



Factsheet 1: Emotional care of the seriously ill person

Caring for someone at the end of life also involves caring for their emotional wellbeing. People who realise they are coming to the end of their life will be managing many different emotions.

Emotional Care

People who are at the end of life are adjusting to physical limitations, discomfort, loss of independence, and ultimately, the knowledge that they will die. 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 symptoms, to a fear of death or worry about what will happen to their loved ones once they die.

It is difficult to know how to respond to these expressions of emotion but you are not expected to have all the answers. Try to gently encourage the person to

talk about how they are feeling.

This may be with yourself, other family or friends or a health care professional. Reassure them that you are there for them and that their feelings matter, and suggest that they also talk to their doctor about their feelings if you are concerned.

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
- 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 and social visits.

It can also be useful to remember to use good communications skills when responding to emotions:

- Recognise and name the feeling ("You seem angry with me")
- Ask them to talk about their feeling ("Can you tell me more about why you feel angry")
- Listen to what they are saying. The less you talk, the more space there is for them to express themselves
- Allow silences. Sometimes people need silences to reflect
- Gently encourage them to continue ("Go on, tell me more about that")
- Acknowledge what they have told you and thank them for sharing
- Respond with any ideas to improve the situation ("I will try and remember not to talk to you in such a way. Perhaps you can help remind me when I do that").

In some instances, patients become depressed or anxious. This means that they are having intense feelings for longer periods of time. If you are concerned about the person you are caring for, talk to a health professional.

Emotional care in the last few days

It is quite normal for people in the last days of life to withdraw and stop talking. This is part of the normal dying process. It can be helpful to reduce visitors at this time, keep visits short, and explain to visitors that the person may not wish to talk.

Further useful information on depression and anxiety can be found on the beyondblue website:

www.beyondblue.org.au/the-facts/depression

www.beyondblue.org.au/the-facts/anxiety





Factsheet 2: Caring for the dying person

When the person is dying, you will be seeking to provide comfort and continue care. There will be practical things to do but taking the time to just be with the person can also be important.

Create a comfortable space

If you are at home and you have a window in the room, it may be valuable to position the bed so they can see out the window.

A single bed or hospital bed may be a good way to provide the care that is required. Talk to your GP, palliative care team, or other health care professional about where to hire a hospital bed.

There are also private companies that hire out hospital beds: www.ilsau.com.au/hospital-bedsin-australia

A portable toilet (called a commode) can be useful. Alternatively you can ask at the pharmacy or your health service where you can buy large absorbent pads to assist if the person is unable to tell you when they need to go to the toilet.

Playing the person's favourite music and using gentle lighting can make it a nice environment for the person.

Take the time to just sit with the person. Holding their hand can help you feel connected.

An extra chair in the room for visitors would be valuable.

Eating and drinking

The person you are caring for may have little interest in food and fluids. This can become quite concerning for you as a carer, however it is a natural process.

Forcing someone to eat or drink at this stage can be distressing and cause more discomfort for them. Some people may also have difficulty swallowing at this stage and solid food may actually cause them to choke.

2 When illness is advancing



Medication in the last few days

If the person you are caring for is having difficulty swallowing, medications that are usually given by mouth may be given by other means as necessary.

They may be given under the skin by a syringe driver which delivers a drug via a tube with a small needle under the skin. If you are caring at home, then a nurse will come to your home to change the syringe each day.

Some medications will also be stopped at this stage depending on the reasons for them taking the medications in the first place. Talk to your health care team about whether all medications are helpful at this stage. Don't stop a medication without seeking medical advice.

In the last few days of life one of the priorities is to maintain comfort. Therefore, if you are caring at home you may be asked by the GP or palliative care doctor to get some medication to have in the house just in case it is needed.



Instead of trying to find a pharmacy open late at night or on the weekend, you will have immediate access to the medication if the person needs it. Having extra medication in the house, just in case, can also reduce the need for the person to go to hospital unexpectedly.

Mouthcare

Dry mouth is a common problem. Keeping the mouth moist will provide comfort for the person you are caring for.

This can be done by offering sips of water or by using a moistened swab.

Ask your nurse how to provide this type of mouth care. Use a lip balm or a moisturizer on the lips to keep them moist.

Factsheet 2: Caring for the dying person

Not able to talk – How do I know if they are uncomfortable?

The person you are caring for may not be able to tell you if they are uncomfortable. You, and the health care team, may need to try and judge this by their facial and body expressions. It might be hard to work out what their needs are but changing positions, a hand or foot massage or simply putting on some favourite music may help.

If you are concerned that the person you are caring for is in pain or discomfort, and you can't seem to get the pain under control speak to the health care team for advice.



If the pain seems to be from positioning in the bed, regular position changes should be made (every 4 to 6 hours). This is not necessary overnight.

Hygiene

Hygiene needs will vary from day to day. A full body wash may not be needed every day at this stage.

Comfortable clothing and loose bed sheets may be helpful.

Incontinence

You may notice that the amount of urine is less in the last few days and may also be darker in colour.

Do not be alarmed. As the person you are caring for stops or reduces the amount they are drinking (and eating), the amount of urine (and faeces) also reduces.

The person you are caring for may lose control of their bladder and bowel function. This does not happen to everyone but if it does there are pads that can be used and absorbent sheets that will help with comfort.



Breathing changes

Changes to breathing may occur. There may be noisy or rattly breathing or a time when breathing appears to stop for long periods of time. You may find it difficult to listen to the noisy breathing, but it is unlikely to be distressing to the person.

There are medicines available to help lessen the noise.

Sometimes opening a window or putting on a fan may help with the breathing.

Restlessness

The person you are caring for may seem restless at times; they may call out, groan and may appear agitated. This occurs due to the decrease in circulation of blood to the brain. A change in position may help or a gentle massage or quietly playing their favourite music. If restlessness persists, seek advice from your health care team.

Disorientation

The person may appear disorientated or confused as to where they are and who is with them. They may become agitated and distressed. Please speak to your health care team. They may prescribe medications to help with this.

Lapsing in and out of consciousness

There may be periods of the person lapsing into and out of consciousness. Despite them appearing to be asleep, their hearing may still be present.

Some people go into a deep sleep and may not awake, while others may have periods of being alert, and if words are spoken they may not appear to make sense. This is normal.

Further useful information can be found at https://bit.ly/CarerHelp_Pathway4





Factsheet 3: Recognising dying

How will I know when they are dying?

Knowing that someone is now in the last days of their life can be difficult. There are some common indications that death may be very near.

These may include:

- Large portions of the day being spent in bed
- Inability to move freely out of the bed or chair
- Difficulty swallowing solid foods
- Sleeping for long periods of time
- Not talking very much
- Occasional confusion
- Restlessness
- Unable to tell you when they need to go to the toilet
- Changes in breathing.

If you think the person you are caring for is very close to death, speak to the doctor or other health care professional as they will be able to assist you. It is okay to ask the health care team about whether they believe the person is dying or ask when they think the person will die.

How will I know when death has occurred?

Death has occurred when:

- Breathing stops – there are no more breaths being taken
- The person cannot be woken up
- There is no pulse or heart beat
- The person's pupils are fixed
- The person's eyes and mouth can be open or closed.

The person who has died may now look different to you. They may appear pale and their hands and feet may feel cold – this is due to blood no longer circulating. Their jaw may drop as the muscles have relaxed. There may also be passing of urine and faeces. If the person's position is changed you may hear a sigh or a sound like breathing – this is due to the escape of air from the lungs.

When you are ready, call the doctor or health care team to verify the death. If you are in the hospital or aged care facility contact one of the staff members.



Factsheet 4: Caring for yourself at the bedside

It can be very difficult to get time for yourself when you are caring for someone who is nearing death. You may be spending a large amount of time just sitting at the bedside with the person.

However, it is really important that you take time to eat, go to the toilet, rest, sleep (if possible), and get a few moments away from the bedside. You will probably be experiencing a range of emotions and have lots of thoughts on your mind.

Ways to take care of yourself

Here are a few suggestions to help you care for yourself while you are at the bedside:

- Close your eyes and listen to some relaxing music
- Ask for a comfortable chair (if you are not at home)
- Ask someone else to sit with the person and go out to the garden so you can get some fresh air
- Ask someone to bring you some food or make you a cup of tea

- Have a paper and pen to write things down as they come to mind
- Ask someone to sit with you
- Read a favourite book.

Remember, it is okay to ask for help from health care staff or from friends and family at this time.

People are usually wanting to help you and are just waiting for some guidance from you.





Factsheet 5: Injections and syringe drivers

Medications can be administered in many different ways, for example:

- Into the mouth or orally in the form of a tablet, capsule, liquid or puffer
- Some can be dissolved under the tongue
- Into the rectum or vagina in the form of a suppository or cream. If someone feels ill or is vomiting, this is an alternative way medication can be administered and help
- Into the ear or eye in the form of drops or creams to help with dryness or infections
- On the skin in the form of a patch
- Injections under the skin or into the muscle via a needle.

Injections

Sometimes medications are administered into the muscle or under the skin using a needle.

Medications given into the muscle are given by a once-off injection.

Medications given under the skin or subcutaneously are given through a small tube or cannula that will be left in place, secured with a dressing and changed regularly.

Medications given under the skin can be given as required in what is known as a single bolus, or they can be given slowly over time using a syringe driver.

Syringe drivers

A person having difficulties taking oral medications may receive them under the skin using a syringe driver, which is a small, portable, battery operated device. A syringe driver is used to slowly administer a continuous dose of medication in a less invasive way.

Using a syringe driver can make administering medications easier, as it removes the need for repeated doses of medication. They are usually effective in managing common symptoms such as nausea, vomiting, pain, difficulty breathing and excessive secretions.

The health care team will provide you with training on how to use a syringe driver.

This training may also include how to use a syringe and needle to prepare the medicine and then how to put the syringe into the driver.



There are a few things you will need to keep in mind when using a syringe driver and they include:

- Checking the battery life
- Checking the tubing is not kinked
- Checking the small tube under the skin is still in place, particularly if the person you are caring for becomes agitated
- Observing to see if the medication is covering the needs of the person you are caring for
- Sometimes a 'top up' of additional medication might be required.

If you have any questions about medications, how they are given or the use of a syringe driver, please ask the health care team.

Some carers find it stressful to manage medications. It is important to talk to the health care team if you are uncomfortable giving medications or using a syringe driver.





Factsheet 6: 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 you are concerned about 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:

- Sitting with the person you are caring for and providing a reassuring presence
- Using a fan or opening a window to increase airflow around the person you are caring for
- Encouraging the person to sit upright
- Wearing loose fitting clothing
- Putting on calming music or offering the person a foot or hand massage
- Encouraging the person to drink more water
- Oxygen if prescribed by a doctor

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

2 When illness is advancing

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

Factsheet 6: Tips for managing common symptoms at end of life

- 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
- 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
- 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.

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 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. 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.