

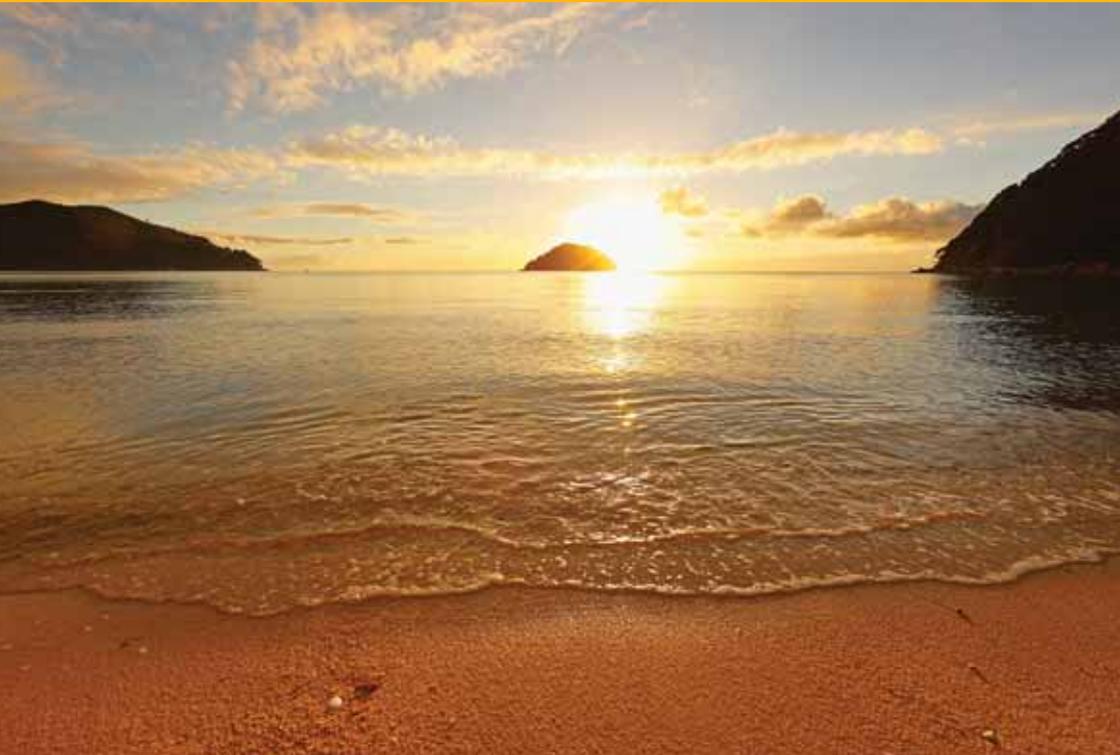


LIVING WITH CANCER

Talking about grief and loss



A guide for people dealing with the death of someone close



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Publications Statement

Our aim is to provide easy-to-understand and accurate information on cancer and its treatments. Our patient information booklets are reviewed and updated by cancer doctors, specialist nurses and other relevant health professionals to ensure the medical information is reliable, evidence-based and up-to-date. The booklets are also checked by consumers to ensure they meet the needs of people with cancer.

Other titles from the Cancer Society of New Zealand/Te Kāhui Matepukupuku o Aotearoa

Booklets

Advanced Cancer/Matepukupuku Maukaha
Bowel Cancer/Matepukupuku Puku Hamuti
Bowel Cancer and Bowel Function: Practical advice
Breast Cancer/Te Matepukupuku o ngā Ū
Breast Cancer in Men: From one man to another
Cancer Clinical Trials
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Being Active When You Have Cancer
Being Breast Aware
Bowel Cancer Awareness
Gynaecological Cancers
Questions You May Wish To Ask
Talking To a Friend With Cancer
Thermography

Talking about grief and loss

This booklet has been prepared to help you understand more about your feelings when someone close to you has died.

We hope this information will answer some of the questions you may have.

If you find this booklet helpful, you may like to pass it on to your family or friends.

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Grief is normal

Grieving is the process of adjusting to your loss and learning to live with the changes it brings to your life. Grief is often accompanied by strong and painful feelings that change frequently. This booklet aims to help you to understand some of these feelings. Not everything in this booklet will apply to you. You might like to re-read the booklet when some more time has passed.

The most important thing to remember is that grieving is a normal response to loss.

People grieve differently

How people experience grief depends on a number of things. Among them are:

- your age and gender
- your personality
- the circumstances of the death
- the support you have from other people
- the relationship you had with the person who died
- the degree to which your life will change as a result of the death
- the losses you've had in the past
- your cultural background.

Everyone responds to loss, and shows their grief in different ways. Even members of the same family can grieve in different ways and it is important to remember that grief is individual to each of us.

There may be different ways in which women and men grieve.

Men may prefer 'doing things', getting back into work, going for a walk or getting busy doing jobs like mowing the lawns. Women tend to talk about the person and cry, and may be open about how they feel. Both men and women are feeling the loss but doing it differently.

Many of us use a mixture of these two styles of grieving. It can be difficult for us to understand each other's ways of grieving and this can lead to tension in relationships. By allowing and respecting differences in how a person grieves you are less likely to misunderstand each other. Ask the other person 'What would be most helpful for you?'

Remember there's no 'right' or 'wrong' way to grieve. Sometimes people find that a death brings back memories of other losses from the past. This can add to your loss and increase your sense of mourning (deep sadness).





How a person dies affects your grief

What happened in the hours and days before your loved one's death, and at the time of death, can make a big difference to how you grieve.

If someone was terminally ill with a disease such as cancer, you may have had time to get used to the idea they are dying. You may have been able to spend time with them and, perhaps, talk about their death and what it will mean. This is often helpful in the months that follow, even though you may feel you can never be truly prepared for their death. If they die peacefully, you might find you draw comfort from this.

Sometimes, even when a death is expected, when it actually happens, it still feels like an unbelievable shock. If the person has rallied again and again in the past, you may have felt that they will always 'pull through' somehow.

If the death was very sudden, it can take a long time to get over the shock and the sense of things being left unfinished or unsaid. A difficult and painful death can stay in your memory for months or years before it begins to fade.

Sometimes it may be important to find ways to say the things that haven't been said, maybe writing a letter to them and putting it in the coffin with them, or taking the letter and reading it at the grave side, or writing on a balloon and letting it go can help.

Grieving doesn't always begin when someone dies

When someone is ill for some time, they and their loved ones often begin to grieve for their death before it happens. While there may be a lot of attention taken up with caring for a very sick person in the family, there's still often the thought: "How will it be when they are not here?" "How will I cope on my own?"

Sometimes people are shocked by how little they feel when their loved one actually dies. At times like this they sometimes comment that they feel they've done much of their grieving already. This is a normal response, and doesn't mean that they're denying the loss.

Some people feel a sense of relief that the person has died and no longer suffering or in pain. People often feel guilty about this but it is a normal response. Caring can be exhausting both physically and emotionally.

Some people find they were not as affected by their loss as they expected at the time of the death, but find it harder as time passes. This is quite normal.





Grieving is an up and down process

Grieving isn't something you begin one day, move through step by step and arrive unchanged from at the other end.

People sometimes speak of the 'stages' of grief, but, for most people, it's an up and down business: a bit like a roller coaster. Most find they move through it gradually, but don't despair if you find yourself at the beginning again and again – that's normal.

You might find there's a time of day, a song, a smell, an anniversary or doing something you used to do together that reminds you of them, and suddenly you feel emotional.

Grieving changes over time

When people find grief particularly hard they sometimes worry that they'll be unhappy for the rest of their lives. For most people it isn't like that. After a while the hurt will lessen. You may remember the funny things that make you laugh or smile. Surprisingly, you'll find yourself enjoying things and feeling enthusiastic about life again. For a lot of people, coping with grief doesn't mean getting over the loss; it's about finding ways to live with it and adjusting to life being different.

How long does it take?

Sometimes other people or you may expect you to be back to normal after just a few weeks or months. Friends and family may make comments like "Life has to go on. It's time to pick yourself up and get on with living." These comments could feel like criticism, and you may feel you're being told not to grieve any more.

For many people, though, it's a long time before the loss is no longer overwhelming. For some, grief never goes away completely. When someone has died, you may miss them throughout your life.

Try to be patient with yourself. Many people make things harder for themselves by saying "I should be over this by now". Giving yourself time to grieve allows you to acknowledge the person, your love for them and to make sense of all that has happened. They mattered; your relationship to them mattered.





How does grief feel?

Grief is not just sadness. It's a whole range of feelings and experiences. You may feel guilty, happy, sad, tearful, feel like laughing or screaming. You are not going crazy. Your mood may change but that's normal.

Numbness

Sometimes people feel nothing. They just can't believe it's true. It may feel like the person who has died has just gone on holiday and one day they will suddenly walk in the door and say, "I'm home again!" You may feel like you're in a bad dream and one day soon you'll wake up.

Shock and the sense of numbness help us through the first days and weeks after a loss. Don't feel you have to push yourself past this. The sense of numbness will start to fade although it may return from time to time. As time passes the reality of your loss will become clearer.

Sadness

Sometimes you feel like you'll never stop crying. You long to see the person so much you just don't know what to do with yourself. At other times you might feel terribly sad but can't seem to cry, even though you feel you are crying inside.

Anger

Some people feel angry at times. Some people feel angry with God, with the person who has died, with death, with themselves, with health professionals or family members. Sometimes someone does something small that makes you very angry – just out of the blue for no reason at all! This is normal. Try to notice when this happens. What is this really about?

Loneliness

Loneliness is common. You may miss having someone around to chat to about the ordinary things. It can be lonely, when others move on in their lives, while you're still feeling your loss.

Relief, guilt and regret

Relief can also be a common emotion when someone dies. Sometimes it's a relief that it has happened at last: that this death that you've been worrying about for months has finally happened. It's normal to feel pleased that a person's suffering is over, or relief that someone you had a difficult relationship with is no longer around.

It may be hard not to feel guilty about feeling relieved. Although you may be surprised by your feelings, they are a normal response to your situation.





You may feel guilty about the things you did or wish you had done differently, and there may be regrets for the way things happened in the past. When someone dies we lose the opportunity to change things. Try to remember that no one is perfect. Often, talking it over with someone else helps. You might also feel guilty for joking and laughing, or feeling happy at times. But it's okay to do those things: it doesn't mean that you aren't grieving.

Fear and panic

People often become very fearful when they have a major loss in their lives. You may feel worried about other people you love, or fear for your own safety. Little things that were no trouble to you before can throw you, and you worry about how you'll cope. This will pass; there is a lot going on. If this continues, think about seeing your doctor or a counsellor to talk about ways to manage this.

Depression

Sometimes people can feel depressed or not interested in things going on around them. This may express itself as a loss of self-esteem, a lack of direction or purpose. "Why me?" is a question people find themselves asking a lot. If you feel down most of the time, or others close to you are concerned about you, talk to your doctor or a counsellor.

Rejection

When someone dies or leaves, you might feel rejected and left behind. People with a religious faith may feel that God has forgotten them, at a time when they particularly need support. Sometimes people feel rejected by the friends they thought would be most supportive or out of place at social functions because of their changed situation. Grieving people are often surprised by which people offer the best support; often it's someone who has experienced a major loss themselves in the past.

Confusion and forgetfulness

Often people find they are confused and forgetful, and even getting simple tasks done can seem hard. It's as if your mind is filled with thoughts of what has happened, or foggy and you may find it hard to think clearly. Make a list and tick items off. This may help you feel like you are doing things and remembering them.

Being very tired

Don't be surprised if you have no energy and always feel tired. Getting used to change is tiring. You may find you can't sleep well or you want to sleep all the time.





Dreams and visions

Dreams and nightmares are common after a major loss. When someone has died, people often experience them in some way. Hearing their voice, feeling their presence or sensing them around can be a common experience. If you believe people live on after death, you may find this comforting; if not, you may be frightened or disturbed by it. Sometimes, you might see them everywhere; catching sight of them in the distance in the street, only to find it's someone else when you get closer. This is normal. If you are worried, talk to someone about it.

Physical effects

Grief is experienced in your body too: feeling tense, having a headache, not feeling hungry, feeling sick, unexplained aches and pains or a tight feeling in the chest are all common.

These things are normal, but talk over anything that's worrying you with your doctor. If lack of sleep becomes a real problem for you, tell your doctor about that too: a short course of something to help you sleep may make things much easier to deal with. Lack of sleep can make anybody's day feel awfully grim. Ring and talk with an information nurse at the Cancer Society. They may be able to help with ideas that others have found helpful.

Anniversaries and other special times

Anniversaries of the death (especially the first anniversary) and other special days such as birthdays, holidays and getting together with families or friends may feel overwhelming, confusing or worrying. Don't be surprised by this, it's very common. Often the best way of handling it is to be prepared.

Think about what you would like to do. Many people find planning activities with others around these times gives them a focus and provides support. Ideas include planning to visit the grave, having a family dinner, visiting a beach or park that you know the person enjoyed, looking at photos, watching a DVD they loved, making their favourite recipe or lighting a candle.





How you can help yourself

Grieving can be hard work, but the year/s ahead don't need to be a time of constant sadness or distress. There's always something you can do to help yourself.

Here are some suggestions:

- **Remember you are not alone** – loss is part of being human. Find someone you can talk to, someone who'll really listen. Seek out professional support if you feel your family and friends are not listening to you, or you feel you're burdening them.
 - **Try a support group or a grief group.** Talking to others with a similar experience can ease the loneliness of grief. Check at your local Cancer Society if there's a group running locally.
 - **Get plenty of rest.** Grieving uses a lot of emotional energy, and you'll probably feel very drained. The important thing is to try to balance rest with some activity. Being busy helps rest your emotions and creates a distraction. Getting some things done in your day can help you to feel better.
 - **Set yourself small, achievable goals** and give yourself a pat on the back when you reach them.
 - **Keep decision-making to a minimum.** Try not to make any major changes for a while. People may want to hurry you to sort out the belongings of the person who has died, or make a decision about where you live long term. Don't be rushed into these things – you're already dealing with a lot of changes in your life. Sometimes when we rush into doing these tasks too soon we make decisions which later we regret.
 - **Ask others for help.** Sometimes it's best if you're specific about ways others can help you. Do you need someone to mow your lawns, or do you just need a shoulder to cry on? Let others know if you need to talk about the person you are missing and that it would be helpful if they listened. Let the person know that even if you cry that you are okay.
 - **It's normal to feel angry.** Find ways to be angry safely – scream in your car with the windows up, hit a pillow or scream in the shower. You may feel silly, but action often helps.
 - **Try to eat well.** If you don't feel like eating, eat healthy snacks often. Try to avoid fast food, skipping meals or alcohol.
 - **Pamper yourself** – hot baths, massages, a special magazine, listening to music – anything that helps.
 - **Learn ways to distract yourself** on the days when you feel you just can't face life. Reading a good book, playing cards with a friend, watching a movie: anything that takes you away from yourself and your troubles for a little while.
- 



- **Try keeping a journal.** Write whenever you feel like it. Looking back over past entries helps to remind you that you're getting somewhere and putting your thoughts on paper is a good way of getting them straight.
- **Get some exercise** – a good walk can turn your mood around. Even giving the house a good vacuum or mowing the lawn can help if you're feeling tense.
- **Have something to look forward to** every day. It may be something like having coffee with a friend, watching your favourite TV programme, eating your favourite meal.
- **Look after your memories.** Have some photos and other mementos around. You may want to think about making a memory book or memory box. This can be a collection of things that remind you of the person who died or things that were important to them, and may include things like photos, cards, their handwriting, their favourite music, certificates they were awarded, some of their favourite things, recipes, things they made, letters, postcards, poems, tickets from holidays and shows or some personal possessions.
- **Try to find spiritual peace** in whatever way is best for you. For some people this will mean going to church, talking to a priest or minister or meditating. For others it will be a walk on the beach or in the bush, or listening to music – whatever reminds you of a different perspective on life, a larger way of seeing your situation.
- **Remember other difficult times you have had** in the past. What helped you then may help you now.

Helping children in your family

When there's a major loss in the family, everyone is affected. Children and teenagers feel grief just as adults do but they may express it differently. They may express their grief in outbursts of anger, sulkiness, worrying about you or by becoming very withdrawn.

The ways children and young people understand death and experience grief are different for different ages and stages of development. Like adults, they need support and the opportunity to understand and express their feelings and feel part of what's going on. Seeing the adults around them crying and talking can be helpful. Spending time talking with the children about their memories of the person who has died, looking at photos and drawing pictures can be helpful.

'Being there' for your children is especially hard when you're grieving yourself. Sometimes people feel they just don't have any emotional energy left for their children. Sometimes teenagers may talk to their friends rather than talk to you.

Letting others help is important. Extended family, friends and school can make a big difference. Stay in touch with your child's school or preschool so that their teachers are aware that your child is having a difficult time.





Skylight is a national organisation that works specifically in the area of children and young people's grief. It offers information and support for parents and professionals who work with grieving children. You can contact skylight at **0800 299 100**, at PO Box 7309, Wellington South or by emailing them at skylight@xtra.co.nz

Skylight has a useful website (www.skylight.org.nz) which has more detailed information on children and young people's grief, on ways to support them, and resources that you can loan and/or buy.

How to manage if you feel stuck or desperate

Many people have times after a major loss when they feel they just can't go on. The pain of grief is too hard, or just doesn't seem to be getting any better.

At times like this it's very important that you look for help from others. Don't struggle on alone feeling desperate. Professional support can make a big difference. Talk to your GP, or to a counsellor who specialises in working with grieving people.

Some people find they can 'ride it out', and realise there's a pattern of good days and bad days, with the good ones gradually increasing.

What professionals can offer

Hopefully, you'll have family or friends to support you through the next months but, sometimes, it helps to talk to someone who is not a family member or a friend. Perhaps, at the moment, you're not feeling too upset by what has happened, but if you do find things difficult, keep this in mind.

It can help a lot to talk to a professional counsellor, particularly one who's experienced in dealing with grief. They can't do your grieving for you, but they can support you.

Counsellors usually charge a fee. There may be agencies that offer a free or small fee service. Choose a counsellor who is part of a professional organisation, such as the New Zealand Association of Counsellors.

If the first person you talk to isn't helpful, don't give up. Try someone else. Your local Cancer Society may be able to assist and will have information about suitable counsellors, support services and groups available in your area.

This booklet is part of a series called Living with Cancer, which is published by the Cancer Society. These booklets, and booklets from the Understanding Cancer series, can be viewed and downloaded from our website (www.cancernz.org.nz).





Suggested resources

Internet-based memory/grief sites:

The New Zealand Childhood Cancer Memorial:

www.kiwiangels.org – a New Zealand memorial site for children who have died of cancer.

1000memories.com – a site where you can digitise, upload, organise and share photographs online. You can add dates, tags and captions to your photographs and are able to scan and share them with an iPhone by using an app called ‘Shoebox’.

www.tributes.co.nz – NZ-based site where you can create a tribute page for the person who has died. All funeral homes here have immediate access to this website and can create a tribute page for you.

www.griefnet.org – an internet community of people dealing with grief, death and major loss, is a useful US-based site with a comprehensive list of resources available, and online support groups for both children and adults.

http://www.webhealing.com – Tom Golden’s interactive website. Tom is an American grief counsellor and writer who specialises in working with men. His website offers parents opportunities to read other parents’ stories, and articles about grief.

There is a huge range books about grief for adults, young people and children. Talk to a librarian or a good bookseller about what is available that will suit your particular need. For an updated list of good grief resources, go to the National Association for Loss and Grief (Nalag NZ) website (www.nalag.org.nz).



Suggested reading

Beattie, Kath. (2007). *Walking Backwards Into Your Future*.
Dunedin: Kath Beattie.

Golden, Thomas. (2000). *Swallowed by a Snake*.
USA: Golden Healing Publishing.

Heaney, Pam. (2002). *Coming to Grief: A survival guide to grief and loss*. Dunedin: Longacre Press.

Ironside, Virginia. (1996). *You'll Get Over It: The rage of bereavement*. UK: Penguin.

The Dougy Center for Grieving Children. (2004).
35 Ways to Help a Grieving Child. USA: The Dougy Center for Grieving Children.

Wallbank, Susan. (2010). *The Empty Bed: Bereavement and the loss of love*. London: Darton, Longman and Todd.

Books for children to read

Boritzer, Etan. (2000). *What is Death?*
USA: Veronica Lane Books.

Bryers Holloway, Judith. (2001). *Hine's Rainbow*.
New Zealand: Mallinson Rendel.

Gootman, Marilyn E. (1994). *When a Friend Dies*.
Minneapolis: Free Spirit Publishing.

Hager, Mandy. (1995). *Tom's Story*.
New Zealand: Mallinson Rendel.

Mellorie, Bryan and Ingpen, Robert. (1983).
Lifetimes: A beautiful way to explain death to children.
New York: Bantam Books.

Rosen, Michael. (2004). *Michael Rosen's Sad Book*.
London: Walker Books Ltd.

Simon, Norma. (1986). *The Saddest Time*.
Illinois: Albert Whitman and Company.

Varley, Susan. (1984). *Badger's Parting Gifts*.
New York: Lothrop, Lee & Shepard/HarperCollins.

Viorst, Judith. (1971). *Tenth Good Thing About Barney*.
New York: Aladdin Paperbacks.



Notes

You may wish to use this space to write down any questions for, or advice given by, your doctors, nurses or health providers at your next appointment.



Notes

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Otago/Southland Division

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Telephone: (03) 477-7447
Covering: Urban and rural Otago and Southland

Cancer Information Service

0800 CANCER (226 237)
www.cancernz.org.nz

Feedback

Talking about grief and loss

We would like to read what you thought of this booklet, whether you found it helpful or not. If you would like to give us your feedback, please fill out this questionnaire, cut it out and send it to the information manager at the address at the bottom of the following page.

1. Did you find this booklet helpful?

Yes No

Please give reason(s) for your answer.

2. Did you find the booklet easy to understand?

Yes No

Please give reason(s) for your answer.

3. Did you have any questions not answered in the booklet?

Yes No

If yes, what were they?

4. What did you like the most about the booklet?

5. What did you like the least about the booklet?

6. Any other comments?

Personal information (optional)

Are you a person with cancer, or a friend/relative/whānau?

Gender: Female Male Age _____

Ethnicity (please specify): _____

Thank you for helping us review this booklet. The Editorial Team will record your feedback when it arrives, and consider it when this booklet is reviewed for its next edition.

Please return to: The Information Manager, Cancer Society of New Zealand, PO Box 12700, Wellington.



Information, support and research

The Cancer Society of New Zealand offers information and support services to people with cancer and their families. Printed materials are available on specific cancers and treatments. Information on living with cancer is also available.

The Cancer Society is a major funder of cancer research in New Zealand. The aim of research is to determine the causes, prevention and effective methods of treating various types of cancer.

The Society also undertakes health promotion through programmes such as those encouraging SunSmart behaviour, eating well, being physically active and discouraging smoking.

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Photography

Cancer affects New Zealanders from all walks of life, and all regions of our beautiful country. Our cover photo of an Onetahi Bay sunrise was taken by Rob Suisted Photography.

Cancer Society

For cancer information and support, phone **0800 CANCER (226 237)**

www.cancernz.org.nz

ANY CANCER, ANY QUESTION

0800 CANCER (226 237)

Cancer Information Helpline

