedies or natural supplements as they may react with other medication you take.

Keep a good supply of your pain medication on hand so you do not run out.

### Side effects of pain medication

Pain medication can cause side effects but most of these are temporary or can be managed easily. Side effects of pain medication include constipation, nausea and vomiting, drowsiness or confusion, dry mouth or itchy skin. Speak to your doctor or palliative care team if any of these side effects occur.

### Concerns about opioid use for pain management

Opioids (such as morphine) are prescribed for some types of pain that do not respond to milder medicines. For people with a life-limiting illness, opioids usually provide the best relief for most pain; they are predictable in their effect and the dose can be adjusted precisely.

Some people fear opioids because they think they might cause addiction or hasten death. People who take opioids for opioid-responsive pain do not become addicted to them. It may be reassuring to know that the body naturally makes chemicals (endorphins) that work in the same way as opioids. It's also important to know that what causes death is the underlying disease, not the medication, when taken as prescribed. People with a life-limiting illness often take opioids for long periods without death being close.

If your doctor suggests the use of opioids, it is important that you know about the effect of these medicines and why they are used. Ask your doctor and palliative care nurse for more information. If side effects do occur, your doctor will manage them by prescribing other medicines, such as an anti-nausea tablet, or by carefully reducing the opioid dose.

### Managing pain using complementary therapies and self-management techniques

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You can lower your everyday levels of pain by learning some self-management techniques and using complementary therapies. You can use these as well as taking your pain-relieving medication. Your GP or palliative care team may be able to recommend reputable complementary therapists. Helpful therapies may include:

- **heat or cold (used safely)** – heat packs can aid relief of chronic musculoskeletal pain. An icepack can be used to help reduce swelling immediately after an injury, such as after a fall
- **physical therapies** – walking, stretching and muscle strengthening exercises may help relieve pain. Physical activity can also help you maintain mobility and improve your mood. Ask a physiotherapist or osteopath to design a program specifically for your pain condition
- **breathing and relaxation – correct breathing technique** [<http://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/decrease-stress-by-using-your-breath/art-20267197?pg=2>], using the diaphragm and abdomen, can soothe the nervous system and manage stress
- **hypnotherapy** – uses imagery to induce a dreamy, relaxed state of mind. Hypnotherapy can also help to ease some of the side effects of cancer treatment, such as nausea
- **massage** – soothes muscles, encourages relaxation and increases circulation to the area being massaged
- **meditation** – the deliberate clearing of the mind to bring about feelings of calm and heightened awareness. The regular practice of meditation offers many long-term health benefits, such as reduced stress and blood pressure
- **tai chi** – a Chinese form of non-combative martial arts that consists of gentle movements to clear the mind and relax the body
- **yoga** – an ancient Indian system of postures that are done in time with the breath
- **mindfulness** – techniques in meditation and other attention exercises to assist your wellbeing
- **acupuncture** – this ancient form of Chinese medicine involves inserting and stimulating fine needles into specific points of the skin. Scientific studies have proven acupuncture to be an effective treatment in some pain syndromes, but there is little research into cancer pain.
- **transcutaneous electrical nerve stimulation (TENS)** – a very small electrical current is passed through the skin via electrodes, causing a pain-relieving response from the body.

Always check with your GP or palliative care team before beginning a new type of pain management treatment and follow their instructions carefully to avoid making your pain worse.

### Talking to your GP or palliative care team about pain

The palliative care team and your GP work together to enhance your quality of life. This includes managing your pain so you can focus on the things you enjoy. If your pain changes or is concerning, contact them and describe the problem. The GP or palliative care team will ask you:

- Where is the pain?
- How long has the pain has been there?
- What type of pain is it – sharp, tingling or aching?
- Is it a new type of pain?
- Is the pain persistent, or does it come and go?
- Have any other lifestyle changes occurred?
- Do you feel like vomiting?
- When did you last have a bowel movement? (Constipation can cause pain.)
- How would you rate the pain on a scale of one to ten? (1 being 'no pain' through to 10 being 'excruciating pain') Anything scoring more than 4 out of 10 is regarded as pain that needs attention.

### Keeping a pain diary

If you are having difficulty keeping track of when your symptoms occur, it is a good idea to use a pain diary. By recording your pain every time it occurs, your healthcare team can chart the changes and make sure your medications are working correctly.

Medication charts are also useful tools. They can help you to remember to take your medication, take the right dose, and chart changes and progression of your symptoms. Ask your GP or palliative care team about using a medication chart.

Talk to your doctor or palliative care provider about setting up a pain diary or medication chart. Alternatively, you could download a [pain diary](#) from the Pharmacy Guild of Australia.

### **Managing nausea**

You have nausea when you feel the urge to vomit or just feel sick. Nausea can be due to the disease itself, or occur as a result of medications, chemotherapy, radiotherapy, constipation or an imbalance of chemicals within the body.

If you have been prescribed anti-nausea medicines, and you feel nauseous, take them as directed, unless the thought of trying to take a tablet makes you feel worse.

Some people prefer not to eat or drink anything until the nausea passes; others find small amounts of food or drinks helpful. Rest or try deep breathing or play some soft music. A massage or bath or shower may help.

If nausea is not relieved after one hour or gets worse, contact your doctor or the palliative care team.

### **Managing constipation**

Constipation occurs when your bowels do not open for several days. This can cause nausea, pain and tiredness. Constipation can occur due to not drinking enough fluids, limited mobility, poor diet or the illness itself. It can also be a side effect of medication or some treatments. In most instances constipation can be prevented.

To prevent constipation:

- drink plenty of fluids such as water or juice
- eat foods high in fibre
- take a short walk each day if you are up to it
- ask your doctor to prescribe a laxative if you have been prescribed strong pain medicines (such as morphine).

### **Treating constipation**

If you have not had a bowel action for several days longer than usual, speak with your palliative care team, who will set up a plan specific to your needs.

There are many natural and over-the-counter remedies for constipation that can be used in conjunction with prescribed medicines. Ask a member of the palliative care team for suggestions.

Treating constipation may include:

- dietary changes – such as increasing the amount of fibre in the daily diet
- more fluids – liquids help to plump out faeces, however, it is important to restrict the intake of diuretic drinks such as tea, coffee and alcohol
- fibre supplements – these may be helpful if you are reluctant or unable to include more wholegrain foods, fresh fruits or vegetables in your daily diet
- exercise, if able – one of the many benefits of regular exercise is improved bowel motility
- removal of the impacted faeces – which may involve enemas, stool softeners and a short-term course of laxatives.

For more detailed information about constipation generally, see the BHC [constipation](#) fact sheet.

### **Managing breathlessness**

Breathlessness is an unpleasant feeling of having difficulty breathing. It can be caused by lung disease, asthma, emphysema, chest infection, pressure from other body organs, or anxiety. Being breathless can cause further anxiety and distress.

If you are feeling breathless, tell someone and ask them to stay with you. Sit in an upright position. If you can, turn on a fan or open a window. Wearing loose fitting clothing or listening to calming music may also help.

If you have been prescribed medicines for breathlessness, take them as directed. (Morphine is often effective for relieving breathlessness.) If the breathlessness is not relieved and is causing distress, phone your GP or the palliative care team.

### **Managing fatigue**

Fatigue is very common in people with life-limiting illness. It is a feeling of weariness, tiredness, or lack of energy that does not go away when you rest. You may feel fatigued in body or mind. Fatigue may reduce your ability to be active, and can be frustrating and debilitating.

Possible causes of fatigue are lack of sleep, low blood oxygen levels, poor diet, depression, effect of chemotherapy or radiotherapy, infection, or the effects of the disease itself. The following strategies may help manage fatigue:

- Have short naps during the day.
- Do some regular gentle exercise.
- Have nutritious food and drinks.
- Plan the most energetic tasks (such as having a shower or bath) when your energy levels are higher.
- Take up a hobby that does not require a lot of energy. For example, board games, talking books, listening to the radio or watching television or videos.

If you think your fatigue has become worse, speak with your GP or palliative care team.

For further information on assessing and managing common symptoms, visit the page '[Dealing with common symptoms](#)'

### **Cost of medication**

Many medications used in end of life and palliative care are supported by the Pharmaceutical Benefits Scheme (PBS), which means that the Australian Government covers most of the cost. If you cannot afford your medication, talk to your doctor.

Most branded medication is also available through generic brands at a lower cost. Speak to your pharmacist about finding lower cost medication that has the same active ingredient.

You are entitled to extra discounts through the PBS if you hold any the following cards:

- Australian Seniors Health Card
- Health Care Card
- Pensioner Concession Card
- Department of Veterans' Affairs (DVA) Gold, Orange or White Card.

For more information see the PBS information on our [Paying for healthcare](#) fact sheet.

### **Ask questions about managing your pain and other symptoms**

Asking questions not only helps you understand what is happening with your condition but also helps you make decisions relating to your care.

If your doctor uses words you don't understand (for example, when describing test results, treatment options or the side effects of medication), ask them to explain it again.

*Acknowledgment: Adapted from Hudson P and Hudson R 2012, Supporting a person who needs palliative care – a guide for family and friends, Palliative Care Victoria, and Palliative Care Expert Group 2016, Therapeutic Guidelines: Palliative Care Versions 3 and 4, Therapeutic Guidelines Limited, Melbourne.*

**This page has been produced in consultation with and approved by:**

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