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# 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

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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



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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.