Palliative care – dealing with common symptoms

Summary

- Common symptoms at end of life may include pain, constipation, nausea, breathlessness, fatigue and delirium.
- Relieving these 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.

Every person is different and symptoms experienced at end of life vary. Some common symptoms are pain, constipation, nausea, tiredness, breathlessness, fatigue and delirium.

In most cases symptoms can be controlled to a comfortable level, but some symptoms may not disappear completely.

Relief of symptoms is one of the major aims of the palliative care team. As a carer, you can help the person you are caring for by assisting them in recognising and managing their symptoms. Only do this if you feel comfortable doing so and if your relative is happy for you to do so. Otherwise, contact your GP or a palliative care team member if you are concerned about symptom management.

Pain

Many people worry about the comfort of their loved one and their level of pain as end of life nears. Pain management is a key part of end of life and palliative care. If pain is well managed, quality of life will be better. The person is likely to sleep better and have more energy during the day. If they feel less pain, they can be more active, which also reduces the 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. Some people may feel uncomfortable if they feel sick, tired, worried or restless and this can result in feeling more pain. The palliative care team and the person’s GP aim to reduce the pain as much as possible. Although there have been many advances in treatment of pain, it may not always be completely eliminated.

Managing pain with pain medication

Pain relievers (or analgesics) are used frequently in end of life and palliative care. Ensure the person follows the instructions for taking their pain medication. Talk to the person’s doctor or pharmacist if you think the medicines are losing their ability to reduce pain or are causing side effects. This can occur if the person is taking pain relief medications for a long time.

Let your doctor know if the person you’re caring for considers taking any over-the-counter medication, herbal remedies or natural supplements as they may react with other medication.

Ensure there is a good supply of pain medication so it doesn’t 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 in the person you are caring for.

Assessing pain

If you are concerned about your loved one’s pain, use the following guide. It helps to have this information if the pain does not ease and you need to call the palliative care team or doctor. Ask:
Where is the pain?
How long has the pain 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.**

Managing pain
In order to help the person manage their pain:

- Ask them to lie on the bed or to sit down.
- Ask them to take 10 deep breaths.
- If they have been given some medicines for pain, check first to see what pain medicines they have already taken that day. If they have had as much as they are allowed, contact the palliative care service. Otherwise give the medication as directed on the container.
- Try to take their mind off the pain by encouraging them to read, watch television or listen to music.
- Suggest a complementary or self-management technique [link to Natural techniques for managing pain (Is it possible to link to an ?)] such as those listed below.
- If you think nausea (feeling like vomiting) or constipation (no bowel action for several days) may be causing the pain, refer to sections on nausea [link to Nausea ] and constipation [link to Constipation ] below.
- If the discomfort has not eased after 30 minutes phone the palliative care team. They will be able to review the problem and suggest other ways to reduce the pain.

Managing pain using complementary therapies and self-management techniques
These therapies and techniques can be used to manage pain, as well as taking pain-relieving medication. Deep physical and mental relaxation can reduce anxiety and ongoing pain. Your relative’s doctor may be able to recommend reputable therapists for natural pain relief.

Helpful therapies may include:

- heat or cold (used safely) – heat packs can aid relief of chronic musculoskeletal injuries and associated 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, depending on its cause. Physical activity can also help people to maintain mobility and improve mood. A physiotherapist or osteopath can design a specific program
- 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 series of postures that are done in time with the breath
- acupuncture – this ancient form of Chinese medicine involves inserting fine needles into the skin at specific

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points. It can be an effective treatment in some pain syndromes, but there is little research into acupuncture and 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.**

**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.

**Nausea**

Nausea is when a person feels the urge to vomit or just feels sick. The cause of nausea can be related to the disease, medications, chemotherapy, radiotherapy, constipation or an imbalance of chemicals within the body.

If your relative has nausea follow this guide:

- Ensure a bowl or bucket is within easy reach in case they vomit.
- Ask how they rate the nausea on a scale from 1 to 5. (1 being ‘very little’ nausea and 5 being ‘extreme’ nausea).
- If anti-nausea medicines have been prescribed, check to see if they have been taken as directed. If the prescription allows, give the anti-nausea medication – unless the thought of trying to take a tablet makes your relative feel worse.
- If your relative prefers, do not give them anything to eat or drink until the nausea passes. Alternatively, they may find that small amounts of food or drinks help them feel better.
- Ask when was the last time they had a good bowel motion. If it is longer than two days ago, follow the ‘Treating constipation’ directions below.
- Encourage your relative to rest. Suggest deep breathing. Play some soft music. Offer a foot or neck massage. If your relative feels up to it, a bath or shower may help.
- If nausea is not relieved after one hour or if it gets worse, contact the palliative care team.

**Constipation**

Constipation occurs when a person does not open their bowels for several days longer than the usual time for this person. This symptom can cause nausea, pain and tiredness. Constipation can occur due to decreased fluid intake, limited mobility, poor diet or the person’s illness. It can also be a side effect of medication or some treatments. In most instances constipation can be prevented.

**Preventing constipation**

In order to prevent constipation, encourage the person to:

- drink plenty of fluids such as water and juice
- eat foods high in fibre, if possible
- have a short walk each day, if they feel up to it
- ask their doctor to prescribe a laxative if they have been prescribed strong pain medicines (such as

[link to Treating constipation]

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Do not assume that if your relative is not eating they do not need to use their bowels – constipation can still occur even when little food is eaten. If you think the person is becoming constipated, keep a record of when their bowel actions occur. Note the nature of their bowel actions (are they hard, soft, small, or liquid?).

**Treating constipation**

If your relative has had no bowel action for several days longer than what is usual for them, speak with the palliative care team, who will set up a plan specific to the person’s 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 the person is reluctant or unable to include more wholegrain foods, fresh fruits or vegetables in their 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.

**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 further cause anxiety and distress.

More specific treatment may be needed but some general tips that may help include:

- Encourage your relative to sit in an upright position and stay with them.
- Put on a fan or open a window.
- Suggest that your relative wear loose fitting clothing.
- Put on some calming music.
- Maintain a gentle, reassuring presence – you could offer a foot, hand or shoulder massage, or hold their hand, if it makes them feel better.
- If medicines for breathlessness have been prescribed, ensure they have been taken as directed. Morphine is often effective for relieving breathlessness.
- Oxygen via a mask or nasal prongs is not routinely needed and requires a doctor’s order to be used.
- If breathlessness is not relieved and is causing distress, phone the person’s GP or palliative care team.

**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. People may feel fatigued in body or mind. Fatigue reduces the ability for people to be active, and can be frustrating and debilitating.

Possible causes are:

- lack of sleep
- low blood oxygen levels
- poor diet
- depression
- effect of chemotherapy or radiotherapy
- infection
• the effects of the illness itself.

The following strategies may help manage fatigue:
• Encourage short naps during the day.
• Suggest regular gentle exercise.
• Encourage nutritious food and drinks.
• Plan to do the most energetic tasks (such as having a shower or bath) when energy levels are higher.
• Encourage your relative to 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 that fatigue has become worse, speak with the person’s GP or palliative care team.

**Delirium**

Delirium is a change in a person’s thinking, memory and behaviour. It can be distressing for the person who has it, and for their family. People with delirium may:
• become confused quickly
• experience sudden and fluctuating changes in behaviour and mood
• not recognise familiar people
• have difficulty remembering new information, concentrating and paying attention
• become fixated on one thing
• have difficulty telling day from night
• experience hallucinations (see things that are not actually there).

Delirium is caused by a disturbance in brain function. It may be caused by several factors, including dehydration, illness, recent surgery, medication or any combination of these. If the person is older, or already has some memory problems, they may be more likely to develop delirium.

**Treating delirium**

The doctors and palliative care team looking after your relative will look for causes of delirium and try to treat them so that the delirium is reduced. Changes in the person’s thinking and behaviour when they have delirium are not usually permanent. However, patients in a palliative care setting may be very ill and close to the end of life. In this situation the thinking, memory and behaviour problems associated with delirium may not be resolved completely.

Suggestions for helping someone with delirium include:
• When you are talking with a person with delirium, make sure you have eye contact with them. Speak slowly and calmly and remind them who you are, where they are and that you are there to help.
• Have family or friends stay with the person whenever possible.
• Try not to have too many visitors at once, or to have too much stimulation such as loud music or television.
• Encourage them to drink fluids as they may get thirsty, especially if they are restless.

Advise the GP or palliative care team if you think there are changes in your relative that might mean they are developing delirium. Provide as much information as you can about your relative’s recent health history. The GP or palliative care team may also ask you about any previous memory problems the person may have experienced. This information can be helpful in diagnosing the cause of the delirium, and preventing its recurrence.

**Complementary therapies**

Complementary therapies are treatments used together with conventional medicine.

Physical and psychological therapies include (among others) massage, acupuncture, reiki, hypnosis, guided imagery and aromatherapy. Music, art and pet therapy are very popular and have been shown to be effective.

Complementary therapies can have beneficial outcomes in some circumstances. However, it is strongly recommended that you speak with a health professional for further information about which complementary therapies might be suitable for your loved one.

It is quite common for people with life threatening illness to consider other medical treatments that are not routinely
used by doctors. This is because people often want to explore all possible treatment options. Discuss these options with your relative’s GP or the palliative care team.

Some palliative care services have links to services that offer complementary therapies.

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.