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English (Chinese and Vietnamese)

Tips for managing common symptoms at the end of life

Regardless of the disease there are a number of common symptoms that people have when they are at the end of life. This factsheet provides information on common symptoms and tips for managing those symptoms.

It is important to discuss any symptoms that concern you with the health care team. You may want to ask your doctor for a referral to a palliative care team. Palliative care focuses on managing complex symptoms, providing holistic support and improving quality of life.

For any symptoms, we suggest you keep a diary of the severity of the symptom, how often the symptom has occurred, and what you have done to manage the symptom. This information will help the health care team.

Breathing changes

Breathing can change if a person is anxious or in pain. Breathing changes can be a result of the illness or a normal part of the body slowing down at the end of life.

You may notice that the breathing may become 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 as much as you can
- Use a fan or open a window to increase airflow
- Encourage the person to sit upright
- Dress them in loose fitting clothing



- Put on calm 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 continues and is causing distress, talk to your health care team

Confusion or delirium

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

Confusion at the end of life may be reversible or temporary. It is usually caused by a change in brain function due to the illness, can be a result of medicines, can happen following surgery or occur when someone has an infection.

It can be distressing for you as the carer and also for the person you are caring for.

The doctors treating the person will do their best to identify the cause of the confusion and treat it. However, for people who are at the end of life and close to passing away, the confusion may not fully settle even with treatment.

Ways to help your family member are to:

- Maintain eye contact
- Speak slowly, remind 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 they may 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 including medicines, illness and dehydration. It may cause them to feel nauseated and uncomfortable.

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

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
- 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

Emotional Reactions – Depression, Anxiety, Anger

People who are at the end of life are adjusting to physical limitations, discomfort, loss of independence, and ultimately, the knowledge

that they are at the end of life. It is common for people at the end of life to experience a range of emotional reactions including anxiety, fear, sadness, anger, guilt, and hopelessness. Sometimes they will lash out in anger towards those around them or act in ways that are out of character. Sometimes people will withdraw and not want to talk at all. It can be for many different reasons. It could be related to their illness or symptoms, a fear of passing, or concern about what will happen to their loved ones after they are gone.

If at any time you feel unsafe due to the person's aggressive behaviour, please let the health care team know immediately.

It can be helpful to:

- Provide them with some time alone each day, if desired
- Ask if there is anything you can do to help or if they want to talk about their worries
- Ask them if they want help to get their affairs in order or reconnect with anyone
- Suggest some enjoyable things to do together
- Remember that it is normal to feel down or worried sometimes
- Encourage their involvement in day to day activities
- Encourage them to speak with a health professional

Fatigue

Fatigue is a persistent feeling of tiredness, weakness, or lack of energy. 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.

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 (but do not force)
- 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 (pee) and/or faeces (poo) onto their clothing or bedding. This is known as incontinence.

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. Your local pharmacist will also be able to assist you with ordering products.

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, adult nappies, or absorbent 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 and Vomiting

Feeling like you are going to vomit is described as nausea. Nausea can be a result of constipation, the illness, having a reduced appetite, or due to the medicines they are taking.

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

- Giving any prescribed anti-nausea medication as directed
- Deep breathing, listening to soft music, having a foot or hand massage, or a warm bath
- Offering sips of water or ice chips to suck on
- Offering small amounts of bland food more often
- Drinking warm ginger or peppermint herbal tea
- Avoiding strong odours
- Managing 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.

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 on 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.

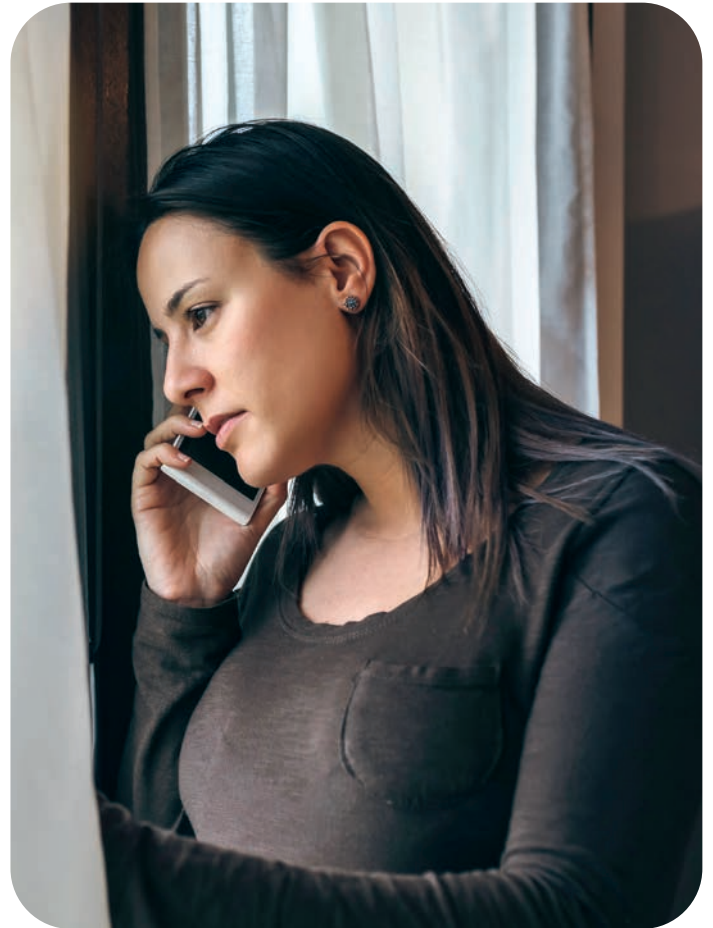
Pain

There are many reasons for pain towards the end of life including the illness, constipation, and limited mobility. 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?
- Does it go away if they change position?
- When did they last have their bowels open or do a poo?
- 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 medicine 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 them to take their mind off the pain by reading, watching TV, or listening to music

- Offer a massage of feet, hands, or shoulders
- Encourage them to change position.

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

Body temperature changes

At the end of life body temperature can become an issue. Sometimes people have very cool skin, others develop a mild fever. You can try:

- For cool skin using warm blankets can keep the person comfortable
- For fever using a cool and moist cloth on the forehead and neck can be comforting.

Skin conditions

Skin care is important at the end of life. The person's skin may be dry and fragile and they may get sores from spending a lot of time in bed. It is important to:

- Wash and dry the skin carefully, avoid rubbing the skin
- Regularly check the person's skin for sores or breaks in the skin
- Use moisturiser regularly for very dry skin (ask the pharmacist for an appropriate brand)

- Try to change the person's position every couple hours (except overnight)
- Inform the health care team of any skin issues that you notice

Mouth care

Towards the end of life you may notice that the mouth of the person you are caring for becomes very dry. You might find comfort in:

- Offering sips of fluid
- Applying a moisturizer to the lips
- Or gently cleaning their teeth with a soft toothbrush