PALLIATIVE CARE BEREAVEMENT SUPPORT GUIDELINES

MidCentral District Health Board
Te Pae Hauora o Ruahine o Tararua

clinical networks

Authors and Consultants

These Guidelines have been developed by:

The MidCentral District Health Board (MDHB) Palliative Care District Group.

The Working Group:

- **Reverend Sande Ramage,** Chaplain, Palmerston North Hospital, Interchurch Council for Hospital Chaplaincy (ICHC)
- **Dr Simon Allan,** Director of Palliative Care, Arohanui Hospice
- **Kate McKenzie,** Reg. Social Worker, Family Support Team Leader and Bereavement Support Coordinator, Arohanui Hospice
- **Maria Berrett,** Senior Clinical Psychologist/Coordinator of Health and Cancer Psycho-oncology Services, Massey University, Palmerston North
- **Lee Hefford,** Reg. Social Worker, MidCentral District Health Board
- **Bridget Marshall,** Palliative Care Network Coordinator, MidCentral District Health Board.
- **Graham Black** (resigned due to change in role), Mental Health Team, Tararua, Central Primary Health Organisation.

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An Overview

Bereavement support is a key component of quality palliative care.

The death of a person is one of the most significant and difficult life events families, whānau and close friends can experience. Bereaved people experience loss and grief in their own individual ways. Their reactions and support needs will vary according to a range of factors including the circumstances of the death, their age, personality, gender, culture, beliefs, previous loss experiences and the level of personal support they have.

The Palliative Care Bereavement Support Guidelines (from hereon called the Guidelines) set out the principles and goals for bereavement support which are endorsed by the MidCentral District Health Board (MDHB) Palliative Care District Group. They specify evidence based standards of care that are recommended for use by any organisation delivering palliative care within the district, including specialist and non-specialist palliative care services.

Benefits and expected positive outcomes in using the Guidelines

- Raising awareness and normalising the grief process
- Recognition of resilience
- Promoting safe and effective bereavement care
- Reducing poor health outcomes
- Improved communication
- Information and resources
- Increasing knowledge and skills
- Equitable access to support if needed
- Working together
- Promoting bereavement care as a wider responsibility
- Promoting resilience and autonomy.

The purpose of this document

- Describe the background and development of the Guidelines
- Outline the underlying principles
- Outline the guidelines
- Describe how to use the Palliative Care Bereavement Support Guidelines.

The Guidelines provide a systematic and integrated set of both principles and practices. They have been developed for use by health professionals and services caring for those with a palliative care need.

Eight principles describe the foundation and key values that underpin the guidelines.

The principles are person, family and whānau centred and acknowledge the New Zealand context.

They are:

1. Family, whānau and close friends matter
2. Most people have resilience
3. Effective, compassionate communication provides the foundation for support
4. Bereavement support begins with preparation for dying
5. Cultural diversity needs to be reflected in bereavement support
6. Spiritual diversity and care needs to be recognised and supported
7. Bereavement support requires flexibility
8. Continuous reflection is required.

"There is no detour round bereavement."

Rabbi Earl Grollman[1]

The Guidelines are divided into three areas and contain eight elements:

Preparing for death

1. Interdisciplinary teams know the person's family, whānau, friends and caregivers, 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.

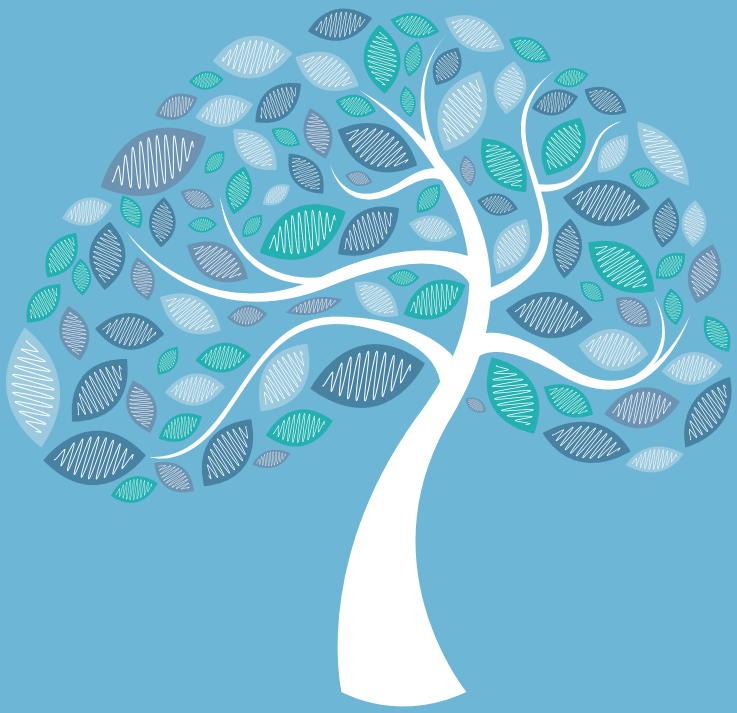
Bereavement support after death

4. Interdisciplinary teams acknowledge death with family, whānau and friends.
5. Bereavement information is 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.

The Guidelines are accompanied by a Resource Toolkit to assist in the implementation of the Guidelines. The Guidelines and Resource Toolkit can be accessed via the MidCentral DHB website www.midcentraldhb.govt.nz/Publications/AllPublications



Section 1
Background

Introduction

Where do people die?

Just over 1300 people die within the MidCentral DHB each year.[2] Approximately 90% of these die from a long term condition or life limiting illness.

Where a person dies is influenced by a range of factors, including their age, ethnicity, level of deprivation and the underlying cause of death. National statistics[3] indicate most deaths occur in a hospital setting (34%), followed by residential care (31%) and private residence (22%). Relatively few deaths (6%) occur in a hospice inpatient setting. However, hospice services do support a number of those who die in the community or in an aged residential care facility.

The place of death, whether at home, in hospital, hospice, or in aged residential care, is an integral part of people's wider experiences of palliative care. It may be the dying person's preferred place of death; it may reflect the resources available to family, whānau and friends as caregivers; or it may be related to the need for specific types of care.

Compared with other Western countries, New Zealand has high rates of death in aged residential care facilities for those aged over 65.[4] As a result, those working in aged care have a significant role to play in supporting people requiring a palliative approach to care, in caring for the dying, and in offering bereavement support to their family, whānau and friends.[5]

The provision of bereavement support can vary greatly among organisations. While those dying within aged care facilities may have access to some bereavement support, such support is not a requirement within those facilities' contracts.

Acknowledgement of death, information following death and bereavement support is not routinely available through Palmerston North Hospital, despite it being the place where the majority of people die.

Bereavement support – why is it significant?

Palliative care does not end with the death of a person. Bereavement support is a key component of quality palliative care.[6] It includes supporting both the person being cared for and their family, whānau and friends, from time of diagnosis until after the death occurs.

One of the fundamental principles of palliative care is that the person and their family, whānau and close friends comprise the unit of care.[7] They are often the primary carers for those who are ill and at home, and offer the most emotional support. Much has been written about the needs of carers and the role carers take in the "frontline of primary care".[7,8] Carers are more likely to have poor health and wellbeing outcomes if they perceive that support has not been available both before and following the death of the person they are caring for.[7,8]

Evidence suggests the provision of bereavement services* for all bereaved people is not necessary. Offering therapy to resilient individuals who are coping well with their grief has been described by Agnew et al, to be "unhelpful and indeed harmful."[9]

What is helpful is professional support that is offered and available as a supplement to private networks of support. This includes appropriate information relating to the grief process and bereavement experience, and to accessing additional supports if required.[10]

Grief

The death of a person is one of the most significant and difficult life events families, whānau and close friends can experience, particularly if the death is that of a child or young person. Grief is the normal human response to difficult loss, such as a death. The grief process assists a person to gradually adjust to the reality of what has happened, experience the pain of the loss and become able to move forward.

Many find grief's impact more intense than they expected. It can raise levels of distress and disrupt daily lives, even be overwhelming, but over time most people find their grief's intensity lessens. Being a process, it inevitably takes time. The time this 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.

* Bereavement services may include counselling, therapy and structured group or individual support programmes.

Bereaved people experience grief in individual ways. Their reactions and needs will vary according to a range of personal 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.[10,11]

A bereaved person's experiences will also be shaped by their level of natural resilience. That is, their instinctive ability to adapt and cope in times of adversity. Their experience will also be influenced by the diverse needs they and/or their family, whānau and friends may have as a direct result of the death.[9] Grief can also be experienced as, 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.

- Emotionally
- Physically
- Mentally/Cognitively
- Spiritually
- Socially.

Poor health outcomes, depression, social isolation, and increased mortality have been associated with lack of bereavement support.[12]

Anticipatory grief

In palliative care situations anticipatory grief often occurs prior to the death of a person. A family, whānau or friends can have many months, even years, of supporting their loved one through life threatening illness prior to the death. During this time a range of associated realisations and losses can accumulate and be grieved for. Such as:

- the realisation that their loved one is dying and won't be with them in the future
- the loss of their loved one's health and wellbeing, and their increased suffering or distress
- not being able to do things with them like before
- new financial challenges to cope with
- changes in their personal role/s (e.g. now a carer, having to work, single parenting, managing house matters alone etc)
- changes in identity (e.g. I am going to be a widow)
- future plans and expectations lost.

It is important to recognise that anticipatory grief may not always occur. How anticipatory grief affects bereavement grief after the death is unclear. Some researchers have found that grieving in an open and adaptive manner before death can be beneficial for carers after death.[13] It can allow for preparation for death and the development of coping skills for the life changes following the death of a person. However, others have found that despite the anticipatory grieving experience, it is unlikely that grief post death is lessened.[14]

Prolonged and complicated grief

There may be instances when palliative care bereavement support staff continue to have contact with bereaved family, whānau or friends for a considerable time after a death. This means they are able to observe their grief experience over many months, and perhaps years. Concerns may be raised if a person continues to experience extreme, disabling and even increasing distress several months after the death. Determining when normal grief becomes prolonged and complicated can be difficult, but a small, significant percentage of bereaved people (variously estimated between 7 and 15%) will experience a prolonged and complicated grief response to a death.[15,16,17,18,19] This group needs extra targeted support to assist them to move forward in their grief process.

Prolonged and complicated grief describes a cluster of experiences that may include separation distress, an inability to cope with normal daily functioning (including work), and post-traumatic stress reactions, such as pre-occupation, avoidance and flashbacks. These symptoms interfere with grief's natural healing process. Stroebe and colleagues (2013) define prolonged and complicated grief as: "a clinically significant deviation from the (cultural) norm in the time, course or intensity of specific or general symptoms of grief, and/or the level of impairment in social, occupational, or other important areas of functioning" (p. 136).[20] It is also sometimes known as traumatic grief.

Prolonged and complicated grief has been associated with impaired emotional and mental health, increased medication use, increased alcohol and drug dependence and negative consequences on physical health.[17,20]

Pre-screening

Research indicates that risk factors for prolonged and complicated grief post death can be assessed prior to death.[21] If a person evidences related risk factors pre-death, these are the strongest predictors of post death prolonged and complicated grief occurring at six months and thirteen months.[22]

To assist with such risk assessment, it can be helpful to use a validated screening tool. This will screen family, whānau and close friends for prolonged and complicated grief risk factors on their loved one's entry to palliative care.[23] However, it is also recognised this may not always be feasible for some services, due to time constraints, skill level of practitioners, and follow-up availability. It is also being increasingly recognised, in light of newer models of grief (for example, the Dual Process Model),[25] that the autonomy and resilience factors which moderate the bereavement experience need to be taken into account. [9]

Targeted Support

If prolonged or complicated grief factors have been identified during bereavement, effective support will usually include a tailored mix of the following elements:

- a visit to a GP to screen for any other health factors in play
- referral to counselling or therapy by a specialised professional
- use of an intentional and personalised self-care regime, including regular exercise and good nutrition
- accessing ongoing support from existing support circle or external providers, such as a social worker, grief support worker or a help line
- information provided to the person about prolonged and complicated grief, to facilitate increased understanding and strategies to try.[25,26]

International bereavement guidelines

The United Kingdom's National Institute for Clinical Excellence (NICE) Supportive and Palliative Care for Adults with Cancer (2004)[27] outlines bereavement support in a three stage approach:

Stage 1: The large proportion of people experiencing normal grief reactions are able to adjust to loss and bereavement using their own personal resilience, resources and support systems.

Stage 2: A small number of people may need formal support and are more at risk from physical or mental health consequences if they don't receive this support. They often need to debrief their experiences with community groups or volunteers. Referrals would need to be made for those who are assessed as needing more specialist bereavement support.

Stage 3: A minority of individuals will require specialist intervention for assessed prolonged and complicated grief. They will need support from specialist mental health services or from bereavement or psychosocial services.

Similarly to the NICE guidelines, a public health approach to bereavement is gaining momentum.[27,28,30] This approach recognises that most bereaved people have the strengths and resilience within themselves, their families, whānau, friends and existing communities to adjust to loss. A three tiered approach is suggested, reflecting the previous stages described the NICE approach.

The public health approach builds on the existing strengths of the population and ensures the needs of the bereaved family, whānau and friends are met, whilst also remaining cost effective.

The Australian Guidelines for Psychosocial and Bereavement Support[30] outline the requirements for health professionals supporting caregivers prior to and following a death. The indicators that should trigger psychosocial support being offered to caregivers are:

- those who feel excluded from information and care planning, and feel unprepared for the care-giving role
- those with little prior experience of death and limited knowledge and understanding of disease progression
- increased financial disadvantage
- social isolation
- reported unmet needs.

New Zealand

New Zealand does not have a National Palliative Care Bereavement Service or National Palliative Care Bereavement Support Guidelines.

Hospice New Zealand have developed Standards for Palliative Care which are available for all organisations providing palliative care.[31]
The specific standard relating to bereavement support is Standard 10:

> *Formal mechanisms are in place to ensure that the patient and their family and whānau have access to bereavement care, information and support services (p.37).*

Hospices have a history of providing support to bereaved family, whānau and close friends as bereavement support is a recognised component of quality palliative care provision.[6,27,29] However, this support is accessible predominantly for those who had been referred to their specialist palliative care services. There are many who receive palliative care and die outside of hospice services whose family, whānau and friends also need bereavement support.

MidCentral District

The mandate for the development of localised Palliative Care Bereavement Support Guidelines originated from the MDHB Palliative Care Strategic Plan (2012–2017).[32] This was written to promote quality care within the MidCentral district regardless of diagnosis or place of care. The vision for the district-wide palliative care strategy is for palliative care services to be such that:

> *"All people with life limiting conditions live well and die well, irrespective of their condition or care setting"* [32]

A Palliative Care District Group was established to drive the implementation of the Strategic Plan. A working group (Appendix 1) was developed to progress the goal 'support is available and accessible for family and whānau'. The development of Palliative Care Bereavement Support Guideline was viewed as a key focus for achieving this goal.

The aim of this project was to develop guidelines which would assist palliative care providers (specialist and non-specialist) to:

- support those who are bereaved and grieving
- promote access to support options in a timely manner
- identify those at risk of prolonged and complicated bereavement outcomes and provide appropriate support pathways.

At a district level, there is a need to have a wide range of bereavement support services and information in place to meet the spectrum of population need. Health professionals need to be aware of the bereavement support services available and what the appropriate referral processes are.

Within MDHB, there have been no identified guidelines or systematic processes for acknowledging bereavement, identifying those who may need further support, or for referring those who requiring appropriate specialist services. These guidelines address this gap.

Current Bereavement Support Services in MDHB

The working group undertook a review of current services and practices in bereavement support within MDHB.

Identified organisations were contacted by members of the group and six questions were asked:

1. What service do you offer?
2. Who do you offer the service to?
3. What do you offer within your service? (e.g. group counselling, face to face, resources)
4. How many people do you accept to your service?
5. If you do not offer bereavement support who do you refer to?
6. Are there any identified gaps?

The results of this survey revealed that a variety of organisations and services provide bereavement support within MDHB. Each organisation has specific referral and service provision criteria. In some instances there are long waiting lists or specific criteria to meet in order to access services. Some services are provided by professionals and others by volunteers.

Two services were identified as having the greatest number of deaths – Palmerston North Hospital and Aged Residential Care facilities. In these either no bereavement support was provided or, where it was provided, there was variability in the type of service provided, by whom and for how long.

MDHB Palliative Care Bereavement Support Guidelines

What are clinical guidelines and why should we use them?

Clinical guidelines are systematically developed and designed to assist members of relevant health care teams to make appropriate decisions about a specific way of working.

Guidelines have been shown, when used together with clinical judgement, to effectively achieve consistency in the provision of quality care.[33]

The proposed guidelines have been developed from examination of the best evidence currently available internationally. In addition, local, national and international knowledge relevant to bereavement support, including expert opinion, has been consulted. The guidelines provide a systematic and integrated set of principles and practices.

They are applicable for health professionals caring for adults, children or teens. They are not designed for supporting those who have experienced sudden death as a result of an accident, suicide or acute medical event.

Section 2
Underlying Principles

Underlying Principles of the Palliative Care Bereavement Support Guidelines

1. **Family, whānau and friends matter**
2. **Most people have resilience**
3. **Effective, compassionate communication provides the foundation for support**
4. **Bereavement support begins with preparation for dying**
5. **Cultural diversity needs to be reflected in bereavement support**
6. **Spiritual care and support needs to be recognised**
7. **Bereavement support requires flexibility**
8. **Continuous reflection is required**

Eight principles underpin the foundation and key values of the Palliative Care Bereavement Support Guidelines. The principles ensure that the Guidelines are person, family, whānau and friend centred and also grounded within the New Zealand context. The Guidelines are deliberately inclusive based on evidence from literature and clinical excellence and knowledge.

"[Life] will always be tinged with the sadness of longing. Every happiness is weighted. It's like a vice slowly squeezing your heart. Whenever you feel happy, you remember that your child isn't here to share it, that she isn't here to have the joy in her life she deserved to have. It is always that minor chord intoning in the background."

Judith Bernstein[36]

1. Family, whānau and friends matter

Family, whānau and friends are the significant unit of care, playing an essential part in the care of the person who is dying.

Palliative care supports family, whānau and friends. It optimises quality of life, maintains mana and enables free expression of cultural values and practices relating to death, dying and bereavement.[34] Palliative care recognises that the health of one family, whānau and friend member affects the health, well-being and everyday life of the entire family, friend whānau or friend circle.[35]

Whānau can be multi-layered, flexible and dynamic. The following pepeha (saying) encapsulates the essence of the individual within the whānau:

> *Ehara taku toa i te toa takitahi engari he toa takitini taku toa. My strength does not come from my individuality, my strength comes from many.*

Whānau and family or friend values, preferences and context are influential factors in how they might access services, including bereavement support. Knowing and understanding the values of a family, whānau and friend can help the health professional to offer appropriate support. Being mindful of culture, spirituality and wairua is important. For instance, some may find support through religious or church groups, whereas others may find meaning and support through elders and community leaders, other groups or their own personal networks.

Close friends can often play a crucial caregiving role, especially in the absence of family or whānau. They are often considered and respected as being in the family or whānau. Their bereavement equally needs support and assessment.

2. Most people have resilience

A strengths-based approach underpins the Guidelines. This approach accepts that the majority of people have some resilience. That is, a natural ability to adapt and cope in times of increased stress and adversity. They are able to manage well, adjusting to loss with the support of their family, whānau, friends and existing community supports. Factors that enhance resilience are contained within the Guidelines Toolkit.

3. Effective, compassionate communication provides the foundation for support

Good communication is vital in any healthcare relationship and setting. Strong communication skills enable health professionals to build relationships and demonstrate that they care as "bereavement care is based on the use of therapeutic communication which is more than the use of words; it attends to genuine presence, active listening, conveying empathy and compassion, as well as touch" (p. 388).[37]

A qualitative study by Caelli, Downie & Letendre in 2000 found that the single most important factor and "what made a difference" to bereaved parents was active listening, understanding the experiences and communicating empathy.[38] This is also reflective of the needs of bereaved people generally.

Effective, compassionate communication was a major theme within the recently published survey report which described the palliative care experiences of those in the MidCentral DHB.[39] The report reviewed information gathered from a number of sources which elicited personal experiences: focus groups, local research, satisfaction surveys, compliments and complaints, theses and other written material such as newspaper letters. "Personalised communication that is timely, culturally appropriate, respectful, compassionate, kind, meaningful (e.g. verbal, non-verbal, written) and demonstrates active listening with patients, families and whānau was integral to the positive experiences of receiving care and feeling cared for" (p. 4).[39]

Effective communication is essential between healthcare professionals and the family, whānau and friends of the dying, as well as between health care professionals and any organisations providing care. Such communication needs to include clear and timely sharing, an exchange of information, and a good understanding of roles and responsibilities.

4. Bereavement support begins with preparation for dying

Assisting family, whānau and friends to prepare for the death of a person should begin early. All discussions with them, and other associated caregivers, during the pre-dying phase should be documented and reviewed by the interdisciplinary team. Services should personalise these interactions and respond to any age, cultural and belief diversity, disability or gender factors which may be adversely affecting interpersonal dynamics. Such issues should be dealt with in a sensitive and inclusive way.

Preparation for dying includes:

- providing information to family, whānau and friends about what to expect
- identifying the preferred place of dying
- providing access to information about post - death factors that are consistent with a family's, whānau's or friend's needs (such as funerals, tangi or memorial practice options).

Information needs to be clear, up to date, reliable and both written and verbal.

Although it is not always possible to completely prepare for death, families, whānau and friends value the ability to prepare themselves and others. Having trusting relationships with health professionals can help them to process information, ask questions, seek extra help if needed and complete important tasks.

An Advance Care Plan (ACP) is a valuable resource for health professionals to gain insight into the wishes of the dying person. Advance Care Planning is a process that helps a person to identify the kind of care they wish to receive near the end of life. This may include valuable information for family, whānau and friends, as well as health professionals, which can help with preparation for dying and after-death wishes.

"Work around passing... at the end of life of a Māori person, there's actually a lot of preparation to be done, and if you're not that way inclined [knowing tikanga], you won't know and you can balls it up for that family on top of their grief. So, for an example, when somebody passes away, Māori will have this [protocol], you get in there, and you do the karakia... if you don't know that, that could just balls the whole thing up. So it's all about knowing all that before the work actually comes in.[41]

When engaging with Maori whānau regarding end-of-life or post-death decision making, consideration must be given to when, where, what manner, and who within the whānau you are engaging with. Identifying leadership within Māori whānau is important as they are able to provide guidance and direction regarding the process to other whānau members. This person is usually someone who has experience and knowledge of the processes and is also able to provide a centralised point of contact for whānau.

5. Cultural diversity needs to be reflected in bereavement support

Cultural diversity needs to be acknowledged and honoured. MDHB district has over 130 ethnicities including a large number of refugees. There is also a higher proportion of Maori residents living in MDHB than in New Zealand overall (17.4% and 14.1% respectively).[40]

The weaving of cultural awareness, knowledge and responsiveness through organisations which provide palliative care will assist in supporting those with diverse needs. For example, bereavement support for people with refugee status needs to be responsive to those from a variety of ethnic backgrounds who may have previously experienced multiple, and possibly traumatic, losses.

Resources for death and dying for whānau within MDHB are being developed by Te Ohu Whai Oranga, on behalf of the Whānau Ora Strategic Innovation and Development Group (WOSIDG). These resources will assist whānau to understand the processes involved when whānau die and encourage them to talk about death. When available, the resources will be included within the Resource Toolkit.

6. Spiritual care and support needs to be recognised

Broadly speaking, spirituality is the way "individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred."[42]

For some people this will incorporate a religious framework but for others it will not. For some there will be a mixing and mingling of ideas. "Spirituality means different things to different people."[43] Finding words to express this important part of the human condition is often difficult, especially when significant numbers of our population have moved away from traditional God language.

"For Māori, the terms 'wairuatanga' or 'wairua' are used to speak of the spiritual dimension and things pertaining to the spirit of an individual or living being."[44] These terms have become well embedded into New Zealand daily life and so many may relate to them.

As language can be extremely difficult in this area, the most important task for a health professional is to listen carefully to what matters to family, whānau and friends. Ask simple questions like; What gives your life meaning? What matters most to you? or, what do we need to know about you or your family member/friend to give the best possible care?[45]

It is important that health professionals put aside their own worldviews and beliefs. This helps them to hear what matters to the grieving person and to learn what rituals or customs might assist them process the death.

While ideas about death and dying may be diverse in New Zealand, patients want doctors "to ask about their source of spiritual support and facilitate access to it." People want to be treated holistically and be able to discuss their fears. A health professional's willingness to hear what matters in terms of spirituality can enable this to happen.[46] Other community people who can help with matters of spirituality are ministers of religion, hospital chaplains, kaumatua and kuia, and other cultural leaders.

7. Bereavement support requires flexibility

Access to palliative care bereavement support should be available to all who have a need for it, irrespective of where the person has died (hospice, hospital, aged care facility or home). Support should be easy to access, received in a timely manner and be responsive to the individually assessed need.

Because the experience of grief, loss and bereavement is unique to each individual, support services need to be flexible enough to meet the varied needs people have. For example, age and cultural appropriate one to one sessions, specialised support groups, bereavement support activities and different information media can provide people with optional support tools.

Acknowledgement of loss with family, whānau and friends members is an important step in the provision of bereavement support. When such support is offered by health professionals who have been involved in the care of the person, it is particularly effective.[10] Follow-up by phone call, visit, or letter, is highly likely to help the bereaved person feel acknowledged and consoled. Such follow-up also provides an opportunity for them to seek further assistance if required, and to understand more clearly the circumstances surrounding the death, should such clarification be needed.[47,48]

Whilst the majority of bereavement support is provided by other family, whānau and friends, support from professional staff is particularly required if family and friend networks are not present, when the bereaved person does not want to burden others they know or when supports are dysfunctional.[10] In these situations professional support needs to be provided as soon as possible.

Health professionals need to know about the support services available and the referral processes. This enables them to confidently facilitate access to them by family, whānau and friends, and in a timely manner.

8. Continuous reflection is required

All organisations delivering care have responsibilities to engage in quality improvement. Service quality is determined by the ability to meet the needs of those who are accessing services, to anticipate their prospective needs and expectations, and to engage in productive relationships with them as stakeholders. Ongoing reflection on the success of these elements is essential.

MDHB's quality framework outlines four key principles necessary for the effective improvement of services:

1. A client, whānau and community focus
2. Being able and willing to learn
3. Doing the right things
4. Being up to the job.[49]

The Guidelines demonstrate best practice for bereavement support and are family, whānau, friend and community focused.

Continuous reflection and review are ways palliative care organisations can assess whether they are "up to the job" and "doing the right thing". For example, a review could include a focused collegial reflection on how the service supported the death of person and their family, whānau or friends within their service, both pre and post death. Reflection on an organisation's bereavement support service could occur in the course of regular staff meetings when care quality can be routinely considered. Simple questions such as "What went well in the care of this family, whānau or friend?" and "What did not go well?" can facilitate helpful insights into what's going well, what's not, and which improvements to the bereavement support service need to be made.

Some people read literature that is left about, but others don't even see it.

(Nurse acute care setting)

Section 3
The Guidelines

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.**

Preparing For Death

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

The New Zealand palliative care definition includes family, whānau and friends and acknowledges that support is required "through the illness and after death".[50] Knowing who the family members are and identifying significant relationships and supports, ensures that health professionals provide whole-person individualised care that recognises and respects those who are close to the ill person. They may provide much of the caregiving. Friends may be considered significant members of the extended family and whānau network and need to be included.

It is recognised that families, whānau and friends have strengths, expertise, and access to supports to manage their own care, including bereavement. The needs of the individual members of the family, whānau and friend groups need to be identified, addressed and 'balanced with the service providers' legal and professional responsibilities'.[31]

A meeting of family, whānau and close friends, as appropriate, provides an opportunity not only to share information and plan care for the dying patient but also to understand and observe family functioning and relationship dynamics. This helps to gather additional information which can inform assessment of bereavement risk and needs.[51]

The use of tools, such as genograms, provides one way to identify and record family, whānau and friends and the relationships among them. Advance care plans also provide information regarding family, whānau and the relationships within them. By reviewing the completed advance care plan health professionals can be made aware of any noted needs or expectations of the person's family, whānau and friends.

Evidence:

30, 31, 49, 50, 51, 52, 53

Resources:

Included in the Resource Toolkit are instructions on how to develop a genogram, together with an example of genogram. The resource toolkit contains access information regarding Advance Care Plans (ACP) documentation and the process for its completion.

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

To promote accuracy of assessment, it is important that a person's assessment includes recognition of both risk factors and resilient coping strategies. It is also important to engage family members or friends themselves in the assessment process. This is likely to lead to more accurate and complete assessment and to encourage those with higher risk to access available support.[9,51]

Resilience factors which facilitate a person's coping and adjustment to loss through the grief process include:

- having positive connections with family, whānau, friends and other social support networks
- being able to use one's own strengths and resilience to deal with adversity
- emotional and practical support is available, if needed
- an understanding of grief as a normal and helpful process
- being able to draw on past experiences of surviving loss or adversity to identify coping mechanisms that work for them
- good self-care
- having a hopeful outlook.

While evidence suggests that most people do have resilience and receive support that is adequate to meet their needs, a small number of bereaved people will require extra support (7-15%).[15,16,17,18,19]

Assessment of bereavement needs can occur both prior to and during the after-death period. Using clinical judgement and knowledge, health professionals can identify those who may require further support or are at risk of developing a prolonged and more complicated grief condition.

Such clinical judgement is developed through the health professional's training, ongoing professional development and professional experience. Palliative care specialist teams are usually well qualified and experienced in recognising those who could benefit from some more formalised support options, or who may be at increased risk of prolonged and complicated grief. They are well placed to work with family, whānau and friends to plan personalised strategies to reduce any negative outcomes.[9]

Recognition of those who may require extra bereavement support includes assessing the coping mechanisms which are currently in place and any identifiable risk factors for prolonged and complicated bereavement.

Risk factors include such things as:

- previous experiences of difficult loss and grief
- challenging circumstances surrounding the illness and death
- relationship between bereaved and deceased – very close or conflicted
- poor existing mental or physical health
- a difficult family or living situation
- little personal support available
- age.

All of these can have an impact on the bereaved person,[19,20] intensifying and further complicating their grief experience.

In many circumstances, assessment may be multidisciplinary, especially in situations where a family member or friend provides information to different health professionals at different times. Having well understood and well-practised processes for clear communication between health professionals, and for referring on to others in the care continuum, is important.

Using a bereavement risk assessment screening tool can provide standardised and timely information to assist clinicians to recognise when additional support may be required.

Around the time of death, a screening tool can be used to:

- gain a clinical picture of potential risk (and resilience) factors for prolonged and complicated grief
- assist to reduce variability in practice
- facilitate useful conversations between health professionals and family, whānau and friends
- assist in objective decision making
- determine the level of potential risk of prolonged and complicated bereavement and the level of support required.

Although there are a number of bereavement risk screening/assessment tools available for use, very few of these are validated. Research is still emerging regarding which tool(s) may be the most effective. Where assessment tools are used, it is important to consider a number of factors, including whether they are suitable for those screened, are practical for the professionals completing the screening, and are appropriate for the organisation or setting in which they are used.

Currently, within MidCentral DHB, Arohanui Hospice uses a modified Bereavement Risk Assessment Tool (BRAT)54 , which is widely used in Victoria, Australia. This psychosocial assessment tool is used by the care team to identify personal, interpersonal and situational factors that may place a caregiver or family, whānau and friends at greater risk of a negative bereavement experience. The BRAT also includes a look at resilience factors. This information can be collected prior to death and used to determine an appropriate level of support for people when death occurs.

It is important that health professionals, services and organisations assessing family, whānau and friends bereavement needs have appropriate processes in place. These should encompass how the assessed information is gathered, stored and utilised to provide support to the bereaved person (including appropriate feedback given). Additionally, what follow-up will be put in place, when and by whom.

Evidence:

9, 11, 18, 22, 48, 51, 55, 56

Resources:

- The Resource Toolkit provides a list of: common grief reactions, grief and bereavement for a child or young person, resilience factors, and communication techniques.
- The Resource Toolkit also provides a list of considerations for selection of appropriate screening and assessment tools.

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

Preparing family, whānau, friends and caregivers for death has been identified as a way to help reduce the risk of developing negative mental health outcomes.[52] Life experiences such as the duration of illness and the period of caregiving, previous experiences of caring for the dying, discussions about advance care planning and medical literacy can all affect the degree to which family, whānau and friends are ready for death and subsequent bereavement.

Uncertainty about what to expect can lead to anxiety and fear, so it is important that reliable and clear information is communicated by health professionals and relationship-centred care is provided.

Information given to family, whānau and friends needs to be age, gender, and culturally appropriate. Consideration must also be given to its timing. It needs to be provided when people are ready to receive it. It may need to be repeated or given again at intervals so there is opportunity to digest one piece of information before more is given. Encouraging people to ask questions whenever they need to is also important, even if the same question has been asked before.

Evidence suggests that people require good information about available practical support, and how to access it. (For example, what to do after a death, funeral planning, ACP.) A systematic review of informal carer needs established that information detailing practical support is often not available. It also found that when it is available, it is often provided too late, is not clearly described, or is not given in written form despite many specifically requesting written information.[57] Written information that avoids medical jargon and is clearly presented ensures there is baseline of information to which all clinicians can refer when providing bereavement support and has been found to give family, whānau and friends a sense of security.[58]

Practical information may be needed provided as people prepare for after-death rituals, including information about the appropriate care of the deceased person. New Zealand's ethnic diversity is increasing and so is the range of after death practices being followed. Information should be available regarding the legal requirements related to the disposal of a deceased person's body and about where to access support catering for specific ethnic needs.

Evidence:

10, 47, 52, 57

Resources:

Examples of resources and information that may be appropriate are available within the Resource Toolkit.

- Written information should be provided to supplement verbal conversations, which may not be remembered.
- Brochures that may be useful are; *"What to Expect when Someone is Dying", "Preparing for Death". "Preparing for a Funeral"* and *"Talking to Children and Young people."*

Accessed via www.midcentraldhb.govt.nz/Publications/AllPublications

Bereavement Support Post Death

4. Interdisciplinary teams acknowledge death with family, whānau and friends

Personal acknowledgement of a person's death to their family, whānau and friends is a fundamental task in the provision of bereavement support. This is particularly so for the caregiver(s) most closely associated with the deceased person. Benkel et al's survey of bereaved relatives (2009) showed that respondents appreciated acknowledgement and support from health professionals closely associated with the death, preferably as soon after the death as possible.

An example of this may be seen in the supportive relationships that usually develop between healthcare professionals and family, whānau and friends during the treatment phase and/ or the death of a child or young person. These relationships are significant and part of people's support network.[59] Good relationships place health professionals in a positive position to support family, whānau and friends well, thereby helping to facilitate healthy grief experiences.

Follow-up phone calls or condolence letters or cards are effective ways of acknowledging the death of a person. Milberg et al, 2008, state that effective follow-up procedures after a death help the bereaved feel valued. They can also assist in alleviating any feelings of guilt which might be troubling a bereaved person. Lundberg et al reports (2013) that families find condolence letters (p. 286) to be a "source of strength for them". Such letters can reassure a family, whānau or close friend that they have done nothing wrong.

The Arohanui Hospice Service has followed a process for acknowledging death and bereavement for many years, and for meeting the needs of those who require more than baseline support. Condolence letters, information addressing a bereaved person's needs, and the provision of specialised support for those who seek it, have all contributed to an effective bereavement support service.

The Intensive Care Unit at Palmerston North Hospital supports people through follow up phone calls by clinical staff who have cared for the deceased person, and their family, whānau and friends. Staff offer people the opportunity to ask any questions they may have about the death of their loved one.

Around New Zealand there are a number of regions where a systematic process for early bereavement support is also in place. For example, Whanganui Hospital sends condolence letters to all next of kin of those who have died. They also offer the opportunity for follow up conversations with the Customer Relations and Complaints Officer and with their Chaplain and Spiritual Care Coordinator.

Evidence:

10, 11, 29, 47, 48, 59, 60

Resources:

A template for a condolence letter is included and can be individualised.

5. Bereavement support information is available to family, whānau and friends

Effective bereavement support aims to promote resilience, autonomy and the confidence to access help if it's required. It is recommended that organisations provide bereaved family, whānau and friends and caregivers with written information that can help increase their knowledge about grief and bereavement, and about relevant support and self-referral options.[11] Information should be focused on practical and emotional grief support. It should be age, gender and culture appropriate and easy to understand.[7] Sharing information at an early stage creates an opportunity for health professionals to normalise grief reactions and to make family, whānau and friends aware of what to expect when grieving. They can also refer to it whenever they wish.

Providing clear information on the dynamics of bereavement grief and detailing where to seek help, even if it is not required or accessed, contributes to the wellbeing and comfort of the bereaved.[10,47] Book references, websites, social media sites, internet support groups, telephone help-lines and community courses provide different ways that information needs can be met.[57]

The strengths based approach recognises that the majority of people are able to access support through their own networks. Giving them information pathways to follow themselves is empowering, such as key weblinks, recommended reading or relevant support option contact lists.

Targeting interventions and information specifically for children, teenagers and young adults is another important aspect of bereavement support. Lundberg et al, (2013), report that as bereaved family members seldom take the initiative to make contact on behalf of this group, providing access for them to good information is both necessary and important.

Awareness of, and responsiveness to, their grieving is also very important for health care professionals and for their family, whānau and friends. These groups may seek advice and information from trusted health care professionals about how to respond to their grief.

Key factors influencing the grief of children, teenagers and young adults include their previous experiences of loss, or lack of it, and the age and development stage they're at.[60] It is vital to learn the ways grief experience can be different for these younger age groups, as well as which strategies caring adults can use to support them well.

Given MidCentral's ethnic diversity, relevant information appropriate for diverse cultural groups, as reflected in Guideline 3, is also very important. Information about burial options, cremation and access to funeral directors is not commonly held by people. Palliative care services need to have it readily available, kept up to date and relevant and appropriate to all the population groups they serve.

Evidence:

6, 10, 11, 47, 57, 59, 60

Resources:

Bereavement support information is available in the Resource Toolkit and can be used as a basis for supporting families, whānau and friends. This includes preparation for rituals and funerals. Further resource links are listed and can be accessed as required for those with specialised needs. Information specific to children and teenagers is also available in the Toolkit, as well as further recommended resources.

6. Reassessment of bereavement support needs is important

Assessing for distress (psychological, physical, spiritual) related to bereavement is an ongoing process. It typically needs to occur across many months – from prior to the expected death of a person until the months following the death. In some instances, it may be for longer than a few months post-death.

Although there are a number of tools available, there is little consensus the most appropriate time to reassess support needs. Some research suggests between 6-13 months is a good time to reassess bereavement support needs, particularly if the death was unexpected, or of a child or teen.[58,60]

Distress from bereavement can manifest itself in many ways – physically, emotionally, spiritually, and mentally/cognitively and socially. Reactions can appear intense but be healthy and normal. Understanding the grief process well, what grief can look like and the wide variety of possible reactions is crucial to be able to make effective assessments.

Distinguishing between depression and grief can be particularly difficult. It has been increasingly recognised that some people may experience both simultaneously. A valuable table adapted from the Victoria Hospice Society is included within the Toolkit to assist clinicians in differentiating between grief and depression.

An assessment tool for identifying prolonged and complicated grief risk can be used to assist in providing an objective assessment of need.[17,61,62] For those previously assessed at risk of prolonged and complicated grief (prior to, or at the time of death), follow-up must be provided. This may, for example be in the form of one or more phone calls at particular time frames following the death to monitor/re-assess how the person is coping. This contact may provide evidence that additional support is required. Alternatively, it may be more appropriate to make a referral to another (bereavement) service for follow-up.

It is important to be aware that those experiencing prolonged and intense grief may present to a variety of different health professionals or organisations in the months to years following the death. As bereavement is a unique process which is highly variable, unpredictable, and influenced by many factors, General Practitioners may be particularly well placed to assess those who present with elevated bereavement distress. They can then refer them for specialist support, if required.

For those identified as having prolonged or complicated grief there are a number of emerging research-informed therapies that may be helpful both for use prior to and after the loss. These therapies assist in making meaning, are often family focused and are delivered by mental health and grief support professionals.[63]

Research into components of best practice in palliative bereavement assessment and care will continue to provide new information. Attention to new developments in the field is essential and an ongoing task for bereavement service professionals in palliative care.[20]

Evidence:

9, 15, 17, 18, 48, 61, 62, 63, 64, 65, 66

Resources:

Guidelines for the use of assessment tools are available in the Toolkit. Contact details for organisations available to assist with various levels of grief, including prolonged and complicated grief, are also included.

Organisational Responsibilities Are Met

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

Organisations have a responsibility to support health professionals in their bereavement care work by providing professional development, education and resources.

It has been recognised that "professionals are often not adept at addressing, predicting and responding to families' and carers' bereavement needs, both before and after death"(p. 157).[9,27] Health professionals, and volunteers, need to receive appropriate training and education to enhance their bereavement support skills and grief process knowledge. Through policy and professional development, organisations need to intentionally facilitate effective training so staff have the skills and knowledge to respond effectively to those bereaved, and to readily identify and respond to those at risk of developing, or who have developed, prolonged and complicated grief.

Health professionals providing palliative care come from a variety of clinical backgrounds, usually with differing educational preparation in bereavement work. Ongoing professional development is essential for health professionals if they are to be effective in providing appropriate support.

For example, it has been noted earlier how vital effective communication is, but it can be challenging and requires knowledge, skill and practice. Where communication skills training is provided for health professionals, confidence, engagement in conversations and the experience of bereaved families has been improved.[67]

There are a number of practical protocols that can be used by health professionals to improve communication skills. For example, Buckman's six skills which include: setting, perception, invitation, knowledge, emotions, strategy and summary, known as SPIKES.[67] However, like all clinical interventions, effective communication requires motivation and practice for success, along with organisational investment.[68]

There is currently no accredited or quality assured bereavement support training programme available for interdisciplinary teams in the MDHB. However, there are professional development courses available through the specialist palliative care services from time to time. Organisations could consider supporting staff to access these courses and other training and education opportunities, such as those offered by Skylight (www.skylight.org.nz).

8. Employers have a plan to support bereaved staff

Organisations have an important role to play in nurturing and supporting their staff's wellbeing, including those who employ health professionals. They now have an obligation under the Health and Safety legislation to ensure workplace environments are safe and healthy. However, often managers are ill-prepared to adequately understand and support grieving employees.[69]

There is a cost to caring.[70] Professionals who care for the dying and bereaved individuals also need to be sensitive to their own risks for physical, psychosocial, psychological and physical difficulties in response to their work. They may experience grief reactions related to the death of those they have cared for. Health care professionals regularly working with death and dying are more at risk of experiencing compassion fatigue, post-traumatic stress symptoms and burnout.

"Staff manage the care [of the dying] as a component of their usual day in the ward. If emotionally upset, peers support each other [while carrying on] with usual workloads... However some have become numb to it [care of the dying]".

Aged care staff

The impact of employee grief on a workplace can manifest itself at individual, team and organisational level. Symptoms such as fatigue, lack of concentration or ongoing emotional distress can have a negative effect on work life.[71] Resources for supporting those who are grieving within an organisation can be found in the Resource Toolkit.

Organisations need to provide ongoing support for their health professionals. Workplaces need to have a plan for responding to grief when it occurs among employees to ensure safe clinical practice and reduce staff burnout.

Elements of a plan could include:

- Acknowledgement of loss and grief when it occurs.
- A variety of rituals that allow diverse staff to acknowledge deaths within their workplace.[59,70,72,73]
- Strong social and collegial supports in place, such as time to talk together.
- Opportunities for debriefing, which allows staff to reflect on death related events that have occurred and their meaning (personally and/or as a team) and to identify possible areas for improvement. Organisations should use debriefing wisely with grieving staff. Their grief support is the first priority. However, a debriefing could serve also as a learning tool, leading to needed quality improvement. This could bring positive change and increased support for those grieving in the workplace in the future.[74]
- Clinical supervision for clinical staff. Evidence suggests that individual and/or peer Clinical Supervision provides support and stress relief for health professional staff as well a means of promoting professional accountability and skill and knowledge development.[75,76]
- Regular professional development provide end of life care and grief awareness.
- Access to employee assistance programmes.
- Actions that show staff they and their work is valued by the organisation.

Evidence:

53, 59, 65, 66, 67, 69, 70, 71, 72, 73, 74, 75, 76, 77

Resources:

The Resource Toolkit provides a list of professional development opportunities on bereavement and grief available in MDHB and online. Information is also provided on the protocol for breaking bad news, SPIKES, which describes a six step process for health professionals to support and aid communication.

Section 4
Implementation

Who Should Use the Guidelines?

The Guidelines are designed to be used by health care professionals working in the MDHB who care for the families, whānau and friends of people who are dying. The Guidelines will inform service design and delivery in MDHB.

The Guidelines are readily available throughout MidCentral DHB on several websites:

www.midcentraldhb.govt.nz/Publications/AllPublications

www.arohanuihospice.org.nz/useful-links/resources

Benefits and Expected Positive Outcomes in Using the Guidelines

- Raising awareness and normalising grief.
- Recognition of resilience.
- Promoting safe and effective bereavement care.
- Reducing poor health outcomes.
- Improved communication.
- Information and resources.
- Increasing knowledge and skills.
- Equitable access to support if needed.
- Working together.
- Promoting bereavement care as a wider responsibility.
- Promoting resilience and autonomy.

"Death ends a life, but it does not end a relationship, which struggles on in the survivor's mind toward some final resolution, some clear meaning, which it perhaps never finds".

Robert Anderson[78]

How to Put the Palliative Care Bereavement Support Guidelines into Practice

The Guidelines have been developed to be used as a 'best practice' reference for palliative care clinicians and services. They represent both an ideal and a pragmatic approach to bereavement support in all settings providing palliative care.

It is intended that these Guidelines will inform health professionals about the normal bereavement grief process, the range of common reactions, ways of supporting those grieving, and the importance of identifying and following up on those whose grief reactions indicate they need extra support.

These Guidelines will stimulate reflection within the health service on the process and provision of bereavement support. They will empower health professionals to work more effectively with bereaved family, whānau and friends.

Clinical guidelines, whilst rigorously developed, are only one option for improving quality of care. Individual circumstances, clinical judgment, previous experience and personal choice must also be taken into consideration and may result in appropriate variations from the guidelines. They are not a substitute for accurate diagnosis, considered treatment or support decisions or the provision of advice by an appropriate health professional.

Each organisation wishing to adopt the guidelines will need to align them with their policies and procedures. There may be aspects of the guidelines which organisations are already completing, for example, providing written information to family, whānau and friends on the grief experience and how to access further support, if needed.

The following stepped approach can be used as a prompt for organisations wishing to implement the guidelines. A resource toolkit is available with a range of content that may be useful in implementation of the guidelines. A flow diagram listing the guidelines and associated resources is on page 41.

These resources are available on www.midcentraldhb.govt.nz/Publications/AllPublications

Implementing the Palliative Care Bereavement Support Guidelines

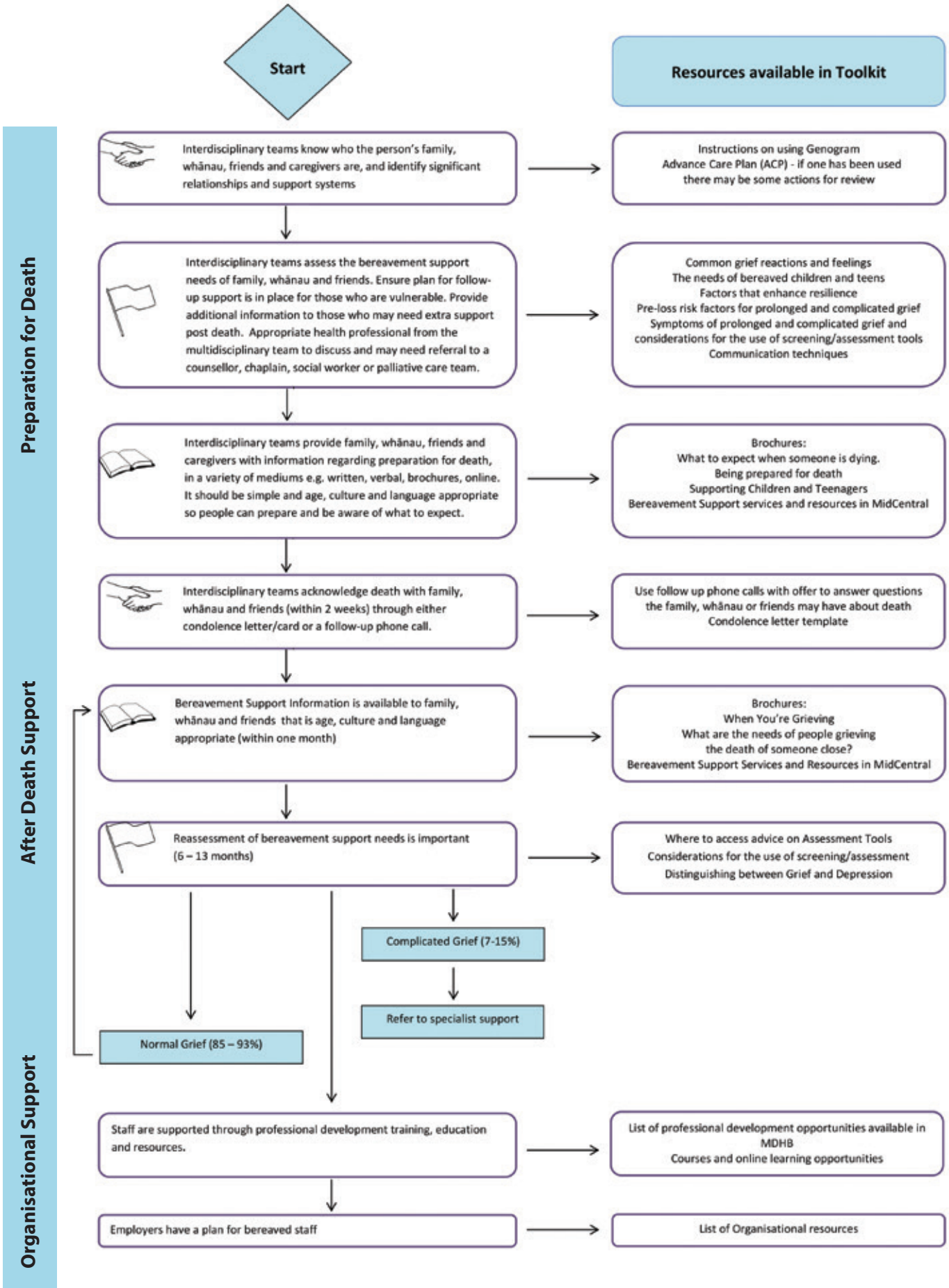
		Guideline	*Action for Health Professional*	*Key Decisions for Organisational*
PRE DEATH	Guideline 1	Interdisciplinary teams know who the person's family, whānau, friends and caregivers are, and identify significant relationships and support systems	• Document family and significant relationships and contact details	• 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	• 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	• 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 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	• 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)	• 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

		Guideline	*Action for Health Professional*	*Key Decisions for Organisational*
AT TIME OF DEATH	Guideline 4	Interdisciplinary teams acknowledge death with family, whānau and friends (within two weeks)	• Contact main carer or key family members, whanau or friends either by phone or using a condolence letter or card. Family, whānau, friends or carer may have questions around the death that a health professional can follow up on	• 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)	• Give appropriate written information and brochures such as What to Expect When You Are Grieving, Bereavement Resources and Support Services	• 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)	• 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	• 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 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	• 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	• 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



Glossary

Anticipatory Grief

Anticipatory grief occurs before an expected death, and may be experienced by both the dying person and their loved ones. Anticipatory grief often involves experiencing many of the same emotional, physical, mental, social and spiritual reactions that grief after a death involves, but it is also unique and marked by a sense of waiting, being on alert and missed emotions.[14]

Bereavement

The period after a loss during which grief is experienced and mourning occurs. Although there can be similarities in people's responses, there are also marked differences. Each person will grieve and recover in their own way and in their own time. [79]

Prolonged and Complicated Grief

Describes a mix of grief reactions that continue in intensity, or even increases in intensity, over the months in which some form of adjustment is normally expected, and to an extent that is significantly disruptive to a person's life. A key indicator is ongoing yearning for the person who has died.[22]

Grief

Describes the normal process experienced after significant loss which enables a person to gradually adjust to the reality of the loss, experience the pain of the loss and be able to move forward. It has a multidimensional impact on a person's life, with a wide range of possible reactions affecting them emotionally, physically, mentally/cognitively, socially and spiritually.

Mourning

Describes a behavioural and cultural response to bereavement grief, including participation in rituals and customs. It is the outward expression of grief.

Palliative Care

Care for people of all ages with a life-limiting illness which aims to:

1. Optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.
2. Support the individual's family, whānau, and other caregivers where needed, through the illness and after death.

Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quality of life. It should be available wherever the person may be.

It should be provided by all heath care professionals, supported when necessary by specialist palliative care services.

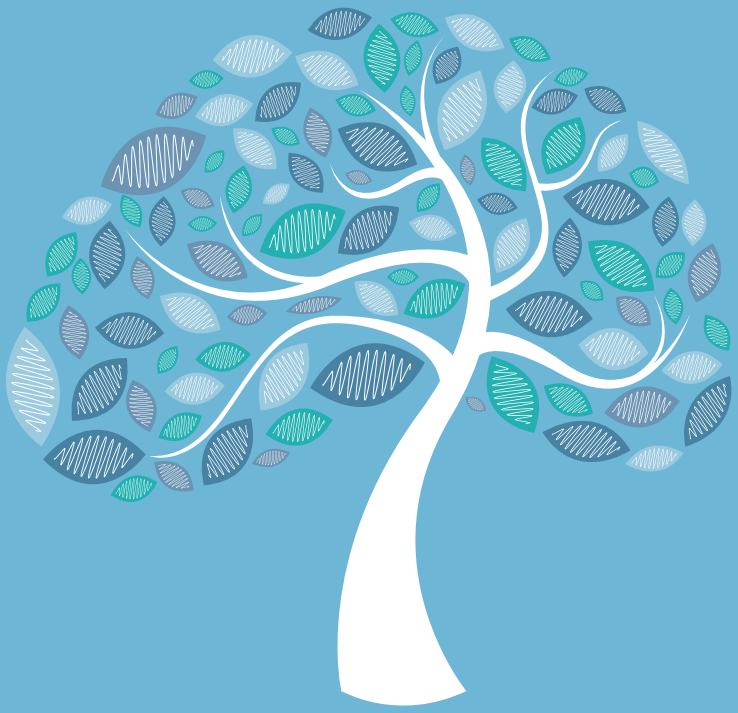
Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Maori, children and young people, immigrants, refugees, and those in isolated communities.[50]

Primary Palliative Care

Primary palliative care is provided by all individuals and organisations that deliver palliative care as a component of their service, but their substantive work is not in the care of people who are dying. It is palliative care provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice and by a healthcare professional who is not part of a specialist palliative care team.

In the context of end of life care, a primary palliative care provider is the principal medical, nursing or allied health professional who undertakes an ongoing role in the care of patients with a life-limiting or life-threatening condition. A primary palliative care provider may have a broad health focus or be specialised in a particular field of medicine. Care is provided in the community by general practice teams, Maori health providers, allied health teams, district nurses, and residential care staff etc. It is provided in hospitals by general ward staff, as well as disease specific teams, for instance oncology, respiratory, renal and cardiac teams.

Primary palliative care providers assess and refer patients to specialist palliative care services when the patient's needs exceed their services capability.[79]



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Appendices

Appendix 1

Working Group		
Member	*Title*	*Organisation*
Reverend Sande Ramage	**Chaplain, Palmerston North Hospital**	Interchurch Council for Hospital Chaplaincy (ICHC)
Dr Simon Allan	**Director of Palliative Care**	Arohanui Hospice
Kate McKenzie	**Reg. Social Worker, Family Support Team Leader and Bereavement Support Coordinator**	Arohanui Hospice
Maria Berrett	**Senior Clinical Psychologist/Coordinator of Health and Cancer Psycho-oncology Services**	Massey University, Palmerston North
Lee Hefford	**Reg. Social Worker**	MidCentral District Health Board
Graham Black (resigned due to change in role)	**Mental Health Team**	Tararua, Central Primary Health Organisation
Bridget Marshall	**Palliative Care Network Coordinator**	MidCentral District Health Board

Palliative Care District Group	
Member	*Organisation*
Dr Simon Allan	Arohanui Hospice
Anna Blackwell	Manager, Ranfurly Manor
Denise White	MidCentral DHB
Adele Berquist	Whānau Ora Systems Navigator
Kare Iraia	Maori Perspectives
Monique Hayes	Somerset
Nicki Twigge	Arohanui Hospice
Dr Paul Cooper	Central PHO
Dr Jean Clark	MidCentral DHB
Gaye Fell	Community Representative
Jo Smith	MDHB Senior Portfolio Manager
Lee Hefford	Social Worker MDHB
Clare Randall	Arohanui Hospice
Faye Davenport	UCOL Polytechnic

Appendix 2

How Were the Guidelines Developed?

Review of Literature

A literature review was conducted using the following search terms: bereavement, bereavement support, bereavement support guidelines. The selection period was for the five year period: 2008–2014. As there were so few articles identified from New Zealand the search period for New Zealand literature was extended and articles were included for the period 2004–2014.

The databases used for the search were accessed through Ebsco Host which hosts Medline, CINAHL, Psychology & Behavioural Sciences Collection and Health Business Elite databases.

- Medline –1965 to present (some full text available)
- CINAHL – (Nursing & Allied Health) – 1937 to present (some full text available)
- Psychology & Behavioural Sciences Collection – provides approx. 575 full text publications. Covers topics such as psychiatry, psychology, mental processes.
- Health Business Elite – contains approx. 450 full text journals on health business management.

Included papers were English language journal articles within the search periods. This approach was supplemented by checking the reference list of each of the identified papers. Review papers, editorials and commentaries were included and due to so few articles and studies from New Zealand, NZ theses were also included.

Evidence and Guideline Recommendation Grading System Used for Guideline Development

The Bereavement Guideline development team agreed to rank the evidence according to the revised system of the Scottish Intercollegiate Guidelines Network (SIGN).[80]

Levels of Evidence		
	1++	High quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias
	1+	Well conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias
	1-	Well conducted meta-analyses, systematic reviews of RCTs, or RCTs with a high risk of bias
	2++	High quality systematic reviews of case-control or cohort or cohort studies with a very low risk of confounding, bias, or chance and a high probability that the relationship is causal
	2+	Well conducted case control or cohort studies with a low risk of confounding bias, or chance and a moderate probability that the relationship is causal
	2-	Case control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal
	3	Non-analytic studies, e.g. case reports, case series.
	4	Expert opinion

Critical Appraisal of Included Studies

The majority of the studies employed a descriptive qualitative design. Twelve used questionnaires or surveys (the majority using non validated scales). Eight used interviews or focus groups and an additional seven used both methods.

In addition, two studies used randomised controlled trials while 11 used descriptive studies by experts.

A subcommittee of the working group reviewed the quality of the evidence and its relevance and applicability to the Guidelines within the NZ context. Consideration was given to the relative strengths and weaknesses of the gathered evidence. Using clinical expertise, the subcommittee members determined the level of recommendation to be assigned each item of evidence after first assessing its strength and generalisability. Although research provides the basis for examining the evidence, it is recognised that research is not the single determinant of use of evidence in practice. The aim of this process was to be explicit and transparent regarding the use of clinical expertise in the final determination of the level of recommendation.

These Guidelines and the Toolkit can be found at www.midcentraldhb.govt.nz/Publications/AllPublications

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