



PALLIATIVE CARE BEREAVEMENT SUPPORT GUIDELINES

RESOURCE TOOLKIT





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Introduction

The resource toolkit has been developed to accompany the Palliative Care Bereavement Support Guidelines.

It contains a number of resources and tools to assist the implementation of the Guidelines in practice.

The implementation of the Palliative Care Bereavement Support Guidelines is the responsibility of each individual organisation. It is hoped the tools and resources within this toolkit will be helpful to both organisations and health professionals in facilitating good communication and providing effective bereavement support for families, whānau and friends.

Some of the brochures mentioned within the toolkit are available for download on the MidCentral District Health Board website www.midcentraldhb.govt.nz/Publications/AllPublications. Other resources have access points listed.

The Guidelines

Preparing for Death

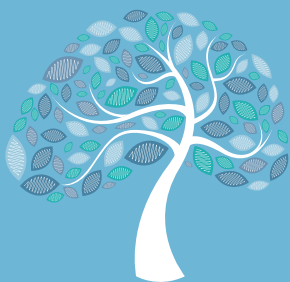
1. Interdisciplinary teams know who the person's family, whānau, friends and caregivers are, and can identify significant relationships and support systems.
2. Interdisciplinary teams assess the bereavement support needs of family, whānau and friends.
3. Interdisciplinary teams provide family, whānau, friends and caregivers with information regarding preparation for death.

Bereavement Support Post Death

4. Interdisciplinary teams acknowledge the death with family, whānau and friends.
5. Bereavement information is made available to family, whānau and friends.
6. Reassessment of bereavement support needs is important.

Organisational Responsibilities Are Met

7. Staff are supported through professional development training, education and resources.
8. Employers have a plan for bereaved staff.



Implementing the Palliative Care Bereavement Support Guidelines

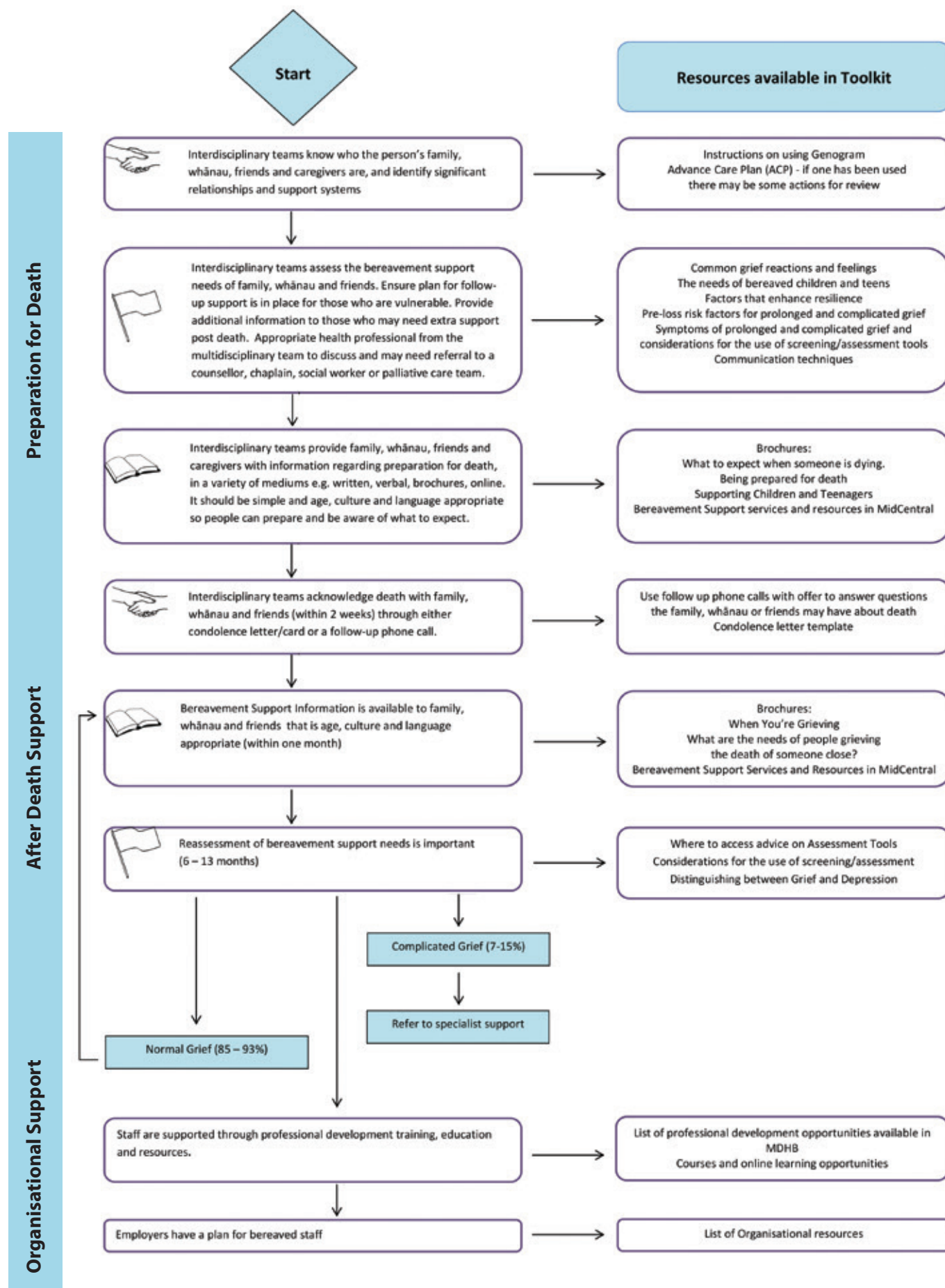
		<i>Guideline</i>	<i>Action for Health Professional</i>	<i>Key Decisions for Organisational</i>
PRE DEATH	Guideline 1	Interdisciplinary teams know who the person's family, whānau, friends and caregivers are, and identify significant relationships and support systems	<ul style="list-style-type: none"> • Document family and significant relationships and contact details 	<ul style="list-style-type: none"> • Align to current documentation • Consider using genogram tool • Have process for identifying whether a person has completed an Advance Care Plan (ACP)
	Guideline 2	Interdisciplinary teams assess the bereavement support needs of family, whānau and friends	<ul style="list-style-type: none"> • Familiarise yourself with the grief process and common reactions • Give person, family, whānau and friends additional information on available grief resources and support services • Familiarise yourself with risk and resilience factors for developing prolonged and complicated grief • Use appropriate validated assessment tool following guidelines for use • If identified as potentially needing extra support or at risk of developing prolonged and complicated grief refer to appropriate provider: Specialist Palliative Care Team, Psychologist, Specialist Grief Counsellor, Chaplain or Social Worker 	<ul style="list-style-type: none"> • Ensure staff are adequately trained in the nature of the grief process and of bereavement, common reactions, effective support components, and the nature of prolonged and complicated grief • Ensure staff are familiar with available information and support service options • Consider if an appropriate assessment tool is required • Ensure staff are adequately trained in using assessment tool • Ensure written information is available for staff to give the person, family, whānau and friends • Ensure referral processes are in place for those who are identified as potentially needing more support during bereavement
	Guideline 3	Interdisciplinary teams provide family, whānau, friends and caregivers with information regarding preparation for death	<ul style="list-style-type: none"> • Give appropriate written information and have specific conversations about what to expect when someone is dying, and after they have died (planning for after death care) 	<ul style="list-style-type: none"> • Consider which written information is appropriate for your organisation • Ensure it is reviewed annually and kept up to date • Align to current policies and processes

		<i>Guideline</i>	<i>Action for Health Professional</i>	<i>Key Decisions for Organisational</i>
AT TIME OF DEATH	Guideline 4	Interdisciplinary teams acknowledge death with family, whānau and friends (within two weeks)	<ul style="list-style-type: none"> • Contact main carer or key family members, whānau or friends either by phone or using a condolence letter or card. Family, whānau, friends or caregivers may have questions around the death that a health professional can follow up on 	<ul style="list-style-type: none"> • Develop process for staff to acknowledge the death of a person. This could be follow-up phone call, condolence letter/card • Identify a person to follow-up with any questions family, whānau or friends may have
	Guideline 5	Bereavement support information is available to family, whānau and friends. Information that is age, culture and language appropriate (within one month)	<ul style="list-style-type: none"> • Give appropriate written information and brochures such as What to Expect When You Are Grieving, Bereavement Resources and Support Services 	<ul style="list-style-type: none"> • Ensure appropriate written information is available for staff to give to family, whānau and friends • Ensure there is a process for written information to be distributed to family, whānau and friends that is aligned to organisational policies and procedures
BEREAVEMENT PERIOD	Guideline 6	Reassessment of bereavement support needs is important (6–13 months)	<ul style="list-style-type: none"> • Assess the grief experience of family, whānau and friends, in general terms, identifying strategies in place for coping • If grief is continually intense and disabling from six months onwards, assess for prolonged and complicated grief using validated assessment tools • Use validated support tools and guidelines • If a person is identified with prolonged and complicated grief refer them to specialist support 	<ul style="list-style-type: none"> • Consider staff education in the grief process, common grief reactions and the nature of prolonged and complicated grief • Consider appropriate risk/screening assessment tool • Ensure staff have adequate training in use of the assessment tool • Ensure systems in place for referral to specialist support services if family, whānau or friends are identified as requiring further support

Organisational Responsibilities

ORGANISATIONAL SUPPORT	Guideline 7	Staff is supported through professional development training, education and resources	<ul style="list-style-type: none"> • Ensure staff leaders and managers have access to education and training in understanding grief, loss and bereavement support in the workplace • Access local courses through Professional Development Calendar www.centralpho.org.nz/OurServices/CPDCalendar.aspx
	Guideline 8	Employers have a plan to support bereaved staff	<ul style="list-style-type: none"> • Ensure a plan is in place for staff support when a patient dies and that staff leaders and managers fully understand their active role in its implementation • Use available key resources, such as Managing Trauma, Loss and Grief In The Workplace (Skylight) • Ensure regular clinical supervision is available for staff • Use a well-planned debriefing process for staff after all deaths • Use EAP services for staff support, as required • Review the plan annually, in consultation with senior staff

Palliative Care Bereavement Support Guidelines and Resources Flow Diagram





Tools for Guideline 1

Interdisciplinary teams know who the person's family, whānau, friends and caregivers are, and identify significant relationships and support systems

1.1 Genograms

What is a genogram?

A genogram is like an illustrated family tree; a multi-generational diagram of a person's family and social network including significant friends. It allows users to view multiple relationship dynamics and identify trends. Each person on a genogram is represented by a symbol. The symbols are then linked with lines to depict various dynamics and significant individual qualities.

Genograms are used by a range of professionals including doctors, researchers, Whānau Ora navigators, psychiatrists, counsellors, mental health workers and psychologists.

How genograms are applied to the bereavement guidelines

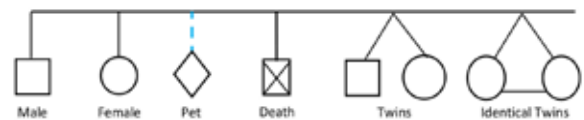
Using a genogram alongside the Bereavement Support Guidelines will help you have an understanding of a person's whānau and key relationships. Understanding the purpose will help you focus on the type of family or friend information you need to collect. It can also help you decide with whom you will share the completed diagram – sometimes the information might be considered upsetting or too sensitive for some family members, so you'll need to judge that depending on the context.

How to complete a genogram

Genogram templates are available to be completed online or filled out by hand. It is often included as part of the person's care planning information.

Use standard genogram symbols to represent family members and their relationships. The symbols act as a visual indicator of the information gathered from your discussions. You can draw the standard genogram symbols by hand or by using the "draw" or "shapes" options in a word document.

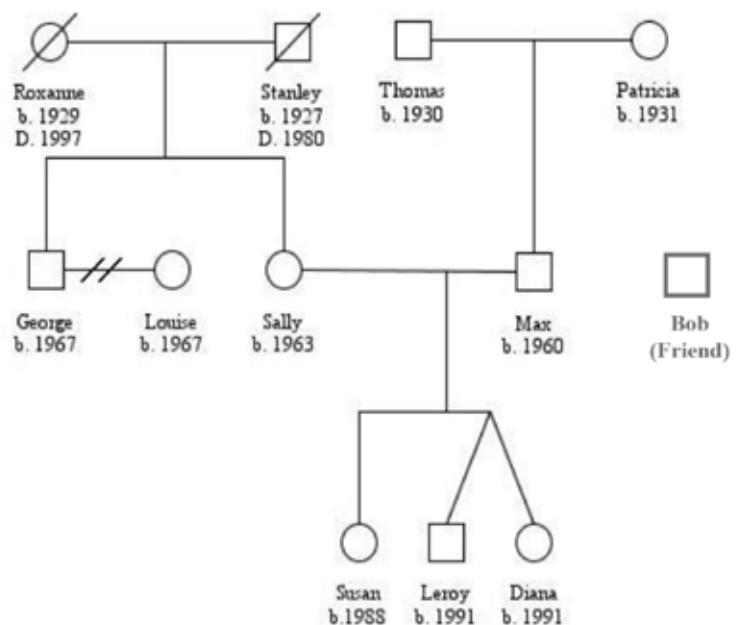
Genogram Symbols



Family Relationships Symbols



An example: Genogram Depicting Three Generations



Organise the chart based on family interactions. Begin with the oldest generation you want to represent. For example, you may decide to start your genogram with the grandparents or even great grandparents. Genograms can be used to show the diversity in family and friend relationships, as well as patterns of illnesses.

1.2 Review the Completed Advance Care Plan (ACP)

If a person has completed an Advance Care Plan (ACP) it may contain useful information to guide or direct their family, whānau and friends in relation to any after death wishes they had. Reviewing this information is a priority. It can also be a comfort for the family, whānau and friends to know that they are following the wishes of the person.

What is ACP?

ACP is a process of discussion and shared planning for future health care. It is focused on assisting the individual to identify their personal beliefs, values and priorities and then incorporate these into plans for their future health care. Planning may also involve input from the healthcare professionals responsible for the person's care, along with family, whānau, friends and caregivers, if that is the person's wish.

An advance care plan is not intended to only be used to direct future medical treatments and procedures when the person loses capacity to make their own decisions (becomes incompetent). However, it can and should be used to inform decision-making in this situation, along with other measures such as discussions with the individual's Enduring Power of Attorney (where one has been appointed) and with family, whānau and friends.

Where do I find further information and documents?

To access further information to assist individuals to discuss ACP:

Our Voice

www.advancecareplanning.org.nz

Families, whānau, friends and caregivers need to be aware if an ACP has been written, so that they can take into account a person's wishes if they become responsible for making decisions regarding pre and post death.





Tools for Guideline 2

Interdisciplinary teams assess the bereavement support needs of the family, whānau and friends

There are many resources for health professionals to assist in assessing the bereavement needs of family, whānau and friends. To aid clinical judgement when assessing, it is very important to be aware of the nature of the grief process, the bereavement experience and the wide range of possible grief reactions, for all ages. Having additional knowledge about factors that enhance personal resilience, symptoms of prolonged and complicated grief, and an understanding of effective communication strategies will further enhance the way health professionals work with people. Accessing regular professional development activities will broaden knowledge and improve assessment skills.

2.1 Grief and the Grief Process

Grief is the normal human response to difficult loss. It is a process which assists a person to gradually adjust to the reality of a loss, experience the pain of that loss and become able to move forward.

Being a process, it takes time. The time it takes is different for everyone. Elements of grief are likely to remain throughout a person's life and these will commonly be triggered by reminders, often unexpectedly.

Bereaved people will experience the grief process in individual ways. Many find the impact of the process of grief more intense and preoccupying than they expected. It can disrupt their lives, even be overwhelming at times, but over time most people find their grief intensity lessens. There are no 'grief rules' to follow.

Bereaved people's reactions and needs will vary according to a range of factors, including:

- the kind of relationship shared with the person who died
- the way in which their loved one died, and if they were present or not
- age and stage of development
- personality
- gender
- culture
- spiritual beliefs
- pre-existing health conditions
- usual coping mechanisms
- previous experience of loss and grief
- the degree of personal support available.

A bereaved person's experiences will also be shaped by their level of resilience. That is, their natural ability to adapt and cope in times of increased stress and adversity. The diverse needs they and/or their family, whānau and friends may have as a direct result of the death will also influence their grief. Grief can also be experienced as an individual and/or with a group.

Grief affects the whole person, not just a person's emotions.

Five key areas of a person's life are impacted. The range of common reactions is very wide and can be experienced:

- emotionally
- physically
- mentally/cognitively
- spiritually
- socially.

Poor health outcomes, depression, social isolation, and increased mortality have been associated with lack of bereavement support during the grief process.

2.2 Common Grief Reactions

The range of possible grief reactions is very wide. It is normal that any of these reactions can be strong and intense and any mix of them can be experienced simultaneously. Examples of common reactions include:

Emotional Reactions:

- Numb – shocked
- Disoriented – bewildered
- Sad – sorrowful
- Yearning
- Fearful – anxious – worried
- Tense – on edge
- Irritable – angry
- Betrayed
- Guilty – regretful – self blame
- Despairing – hopeless
- Powerlessness
- Lonely – isolated
- Relieved
- Agitated – buzzy
- Strong – invincible
- Ashamed – embarrassed
- Low self-esteem – reduced confidence
- Empty – not caring
- Feeling strange – not like themselves
- A sense of observing themselves.

Physical Reactions:

- Exhausted – fatigued
- Weak – wanting to sit or lie down - little energy
- Aching limbs – tense muscles
- Shaking
- Adrenaline-filled energy surges – unable to keep still
- Tearful – crying – moaning – sobbing
- Tight chest – shallow breathing – breathlessness – deep sighs
- Shouting – yelling – screaming
- Nervous laughter
- Heart beating fast
- Feeling hot and cold
- Headaches – migraines
- Stomach aches – nausea – digestion problems
- Difficulty in swallowing
- Existing conditions triggered
- Changed eating patterns
- Changed sleeping patterns
- Dehydrated
- Clumsy – having falls or small accidents
- Getting ill more easily
- Bedwetting – soiling
- Increased sensitivity to sounds and sights
- A release of body tension (especially after anticipated loss).

Mental/Cognitive Reactions:

- Slowed thinking or processing
- Disbelief – denial
- Confusion
- Difficulty concentrating
- Forgetfulness
- Preoccupied by the loss – distracted
- Reacting slowly to questions or instructions
- Difficulty making decisions, even small ones
- Forgetting the loss has happened
- Perceiving things differently – changed priorities
- Vivid dreams or nightmares
- Flashbacks
- Difficulty imagining a positive future
- Focused on keeping busy, to avoid thinking about it
- Extreme positivity – blocking any negative or sad thoughts
- Negative thoughts – possibly suicidal thoughts that need immediate assistance.

Spiritual Reactions:

- Questioning – why?
- Looking for meaning in events
- Feeling closely connected to the deceased
- Seeing or sensing their presence
- A sense of closeness to, or distance from God
- Moving towards or away from faith or cultural beliefs or spiritual community
- Strengthened by faith or beliefs, questioning them, or finding new beliefs
- Feeling very spiritually alive or spiritually numb
- Wanting to pray
- Feeling let down or punished by God
- Having a need to be forgiven.

Social Reactions:

- Wanting to talk about it – or not
- Wanting to be with others more – or less
- Withdrawal – wanting to be alone
- Needing to know where loved ones are
- Instinctively searching/looking out for the deceased person
- Being very sensitive to what others are thinking or saying
- Impatience with others grieving in a different way
- Increased marital or relationship tension or conflict
- Wanting physical touch – or avoiding it
- Increased or decreased interest in sex.

Courtesy of Skylight, www.skylight.org.nz

2.3 Grief and Bereavement in a Child or Young Person

Bereaved children and young people experience grief in different ways to adults, reflective of their age, developmental stage and having less understanding and experience. Often their grief needs can be overlooked. They can be grieving as they play outside, so adults incorrectly assume 'they are not really affected at all'. Families can struggle to talk to their children about illness, death, dying and bereavement.

What does a grieving child or teen need the most?

- To have their own loss and grief acknowledged.
- To feel safe and cared for.
- To have their grief and coping style respected.
- To express thoughts and feelings in the ways they need to.
- To be listened to.
- To have questions answered with honesty.
- To be spoken to with words they can understand.
- To have things explained clearly.
- To have people around them show that they genuinely care.
- To be given information about what's happening, in manageable amounts.
- To have key information repeated.
- To be involved in decisions and events, where possible.
- To be given regular reassurance and encouragement.
- To be supported to learn and to make meaning, from their experience of loss.
- To have people around them who will support their grief journey into the future, as it affects their development and identity.
- To be given some extra help if things have got too difficult for them to manage.

Courtesy of Skylight, www.skylight.org.nz

Skylight has a large number of information resources and tools relating to the nature of child and youth bereavement, and ways to support them well when they grieve:

Supporting Children and Young people living with Anticipatory Loss

– www.skylight.org.nz/uploads/files/anticipated_death.pdf

Bereavement at Different Ages and Stages

– www.skylight.org.nz/uploads/files/bereavement_at_different_ages_and_stages.pdf

Supporting a Bereaved Teen

– www.skylight.org.nz/uploads/files/supporting_a_bereaved_teen.pdf

A range of child and youth friendly resources and tools can be purchased through Skylight, including on ways to speak to children and teens about death and dying.

– www.skylight.org.nz/Shop/Bereavement+Grief

See www.skylight.org.nz or phone 0800 299 100.



2.4 What's it Like Grieving a Death?

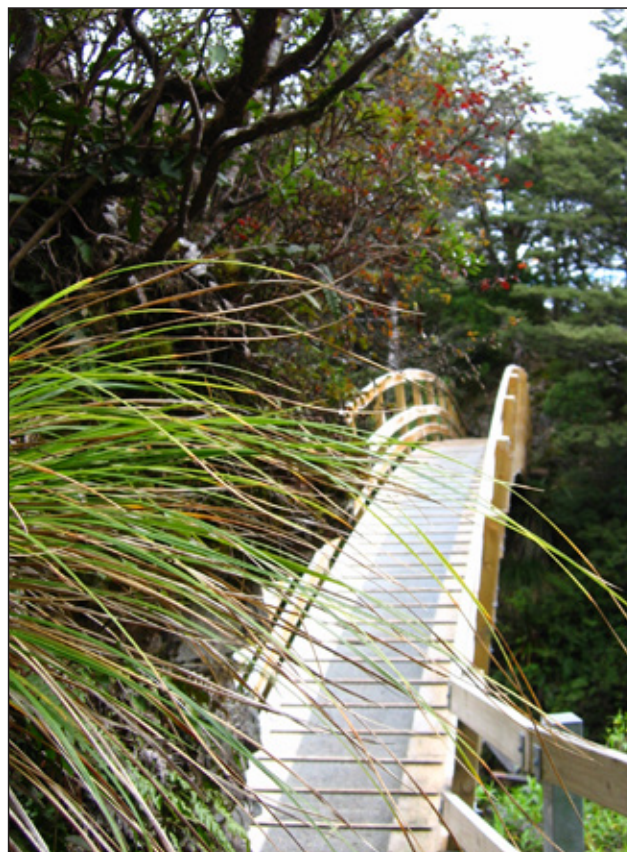
These comments have been collected by Skylight to provide an insight into the grief journeys of those whose loved one has died.

They were asked:

What do you want people to know about your grief?

- Don't be afraid to say the name of the person who has died. They were very important to me. So was their life and the memories I have of it. I need to hear their name sometimes.
- Don't expect me to grieve the way you do, or the way you think I should. Let me grieve in my own way, because how we experience grief is as individual as our fingerprints. We're all different.
- If I cry or get emotional when we talk about the person, it isn't because you've hurt me. It's because they've died. It's a really painful time. If you allow me to cry, I'm grateful. Crying and expressing my emotions helps me.
- If I can't cry don't make me feel bad about that either. We're all different. I might choose to express my feelings in other ways, or very privately.
- Don't let the person die again by taking away photos of him/her or other remembrances from your home. Or by never referring to him/her when you talk about things. That makes it seem like they've never lived, or that I should feel ashamed of them or embarrassed by the fact that they've died.
- I will have emotional ups and downs. Don't think that if I have a good day my grief must be over, or if I have a bad day that I suddenly need psychiatric counselling.
- Being a bereaved person is not contagious, so don't stay away from me.
- All the grief reactions I'm having are normal, even if I might seem a bit crazy at times.
- Don't expect my grief to be over in weeks or months. Grief is a process I have to go through and in my own time. It will take as long as it needs to take for me. I can't help that.
- Please understand that my reactions to grief might be physical. I might gain or lose weight, sleep a lot or very little, be accident prone, be more likely to become ill, or experience aching all over. All of these sorts of things are common in grief. They are very real.
- My loved one's birthday, the anniversary of his/her death and special holidays are likely to be terrible times for me. Perhaps you could tell me that you're thinking of them on these days. And if I get quiet and withdrawn just know that I am thinking about them too and don't try to make me be cheerful. Just let me feel what I feel. It's a natural part of my grief journey.
- It may be a while before I'm ready for social occasions such as parties, but please don't stop asking.
- Some days I might be inconsolable. That's okay. Loss is sad. That's just how it is and it isn't bad. It just is what it is. Don't feel you have to fix it and cheer me up to make it go away. It's part of my journey.
- Understand that experiencing grief changes people. When someone close to you dies, you often see the world differently, and learn a lot about yourself and about others. I'm just not exactly the same person I was before my loved one died. I will never be able to be that person again, because I've grown and learned things inside. If you keep waiting for me to 'get back to my old self', you will just keep being frustrated.
- Take time to get alongside me in the days ahead and get to know me in new ways. I'm getting to know myself in new ways too.

Courtesy of Skylight www.skylight.org.nz 0800 299 100





2.5 Factors that Enhance Resilience

General resilience factors

Research indicates the following key factors play a significant part in helping build up personal resilience to cope with life's adversity:

- A support circle
- A sense of self worth
- A sense of competence
- Key life skills – particularly problem solving, decision making, communication, setting goals, sourcing information, asking for help
- A sense of humour
- Flexibility – being able to adjust as situations change
- Perseverance
- Creativity – approaching things in new ways, with fresh eyes
- Self-care
- A hopeful outlook.

Courtesy of Skylight, www.skylight.org.nz

Lutha, C., O'Neill, M., Saakvitne, K., & Tedeschi, C. (2015). *The Road to Resilience*, American Psychological Association, www.apa.org/helpcenter/road-resilience.aspx

Ungar, M. (2015). *Working with Children and Youth with Complex Needs: Skills to Build Resilience*. New York, NY: Routledge.

Resilient bereaved individuals tend to demonstrate resilience through times of grief in these ways:

- Draw upon past experiences of loss survival
- Connect with their family, whānau, friends and community of care
- Draw upon religious and spiritual beliefs and practices
- Identify and use their internal and external strengths and resources
- Reconstruct a world of meaning and personal identity following the loss
- Draw upon the experience and support of other bereaved people
- Have higher levels of practical support
- Hold a belief in a just world and acceptance of death
- Gain comfort from talking or thinking about the deceased.

Adapted from *Bereavement Support Standards for Specialist Palliative Care Services* (2012). Department of Health; State of Victoria, Australia

2.6 Symptoms of Prolonged and Complicated Grief

Grief that continues in intensity beyond a time frame in which some form of adjustment is expected, and to an extent that is significantly disruptive to a person's life is known as prolonged and complicated. Sometimes it is termed traumatic grief.

A small, but significant percentage of bereaved people do experience a prolonged and complicated grief response to a death, (variously estimated between seven and 15%). This group needs extra targeted support to be enabled to move forward in their grief process.

If a person has many of the following symptoms for more than six months after the death of a loved one, they may be suffering from prolonged and complicated grief:

- Strong feelings of longing or yearning for the person who died
- Strong feelings of disbelief about the death or finding it very difficult to accept the death
- Feeling very emotionally or physically activated when confronted with reminders of the loss
- Avoiding people, places, or things that are reminders of the loss
- Strong urges to see, touch, hear, or smell things to feel close to the person who died
- Thinking so much about the person who died that it interferes with doing things or with relationships with other people
- Feeling intensely lonely, even when other people are around
- Strong feelings of anger or bitterness related to the death
- Feeling shocked, stunned, dazed or emotionally numb
- Finding it hard to care about or trust other people
- Feeling like life is empty or meaningless without the person who died.

The Centre for Complicated Grief: www.complicatedgrief.org/bereavement/how-to-recognize-complicated-grief/17/



2.7 Pre-Loss Risk Factors for Prolonged and Complicated Grief

Research suggests that the following characteristics of the individual, family, whānau or friends, the death itself, and the treatment context are associated with increased adjustment difficulties in bereavement:

Background Factors	Death-Related Factors	Treatment-Related Factors
Close kinship to the dying patient (especially spouse or child loss)	Bereavement overload (multiple losses in quick succession)	Aggressive medical intervention
Female gender (especially mothers), lower education levels, older age, and lower socio economic status	Low acceptance of impending death	Ambivalence regarding treatment
Low social support (before and after death)	Suddenness of the death including violent and/or traumatic death	Family conflict regarding treatment
Insecure attachment style	Finding or viewing the loved one's body after violent death	Economic hardship created by treatment
High pre-loss marital dependency	Death in the hospital (vs home)	Caregiver burden
History of previous (traumatic) losses (may include divorce, loss of a job etc)	Dissatisfaction with death notification	
History of anxiety or depression		

Adapted from Neimeyer R.A. & Burke, L.A. (2013) Complicated grief and the end of life: Risk factors and treatment considerations. In Werth, J.L. Counselling clients near the end of life. NY; Springer and from Shear, K., Ghesquiere, A. & Glickman, K. (2013). Bereavement and complicated grief. Curr Psychiatry Rep, 15(11).

2.8 Considerations for the Use of Screening/Assessment Tools for Risk of Prolonged and Complicated Grief

Before using a screening or assessment tool, an organisation must consider a number of factors including:

- Which validated screening or assessment tool will be chosen?
- What guidelines are provided by the developers of this screening or assessment tool?
- Setting in which the screening will be carried out – is it a specialist palliative care setting; aged residential care facility; hospital; general practice?
- Who will do the screening?
- How will staff be trained in the use of the screening tool?
- Is the measure reliable and valid?
- At what time point is the screening being carried out?
- Who will be screened?
- Is it culturally appropriate to use the assessment tool and does the tool account for cultural difference?
- Is the screened person aware of, consenting and directly involved in the assessment?
- Both risk and resilience factors need to be recognised and incorporated into screening/bereavement assessment.
- Feedback should be given to the person assessed, i.e. explanation of the screening results.
- How will the information be stored?
- When risk is identified, what support options are in place for follow-up?

Compiled in collaboration with Massey Health and Cancer Psychology Services, 2015.

2.9 Communication technique – SPIKES

This is one tool that health professionals may find useful when having difficult conversations, particularly breaking bad news.

SPIKES: A Six-step Protocol for Having Difficult Conversations, or Delivering Bad News

This protocol contains a number of key communication techniques that facilitate the flow of information.

1. “S” Setting up the interview

- Arrange for some privacy
- Involve significant others
- Sit down
- Make connection and establish rapport with the patient
- Manage time constraints and interruptions

2. “P” Assessing the patients perception

- Determine what the person knows of their condition
- Listen to the person’s perception
- Correct misunderstandings if appropriate
- Determine if the patient is engaging in behaviours such as denial, wishful thinking, omission of unfavourable information

3. “I” Invitation from the patient to give Information

- Ask patient if she/he wishes to know the details of the medical condition and/or treatment
- Accept patient’s right not to know
- Offer to answer questions later if she/he wishes
- Manage time constraints and interruptions

4. “K” Knowledge: giving medical facts

- Use language intelligible to patient
- Consider educational level, socio-cultural background, current emotional state
- Give information in small chunks
- Check whether the patient understood what you said
- Respond to the patient’s reactions as they occur
- Give any positive aspects first, e.g. cancer has not spread to lymph nodes, highly responsive to therapy, treatment available locally etc
- Give facts accurately about treatment options, prognosis, costs etc

5. “E” Explore emotions and sympathise

- Prepare to give an empathetic response
- Identify emotion expressed by the patient (sadness, silence, shock etc)
- Identify cause/source of emotion
- Give the patient time to express his or her feelings, and then respond in a way that demonstrates you have recognised connection between 1 and 2.

6. “S” Strategy and summary

- Close the interview
- Ask whether they want to clarify something else
- Offer agenda for the next meeting, e.g. I will speak to you again when we have the opinion of cancer specialist

This is an adaption from Baile, W. et al. SPIKES – A six step protocol for delivering bad news: application to the patient with cancer. The Oncologist 2000; 5:302-311.



Tools for Guideline 3

Interdisciplinary teams provide family, whānau, friends and caregivers with information regarding preparation for death

Key information needs to be age, culture, gender and language appropriate. Information may need to be given several times and in a variety of ways, e.g. verbal, written or online.

The following resources can be used to support family, whānau, friends and caregivers prior to death.

3.1 Brochures

The brochures below are useful tools to assist with conversations between health professionals, families, whānau and caregivers. They can be downloaded for use from the MidCentral DHB website.

Supporting Children and Teenagers

Skylight have a number of information resources that consider the nature of child and youth bereavement, and ways to support them well:

- **Supporting Children and Young People Living with Anticipatory Loss**
www.skylight.org.nz/uploads/files/anticipated_death.pdf

- **Bereavement at Different Ages and Stages**
www.skylight.org.nz/uploads/files/bereavement_at_different_ages_and_stages.pdf

- **Supporting a Bereaved Teen**
www.skylight.org.nz/uploads/files/supporting_a_bereaved_teen.pdf

A range of child and youth friendly resources can be purchased through SkyLight, including on ways to speak to children and teens about death and dying.

www.skylight.org.nz/Shop/Bereavement+Grief

See www.skylight.org.nz or phone 0800 299 100.

What to Expect When Someone is Dying

Describes the possible changes a person may experience in the last hours and days of life. Originally developed by Arohanui Hospice and now available at www.midcentraldhb.govt.nz/Publications/AllPublications



Being Prepared for Death

This can be used to assist in conversations about how family and whānau wish to care and honour a person following death available at www.midcentraldhb.govt.nz/Publications/AllPublications



3.2 Bereavement Support Services and Resources in MidCentral DHB District

Where to seek professional help

Many people find talking through their experience of grief helpful, as well as finding out more about grief, what to expect from it and strategies to use to cope with it.

The primary provider

Contacting the primary provider previously involved with the care of the deceased may be useful. For example, the hospital chaplain, Alzheimer's Society, the Cancer Society, Motor Neuron or Parkinson's community workers.

Counsellors, psychologists or psychotherapists in private practice

- Look for names and contacts in the local phone directory or yellow pages.
- Ask for recommendations at the local medical centre or GP.
- Local funeral homes may provide some counselling services.
- Ask family, whānau and friends for recommendations.

General practitioner

Directing people toward their GP is also helpful if they have health concerns associated with grief, particularly if an existing condition has been triggered or they are having serious sleeping or eating issues.

Support organisations

- **Arohanui Hospice**
www.arohanuihospice.org.nz
Address: 1 Heretaunga Street, Palmerston North
Phone: (06) 356 6606
Email: enquiries@arohanuihospice.org.nz
- **YOSS (Youth One-Stop Shop)**
www.yoss.org.nz/who-are-we.html
Address: 31 Princess Street, Palmerston North
Email: trissel@yoss.org.nz
- **Skylight – for grief support**
www.skylight.org.nz
Phone: 0800 299 100
Address: Level 3 HMR Building, 5-7 Vivian Street, Wellington
Email: info@skylight.org.nz
- **Starship Hospital**
www.starship.org.nz/patients-and-families/directory-of-services/#g
The Palliative Care Team are a valuable resource for accessing support and resources for those experiencing the bereavement of a child or young person.
- **Methodist Social Services**
Address: 663 Main St, Palmerston North
Phone: (06) 357 3277
Email: www.methodistsocialservices.org.nz/mss/?page_id=23
- **Across**
www.across.org.nz/
Address: ACROSS Te Kotahitanga o te Wairua, 294a Church Street, Palmerston North
Phone: 0800 ACROSS (0800 227 677)
Phone: (06) 356 7486
Email: enquiries@across.org.nz
- **Te Aroha Noa**
www.tearohanoa.org.nz/
Address: 12–32 Brentwood Avenue, Palmerston North
Phone: (06) 358 2255
Email: reception@tearohanoa.org.nz
- **Health Conditions and Cancer Psychology Services**
Contact: Maria Berrett, Coordinator
M.J.Berrett@massey.ac.nz
Phone: (06) 3505180
Direct Dial: (06) 3505799 x81887
- **Youthline**
palmerstonnorth.youthline.co.nz
Phone: 0800 376 633
Email: talk@youthline.com
- **Seasons for Growth – children's school-based grief programme**
www.goodgrief.org.au/seasons-for-growth
or Sue Devereux (04) 496 1777
Wellington Catholic Diocese

Maori Health Providers

- **BestCare Whakapai Hauora Charitable Trust**

Address: 140–148 Maxwells Line,
Palmerston North
Phone: (06) 353 6385
Email: bcwh@rangitaane.iwi.nz

- **Te Whakahuia Manawatu Trust**

Address: 56 Pembroke Street,
Palmerston North
Phone: (06) 357 3400
Email: anaw@rauakawa.iwi.nz

- **Te Kete Hauorao Rangitane**

Address: 91 High Street, Dannevirke
Phone: (06) 374 6860

- **He Puna Hauora**

Address: 160 Grey Street,
Palmerston North
Phone: (06) 356 7037

- **Muaupoko Tribal Authority**

Address: 306 Oxford Street, Levin
Phone: (06) 367 331

Useful Web sites

- **Skylight**

Skylight is a not for profit organisation that provides expert grief related information, resources, education, training and counselling services for all ages and stages and for those who assist, such as health professionals. Free downloads.

www.skylight.org.nz

Phone: 0800 299 100

Email: info@skylight.org.nz

Address: Level 3 HMR Building,
5–7 Vivian Street, Wellington

- **Kidshealth**

A joint initiative between the Paediatric Society of New Zealand and Starship Foundation – offers a range of grief articles relating to bereaved children, siblings, parents and families.

www.kidshealth.org.nz/search/node/grief

Sesame Street Grief Resources for parents and children

www.sesamestreet.org/parents/topicsandactivities/topics/grief#

- **Grief Centre**

Useful information and a downloadable book available at www.mentalhealth.org.nz/get-help/a-z/resource/41/grief-and-loss

- **Healthline**

Healthline is available 24 hours, 7 days a week. Free to callers throughout New Zealand, including from a mobile phone.
Phone: 0800 611 116.

- **My Grief Assist**

My Grief Assist is a service provided by InvoCare, Australia's largest funeral homes, crematories and cemeteries. The website has many resources and helpful downloads www.mygriefassist.com/about-grief.aspx

Support Services and Resources

A list of bereavement support services and resources mentioned above is downloadable in a brochure to give to families, whānau and friends from www.midcentralthb.govt.nz/Publications/AIIPublications





Tools for Guideline 4

Interdisciplinary teams acknowledge
with family, whānau and friends

Acknowledgement of a person's death is a fundamental aspect in providing bereavement support for family, whānau and friends, in particular the caregiver(s) most closely associated with the deceased person.

This can be done in a number of ways through a phone call with an offer to answer any questions that the family, whānau or friends may have, or through a condolence card or letter.

4.1 Example of a Condolence Letter

The following is an example of a condolence letter to be used by a service to assist in acknowledgment of death.

Other examples can be found on pathways-care.org/hospice-care/bereavement-support-letters/

Date

Name and address of next of kin

Dear.....,

On behalf of the xxx District Health Board, please accept my sincere condolences for the loss of (father's/mother's/brother's/sister's first name). This is likely to be a difficult time for you and for your family and whānau.

If you and/or your family require extra support while you are grieving, you are most welcome to contact the Co-ordinator of Spiritual/Pastoral Care, name, DDI (add in number) or (add in mobile number).

You may have some questions around the death of (name). We would like to be able to answer these for you, if possible.

We would like you to know that we review the deaths of all patients who die in our hospital. So if you have any questions, concerns or feedback, or would like more information regarding the review process, please feel free to contact me on telephone (06) 348 1235, Extension 8405.

If you and/or your family require extra support while you are grieving, you are most welcome to contact the Co-ordinator of Spiritual/Pastoral Care, name, DDI (add in number) or (add in mobile number).

Yours sincerely,

Name

Title



Tools for Guideline 5

Bereavement Information is available to family, whānau and friends

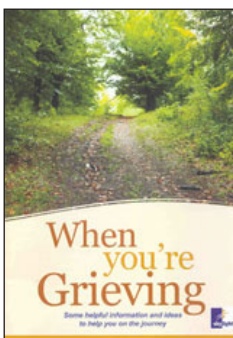
All people who have lost a significant person through death, whether they are family, whānau or a close friend, needs to be given information about grief and the reactions they may experience. Also, up-to-date information on how to access further support if they require it.

5.1 Brochures

The brochures below are useful tools to assist with conversations between health professionals and families, whānau, friends and caregivers.

When You're Grieving

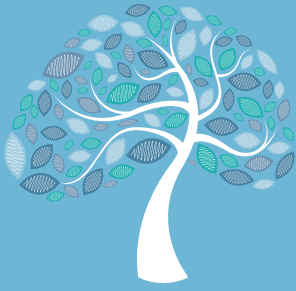
These brochures explain the grief process and describes common grief reactions. They also have useful ideas about coping with grief and supporting others through it. "When You're Grieving" is available to purchase at a small cost from Skylight. www.skylight.org.nz/Shop/When+You+are+Grieving+-+a+support+booklet or phone 0800 2909 100.



5.2 Support Services and Resources

A list of support services and resources mentioned is downloadable from www.midcentraldhb.govt.nz/Publications/AllPublications





Tools for Guideline 6

Reassessment of bereavement support needs is important

Reassessment of the support needs of bereaved family, whānau, friends and caregivers is likely to occur with a primary care provider. The grieving person may be accessing the primary care provider with health issues that at first may seem unrelated to grief. Using a validated assessment tool may assist the health professional in an objective manner to ensure the appropriate underlying cause is identified and appropriate support is accessed.

6.1 Assessment Tools

There are several assessment tools that may be used to identify prolonged and complicated grief. Often these are validated within certain care settings such as specialist palliative care series or primary care, so it is difficult to recommend specific assessment tools.

If an organisation wishes to use assessment tools, advice can be gained by contacting:

- Family Support team Arohanui Hospice on ph (06) 356 6606
- Massey Psychology team on ph (06) 350 5180.

There are many factors that must be considered prior to using an assessment tool.



Considerations for the Use of Screening/ Assessment Tools for Risk of Prolonged and Complicated Grief

Before using a screening or assessment tool, an organisation must consider a number of factors:

- Which validated screening or assessment tool will be chosen?
- What guidelines are provided by the developers of this screening or assessment tool?
- Setting in which the screening will be carried out – is it a specialist palliative care setting; aged residential care facility; hospital; general practice?
- Who will do the screening?
- How will staff be trained in the use of the screening tool?
- Is the measure reliable and valid?
- At what time point is the screening being carried out?
- Who will be screened?
- Is it culturally appropriate to use the assessment tool and does the tool account for cultural difference?
- Is the screened person aware of, consenting and directly involved in the assessment?
- Both risk and resilience factors need to be recognised and incorporated into screening/ bereavement assessment.
- Feedback should be given to the person assessed, i.e. explanation of the screening results.
- How will the information be stored?
- When risk is identified, what support options are in place for follow-up?

Compiled in collaboration with Massey Health and Cancer Psychology Services, 2015.

6.2 Distinguishing Between Grief and Depression

Distinguishing between grief and a clinical depression isn't easy because they share many similar symptoms. It is possible to be grieving and depressed at the same time. The following table is a quick reference guide outlining the ways to distinguish between them.

It has been adapted from the Victoria Hospice Society and accessed from medicine.dal.ca/content/dam/dalhousie/pdf/faculty/medicine/departments/department-sites/family/Education%20Documents/clerkship_objectives/Mood%20Disorders/BC%20G%26P_Grief_2011.pdf

<i>Feeling</i>	<i>Grief</i>	<i>Depression</i>
Mood states	<ul style="list-style-type: none"> • Greater range of moods and feelings • Quick shifts from sadness to normal state in the same day • Variability in mood, activity, communication, appetite and sexual interest in the same week 	<ul style="list-style-type: none"> • Moods and feelings are more static, little variability • Consistent sense of depletion, psychomotor retardation, anorexia, and/or decreased sexual interest or compulsive communication, eating and/or sexual behaviour
Expression of anger	<ul style="list-style-type: none"> • Open, externally directed 	<ul style="list-style-type: none"> • Absence of externally directed anger, internally directed
Expression of sadness	<ul style="list-style-type: none"> • Weeping 	<ul style="list-style-type: none"> • Difficulty weeping or controlling weeping
Self-concept	<ul style="list-style-type: none"> • Guilt associated with specific aspects of the loss • Experience the world as empty • Preoccupation with the loss 	<ul style="list-style-type: none"> • The loss confirms the person is bad or worthless • Focus on punitive thoughts, guilt has global aspect • Preoccupation with self
Responsiveness	<ul style="list-style-type: none"> • Periodic • Want solitude but respond to warmth and involvement 	<ul style="list-style-type: none"> • Static • Fear of being alone or unresponsiveness to others
Pleasure	<ul style="list-style-type: none"> • Periodic • Want solitude but respond to warmth and involvement 	<ul style="list-style-type: none"> • Restrict all pleasure • Loss of sense of humour
Reaction to others	<ul style="list-style-type: none"> • Others want to offer support 	<ul style="list-style-type: none"> • Others often feel irritated • Rarely feel like reaching out





Tools for Guideline 7

Staff are supported through professional development, training, education and resources

The following courses are available for professional development for staff working in the MDHB district.

Grief, Loss and Bereavement

Half day seminar at Arohanui Hospice – the aim is to provide an opportunity to explore the impact that grief, loss and bereavement have at all stages of our lives. It is not a therapeutic session but one that raises awareness about the complexity and dynamics of the grief journey.

Understanding Me When I am Dying

Full day seminar at Arohanui Hospice – the purpose is to raise awareness and understanding of the increasing spiritual and cultural diversity that exists within our community, enhancing our ability to offer the most appropriate care.

Fundamentals of Palliative Care

A comprehensive palliative care programme developed by Hospice NZ with nine learning packages that are relevant to all people working in health care – aged residential care facilities, home care and hospital settings. Included within the programme is a two hour learning module on grief and loss. A request can be made to Arohanui Hospice for this specific module to be given.

Contact Hospice Education and Research Centre for dates, times and further details.

www.arohanuihospice.org.nz/education/other-palliative-care-courses/

Phone: (06) 356 6606

Topping up Compassion

A two hour workshop at the Palmerston North Hospital Education Centre. The purpose is to understand the impact that compassion fatigue has on staff and patients, get an appreciation of the academic literature and learn new skills to improve patient experience whilst topping up your own compassion.

Contact MidCentral DHB or Central PHO for dates, times and further details.

www.midcentraldhb.govt.nz/WorkingMDHB/Pages/Education-Training.aspx

www.centralpho.org.nz/OurServices/CPDCalendar.aspx

Skylight Training

Skylight's professional development training is provided throughout New Zealand. Either regular or planned Skylight trainings can be attended or workshops can be tailor made to the requirements. These will focus on professional understanding and strategies relating to general or specific aspects of how difficult change, loss, trauma and grief impact on all ages, and on ways to support them as they deal with it.

Training and education programmes in MidCentral DHB could be made available through negotiation with Skylight's professional development team.

Email: pd@skylight.org.nz

Phone: 0800 299 100

www.skylight.org.nz

Online Learning Modules

Advance Care Planning E-Learning

www.advancecareplanning.org.nz/healthcare

LearnZone Macmillan Cancer Support E-Learning Site

A new free online toolkit for health and social care professionals provides information and resources on working with children and young people when a close adult has a life-limiting illness. www.learnzone.org.uk/courses/course.php?id=95



Tools for Guideline 8

Employers have a plan for bereaved staff

8.1 Resources for Organisations

Managing Trauma, Loss and Grief in the Workplace

skylight.org.nz/Shop/Managing+Trauma%2C+Loss+and+Grief+in+the+Workplace

Skylight & EAP Works Publication, 2014

A comprehensive resource for employers, senior executive teams, board members, health and safety representatives and managers to increase understanding about the impact of trauma loss and grief in the workplace. It also offers practical guidance and resilience-building strategies to assist and support employees, clients and customers through difficult life situations.

www.skylight.org.nz 0800 299 100

How to be a Compassionate Employer

Australian Centre for Grief and Bereavement and the Compassionate Friends Victoria.

A resource to improve and support workplaces in the area of grief and bereavement based on employees lived experience of what they have found to be helpful.

www.grief.org.au

Employment Assistance Programmes (EAP)

This is provided by a range of providers. They provide practical assistance when personal or work issues arise that may impact on someone's ability to do their job, or affect their wellbeing, such as:

- grief and loss
- stress and pressure – personal or work
- depression and anxiety
- workplace issues and changes
- bullying and harassment support
- anger and conflict issues
- relationship and family matters.

Some well-known examples are:

- EAP Services Limited: www.eapservices.co.nz
- EAP Works: www.eapworks.co.nz
- Vitae: www.vitae.co.nz
- Workplace Support: www.workplacesupport.co.nz
- OCP: www.ocp.co.nz
- Stratos: www.stratos-ltd.co.nz





