
Caring for a loved one

Support from family and friends is crucial when coping with a life limiting condition. What you do as a carer is vital to the physical, emotional, social, and spiritual wellbeing of the person you're looking after. This section looks at your relationship with the person nearing death: the choices and questions you face; how they may react, what their total needs are, how your relationship could change, communication between you, and how you might help them.

What you and your loved one may be going through

When someone finds out they have a life-threatening condition, it usually unleashes many strong feelings. Knowing how your loved one may respond will help you both to focus on and manage these feelings and thoughts together. None of the feelings and thoughts you may have are right or wrong. They are a normal part of the process of adjusting to a diagnosis and learning that your loved one's life now has a time limit.

Fear of the unknown is one of the hardest things to handle. The person you're caring for may feel a sense of loss, grief, shock, anger, panic, hopelessness, and emotional turmoil. Denial is also a common response – many people just don't want to face their approaching death. These may be the same feelings you are feeling. Ignoring them does not make them go away. Talking about them might ease the fear and make handling them a little easier.

Some respond by finding out as much as they can – it helps them feel they're in control again and that their life is understandable and in order. This is quite natural in the face of fear. At first, you may be able to help keep their sense of control. This might change as they get closer to dying and helping them adjust to an increasing lack of control and dependence will be one of the challenges you will face.

Early questions and choices

Some questions you and your loved one face will be unanswerable. You may have to deal with some questions immediately, while others reveal themselves gradually, depending on the person's illness and your own situation. You'll probably find yourself asking questions such as:

- How long will we have?
- Can I do this?
- What pain and symptoms will there be and how can they be managed?

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- How can I care for my loved one and keep them comfortable? Can I do this?
 - What decisions can we make together that will allow my loved one to live the last stage of their life as well as possible?
 - Who will help us cope?
 - How will I know what to ask for and when?
 - Where might care be provided – at home, in a hospice inpatient facility, in an aged residential care facility or in hospital?
 - Will they be able to stay at home at the end?
 - How will I cope throughout all of this?
 - How will our family live without them?

Supporting your loved one

One of the first things to do when someone close to you finds out they have a life limiting condition is to ask what they want and need. Together you can make a plan that works for both of you. It may not be an easy conversation but it's the first step in a series of issues to face, questions to be asked and solutions considered.

- Do your best to be a good listener.
- Think carefully about what you can do to help your loved one live every moment fully until they die.
- Be truthful when asked for your thoughts and feelings on issues.
- Be ready for your loved one to feel very strongly, and possibly direct their anger at you.
- Enjoy the good days. Make the most of your time; think and talk about your life together and try to resolve any unfinished business. If necessary, get the help of someone you both feel comfortable with.
- Help your loved one do what they need to do to accept they are going to die – put their affairs in order, organise oral or family histories, write letters, and put together family scrapbooks and photo albums – anything that will give their life lasting meaning.

Your loved one's needs

Understanding what your loved one needs will help you accept what is happening and help them face their death. Everyone's experience will be different because everyone's physical, emotional, social and spiritual needs are different.

Day-to-day care

You may need to become skilled in hands-on care and other practical aspects of caring for someone. Most carers find that the more practical information they have the better prepared they are. You may need to learn a lot about physical care, especially if you've decided to look after your loved one at home. You'll need to know how best to feed them, keep them clean and comfortable and manage their medication. You may need to learn how to move them safely and manage their pain and other symptoms.

Care giving can be the ultimate test of resourcefulness. You may find yourself spending a lot of time looking for ways to make life easier and more 'normal'.

If things puzzle you during the illness, don't be afraid to ask questions. Health workers such as hospice team and other carers are all people to ask questions of and pick up tips from. They are there to help and support you throughout this time and to make life as positive as possible for you and your loved one.

Bookshops, public libraries and the internet are useful too. You can look on the Hospice New Zealand website (www.hospice.org.nz) for many questions and answers.

Emotional needs

Remember that your loved one's feelings and responses are normal and there's no easy way to get through them. However, there may be ways you can help your loved one meet their physical, emotional, social, and spiritual needs so that they understand and even come to accept what is happening and have a good quality of life in the time they have left.

Staying hopeful

It's often important for people nearing the end of their lives to stay hopeful. Hope means different things at different times. When an illness is first diagnosed, being hopeful might mean expecting a cure. This may change into hope of living as normally as possible. Hope may also mean reconciling with the reality of life and death – a practical and emotional preparation for death. Relationships can make a seriously ill person's life meaningful and this meaning can give them something to live for until the end. As days move on, the "hopes" will change from large future-focussed hopes e.g. the hope to travel overseas for a month to smaller more achievable ones e.g. the hope to be able to travel to watch family play weekend sport.

Anticipatory grief

Many people near the end of their life feel something called anticipatory grief: they are mourning their own deaths and may feel depressed and sad. This grief can also be a time of searching and growth, and of making connections that give the final separation meaning.

The most difficult thing about dying may be coming face to face with the truth of the situation; reflecting on a life lived and thinking about the meaning of this life. This might include confronting and understanding suffering, coping with losses, accepting love, and facing up to dying with a sense of dignity.

Spiritual needs

Spirituality means different things to different people. It covers what matters most for people and could include their beliefs, values, sense of meaning and purpose, identity and for some people religion. Often at this time of life a fear of death and dying and/or a fear of leaving nothing behind become strong emotions to face and deal with.

The person may long to be reunited with loved ones or with a spiritual community, and need to draw strength from rituals and faith, or they may feel a sense of betrayal and abandonment. Some turn to the distraction of work and hobbies. Others find comfort in the presence of family and friends.

Your relationship

Your relationship with your loved one might be transformed in the last stages of their life. You may, for instance, change roles – a mother and carer of children could become the one who is cared for. If you're losing your spouse, it may affect how your family relates to each other, your financial stability, your work or your day-to-day life and habits.

Your loved one may act in unfamiliar ways. You may find you don't 'recognise' them because disease can change people's personalities as well as their bodies. This time can deepen your relationship and draw you closer together than ever before as you both focus on things that really matter in your lives. But the opposite can happen too – sometimes the burden of dying strains relationships and gaps appear.

Sexuality

Sexuality is more than just a physical relationship – it is how you view what it is to be you (whether male or female). The way your loved one sees themselves as a person and the way that you see them will change throughout their illness. Dressing in usual clothes, wearing make-up and perfume, being able to do the normal things they do (even with the limitations they have) and being as independent as possible are all ways to maximise the way people feel about themselves.



Your sexual relationship will change. You may not be able to enjoy the normal physical sexual relationship you have been used to but you can still explore different ways to feel close to each other. The skin is one of the most sensual organs of the body. Throughout your loved one's illness, you might find that touch is a more gentle way of sharing intimacy. Fear of hurting your loved one during sex or intimate times is a common worry—talk to your doctor or nurse about what your fears are in this area.

Other psychological and emotional needs

Serious depression is part of end-stage illness for many, so caring for your loved one's psychological needs may mean talking with your doctor or nurse. Depression can be triggered by disease or be a side-effect of commonly prescribed drugs. Signs of depression are chronic sadness, lack of energy, difficulty sleeping, loss of appetite, frequent crying, withdrawal and suicidal thoughts. Discuss these with a health professional so the depression can be addressed and managed.

Getting the right professional care (i.e. counselling) for the overwhelming emotional and psychological effects of a life-limiting illness often helps the dying person feel better. Sometimes long-standing emotional issues can make physical pain feel worse.

Communicating with your loved one

It is hard to know what to say when someone we care about is dying.

One way to start is by putting yourself in your loved one's shoes or imagining yourself in a crisis: think how you'd feel, what you'd want and what you'd most appreciate from the other person. Listening is important. Listen for the feelings behind statements (read in between the lines).

Acknowledge them as a person. Just be there – show them and tell them you care. Try to give the person you're caring for as much control as you can; becoming more and more dependent on others can cause distress.

A dying person may need to tell you about something that's important to them. They may want to resolve long-standing conflicts and satisfy final wishes. Take your cues from them and try to be a good listener. Help your loved one contact and communicate with family and friends. Doing this may help relieve their sense of isolation.

When families/whānau and carers are aware of and negotiate the changes going on in all their lives, it's easier for them to adjust. Open, honest discussion between you and your loved one as well as amongst all family members is very important.

Your loved one may have an illness that affects what they can do and feel, so you might have to change the way you're used to communicating with them. It might not be possible to have conversations, especially if they're confused. You may feel they're not the person you knew.

Remember there are many ways to communicate. Non-verbal communication can take the place of talking and listening, especially if your loved one can't function as they used to. Even people in a coma know when they're being touched and spoken to, so don't stop communicating with them. Touch becomes more and more important. Look for subtle messages such as changes in breathing, changes in the look on their face, changes in how they hold their body: all are signs that your loved one might be sending and receiving messages.

Palliative care focuses on living as well as possible. This means:

- Living with minimal pain and having it well managed (many people find strength in their suffering and don't want to take drugs that might stop them communicating).
 - Keeping your dignity.
 - Having your decisions and choices respected.
 - Being treated with openness and honesty.
- Being cared for with love and respect and without feeling you're a burden.
 - Dying as you would wish (either alone or surrounded by loved ones).
 - Dying where you wish (either at home or somewhere else)