

Tips for managing common symptoms at end of life



One of the most frequently asked questions from carers is around managing symptoms at the end of life. Below is a list of some of the most common symptoms at the end of life. This is regardless of the type of disease the person you are caring for has.

Always discuss any symptoms that concern you with the health care team. If the person you are caring for has symptoms that are very uncomfortable then you may want to ask your doctor for a referral to a palliative care team. Palliative care is an area of health care that focuses on managing end of life symptoms and improving quality of life.

For any symptoms, we suggest you keep a diary so that you can show the health care team what has been happening, how often, and what you have already tried to manage a symptom.

Breathing changes

Changes to breathing are a common symptom at the end of life. The way a person breathes can change as the body slows down and death approaches. Breathing can also change if a person is anxious or in pain. Breathing as death approaches may be slow, shallow, irregular with long pauses between breathes, rapid or noisy or rattly.

The following tips might be useful:

- Sit with the person you are caring for and provide a reassuring presence
- Use a fan or open a window to increase airflow around the person you are caring for
- Encourage the person to sit upright
- Wear loose fitting clothing
- Put on calming music or offer the person a foot or hand massage
- Encourage the person to drink more water
- Use oxygen if prescribed by a doctor.

If breathlessness is not relieved and is causing distress, talk to your health care team.

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Confusion or delirium

People who experience delirium have difficulty remembering things, trouble concentrating and sometimes may have difficulty distinguishing between day and night. The person with delirium may not recognise familiar people or places, or they may become fixated on one thing or become suspicious. It can sometimes cause hallucinations when people see things that aren't actually there.

Delirium or confusion at the end of life is common and may be reversible or temporary. It can be distressing for you as the carer and also for the person you are caring for.

It is usually caused by a change in brain function which can be a result of the illness or sometimes medicines. It can also happen following a surgery or when someone has an infection.

The doctors treating the person you are caring for will do their best to identify the cause of the delirium and treat it. However, for people who are at the end of life and close to death, the delirium may not fully settle.

Ways to help your family member are to:

- Maintain eye contact

- Speak slowly, reminding them of who you are, where they are and that you are there to help
- If the person you are caring for is in hospital, it may be helpful for you to stay with them (where possible) as people with delirium respond better to familiar people than strangers
- Reduce number of visitors, and reduce stimulation and loud noises such as TV.

Constipation

Constipation is when there is no bowel motion for several days. Constipation can be caused by many things and may cause the person you are caring for to feel nauseated and uncomfortable.

If constipation is causing a problem, talk to the health care team so they can prescribe the most appropriate medication.

Maintaining a healthy bowel can be difficult for someone at the end of life.

If possible:

- Encourage regular drinks such as water and juice
- Suggest that they eat foods high in fibre (as well as regular drinks)
- Encourage them to go for a short walk each day if they feel up to it

- Keep a diary of bowel movements (when they occur, how often, and whether they are hard or soft).

If the person you are caring for is prescribed strong pain medicine, also request laxatives.

If there is no bowel action for two days, talk to your health care team.

Constipation can occur even if the person is not eating much food.

Fatigue

Fatigue is a persistent feeling of tiredness, weakness, or lack of energy and is very common with people who are at the end of life. Fatigue can also present as feeling heavy or heavy-limbed, having an altered sleep pattern, difficulty carrying out usual tasks, memory loss, difficulty with concentration, low mood and lack of motivation.

The possible causes of fatigue include:

- Disease progression, infections, treatment
- The person you are caring for is spending more time in bed
- Muscle weakening and weight loss
- Increased pain
- Loss of appetite, reduced food intake, or poor nutrition
- Breathing difficulties

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- Low oxygen levels or a low blood count or anaemia
- Some medicines used to reduce pain.

Fatigue can be hard to manage but the following tips may help.

- Encourage short naps during the day and good sleep habits at night
- Suggest regular but gentle exercise
- Encourage nutritious food and drinks
- Plan to do the most energetic tasks (e.g shower) when energy levels are higher
- Encourage activities that do not require a lot of energy (board games, audio books, watching TV or reading)
- Avoid activities that tire such as long conversations or lots of visitors.

If you think that the person's fatigue has gotten worse, talk to your health care team. However, it is not always possible to prevent this decline.

Incontinence

At the end of life, people may lose the ability to control their bladder or bowels and pass urine and/or faeces onto their clothing or bedding. This is known as incontinence.

Diarrhoea can cause incontinence. This could be a one-off thing or could be what's

called 'overflow' from when a person is constipated. If the person you are caring for has had constipation and then develops diarrhoea you should talk to the health care team before taking any more medicine for constipation or diarrhoea.

Incontinence can be a result of:

- The disease or illness
- Muscles relaxing at the end of life
- Confusion or an inability to express the need to go to the toilet.

Helping your friend or family member to use a bedpan or go to the toilet may make you and the person you are caring for feel embarrassed and uncomfortable. Please speak to the health care team if you would like assistance.

Suggestions for managing incontinence:

- The health care team can loan equipment such as bedpans, urinals, and a portable toilet or commode chair
- A mattress protector or bed pads can be used to protect bedding
- Absorbent pads or underwear can be used to catch urine and faeces
- Disposable wipes can be used to clean the skin.

Sometimes a urinary catheter can be inserted which drains urine into a bag through a tube.

Nausea

Feeling like you are going to vomit is described as nausea. Feeling nauseated is common for people at the end of life. This may be because they are constipated, have reduced appetite, or due to the medicines they are taking.

It is good to treat nausea early. Ways to help may include:

- Give the person you are caring for any prescribed anti-nausea medication as directed
- Encourage rest and relaxation including deep breathing, listening to soft music, having a foot or hand massage, or a warm bath
- Offer sips of water or ice chips to suck on
- Offer small amounts of bland food more often
- Offer warm ginger or peppermint herbal tea
- Avoid strong odours
- Manage constipation if you suspect that is the cause of the nausea
- If the nausea does not improve in a few hours, please call the health care team.

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Vomiting

If someone is weak, you may need to assist them if they are vomiting. Some important tips when managing vomiting include:

- If the person you are caring for is lying down while vomiting, turn them on their side so they won't inhale the vomit
- The person might like to suck on some ice chips to assist to rehydrate
- There are other ways to give anti-nausea medication other than by mouth, please ask your health care team.

Call the health care team if:

- The person has vomited more than three times for more than three hours
- They start to vomit blood or a dark coloured fluid
- You think they may have choked on some vomit
- They are dizzy and confused
- The urine becomes very dark.

Pain

There are many reasons for pain towards the end of life. To better understand the pain, you

may want to ask the person you are caring for the following questions:

- Where is the pain?
- What does it feel like? Does it feel sharp, throbbing, or burning?
- Is it a new pain?
- How long has it been there?
- When did they last have their bowels open or do a poo? (Constipation can cause pain)
- Do they feel like vomiting?
- Using a pain scale how would you rate the pain from 0 (no pain) to 10 (very bad pain)?

This information will assist the health care team.

Tips on pain medicine:

- Give the person their pain medicine as directed on the label
- Keep track of how often they are having their medicine
- If they have had as much medicine as they are allowed that day and are still having pain, call the health care team.
- Many people are concerned that pain medication will hasten death but this is not the case.

Tips on managing the pain without medicines:

- Ask the person you are caring for to lie on the bed and take 10 deep breaths
- Ask the person you are caring for to try and take their mind off the pain by reading watching TV, or listening to music
- Offer a massage of feet, hands, or shoulders.

The person you are caring for may already have chronic pain however please contact your health care team if:

- The pain medicines are not providing as much relief as they were before
- The pain increases
- Something about their pain changes.

Cool skin

Cool skin can be a common symptom at the end of life. Use warm blankets and keep the person comfortable.

Fever

An increase in body temperature is common. Using a cool and moist cloth on the forehead and neck can be comforting.