
Home nursing tips

This section is designed to provide you with advice and information to help you care for your loved one at home. It also includes a section that will help you identify specific symptoms when death is near.

Getting your home ready

You may have to make some changes around your house to make it easier to care for someone at home.

Look first at where the person is going to sleep or spend most of their time. If they can't get about easily, where's the best place for the bed? It might not be the bedroom.

Changing things around can be a disruption. Talk about how to get the house ready to help make everyone feel comfortable. Your loved one could feel isolated or depressed if they're away from the comings and goings of everyday life. Putting their bed into the living area may be a good move and gives more room around their bed to care for them.

Make sure that you have an area set up to relax in. You and others at home will also need space away from the bedside to rest and have private time.

If your loved one can get around, encourage them to get up for meals, use the toilet when needed and walk to the bathroom for their shower. As they become less able to do things for themselves, their needs will change. Be prepared to change your set up when needed.

Helpful tips

- Give your loved one a way to call you for help – this will be reassuring for them. It might be hand bell or you may want to buy something like an electric door bell, a baby monitor or a set of two way radios so you can be reached from anywhere in the house and garden.
- Move any furniture and rugs you don't need away from the bed. Keep the bed space as clutter free as possible.
- If the person can move from their bedroom to the living area it is useful to set up a special spot with a comfortable chair or day bed that has everything they need nearby. Try to give them a view of the garden or anything else pleasant or interesting.
- Put things like a clock, drinks, radio and torch, TV and stereo remotes near the bed.
- Put a telephone near the bed if you can.
- A basket or drawer may be needed to store equipment or dressings the hospice nurse leaves.

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- You need a convenient but safe place for any medications. If there are likely to be children around, be sure to keep all medications and medical equipment out of reach.
 - Make sure it is easy for your loved one to get to the toilet or bathroom from where they spend most of their time.
 - You may need to make room near the bed for a toilet chair (commode) if the person can't get to the toilet.
 - A bathroom can feel very small once you try to fit in the person, who might need a shower chair, you and possibly a nurse too. You might need to make some changes here. For instance, if there's a drain hole in the bathroom floor, shower the person on a chair outside the shower cubicle. You could fit a shower hose on to the taps. Be careful of slipping – a non-slip mat is a good idea. Use a raised toilet seat (if your one is too low) and fit handrails. The bathroom door can be made to swing out rather than in, to make access easier.
 - You may need to loan equipment such as shower chairs, raised toilet seats, bath stools, toilet chairs that you can use to make showering and toileting easier. Ask your hospice nurse about your requirements.
 - You can get ramps fitted up steps, which will make it easier for wheelchairs. You can fit handrails where they're needed to help your loved one move more safely around the house.

Personal care

Showering or washing

Having a daily wash or shower can be refreshing, but it can also be tiring to have. Be aware that your loved one may not want a shower every day. This is okay.

If your nurse or home care assistant is doing personal care, you can be their apprentice and learn how to do things yourself. Nurses/home care assistants don't usually visit every day to do this. If you're looking after personal care yourself, work out what you can do without too much of a struggle. If a shower means heavy lifting or needs too much of their energy, you can wash them quite well in bed or on a chair.

Maintaining privacy is important. Use a sheet or towel to cover them when getting ready for a wash/shower/bath. Using fresh, dry, warm towels makes having a wash much more enjoyable and using scented soaps/shower gel or cologne leaves a lasting impression for them.

Sponging in bed using a bowl of warm water, facecloths and towels can work just as well. Another way of washing someone in bed is called a hot towel bath because it uses warm, damp towels. Your hospice nurse will be able to show you how to do this.

Skin care and massage

If your loved one spends a lot of time in bed or in a chair, check their skin everyday for red areas, sore spots or dryness, especially on the bottom, back, ears, heels and elbows. Feet can get particularly dry.

When you're helping them with personal care it may be a good time to try some gentle massage. You don't have to be especially skilled: just try gentle stroking and rubbing. You can use scented (or unscented, if they prefer) oils, lotions and creams to massage dry skin and sore spots.

Massage is often comforting and helps keep skin soft and supple. Don't massage where the skin is infected or inflamed, around the stomach area, or their legs if they have a clot (deep vein thrombosis). If you're unsure, check with your doctor or your nurse.

Bed linen

Change the sheets as often as you can without stressing yourself too much. You can do it while your loved one is in bed: ask the nurse to show you how. You can put the top sheet to the bottom and put a clean one on top every day or two. A draw sheet/large towel or folded sheet on top of a piece of plastic or a kylie over the bottom sheet will protect the mattress from any soiling from incontinence and will mean you don't have to keep remaking the whole bed. If they have ongoing incontinence, there are aids to contain this. Talk to your hospice nurse and tell them where you need help.

Handling your loved one

Someone who spends their time in bed must be moved regularly, usually every two hours during the day and once or twice at night. If they're very sick and near death it may be better to move them less or maybe not at all. The nurse will help you work how often your loved one should be turned.

You could find yourself having to help your loved one move. Bending and twisting while lifting can injure you. An occupational therapist, physiotherapist or your nurse will teach you how to lift and move someone so you don't risk hurting yourself. Look after yourself by learning the right way to do things.

If your loved one has fallen and you don't think you can pick them up safely, it is better to leave them there (covered with a blanket and pillow under their head if necessary) than injure yourself trying to pick them up. Calling neighbours or family to help is an option. If there's no-one around, ringing an ambulance is a good idea.

Mouth care

A dry mouth is a common problem. This is usually a result of medication or oxygen therapy. While special preparations are available from pharmacies, try pineapple or feijoa juice, frozen pineapple chunks, ice cubes, or acid/sour lollies to encourage saliva production and to refresh their mouth.

If your loved one can swallow, small bits of ice will keep their mouth moist. If they're not eating or drinking, wipe their lips and tongue every hour or two during the day with a wet swab and whenever you see to them at night. Iced water is usually the most comfortable and refreshing.

Sick people are much more likely to get mouth infections like thrush, which looks like small white patches on their tongue, gums and lips. It can make their mouth very sore and eating difficult. Thrush is easily treated with regular mouth washing combined with prescribed drops, lozenges or tablets.

When your loved one can't swallow properly and food gets left in their mouth they are more prone to other oral infections. Check their mouth every day and keep it clean. If using an ordinary toothbrush hurts too much, try a very soft one, or use special mouth swabs from your hospice nurse, or some moistened gauze wrapped around your finger. You can use commercial mouthwashes or a weak solution of bicarbonate of soda (baking soda) and salt (half teaspoon of baking soda and a pinch of salt in half a glass of lukewarm water).

Applying vaseline, lanolin or lip balm to their lips every few hours will help prevent dry and cracked lips.

Nail care and shaving

It is important your loved one continues to feel good about how they look. You can keep their nails cut and clean yourself, or call a podiatrist to trim hard and thickened toenails. A man might enjoy a daily shave – you can get the things ready for him or do the shaving yourself. A woman might like her legs and underarms shaved or her eyebrows shaped if it's part of her usual beauty routine. She might also enjoy wearing some perfume or makeup.

Hair care

Clean hair can make the world of difference to how someone feels. It is quite possible to wash someone's hair in bed. If you have a plastic sheet, towels, a jug and a bucket or bowl you're in business! A few days before, ask your nurse to show you how to do it. It may be possible for your loved one to have their hair cut or permed at home. Look in the Yellow Pages for mobile hairdressing services. Hospices may know of hairdressers who are willing to come to your home.

Clothing

Dress your loved one in comfortable clothes that can be easily put on and taken off. On the one hand it's not a good idea for them to wear nightclothes all day (unless they're very sick and in bed all the time) because it emphasises their sickness. On the other hand, day clothes like skirts, tights, shirts and

tailored trousers may feel tight and uncomfortable and be hard to put on and take off.

Clothes like track suits or T-shirts of soft stretchy material are much easier to deal with and can be just as stylish. Correct fitting shoes or slippers are important to prevent tripping or slipping when walking.

When your loved one becomes less mobile or unconscious changing clothes can take time and be difficult. Blouses, shirts, T-shirts and pyjama jackets can be cut and hemmed down the centre back and fastened at the top with velcro. This allows the "look" from the front to be the same but makes them easier and quicker to change when needed.

Common symptoms

Pain

Pain is something people are most frightened of yet it can usually be managed well. Taking the right amount of the right painkillers (analgesics) regularly is the best way to prevent pain rather than waiting until the pain occurs. The aim is to take doses of medication that give constant relief. Extra doses can then be taken when the regular dose isn't enough (e.g. prior to excess movement such as showering, going out, or sudden increases in pain). These are called rescue or breakthrough doses.

Painkillers come in various forms – tablets, syrups, suppositories, injections or skin patches. Your doctor may prescribe morphine or something just as strong.

These drugs aren't the last resort or just for someone close to death; in fact, they're the most common pain medication used in palliative care. There is no risk of someone becoming addicted to these drugs when they are used to control pain.

Other medications such as antidepressants, steroids or milder painkillers may be used to help pain relief, along with strong analgesics. You might be puzzled to find your loved one is expected to take more than one drug to control their pain.

Different drugs work in different single ways to relieve pain but together they have a shared effect and give much better pain control.

As well as benefits, strong analgesics, like all drugs, have side effects. These may include constipation, nausea and vomiting, drowsiness and confusion. Talk to your doctor or someone from your hospice team so you understand how each drug works and what can be done to make side effects less of a problem.

Pain can get worse when it is coupled with social or emotional problems. Being able to talk to someone about their fears and problems may help your loved one more than medication alone.

Constipation

Sick people often get constipated because they're not moving around much, and aren't eating well or drinking enough. Try to avoid constipation because it makes other symptoms, especially pain, worse. Strong painkillers like morphine slow down bowel movements, and people often need to take laxatives. Even when someone's eating very little, they should have a bowel motion at least every three days. It is really important that bowel motions continue regularly. If they don't, suppositories or an enema may have to be given to help relieve their constipation.



Encourage your loved one to take any prescribed laxatives regularly, drink plenty of fluids and move about while they can. Extra fibre will help people who are still eating fairly normally – try vegetable soups and fruit (both of which can be puréed), wholemeal bread and porridge. Some herbal teas e.g. Smooth Move, Alpine Tea can assist in relieving constipation as well.

Nausea and vomiting

Some medications and some diseases in the abdomen or other medical problems can cause nausea and vomiting. Your doctor will investigate the cause and may prescribe medication to help. It also helps to get rid of any smells that make nausea worse, like cooking smells. Sometimes fresh air, changing body position or sipping soft drinks like lemonade, gingerale or herbal teas such as peppermint or ginger tea will help. Sucking peppermints can sometimes help and are great for refreshing the mouth.

Weakness/Tiredness

Weakness and tiredness is a common frustrating symptom of advanced illness and very difficult to overcome. Treating it with tonics or vitamins won't help much. If your loved one is anaemic, blood transfusions may help for a while. As the illness progresses, they may spend more and more time in bed or in a chair. It is still valuable to get up and about but having a rest between outings and visitors will become more important.

Losing appetite and weight

It is common to lose your appetite when you are very sick but it can be hard for carers to accept. There's usually no point in trying to feed someone up or force them to eat, especially if they have no appetite. It can make you both tense and them feel more sick.

Buying new clothes that fit or altering ones they already have will help them feel as attractive as possible. If they have lost a lot of weight, they could feel the cold more than usual and need extra layers of clothes and more heating.

Confusion

Confusion or delirium often occurs in advanced illness. It might be caused by medication or changing body processes.

A dying person may not recognise people they know or may misinterpret what's going on around them or what people are saying. They may have nightmares, vivid daydreams or hallucinations. They may become restless and try to do things they can't do any more, like getting out of bed if they need to urinate or have a bowel movement. They may be in pain but unable to let you know. If restlessness becomes a real problem talk to your doctor or hospice nurse. Your loved one might have a full bladder that needs draining or they may need medicine to make them more relaxed.

Keep your loved one safe from falling or from hurting themselves. Sit with them and talk about what they're going through and try to reassure them. If things are becoming too difficult, get in touch with your doctor or hospice nurse.

Drowsiness

In their last days your loved one may become drowsier and spend more time sleeping than awake. During this time, if they become a bit restless or more conscious, then it is time to change position. In the last few hours often there's no need to move them at all.

Food

People with advanced illness often lose their appetite because of tiredness, pain, nausea and vomiting, depression, sore dry mouth or throat, constipation, alteration in taste and diarrhoea.

Though something can be done about some of these causes, it's quite likely your loved one will need different food than they have in the past. Offer them a choice of small portions of savoury and sweet foods, and don't forget they might still enjoy alcohol (ask your doctor if alcoholic drinks are okay). Often people have less sense of taste and might like spicy foods when they're ill.

Don't be too disheartened if they change their mind about food they wanted and that you've gone to so much trouble over. This is common and it's to do with the illness, not your loved one being difficult.

Some things worth remembering when making food for your loved one are:

- Smells – sometimes the smell of cooking can be off putting. Keep smells down by turning on the extractor fan or opening the windows.
- How often and how much – it's better to offer small meals often than big ones not so often. Bring food when your loved one wants it and try to make it look nice. When

you cook, freeze some portions you can warm quickly in the oven or microwave.

- Food in a hurry – ready packaged or canned food could be an option – soups, yoghurts, creamed rice, or custard. Baby foods are a good way of having readily prepared small amounts of food on hand in a variety of different flavours. Sweets can be eaten alone while savoury baby foods can be heated and mixed with a bit of milk or cream to make a delicious cup of soup. Soups and milky drinks are tasty and nutritious if your loved one can only manage fluids. Specially fortified drinks (available from pharmacies or ask your nurse) can replace a whole meal and might be enjoyed more if chilled. You can freeze fruit juice onto a stick, which is especially enjoyable in hot weather. You can fortify food with dried milk, ice cream, eggs, honey and dried food supplements to make it more nourishing.
- Texture – the feel of food is important. If your loved one has a dry or sore mouth, they might prefer soft food. If solid food is a problem, blend it or strain it through a sieve. Make smoothies. Keep each part of the meal separate if possible rather than blending it all into a grey mash.

- Presentation – try to make food look appetizing. Place small amounts on a small plate. Present on a tray with flowers and a glass of wine or beer.
- Company – it is always better to eat with company than by yourself. Time meals so that you can eat with your loved one or sit and have a drink with them while they are eating. You will find that they will probably eat more with you there. Use this time to sit and relax and talk about things together.

The need for food and fluid

People in the last stages of illness often lose interest in fluids as well as food. You might be anxious they aren't drinking but it might not be making them uncomfortable; it is part of the body getting ready for death. It prevents the build up of saliva, which is often an effort to swallow. It makes breathing less noisy in the back of the throat which leads to less coughing and vomiting. It also reduces the amount of urine the person must pass.

A dry mouth may be uncomfortable. If their mouth is dry, use large mouth swabs dipped in iced water, give small ice chips to suck, and moisten their lips with vaseline, lanolin or lip balm. If you are worried about dehydration, talk to your hospice nurse or doctor who will assess your loved one for this.

Cooking for yourself

Don't forget about your own needs – try to eat at regular meal times and eat enough. If you prefer to make your loved one's food, don't stop your family and friends making meals for you. They could make food for the freezer or work out a roster to bring food in for you.

If you're having difficulty and have no one to help you, ask your doctor or hospice nurse to refer you to Meals on Wheels service. There are also supermarkets, caterers and private companies that supply ready made meals that are reasonably priced.

Even if you are not hungry or cannot face food making a smoothie (yoghurt, milk, egg, fruit) can be a health alternative and will help to keep your strength up. Snacking on peanuts, cheese and crackers, fruit (e.g. bananas) or snack bars is also a good way to keep your calorie intake up. When you have a few minutes, prepare a jug of smoothie, cut up some cheese chunks or make platter of fruit and sandwiches and leave them in the fridge for you to grab "on the run" when you are busy.

Natural therapies

Natural therapy is a term used to describe non-medical treatments. Sick people and their families often want other sorts of remedies as well as those that their mainstream health professionals offer.

There are two main kinds of natural therapy:

Alternative – treatments used instead of usual conventional ones, and

Complementary – treatments used as well as conventional ones, like:

- Massage
- Reiki
- Some aspects of aromatherapy
- Creative visualisation
- Relaxation
- Therapeutic touch
- Reflexology
- Music therapy.

Your hospice may offer these services.

It is important your loved one doesn't feel pressured into treatments just because others are enthusiastic about them. Before starting or during any of these treatments you might like to ask yourself:

- Do I completely understand how it could help and what the side effects might be?

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- Will this therapy react with any of the other medications currently being taken?
 - Do the appointments take a lot of time and energy?
 - What does it cost? Can we afford it?
 - Is this therapy working for us?
 - Is the person giving the therapy qualified or experienced? Are they an accredited member of a professional society or similar group?
 - If we're worried or not satisfied will we be able to say so?
 - What does my doctor or nurse know about the therapy?

The changes that occur when death is approaching

When someone has an advanced illness, death usually comes gradually and peacefully. Most changes at this time are normal and don't need special treatment, hospitalisation or professional help. If you're unsure, call your hospice doctor or nurse. It is impossible to predict the actual time of death but doctors and nurses can give you an idea of the span of time that you have left. Even then, they can be wrong.

Some of the main changes that occur as a person nears death are detailed in this section. There are also ideas on what you can do to help during this time.

Not eating or drinking

As people get closer to dying, the body does not need food and fluid to function. Your loved one is likely to lose interest in food and drink to the point that they're not eating or drinking anything at all. They may have lost the ability to swallow, so don't try to give them drinks at this stage because liquid may collect at the back of their throat.

Increased confusion and restlessness

It is common for dying people to be quite restless or agitated in the last 24 to 48 hours before they die. Try to reassure them by talking calmly and saying who you are. Don't make sudden noises or startle them. Constant touching or stroking may be disturbing, try gently holding their hand. Playing their favourite music may help to calm them at this time.

Vision and hearing

Sometimes dying people's vision clouds – they get a faraway look in their eye and don't seem to focus on anything or anyone. Leaving a soft light on all the time may help. Hearing may not be as acute as it was, although this may be the last sense to be lost. Encourage quiet conversation in the room so your loved one knows people are there, but make sure they don't have to hear any distressing conversations e.g. family members arguing. Many people enjoy hearing music and quiet singing, and this



can also give those in attendance a way to participate and share feelings, especially valuable when it is hard to find the 'right' words to say.

Incontinence

People near death often lose control of urination and bowel movements (incontinence). Make sure there's protection of some sort for comfort and hygiene. Usually a decision is made along the way regarding incontinence pads/pants/catheters. While wearing incontinence products may look somewhat undignified, sometimes it is more dignified than being incontinent in bed.

Breathing

As your loved one finds it harder to swallow, saliva and secretions may collect at the back of their throat and make a noise when they breathe – it's sometimes called the 'death rattle'. This isn't distressing for the person who is dying but it might be to you. Sometimes raising the head of the bed with pillows helps. Your doctor may prescribe medication to reduce the secretions, but these don't always work.

As death approaches you'll notice your loved one's breathing pattern changes. There may be gaps: seconds or minutes between breaths. This irregular breathing pattern is often called Cheyne-Stoke breathing or Cheyne-Stoking. When the gaps between breaths get longer and longer it's a sign that death is close.

Sometimes when the person is taking their last breaths they may seem to grimace. This isn't because they're uncomfortable, it's just the muscles in the upper part of their body and face contracting and relaxing.

Changing colour

As blood circulates more slowly, your loved one's arms and legs will start to feel cool and may look patchy/mottled and dark. Their face may be pale and pinched looking, their nose may feel cold and the beds of their fingernails and toenails may turn blue in colour. You may notice their skin is clammy and marks easily where they're touched even by clothing and bedding. There's no need to put on a lot of extra bedding or an electric blanket – this might just make them restless. Depending on the weather, a sheet and a few warm blankets should be enough.

How to tell if your loved one has died

- Their breathing stops
- Their chest stops moving up and down
- They will have no heartbeat or pulse
- They don't respond when you shake them or talk loudly
- Their eyes are fixed, their pupils are dilated. (Sometimes their eyelids stay open).

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- Their jaw relaxes. (Sometimes their mouth stays open)
 - They may have lost control of urination and bowel movements.

What to do when your loved one dies

You don't have to do anything straight away. There's no need to call the police or an ambulance. You will need to call your hospice, G.P. or hospice nurse at some stage to tell them your loved one has died. A doctor will need to prepare a death certificate. If death occurs at night and you are comfortable being at home with your deceased loved one, make these calls in the morning – usually after 7am.

Your loved one's body can stay at home for several hours for relatives and friends to visit and pay their respects. Phone your hospice nurse if you need help at this time. If not, you'll need to lie your loved one on their back with their head and chest raised slightly on pillows and their hands on their chest. You can roll up a towel to tuck under their chin and close their mouth. You can usually take this away after a few hours when stiffness (rigor mortis) sets in. Cover them only with a light sheet. Make sure electric blankets and heaters are off and the room is cool. You may want a friend, someone from your family or whānau or a minister to be with you now. You could ask someone beforehand to be ready at short notice.

The time between death and the funeral director arriving is a very special time. It is a time where you can be with your loved one and reflect on the journey you have completed. It is a time of great sadness but also peace and quiet before all the hustle and bustle of the funeral preparations starts. Take this time to sit quietly, remember and celebrate the wonderful gift you have given your loved one – the gift of your care of them during this time.

Contact the funeral director when you want your loved one's body attended to. They can usually visit fairly quickly. It is possible to have your loved one's body taken away at night, though there maybe an extra charge for this. If you haven't already arranged a funeral director, choose one from the Yellow Pages. You may want a friend or relative to do this for you. The funeral director will make an appointment later that day or early the next to talk to you about arrangements and costs.