



Understanding Grief

A guide for family and friends when someone has died from cancer

Coping with cancer

Cancer Council Helpline

13 11 20

www.cancercouncil.com.au

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A guide for family and friends when someone has died from cancer

First published April 2014

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ISBN 978 1 925136 09 8

Understanding Grief is reviewed approximately every three years. Check the publication date above to ensure this copy of the booklet is up to date. To obtain a more recent copy, phone Cancer Council Helpline 13 11 20.

Acknowledgements

This edition has been developed by Cancer Council Queensland on behalf of all other state and territory Cancer Councils as part of a National Publications Working Group initiative.

We thank the reviewers of this booklet: Di Moncrieff, Director Psychosocial Services, Central Adelaide Palliative Care Service; Aurilea Augustine, Cancer Connect Volunteer/Consumer; Frankie Durack, Counsellor WA; Vic Dwyer, Silver Chain WA; Tracey Gardner, Psychologist, Cancer Council QLD; Carmen Heathcote, Helpline Operator, Cancer Council QLD; Yvonne Howlett, Helpline Operator, Cancer Council QLD; Claire Maskell Gibson on behalf of Palliative Care Australia.

Cancer Council acknowledges: Lois Tonkin and the Cancer Society of New Zealand for content adapted in *Understanding Grief*, a booklet developed by Cancer Council Queensland used in part as source material; and Palliative Care Australia for content adapted from their booklet *Now What? Understanding Grief*. Thanks also to Annie Angle, Specialist Cancer Nurse, for sourcing some of the quotes used in this edition, and to those whose words have been included.

Editor: Amanda Gibson. Designer: Cove Creative. Printer: SOS Print + Media Group.

Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain appropriate independent professional advice relevant to your specific situation and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.



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Introduction

This booklet has been prepared to help you understand more about your grief when someone close to you has died from cancer. We hope this information will answer some of the questions you may have, and provide you with suggestions on ways to help you cope with your loss.

This booklet is a general guide only, because each person's experience of grief is unique to them and their situation. Although it is intended to be helpful, the booklet may stir up feelings at this difficult time. You may like to read the parts that seem useful now and leave the rest until you're ready.

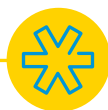
If you find this booklet helpful, you may also like to pass it on to your family or friends.

For many people, coping with grief doesn't mean getting over the death of a loved one. It is about finding ways to live with the change and adapting to life without them.

How this booklet was developed

This information was developed with help from a range of health professionals who specialise in assisting with bereavement, and also from people who have experienced loss due to cancer.

If you're reading this booklet for someone who doesn't understand English, let them know that **Cancer Council Helpline 13 11 20** can arrange telephone support in different languages.



“ I knew he was going to die, but nothing prepared me for the depth of my sadness when he did. Even though I was surrounded by family, I felt so very alone. It has taken time, but I can now see through my tears and see his smile, which will always be with me. ” *Vanessa*

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What is grief?

Grief is a normal response to loss. We experience grief when someone close to us dies and when we have other significant losses such as loss of relationships, health, a pet or employment.

While there are common grief reactions, you will grieve in your own way and your own time. Even though grief is normal it can be a confusing and overwhelming experience accompanied by strong and painful feelings.

““ I felt so lost and sad after losing my Mum. ”” *Anne*

How does grief feel?

Grief is not just sadness. It can be a whole range of feelings and experiences.

Sometimes people are overwhelmed by the intensity of their feelings and wonder if they are losing their mind. Your mood may change quickly and often. These are all natural reactions to the experience of loss.

See page 16 for tips that may help manage these feelings.

Numbness

When someone dies, you may feel nothing at first – this may be because you can't believe it's true. It may feel like the person who died has gone on holiday and will suddenly walk through the door again.

This numbness may be helpful during the first days and weeks after a loss, when you may be making practical arrangements, such as planning and attending the funeral. Don't feel you have to push yourself past this. The sense of numbness will start to fade in a few days or weeks, although it may return from time to time. The reality of your loss will become clearer as time passes.

Sadness

Sometimes you feel like you will never stop crying. You may long to see the person so much you don't know what to do with yourself. At times, you may cry or be teary. You might also feel terribly sad but can't seem to cry, even though you feel you are crying inside. Both reactions are common.

Anger

Many people feel very angry when they are grieving. You may feel angry with your God, the person who has died, the fact of death, yourself, those involved in caring for the person who died, even the driver in the car behind you, or for no reason at all.

Loneliness

Loneliness is very common – you may miss having someone to chat to about the ordinary events of life, or sleep next to in bed. After some time has passed, you may still feel your loss very strongly,

but everyone around you may seem to have moved on. You may also find you sometimes withdraw socially. These things can also make you feel alone.

Relief and peacefulness

You may feel a sense of relief that the person has died, especially if they have been unwell for a long time. Sometimes it's relief that it has happened at last; that this death you have been worrying about for months is finally a reality you can deal with, and you can get back to familiar routines.

You may also feel glad that the person's suffering is over, or relief that someone you had a difficult relationship with is no longer around.

It's hard not to feel guilty about this sense of relief. We often seem to be expected to idolise or 'put someone up on a pedestal' when they have died – but they were human, with good traits and bad ones, and you are too.

Guilt and regret

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 may feel guilty for joking and laughing, feeling happy at times, or getting on with life. But it's okay to do these things.

Fear and panic

People often become very fearful when they have a major loss in their lives. You may feel terribly worried about other people you love, or fear for your own wellbeing. Little things that were no trouble to you before can throw you, and you may worry about how you will cope.

Depression

Some time after the loss, when the reality of it sinks in, you may find your sadness overwhelming. A loss of enjoyment in life and a lack of direction or purpose are common, especially if you feel you are taking a long time to come to terms with the loss. However, if these feelings persist for an extended period of time, it may be a sign of depression.

For more information on depression, see *How to manage if you feel 'stuck' or desperate* on page 14.

Rejection

When someone dies or leaves, you might feel abandoned and rejected. If you are religious, you may feel that your God has abandoned you at a time when you particularly need support. Sometimes you may feel neglected by the friends you thought would be most supportive, or you may feel uncomfortable at social functions because of your changed circumstances.

You may be surprised by who offers the best support; often it's someone who has experienced a major loss themselves.

Confusion and forgetfulness

Frequently people find they are confused and forgetful, and even getting a simple task done seems like a big hurdle. It's as if your mind is filled with thoughts of what has happened, and you can't concentrate on anything else.

Exhaustion

Don't be surprised if you have no energy and feel constantly tired. Adjusting to any major change is exhausting. You may find you can't sleep well, or you may find you want to sleep all the time.

This is your mind trying to process and make sense of what has happened. An ongoing lack of sleep can make it difficult to cope with daily life. It is important to be gentle with yourself and, if lack of sleep becomes a real problem for you, talk to your doctor.

Death ends a life not a relationship

Many bereaved people report a sense of presence, and dreams of the person who has died. Even though your relative or friend is no longer physically present, they remain part of you and your life. You will hold them in your mind and heart always, and this ongoing connection can be a source of comfort in your grief.

Grief can be physical too

Grief is experienced in your body too. Feeling tense, experiencing headaches, having no appetite, feeling sick, unexplained aches and pains, and a tight feeling in the chest are all common physical responses to grief.

If someone has died from an illness, such as cancer, it's not unusual to have symptoms similar to what they experienced. It may be helpful to talk to your doctor about anything that is worrying you.



Everyone grieves differently

Everyone responds to loss, and grieves in different ways. Often, family members mourning for the same person may misunderstand one another's way of grieving, especially if it is different from their own.

How you experience grief depends on a number of things, such as:

- 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
- how much your life will change as a result of the death
- the losses you have had in the past
- your cultural background, including any rituals or customs associated with death.

Remember there is no right or wrong way to grieve. Sometimes people find that a death brings back memories of other losses from the past, and they feel they are mourning for those again.

Some people want to express their grief through crying and talking, others prefer to keep busy. People may behave differently at different times. It is important to respect each other's way of grieving.

🗨️ I think time does heal, but the pain is still there and you just learn to cope with it. Sometimes I still cry out ‘Why?’ Darren was so full of life and never complained about anything; I’m still amazed at how he coped with it all. 🗨️ Troy

Circumstances can affect your grief

What happened in the hours and days before your loved one’s death can make a big difference to how you grieve.

Sometimes knowing a loved one is dying, however difficult that is, prepares you in some way. You may have been able to spend time with them, talking about their death and what it will mean. This is often helpful in the months that follow, even though you may feel you could never have been truly prepared for their death. If they die peacefully, you might find you draw comfort from that peace; there is perhaps a sense of acceptance about the loss, even if you feel sad.

If the death was very sudden, or in traumatic circumstances, there may be a sense of things being left unfinished or unsaid. It is not unusual for grief to be more complex when this happens.

Sometimes, even when a death is expected, it may still feel like a great shock. This can be especially hard if the person has rallied again and again in the past, and you may have thought that they will always ‘pull through’ somehow.

Grieving can begin before someone dies

When someone is ill for some time, they and their loved ones often begin to grieve their death before it happens.

While there may be a lot of attention taken up with caring for a sick person in the family, there is 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, and say that they feel they have done much of their grieving already. This is a normal response, and doesn't mean they are denying their loss.

On the other hand, sometimes people find they are not greatly affected by their loss at the time of the death, but find it harder as time passes, and they experience their loss in a delayed way. Again, this is quite common.

Cancer Council produces a number of resources, including *Living With Advanced Cancer*, *Understanding Palliative Care* and *Facing End of Life*, which may help prior to the death of a loved one. Call Cancer Council Helpline **13 11 20** to obtain copies and further information.




How long will it take?

People often expect to be back to normal after just a few weeks or months. Friends and family can add to this feeling with comments such as: “Life has to go on. It’s time to pick yourself up and get on with living.” Often these messages feel like criticism, and you may feel you are being told not to grieve any more.

Many people talk about the first year - all the ‘firsts’ without your loved one – as being especially difficult. As all of these events pass most people learn to cope a little more, and with time they find it does get easier.

Try to be patient with yourself. Many people make things harder for themselves by saying: “I should be over this by now.” Don’t expect too much of yourself. Giving yourself time to mourn is the best way to heal.

“Grief is so painful at first and very overwhelming. It gets easier to cope with as time goes on though. It is so true what they say – time does help to heal.”  Anne

Grieving is ‘up and down’

Grieving isn’t something you begin one day, move through step by step, and emerge unchanged from at the other end. People sometimes speak of ‘stages’ of grief, but for most people it is best described as similar to being on a roller coaster.

Most find they move through grief gradually, but don’t despair if you find yourself at the beginning again and again – this is common.

You might find there is a time of day when you miss the person who has died most. Or it might be a song, a smell, an anniversary or doing something you used to do together that reminds you of them, and you may feel upset again. See page 16 for ideas on how to help yourself through these times.

““ At times the sadness and pain I feel is all consuming and hard to bear, while at other times these feelings are just in the background of my day to day activities. ●● Anne

When people find grief particularly hard they sometimes worry they will be this unhappy for the rest of their lives, but for most people it isn't like that. After a while it doesn't hurt as much as it did at the beginning, and you will find yourself starting to enjoy things and feeling enthusiastic about life again. For many people, coping with grief doesn't mean getting over the death of a loved one. It's about finding ways to live with the change and adapting to life without them. It's not that your feelings about the person lessen, so much as the loss becomes part of your life.

How to manage if you feel 'stuck' or desperate

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

Talking to family and friends about the way you are feeling can often help, along with being kind to yourself and knowing that it is okay to have some down days. In a week or two things will change and you will realise there is a pattern of good days and bad days, with the good days gradually increasing.

But sometimes a person may begin to feel 'stuck' in their grief and become very depressed. Or worse begin to feel suicidal, as though not going on is a real option. If this is the case for you or someone you care about it is important to seek help.

You may need to seek professional help if you:

- begin to rely on alcohol or drugs
- stop eating regularly
- begin to neglect your personal hygiene
- appear to be sleeping too much or having trouble sleeping
- feel aggressive or show signs of other anti-social behaviour
- think about self-harm or taking your own life.

At times like this it is very important that you look for help from others – there is no need to face these feelings alone. Professional support can make a big difference. Talk to your GP, Lifeline **13 11 14** or call Cancer Council Helpline **13 11 20** to find out about your options for professional support. See also *Getting professional help* on page 23.

If you are having suicidal thoughts call Lifeline **13 11 14** immediately.





What can help?

Grief can be hard, but the time ahead doesn't need to be one of constant sadness or distress. Here are some suggestions to help through difficult times:

- Accept that your feelings are normal and natural. You may feel pressure from yourself or others to feel a certain way, but everyone is different and copes in their own way.
 - Be patient with grief. You may feel that after a certain time you should be coping but grief can be ongoing and can change.
 - Remember you are not alone. Loss is part of being human. Find someone you can talk to who will listen. Ask your GP about accessing counselling if you feel you are burdening your friends.
 - Join a support or grief group if there is one available, or consider an online group.
- Talking to others with a similar experience can ease the loneliness of grief. Call Cancer Council Helpline **13 11 20** for information on bereavement support groups and programs.
- Balance rest and activity. Grieving uses a lot of emotional energy, and you will probably feel exhausted. Keeping busy helps rest your emotions, and getting something 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 get the deceased's clothes and personal items sorted out quickly, or make a decision about where you live long term. Don't be rushed into these things – you are already making a huge adjustment to

the change in your life. Wait until you are ready to do this, if you are able.

- Ask others for help. Sometimes it's best if you are specific about ways others can help you. Do you need someone to mow your lawns, or do you just need someone to listen?
- Remember that it's normal to feel angry. Find safe/healthy ways to show emotions such as anger – play vigorous sport, scream in your car with the windows up or hit a pillow. You may feel silly, but action often helps.
- Try to eat well. If you have lost your appetite eat frequent, nourishing, easily digested snacks.
- Pamper yourself: hot baths, massages, comforting food, a favourite drink, a special magazine, listening to music, anything that helps. Call Helpline **13 11 20** for resources to assist with relaxation.
- Read a book, play a round of cards with a friend or watch a movie that may take you away from your grief for a little while.
- Keep a journal. Write whenever you feel like it. Looking back over past entries helps to remind you that you are getting somewhere, and putting your thoughts on paper is a good way of processing what has happened.
- Get some exercise. A good walk can turn your mood around. Try swimming, vigorous digging in the garden or playing sport. Even giving the house a vacuum or mowing the lawn can help if you're feeling tense.
- Draw on your spiritual resources, in whatever way is best for you. For some people this will mean going to church or talking to a priest or minister. For others it will be a walk on

(Continues page 18)

the beach or in the bush, or listening to inspirational music – whatever reminds you of a different perspective on life, and a larger way of seeing your situation.

- Celebrate memories. You might like to honour the person who has died by creating ways of remembering – for example planting a tree or garden, making a memory box, keeping a promise you made to the person, involving yourself in a cause that was special to them, or creating special rituals such as lighting a candle or listening to special music.
- Try to develop a sense of your personal coping style, the things that work best for you. Remembering how you have coped in difficult situations in the past may help you feel more able to cope now.
- Avoid drinking too much alcohol or using other drugs. While you may think this helps at first, it can cause other problems.
- Forgive yourself for the things you didn't say or do.
- Talk about the person you have lost. You may feel uncomfortable but sharing your memories can help you cope.
- Prepare for birthdays, anniversaries and holidays by planning how you want to remember the event.

Helping someone who is grieving

It can be hard to know how to help someone who is grieving. You may become stuck for words, or avoid doing anything practical to help. This is often not because you don't want to help but you fear saying or doing the wrong thing. When someone is grieving they may be easily upset, and you will need to be sensitive to this. However, if you feel you can help, offer.

Be honest right from the start. You may need to say "I want to help but I'm not sure what to do." Or "I don't know what to say but I want you to know I do care and I am here if you need a shoulder to cry on." Your honesty will always be appreciated.

Try not to say that you know how they feel. Each person grieves in their own way. You cannot know exactly how they feel, even if you have been through a similar experience. This doesn't mean that your experiences won't give you a better understanding of someone's situation, but remember that they may not react in the same way as you would or did.

Sometimes, people experiencing grief can become overwhelmed and may develop depression or suicidal thoughts. You could suggest the person grieving seeks professional help if they:

- begin to rely on alcohol or drugs
- stop eating regularly
- begin to neglect their personal hygiene
- appear to be sleeping too much
- become aggressive or show signs of other anti-social behaviour
- talk about taking their own life.

If the person you are supporting continues to have difficulties then you may need to talk to a health professional to get some advice on how you can cope with the situation.

tips

Ways you can help someone who is grieving:

- Be patient. Don't expect them to feel or behave in a certain way by a certain time. Allow them to do things in their own time.
- Be aware that the person's feelings may change often. Grieving involves a roller coaster of emotions. One day the person may feel hopeful, the next day all they may feel is sadness and despair.
- Be a good listener but don't force someone to talk. Just being by their side may be enough. They will talk when they are ready.
- Give reassurance where you can. Empathise without making out you know exactly how they feel. Say things like, "That must be very difficult to cope with", or "I imagine you must feel very uncertain about what to do next."
- Don't withdraw your support once you feel the person is coping better. Grief from a major loss can take a long time. Your support may be more helpful six to 12 months down the track than when the person died.
- Offer to help with practical chores such as shopping, cleaning, gardening, picking the kids up from school, helping care for elderly parents, paying bills, cooking and driving. Knowing someone else can help do these things can be a great relief to someone who is struggling with grief.

Helping children in your family

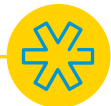
Children and teenagers feel grief just as adults do when someone close dies, but they may express it differently. They may express their grief in outbursts of anger, or by becoming very withdrawn, for example.

The ways children and young people understand death and experience grief changes with their age and development. Like adults, they need:

- acknowledgement of their loss, support, and the opportunity to understand and express their feelings
- to feel part of what's going on
- for the adults around them to model grief for them, and to show them that it's okay to cry or to be angry in ways that don't hurt themselves or others
- to be encouraged to cherish their memories.

It's especially hard to be there for your children when you are grieving. Sometimes people feel they just don't have any emotional energy left for their children. 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 their teachers are aware your child may be having a difficult time.

If you would like more information on how children of different ages cope with cancer, including a copy of *Talking to Kids about Cancer* call Cancer Council Helpline **13 11 20**. See also page 24 for a number of websites which specialise in support for children and young people.



Peer support services

Meeting other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone. There are many ways for you and your family members to connect with others for mutual support and to share information.

In these support settings, people often feel they can speak openly and share tips with others. You may find that you are comfortable talking about your experiences, your relationships with friends and family, and your hopes and fears for the future.

Ask your nurse, social worker or Helpline about suitable support groups and peer support programs in your area.

Types of support services*

Face-to-face support groups – often held in community centres or hospitals

Online discussion forums – where people can connect with each other at any time – see www.cancerconnections.com.au

Telephone support groups – for bereavement, facilitated by trained health professionals

Peer support programs – match you one-on-one with a trained volunteer who has lost a loved one to cancer

Palliative care team – if you accessed palliative care prior to the death of your loved one they may be able to offer bereavement care for a period of time

** Not available in all areas*

Getting professional help

Most people get through the hard times and learn to live with their grief with support from family and friends. However, sometimes you may feel that others don't understand your grief or you may feel stuck and unable to move forward.

Talking to a professional counsellor or psychologist, particularly one who is experienced in coping with grief, can help in these situations. Palliative care services can also assist you to access bereavement counselling.

Bereavement counselling can help you understand the natural course of the mourning process and help you adjust to the changes in your life.

You may have family or friends to support you through the months after a loss, but sometimes it helps to talk to someone outside as well.

If at any time you feel things are too much and support from friends and family isn't enough, call **Cancer Council Helpline 13 11 20** for advice on how to access bereavement counselling. If you are feeling suicidal at any time, contact **Lifeline 13 11 14** immediately.





Useful websites

The internet has many useful resources, although not all websites are reliable. The websites below are good sources of support and information.

Australian

Cancer Council Australia.....	www.cancer.org.au
Palliative Care Australia.....	www.palliativecare.org.au
Cancer Connections.....	www.cancerconnections.com.au
Carers Australia	www.carersaustralia.com.au
Department of Health	www.health.gov.au
Health InSite	www.healthinsite.gov.au
Lifeline Australia	www.lifeline.org.au
Kids Helpline	www.kidshelp.com.au
Mensline	www.mensline.org.au

Grief specialist sites

Australian Centre for Loss and Bereavement.....	www.grief.org.au
beyondblue.....	www.beyondblue.org.au
Cancer in Young Adults.....	www.cancerinyoungadults-throughparentseyes.org
Canteen Australia	www.canteen.org.au
Caring Bridge	www.caringbridge.org
Good Grief.....	www.goodgrief.org.au

International

American Cancer Society.....	www.cancer.org
Macmillan Cancer Support.....	www.macmillan.org.uk
National Cancer Institute.....	www.cancer.gov



Glossary

You may come across new terms when reading this booklet or talking to health professionals. You can check the meaning of other health-related words at www.cancercouncil.com.au/words or www.cancervic.org.au/glossary.

advanced cancer

Cancer that has spread deeply into the surrounding tissues or away from the original site (metastasised) and is less likely to be cured.

bereavement

The sorrow you feel or the state you are in when a relative or close friend dies.

carer/caregiver

A person who helps someone through an illness or disability such as cancer.

complementary therapies

Supportive treatments that are used in conjunction with conventional treatment. They improve general health, wellbeing and quality of life, and help people cope with side effects of cancer.

depression

Very low mood and loss of interest, lasting for more than two weeks it can cause physical and emotional changes.

diagnosis

The identification and naming of a person's disease.

grief

A reaction to any loss or major change that is painful. Intense sorrow caused by a major loss in a person's life.



How you can help

At Cancer Council we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer many free practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



Cancer Council Helpline 13 11 20

Cancer Council Helpline is a telephone information service provided by Cancer Council NSW for people affected by cancer.

For the cost of a local call (except from mobiles), you can talk about any concerns confidentially with oncology health professionals. Helpline consultants can send you information and put you in touch with services in your area. If you need information in a language other than English, an interpreting service is available.

You can call the Helpline, Monday to Friday, 9am to 5pm.

If you have difficulty communicating over the phone, contact the National Relay Service (www.relayservice.com.au) to help you communicate with a Cancer Council Helpline consultant.

For more information, go to www.cancercouncil.com.au.

Regional offices

Central and Southern Sydney

Woolloomooloo
02 9334 1900

Hunter and Central Coast

Charlestown
02 4923 0700

North Sydney

Crows Nest
02 9334 1600

Northern

Byron Bay
02 6639 1300

Southern

North Wollongong
02 4223 0200

Western

Wagga Wagga
02 6937 2600

Western Sydney

Parramatta
02 9354 2000

Produced in collaboration with:



Palliative
Care
Australia

For support and information on cancer and cancer-related issues, call Cancer Council Helpline. This is a confidential service.

For further information and details please visit our website: www.cancercouncil.com.au

