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# 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

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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.

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## 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

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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

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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.

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## 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



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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.

