



A Guide for Carers

Information and support for people caring for
someone with a life limiting condition.



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About this guide

There are few experiences more challenging than caring for someone at the end of their life. Each of us faces death as uniquely as we live our life. We all hope that when death comes to us or someone close to us it will be as peaceful and dignified as possible. We also hope we'll face it feeling comfortable in our surroundings, well cared for and that those we love are well supported.

You're not alone

This booklet draws on the skills of all the hospices in New Zealand and combines their experiences of looking after dying people. You and the person you are caring for will have many decisions and choices to make. We'll tell you about situations you're likely to come across, and how you and the person you are caring for can look forward to living every moment you have left.

The booklet talks about how hospice can support you during this journey. It suggests ways of managing your situation – whether you're caring for a dying child, a parent, spouse or good friend. It has guidance on comforting your loved one, managing pain and other symptoms, communicating effectively with everyone in the family/whānau and care team, as well as offering practical and emotional support.

What is palliative care?

Palliative care is for people who have a life limiting condition; that is they have been told there is no cure for their condition – that is they are living with an advanced life-limiting illness. The primary goal is to provide comfort and dignity for the person living with the illness until they die, maximising the best quality of life for them and those around them.

Palliative care focuses on the patient and their loved ones' physical, emotional, social, and spiritual needs. The care is individualised and emphasises living fully, with dignity and comfort in a circle of support, until the end. Anyone, adults, or children, with any life limiting condition may have hospice involved in their care. Palliative care is provided in any setting – at home, in an aged residential care facilities, a hospice, or a hospital. Hospices are organisations that deliver specialist palliative care in any of these settings and work alongside other health workers such as General Practitioners, District Nurses, Hospital staff, etc.

You are not alone – alongside you are many other New Zealanders looking after loved ones with a life-limiting illness. There's a network of organisations that understand the principles of palliative care. They are there to support you to get the most from life at this time.

How is this booklet organised?

This booklet is organised to help you find support to improve the quality of your own and your loved one's life during this time. It focuses on your relationship with them, how you might feel about being a carer, and on your relationship with the support networks available to you: your family and friends, your care team, your community and the health system. It also provides practical hints for caring for someone and paperwork issues you might like to think about.

This booklet will provide answers to some questions you may have. Read the booklet from beginning to end, or just look at sections about queries that you have at different times. You'll notice it doesn't talk about patients but about loved ones. When we use the word family/whānau, we mean whomever the person thinks of as their family: relatives, partners, and friends.

Our experience has taught us:

- Dying is a natural process.
- When people's physical, emotional, social and spiritual needs are met, dying, although challenging enriches the meaning of one's life and those around them.
- When a dying person's pain and other symptoms are well managed, they have more energy for living from heart and spirit.
- If carers are supported practically, emotionally and spiritually through every stage of illness and bereavement, they and their loved ones are often able to experience an intense connection with one another.
- Everyone faces death in their own way; making choices and having control is an important way to keep dignity at the end of life.
- Carers and those who have a life limiting condition are an integral part of the care team. It is essential that you are kept well-informed and feel welcomed to speak up for the care you would like your loved one to receive at the end of their life.



There's no right or wrong when it comes to your feelings. Take care of your own physical needs and ask for professional help if you need it.

Being a caregiver

You are facing what might be one of the most demanding and challenging experiences of your life. We all know we're going to die, but we don't appreciate it fully until you live through the end stage of life, day to day, with someone you love. Taking care of yourself will mean you can better care for your loved one and handle the extreme physical and emotional demands of caregiving.

Caring for yourself

If you're going to be the main carer, you face a time of many questions and few easy answers. There'll be more and more demands on your time and energy. It may take a toll on your physical, emotional, social and financial wellbeing.

When considering the changes you may face in taking on the care of your loved one, some questions you may ask include:

Can I do this?

- Can I take a leave of absence from work? Do I need to?
- Is it a good idea for me to look after my loved one at home?
- How can I set up our house to care for them at home?
- How will we cope financially?
- How will I juggle work, children and day-to-day care of someone I love so much?
- Will I get the physical and emotional strength and practical help I'll need?

If you can't care for your loved one fulltime, it doesn't mean you can't care for them at home, but you'll need to think carefully about your resources as you may need to pay for some care privately. Plan ahead. If you realistically believe you can't care for your loved one, no matter how much you'd like to, it's better to say so at the beginning rather than risk being disappointed when you make changes in the future.

General coping tips

- Accept that you will need help from others. Welcome this support.
- Identify the people that might be able to help you early on and call on them EARLY when needed (they need to help as much as you need them to).
- Talk regularly with family/whānau, friends or health professionals – about what you feel, what you need, how they can help.
- Find a local or online support group and share your feelings so they don't grow into problems.

- Be realistic. Know your limits, and learn to say no – don't take on more than you can handle.
- Eat well, exercise regularly and get enough sleep.
- Let go of unrealistic expectations and demands. Don't be a martyr.
- Hang on to your sense of humour.
- Make a list of names and phone numbers of everyone who can help you.
- Identify things you enjoy and take time out to do them.

Getting the help you need

You're not alone on this journey and it's important to know how to get the help you need from others. Asking for help isn't a sign of weakness or an admission of failure. Don't feel guilty about accepting help with shopping, cooking, housework or sitting with your loved one, so you can do things away from home or just have time to yourself.

Where will help come from?

Being the carer involves many things. You'll be part of a team that may include:

- Family/whānau and friends,
- Primary health care professionals: G.P.s, practice nurses, community nurses,
- Specialist hospice staff – doctors, nurses, counsellors, occupational therapists, physiotherapists, social workers, spiritual carers, dieticians and volunteers,
- Hospital Staff – oncology doctors and nurses, radiotherapy staff, ward staff,
- Community organisations and support networks – e.g. Cancer Society, Home Care organisations.

What you can expect

Caring for someone approaching death can affect every part of your life. It's a time of strong emotions – sadness, helplessness, unconditional love, anger, joy, hopelessness, fulfilment, fear, anxiety, frustration and hope. These can change from day to day or even minute to minute! This is normal.

During this time it is also normal for you to grieve for your loved one before and after they die. Knowing that your loved one is near death can trigger many different feelings. One deep reaction you and your loved

one may have is the grief you feel anticipating death. Feeling this grief before someone actually dies can get us ready to accept the inevitable. When you are grieving, you may go off food and have trouble sleeping, you may find you become forgetful or that your vision is blurred, or that you're getting panic attacks. You may become uncomfortably aware that one day you are going die. You may feel helpless, guilty and angry with everyone, including the person who's dying. Crying is the most visible sort of grieving, but not the only one. All are normal and okay.

Take care of your own physical needs and ask for professional help if you need it.

In the midst of this journey you may feel that all you can see is darkness or a black hole, and that things are only worsening. You may feel that life is revolving around sickness, dying and death. While this is true, try to focus on building yourself a "bridge". Find a project (e.g. start a patchwork, building project, life story of your loved one, develop a new hobby e.g. photography) that will carry you through to when your loved one has died. This will become your link to a life that will go on without your loved one. It will also help you to focus on something just for you during this time and your future without them in some positive way.

You may feel guilty or ashamed for wishing it were all over or thinking your loved one has already gone

intellectually. It's important to remember all these feelings are normal.

Many carers find their own physical and emotional health gets worse. You might get depressed – nearly half of all carers do –and suffer from emotional turmoil. Don't demand too much of yourself. Work out priorities and let other things go for a while. Cut yourself some slack – don't expect to get everything done all the time, on time, always right – this is an unrealistic expectation. No-one is perfect. Goals you've set might have to be put on hold or you might need to get help from others to achieve them.

Mourning and bereavement

People do not just mourn and grieve at the time of or after a death. Along this journey you will both continually grieve for the many losses you have had or will have until the final loss of death.

Losses can be big or small – some examples are loss of the ability to work, loss of companionship of workmates, loss of the ability to do household chores e.g. lawns, firewood, loss of the ability to shower independently, as well as the bigger loss of future hopes and dreams. All are equal losses and it is normal and acceptable to mourn their loss. Mourning these losses as they happen allows both you and your loved one to adjust together to your new way of being in a healthy way.

Grieving may involve these stages:

- Accepting the reality of the loss
- Feeling emotional pain and suffering
- Getting used to living without the loved one

Supporting bereaved people is a part of the care that hospices provide. You may find your grief so painful and difficult that you don't know how you're going to carry on. The months after a loved one has died can be particularly difficult because the people who were your support network go back to their lives while you struggle to find a new way of being 'normal'. Some people can travel through their grief and adjust to life without their loved one quickly while others take longer. There's no easy answer on how long bereavement will last – there is no set "usual" time. It may hurt less over time, but you might find there are triggers or significant occasions, like holidays and celebrations, that bring it all back. These might be happy or sad memories. You might have to deal with practical problems as you go back to work or change your habits and routines. You will find that you'll adjust in different areas at different times so that you can get on with your life while getting used to the changes. Many people expect you to "get over it". This is unrealistic. You will adjust to life without your loved one and "get on with it". Getting on with it allows the memories of your

loved one to be a part of your life without them hindering your positive progress forward.

Carer fatigue

There will be times when you'll feel physically and emotionally drained. You have a feeling of deep sympathy and sorrow for someone who is going through a bad time and is suffering and you feel helpless because you want so badly to make the person's pain go away or cure what's causing it. Living through these feelings is hard.

You could be suffering from carer fatigue if:

- You feel weary and exhausted and nothing you do seems to be enough,
- You're feeling constantly tired and find it hard to pull yourself out of bed in the morning,
- You're having trouble sleeping and eating,
- You lose patience and get angry with your loved one often,
- You can't concentrate or think clearly,
- You have no time or place for yourself,
- You are feeling totally stretched – physically, emotionally, financially, and socially,
- You're becoming more dependent on tobacco, alcohol or drugs,

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- You've lost or gained a lot of weight,
 - You see you have no options ahead of you,
 - You cannot appreciate any happy times in between your sad times.

Remember – you are no good to your loved one if you do not look after yourself. Taking good care of yourself will allow you to take good care of them.

Coping tools

Everyone has a 'toolbox' of coping mechanisms that gets them through difficult times. It's worth taking stock of your own toolbox and making sure you use the tools that can help you. Work out what problems are yours and which ones belong to other people. Don't be tempted to take on the issues other people have relating to the illness of your loved one. Be aware and be very clear on what you can and can't cope with at any particular moment.

Spiritual coping tools

When you're caring for someone with a life limiting condition it's often time to look at, question and come to terms with what you believe about death and dying. Where do you get your strength from: your family, your faith, nature? What does the death of someone you're close to mean to you? Do you need to do more of the



things that give you strength? Do you need to gather friends around you to support you with these spiritual needs? Does your loved one need support in this area as well?

Physical coping tools

Don't give up doing the physical things that let you blow off steam or relieve tension: going for walks, swimming, gardening, whatever you do to stay balanced. Maybe housework is the last thing you want to do, so delegate it to someone who has offered to help. There could be a home care agency which provides services you could access. Ask your hospice team for advice on this.

Try to eat well. Make double of everything you cook or ask people who have offered to help to cook some meals. Look after your health.

See your doctor if you need to or, if you're feeling overwhelmed, ring the hospice service.

Look carefully at your physical needs right now: how are you coping and what do you need to do? Make yourself a list.

Emotional coping tools

Look back over your life for ways you've coped emotionally before. Do you talk about things, write about them in a journal or get help from a counsellor or social worker? Do you make enough time to talk with your loved one?

Sometimes it helps to make time to think about things, to be sad and cry but also to feel happy about something and to laugh. Give yourself permission to feel what you're feeling – the more we bury feelings, the harder they are to deal with.

There's no right or wrong when it comes to your feelings. You may feel you need a way of resolving or completing your relationship with your loved one. You might need to say, "I love you", "I forgive you", "Forgive me", "Thank you", "Goodbye" or "It's okay to go now – we'll be alright".

Some people find organised carer support groups helpful. They like to hear how others have met similar challenges and to share stories. Ask your hospice team to suggest the best support group for you.

Social coping tools

How are you coping socially? Ask your hospice team if there any resources you haven't considered. Look at your social life: how much energy do you have for it? Is it supportive or would it be better for you to have fewer social contacts and save your time and energy? You will find that many people want to be involved or updated regarding your situation. Use technology such as email or answer phone messages to do this rather than having to talk to each and everyone. They will appreciate the update and will understand you using this technology to keep them informed.



Fear of the unknown is one of the hardest things to handle. Some questions you and your loved one face will be unanswerable.



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)



Family/whānau, friends and community, members of social organisations or faith communities you belong to, will help you and your loved one throughout this journey.

Circles of support

Navigating the end-of-life journey, there's help out there and being able to use it will be very valuable to you. How you use these support networks is vital to making sure your loved has high quality palliative care.

Find out what help is available in your community early on, even if you don't need it straight away.

Creating support networks

Our health system isn't perfect. You may be disappointed, frustrated or inconvenienced by the care and services you get, and this adds to the stress of care giving. Parts of care giving will call for all your patience and understanding. Having networks of support will help relieve stressful situations and provide direction when needed. You will feel overwhelmed at times. It is a natural reaction. Find people who can support you through this journey. Having someone who is able to go to appointments with you; to ask the questions you may not be able to ask, to hear the things you may not have heard is important. Work out who this person might be early on in your journey and talk over with them the important things you must know so that they are aware of your needs so that they can support you the best they can.

What are hospices?

Hospices provide palliative care. They take a lead role in someone's care when there's no longer a cure for the person's illness (though it's also helpful earlier in the illness when it's combined with treatment such as chemotherapy or radiation therapy). Palliative care is available for people with cancer and other diseases such as end-stage heart, respiratory and kidney disease, Alzheimer's, AIDS, motor neurone disease and multiple sclerosis.

In addition to the health professionals on staff, some hospitals also have a team of palliative care specialists who provide medical and nursing care to patients as well as advice and support to hospital staff, palliative patients and their families.

Hospices offer specialist care specifically to people with a life limiting condition and their families/whānau. Most care is provided at home. Home-based care is a part of the comprehensive programme of care hospices provide. It includes specialist nursing care and other support services such as day or respite care (This means someone

will take over for a while so you can go shopping or have a break. Alternatively your loved one could be admitted to the hospice inpatient facility for a short break). The home-based team also co-ordinates referrals to another care setting when needed, for example, residential care.

People with acute needs can be cared for in the hospice inpatient facility instead of a hospital and once their condition is stable they go home again. Sometimes people go into a hospice because their carer needs a longer break than one day or they can't look after them for short periods. Inpatient facility stays are usually short term. People may also choose to die in a hospice.

Bereavement support is an important part of the care that hospices provide. Bereavement support can start before death, especially when a child is dying. As the person nears death, bereavement support begins for carers. This support may carry on for a year or more after the death of a loved one.

Hospices often have bereavement groups, including grief groups for children, adults and families. Family service agencies, as well as funeral homes also offer support.

Community volunteers help the professional team provide a range of support services, such as information and practical help for both carers and their loved ones. Some hospices may be able to offer other things such as equipment (beds, wheelchairs, commodes), transport to

appointments, meal delivery or respite care. Ask your hospice team what support is available.

Many hospices and other community groups offer day care which may include social support, outings, complementary therapies and art activities.

Most people want to be able to die in familiar, comfortable surroundings, but their carers generally feel they'd need outside help to properly look after a family member with a life limiting condition. Being at home may help people stay involved with their families and live as normally as possible. Some people feel that when they're at home they have more freedom to choose the care they get. Others prefer not to die at home. It is important to tell your hospice team your preference as early as possible. The team will then be able to explain what options there are, which may depend on where you live.

Who pays for care?

Hospices don't charge for their services. Hospices are charitable organisations that get some funding from the Government through District Health Board contracts. The rest of the money they need comes from the community they serve through fundraising activities, grants, donations and bequests. Public hospitals provide palliative care without charge to patients. Private hospitals and residential care homes usually charge for the care they provide. G.P.s may charge for visits to patients with palliative care needs.

The multidisciplinary health team

Who is your healthcare team?

It's vital for your loved one's total comfort that you have good channels of communication with your doctor and other team members. The team may include your usual General Practitioner (G.P.), a palliative care physician, hospice care co-ordinators, a hospice nurse, a district nurse, a counsellor, an occupational therapist, a pharmacist, a dietician, a complementary therapist, a physiotherapist, a social worker and a spiritual carer as well as volunteers, personal care workers or home support workers. While this team works with and for you, your primary family doctor (G.P.) will usually field the first line medical queries you may have.

Alternative/complementary therapies

Many people consider the use of alternative/complementary therapies when mainstream medicine can no longer offer a cure. If you are considering using alternative/complementary therapies, talk to your doctor about the therapies you wish to use. Some therapies may interact with prescription medicines and it is important that you get the best out of all therapies. Tell your alternative/complementary therapist what other medicines your doctors have prescribed your loved one so they can tailor treatment to maximise the benefit of their particular treatments.

Although some alternative/complementary therapies may offer hope and a sense of regained control, scrutinise them as carefully as you would any treatment. Ask how they'll improve your loved one's quality of life, whether they'll interfere with other treatment and what you can expect from them. Seek out reliable research to back up any claims made for treatments. Consider the cost of these remedies as a part of your overall budget – can you afford it?

Many alternative/complementary therapists are registered, including those practising massage, herbal therapies, reflexology, aromatherapy and chiropractic medicine. Some hospices have complementary therapists working within their programme of care – ask your hospice if they have this service available to you.

Communicating with the team

The key principle of palliative care is that the person is ultimately responsible for making decisions about how they are looked after. As their carer, you may find yourself working on their behalf with other members of your healthcare team. You and your loved one must be able to communicate well with its members. You and your loved one will need to talk with various team members about the many decisions you have to make. Making clear and appropriate decisions about end-of-life medical care is difficult. Some people want to keep having treatment

to extend their life as long as possible, no matter what the side effects or risks. Others value quality of life more than anything else. They'll make decisions on that basis.

Helping

The following tips may help you communicate openly and honestly with your loved one and your doctor, especially if you're the main person who speaks for your loved one:

- If you've decided to care for your loved one at home, find a doctor who'll visit you there. Check the cost of these visits.
- Make appointments for an appropriate amount of time – the average doctor's visit is about 15 minutes so write a list of questions beforehand.
- G.P.s might want to refer you to hospice or hospital palliative care specialists who can explain side effects, offer more specialised treatment and answer questions about your expectations. You can also ask that letters, results or reports to or from different members of the team are copied to and sent to you. These are a written record of tests, treatment and appointments attended.
- If you are comfortable doing it and your loved one is unable to speak for themselves – be your loved one's spokesperson.
- Don't feel fobbed off! Speak up if you don't understand something you've been told. Ask if you want to know more; you are entitled to the best information available.
- Questions for your doctor might include: What can we expect from this treatment or procedure? What is its goal? If, for instance, palliative chemotherapy is offered, is the goal comfort or less pain? What kind of crises can we expect and what might go wrong?
- Some of your questions will stem from fear of the unknown, and many will have no answers. No one can predict how long someone will live – it's more realistic to talk about probabilities than ask for precise answers.
- It's okay to ask for a second opinion.
- As the main carer, it is important you go to all appointments. Take notes so you can refer to them later or organise to take a voice recorder with you. Sometimes this is the best way of getting the information repeated so you can process it in your own time. It is frustrating to come away from an appointment wishing you had asked something at the time or feel you didn't quite hear something that was said.

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- Keep a logbook or journal of all care and treatment; include details of drugs given, appointments, names and numbers of the healthcare team. Keep a file of all the letters and pieces of paper you are given along the way. Not only will this help you, but will create your own file for you to take to appointments. After appointments, ask for a report or a diagnostic summary if you feel it would help.
 - Because you know your loved one so well, you'll recognise changes that are not obvious to others. If you're worried or unsure, don't be scared to ask. Hospices have a phone line for you to ring if you have queries. There is no such thing as a silly question.
 - If in doubt – check it out!

Support circles

Family/whānau, friends and community, members of any social organisation's or faith communities you belong to, ministers, priests or other spiritual advisers are all crucial members of your non-medical support network. These people will help you and your loved one throughout this journey. It's best to actively organise this help – think about who is available and what they may do. Be clear with them about what they can do, how they can best do it and when they are available to help.

Family

Family relationships may change when one of you is dying. Sometimes this can be difficult.

The more openly you talk to each other the better. Family discussions are an essential part of making decisions about care. Being a part of these decisions helps family members understand, respect and support the decisions made even if they don't agree fully with them. Direct, clear communication is vital. Some families don't want to tell the dying person the truth for cultural or other reasons, but usually people appreciate you talking to them honestly and sympathetically.

A family meeting is a good way to get the family together with your loved one, to talk through important issues about the plan of care, such as where they should be cared for, who should

care for them, whether and at what point there should be an order not to resuscitate them, and review power of attorney for finances and health.

Emotions can run high in families at the best of times, but particularly when a member is dying. Sometimes having someone outside the family “chair” such meetings allows all members to be equal when they are at the meeting. Honesty and openness at these meetings is very important. It may help to begin family meetings by having some of you talk about how you’re changing because your loved one is facing death.

Sometimes, family dynamics can be difficult to cope with. A family illness such as a life limiting condition can open up long held family wounds and can sometimes inflame already smouldering situations. Decide early on if you have the energy to deal with these. If not, find someone within your family to “manage” these dynamics on your behalf. Complex family situations can take a lot of time and energy and take your focus away from the care of your loved one. Such things can wear you down if not dealt with at the right time by people who have the energy to sort problems out. This does not necessarily have to be you!

Getting help from friends, family/whānau and community

Informal “non-family” support can be a huge help to you and your loved one as well as your family/whānau. It can include friends, workmates, neighbours or members of any social organisations or other communities you belong to. Community support places could include neighbourhood centres, schools, churches, mosques, Marae, women’s groups, family resource centres and public health services.

Be crystal clear when telling family and friends how they can best support you. Do you need meals cooked? Do you need help with housework? Do you need someone to take on the job of phoning or emailing people with news of how your loved one is doing? Do you want people to drop by informally or is it best they let you know first?

Don’t be afraid to ask for help. Most people want to help, but they may be as inexperienced a supporter as you are a carer, and they’ll be happier with clear boundaries based on what your loved one needs and can accept. Friends and family feel helpless in this situation. Doing something gives them a job and makes them feel that they are sharing the load in a positive, purposeful way. Some people make a list of what they need done and put it on a board so visitors can sign up for a task; thus everyone knows who’s doing what and when. Sometimes making a roster for people to visit, sit with your loved one, cook meals or help with children is a great help.

More tips for getting help

- Be as honest as you can about what is happening.
- Involve those close to you in making decisions and solving problems so they'll better understand the situation and what you're doing.
- Involve family and whānau in the caring tasks. Discuss your commitments honestly with others. They may need to fill in for you or completely take over some tasks you used to do.
- Share your feelings about the difficulties, joys and grief as they come up.

Visitors

Visitors can be welcome but at times can be too much, too many and stay too long. This can exhaust both you and your loved one. Talk about the possibility of limiting visits to 10 minutes; some find using a roster system for visitors is helpful. You may want to put a nicely worded sign by the front door telling visitors what convenient visiting times are and leave a notepad there for people to leave a message. Get a telephone answering machine or service (Call Minder) to take calls when you can't get to the phone. If you use email, send a weekly or daily email to a group of friends updating them on the situation. This keeps them up to date but doesn't involve them ringing you or visiting.

Talking about dying

Friends and family may be uncomfortable talking about death; it can be like having an elephant in the room that everyone's trying to ignore. Denial – when people try to pretend something isn't happening – can be very powerful and often we don't have the words for talking about dying, or feel uncomfortable doing so. If you are comfortable about it, encourage people to talk openly about your situation.

Dying people still have a lot to give their families and part of holding onto hope is helping them to realise this and find opportunities to make this happen.

It may help to ask your loved one questions like:

- If I could change one thing to make things better for you today, what would that be?
- Now you're at this stage of your life, what things do you need to do?
- How can I help you the most right now?
- It can be useful to ask family members to think whether anything about their relationship with the dying person needs to be addressed, and to help them find the words to do it or ways to show it.

Talking to children about death

It's often easier for children to grieve if adults are open and honest with them about death. The attitude of adults to dying and death are reflected in the way children deal with it. Often it is easier to talk to children while doing other things –e.g. driving to and from school, giving them a bath, at night time when putting them to bed or when discussing a painting/story they have done recently.

- Encourage children to talk about how they feel about illness and death.
- Children have to learn to cope with loss; if we don't talk about it with them, they get the message that the subject is off-limits.
- When you're talking to children about death, use words like cancer, died and death. Words like passed away, he's sleeping or we lost him can confuse children and lead to misunderstandings.
- Children need explanations that are simple, direct and truthful. Give a child as much detail as they can understand and answer their questions honestly and directly. Often they are more aware than we give them credit for. Often they need the same information repeated.
- Letting them see your tears and sadness shows them it is okay to grieve openly. This gives them permission to do the same when needed.
- Very young children may feel everything is their fault. Reassure them often that it is not, and give them a care giving task, so they feel part of the caring team. Rubbing oil/cream into hands and feet of your loved one is a great thing for children to help with.
- Give children lots of reassurance that they're safe. They often worry that they'll die too or that their surviving parent will also go away.
- Keep their routine going as much as possible.
- Explain the physical changes illness can cause so they know what's happening. Allow them to ask the questions they have. It is okay to say "I don't know, but I'll ask someone if they know". Ask the Dr/nurse to explain if needed.
- Use a story (Lifetimes by Mellonie and Ingpen, The Memory Book by Bev Gatenby and Tricia Irving, Badgers Parting Gifts by Susan Varley and The Challenge of Change by Trey Malicoat, Amy Morris and Tricia Irving are good ones) to help children talk about living and dying.
- If you are okay with it, let children see their loved one during the dying phase and after death. This helps them process the transition of life to death. Being with their loved one in death reinforces to them that death is natural, not scary and lets them see for themselves the peace

that surrounds their loved one in death. It allows them to witness, express and share the raw grief that is a part of this time.

- Grieving children are helped by being included in the planning of memorial ceremonies, and taking part. Children shouldn't be forced to get involved in these ceremonies but encouraged to do as much as they feel comfortable with. These occasions help children (and adults) remember loved ones. Encouraging them to draw pictures, place flowers or write stories for or about their loved one is healing. These may be placed with their loved one as a "special gift" from them. Allowing them to stand with their family members during eulogies or readings is a way of including them in the ceremonies.
- Don't forget that like you, their grieving will continue. Continue to support them in the day, weeks and months ahead.





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.

Family/whānau often feel confused, tense, exhausted and numb when their loved one dies, so taking care of business affairs beforehand can ensure that these things are sorted well before time.



Practical matters

Being near the end of life often makes people want to put their affairs in order and make their wishes known about certain things. Helping your loved one make these plans can be a good way of reducing your own fear and anxiety about their death. It may also help to reassure you and your loved one that any important legal issues are understood and clarified between you at an early stage.

Other practical issues

Family/whānau often feel confused, tense, exhausted and numb when their loved one dies, so taking care of business affairs beforehand can ensure that these things are sorted well before time. Discussing “what do you want to happen when” scenarios opens the conversation for welcome discussion around difficult topics. If these issues are discussed early, requests are known and can be supported throughout the journey.

It may include your loved one writing down what they want to happen with their medical care and other matters, choosing an enduring power of attorney to speak and act for them and detailing what they want for their funeral or memorial service.

What if questions could include:

- How do you feel about different treatment options e.g. chemotherapy, antibiotics, going to hospital if needed?
- Where do you want to die? At home, in hospice, in hospital?
- Who do you want to look after you when you are sick? Who don't you want caring for you?
- Who do you want to speak on your behalf on financial matters/ property matters/health matters when you are unable to?
- Which funeral director do you want?
- What do you want for your funeral? What type of coffin? Where would you like it held? Who would you like to be the pallbearers? What music, readings/poems would you like?

During illness

Taking stock of assets and important documents

Make a list of assets like insurance policies, shares, bonds and assets in bank accounts and safety deposit boxes, and record where they are. You may also want to note the whereabouts of important documents like Powers of Attorney, your loved one's Will, their social insurance number, their birth certificate and their parents names and dates of birth. Make sure life insurance premium payments and beneficiary clauses are up to date.

A person's bank accounts are frozen on death. Joint accounts are not usually frozen. Before they die your loved one may want to set up a savings account in their spouse or partner's name; this means there'll be money for the family as soon as they die.

Wills

A Will is a legal document setting out certain requests a person wants once they have died. These could include: guardianship of children, how they wish their body to be treated (burial or cremation) after death, where they wish to be buried, or have they wish their ashes to be placed, and how they wish their assets and belongings to be distributed. It is advisable that everyone make a Will, otherwise their

wishes regarding certain issues may not be respected after death. An executor will be named. It is their role to ensure that the wishes in the Will are carried out.

Make arrangements to have your loved one's Will drawn up if it hasn't been done before. Many people have a lawyer involved when making a Will but this is not always needed. The Public Trust will prepare Wills without charging, or you can get "will kits" from the internet which are useful.

If your loved one already has a Will, make sure it is current and reflects what they want – who the executor is for instance, guardianship of children or financial arrangements.

Powers of Attorney

Sometimes dying people want to give someone else the permission (e.g. a family member, close relative, friend or professional) to make decisions in certain areas for them if or when they no longer can. A Power of Attorney is a document that appoints someone legally to act in matters that you choose e.g. money, health or property. For this type of attorney to be valid the person giving the power must be capable of instructing the attorney in such matters.

An Enduring Power of Attorney is able to act independent of the person they act for a person if that person becomes mentally unfit. There are two types of Enduring Power of Attorney;

- personal care and welfare; which gives the attorney the right to make legal decisions about a person's personal care and welfare.
- property; which gives the attorney authority to manage a person's financial affairs and deal with their property.

A solicitor or public trustee (for a fee) can help to set these up or alternatively you can access forms off the internet.

Living Wills and Do Not Resuscitate Orders

You may want to help your loved one plan for their medical care in a document called a Living Will, or advance directive. If these wishes are in writing it means you, family and health professionals will know what your loved one wants even though they might be unable to tell you when the time comes.

Living Wills vary in name and powers, depending on where you live. They say what healthcare you want, including whether you want doctors to use extreme measures to keep you alive or you'd prefer not to be treated – sometimes called a Do Not Resuscitate order or DNR. Living Wills might also include decisions about accommodation (where your loved one will live) and other legal matters not to do with money.

Ask your solicitor for more detailed information or to find out if a particular Living Will is valid.

Funeral arrangements

It is a good idea to think about arranging the funeral or memorial service before your loved one dies. Your loved one may want a particular poem or psalm to be read or a favourite piece of music played. They may wish to meet with the funeral director that will be caring for them once they have died. This sometimes helps to allay any fears they have about what will happen to them once they have died. It also means that after your loved one has died, you will not be meeting a stranger.

Discussing costs ahead of time mean these are a known cost at the time of death and you can plan ahead of time. A funeral director will be able to arrange for you to buy a cemetery plot or put you in touch with the right council official if this is needed.

After death issues

After your loved one's death, there is a lot of paperwork to be completed. Assets must be transferred from joint ownership to single ownership. Bank accounts, insurance policies, memberships must be closed or changed to yours only. If you are unable to cope with all of this, enlist the help of a family member or friend who can help you with this. To help with this, make a list of things you will have to change afterwards.

Meeting with lawyers and executors

Arrange to see your loved one's solicitor and executor or co-executor two or three days after the funeral. It is important not to put it off in case there are issues with the Will. For instance, if the value of the deceased person's estate is above a certain limit, the executor will first have to obtain the court's approval giving them the right to deal with the estate (this is the 'grant of administration' or 'probate').

The death certificate

The funeral director will register your loved one's death and will request a formal death certificate. Delivery of the death certificate should take no longer than ten days after the death is registered. Insurance companies and other organisations will need copies of your loved one's Birth, Marriage and Death Certificates before they can make any payouts. Once you have the certificate, make a dozen copies to have on hand for when you will need them.

Life insurance forms and banking

Get in touch with any companies who insured your loved one's house and contents, health and car as well as life insurance companies to inform them of your loved one's death. You may need to ask some companies (e.g. life insurance) for claim forms. Get in touch with their bank too. They will freeze their accounts. Let credit card companies know your loved one has died and cut up or hand back their credit cards.

Life after your loved one's death

Life will be difficult after the death of your loved one but you will be okay. Allow yourself time to remember, grieve and heal. Don't have too high expectations of yourself. Continue to ask for help if/when needed.

Useful information

Information and resources

You can find a lot more detailed information about hospice in print and on the internet. Start with

Hospice New Zealand

PO Box 11557
Manners Street, Wellington 6142
(04) 381 0266
www.hospice.org.nz

Hospice contact details:

Other national information sources

Alzheimers New Zealand

<http://www.alzheimers.org.nz>

Cancer Society

www.cancernz.org.nz

Carers NZ

www.carers.net.nz

Child Cancer Foundation

www.childcancer.org.nz

Justice Department

www.justice.govt.nz

Ministry of Health and Your District Health Board contacts

www.health.govt.nz

Motor Neurone Disease

www.mndanz.org.nz

Multiple Sclerosis Society of NZ

www.msnz.org.nz

National Heart Foundation

www.heartfoundation.org.nz

NZ Aids Foundation

www.nzaf.org.nz

NZ Association of Counsellors

www.nzac.org.nz

Parkinson's New Zealand

<http://www.parkinsons.org.nz>

Public Trust

www.publictrust.co.nz

Skylight (for children, teenagers and their families)

www.skylight.org.nz

Starship Hospital

www.starship.org.nz

Stroke Foundation of NZ

<http://www.stroke.org.nz>

Work and Income NZ

www.workandincome.govt.nz

