



BEREAVEMENT SUPPORT ACROSS CULTURES



A Resource for Health Professionals

Calvary Bereavement
Counselling Service

In the tradition of the sisters of The Little Company of Mary

Introduction

The literature review conducted for this project identified a lack of easily available material for health professionals about how to support bereaved people from a range of cultural and religious backgrounds. There was clearly a need for an accessible resource that integrates the principles and practice of cultural competence with information about bereavement support.

Multiculturalism in Australia is here to stay, and cultural competency therefore needs to be embedded in our work as health professionals. In particular, Australia's ageing CALD population indicates a need for us to be better informed and educated about grief and bereavement support. The Australian Institute of Health and Ageing predicted that in 2011, 1 in 5 people aged 80 or more will be from a CALD background. By 2026 the number is predicted to grow by 321%, compared to a 90% growth rate for the Australian-born population. It is not just the aged who are affected by death, grief and bereavement of course, but those at all life stages.

For those who work in South East Sydney Local Health District the practice of diversity health is particularly relevant because 25% of its residents are born overseas. The main language groups in the area are currently Arabic, Chinese, Greek, Italian, and Macedonian, with growing groups being Chinese, South African, Indian, South Korean and Vietnamese. The range and diversity of groups is expected to increase. An understanding of the needs of bereaved people across cultures is therefore central to providing a better service in the area.

The aim of this resource is to fill the gap identified by the literature review: to provide health care workers with an understanding of how to apply the principles of cultural

competency in their work with bereaved people across cultures, enabling them to better support their patients and clients.

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Megan Wynne-Jones, October 2012



Overview of content

The resource has been divided into four sections. Section 1 outlines the core principles of cultural competence, and describes how they might be embedded in our work. Section 2 provides general information about what might be expected in grief and bereavement, and the importance of exploring its context for the individual. Section 3 explores ideas and meanings of spirituality and religion, and their relevance to the bereaved person, with an emphasis on the importance of ritual. Section 4 provides a summary of the content and a list of resources that may be useful when working with bereaved people across cultures.

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Section 1: Cultural Competence

Australia is one of the most culturally and linguistically diverse countries in the world and increasingly so. 45% of the population were born overseas or have at least one parent who was. Hundreds of languages other than English are spoken here, and most of the world's religions are practiced.

An awareness and understanding of cultural diversity therefore needs to be embedded in our core work. This section describes the key terms and explores how the principles of cultural competence can be put into practice in a health setting.

What is cultural diversity?

Diversity can be described as all the ways in which we are unique and different from others. It encompasses issues of language and cultural background as well as other factors such as age, (dis) ability, sexual orientation, health status, and socio-economic status. This resource focuses on understanding and working with diversity as it relates to a person's country of origin and their first language.

It's important to understand that cultural diversity is not static and fixed but is fluid in nature. Beliefs, practices and behaviours change over time and between individuals, depending on a number of factors. Everyone has their own unique cultural background, which may also change over a person's lifetime as they learn from and are influenced by what they experience.

This paradox is at the heart of working with cultural diversity: we may know something about a person's cultural context, and need to respect and acknowledge that, whilst also putting that knowledge aside and finding out what that individual person needs at that particular point in time:

“ When I asked the person who had written ‘ Egyptian’ on his form ‘can you tell me more about your family ?’ he told me that he had been born in Egypt to an Italian mother and Lebanese father, and migrated to Australia when he was young. He had been brought up by his grandmother who was Italian, so that was his first language. His father had adopted the Coptic faith in Egypt, but converted to Catholicism when he got married. He himself had no particular faith, he said. If I hadn’t asked the question, I might have made all sorts of wrong assumptions about his background, language and religion. From there, we were able to explore how I could best help him in his bereavement. ”

Social worker

As health care providers, like our patients, we have our own cultural background too, which will have an impact on the way we work. We need to be aware of how our own culture influences the way we perceive, think and behave, and the effect this might have on our patients or those we work with. It’s important not to make assumptions, either about patients or colleagues:

“ Although I’m of Aboriginal descent, I’ve chosen not to identify as Aboriginal, and I’m not dark-skinned. Most people at work don’t know about my background, and they’d probably assume I was Anglo. But it does affect who I am, how I behave, how I respond ..I was very deeply affected by the apology from Kevin Rudd, for example, which we watched on TV at work. I just couldn’t stop crying. Others were moved too, but it was obviously particularly meaningful for me. My colleagues wouldn’t have known that, though. “

Bereavement counsellor



What is cultural competence?

‘Cultural competence is a set of congruent behaviours, attitudes and policies that come together in a system, agency or among professionals; enabling that system, agency or those professionals to work effectively in cross-cultural situations.’ (Cross et al, 1989).

Cultural competence has a broader meaning than commonly used terms such as ‘appropriateness’, ‘sensitivity’ or ‘awareness.’ It is a holistic and systemic response to cultural diversity, an organisation-wide approach that provides a framework for integrating culture into how we deliver services. A culturally competent organisation acknowledges and values the diversity between and within cultures, and is able, all the way through the organisation, to adapt its services to reflect this understanding.

“ Years ago I worked for this amazing little community centre who were quite forward thinking in their approach to reaching CALD communities... They developed and maintained strong relationships with local religious and community leaders from CALD backgrounds, and organised cultural awareness training in partnership with neighbouring service providers. They had welcome signs on display in languages other than English, and used translated consumer evaluation feedback forms. They facilitated cultural exchange days and recruited bilingual volunteers and paid staff who were reflective of the local demographic. “

Multicultural project officer

As individuals within a culturally competent organisation or system, we need to develop and use particular skills and behaviours, outlined below, in order to respond to those we work with.

Why is it important when we are working with people?

Culture is universally applicable. Culture applies to all patients and all staff, and is a key determinant of health outcomes.

Cultural competence helps to ensure equitable access to health services. It recognises that each patient is different and each encounter is a unique event requiring a unique response.

How can we be ‘culturally competent’?

The provision of quality patient-centred care is based on the principle that patients and their families are treated as partners in their own health-care management, rather than as passive recipients of treatment. Information is shared so that the patient has a real voice and can make an informed choice. The whole person is considered in order to facilitate this shared response to health-care.

The way we relate to and communicate with others is central to providing person-centred, culturally competent care. Good communication depends on self-awareness, so it’s important to examine our own beliefs and biases, which may be derived from our culture of origin, from our professional training, or from the culture of our workplace:

“ When I read the words ‘appropriately distressed’ describing how a family member is behaving at the time of the loved one’s death, I wonder what this really means. For whom is the distress appropriate? For the workers themselves, or for the person? According to what cultural norm? ”

Bereavement counsellor



The development of cultural competence is an ongoing process of learning and adjusting, just as culture itself is something that is evolving and changing. We don't need to know everything about a person's culture in order to help them. More important than knowledge, is our willingness to listen, to be interested, open and non-judgmental.

It helps to acknowledge that the patient and their family are the greatest source of knowledge about themselves. We don't know more than they do, but we are willing to collaborate with them and with other workers so that we can respond to their *individual* needs:

“ When a Jewish patient died in the hospital, all the nurses were running around in a flap thinking they had to quickly help the family organise things in the Jewish way. I said, hold on, has anyone actually asked them what they would like to happen? It turned out they weren't wanting a strictly Jewish funeral. “

Former nurse

With all patients, we use our curiosity and sensitivity as we listen, allowing the person to express feelings and thoughts without judgement. We respond empathetically and ask open-ended questions. We need to do this for everyone, regardless of his or her cultural background.

In particular, when we are working with CALD patients, we use interpreters and translated materials, when needed. Communication cards or cue cards can also be useful. We attempt to understand and appreciate the patient's background. This includes their family, their experience in their country of origin, and how they came to live in Australia. Although migration may have been a choice it is likely to have been a difficult experience for some.

Refugees in particular are likely to have experienced severe hardship and trauma, which may affect every aspect of their life:

“ A patient from Thailand who was dying was telling me about her experiences as a refugee. She had come to Australia on a boat with 90 people on board, most had died on the way. She’d been attacked and sexually assaulted by pirates on the journey. I too was a refugee and had some terrible experiences. I think that’s why she trusted me to talk to. She hadn’t told many people. “

Pastoral care worker



“ I’d been seeing a person from Lebanon for quite a while before I thought to ask him more about how he came to be in Australia. It was then that he started telling me about his experience of living through war. I realised how this was having an impact on his current grief. I wished I’d asked the question before. It might have been more helpful for him. “

Bereavement counsellor

As well as asking questions sensitively, it’s also helpful to be aware of non-verbal cues such as items of dress, without making assumptions. This might help us to be aware of what a person may need.

Adherence to traditional cultural practices and customs varies widely depending on many different factors including age and gender, whether the person is from a rural or urban background, whether he or she is religious or not. For Chinese people for example, practices and behaviours may be based on

a mixture of beliefs, superstitions, folklore and religions, (Buddhist, Confucianism, Taoist, Christian). Knowing there are great variations in adherence to culture we enquire about the person's own individual values, preferences and beliefs:

“ I was aware that for Aboriginal people it can be important not to use the name of the deceased, and I also knew it was important to check this. So I asked the family what they wanted, and they said they wanted to use her name, they wanted to keep her alive. In fact they all had different names for her, and each of them respected the other's name when they talked about her. I tried to do the same. I was really glad I'd asked. I think it made a difference to them. “

Bereavement counsellor



Section 2: Grief and Bereavement

This section provides general information about grief and bereavement: how it may affect us personally, what commonalities across cultures there may be, the context of the bereavement, and what we might expect to see in a bereaved person over a period of time.

Firstly it's important to acknowledge that as health care workers our own grief and loss experiences or issues may be activated when working with bereaved people. Feeling emotionally stirred is a normal response to a distressing situation, and can help us feel empathy for the patient, but there may be a danger that it prevents us from being effective in our work:

"I'd had a miscarriage and had come back to work the day after. My colleagues didn't know I was pregnant so it was hard to tell them what had happened, but I did, and it was agreed I wouldn't work with clients where there had been a neo-natal death. I saw a new client that day whose husband had died, but as it turned out she had also lost a baby some time ago shortly after delivery, and wanted to talk about this. I found it very hard to stay present for her. I realised how vulnerable I was and that I needed more time to deal with my own loss. It's important to do this because you can't prepare for everything and emotional triggers for grief can come unexpectedly, from anywhere. "

Bereavement counsellor

Self-care is important. We need to be aware of our responses to the grief and loss we see in others and to seek help from our colleagues, manager, employee counsellor or supervisor. One hospital, for example, facilitates rituals for staff to honour the death of a patient:

"If a particular death has affected us deeply, it can help to do a ritual in order to acknowledge the impact it's had. "

Pastoral care manager

Are there commonalities across cultures?

While acknowledging that individual beliefs and attitudes can vary enormously, in most cultures and religions death is seen as a transition for the soul, spirit or consciousness of a person. How a person prepares themselves for death and how the survivors behave after a death varies extensively between cultures, but sadness -expressed through crying- as well as fear and anger are extremely common across all cultures. Mostly the public expression of these emotions is sanctioned through rituals of different kinds. (as discussed in section 3).

What happens and who is involved at the time of death may have a significant impact on the bereaved person and how they grieve. For most cultures a 'good death' is important. What this constitutes may vary however, so it's important to ask:

“ My great-uncle died in his sleep at home when he was 84. People regarded this as a good death because he died of a natural cause, he wasn't in pain and his four sons, eight grand-sons and four great grand-sons were there. Having extended family present is important, particularly males, the more generations the better. He lived with his eldest son's family, and all the other family members lived in the same suburb and visited him often. He was a retired board director of a local primary school and served long term as a village leader. Over 1000 people attended his funeral including local government officers. He was well-respected and honoured. A big banquet was also organised after the funeral. After the banquet, people were expected not to mourn because it was over and it was a good death. “

Chinese bereaved

There may be a particular aspect of the death that is difficult for the bereaved person to accept, and this can have a significant impact on the grieving experience, possibly prolonging and complicating it:

“ Although I’d spent every day in the hospital for weeks when she was ill, and though I was there in the room when she died, all the family were, I’d fallen asleep in my chair when she took her last breath. I’m finding it hard to forgive myself. I wanted to be there, holding her hand, looking into her eyes. “

Anglo/Australian bereaved

Most religions have specific rituals that are practised at the time of death (Refer to Section 3). The wishes of a dying person regarding the use of ritual may sometimes be different from a family member’s wishes. This can have an impact on the bereavement:

“ In Catholicism, anointing is very important. It’s a sign of the cross made with oil or holy water on the forehead and the hands, with prayers, a blessing from a priest. It happens 3 times in your life, once at baptism, once at confirmation and once at death, and it symbolises a commitment to your faith. Anointing is like the presence of God, walking with you into paradise. Traditionally in Catholic beliefs if you’re not anointed, you wouldn’t go to heaven, you’d burn in hell. But there may be differences between what the dying person wants and what the family wants. We always try to do what the dying person wants. There was a young woman who was dying and her brother wanted her to be anointed but she had told us she didn’t want to be. Her brother had a great fear that his sister wouldn’t go to heaven if she wasn’t anointed, and this would have really affected his grieving. Not doing what she wanted might also have affected him badly too. So I had to try and find a way to help him feel at peace with his sister dying without having been anointed. “



The context of the bereavement

What sort of relationship was it?

In addition to cultural differences there are many other factors that affect how a person grieves. Perhaps the most important is the nature of the relationship with the person who died, its degree of intensity and how central it was for the bereaved person. We need to explore this by asking questions sensitively, and not make assumptions. 'How close were you to the person who died?' or 'What did that person mean to you?'

For some Aboriginal people for example, the death of an aunty or cousin may be as great a loss as that of a parent or sibling. We might assume that the loss of a partner of 50 years will be more distressing than the loss of a neighbour or a pet, but this may not be the case. How a person copes in bereavement may also be affected by the degree of inner strength and security they are able to draw on, usually developed through the experience of safe and securely loving relationships in childhood.

What were the circumstances of the death?

The circumstances surrounding the death may have a significant impact on the bereavement experience. If the death was sudden for example there may not have been a chance to say good-bye, and feelings of shock and disbelief may linger for a considerable length of time.

If it was an expected death after a long illness, there may still be shock and disbelief, or relief. Also the carer may have become isolated over the course of the illness and might need extra support:

"I just stopped going out while I was caring for Mum. It was too hard to do it together and anyway I wanted to be with her. But I've lost touch with many of my friends now, and it's been years since I've worked, so I wouldn't know what to do. I've lost confidence. I don't know who I am anymore."

Bereaved carer

Sensitive exploration of the circumstances of the death will help in understanding the experience of a bereaved person and how they are responding. If their loved one died young, this may affect them differently than losing someone who lived out a long life, for example.

Where the person died may also affect the bereavement. A death at home may have a very different impact on bereavement than one that happened as the result of an accident or in hospital for example. When the death happens overseas, as is common for many migrants, the ramifications can be extensive:

“The bereaved have to make difficult decisions about getting to see the deceased before they die, which has an element of crisis and trauma to it. If the bereaved don't get there, there is often regret and guilt about not contributing to the care and/or missing out on opportunity for goodbyes. There may also be a sense of the unreality of the death, because there are not the usual grief triggers to be encountered on a daily basis, so the deceased can be thought of as still just a phone call away. There is a lack of the usual supports available in terms of other mourners, who knew and can talk about the deceased. There are also not the rituals (funeral, remembrance days, attending the cemetery) for grief expression, which severely hampers the grief process. It is often not until the bereaved return to their homeland that some of this real grief gets underway. This can be a very delayed and complex grief, depending on the time lapse.”

What kind of social support do they have?

The type of social support a person receives will also have an impact on the bereavement. In most cultures family and community support through bereavement is very important:

“ We put a note on the shop window and said “You’re all welcome” (to the funeral)....It’s been wonderful because our whole community has been involved. I spent probably the first three or four months only in our community. I didn’t feel strong enough to move outside. Because I knew everyone knew who I was and so I didn’t have to explain myself to anybody. Didn’t have to fear anything...”

Julia Bianco, Insight, SBS

“ The community generally takes care of a person in grief. They don’t have to be as involved in everyday life. “

Aboriginal health worker

But the extensive time and energy involved in providing this support means that it may be lessening in some cultures. It’s important therefore not to assume that a person from a particular culture will necessarily have extensive support:

“ In Lebanon support from family, neighbours and community is very important. For around 6 months, the bereaved person is never left alone. I think this happens less in Australia, because people are busy and there is less time. “

Lebanese support worker

In addition, cultural expectations to provide ongoing support can create difficulties for the bereaved person:

“ Although I wanted to do it, it was stressful and tiring having to organise all the rituals at the cemetery, after my mother died. In the first year there are five separate ones to arrange. Also it’s expensive – the priest has to be paid and special food made for everyone It’s not just a few people, it can be many. “

Macedonian bereaved

It's important to take into account where the patient gets support. Is it from family, close friends, neighbours, a religious or spiritual community? Are they aware of the professional supports available for a bereaved person?

Losses, which aren't acknowledged by others, for example if the relationship was hidden or not socially sanctioned, can, create particularly complex bereavement. 'Disenfranchised' grief may mean a heightened sense of isolation and distress for the bereaved person:

"One woman I was seeing had been having a long-term relationship with a married man, and although his wife knew about it, this woman had chosen not to tell her own friends or family. They believed he was just a friend. When he became ill and died, she was naturally grief-stricken. But there was a lot of confusion from others about why she was so distressed and needed a lot of time off work for example, because people weren't aware of their relationship. "

Bereavement counsellor

Sometimes too there is the possibility of being ostracised because of the nature of the death. Suicide in particular can leave a bereaved person feeling stigmatised and isolated:



"My friends avoided me after the suicide of my sister because they believed it was bad luck. This made me feel very lonely. "

Japanese bereaved

How might the gender of the bereaved person affect the bereavement?

Differences in the way males and females behave can vary between individuals, within cultures and can depend on the time since the loss. Current bereavement theory suggests that 'masculine style' grievers are more likely to express their grief in an active way by doing things, for example building or making something, starting a campaign, or writing a book. 'Feminine style' grievers are more likely to show their emotion and share it with others. But immediately after the loss of a family member for a Greek or Lebanese family for example, it's accepted that men will wail and cry together with the women. The examples below show that the way men grieve may be changing, and remind us again of the importance of not making assumptions.



" I think it's becoming more socially acceptable for Anglo men to show emotion. They don't hold back as much as they used to. They might still feel a bit embarrassed, but they will cry when someone they love dies..."

" Traditionally men would go walkabout. But now, there's not much difference between the way men and women grieve "

Aboriginal health worker

" In Vietnamese culture, the men would usually be quiet in their grief on their own, but they would talk about it when they get together with other men. "

Pastoral care worker

How will other losses affect bereavement?

Any previous losses will probably affect how a person grieves, and may compound the effect of the additional loss:

“ My husband died ten years ago and I had three young children to look after. I just had to get on with things. Then, last year, both my parents died. I feel as if all the grief is rolled into one. I’m just not coping.”

Anglo/Australian bereaved

It’s also important to take into account how cultural losses can affect the experience of grief. Many Aboriginal people have suffered the loss of their land, culture, language and family, which may be experienced both personally and collectively:

“ Seeing a loved one die in a hospital in the ‘white system’ may bring up grief about the loss of their own culture. “

Multicultural health worker

Ancestral grief, childhood grief, and migration grief may have a big impact on any additional loss. A sensitive exploration of a person’s background might help us understand how to help them better.

The loss of homeland is a significant factor for many Australian migrants:

“ For many Greek people migration is referred to as ‘xenitia’. The experience has strong connotations of bitterness, grief and enforced separation. This is on top of longing for the homeland and loved ones left behind. Often there is the intention of one day returning to the homeland. “

Greek welfare worker

“When both my parents died, I felt the loss of my link to home as well as losing them. I had to try and find ways to keep that connection with my home and culture.”

Italian bereaved

The refugee experience of loss of homeland and family, together with trauma of war, may have a significant impact on how a person grieves:

“People from Vietnam have been through war and seen many deaths, and had to escape their country. It affects how you grieve. In 1975 I was 5 years old when I saw terrible things. Later, when I was 12 there was a terrible storm that destroyed my whole village, and I saw bodies floating in the water, but I didn’t feel anything. I was numb. It was later when I came to Australia and I was able to get help to talk about what I saw, that it changed.”

Pastoral care worker

The distress caused by a traumatic death such as war, suicide, murder, accident, or large-scale disaster can be prolonged and intense. There may be feelings of numbness, intense anger, frustration, anxiety, and a search for justice. In addition, there may be an element of trauma in deaths that occur at home or hospital, due to the nature of the illness or the manner of the death. Professional help in dealing with this is usually recommended.



What are the range of behaviours, feelings, and experiences of a bereaved person and over what time period?

A mixture of the individual's response to bereavement together with cultural influences and expectations may shape the grief experience. There is a broad range of behaviours and feelings that someone may experience for varying amounts of time. We need to be careful not to assume that grief should be 'over' after a certain period of time:

"As a culture we don't believe it's the end of a life. They're moving on to a new life. That mourning period is there, for as long as a person wants, but whether they choose to move on quickly or not is not looked down upon. My mum's still mourning my grandfather, and he died 13 years ago. It could last a lifetime."

Aboriginal health worker

Grief can be seen not so much as a linear process but as an oscillation between feelings of loss, and a movement towards acceptance and adaptation:

"I still feel sad about losing Dad, and I miss him every day, but it's Mum's 70th birthday coming up and I know he'd want us to celebrate for her, so we're planning to have a party."

Italian bereaved

Depending on the nature of the bond, it's usual that a person will feel a strong connection with the one they have lost and want to maintain this. Often this happens in a religious context through ritual (see Section 3) but people also find their own ways:

"I like to sit down and watch Mum's favourite TV program every week. Even though she's not there, it's as if she's there."

Anglo/Australian bereaved

The concept of phases through which a person passes in their grief is a development of 'Western' culture and thinking. These phases are approximate, fluid and overlapping, and may have no relevance to some cultures. They may however be useful as a guideline of what might be expected in bereavement. Again, the sensitive use of questions will be more helpful than an assumption made about a person based on how much time has elapsed since the loss.

Before an impending death and at the time of death

What is called 'anticipatory' grief may begin when a terminal illness is diagnosed or when significant deterioration in memory and functioning happens, as with Alzheimer's disease:

"...I believe my grief started all those years ago....when we made the decision to have chemo or not ...radiation or not. You know, being there virtually every day really and seeing her go through the process. Towards the end it was great, she had a peaceful death and we were all there.."

Amanda Narvo, Insight, SBS

For others however, this is not the case:

"I think you could say generally that many Asian people maintain hope for the dying person till the last moment. So they don't prepare for the death at all, and when it happens it is a shock, like a sudden death. There may be feelings of guilt or blame then, trying to explain why it happened. The emotions can be very raw and intense."

Pastoral care worker

“ Often the family of the dying person may hold back from giving their loved one the correct or complete medical information so as to protect the dying person and prevent further suffering. This is particularly true when the diagnosis is cancer, which is often referred to as ‘ un brutto male’ (a bad illness). Family and friends may...talk about things they will all do together when the patient is well enough to leave the hospital. It’s important that the patient is asked (via interpreters if required) how much information they would like to be given. “

Italian community worker

The time when a patient begins palliative care may also be of great importance as it can signify the transition from living with hope to an acceptance of the forthcoming death. The transfer of trust between treating team and the palliative care team has been demonstrated to assist this transition:

“ Grieving begins from the day the person is admitted to Calvary (palliative care hospital). “

Lebanese community worker

“ For traditional Greek families the period of dying is a time for family members to sacrifice even their own self care. There may be reluctance to accept professional help and this has a cultural basis. There is an entrenched expectation that the family – including extended family – will take care of the person’s needs.. Asking for help may imply that the family is unwilling or incapable, either of which do not reflect well on them.”

Greek welfare worker



In preparing for death, in many cultures there is a gathering of family, often in large numbers. Hospitals are not often equipped to support this way of being:

“Greek grief is loud. I have seen about twenty family members and friends in the waiting room and spilling into the corridor of the hospital ward waiting for the loved one to die. One middle-aged man is hitting his head against the wall, others are crying audibly; there appears to be no awareness that they are in a public place or that there are other patients in the ward.”

Greek welfare worker

“Within the Italian Catholic community the Last Rites is performed by a priest before the person dies, or sometimes after, and the recital of the Rosary. The immediate family are present for this. Extended family and friends may visit to pay their last respects. Some families may request that they dress the deceased or they may provide clothes for their loved one to be dressed in before leaving the hospital to go to the funeral home.”

Italian community worker

“In Anglo culture it seems that the closer to death the person is, the smaller the group, until it’s just the immediate family there. And they tend to show a lot less emotion.”

Pastoral care worker

Whilst it’s important to understand what families need at this time, accommodating these needs, may be difficult:

“There was a Samoan family here who brought in cauldrons of food to eat while their relative was dying. They took up almost all of the dining room, and we had to ask them to make room for other relatives of patients.”

Pastoral care worker

The need for family to honour the cultural or religious traditions of the person dying is important, but it may create considerable complexities for everyone involved in the care. This can be especially so when families are disconnected from country of origin:

“ My family are Hindu, of Brahmin background, with strict beliefs, and we’ve been living in Australia for 26 years. My father was in a coma for 3 weeks before he died, after a long illness. It was really hard because you’re not supposed to prepare for a person’s death before they have gone, but we needed to organise having a male present at the funeral. We believe that the eldest son should say the prayers for his father at the funeral. But in our case, we have no brother and my son was overseas and my young nephew was in the midst of preparing for his HSC exam. In India it wouldn’t have been a problem, there would be men around who could do it. We really needed help. We asked different priests what to do, and eventually we found one who said let the young grandson do it and then when the elder grandson comes from overseas he can take over the rest of the rituals. So my nephew did it. He had his HSC exams the very next day. It was traumatic for all of us, making these arrangements. But we were very happy at how the funeral went, it was according to my parents’ religious needs.”

Indian community worker

In summary, there are many times in the journey of living with a life limiting illness when people are confronted by the reality of an eventual death. The grief response to this has been termed “anticipatory grief”. There are many traditions and rituals that are important to people at the time of death and after death. People may also die alone, or with only one or two people present. Exploring what this might mean for the bereaved is important, without assuming anything based on knowledge of their culture.

Immediately after the death

Crying or not

Crying and wailing after the death is common behaviour in many cultures, and may be done in public or not:

“ The wailing sounds like screaming. It is loud and out of control. Both men and women do it, it is the only time you see men cry. It might go on for two or three days. Sometimes the bereaved will lose their voice, not eat or even not drink anything. Wailing also happens at the burial, louder than the first day.”

Lebanese community worker

“ In our hospital patients are moved to individual rooms when they are close to death, but this can't always happen. A Muslim patient died in a room with three other patients present and the whole community came. His wife was wailing and hitting herself. There were about 30 people there including children, and they couldn't fit in the room. It was quite overwhelming for the other patients, so I explained this to the community leader and he asked them to move to the hospital lounge room.”

Vietnamese pastoral care worker

“ In some Spanish speaking communities, crying is viewed as a healthy emotional response to a loss. Crying openly is seen as healthy. Grief is expressed openly and people offer support to each other through kisses and hugs. However for the Uruguayans for instance, grieving is covert and done on the inside. They may deal with the grieving process with less emotion than other Latin American communities.”

South American community worker.

“ The mourners cry out loud. It's very painful. You're mourning for the soul and you're getting it out of your system. But in the hospital that wouldn't be proper. We wouldn't want to disturb other patients. “

Indian community worker

“ Grief may be expressed quietly or openly by wailing or crying. Generally only the women will display open grief as men are expected to display composure. “

Italian community worker

Practices relating to the body

There may be specific practices observed by different cultures in relation to the body:

“ After a Buddhist patient died, his family didn’t want the body touched for 8 hours after his death. So the death couldn’t be certified straightaway. His body wasn’t left alone during that time. Other Buddhists haven’t requested that though. We needed to ask them what they wanted. Sometimes people aren’t sure.”

Pastoral care worker

“ There’s a belief that when a Muslim dies his or her soul remains close to the body, watching over it, observing the ritual of bathing and shrouding. Men wash the male body and females wash the female body. Then the corpse is embalmed and shrouded in white cotton cloths and buried as soon as possible.”

Multi-cultural health worker

For families of mixed cultural or religious backgrounds there may be particular difficulties associated with practices:

“ I know of a woman of Anglo background whose physically and mentally disabled son was in a relationship with a Muslim woman. When he died, the partner wanted him buried as a Muslim which was traumatic for the mother, because of the quickness of the removal of the body, and the women being kept separate at the mosque. She was extremely distraught and couldn’t attend the funeral. Later she held a memorial service for him, which helped. “

Bereavement counsellor



Shock and disbelief

Shock, denial, disbelief or numbness are all common responses to a death. This may look as if the person is unaffected, and the feeling may continue for some time. In the case described below, a cultural expectation of the bereaved person made the experience of numbness difficult for her:

“ If there is a death ... people gather. There is that expectation ... as soon as you get there, you’re supposed to cry... you know, really scream and yell out and express yourself. But, you know, with me it was a bit different, because ... I just couldn’t cry straightaway. Because I had that ... delayed reaction. But then that’s not acceptable in my culture because it was my brother. So straightaway because everyone else was yelling and screaming and carrying on – they called me a witch. They called me names and other things... A bit later on, that’s when it hit me...when I started to cry...”

Janet Phiri, African, Insight SBS

Dreams or a sense of presence

Many bereaved people have dreams of the deceased person, both immediately after the death and possibly for a long time afterwards. Some people feel a sense of their presence, or see ‘signs’ that they are still around. This can be a reassuring and comforting experience, or may be disturbing. Nightmares can occur too, particularly if the death was sudden or traumatic. Some people choose to visit mediums or psychics in order to get information about or make a connection with their loved one.

Blame and anger

Another response to the loss is to blame doctors or those treating the loved one, or blame the treatment. Sometimes there may be culpability, but more often it is a way of expressing some of the feelings associated with the loss:

“ I wasn’t satisfied that my father had been diagnosed properly. I don’t believe they’d done everything they could. If they’d been more thorough he might still be alive. I feel so angry about it.”

Italian bereaved

Relief and peace

For many people, there may also be a sense of relief at first, particularly if the loved one had been suffering a lot of pain, or after a long illness.

After the immediate

Dealing with the practicalities

There may be a period of intense busy-ness after a death, as there are usually a lot of administrative and financial arrangements to deal with. This can be both time-consuming and difficult especially for someone who is unaccustomed to it. Decisions need to be made too about dealing with the deceased's belongings. The timeframe for doing this varies, but for most people it is a very significant part of the grief experience:

“Someone I know had emptied the house of his wife’s belongings within a month of her dying. I’m not doing that. Her things are part of her. That’s all I have to connect me with her.”

Anglo-Australian bereaved

“I’m using some of his clothing to make a quilt. That’ll be one way I can remember him forever.”

Italian bereaved

Physical symptoms

There is a range of physical symptoms that can accompany grief. Bereaved people are more susceptible to illness in general. In particular chest or abdominal pain, headaches, palpitations, breathlessness, appetite changes, sleep disturbances, sexual desire changes, restlessness, and tiredness are all commonly experienced.

Emotional confusion

The bewildering array of emotions, thoughts and behaviours may make a bereaved person feel as if they are 'going crazy.'

Characteristically there is a yearning and longing for the deceased, and a preoccupation with thoughts and memories of them. Sadness, despair and hopelessness are commonly felt, as well as fear and anxiety or panic:

" Since Dad died, we can't leave Mum alone, she gets panicky and afraid. One of us has to be there with her all the time. We take it in turns. "

Italian bereaved

Confusion and forgetfulness is very common. A grieving person may be absent-minded and disorganized:

" Things I used to do easily, just seem really hard now. I couldn't imagine going back to work. I wouldn't be able to concentrate."

Greek bereaved

For others, going back to work helps to restore normalcy:

" Work was the only thing I could do. It helped to take my mind off her. It gave me a purpose."

Anglo/Australian bereaved



Guilt, regret and anger

Often there are feelings of guilt and regret following the loss of someone close. It's common to feel anger too, with the person who has died or with those who cared for them, with other family members or with 'God'. This can lead to a sense of meaninglessness or a loss of faith:

"I don't know what to believe in anymore. I just want to know why. I keep asking God, why did you have to take him?"

Catholic bereaved

Social behaviours

A bereaved person may tend to withdraw, and intense feelings of loneliness can accompany this withdrawal. There may be a feeling of not wanting to burden others with their grief. In some cultures, this withdrawal is sanctioned, and a bereaved person would not be expected to attend social events, but this is not so for everyone. Again, it's important not to make assumptions:

"I can't do social events. I can't cope with it, having to talk to people. What's happening to them seems insignificant compared to what I'm feeling. I just want to be at home."

Anglo/Australian bereaved

"I was very upset that my nieces and nephews went out and sang karaoke just after my brother died. They sang all his favourite songs. It felt really wrong to me. But obviously not for them."

Macedonian bereaved

"My partner's mother couldn't believe I would want to use Facebook to talk about him when he died. But it was just natural to me. I didn't see anything wrong with it."

Anglo/Australian bereaved

Some people become extremely active in their grief, and like to keep busy. For others, there may be a strong need to share the experience by talking about it. If their social networks aren't adequate, referral to individual professional help or a support group for bereaved people may be appropriate.

Drugs and alcohol

In order to cope with feelings there may be overuse of drugs or alcohol:

" We always liked to have a drink together a couple of nights a week, but now he's gone, it's every night and it's more than just one or two drinks."

Anglo/Australian bereaved

Despair

There may be a lack of motivation and feelings of hopelessness and low self-esteem. Sometimes a bereaved person may feel that they don't want to go on living, or that they wouldn't mind if they died. Death may be seen as a relief from the pain or there may be a belief that they would be joining their loved one. These feelings need to be taken seriously and the risk of suicide assessed and acted on if necessary.

In the longer term

Usually over a period of time there is a gradual acceptance of the loss. However this varies according to each person and is influenced by many factors including culture, and the nature of the loss:

" Traditionally the grieving period was three years, but nowadays it is less, maybe one year. For that first year the grieving person wears black and won't attend celebrations, play or sing music or dance, and sometimes won't eat meat. But after my mother died of cancer when she was 29, my grandfather and grandmother wore black until they died, because she died so young. They never stopped grieving."

Macedonian welfare worker

“Closest family members are expected to mourn for one year. They don’t attend festivities or weddings, especially the son as he still belongs to the family whether he is married or not, but once a daughter is married she is considered to belong to another family, so she doesn’t need to be in mourning. Traditionally widows would have been excluded, considered unimportant, which can lead to them becoming dejected and depressed but education is changing things now and that’s not so much the case.”

Indian community worker

“The Jewish practice is to refrain from going to parties or social events for a year after the death. When my grandfather died, even though he was very old and had been ill for a long time, my father was in a state of shock for 18 months. He was normally a gregarious outgoing person but he became sombre and withdrawn.”

Jewish health care worker

Rather than ‘moving on’ or ‘letting go’, it can be more helpful to think of how a bereaved person can be encouraged and supported to maintain a ‘continuing bond’ with the deceased person. Religion may provide a formalised way of doing this, but people also find many other ways of remembering and living with their loved one:

“A woman I was seeing of Anglo-Australian origin told me that when her husband (a Malaysian Buddhist) died, she created a kind of ‘shrine’ for him, with flowers, incense and a photo. Every morning she would make tea and light incense and sit down and have tea with him. It helped her to feel connected with him as they always had a cup of tea together in the morning, and she felt it was ‘a bit Buddhist’. It was also the only ‘still’ part of her day. She said her sons started to go and light incense too.”

Bereavement counsellor

There may still be a wide range of emotions experienced in grief, but they tend to be less often and with less intensity as time goes on. However at special times such as anniversaries, birthdays, Christmas or other religious days, these feelings can be very strong.

Generally the bereaved person will gradually adapt to their loss and all that accompanies it. This may include a changed role or status, changed circumstances, change in financial situation or geographical location. There may be a sense of a new beginning and new meaning in life, with a return in energy levels, the development of plans and activities and possible new relationships. Periods of grief may return indefinitely however.

“ I’m going to go and do the travelling I could never do while she was alive.”

English bereaved

“ I still miss him and think about him a lot, but I really miss the closeness and this makes me think about finding a new partner.”

South American bereaved



Prolonged grief

Usually with the support of family and friends, and sometimes with professional help, a person lives through the intense grief until it lessens. However if intense or complicated grief continues for a lengthy period the person may need extra help in adapting to the loss. The symptoms and timeframe of ‘prolonged grief’ are debatable, and may vary according to individuals, cultural practices or expectations.

How do children and young people grieve?

Depending on their age and stage of development a child will absorb the concept of death slowly. They may ask questions repeatedly and need to talk about death and the person who has died. It is normal for them to feel a range of emotions in quick succession, for example to be sad and crying for a while and then playing happily. Depending on their age, they may express their feelings through play and not with words.

“My three year old son kept asking when his uncle was going to come back, and I often heard him talking to his uncle when he was playing.”

Mother of bereaved child

Depending on their personality or degree of security, they may withdraw or seek attention, become hypersensitive, revert to regressive behaviours such as bedwetting or thumb sucking, feel separation anxiety, or have difficulties at school. There may be changes in eating and sleeping patterns, with nightmares or grief dreams a common occurrence.

Young people are generally reluctant to show their emotions outwardly, which is related to their need to become independent. However all adolescents grieve when someone they love dies. They may withdraw or become angry and they tend to grieve in doses with intense outbursts of a range of emotions especially at important milestones.

“I didn’t want to be around the rest of the family at all on my sister’s birthday. It was just too intense. I stayed in my room and looked at photos of her and read a letter she’d written me. But I didn’t want to talk about her. Mum got really upset with me. She didn’t understand.”

Bereaved teenager



Section 3: Spirituality and religion

(adapted from Spirituality and Religion in Health Care Practice: Staff Resource, POWH, 2007)

This section explores the importance of spirituality and religion in the context of death and bereavement, and describes how we can support the grieving person through respecting their beliefs and practices.

Although a significant proportion of Australians are not religious, and in some cultural groups the majority may not be, we do know that spirituality or religion is significant for the majority of Australians. This is true especially in rural and elderly populations. At death and during the time of bereavement spirituality and religion can become more important. We also know that patients want clinicians to consider and respect their beliefs and practices. There is often a strong connection and overlap between culture and religion or spirituality, so we need to consider this in our work, by asking sensitive exploratory questions.

What do religion and spirituality mean?

Religion and spirituality relate to the deepest aspects of a person's life: how we make meaning, develop our ethics and values, and form our connections. Religion or spirituality may be a source of inspiration, replenishment and guidance, providing us with a framework for understanding and decision making, and supporting us in coping with adversity. Religion and spirituality may encompass a belief in an immaterial reality, or a sense of connectedness with other humans, with nature or the universe.

How do they differ?

Religion tends to be institutionalised, structured, formal, integrated into culture and rooted in tradition, with shared beliefs and practices. It may cross geographic, language and

cultural boundaries, for example the Christian Orthodox and the Islamic faiths. It may also be a way of identifying cultural heritage or family background rather than adherence to beliefs and practices.

In Australia although traditional religiosity is in decline, spirituality may be growing. Spirituality tends to be more fluid, eclectic and individual. It may be part of a range of beliefs and practices including religious beliefs, or New Age concepts such as fatalism 'it wasn't meant to be' or 'everything happens for a reason'. It may be personal and self-developed or influenced by traditional cultures. A type of spirituality related to a deep connection with land and nature for example, may be inspired by Aboriginal culture.

To be spiritual or religious does not necessarily mean attendance at a place of worship but it does generally mean that a person holds a spiritual worldview, which may be the most important thing in their life. This worldview may be complex and diverse, incorporating many different influences and changing over time according to life events. It is very common for a person's spiritual worldview to be strongly challenged by bereavement and sometimes a loss of faith to be experienced:

"I believe a person's time of death is determined by fate, and I try and remember this when I feel so bad. But it's hard. I keep asking why? I'm just not sure anymore."

Greek bereaved

How to help

If we *expect* that a spiritual worldview might be important for a person, especially in bereavement, this helps us respond to their personal beliefs, and means we are less likely to make generalised assumptions about them. Finding ways to cope with the loss and make meaning from it are core issues in

bereavement. We need to understand these needs by finding out how the person wants to be supported.

We don't need *knowledge* about a person's cultural/religious/spiritual needs, just an ability to engage with and show respectful interest in them. We do this by listening, responding and asking open-ended questions sensitively and supportively.

People use words like God, fate, prayer, or meditation in different ways with different meanings, and there might be a danger of misinterpretation. So we might ask:

- *Where do you get your strength from?* (indirect question)
- *Who or what supports you in life?* Or
- *Are you a religious or spiritual person?* (direct question)
- *What is important for us to know?*

We need to work holistically and know how to use resources, and when to make referrals to a chaplain, a pastoral care worker, a social worker, someone from the patient's own religious community, or a bereavement counsellor.



The special place of customs and ritual practices

We need to recognise and respect the significance of rituals for many patients and their families. Rituals are an important component of religion and spirituality, as are practices like meditation, prayer and contemplation.

Ritual is used to mark an ordinary person's journey, making the experience significant and connecting it to wider universal meanings of life and existence. It is especially important at the end of a person's life, marking the transition from this world to an afterlife. Ritual connects us with family, friends and community, with faith and traditions, and with a framework for meaning. It provides support, comfort and reassurance when dealing with illness, death, and bereavement, and can enable a sense of purpose and control. Many people who would not call themselves 'religious' may however want ritual at the end of life or other significant life events:

" Though we weren't particularly religious and neither was my grandmother, we wanted her to have a strict Jewish funeral. As Russian Jews we were banned from practising our religion under Russian communism, so it has become important to keep the rituals of religion alive here in Australia. Many people don't necessarily practise it on a daily basis but are still affiliated with the Jewish faith."

Jewish health care worker

" I think many people don't necessarily know why they are doing it, but it gives them something to do, it provides a structure, and that helps."

Bereavement counsellor

Generally speaking, rituals may be important at several different points in the bereavement experience. Examples below of the wide variety of practices demonstrate the importance of needing to ask, not to assume, remembering that by no means every person of that culture or religion will practice all or indeed any of the rituals.



Before or at the time of death

Prayers or final rites

“ Before my father died we read the Baghavad Gita and said prayers at his bedside so that when he took his last breath he would hear the Lord’s name. The priest was called to conduct the final rites. At home in India they move the dying person to a new grass mat on the floor as death should take place in the arms of Mother Earth, but that’s not possible in a hospital.”

Indian Community worker

“ It is important for Maori loved ones to surround the person during their time of passing or when one is undergoing a serious operation. We come together under the mantle of whanaungatanga (family relationships) through love, respect and sorrow, to grieve unashamedly in the Maori fashion. Tangihanga (Maori Mourning) also has a number of stages and procedures that need to be carried out, as it is Tikanga Maori (Maori lore) passed down from Tupuna (ancestors). When someone is near death, and there is no more hope that the person is trying to forestall death, Tuku Wairua (spirit leaving) is performed to help the spirit depart from the body for fear that the wairua becomes restless and wonders. Traditionally this was performed by the Tohunga (priest). Today, a family member familiar with the rite can perform the procedure, otherwise a minister or priest can be called to give the person a ‘holy blessing’. At the moment of death, my tupuna(ancestors) believed the tupapaku (dead body) to be in a state similar to sleep. The Tupapaku is dressed in their finest traditional dress. Though gone from the body they believed still the wairua to travel to its old haunts before it’s ascension to Te Rerenga Wairua (the top of the North Island, NZ to depart). The body is prepared for viewing to lay in state with the family, usually, if possible, in their home. Ideally the person is to be transported back to New Zealand to their family marae (traditional place).”

Maori community member

“ My great grandfather passed away in our home, the preferred way for our family. We placed him in our traditional fabric and mats and laid him in our good room. Family and community members came from everywhere to show their respects. My eldest aunts and grandmother stayed with the body for the entire time, wailing over the body, and often burning their hair. The entire family is present during the open mourning period, which can last several days. Our family home is open to the our entire community to pay their respects and my role as a younger woman of the family is to cook for all of the guests. Everyone dons black attire covered by traditionally weaved mats in respect and honour for my great grandfather and my closest family can continue to wear this for several years.”

Tongan community worker

At the funeral and soon after

“ The period after death is called sorry time. You go home to the land, the country and the family gathers together. It’s up to the individual, family or community how long it goes on. It may be a couple of weeks or months. This can be difficult because most workplaces only grant two or three days compassionate leave.”

Aboriginal health care worker

The viewing

“ My grandfather died in his favourite chair at home and his body wasn’t taken away till all the family had been to see him. I have wonderful memories of my grandfather sitting in his chair looking so peaceful. We went and had a viewing a couple of days later, and then the funeral on the tenth day. My grandmother’s belief is that the crossing-over period is after ten days...”

Aboriginal health worker

“ Some families remain with the deceased person for a long time at the viewing, as this is a way to show respect and honour to the deceased and is seen as a way of supporting the relatives. Relatives or friends bring a lot of flowers which are decorated in specific ways for this occasion.”

South American community worker

“ For Chinese people there are different practices, it may be important either to look or to avoid looking at the body. Traditionally it was important for children to see the body, but now things have changed and they don't have to. It is an open coffin, and you can look if you want to.”

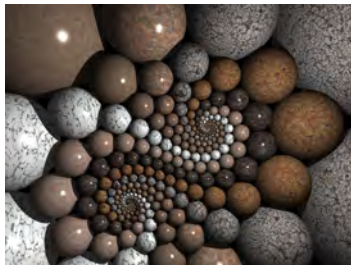
Chinese community worker

“ You don't let children see the body, because that would be their last memory and it's better to remember them healthy. It's for their protection. But the coffin is open and candles are lit around it in the church. I think this signifies lighting the way for the soul. We think the spirit stays on earth for 40 days and goes to the places where it's been, it goes everywhere.”

Macedonian community worker

“ At Lapa (La Perouse, Sydney) they do smoking ceremonies around the coffin with gum leaves. That's very common now. But it varies...that was for a well-respected elder. It's the individual family's decision... Traditionally you wouldn't show images of the person who's passed. But at my auntie's funeral, her photo was on the coffin.”

Aboriginal health worker



Length of time

“ Traditionally the funeral would take three days and three nights, but now because people are too busy, it usually happens all in one day and one night. Cremation is more common now due to lack of space for burial, and the ashes are usually kept at home. You may not go visiting for 40-100 days after the death.”

Chinese community worker

“ At my uncle’s funeral, his body laid in state for 3 days, the women in the family lay near the body and wail whenever a new group of people come to give their respects. All of the community stay for the three days and the body isn’t left alone. We are never allowed to eat or drink near the body during this time. The night before my uncle was buried, people were singing and telling stories about my uncle’s life, it’s a celebration, with laughter, dancing and singing.”

Maori community worker

“ There is a strict formula to be followed with Jewish funerals, depending on whether the person is Orthodox or not. Burials are done within 24 hours, where possible. When my grandmother died, there was a delay of a few days because it happened at a special religious time between Yom Kippur and Rosh Hashanah. After the funeral the immediate family and friends went home to provide company and consolation for the mourners who are ‘sitting shiva’ - traditionally for a week, but now for 3 days or sometimes only a day. The mourners wear slippers to signify that they are not going outside, and sit on low stools to signify their emotional state. The mirrors are covered so that they don’t see their sad reflection. Sacramental wine or scotch is served, with cakes. Sometimes up to a hundred friends of the mourner come too. My mother found this comforting; the more people who came the better because it showed how many people respected and were paying tribute to my grandmother. The grandchildren put together a power point presentation with photos of her and the paintings she’d done and they showed that after the prayers. People had a chance to tell funny stories about her.”

Jewish health care worker

“ After someone dies and before the funeral it is common for friends and relatives to visit the mourning family in the family home so that they can offer their condolences. This practice is referred to as 'lutto'. The Rosary is recited the night before the funeral at the funeral home. A full Catholic Mass is held at the funeral which is followed by burial at the cemetery. The mourners visit the family home for coffee and food afterwards. It is customary for family and friends to cook meals for those grieving during the week after the funeral. A dedication mass is held 30 days after the funeral, and a memorial mass on the first anniversary.”

Italian community worker

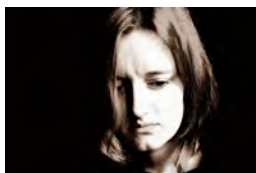
“ The immediate family mourns for ten days. No meat is eaten for that time, and there's no meat in the house. We don't drink alcohol, wear perfume, the 'bindhi', shave or have any sort of entertainment during this time either. Where the body has been, we place a lamp. We don't wear shoes in the house. White is traditionally worn as a sign of mourning, but now dull colours are ok. It's expected to be sad. Then there are a few days of rituals carried out by the priest to send the soul off to merge with God. We pray for his peaceful journey. On the thirteenth day there's a feast with close family and friends where offerings are made and we wear new clothes and give gifts to charities and priests. This marks the end of the social isolation of the family for the past ten days.”

Indian community worker

Return as an animal

“ On the seventh day the person comes back as an insect or an animal. If you see a butterfly coming, that's the person. On the seventh day we go to bed earlier or the spirit won't come back. We don't want to scare it off.”

Chinese community worker



“ A small moth comes in your house, no particular day but soon after the death. It’s seen as the carrier of the soul. You don’t need to be scared, it’s just that the person has come to visit. In Estonia in the middle of winter, it was very cold and there was a moth on the lamp - normally moths don’t live in that sort of cold. Later they discovered that my uncle had died two days before.”

Macedonian community worker

In the longer term

The wearing of **black clothing** or armbands is common across many cultures. For Greek people this may go on past 40 days and often till the first anniversary or later:

“ If the parents have lost a child, they may wear black for the rest of their life, in honour of that child.”

Greek community worker

“ My mother wore black for 35 years after her brother died and cried over him a lot during that time.”

Lebanese social worker

“ I wear black even though I don’t like it. But I do it as a mark of respect and because of what people will think of me if I don’t.”

Macedonian bereaved

“ During the grieving period, relatives keep to themselves and are quiet. They don’t have parties at home and some continue wearing black clothing signifying that they are in ‘Luto’ that means they are undergoing grieving. More recently, newer generations have adopted more flexible ways of expressing their grief.”

South American community worker

“ You don’t go to parties or wear bright colours. White or black is okay but not red. You’re supposed to look sad and be in mourning but you’re not supposed to cry or talk about it with others. It’s not good to put your personal problems on others.”

Chinese community worker

“ When my grandfather died my grandmother, very much a traditionalist, wore black until the day she died, she rarely attended any family celebrations or Italian festivals and she never remarried. Before he died, my grandfather who was quite modern in his way of thinking asked that none of his daughters wear black beyond the day of his funeral. He felt that grief was felt within and did not have to be displayed publicly.”

Italian community worker

Visiting the grave is important in many cultures:

“ There is great respect for the one who has passed away.”

Lebanese community worker

In the Christian Orthodox religion memorial services and visits to the grave are held on the third, ninth and fortieth day, and at six months after the death. Candles and incense are lit; libations of water and wine are poured. Special holy bread (Macedonian) and coffee, brandy, ‘paximathi’, vegetarian food and ‘koliva’ (Greek) are served at a gathering afterwards. For a year afterwards there are no celebrations, music or dancing, and sometimes no meat is eaten:

“ We go to my father’s grave every Sunday, put fresh flowers, we take food and coffee. We make a plate of food for him, bread, cheese, olives, and put a cup of coffee down for him, then we sit and eat and drink with him. I like doing it. At least there’s something I can still do for him.”

Macedonian bereaved

“The putting up of the tombstone is an important milestone in the bereavement. It either happens one month after the death, or 11 months after. When we go to the grave we place a remembrance stone on it near the feet, like a calling card. Any time you visit the cemetery you wash your hands before you leave.”

Jewish health care worker



Annual memorials and in some cases celebrations are significant in many cultures. For example, the ‘Day of the Dead’ is part of traditional Mexican culture, and All Souls Day is still celebrated in Italy and some parts of the United Kingdom. Both involve visiting the graves of those who have passed away and honouring the ancestors.

The place of counselling/professional intervention

In general across all cultures family and community support for the bereaved person is very important. For some, religious help may be sought, but it’s often not usual to obtain professional help from a counsellor.

For many Chinese people for example:

“Bereavement is an alien concept and a sensitive topic. There is a general understanding - particularly if it was an older person who dies without too much suffering - that grief takes time and is dealt with and expressed within the family. Generally there is a stoic attitude, a tendency to not want to talk about feelings of grief or about the loss. Professional help with grief is not part of Chinese culture.”

Chinese community worker

For a Lebanese person of Islamic faith there might be a similar response:

“A bereaved person becomes closer to God which helps them accept and manage their sorrow. Prayer is important, and reading of the Koran day and night. A person might become weak, depressed and stressed. Counselling is not believed in. It is the last option.”

Lebanese community worker

Where the person is open to receiving professional support, grief counselling can be beneficial, in particular where there is lack of social support, or due to the particular nature or circumstances of the bereavement. It is important to be aware of the services available in your area, and to know when and how to make referrals.



Section 4: Summary and key resources

Summary of key points

Culture

- is universal
- is not static or fixed
- changes over time
- varies between individuals

a worker who practices cultural competence and patient-centred care with bereaved people:

- recognises each patient as different
- treats the patient as a partner or collaborator
- uses resources to help –interpreters and translated materials
- regards the patient as the best source of knowledge about themselves
- uses communication skills
 - is self-aware – appreciates that their own cultural background may affect the way they work
 - is interested in the patient
 - listens
 - is open and non-judgmental
 - asks sensitive questions
 - responds with empathy
- is aware of their own responses to others' grief

- knows that the context of the loss might affect the grief experience
- knows the importance of support through bereavement
- understands that grief encompasses many behaviours
- understands that each person's experience of grief is unique
- acknowledges that the timeframe for grief varies between individuals and cultures
- supports the bereaved to maintain a connection with the deceased rather than 'move on' if this is their wish
- assists the bereaved to integrate their memories of and loyalty to the deceased within their broader life
- expects that a person's spiritual worldview is important and may be strongly challenged by bereavement
- understands that a bereaved person is finding ways to cope with the loss, and make meaning from it.
- knows that respect and interest is more important than knowledge of religious or cultural practices
- supports the use of rituals when possible

A worker who practices cultural competence

ASKS

LISTENS

DOESN'T ASSUME

Key resources

Cultural competence

Diversity Health Kit http://seslnweb/diversity_health/kit.asp

Diversity Health Institute www.dhi.org.au

Centre for Culture, Ethnicity and Health www.ceh.org.au

General bereavement information

Caresearch

http://www.caresearch.com.au/caresearch/CareSearchpalliative_careknowledgeNetwork/tabid/80/Default.aspx

Australian Centre for Grief and Bereavement www.grief.org.au

National Association for Loss and Grief www.nalag.org.au

GriefLink www.grieflink.asn.au

National Centre for Childhood Grief www.childhoodgrief.org.au

Translated grief and bereavement resources

A practical guide to coping with bereavement

http://www.health.nsw.gov.au/pubs/2003/bereavement_care.html

Grief and Loss (Family Help Kit)

<http://www.dhi.gov.au/Transcultural-Mental-Health-Centre/Resources/Archived-Resources/default.aspx>

Cultural resources

Multi-cultural palliative care guidelines (Palliative Care Australia)

www.palliativecare.org.au/portals/46/multiculturalguidelines.pdf

Diversity Health Issues at End-of-Life(POW)

http://seslnintranet/POWH/Diversity_Health/pdfs/End of Life Resource rev mar 2010.pdf (Updated 2012)

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