



Palliative Care
NEW SOUTH WALES

Palliare

A Handbook for Palliative Care Volunteers in NSW

Second Edition



Palliative Care
Volunteering

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The primary goal of palliative care is to provide quality of life for the patient and family through a team-based approach.

Chapter 1

Introduction to Palliative Care

What is palliative care?

'Cure sometimes, treat often and comfort always.'

– Hippocrates

To 'palliate' means to 'cloak' or to ease symptoms without curing the underlying disease. The primary goal of palliative care is to provide quality of life for the patient and family, achieved through a team-based approach that includes symptom control and support for the patient and family – whatever the diagnosis.

Palliative care is also known as hospice care in some countries and may refer to care that is home-based or place-based. In Australia, the word 'hospice' generally refers to a place (facility) in which end of life care is delivered. The word 'hospice' has the same derivation as 'hospital' and 'hospitality' and is believed to date back to the 4th century when pilgrims were cared for at an inn or hostel.

Palliative care is firstly understood as a *philosophy of or approach to care* which has influenced systems of care in the interests of helping people to live, die and grieve well.

The philosophy of palliative care

Medicine has traditionally regarded non-beneficial (or futile) treatment as unethical. Consequently 'treating' patients when they were dying was a vexed question for medical practitioners. Some found it unethical to instigate treatment at end of life given that they felt that there was little chance of restoring the person to health, making them appear uncaring or ambivalent toward their patients.

The modern palliative care movement was born out of concerns for this apparent lack of support for people at end of life. Family members, clinicians, members of the community and others argued that people at end of life should, according to their need, receive active treatment and support and that the care should include attention to the needs of their family and carer. They agreed that futile treatment, over-treatment and over-diagnosis should be avoided but they rejected the view that a patient was nothing but 'a problem to be solved'.

Instead they focused on the needs of the person and asked 'at end of life how can we better support the person's physical, spiritual, social, psychological, emotional needs and their relationships with their family and carer?' This philosophy informs all of palliative care and offers a person-centred approach to all care in health services. Consequently this is referred to as the philosophy of palliative care or the palliative approach to care.

The reactionary roots of palliative care can be seen in the life-affirming definition of Palliative Care from the **World Health Organisation (WHO)**¹

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patients illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”*

You will find different organisations, states and countries may have different definitions of palliative care. The definition used for Paediatric Palliative Care is different to this version used for adults. The World Health Organisation and the International Children’s Palliative Care Network each have a different definition of palliative care as it applies to young people (see Chapter 12).

NSW Health endorses the WHO definitions of palliative care.

Systems of care influenced by the philosophy of palliative care

The **philosophy of palliative care** has influenced systems of care in the community. These systems of care arguably include generalist palliative care, specialist palliative care and public health palliative care. When these 3 systems of care are harmonized then practitioners are most likely to achieve optimal palliative care for the community.



Palliative care as a Public Health issue

Public health refers to a social systems approach to understanding the experience of health in the general community.

Contemporary public health asserts that the experience of health is determined not only by the individual's health practices (diet, exercise, relaxation) but also by a person's experience of participation in society's shared wealth and resources. Factors affecting a person's experience of participation are known as the 'social determinants of health' and include employment conditions, gender, education or housing, resulting in social exclusion or marginalization². Consequently we observe that a poor outcome (such as a person who experiences a bad death) might be predicted by the way in which the person experiences access to services in the community. New migrants, people with disabilities, homeless people, frail aged people and people living alone without social support are all potentially at higher risk of a bad death.

The public health approach to palliative care looks at changing the way that society responds to people who are dying. This typically seeks to inform about the experiences of poor outcomes (research, awareness raising, health promotion), to advocate for changes for example to the policies held by health and social service agencies, and to influence local change by educating, informing, sensitizing, and/or mobilizing people around the issue in their community.

Palliative care practitioners in the health system offer expertise and insights into patient experiences that are valuable in informing public health approaches to societal and policy change. Likewise public health approaches offer a methodology for mobilizing support for dying people in local communities by practitioners involved in end of life care, as well as by non-expert advocates, carers and their extended social networks.

Public Health Palliative Care is discussed further in Chapter 2.

Specialist and Generalist Palliative Care

Most if not all palliative care volunteering takes place within a system that is led by specialist or generalist palliative care.

The term 'generalist palliative care' typically refers to care settings which are first-point-of-contact for the dying person and that are able to seek advice and support from specialist palliative care practitioners. These include general practice, community nursing, residential aged care facilities and remote area clinics.

Generalist settings are well placed to identify people who may need a referral to palliative care. By asking themselves 'would I be surprised if this person died in the next 12 months?' and having 'No' as an answer then a referral to palliative care is usually indicated.

Where a person's condition is more complex they may be referred to specialist palliative care. For example this might arise because the person at end of life has, or may develop, multiple disease states (co-morbidities) and/or have unstable symptoms that need careful management. Specialist palliative care typically includes a combination of medical, nursing, allied health, social work and pastoral care working together in a multidisciplinary team. If the service hosts palliative care volunteers then the volunteers are also part of this team.

Most volunteer services are attached to, or have a close working relationship with, a specialist palliative care service. In some services patients may only receive the support of a volunteer if the patient has been referred to specialist palliative care.

People seeking the help of specialist palliative care may be referred by a doctor such as their own general practitioner. In some countries access to palliative care is only available to people who have a cancer diagnosis. This is not the case in Australia where people with one of more of cancer, organ failure or neurodegeneration may be seen by specialist palliative care.

In *Paediatric Palliative Care* a referral to specialist palliative care will usually come through the primary care team associated with the child. In Paediatric Palliative Care the focus of care includes the patient and family but broadens to include the siblings of the patient, carers and grandparents.

For more information on Paediatric Palliative Care see *Chapter 12 Young People in Palliative Care*.

A map of Level 1 Specialist Palliative Care services in NSW can be found on the Palliative Care NSW website at www.palliativecarensw.org.au.

Not everyone will require specialist Palliative Care in hospital at end of life, but those that do may have repeat admissions.

Palliative care service delivery

In Australia more than half of the 160,000 people who die each year are seen by palliative care services³ making palliative care one of the most in-demand medical specialties.

Palliative care is provided in almost all settings where health care is provided, including neonatal units, paediatric services, general practices, acute hospitals, residential and community aged care services, and generalist community services. Specialist palliative care services operate from a variety of settings, including specialist inpatient consulting services, specialist inpatient settings, hospices and community-based specialist services⁴.

Palliative care focusses on comfort care and seeks to neither hasten death nor prolong life. Although dying people may need active treatment for their condition in order to live as fully as possible, one of the challenges of clinical treatment is to find the greatest benefit for the person and to avoid treatment that is non-beneficial or 'futile'⁵. Therefore decisions about treatment has to consider the person's distress and suffering which may result from the treatment⁶ and must always take into account the person's consent about the degree to which they are willing to be impacted by treatment. Unless the possible futility of treatment is properly taken into account a purely 'curative' approach to care may prolong life but significantly diminish the quality of life⁷.

If a purely curative approach were to be taken then the person would cease active treatment upon moving into terminal care (see Traditional Care Model in the following diagram). This is not a great outcome for the patient who may continue to need active specialist treatment for their condition up to the time of death. In many respects this was the approach to care that caused concern amongst activists and led to the birth of the modern palliative care movement.

The contemporary approach to palliative care is to integrate palliative care into the 'curative' treatment of the person as it becomes necessary (see Integrated Care Model in the following diagram). One of the guiding questions used by clinicians is 'would I be surprised if this person died within the next 12 months?' If the answer is no, then generally it is recommended that palliative care become involved.

Traditional Care Model



Integrated Care Model



When should palliative care 'start'? Most people think that palliative care is something you get 'just as you're dying'. While it is true that a person may be referred to palliative care because they have complex health care needs it doesn't necessarily mean that they are actively dying. A person with motor neuron disease might be referred to palliative care at the time of diagnosis and be supported by the palliative care team for years. A child with a life limiting illness might be seen by palliative care from birth, a period that might be more than 10 years in duration.

In some services the term supportive care has been adopted to refer to the care given for an extended period that is designed to relieve the person's experience of progressive chronic disease prior to palliative care in the latter stages (known as 'supportive and palliative care').

In addition to the specialist clinical skills brought into the person's care the philosophy of palliative care helps to promote a more open approach to discussions of death and dying with people and their families through the dying process⁸ and to provide support for healthy grieving (see Chapters 8 & 9).

In *Paediatric Palliative Care* the '12 month' question may not apply to children in Palliative Care. Children with life-threatening illnesses (such as of a genetic and chronic nature) may be involved with Palliative Care for many years.

For more information on Paediatric Palliative Care see *Chapter 12 Young People in Palliative Care*.

The National Palliative Care Standards 2018

Since the first edition in 1994 the National Palliative Care Standards have been guiding the delivery of specialist palliative care services⁹. The National Standards for Palliative Care (5th Edition 2018) are set out below:

Standard 1: Assessment of needs

Initial and ongoing assessment incorporates the person's physical, psychological, cultural, social and spiritual experiences and needs.

Standard 2: Developing the care plan

The person, their family and carers work in partnership with the team to communicate, plan, set goals of care and support informed decisions about the care plan.

Standard 3: Caring for carers

The person's family and carers needs are assessed and directly inform provision of appropriate support and guidance about their role.

Standard 4: Providing care

The provision of care is based on the assessed needs of the person, informed by evidence and is consistent with the values, goals and preferences of the person as documented in their care plan.

Standard 5: Transitions within and between services

Care is integrated across the person's experience to ensure seamless transitions within and between services.

Standard 6: Grief support

Families and carers have access to bereavement support services and are provided with information about loss and grief.

Standard 7: Service culture

The service has a philosophy, values, culture, structure and environment that supports the delivery of person-centred palliative care and end-of-life care.

Standard 8: Quality improvement

Services are engaged in quality improvement and research to improve service provision and development.

Standard 9: Staff qualifications and training

Staff and volunteers are appropriately qualified, are engaged in continuing professional development and are supported in their roles.

Core Values of the National Palliative Care Standards

Quality palliative care is provided by health care workers who:

- Endeavour to maintain the dignity of the care recipient, their caregiver/s and family;
- Work with the strengths and limitations of the care recipient and their caregiver/s and family to empower them in managing their own situation;
- Act with compassion towards the care recipient and their caregiver/s and family;
- Consider equity in the accessibility of services and in the allocation of resources;
- Demonstrate respect for the care recipient, their caregiver/s and family;
- Advocate on behalf of the expressed wishes of care recipients, caregiver/s, families, and communities;
- Are committed to the pursuit of excellence in the provision of care and support; and
- Are accountable to care recipients, caregiver/s, families and the community.

In order to ensure high quality, person-focused and evidence-based services are available to meet peoples' needs, primary care and specialist providers as well as other health care professionals should also:

- Follow established practice standards and requirements for quality management such as leadership and governance, human resource management, safe practice, information management, and continuous quality improvement;
- Adhere to professional and organisational codes of practice and ethics;
- Reflect on and evaluate current practice, and incorporate new evidence into protocols, policies and procedures; and
- Participate in continuing professional development in the knowledge, attitudes, and skills required to deliver quality palliative care as this relates to the Standards in this document.

National Standards Assessment Program (NSAP)

NSAP is a program hosted by Palliative Care Australia that enables services to engage in continuous quality improvement through self-assessment against the National Palliative Care Standards.

Advance Care Planning

Conversations about end of life care are timely to avoid misunderstandings and to reduce distress on the part of the person and their family. In essence this is about asking questions like 'how would you us to treat you at this time in your life?' or 'how much information do you want and how do you like to make decisions?' At law a treating clinician must recognise the wishes of the patient in relation to how they want to be treated. Usually this is done through discussions, but patients are encouraged to plan and write down their expectations for their care in advance of, or in case of, them becoming incapacitated. This is known as Advance Care Planning:

"Advance care planning ... involves you, your loved ones and health professionals talking about your values and the type of health care you would want to receive if you became seriously ill or injured and were unable to say what you want".¹⁰

Advance Care Planning should give the person a greater sense of control during their end-of-life period, and should add to the sense of confidence and calm in their world. Volunteers often have the opportunity to spend time with people in palliative care, and to discuss issues that are of emotional, spiritual, relational or practical significance to the person. By being aware of Advance Care Planning you may be able to talk with people about preparing their own plan, or inform the team if the person already has one.

Paediatric Palliative Care

Advance Care Directives don't apply to young people who have not yet reached the age of consent. Parents are responsible for making care decisions on behalf of young people.

For more information on Paediatric Palliative Care see *Chapter 12 Young People in Palliative Care*.



Additional resources

The Australian Healthcare and Hospitals Association has recently refurbished the online training portal **Palliative Care Online** (www.ahha.asn.au/pallcareonline) specifically aimed at people working in aged care but suitable for clinicians and volunteers anywhere in the healthcare system.

In NSW a collaboration involving HammondCare, Calvary Health Care Sydney and Sacred Heart Health Care have developed an online educational resource **The Palliative Bridge**. The site includes video interviews with specialists from different areas of Palliative Care suitable for clinicians and volunteers (www.palliativecarebridge.com.au).

Online educational resources are also available from **CareSearch** (www.caresearch.com.au). In addition to information about Palliative Care practice and research, CareSearch has a searchable database of Palliative Care services across Australia.

For more about Advance Care Planning see **NSW Health** www.health.nsw.gov.au/patients/acp/Pages/more-info.aspx.



Good palliative care is really about building systems of care that provide for living, dying and grieving well.

Chapter 2

Public Health Palliative Care

Background

Everybody dies, most commonly as a result of chronic disease, not always with suitable access to services. This makes palliative care a subject of relevance to Public Health. Public Health aims to improve the experience of health in the general community by identifying opportunities to influence outcomes and improve equity and access to health promoting lifestyles and practices¹.

Social disadvantage and palliative care

Contemporary public health asserts that the experience of health is determined not only by the individual's health practices (diet, exercise, relaxation) but also by a person's experience of participation in society's shared wealth and resources. The World Health Organization has identified ten social determinants of health including the social gradient, stress, formative early life experiences, social exclusion, work, unemployment, social support and addiction². Others add food insecurity, housing, social safety network, health services, aboriginal status, gender, race and disability³.

Social disadvantage leads to health and 'death' disadvantage. When a person experiences social, economic or other forms of disadvantage they may be less able to access the support that they need and this can impact on the conditions under which they live at the end of life. This is observed in the lived experience of marginalised communities including traditional aboriginal people, new migrants and former refugees, people with disabilities and aged people.

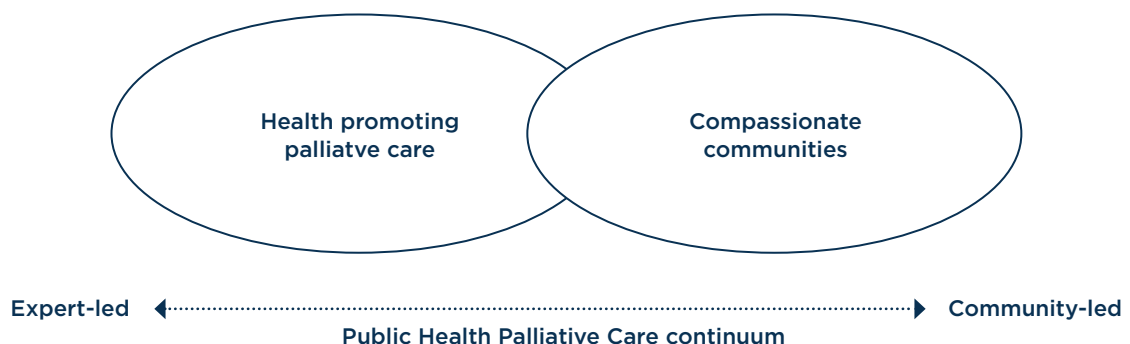
Social disadvantage is diffuse. The Productivity Commission⁴ noted that about 60 per cent of Australians have inadequate health literacy, which increases to nearly 75 per cent for Australians aged 55 years or more and who are most likely to have chronic disease. People with lower education qualifications and income, whose parents have low education, live in regional areas, or have four or more chronic conditions were much more likely to have poor health literacy levels⁵. Of particular relevance to palliative care is the statistic that about 40 per cent of people whose qualification related to health had inadequate health literacy⁶.

Social disadvantage requires a social response. As a systems-based approach, public health palliative care has an interest in influencing upstream policy settings to change downstream lived experiences. Specialist clinicians regularly observe that poor social capital in the community about end of life care results in a downstream concentration of service demand around the hospital system, a lack of GP involvement at end of life, a poor uptake of services by marginalized communities, a late uptake of supportive palliative care, low rates of participation in advance care planning and gaps in systemic planning for end of life care in residential aged care.

Palliative care expertise is needed in order to improve public health systems. Given that public health palliative care intends to improve the lived experience of the community through supportive care and at end of life, there is a place for palliative care expertise in informing public health approaches. In conversation, most specialist clinicians are aware and supportive of the need to raise awareness in the community and to promote public health and palliative care. Service provider activities under the health promoting palliative care⁷ approach may include hosting a community awareness forums, introducing death literacy into service clubs and influencing policy changes to prioritise a dying-friendly approach by hospitals.

Compare this to a situation in which a community group or person (a 'non-expert') takes the initiative to improve end of life care locally. This style of initiative is more likely to be considered a *compassionate communities approach*. A *compassionate communities* initiative by a local community may result in that community developing resources and grouping themselves around the needs of their folk at end of life. This may or may not involve formal 'expert' input (eg by clinicians), and where experts are involved they take a backseat role in providing support and advice to the community leaders⁸.

In simple terms, where an 'expert' leads a public health palliative care initiative it is regarded as a *health promoting palliative care approach* whereas a 'non-expert' lead constitutes a *compassionate communities* approach. The following diagram shows the public health palliative care continuum:



Health promoting palliative care, public health palliative care and compassionate communities

Within a systems framework a public health palliative care approach looks at changing the way that society responds to people who are dying. This typically seeks to inform the experiences of poor outcomes (research, awareness raising, health promotion), to advocate for changes to the policies held by health and social service agencies for example, and to influence local change by educating, informing and/or mobilizing people around the issue in their community.

The goals of public health palliative care have been described as⁹:

- Building public policies that support dying, death, loss and grief;
- Creating supportive environments (in particular social supports);
- Strengthening community action;
- Developing personal skills in these areas; and
- Re-orientating the health system.

Palliative care practitioners in the health system offer expertise and insights into patient experiences that are valuable in informing public health approaches to societal and policy change. Likewise public health approaches offer a methodology for mobilizing support for dying people in local communities by practitioners involved in end of life care, as well as by non-expert advocates, carers and their extended social networks.

Palliative Care and a 'good death'

What is a good death? The notion of a good death versus a bad death is significant to the way in which we imagine the provision of palliative care and the reason why palliative care volunteers are so important in the philosophy of palliative care.

The focus of palliative care is of course never simply on death, but rather on living, on dying and on the experience of grief and bereavement. So good palliative care is really about building systems of care that provide for living, dying and grieving well.

Death typically occurs in medical settings or residential care facilities, but this wasn't the case in the past. Death was an event that took place at home, and as such it was a community role to look after the dying person.

That the caring and sharing domestic environment is more intimate than the clinical environment has led to increasing calls for services to be available to people who prefer to die at home. This is one of the recent policy changes in palliative care that affects the population as a whole.

The purpose of this chapter is to discuss some concepts relevant to palliative care at a population level that asks 'how can the end of life experience of our community folk be improved by promoting the idea of a good life, good dying and good bereavement?' This is particularly relevant for people who experience social disadvantage.

Palliative care and vulnerable communities

Elderly couple found dead in Palm Beach home - *The Australian newspaper*

An elderly blind woman has died alone after her husband passed away in Sydney's northern beaches, leaving her without support. Police were called to the couple's home on Bynya Road in Palm Beach shortly before 9am yesterday. Neighbours described the couple, believed to be Anne and Geoffrey Iddon, as 'together all the time' and 'reclusive'. Mr Iddon was Anne's sole carer who was blind and had other disabilities. Both were aged in their 80s. "Although yet to be confirmed by autopsies, we believe the husband has passed away naturally, unfortunately leaving the wife with no means of support", police said.¹⁰

Social disadvantage can lead to 'death' disadvantage. That is to say, when a person experiences social, economic or other forms of disadvantage they may be less able to access the support that they need and this can impact on the conditions under which they live at the end of life.

In this way, social disadvantage determines a person's experience of health as well as their death. We have previously referred to the social determinants of health including unstable housing, low income, unsafe neighbourhoods, or substandard education are examples of 'social determinants of health' that predict a poor death experience.

There is an increased emphasis on the provision of services to support patients to die at home. This approach allows the person to be surrounded by their family with in-reach support from clinical staff as required.

However, this model doesn't suit all people, and one of the groups who are at risk are those people who live alone. In our community many people live within increasingly smaller social circles in more highly urbanised environments. Demographic data shows that single person households are the fastest growing household type in Australia¹¹. Services report higher rates of comorbidities amongst patients in hospitals and for residents entering residential aged care¹², partly as a result of the success of medical treatment to extend life. Consequently, people who are at end of life might be living alone with a complex set of illnesses.

Social isolation is a growing problem among middle-aged and older people. In 2011, people living alone comprised 28% of all households in the United States, compared with 17% in 1970. The proportion of Americans who said they had no one to talk to about important matters increased from 10% in 1985 to 25% in 2004, and in the 2010 European Social Survey, 27% of respondents aged 50 years and over met friends, relatives, or colleagues once a month or less. Between 1996 and 2012, the proportion of people aged 45-64 who lived alone in England and Wales rose by 53%.¹³

Although services will always do what they can to respond to the needs of patients, the experience of social isolation can mean that people might be reluctant to leave pets, or not want to go into residential aged care, and so do not seek support when they need it. In the more affluent areas of Sydney it is not unusual for single people to die alone and their body be discovered some time later.

Not all cultural groups rely on or trust health service support. Why? Some people or their kinfolk may have experienced systemic discrimination or fear persecution by authoritarian figures or experience other forms of structural vulnerability. These groups include indigenous peoples, former refugees who have fled persecution, former prisoners, and migrant groups with English as a second language. Marginalised groups might rely more on informal support from within their circle of trust than on formal support through health systems like palliative care.

Dr Naheed Dosani is founder of the Palliative Education And Care for the Homeless (PEACH) programme run by Inner City Health Associates in Toronto, Canada. Naheed is a champion of the social determinants of health and the experience of people who are homeless. “Homelessness cuts your life expectancy by 50%...A good death is going to look very different for a member of a vulnerable population. Typically, they want to die how they live, in isolation, on the streets, so to work with them we need to be aware of some of the biases that we bring to the table”. Many homeless people look toward shelter staff as their de-facto family. In responding to the palliative care needs of homeless people he said “keep your eyes on how to build community capacity, it’s about looking to community to come up with strategy”¹⁴.

Some groups are less well known, or even unknown, to service users. These include people in remote areas where services are few, people living with intellectual disabilities who may be inadequately supported, homeless populations who are reluctant or unable to access care, and people who are unable to properly access care for complex behavioural (problematic use of

drugs or alcohol, people who have displayed aggressive behaviour towards staff) or with complex comorbidities (episodic mental illness, dementia, ex-service personnel experiencing the consequences of post-traumatic stress). Some health services report that they have poor systems in place to identify the multicultural character or needs of patients¹⁵. This adds to the experience of vulnerability of those groups to receiving inadequate services.

The experience of vulnerability can also occur in the community where there are inadequate social (informal) support networks around the person who needs support. It might be that the person lives alone, or their network of support is unable or unwilling to be actively involved in day to day care. In such cases the demands on the home visiting service will probably be too great to sustain the needs of the person in their community¹⁶.

Andrea Grindrod heads up the Healthy End of Life Project (HELP) at La Trobe University. With an interest in stimulating the development of supportive communities, HELP uses a health promoting palliative care approach to generate resources that can in turn be used to stimulate collaborative community cultures. But there is no one-size-fits- all approach to community development. “The idea is to go through a process of identifying the assets and people in the community to achieve the desired outcomes...it’s not just about replicating a model from one area and transplanting it into another”. By changing social norms the community can become more responsive to the needs of their vulnerable members at end of life¹⁷.

People can also experience vulnerability as the result of poor health literacy, or in the case of palliative care ‘death literacy’.

Health and death literacy

Health literacy relates to the degree to which a person can understand health information and apply it to their or their family member's life. For example, this might include how to read dosage or usage instructions for medications, or how to seek information about palliative care services. It is generally accepted that when people are better informed about the health system they are better able to make informed choices.

Conversely, inadequate health literacy increases the use of low-value services by consumers and increases overall health care costs. It also contributes to poorer self-management of chronic conditions by consumers and poorer end of life choices. About 60 per cent of Australians have inadequate health literacy, which increases to nearly 75 per cent for Australians aged 55 years or more. The latter group are those with the highest likelihood of chronic disease¹⁸.

Poor health literacy might correlate to inadequate language or reading skills or inadequate cognitive capacity. It might relate to the availability of information in an appropriate format or language, or the opportunity to access the information by the carer or patient. Equally it may relate to the person's ability to absorb and assimilate health care information, or to their skills in interacting with the professionalised workforce of the health care system. And we should remember that, quite separately to their health literacy skills, a sudden and grim diagnosis can render a patient distressed to the degree that any information they subsequently hear may be lost on them.

One approach to overcoming inadequate health care is to provide clear information in multimedia and multi-linguistic formats for consumers to access. Another form of assistance might consist of advocacy in which another person attends and is present for a patient during their interactions. Family members often perform this role, and third-party patient advocacy is an emerging area of the health care system.

Another beneficial activity is the promotion of palliative care to communities in a way that builds the general literacy of the community before they interact with the health care system, or perhaps so that there is less need for them to interact with the health care system. These are all parts of the health promoting palliative care approach.

Palliative care and the consumer voice

A formative influence in contemporary health care is the resistance by consumers (as non-experts) to simply be passive recipients of care and to increasingly be actively involved in shaping their care.

The recognition of the legal status of *Advance Care Planning* (see Chapter 1) has empowered people in palliative care by giving them an increased level of control over their treatment in the final stages of their life, validating their voice in an environment perceived as being dominated by experts. Note that different states apply different requirements and legal status on how care preferences are documented.

Consumer participation has also led to the success of the '*death café*' in which community members (as consumers) meet to share and discuss end of life issues. Although each event might differ, the general theme is information sharing and discussion to de-mystify and de-stigmatise death.

Art and health activism have helped to express fears, conflicts, ambiguity and tension in death and dying in a way that encourages the community to reflect, re-evaluate, and reclaim their collective story about the end of life experience. The Groundswell Project is a community group based in NSW that aims to 'develop innovative arts and health programs that create cultural change about death and dying, while championing others to do the same'¹⁹.

One event with increasing support by the community is *Dying To Know Day* which is held nationally in August each year. *Dying To Know Day* (or *D2K Day*) is an 'annual day of action dedicated to bringing to life conversations and community actions around death, dying and bereavement.'

Another support role is performed by *death doulas* or *death midwives* who directly support people at the end of life, typically at home, much like a midwife would support a mother at the time of birth.

The simple act of being with a person for support, for encouragement, to reduce social isolation, and as an expression of humanity largely explains the role of *palliative care volunteers* who perform the role of a 'non-expert' support-person in expert terrain. A *community hospice* is home-style volunteer-led accommodation for people in their end of life and in need of respite support. For example, Tweed Palliative Support operates Wedgetail Retreat as a hospice and respite service²⁰.



Additional resources

The Australian Healthcare and Hospitals Association has recently refurbished the online training portal **Palliative Care Online** (www.ahha.asn.au/pallcareonline) specifically aimed at people working in aged care but suitable for clinicians and volunteers anywhere in the healthcare system.

Another online educational resource is **CareSearch** (www.caresearch.com.au). In addition to information about Palliative Care practice and research, CareSearch has a searchable database of Palliative Care services across Australia.

La Trobe University's **Healthy End of Life Project (HELP)** uses health promotion and community development interventions to help create, facilitate and stimulate a supportive community response to chronic and end of life support needs (www.latrobe.edu.au/pcu).



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Chapter 3

The Volunteer's Role

Qualities looked for in palliative care volunteers

In many ways the real value of a Palliative Care Volunteer is the peace that they bring into the life of a person and their loved ones. This is part of a set of personal qualities which include:

- Being non-judgemental and holding a genuine commitment to the principles of palliative care.
- Able to understand and accept the values, beliefs, and decisions of others when they differ from one's own values, beliefs, and decisions.
- Non-proselytising – free of the need to convert others to one's spiritual, social, psychological, or medical opinions.
- Having a positive approach to life, with emotional maturity.
- Sensitivity, empathy, sincerity, understanding, tolerance and patience.
- Tact, discretion and dependability.

If you're challenged by anything on this list it is best to be honest with yourself up-front. Your experiences as a palliative care volunteer may well test each and every quality along the way.

Eight things you need to know about Palliative Care Volunteering

1. Working in Palliative Care is one of the most rewarding volunteer choices anyone can make. Not only does it make a huge difference to the person who is dying and their family, but also to the volunteer's own life. Volunteers learn to cherish each day, listen deeply and value life as a precious gift. But it's not for everyone. Death and dying, end-of-life and Palliative Care can be difficult and sometimes confronting subjects for people to discuss. As a volunteer your role will involve supporting people and their families as they grapple with these sensitive subjects. Sensitivity, empathy, life experience, warmth and communication are essential attributes. Volunteers need to be patient, flexible, non-judgemental, understanding and accepting of other people's beliefs and values so they can navigate people through sometimes difficult conversations.
2. Palliative Care volunteers are generally over the age of 18. They have diverse backgrounds including trades, transport and sales, nursing, social work, medicine, law, hairdressing, administration, welfare work, training and education. They might be employed, unemployed, students or retirees. There are no formal qualifications or specific experience necessary, and life experiences and compassion are enormously beneficial.

3. As you will work closely with vulnerable people you should expect to be trained and carefully selected for the role (including security and referee checks). For example, you might have to get a clearance for working with children even in an adult service, because there might be situations where the service will ask you to assist with the care of children as part of your role.
4. Depending on the service you might have the opportunity to work in an inpatient setting, a residential setting, either or both. Volunteers who work in residential settings tend to work in the community and act more autonomously, volunteers who work in inpatient settings have to be skilled at teamwork. With increasing demand for palliative support in residential settings volunteers who are able to work in residential settings are highly valued.
5. You may have recently lost a loved one, and now have a desire to give back into the service to provide support to others. This will be really valuable for enriching your contribution as a volunteer, but make sure you give yourself time to grieve your own loss. Most services will ask you to allow at least 12 months after your bereavement before commencing volunteering.
6. When you have been accepted as a volunteer you should expect to be valued as a member of that team. You must be able to work within a team and provide support & encouragement to your peers. You will also need to understand and accept the philosophy of Palliative Care. Perhaps one of the most important criteria is that volunteers should be happy to be with people and not feel they have to fix or save people. It's about 'presence'. And sometimes it's about saying 'no, sorry I can't help you with that.'
7. Some organisations ask volunteers to sign up for a given time, perhaps a year, because they have made a considerable investment in education, training and resources. Some services will also limit a volunteer's time to, say, four hours per week and one patient. Volunteer commitment varies and is usually governed by the volunteer's availability and the service's needs. Some volunteers will contribute 3 hours a month, some will give 20 hours a month, others more or less depending on the situation and their skills.
8. Volunteers often move in and out of their volunteer role, this is normal and healthy. Volunteer managers know that taking time out for study, holidays, work or family commitments is important so that the volunteer has a life away from the service. They also know that encouraging volunteers to pursue other interests while still remaining part of the team also helps avoids burnout.

Palliative care volunteering in NSW

In NSW about 1,600 palliative care volunteers visit patients and their family and carers in hospitals and in private homes to provide support. Each volunteer is part of a palliative care volunteer service, and each service has a manager or coordinator that oversees the day to day activities of the volunteers following a request or 'referral' from the local palliative care team. There are about 42 palliative care volunteer managers and coordinators across NSW.

Palliative care teams may have either an adult or a children's focus. Of the 1,600 or so palliative care volunteers in NSW about 1,350 are attached to an adult services team and 250 are attached to one of several children's services teams.

Another way to think about volunteer roles is to consider that about half of all palliative care volunteers are involved in visiting people at home, while the other half offer support in inpatient (hospital ward, palliative care unit or hospice) settings.

Palliative care volunteers might undertake one or more visits/shifts per week typically up to a maximum of 4 hours per week.

Volunteers in other community settings are also involved in support for patients at end of life such as in aged care, Meals on Wheels and cancer support. Although they may receive support, guidance and training in palliative care they may not identify as palliative care volunteers¹.

So volunteers support adult and paediatric patients, in community and inpatient settings, in metro, regional and rural areas. Some volunteers may be involved in travelling to see their clients. Some volunteers may also be involved in art therapy, music therapy, biography therapy, diversional activities and other roles to benefit their clients.

The NSW Palliative Care Volunteer Support Services Programme

The Volunteer Support Services Program was established in July 2014 by Palliative Care NSW with funding by NSW Health. The Programme seeks to champion the work and interests of Palliative Care Volunteer Services and volunteers in NSW.

The Volunteer Support Services Programme has done extensive studies of palliative care volunteering. These studies as well as other resources for volunteer training, professional development and management are available on the website www.volunteerhub.com.au and many of them are listed in the table below:

.....
Hansen L & Huntir A (2014) *A Snapshot of Palliative Care Volunteering in NSW 2014*, Palliative Care NSW, Surry Hills.
.....

Burke M (2015) *Palliative Care Volunteering in Residential Aged Care Facilities in NSW: A sample study in Western Sydney LHD*, Palliative Care NSW, Surry Hills.
.....

Huntir A (2015) *Palliare: A Handbook for Palliative Care Volunteers in NSW*, Palliative Care NSW, Surry Hills.
.....

Bowman K (2016) *Investigating Understandings of Palliative Care within Community Volunteer Groups*, Palliative Care NSW, Surry Hills.
.....

Huntir A (2016) *Towards a framework for community hospice in NSW (Part 1): A background paper*, Palliative Care NSW, Surry Hills.
.....

Huntir A (2016) *Towards a framework for community hospice in NSW (Part 2): Accommodation at the end of life*, an overview of the local service context, Palliative Care NSW, Surry Hills.
.....

Huntir A (2016) *Faded away: The life and death of a district volunteer initiative in the bush and lessons for the future of palliative care volunteering*, Palliative Care NSW, Surry Hills.
.....

.....

Flood J & Huntir A (2016) *Where-to with our volunteers? Results of a survey of Palliative Care Service Development Officers in NSW*, Palliative Care NSW, Surry Hills.

.....

Huntir A (2016) *Palliative Care Volunteer Services: Guidance for managers*, Palliative Care NSW, Surry Hills.

.....

Burke M (2016) *Paediatric Palliative Care: A survey of a hospice volunteer service*, Palliative Care NSW, Surry Hills.

.....

Huntir A & Bradley R (2017) *Collecting stories from Palliative Care Volunteers: Narratives, empathy and insight*, Palliative Care NSW, Surry Hills.

.....

Burke M (2017) *It Takes A Village: Discussing the challenges of managing cultural diversity and volunteering in palliative care services*, Palliative Care NSW, Surry Hills.

.....

Bowman K, Burke M & Huntir A (2017) *People I have known: The experiences of rural and regional community visiting palliative care volunteers in NSW*, Palliative Care NSW, Surry Hills.

.....

Marsden J, Bowman K, Burke M & Huntir A (2017) *A space of caring: NSW nurses' experiences of Palliative Care Volunteers in inpatient settings*, Palliative Care NSW, Surry Hills.

.....

Palliative Care New South Wales (PCNSW) (2017) *The Statewide Framework for Palliative Care Volunteering in NSW*, Palliative Care NSW, Surry Hills.

.....

Bowman K & Huntir A (expected 2018) *Investigating involvement in bereavement support by palliative care volunteers*, Palliative Care NSW, Surry Hills.

.....

Petroccitto A & Bowman K (expected 2018) *Perspectives on the value of complementary therapies within palliative care volunteering*, Palliative Care NSW, Surry Hills.

.....

To read more about palliative care volunteering in NSW and for a map to find volunteer services in NSW see www.volunteerhub.com.au.

Volunteers contributing to holistic care

Palliative Care volunteers concentrate on the quality of life aspects of care, and bring a focus of normal living to a situation where all else seems to underline a medical crisis.

– The Oxford Textbook of Palliative Medicine²

One of the important goals of palliative care is to acknowledge the 'wholeness' of the person and to find ways to provide 'holistic' care. Volunteer roles are diverse and may include³:

- Visiting the home to provide companionship and psychosocial support.
- Assistance with medical appointments and access into the community for shopping.
- Social support at home including assistance with the support of children.
- Respite support by attending the home while the carer is away or on break.
- Assistance where socio-demographic or cultural barriers exist.
- Visits to a person when they attend hospital as an inpatient.
- For paediatric patients – special support to siblings to accompany or assist in the care of the child and to go on social outings, assistance with light domestic tasks around the home.
- Bereavement support.
- Assistance with administration, fundraising, community awareness raising in the community.

Sometimes as a volunteer you may feel that your visit is relatively unimportant. However, you should never underestimate the value of just being there and listening.

Getting started as a volunteer

In NSW each service is responsible for managing their recruitment process and induction training. Depending on their turnover of volunteers and demands on the service this might mean that there are several intakes each year or as little as one intake every 2 or 3 years.

There is no 'central' or 'standard' training course for palliative care volunteers in NSW, although the training provided by each service shares many similarities.

During the recruitment process you should expect to be asked for identification, for a police and working with children check, and for a declaration as to your fitness to volunteer. The health service may ask you for other information to help them fulfill their legal obligations and responsibilities.

Many services use a 4-step approach to getting volunteers started:

- **Selection:** Identifying the most likely candidates. This might include advertising, promoting the service, encouraging people to apply to volunteer. Some services have a back-log of applications from interested people which they will filter through.
- **Recruitment:** The volunteer manager may call each applicant, or the most likely applicants, to have a short conversation with them about their skills and interests. The most suitable people will be shortlisted and invited to attend training.
- **Training:** During the training you will learn about Palliative Care and how to perform the role in your particular health-care setting. The training period is also a good time for the manager and the facilitators to get to know you and how you contribute to the group, your attention, punctuality and attitudes. Based on these observations some people may be considered unsuitable to continue.
- **Interview:** At some stage, during or after the training, you may have an interview with the manager to discuss your progress, what you understand about the role and how you are feeling about the expectations of being a Palliative Care volunteer.

As a volunteer how should I expect to be treated?

In 2012 the NSW Department of Communities surveyed people about the ways in which volunteers should be treated by their organisations (including Health Services). These comments are from the subsequent report⁴:

“Participants said that volunteers should be always treated with fairness, respect and dignity, and managed collaboration and inclusion. This was the foundation step in building other elements of respect and dignity and without it, it was difficult, if not impossible, to ensure volunteer rights were acknowledged and met.

“Participants maintained that it was in the best interest of organisations for volunteers to develop and grow in their roles. This means volunteers themselves learn new skills and have new experiences – which support them in developing pathways to further participation and employment – and that this benefits organisations as they gradually draw greater value from the contribution of their volunteers.

These comments are instructive for services with Palliative Care Volunteers. It means that services are obliged to be supportive of volunteers, and cautions them that they must be careful about who and how they recruit.

After all, they want to best meet the needs of the service, to minimize the likelihood of disputes or issues, and to be respectful of your time.

Volunteer Rights and Responsibilities

These notes on volunteer rights and responsibilities are taken from Volunteering Victoria⁵:

Your rights

Volunteers have certain rights under the law, e.g. the right to a safe working environment, free from harassment.

When you volunteer, it is also reasonable to expect a decent and caring attitude that is reflected in how the organisation operates. This is based on what the community believes is the right way to treat people who give their time.

You should expect:

- Not to be asked to do, or support any illegal activity
- Training, policies and procedures to make volunteering fair, rewarding and safe
- Proper equipment and a process you can follow if there's an accident
- To be covered by the organisation's public liability insurance – in case you cause harm to another person or property
- To be covered by volunteer insurance
- Proper supervision – someone you can ask for help
- A reasonable workload
- Reasonable tasks – not just things none of the paid staff want to do.

Your Responsibilities

Rights work both ways – volunteers have responsibilities to their organisation and to the community. As a volunteer you have a responsibility to:

- Follow the rules – especially where they relate to legal requirements or safety
- Undertake training when asked, and follow instructions
- Do your best in whatever you've signed up for
- Try to represent the organisation well in any dealings with the public or clients
- Don't waste their time – do what you've committed to do.



Additional resources

NSW Health Policy on managing volunteers. As a volunteer attached to a Health Service the NSW Health Policy Directive, *Engaging, Supporting and Managing Volunteers* relates to the way in which you are supported as a volunteer. The policy provides overall guidance for the support of volunteers and endorses the NSW Health values for respecting volunteer contribution and the principles of diversity and inclusiveness⁶.

NSW Statement of Principles for the Recognition of Volunteers. The Department of Communities hosts the *Statement of Principles for the Recognition of Volunteers*⁷ which is intended to create best practice guidelines for volunteer management in NSW. By signing-up to the Principles an organisation is asserting their support for values of respect, inclusion, communication, celebration and professional development of volunteers.

Victorian Palliative Care Volunteer Standards. The Victorian Department of Human Services published the Palliative Care Volunteer Standards⁸ in 2005 and these are still commonly referred-to in volunteer management. They provide standards-based guidance for services establishing a volunteer program, recruiting, training and orientating volunteers, monitoring volunteer performance, health and safety.



As a volunteer you should
always be alert to your
Duty of Care and ask yourself
'what are my limits and
obligations?'

Chapter 4

Boundaries and Self-Care

Duty of Care

A service has an obligation to exercise reasonable care and diligence toward staff, volunteers, patients and visitors so as to avoid harming them and to protect them from foreseeable risk of injury. The obligation also requires the individual to take a share of responsibility for their own wellbeing and to act in a way that is consistent with their organisations policy framework. In all they are obliged to exercise reasonable care in performing their roles.

From this obligation arises the legal concept of Duty of Care.

By extension a service must provide to staff and volunteers a suite of expectations about how they must act and volunteers must be accountable for their actions and are expected to take reasonable steps to ensure client safety and welfare.

As a volunteer you should always be alert to your Duty of Care and ask yourself 'what are my limits and obligations?' Don't be afraid to ask your manager – it is better to ask beforehand than to explain later.

Policies and procedures

Creating shared understandings within the workplace is essential to fulfilling Duty of Care. Shared understandings are captured in policies, procedures, instructions and guidelines. We will refer to these collectively as policies.

Policies outline the responsibilities of volunteers and staff in management as well as operational tasks. They create boundaries to protect and safeguard people from unacceptable risks and behaviours.

Your service will have specific policies and procedures and these will be explained to you upon commencement. Policies will vary from service to service but are likely to include:

- Privacy and Confidentiality;
- Workplace Health and Safety;
- Disciplinary Actions;
- Code of Conduct;
- Hygiene and infection Control.

Your manager will assist you with locating and understanding these policies. From time to time policies are updated and changed, or new ones introduced, so watch for notifications in your service newsletter or at (monthly) meetings.

NSW Health also has Policy and Guidelines¹ and these typically are typically concerned with system-wide issues (such as the policies on infection control outlined in Chapter 13).

Policies change over time, so adopt the habit of being alert to updates by attending training sessions, reading newsletters and watching for information on bulletin boards.

Privacy

Caring for someone who is dying and for the family can involve knowledge about very personal aspects of their lives. Volunteers have a legal and moral obligation to respect the person's right to privacy.

The right to privacy can create problems for volunteers, particularly in small communities where everyone knows everyone else. Neighbours and friends of the client and family may already know you are a Palliative Care volunteer nevertheless you are not free to discuss your role with others and must direct any enquiries to the person or their loved ones.

The *Privacy Act 1988*² permits a service to share information about an individual (known as a 'permitted health situation') but only if the shared information is provided to the person responsible for the individual, and the individual is unable to provide the information themselves and the information is shared in the best interests of the person for compassionate reasons and not contrary to their (previously) expressed instructions.

In some circumstances sharing information about a person can be justified, but this is a specialized area and you must be guided by your service's policies.

Confidentiality

Confidentiality means 'entrusted with secrets'. When you volunteer with a Palliative Care service, you will hear confidential information regarding the people you are working with. Staff members may share with you information about people to enable you to perform your job. Sometimes people, as they get to know and trust you, will release personal information about themselves.

Sometimes practitioners hear information that must be shared with others such as where there is an acceptable risk of harm to the individual or someone else, and includes:

- Certain communicable diseases that must be reported by law to the authorities - this is done by a nurse or doctor;
- A medical condition (e.g. mental illness) that may result in harm to self or others; or
- Reasonable suspicions of abuse.

If you hear or note any of the above, you must report it directly to your manager.

Volunteers in palliative care may see elderly people in vulnerable circumstances and may unwittingly witness circumstances that constitute abuse for that person. "Elder abuse in Australian society is increasingly gaining mainstream attention. It is a social issue that we now hear and read about in the media on an almost weekly basis. While we still have no reliable prevalence data in Australia to inform our work, we know that the communities and services we represent have growing demands to provide an adequate response to elder abuse"³. Where you see or suspect abusive treatment talk to your volunteer manager.

Role boundaries for volunteers

As a Palliative Care volunteer, your primary role is to provide support to the person and their loved ones as part of a Palliative Care team. From time to time, you may be asked to perform tasks that are not appropriate to your role so you need to learn how to say no and where to refer to other members of your team⁴.

The following points are designed to give you a guide as to the boundaries of your role. You should refer to your organisation's policies for specific instructions.

Domestic duties: If you are working in the home of a client, requests to perform tasks such as moving household furniture or clearing rubbish from a backyard may be politely declined. Refer requests to your manager if they persist. There are other services that can assist with these tasks.

In Paediatric Palliative Care a volunteer is more likely to assist with light household chores, for example where the parent is caring for several children in the family or where the tasks can be used to engage siblings in helping out.

Transfers: Meaning to manually move the ill person. As a volunteer you would normally decline requests for assistance with transfers unless you have received advanced training in transfer techniques.

Medication assistance: You may assist the ill person with their medication by handing to the person the medication that has been dispensed by the carer and left in a container.

Personal care: If you are asked to cut nails, hair, or shave the ill person with a razor blade, you may politely decline and refer subsequent requests to the manager. Do not assist the client with feeding unless you have been appropriately trained in this area by a speech therapist.

Use of the person's personal belongings:

For example, if you are working in the home of the ill person, use of their telephone for personal calls or motor vehicle for personal reasons is inappropriate unless in demonstrable emergency situations.

Giving medical advice: Typically, you would decline to give an opinion. It might be beneficial for them to see the team again if they are seeking more clarity.

Personal opinions: In general refrain from gratuitously sharing your views on their ethnicity, religion, lifestyle choices or relationships. The person and their loved ones must be assured their privacy will be respected and protected.

Money, material gifts, or gifts in kind: Some services allow volunteers to receive gifts if they obtain a receipt from the person. Other services prohibit gifts. In general, you should never seek a gift. You should always remind the gift-giver that you are a volunteer on behalf of your health service and do not require compensation for your efforts, and always seek advice from your manager before receiving a gift.

Authorised witness or spokesperson:

Typically, a person who is authorised to sign or speak on-behalf of an organisation is either senior in function or is specifically authorised. Check with your manager if you are in doubt.

In Paediatric Palliative Care a volunteer is never alone with the child, the parent or carer must always be present.

For more information on Paediatric Palliative Care see Chapter 12 Young People in Palliative Care.

Palliative Care, stress and burnout

'We in this work are missing an outer layer of skin and must take care to renew ourselves'

– Dame Cicely Saunders

A 2015 study on the impact of working in Palliative Care found that one in three clinicians were experiencing signs of burnout and additionally were at risk of developing anxiety and depression. Insufficient resources, the daily exposure to death and the long working hours for some practitioners can affect people physically and psychologically. To compound the situation, the stress can also affect a practitioner's personal life and emotional supports⁵.

This risk is shared by volunteers who also neglect their own self-care needs.

Caring for people at the end of their life is problematic. On the one hand the genuineness of the relationship you develop with them is essential to fulfilling their need to be supported, and on the other hand the shortness of their life expectancy might mean that your relationship will be short and will involve much sadness at it's passing. In this sense every "hello" has to be a final "good-bye".

Remember that you are not alone, whether in an inpatient setting or if you are supporting a person at home. The volunteer works within a larger team and should be confident that they can look to the team for support.

Burn-out is a state of prolonged stress, or chronic emotional depletion. Uncharacteristic exhaustion and irritability are typical signs, but the psychological reality is far more urgent and intense.

Recovery will occur, but it will take time. It is wiser to take steps toward self-care early so as to avoid the longer-term consequences.

Ultimately, you are the expert on your own body, which intuitively knows what you need. Your life experience may have set you on the path to feeling overwhelmed and burning out⁶.

Some causes of stress associated with Palliative Care include concerns on behalf of and about clients (including symptom control, social isolation, grief, depression), about the work environment (including workload, conflict, and teamwork issues) and about personal factors which intrude into our work life (including health, confidence and self-care).

Remember, you can't always control the events that bring stress into your life, but you can control how you react to them.

Looking after yourself and letting go

There are two aspects to coping with the drain that both intense volunteer-client relationships and the facing of one's own mortality create – self-reflection and self-care. These notes are taken from the Vernon and District Hospice Society's *Hospice & Palliative Care Volunteer Training Manual*⁷.

Self-reflection is having the courage to face your own fear by asking yourself life and death questions. Self-reflection is like a profound dialogue with yourself. For some reflection comes easily; journaling, painting, music, or discussing a concern with a friend. For others, reflection seems like a non-productive waste of time. As a volunteer to a dying person, avoidance is no longer an option. Even preparing to be a volunteer requires reflection upon your own understanding about death and what it means.

Memories of past losses, questions about life and death, reactions to conversations with friends or family, all become grist for our mind's mill as it tries to develop at least a provisional understanding that will stand up to scrutiny. This evolving sense will also stand us in good stead as we are faced with our own personal reactions to the death of clients that we will experience as a palliative care volunteer.

Self-care is staying healthy and doing something for yourself that allows the renewal of body, soul, and spirit by practicing play and relaxation. Self-care is any activity that energises and fills you with joy. You need frequent replenishing in order to give support to another.

Dealing with death and dying on a regular basis requires a lifestyle balance. Though times with clients are not always heavy ones, they can be intense; times for playtime and laughter also need to be scheduled. Volunteers are feeling and compassionate people, which is what makes them such great companions. To spend unhurried and quality time with the dying, volunteers need other outlets that are active and exuberant to rejuvenate their soul and avoid burning out.

NSW Community Services reminds us that we have a mutual responsibility to ourselves and the people we care for⁸:

Not only do we have a responsibility to ourselves to care for our mental, emotional and physical wellbeing; we have a duty of care to our clients to practice self-care in order to have an optimum capacity for obtaining good client outcomes.

Final thoughts – your best life as a volunteer

Remind yourself you are human and not omnipotent. Therefore, you do not have to know what to do all the time. When you are unsure, ask the person what they need or want from you. There are some questions that have no answers.

Ask for help from your manager when you need to.

Even if your heart is in the right place you may well make mistakes and errors of judgement as you get used to the role and later. Share these with your manager and peers, learn from them and use them as opportunities to grow as a person.

Value the relationships you have. Say the things that are important to say and express the feelings that are important to share.

Take time off, get adequate rest and don't feel guilty about it. A change of environment can be very restorative. Maintain your personal space.

Let off steam emotionally and physically on a regular basis. Take your role seriously, but don't take yourself too seriously. Get to know your own strengths and inner resources so that you can feel comfortable with yourself. You will be more effective when you know what it is you have to offer.

Be aware of your different feelings and how you experience them. Then you will be able to allow others to experience their feelings without rushing in to comfort, challenge, change, defend, or retaliate.

Define what your limits are, e.g. the number of people you can work with, the kinds of situations you can manage, your level of competence, the boundaries you need, how available you want to be, separation of your personal and volunteer life, when you have had enough and need time out.

Practice saying no, so that when you need to set limits, you won't hesitate. What is the value of 'Yes' when you are unable to say 'No'?

Become familiar with your own signs of stress and develop ways to deal with them. Be open to new learning, approaches, and values.



Additional resources

National Carer Counselling Program offers short-term counselling for carers and might be a useful contact when working with carers 1800 242 636.

Lifeline is a 24 hour listening service which is available for debriefing and support 13 11 14.

Beyondblue offers 24 hour telephone and online counselling 1300 224 636.



Communication shapes
our relationships, and our
relationships are shaped by
our communication.

Chapter 5

Communication (aka Relationship) Skills

I'm a fantastic communicator

Let's be honest, we each think we are great communicators. But others may think differently. In our working and personal lives, we learn patterns of belief, thinking and acting that are expressed as communication. These are marks of our personality, our being and our character.

We communicate who we are, and how we communicate shapes who we are. This section is designed to encourage you to reflect on how you communicate. The secret to better communication is insight and practice.

Reflection and relationships

We know ourselves through our relationships. Is this true for you? If you were asked 'what sort of person are you?' you might come up with a few salutary comments but ultimately, you'd probably say 'if you really want to know, then go ask my wife/husband/partner/son/daughter/friend' etc.

Communication shapes our relationships, and our relationships are shaped by our communication.

Want to improve the quality of your relationships? Then reflect on how you are communicating.

As a volunteer you will be developing all sorts of new relationships so this is an opportunity to reflect on relationships and communication.

Here is how a medical student reflected on their experience in oncology¹:

"On commencement of this oncology term, I was afraid; afraid of speaking to patients at the end of life, afraid of touching patients, afraid of knowing nothing and being of no use whatsoever to those at need in an overloaded healthcare system. But I knew that textbook medical knowledge alone wouldn't help patients; it's a professional manner, empathy, and communication skills that allow you to give the best holistic care."

The ability to think about how we communicate, to think about how we think, is part of the wisdom of relationship building. The above comment by an undergraduate medical student reveals their beautifully vulnerable deliberations about how to form an appropriate relationship with their patient. You immediately sense a connection with them, because we have all experienced the need for an expert to stop being distant and start feeling.

Equally we might be surprised, even alarmed, if the doctor eclipsed our story with their own personal account, or if they burst into tears, or if they responded with judgement about our situation. We need them to hear us and to feel for us, so that they get a sense of who we are and for us to be assured that they will treat us with respect and consideration. We don't expect to be let into their emotional landscape in quite the same way.

Conversation vs communication

We often hear that 'communication is a two-way street' but we know that sometimes the communication street has three lanes going one way and a small narrow congested lane going the other.

When we talk to our friends we are most likely to open our hearts and expose our inner selves in conversation. We share because we respect each other and we are willing to hear each-others burdens. Conversation is rarely a power-struggle. When you can have a conversation with someone you often feel that you entered their confidence and they have entered yours, and you have made a friend.

Conversation is inherently intimate. In working with patients, conversation is probably not the best approach. You don't need to be the patient's friend. You might well become one in time, but you should aim above all to be respectful of your role as part of the clinical team.

Communication, rather than conversation, is the goal.

How do we communicate so that we demonstrate our willingness to humanly connect with the patient's situation, and yet we reserve or contain our own natural responses to their experiences?

That's a great question and the start of a journey for us all. Hopefully the following comments will help you navigate your path.

Effective communication

There are a few things that a chapter on communication has to include. One of them is to mention 'effective communication'. Effective communication has four key 'players' – the sender of the message, the receiver of the message, the message itself, and the means of communication. It takes careful attention to all four to be an effective communicator.

Another term which is commonplace is 'attentive' or 'active listening'. This is an active process that requires energy and concentration. It involves attention to the person's total message, both the spoken messages and the non-verbal messages that modify what is spoken. The listener must also be aware of his or her own cultural and ethnic influences as well as those of the client or family member.

As with 'effective communication' the key point here is about careful attention, or more specifically careful attention to the context of the relationship.

As a volunteer your role is to help reduce feelings of isolation, to create a sense of connection and acceptance so that others feel comfortable to ask questions.

A person in Palliative Care or their loved-ones will be more at ease with a volunteer who is present, calm and attentive; one who is comfortable in silence, is aware of their own responses, and is able to listen.

People send and receive messages all the time, as they convey and exchange information with each other. Receiving, or listening, is as critical as sending the message.

We only have to remember the childhood game of 'Chinese whispers' to understand that the message sent is not always the message received.

Communication guidelines

These notes are adopted from the Hospice Association of Ontario Visiting Volunteer Training Manual²:

Remain at eye level: Make certain that you are at eye level with the client. Whether or not you look directly at the client depends on the client's comfort level. Cultural considerations come into play here. However, in most cases, looking at the other person while he/she speaks demonstrates your attention and helps keep your mind from wandering.

Be silent: Silence is more than staying quiet or not interrupting while someone is talking. Before you start to talk pause and allow the speaker to catch up his/her breath or gather his/her thoughts. He/she may want to continue. If the message is complete, this short break gives you time to form your response and helps you avoid the biggest barrier to listening which is 'listening with your answer running'. If you make a response before the person is finished, you miss the end of the message that often contains the main point. At the same time, use common sense. Pausing for several seconds may be inappropriate e.g. when someone asks for assistance.

Display openness: You can communicate openness by your facial expressions and body positions. Uncross your arms. Sit comfortably and informally. Sit beside the person and remove any physical barriers, such as a pile of books. Facing a person directly opposite them may be very intimidating and unsupportive.

Listen without response: This does not mean never respond! When listening to another person, we often interrupt with our own opinions, suggestions, and inappropriate comments. Watch your non-verbal response too. A look of "good grief!" from you can keep the person from finishing his/her message.

Give verbal or nonverbal acknowledgment:

Periodically, it is important to let the speaker know you are still there. Your words or non-verbal gestures of acknowledgement let the speaker know you are interested and that you are with him/her and his/her message. These include "Uh uh", "OK", and head nods. These acknowledgements do not imply your agreement; they just indicate that you are listening.

Clear your mind : Clear your mind of your own thoughts to avoid mentally wandering.

Avoid distracting behaviours: Distracting behaviours such as playing with a pencil, drumming your fingers, grimacing, jingling change in your pocket, amongst other things, may take away from your ability to listen and distract the speaker.

Use physical contact only with permission:

Communication through touch can be very effective. However, you must ask permission first. It can be as simple as asking the client if you can hold his/her hand or "give them a hug". It is essential to obtain consent from the client and/or family member before touching.

Telephone communication

These notes are adopted from the Vernon and District *Hospice Society Hospice & Palliative Care Volunteer Training Manual*³.

The client is still the focus of your attention, and concentration is needed to maintain a high level of communication. You will need a quiet space. The client will know if you are not giving them your full focus and being distracted whilst talking and listening to them. Silence still works. You don't need to rush to fill the gap. You may need to say to the client "I'm still here" if the gap is long or they are upset.

When communicating with someone who is visually impaired, you may need to describe what your facial expressions are, for example "You made me smile when you talked about your trip to the beach".

Complicated contexts

Some contexts make for complications in our communications. These are not problems as such, but can become problems if we allow them to get in the way of our sincere desire to build an appropriate relationship with the other person.

These notes are adopted from the Vernon and District *Hospice Society Hospice & Palliative Care Volunteer Training Manual*¹³.

Poor listening skills: We might not always have the energy to devote towards listening, or we can be too concerned about coming up with a proper and sensitive response. As a result, we may not always hear what has been said. Asking questions for clarification helps to ensure a mutual understanding of a situation in emotionally intense situations.

Crisis driven situations: In the event of a sudden and unexpected change in a situation, lines of communication can become strained as clients/family members transfer their energy to the situation at hand. Intensified and increased stress is likely to result in decreased communication.

Cultural and/or language differences:

Culture affects the way in which individuals and families communicate. Interpretations may be inaccurate, leading to misunderstandings. Often translations from one language to another do not fully convey the meaning the speaker intended. When these obstacles are in place, it is best policy to ask for clarification and avoid making assumptions. Don't be afraid to ask for them to repeat what they have said or to offer to repeat what you have said. They may be used to having to repeat themselves.

Impaired communication skills due to disability:

When you are accustomed to communicating with a person who has a communication disability you will find their voice and gestures easier to understand. In the meantime, don't raise your voice unless the person is genuinely deaf, and don't be afraid to ask the person to repeat themselves as they probably know their speech is hard to understand. If you are struggling, then ask them to use different words or spell a word. Don't pretend to understand if you haven't. If they have someone with them then ask for their assistance. If you can't understand them then say so, and ask them whether the message was urgent.

Communicating with someone in a coma:

Coma is a state of unconsciousness in which people cannot be roused but may be able to hear, sense your touch and understand your voice. Watch for tiny clues, subtle messages, changes in breathing pattern, tiny facial expressions, and changes in relation or rigidity of the person's body are all clues to how he or she is feeling. Once you are aware of these clues you will be able to send and receive messages. Speak normally, talk about what you can see and feel and encourage them to do the same, remain relaxed and calm, don't feel the need to talk all the time. Remember that your touch, tone of voice, and inner feelings are all perceptible to the person in the coma.

Intense feelings: The likelihood of misinterpretations and miscommunication is increased when emotions are raw, so the importance of listening and clearly expressing oneself cannot be over-emphasised.

Secrecy: There are times when information which aids a person's understanding of a situation is not always properly or accurately shared. When there are several parties involved, several different interpretations can arise.

What not to say

Although there is no such thing as the ‘proper thing’ to say when you visit people who are ill, there are some things you should definitely not say or do. Simply avoiding these foot-in-mouth phrases will help your visits.

This list³ would be humorous if it weren’t for the devastating impact it has on people who are critically ill, chronically ill, or dying:

Never invalidate the patient’s experience:

“Don’t worry.” “I know you don’t really feel that way.” “Don’t cry!” “It’s not as bad as you think.” “Don’t talk like that.” “You know very well that’s not true.”

No one-upmanship: “This is nothing; you should have seen Fred when it happened to him.” “When I gave birth, I was in labour for 48 hours, you’ve never felt such pain.” “You think your stitches are bad, you should see the scar from my gall bladder operation.”

Don’t give advice: “What you really need to do is think positively.” “Make sure you take your vitamins.” “You ought to get more exercise.”

Avoid guilt trips: “If only you had listened to me this never would have happened.” “Think of all the worry you have caused your wife.”

Avoid clichés: “It could have been worse.” “Every cloud has a silver lining.”

Don’t ask: “What’s wrong with you?” Don’t ask about the illness. If they want to talk about it, they’ll bring it up.

Don’t feel sorry (no pity): “Poor dear, I feel so sorry for you.” “It must be awful.”

Refrain from being patronising: “There, there, it’ll be alright.”

No horror stories: Horror stories include surgical mistakes, incompetent doctors, malpractice lawsuits. “I heard that another one of your doctor’s patients just died.”

Avoid all forms of: negativity, irritation, complaining, blaming or fault-finding – in the client’s presence.

Don’t pretend that the situation is different from the way it really is, or that you know the answer when you don’t.

Don’t try to gratuitously cheer someone up:

There’s nothing worse when you don’t want to be cheered up. You can’t force someone’s mood to change.

Don’t try to fix or rescue people from their problems: You can’t change the fact that the person has a serious illness – but you can help them cope with the situation.



Additional resources

The **Cancer Council booklet**, *Facing End of Life* (2014) provides practical tips for communication with people at end of life (13 11 20).



Suffering is a common human experience. In particular at the end of life a person might reflect on the past and on what life has meant to them.

Chapter 6

Suffering, Total Pain & Spirituality

Suffering, existential distress and total pain

"It is only when caught in the swift, sudden turn of death, that mortals realise the silent, subtle, ever-present perils of life".

– Herman Melville

Suffering is a common human experience. In particular at the end of life a person might reflect on the past and on what life has meant to them. Failures, broken relationships, hardship and experiences of discrimination might trigger regrets or painful unresolved memories or feelings of disconnection.

No-one enjoys suffering, but paradoxically it has the effect of creating character changes in us – sometimes for better, sometimes for worse depending on our experience and our response. For some people their experience of suffering can lead to transformation in self-image, purpose and received wisdom. For others suffering can impose a form of distress commonly referred to as 'existential' distress.

Existential distress is not a mental illness. Some people will be diagnosed with distressing mental illness at end of life (like depressive disorders) which may be treatable, but by comparison existential distress is suffering that is not relieved by treatment of physiological symptoms or that occurs in the absence of physical symptoms¹. Feelings of hopelessness, being a burden to others, loss of sense of dignity, desire for death or loss of will to live, or threats to self-identity are all features of a person experiencing existential distress².

In one study, 289 cancer patients were assessed for mental health issues, existential well-being, grief about their illness, their physical symptoms and acknowledgement of their terminal illness, peacefulness and the desire to live or die. 'Patients closer to death exhibited increased existential distress and

physical symptom burden, were more likely to acknowledge being terminally ill, and were more likely to report an increased wish to die'³. Closeness to death was not associated with higher rates of mental disorders. In other studies, about half of the patients who identified as suffering attributed their suffering to psychological, existential, and social factors, versus suffering that was physical in nature⁴.

In summary, existential distress is common at end of life, is highly personal in origin, is untreatable in a bio-medical sense and impacts negatively on the patient's experience of life and death. Something else is well known about existential distress: it intensifies the experience of pain.

Pain specialists describe pain as both a response to a stimulus and as an emotion. A stimulus-response pain triggers local and central nervous system sensors that say 'ouch that hurts'. An emotion pain creates a balancing (homeostatic) response that stimulates mitigating behaviour (as does hunger, itch or temperature)⁵. This means that when a person is distressed then their sore tooth, bad back or sick stomach will feel much worse than if they were relaxed. It is also thought that the experience of distress might cause feelings of pain.

Whether physical or emotional in nature, collectively what the person feels is referred to as 'total pain'.

'Total pain' acknowledges that a person experiences pain as having physical, psychological, social and spiritual origins. Responding to a person's total pain is an important aspect of palliative care and a big part of why palliative care volunteers do what they do – accompany, support, relieve distress.

Relief of distress, engendering hope

The WHO definition of palliative care asserts that one of the goals of palliative care is the prevention and relief of suffering:

*Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, **through the prevention and relief of suffering** by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual⁶.*

But can all suffering be relieved? And if some suffering is intrinsic to life itself then is it even useful to relieve all suffering. This quote observes, some 23 years ago, the dilemma of suffering and palliative care:

Failure to draw a distinction between pain, which can usually be controlled, and suffering, which eludes control, represents a profound misunderstanding of human suffering. And yet, control of suffering has been presented as one of the more important goals of palliative care.⁷

A more meaningful approach is to accept that, even if suffering cannot be changed or relieved, a volunteer may offer some support leading to short term relief, or at least support the patient to endure.

Cancer Australia notes that when suffering is acknowledged and responded to, individuals tend to feel supported, less hopeless and less overwhelmed. If they are less distressed, patients are often better able to utilise their own physical, practical and emotional resources to address the ongoing challenges of their illness. If they are more distressed, patients' mental health and trust in their healthcare professionals can diminish⁸.

This gives us some important clues about how to offer relief to patients in existential distress: engendering feelings of support, bolstering a sense of hope and responding to overwhelming stimuli in the person's world.

Talking, relating – some verbal signposts

'It is impossible to live without failing at something, unless you live so cautiously that you might as well not have lived at all.'

– JK Rowling, author.

Why was I born? Why are we here? What is the purpose of my life? Why am I suffering? Did I do something to deserve this? How do we converse with people asking unanswerable questions? How do we share time in deep wisdom with another person?

Often people are unsure of the future. They might be anxious for the future of their family, their pets or their relationships. They might be asking for certainty, a certainty about past events and a certainty about the future. But certainty is rarely certain. Certainty-seeking might belie a deeper uncertainty about identity and meaning. In this way suffering, identity and meaning making are inter-related.

Your role as a volunteer is not to bring certainty but to be present with empathy. This leads us to consider some useful tips for talking with people about meaning and identity.

Here are some suggestions for your interactions with others⁹:

- Don't try to find the problem, don't try to fix the problem. Just be and don't do. It is your integrity and sincerity that will make the most impact on the person as they explore their meanings.
- Aim to build bridges and use 'low key' type questions if meeting for the first time. Hear the person's story, their past, present and their hopes for the future.
- Listen with empathy and build a relationship based on trust and mutuality. Learn to be present with the other person when they want to explore difficult concepts or experiences, be comfortable in the silence and allow the other to explore.

- Know your own boundaries, and remember that some people might benefit from specialized counselling if intense feelings are stirred-up.
- Validate the experiences of the other person, and acknowledge their emotions. Aim to create a peaceful environment that nurtures the spirit and wellbeing.
- Respect their choices even if they want silence, respect their space, respect their selection of what they do and don't want to talk about, encourage and allow their autonomy.
- Be sincere. Be open and compassionate, listening carefully, and answering truthfully, even if that means saying "I don't know".
- Don't 'sell' your own meaning-of-life message, but aim to create an environment where the person can explore or express their unique meanings.

A NSW study of volunteers working to support aged and community clients found 45% of respondents said conversations about death and dying have been raised by their clients. "Volunteers are warned it is normal for conversations about death and dying to crop up. They are encouraged to not back away but have a discussion about how that feels, help dispel any fears, go through regrets etc"¹⁰. Given that the volunteers in this study were not working in palliative care it is even more likely that palliative care volunteers will have conversations about death and dying.

Some of the questions you might be asked as a volunteer include:

- Will I die / am I going to die? A question like this may indicate that the person does not understand the nature and role of palliative care or the acuity of their condition. Typically, amongst traditional Muslim people they may not be informed of the nature of their diagnosis, so be respectful of how you respond to questions of this sort.
- When will I die? This might be a question indicating that they want to put their affairs in order, or it might indicate a desire to finish conversations with family members or attend to relationship issues. Often there is no time like the present to attend to important matters when end of life is approaching.
- How will I die? A question like this may mean they are frightened and/or seeking reassurance about the process of dying or about the site of care/site of death.
- What comes after death? No-one has the whole truth and no-one really knows. We continue on in the lives of those we love and who have loved us. This bond goes on after death. This question can provide the opportunity to explore what the person thinks/ believes about death and beyond, rather than to provide reassurances. This can open up hopes and fears, which calls for attentive listening rather than discussion.

In *Paediatric Palliative Care* if a child is asking questions about spirituality or death to the volunteer but not to the family members then the manager (and parent) should be informed. The manager might discuss this with the social worker.

For more information on Paediatric Palliative Care see *Chapter 12 Young People in Palliative Care*.

Spirituality and spiritual care

Each of us has searched for meaning in or made meaning from our own lives. Maybe along the way we have adopted a philosophical leaning, a religious practice, a faith tradition, a set of beliefs about the world, or formed our own unique worldview. Maybe we have a set of beliefs which simply reflect something other than what other people believe.

Your own search for meaning will make you more sensitive to the search that others may take and it certainly will benefit them if we have explored the important questions of life ourselves and attained some level of peace with our own mortality. The more comfortable we are with our own spirituality the better able we will be to develop respect for the spiritual needs of others.

The field and practice of spirituality and the practice of spiritual care share a common interest in bringing hope to people in suffering. Spirituality may be experienced as a quest for meaning, purpose, connection, belonging, and hope. It is intrinsic to being human and for this reason it gives a foundation for holistic care.

Spirituality considers the breadth of meaning, relationship and identity in life:

- Searching for meaning, answers to life's deep questions, hope, a sense of purpose.
- Relating to self, others, nature, the transcendent.
- Seeking how to live with integrity and in relation to the rights and needs of others.

Spirituality can be expressed in many different ways, often unique to the individual, usually drawing on the wisdom of faith traditions and community. Spirituality can deepen with growing reflective capacities and self-awareness, and can become more conscious at major turning points in life.

As an area of practice, **spiritual care** encompasses all the ways in which attention is paid to the spiritual dimension of life. It is most commonly offered in a one-to-one relationship, 'is person-centred and makes no assumptions about personal conviction or life orientation. It offers a way for people to experience and make meaning of their hopes and fears. Spiritual care is provided by practitioners to appropriately meet the individual's spiritual and emotional needs. Spiritual care may include presence, conversations, ritual, ceremonies and sharing of sacred texts and resources.

Spiritual care is not proselytising and does not impose the practitioner's beliefs or values'¹¹.

Children and spirituality

Spirituality and the search for meaning are not unique to adults. Like adults, children explore meaning through stories, nature and art.

The concept of 'death' as a permanent event may not be well developed, or developed at all, before the age of about 6 years. Beyond the age of 6 years the child's concept of death expands and may be thought of as a 'ghost' like event, or being 'bad'. Their understanding is often highly self-centered, and they may perceive events as being the result of their own 'wishing' or thinking and as such they might believe that is it their 'thoughts' that have made death occur¹².

Children readily absorb from their environment and many are highly sensitive to the cues given off by those around them, and the sincerity with which others share information and feelings. Parents may chew-over what to say and how to say it for fear of saying the wrong thing, while the child picks-up on the desire to withhold information and reads it as secrecy and insincerity. It is not unusual for children to elect the person with whom they wish to share information¹³.

This suggests that we approach children with a willingness to listen, but we allow them to choose whether to share with us.

Dr Joan Marston is a Palliative Care specialist from South Africa who's experience with children in Palliative Care¹⁴:

"...showed that spirituality is often misunderstood or ignored in children but they often express their spirituality through true stories. She spoke of one young child, often withdrawn and alone, who connected spirituality to the night sky using the stars as a way of expressing his inner self. She advised that when talking to children about spirituality – we wait for them to talk to us."

The spirituality of the family should also be considered within the context of the child's spirituality. Children will have absorbed ideas from family members which they may or may not have adopted themselves.

Many young people have the task of untangling themselves from childhood influences before they can resolve on their own belief systems. The volunteer can support the expression of beliefs and values, and the reconciliation of ideas, by a thoughtful and reflective approach to communicating.

For more information on Paediatric Palliative Care see *Chapter 12 Young People in Palliative Care*.



Additional resources

HammondCare hosts the **Palliative Bridge** website that has video resources on spirituality that may be helpful for volunteers in learning about spiritual support. The website can be found at www.palliativecarebridge.com.au

Spiritual Care Australia publishes a **Standards of Practice** document to give greater clarity to practitioners, managers and institutions regarding the professional work of those involved in Spiritual Care. The document can be downloaded at www.spiritualcareaustralia.org.au

Cancer Australia publishes **Clinical guidance for responding to suffering in adults with cancer** (2014) which highlights important ways to which suffering can be responded. The document can be downloaded at https://guidelines.canceraustralia.gov.au/guidelines/guideline_22.pdf



However, as a volunteer you should expect to be asked to support people of identities different to your own.

Chapter 7

Cultural Diversity and Families in Palliative Care

What is culture?

Culture occurs with shared meanings. Culture describes an identity to which people ascribe or are assigned. One definition of culture is 'a relatively specialised lifestyle of a group of people, consisting of their values, beliefs, artefacts and ways of communication that is passed on from one generation to the next'¹.

Ethnicity describes a group formed by common ancestry, cultural or national experience. Within an ethnic group there may be more than one language group.

CALD stands for 'culturally and linguistically diverse' and is a commonly used term in service delivery.

Multiculturalism is the existence, acceptance, or promotion of multiple cultural traditions within a single jurisdiction, usually considered in terms of the culture associated with an ethnic group.

Describing cultural diversity

How can we best describe cultural diversity?

Can we describe it in terms of place of birth? Data from the 2016 Census² indicates that roughly a quarter (26%) of Australia's population was born overseas and 49% of people have at least one overseas-born parent. The United Kingdom is the leading country of birth for migrants (representing 3.9% of all Australians), followed by New Zealand (2.2%) and China (2.2%), then India (1.9%). England is still the most common birthplace of migrants to Australia (15%). Over the past five years Chinese migration has increased dramatically (from 6.0% to 8.3%) as has Indian (5.6% to 7.4%).

Can we describe cultural diversity in terms of language? The census showed that less than half our overseas-born population (42%) spoke only English at home in 2016, while 8.3% spoke Mandarin, 3.5% spoke Cantonese and 3.1% spoke Vietnamese. In 2016, 21% of households had two or more languages spoken.

Can we describe cultural diversity in terms of religious affiliation? Religious traditions are one defining feature of culture, with 60% of people in Australia indicating a religious affiliation (including Christian 52%, Islam 2.6% and Buddhism 2.4%). Interestingly, 30% indicated 'no-religion'.

Each of these perspectives helps to paint a picture of cultural diversity. But it is an incomplete picture. What of the multi-generational Australian families who hold to family traditions of language and culture, including Italian, Polish, Turkish, Lebanese, Chinese and Greek people? What of families that embrace more than one religious tradition within their group? What of groups of diverse gender and sexuality within each ethnic, religious, ancestry, national and language group?

Why are these considerations important to your role as a volunteer? It is true that a volunteer who is representative of a particular cultural group can be valuable in providing support to other people of the same group. However, as a volunteer you should expect to be asked to support people of identities different to your own. To do this well will require more than just awareness, it will also require you to be mindful of your own cultural biases and to be thoughtful of how other groups may experience their involvement in palliative care.

Cultural bias, empathy and volunteering

African-Americans, as a demographic group, have deep-seated suspicions of health care like the US Hospice system that supports people with life limiting illness. '...black Americans — far more so than whites — (reject Hospice and) choose aggressive life-sustaining interventions, including resuscitation and mechanical ventilation, even when there is little chance of survival. At the root of the resistance, researchers and black physicians say, is a toxic distrust of a health care system that once displayed “No Negroes” signs at hospitals, performed involuntary sterilizations on black women and, in an infamous Tuskegee study, purposely left hundreds of black men untreated for syphilis’³.

Gender, sexuality, religion, nationality, ancestry, language and ethnicity each forms the basis for what we might describe as cultural identity. By inviting members of the public to work with vulnerable people, the field of palliative care recognises the importance of being culturally sensitive to different expressions of identity.

Definitions of culture are normative: that is to say our understanding of ‘culture’ is often based on our observation of another who we see as ‘not like us’. Serving culturally diverse communities means we need to have an appreciation of their unique shared meanings.

‘Arguably, what we observe in people and call culture are their ways of thinking, living and dying. We make inferences from their behaviour and ‘label’ it culture...In delivering palliative care that is culturally sensitive... the challenge is to understand each culture, that is its belief system and perceptions of health, illness and dying’⁴.

At the heart of cultural sensitivity is empathy, and the desire to be empathetic towards others. During this chapter you are encouraged to examine your own 'cultural biases' or attitudes toward others. Try and immerse yourself in the experience of other groups in your community and ask 'how are they experiencing palliative care, and how can I respond with empathy?'

You might discover that there are certain cultural groups that you cannot bear the thought of being empathetic towards. In the interests of better palliative care, you should be mindful of cultural bias and even confide these attitudes to your volunteer manager. Even with the best intentions, training in cultural awareness may not shift entrenched and negative attitudes.

Cultural bias affects our expectations and perceived norms of different cultural groups, but experiments show that training people in cultural awareness doesn't necessarily shift their culturally-biased attitudes. In one experiment, psychology professor Guy Boyesen placed counselors in three groups based on whether they had received negligible, a little or extensive training in cultural awareness. They were asked questions about different gender and ethnic groups in the community to reveal their cultural bias. No matter how much training the counselors had, their culturally-biased attitudes had not changed. To overcome such entrenched attitudes, Boyesen suggests that multicultural awareness should take the form of cultural immersion rather than classroom training⁵.

Interacting with families in a way that respects diversity

Families are at the centre of most diverse cultural traditions, and working with families is a useful context in which to understand the interplay of cultural tradition on day to day life.

The definition of what constitutes a family varies from person to person. Family consists of people who are tied emotionally, spiritually, economically, and socially to one another, either by birth or by choice. Members are brought together through different circumstances (including birth, marriage, choice, friendship) to form a complex system that functions according to fixed and changing internal and external influences. Like most complex systems, 'the whole is greater than the sum of its parts'⁶.

Within this system, roles are defined by culture and changing circumstances. Each family will be unique in terms of:

- The roles of individual family members.
- The traditional and evolving lines of authority.
- Gender roles.
- Decision-making roles.
- Internal communication (such as family meetings, open sharing of all information, protection of vulnerable members).
- External communication (this might include the designation of a person to speak for the client or the family).

It is often helpful to ask the person to describe these aspects of their family. In palliative care, the family plays a dual role. On the one hand, family members receive care and support from the care team, and on the other, family members provide care and support to the ill person. Each unique family system determines how individual family members will play this dual role. For example, in some cultures the eldest son may make treatment decisions for the ill parent while the spouse is not expected to deal with these decisions.

The family in Palliative Care

'Families relate to each other as if in a dance, where the steps are infinite and varied, and patterns may exist for generations. In supporting families, we must stay off the dance floor.'

– Elizabeth Causten, Victoria Hospice⁷

The impact of illness and end of life affects the whole family network and signals a time of change. Family members react as individuals and families react as groups.

The sudden demise and imminent death of a patriarch or matriarch might evoke a sense of disorientation as the members resolve on a new leader, or permit a new leader to emerge from the family group.

There may well be a yearning for things to be the way they were, before the illness developed. In some cultures, there will be a strong sense of obligation to withdraw from daily routines, to provide care for a loved one, and not to rely on health services.

One of the biggest impacts on the family, and the most difficult to deal with, is a deterioration in the person's mental or cognitive status. Confusion, agitation or personality changes can create anxiety about the person's safety. In particular the family is likely to feel a profound sense of losing the person they once knew and with whom they share such rich memories⁸.

There might be concern about the quality of care their loved one will receive. Will the service really care for my loved one? These feelings can arise in any cultural context and may lead to feelings of frustration, anger and guilt. Caregivers can feel resentful of the situation and the new responsibilities they have assumed.

Families can experience demoralisation and a gradual drop in esteem and feelings of effectiveness. Sometimes family members may withdraw from each other but project their emotional energy onto others.

The 'role changes' that occur as family members respond to the care-giving needs and prepare for life after the client's death have a significant impact on the family.

Changing roles means that family members are faced with learning new skills and making new decisions. Role changes are not limited to household and family tasks. Emotional roles will be altered and the family may need professional support or referral to other community services.

When family members become caregivers, the normal rhythm of the household routines and family interaction is disrupted. Children become caregivers for parents, spouses take on intimate care tasks, and the familiar relationship as a couple is put on hold.

A drastic re-organisation of the family system is not always smooth. The person in palliative care may not want to be around large groups of people, even their own family, or they might resent becoming more dependent on them. Family members may take advantage of the turmoil to pursue longstanding issues.

Cooperation between family members may be strained and break down. Resentment, anger, and frustration can all surface. The client and/or family member may have a history of substance abuse, financial difficulties, mental illness, or disability, or there could be a sudden onset of illness⁹.

How can the volunteer help?

Families have their own individual histories and cultural context which may well be hidden to us.

- Each person is doing the best they can under the circumstances. Remember the importance of not judging; the family is coping the best they can.
- They need support and acceptance, not judgment and disapproval. If you are unsure of particular cultural contexts, find a way to enquire sensitively.
- Each family member has their own way of dealing with difficulties in their lives.

- Everyone has a different experience of the same situation, and appearances are not always what they seem. It is not our job to take sides.
- We are there to support families, not change them.
- One of the most beneficial things we can do for families is to be present with them.

As a volunteer you will be wise to avoid getting entangled in family affairs, particularly where the atmosphere is hurtful or malicious.



Additional resources

Palliative Care Australia has a range of online and printable diverse cultural material with dual translation (English-Other) for Arabic, Chinese (Simplified and Traditional), Croatian, Greek, Italian, Macedonian, Maltese, Polish, Turkish and Vietnamese nationalities suitable for use with clients¹⁰.

Palliative Care Australia also publishes the **Multicultural Palliative Care Guidelines**¹¹ which are aimed at people who work with culturally and linguistically diverse communities.

Palliative Care Victoria has recently developed a suite of resources to promote access to culturally inclusive and responsive Palliative Care services for people from diverse cultural, linguistic and faith backgrounds. These are free to access from their online library www.pcvlibrary.asn.au.

Your local Palliative Care Service may have developed specific information for local catchment populations. For more information about your local catchment's cultural-demographics you can search online using the **Multicultural NSW** website <http://multiculturalnsw.id.com.au/ancestry-select>.

The Decision Assist initiative of CareSearch www.caresearch.com.au has multicultural resources on their website or available from 1300 668 908.



Everyone grieves in
their own way according
to gender, personality,
family, cultural background,
and life experiences.

Chapter 8

Grief and Bereavement

Grief, death and loss

'No one ever told me that grief felt so like fear. I am not afraid but the sensation is like being afraid. The same fluttering in the stomach, the same restlessness, the yawning. I keep on swallowing

– CS Lewis, *A Grief Observed*

Grief, death and loss are intertwined.

The individual's and family's experience of grief may start at the time of diagnosis, possibly well before the person dies. For example a person with motor neuron disease might be supported by the palliative care team for many years before death. A child with a life limiting illness might be supported by palliative care from birth in some cases for more than 10 years. Counsellors refer to this sort of grief as anticipatory in nature. For simplicity the references to grief in this chapter are to the post-death period.

Grief describes our feelings, thoughts and behaviours which result from our loss. Bereavement refers to the social experience of loss of a person in this case through death. For simplicity in this chapter we will use the terms interchangeably.

Also in this chapter we make reference to the 'resolution of grief'. In reality when we suffer a great loss it is a transformative experience for better or for worse. Hence the concept of 'resolution of grief' is possibly better thought of as the 'relocation of grief' or the 'absorption of grief' in our worlds and identities.

Into and out of grief

Grief is a normal reaction to loss. Even so people can experience magical thinking and feelings of derangement. They might sense hauntings, or cling to superstitions, myths, celebrations and rituals to accommodate the intensity of the experience. In subtle and not so subtle ways our reactions to loss are as diverse as the ways in which we make sense of and experience life.

Grieving can be thought of as a process, or as a way of processing loss. The grieving process entails the changing feelings and behaviours that occur over time.

Just as individuals experience life differently so too each person may grieve in their own way. In many the initial reaction to loss is akin to shock and individuals may talk about feelings of disbelief and dismay, emotional blunting and even denial as they struggle to grasp the implications of the event or diagnosis on the cessation of their life and the changing of their relationships. "I can't believe it", "it can't be true". These feelings may transition into more open expressions of guilt or anger directed at the deceased, they may display signs of intense ruminative or disorganized thinking and behaviour (like wandering) and even hostile reactions to anyone who offers consolation, all of these akin to 'pangs of grief'. What we think of as the final resolution of grief might be thought of as the person reorganizing how they think about their attachment to the deceased and how they relate to the new world without them. Resuming old roles, refreshing old attachments and forming new attachments are all part of the task of making sense of the world around them while they continue to live with their grief¹.

While these phases or stages of grief may be stereotypical of the grief journey, an individual's experience of grief may be affected by both personal factors and social influences.

Personal factors that are likely to benefit a person on their journey include mental wellness, positive psychology, resilience, preparedness, positive coping skills and a worldview that affirms life, hope and purpose. Supportive relationships, emotional awareness and insight, help-seeking behaviour, and feelings of healthy resolution with the deceased person are also positives. Conversely there are many personal factors that might make the processing of their grief harder: a history of trauma, gender stereotypes that tend to discourage help-seeking behaviour or reduce access to support, a worldview or system of belief that undermines self-worth, or multiple losses experienced close together each make the experience of bereavement more disruptive. In addition an unresolved or dysfunctional relationship with the deceased, a death that disenfranchises or deprives the person from having their loss accepted and acknowledged by others (such as suicide) or the experience of other forms of loss (loss of income, loss of housing, loss of social status, loss of nationality) with the loss of a partner or child may further intensify, prolong or disrupt the grief experience.

A person's **social influences** may also affect their experience of grief and the social determinants of health (as introduced in Chapter 2) provide a framework for understanding these experiences. For example an individual's education (and their capacity to understand and engage with the health care system as – 'health literacy' – to seek bereavement support), or their security of income (and the risk of unemployment for workers who take prolonged leave for carer duties or in bereavement) are both examples of how social determinants may affect grief outcomes.

For some people the post-death grief period is also associated with finalizing the person's estate (estate administration). This additional role may be particularly challenging if the person has limited social support or literacy, limited educational background or if they experience structural vulnerability because of their aboriginal status, gender, race, sexuality, disability or as a consequence of being a social security or social housing recipient.

We started this chapter talking about the typical phases or stages of grief, but sometimes the grief experience is too complex and dynamic to be characterised in discrete phases. Another helpful way to think about grief is to recognise the disruption that is taking place in the life of the bereaved and their resulting sense of being torn away from their social 'homeland' into a new and strange place.

'I found myself in foreign territory with no guidelines for me, it was very frightening'².

Through this idea of the grieving person being disrupted from their homeland we can reimagine grief as a metaphor for wandering in a new land and the grieving person as someone who is looking for a new place to settle. They might be familiar with the emotional landscape or not, they may have a social network or not, but ultimately the decision on where to settle will be one that only they can make. You, as a volunteer, can help them to feel supported while they explore the geography of their new world.

Eventually we want for everyone to settle with as much contentment about their new homeland as possible, but not everyone will settle as well as others. In a small percentage of cases grief can become abnormal, protracted and unhealthy. Counsellors refer to this experience of 'complicated grief' as being stuck in grief and unable to return to an emotional state of well-being³. In such cases people need additional and specialised support by clinicians in grief and bereavement support (see Chapter 9).

Interacting with people in grief

The pain of grief is just as much part of life as the joy of love; it is perhaps the price we pay for love, the cost of commitment.

– Dr Colin Murray Parkes St. Christopher's Hospice, London, UK⁴

Acknowledge the death as soon as you can. Even if you 'don't know the right thing to say' people will appreciate you acknowledging their loss with sincerity and honesty. Say that you are sorry to hear of the death, mention the person by name, and be willing to listen to what the bereaved person may say.

Be genuine by being yourself. Continue your usual relationship with the bereaved person. A close friend will want and expect caring contact, but do not assume an unfamiliar intimacy.

Usually the person who is grieving will want to talk. Allow them to tell and repeat their story. By listening you may hear the same fears, emotions, stories, and regrets told over and over again. That's okay. It's all part of integrating the past with the present, remembering and saying goodbye. Sharing memories of the person who died can bring comfort. It is okay to reminisce and to bring up the person's name in conversation.

Learn about grief. Ask the library for some books on grief. Check out local resources and the Internet. Accept that you cannot take the pain away. Trying to cheer up a bereaved person denies the significance and depth of his or her grief and in some cases is considered culturally inappropriate.

Reach out to offer support. Many bereaved people are concerned about being a burden on friends and family. Be patient. Mourning takes lots of time and grief may never resolve entirely. Understand that everyone grieves in his or her own way and at his or her own pace. Accept the bereaved person's evaluation of the significance of the loss and the depth of his or her feelings. Remember that there is no right way to grieve. Don't judge how long a person's grief appears to be taking. Avoid criticising how someone is grieving or directing how they should grieve. They are the expert as to what is best for them.

Expect that your own grief may be triggered. Personal feelings of loss or grief may be related to this death or to losses that happened in the person's past. But also acknowledge that the person's experience of grief and the 'shared trauma' you have in common with them is very valuable in helping them feel supported².

We should encourage the person to talk about the past and their memories but in the role of supportive friend rather than counsellor. Recognise when and how to keep silent. Allow the person to not speak about the topic. Say "I'm sorry, I didn't mean to pry", rather than "I'm sorry. Of course, that's too painful for you still isn't it?" This may seem picky but the first response places the responsibility with us whereas the second implies they're not "recovering fast enough".

People who are grieving may lose interest in the mundane day to day chores. Everything can seem trivial and they find it hard concentrating on daily tasks. Help out if it seems appropriate – but offer to perform a particular job rather than making the general statement, "Let me know if I can do anything". This phrase means they have to initiate contact with you and, for fear of appearing needy or troublesome, they probably won't. On the other hand a small gesture of support might be more valuable in terms of easing their sense of burden.

Remember that grief may surface at significant times such as birthdays, anniversaries, at Christmas or at holiday seasons. These can be painful times when the loss of their loved one is brought into sharp focus. Be mindful of these times and think about whether there is anything you can do to provide support.

Grief can manifest in physical, emotional and behavioural experiences, such as tightness in the chest, numbness, breathlessness, fatigue, anxiety, low energy, sleep disturbances, social withdrawal, crying and wandering. A person in grief may even believe that the profound multi-systems response that they are living with is caused not by grief but from some other stress or illness in their life⁵.

These are some of the things that might hinder a conversation with a person who is bereaved:

Don't exhort people to be strong:

"(The person who died) wouldn't want you to cry" or "Be brave. You don't want the children to see you crying."

Don't urge people to hurry up their grief:

"Life goes on" "You'll get over it" or "Try and look to the future. You've got so much ahead of you."

Don't increase guilt about how people are grieving: "You aren't counting your blessings" or "He lived such a full life."

Don't suggest that a religious explanation should be comforting: "God never gives you more than you can handle" or "It was God's will."

Don't discount and minimise grief:

"I know how you feel."

Remember too that most grieving people appreciate kindness and understanding but they rarely want to be ignored or avoided.

Children and bereavement

What is the best way to support a child who has lost, or is about to lose, a parent? Or their sibling? What factors determine how they will cope after the loss of a parent?

Statistics indicate that each year 2% of children are bereaved of a parent before the age of 18 years whether by sudden or progressive decline⁶. Research indicates that the child's reaction is heavily influenced by their developmental stage. The most profound experience for them might be the cascade of consequences of the loss on family dynamics and functioning, although this is typically delayed for some months until the attention of others wanes and the full impact of the loss is experienced. Unlike adults, children typically don't grieve all the time but experience grief in bouts of very short time periods⁷.

Children benefit from sharing their feelings and exploring their thoughts about death and loss, although they must be allowed to instigate discussions⁸.

As a volunteer you may have the opportunity to be invited into a discussion with a child about death and loss. Bear in mind that children who have been more involved in their parent's treatment (or their own) may be much more forthcoming in asking direct questions about treatment and death. If you don't know the answer it is better to say so than avoid the answer or make up what appears to be a suitable response⁹.

For adolescents the impact of displacement and uncertainty are additive to the normal teenage tasks of establishing identity and finding purpose. In adolescence moods can swing to extremes, and this can be exacerbated by grief and loss. Some may respond with more adult-maturity (acceptance, confidence), and others may become more rebellious and argumentative, or withdrawn⁹.

Adolescents may feel too old for children's services, and they may not want to engage with adult services. Services like *Headspace* (www.headspace.org.au) for young people 12–25 years offer support and counselling free of charge and might be a good source of support for a person who is struggling with grief and bereavement.

Anticipatory grief refers to the person's reaction to the anticipation of loss. For parents of young children this includes grieving for the milestones that may not be reached e.g. attending school, graduation etc. Psycho-social support can assist families in managing this so the anticipatory grief doesn't overwhelm their ability to enjoy their time with their child in the present.



Additional resources

National Carer Counselling Program offers short-term counselling for carers 1800 242 636.

Lifeline 24 hour listening service 13 11 14

Beyondblue 24 hour 1300 224 636

Headspace www.headspace.org.au

Young Carers 1800 242 636

Kids Help Line 1800 55 1800

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

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



Grief and Bereavement
Support is a feature of all
specialist palliative care
services in Australia.

Chapter 9

Bereavement Support Programs and Volunteers

Palliative care and grief and bereavement support

Given the profound effect of grieving on individuals, grief has significant consequences for population health. It is estimated that at least 5 close friends or loved ones are left behind for every person who dies¹. This suggests that between 5% and 9% of the general population each year are affected by grief².

Palliative care has an interest in living, dying and grieving well and hence Grief and Bereavement Support is a feature of all specialist palliative care services in Australia. This is confirmed by the *National Palliative Care Standards* (Standard 6: Grief support) which require specialist palliative care services to ensure that families and carers have access to bereavement support services and are provided with information about loss and grief³.

Typically grief and bereavement support aims to reduce the impact of grieving on the person and steer them toward healthy function. Counsellors may be dedicated staff within palliative care or they may be shared with other specialities within the health service. Publications such as the Victorian Department of Health's *Bereavement Support Standards for Specialist Palliative Care Services* help to guide service delivery⁴.

Grief describes our feelings, thoughts and behaviours which result from our loss. Bereavement refers to the social experience of loss of a person in this case through death. For simplicity in this chapter we will use the terms interchangeably.

Volunteers and grief and bereavement programs in NSW

The Volunteer Support Services Programme studied the experience of volunteers in bereavement support in NSW⁵ and found that their most common involvement was one-on-one contact with clients, representing 89% of respondents, with some 62% involved in one-on-one face-to-face contact once a week. Other activities by volunteers included group support (25% of respondents) the provision of 'health-service related information' (10%) and involvement in 'anniversary card' programs (7%). Find the report on the www.volunteerhub.com.au website.

Responding to the need for grief and bereavement support

In Chapter 8 we noted that grief is a normal response to the death of a loved-one, the grief response can be unhealthy if it is protracted and people can be 'stuck' in grief for years with a consequent erosion of their self, health and social connectedness. Hence grief-work deals with the complex ways in which death and loss impacts self and relationships.

There are many different contexts to the bereavement experience. Here are just a few:

- Adult loses a partner
- Adult loses a child
- Child loses a parent
- Child loses a sibling
- Teenager loses a parent
- Teenager loses a sibling.

The term 'grief' suggests an experience that is intimate in nature, whereas the term 'bereavement' relates to the broader social and relational experience of the person. Loss of social networks, income, housing, mutual support, family relationships and social status may each be a part of a person's bereavement experience.

These notes consider 3 programs with different goals:

1. A bereavement support program which aims to provide information and connection during the grieving period;
2. A memorial service as a community event to recognise loss and grief in a supportive environment; and
3. A telephone bereavement follow-up program that aims to be a conduit between the support the family and carers are getting from health services prior to the patient's death and them being on their own post-bereavement.

1. Bereavement support programs: Helping with the task of grief

That grief is a universal experience in relation to palliative care points to the opportunity for a volunteer service to offer support to people who are experiencing normal grief. Bruce Rumbold and others studied the experience of bereaved care givers and identified opportunities for volunteer input into the post-bereavement period⁶:

'While most bereaved people do not require professional counseling, all would benefit from appropriate information and compassion... Additionally, approximately one-third of the bereaved caregivers would benefit from opportunities to reflect upon their loss, which could be provided by trained volunteers and bereavement support groups. For them, a brochure or telephone call alone might not be sufficient, yet they do not require specialist intervention.'

This is part of a public health approach to post-bereavement care, the palliative care equivalent of antenatal classes for expecting parents.

One of the challenges is in creating a socially-acceptable context within which to approach recently bereaved persons and encourage or invite them to share their experience of loss and their feelings. One approach considered here is a mail-campaign to engage directly with people post-bereavement.

Bereavement follow-up cards

A follow-up program with scheduled correspondence is an effective method of providing unobtrusive contact and encouragement to people post-bereavement. One program with the goal of providing non-intrusive support into the life of a carer post-bereavement is the follow-up program run by PACT from Clare Holland House⁷.

Volunteers in the program receive referrals and are then active in preparing and scheduling the correspondence to be sent. Referrals include the date of death and the contact details for the loved ones and family of people who have recently died. There may be more than one person to whom correspondence is sent. Details are provided by members of the clinical team to the manager.

The volunteers then prepare 3 letters which will be scheduled in advance for sending on a defined date.

An initial card is scheduled to be sent 2 weeks post-bereavement. This is a 'with sympathy' message with appropriate wording:

Dear <name>, Following the death of <name> we offer you our ongoing support. If you or your family feel the need of our help, please contact us and a team member will return your call. Remember we are always only a phone call away <phone number>. Kind regards, From the staff and volunteers of <name of service>

Care and attention is needed in the preparation and sending of the cards, as errors in details such as names and dates may reflect a lack of sincerity by the service. Using hand-written cards adds sincerity and human-ness to the contact.

A second letter is scheduled for 6 weeks post-bereavement. This time a standard printed letter is included to which the person's name is added:

Dear <name>, Following on from our card we would like you to know that our support is still available. Grieving is never the same for any two people. Your experience of grief is personal and unique. Care and support from family and friends is invaluable, however you may find it useful to talk to a professional who understands grief and is not personally involved in your loss. There are many people, organisations and activities which may be of help to you. We have enclosed some information about our service and other related services within the <local> area, including our brochure <on grief>. Please feel free to contact us if the need arises. Kind regards, from the staff and volunteers of <name of service>

There are 2 items of additional bereavement information enclosed with the letter: a brochure that outlines the common experiences of grief; and a list of grief and bereavement services which can be contacted or accessed online.

A further card is sent at 12 months post-bereavement. This is a blank card to which appropriate wording is added:

Dear <name>, We are remembering you on this first anniversary of <name's> death. Continuing support is available and you are welcome to contact <bereavement counsellors> on <phone number/s>. Kind regards, from the staff and volunteers of <name of service>.

All the necessary preparation is done in advance. Once the cards (x2) and letter (x1) are prepared they are filed by date in a box-file and the date noted on the outside of the envelope where the stamp is to be later affixed. Upon the date for postage the letters can be easily pulled and mailed. Using more than one volunteer in preparing the letters helps not only with reducing the workload but it also helps with double checking that the details of names and postal dates are correct. This highlights one of the qualities of volunteers in a follow-up program – their attention to detail and care in preparation of correspondence.

At any time, the person being contacted can opt out of the service. The service ceases upon the third correspondence sent at 12 months but people can opt to remain in touch.

In some cases, the cards are 'returned to sender' especially as the time since death increases or if the surviving spouse is elderly as people may move (to be closer to family or into residential aged care).

2. Memorial services: Acknowledging loss and grief, celebrating life

In this section a memorial service refers to an annual event which invites people to collectively commemorate the life, death and memory of their loved-ones in a supportive group service. Although they take many forms, memorial services are generally semi-formal in nature and are hosted in a quiet and peaceful setting that offers the opportunity for reflection and recognition of the loss.

Aims and goals vary from service to service and might include⁸:

- **Offering an opportunity for people to commemorate the loss of a loved-one before others.** By attending a memorial service, a person is recognised as someone who wishes to remember their loved-one and to commemorate them before others, in addition to acknowledging in public the nature of their relationship with the person.
- **Creating a space in which the personal experience of suffering loss and grief can be mutually acknowledged.** Grief and loss will and do exist well beyond the early days of the funeral service, and beyond the initial attention of friends and relatives which may fade after a few months. A memorial service offers an opportunity for a person to be included in a group who has or is experiencing the grief associated with death and loss. The simple act of inclusion by others can demonstrate that acceptance and validation of their feelings. In this way the memorial service can be therapeutic in nature.
- **Allowing an opportunity for people to acknowledge the importance of the emotional and spiritual dimension within their world.** For many people the loss of a loved-one can be overshadowed by the day-to-day demands of life and living in a material body and world. This might be at odds with the existential suffering they experience because of their loss, and may lead them to question their values and purpose. A memorial service gives them the opportunity to pause and acknowledge this emotional and spiritual dimension, and to have these dimensions validated. In this way the deliberate act of attending a memorial service can be an important form of testimony through which a person asserts meaning in their life.

The format may vary but it is intended to be respectful, calm and unhurried. A time for refreshments at the end of the service also serves as an opportunity for individuals to share and reflect with each other outside the formality of the service.

For recently bereaved people it may be too soon to attend a memorial service as the memories may be too raw for them. For this reason, it is necessary to be selective about who is invited to attend a service, and advice should be sought before sending invitations.

Individuals will bring their own meaning to the service and from the service. It is probably not necessary to be too creative or novel in format, as familiarity will do much to offer a sense of safety for the person who has been before and this will be conveyed to those attending for the first time.

3. Telephone bereavement follow-up programs: Helping people disconnect from the system

Apart from the existential experience of loss, there is a practical need for people to adjust to their new life and let go of the supports within the health system that have become so familiar. For some this will come naturally with the death of their loved-one, for others the process might be more protracted. The health service has an interest in seeing people transition out of their support into healthy living.

Aims and goals vary from service to service and might include:

- **Being a conduit between the different supports that people are receiving.** The health system supports the episodic needs of families and loved ones in palliative care, and this support may come through different groups (community nursing, social work, pastoral care) within the system. The bereavement follow-up service can help map how people are involved in the system, in a way that moves loved ones to live more autonomously of health services.
- **Identifying people who are struggling with their loss** and are likely to require specialist support. The bereavement follow-up is not a counselling service and isn't suitable for people who need bereavement counselling. People who may be at risk of complicated grief should be referred on to a counselling service (such as referral to a psychologist).
- **Reducing isolation by guiding people to be involved** with services in the community that can provide a sense of community connection (such as the local Men's Shed). For some the loss of a loved one is experienced as a 'social' death, representing a change in the way that they are accepted amongst society and among their social circles. This requires adaptation to new domestic tasks, circles of friends, responsibilities. Inevitably the experience of social isolation will factor into the role that a bereavement follow-up service performs, and reducing isolation is an important outcome of a follow-up program.

The usual frequency of contact is once a month until 6 months post-bereavement.

Not everyone is available or contactable. People might be at work, or they might have moved or disconnected their phone. If contact cannot be made then a letter is sent to say that contact had been attempted and encouraging the person to call.

Whatever the role and focus of the program volunteers will benefit from proper training and preparation including:

- Understanding how the local health service supports loved ones in palliative care;
- An understanding of grief and loss;
- An awareness of unhealthy grief and of the process to refer a person to specialised support;
- Understanding what local community groups are suitable for people who are post-bereavement, and perhaps at risk of social-disconnection;
- Telephone skills;
- Care and attention to detail, particularly when preparing correspondence and recording tasks completed; and
- Respecting privacy and confidentiality issues.

Bereavement follow-up is a skilled task that requires care and attention in the planning, and interpersonal skills and emotional intelligence in the delivery. To be effective in this role you should take the time to reflect on your own emotional landscape and cultivate a sense of awareness of your own loss experiences so that you can be present for others.



Additional resources

In addition to the grief and loss, bereavement and counselling resources within the health service the following resources might be useful.

If your service doesn't have a brochure on grief then the DL sized brochure from **Palliative Care Australia** *Now What? Understanding Grief* might be of interest. See www.pca.org.au.

The **National Association for Loss and Grief NSW** (NALAG) has an extensive range of resources available through their website www.nalag.org.au which are available for no cost. They also have training programs in loss and grief. NALAG are a member-based organisation which offers benefits to members including eNews and discounts on training.



Part of the role of the palliative care volunteer is to be open to the many and varied responses that people bring into the inpatient setting and to be present with them.

Chapter 10

Inpatient & Residential Settings

Site of care, site of death

Site of care refers to the place in which a person receives care, whereas site of death refers to the place where they die.

For people living with a life limiting chronic illness the site of care is generally the home environment, and for some people a residential aged care facility is their home. At times people may experience symptoms that are so acute or unstable that they need the intensive and specialist support offered by an inpatient setting. This is often true in the last year of life with some services reporting as many as 7 admissions to specialist palliative care by patients in their final 12 months of life for support with managing symptoms like pain¹.

The reason for their admission might be complex: the suitability of support where they live, the availability of suitable services and the preferences of care givers. The site of death is often the result of decisions made while the person is actively dying. The need to provide more intensive support is often the reason why the eventual site of death is different to the preferred site of care.

Consequently, people may be admitted with many and varied experiences, expectations and emotions. They might have been distressed and isolated at home and are now relieved to be admitted; they might be angry that their symptoms are so unstable, and scared that they may never go home again; they might have left pets behind that they fear will be neglected, or left words unspoken that they fear will never be said; they might resent the loss of autonomy and control of the inpatient setting. They might be experiencing a full range of tangled emotions.

Part of the role of the palliative care volunteer is to be open to the many and varied responses that people bring into the inpatient setting and to be present with them. This chapter explores the teams within inpatient settings and the role of the palliative care volunteer in supporting patients and families.

Hospitals & palliative care units

Some **hospitals** and **health services** have dedicated palliative care wards, others have mixed wards with some dedicated palliative care beds, and others have no dedicated beds but rely on specialist input from practitioners who might be on staff (consultancy) or who might visit from outside the hospital (in-reach). Short-stay inpatient allows for multidisciplinary assessment, collaboration and management of symptoms within the hospital environment. Once the patient's symptoms are stabilised and their management plan completed the person is typically discharged home, and for older patients a residential aged care facility is an alternative. A community palliative care service is provided for people who are discharged home.

An alternative is a stand-alone palliative care unit such as the Mt Druitt Supportive and **Palliative Care Unit** (16 beds, 1998) the Concord Palliative Care Unit (20 beds, 2014), and the Wauchope Palliative Care Unit (8 beds, 2014). The palliative care unit offers separation from the usual intensity of the medicalised environment while still offering specialised services. Typically, the palliative care unit is co-located on hospital grounds, but not necessarily.

As a volunteer in a hospital, health service or unit you will be working within the multidisciplinary team (MDT). The multidisciplinary team is a feature of palliative care inpatient support particularly in hospitals and palliative care units. There are many functions of the multidisciplinary team in palliative care, including:

- advocating on behalf of the wishes of patients, families and caregivers
- implementing multiple strategies to address the needs of the individual
- adapting the team composition accordingly in response to changing needs throughout the disease trajectory
- utilising the process of advance care planning.

The composition of the multidisciplinary team can include many members across several professional disciplines including those from other specialties e.g. specialists in pain management, geriatrics and psychiatry².

A multidisciplinary team will mean different things to different services. For some it will mean having many specialist palliative care practitioners involved in the service itself. This could be Pastoral Care Workers, Social Workers, Music Therapists, Bereavement Counsellors or Occupational Therapists. For others it will mean referring to health professionals within the same organisation or health service, such as a hospital physiotherapist. For some in more rural and remote areas this referral to other disciplines may be difficult with long waiting lists and distances to travel for appointments³.

As a volunteer you'll need to be inducted into the multidisciplinary team and setting. Some of the questions to be answered include:

- who do you report to, who do you ask when you need guidance or when you have questions to be answered;
- the daily routine for checking in, reviewing your role for the day, and what to do if and when you are leaving the setting;
- the scope of your role and the expectations about how you interact with the other multidisciplinary team members;
- what to do if you have concerns or observations that you feel should be reported; and
- any particular workplace health and safety or patient care considerations within that setting.

In addition to these things you should be familiar with your privacy and confidentiality considerations. What and with whom can you share patient information? Can you talk with other members of the multidisciplinary team about patient concerns or only to some? What information can you share with other patients? Managing privacy in a team setting takes time to perfect. As always, if in doubt – ask.

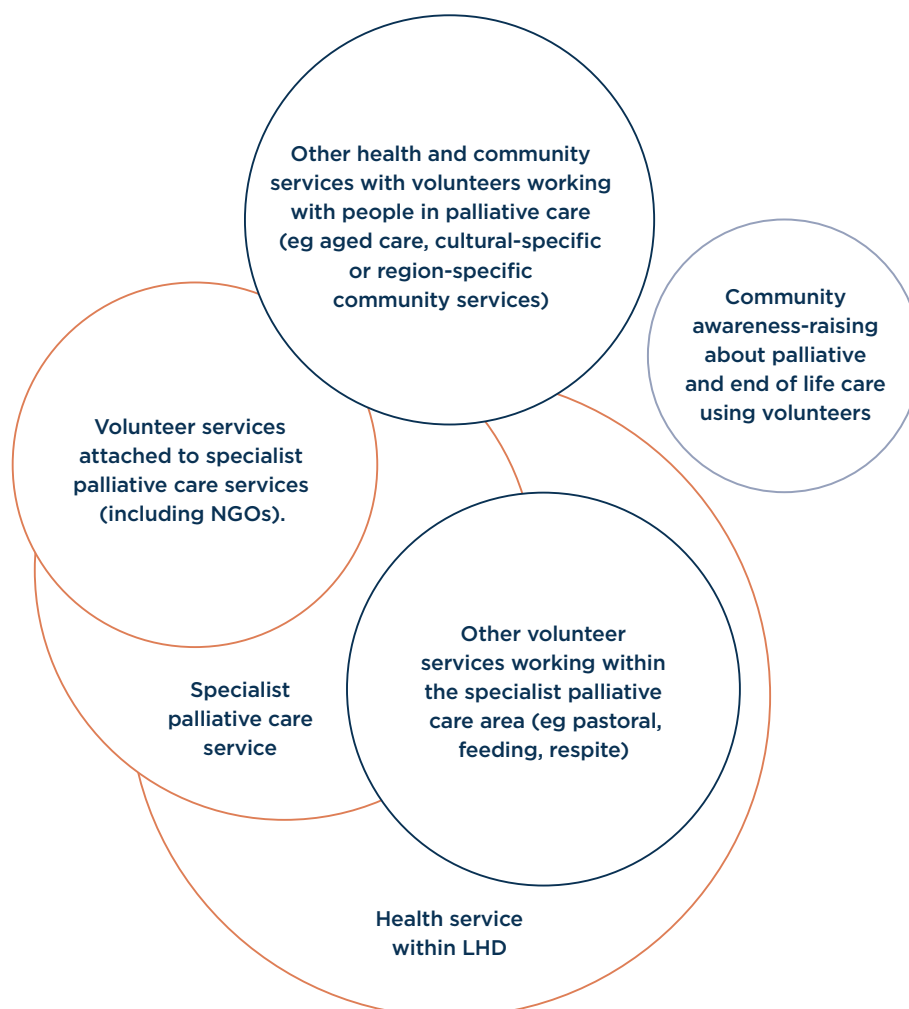
In some health services the palliative care volunteers are designated as 'contingent workers' which allows for them to have staff access to some locations as well as access to online training. If this applies to you then be mindful of the additional burden of responsibility that the designation carries.

Part of your induction training will include topics which are mandated by the health service. These may include work health and safety, manual handling, fire safety, infection control, privacy and confidentiality, use of information technology. Be aware that many of these topics will need renewing from time to time. You may also be required to be immunized depending on the nature of the setting.

Depending on the size and capacity of the unit, hospital or health service there might be other volunteer groups involved in patient support. Some of these might include: Dementia & Delirium volunteers; social support volunteers working in fields like sub-acute rehabilitation, mental health or oncology; pastoral care volunteers; volunteer navigators and guides for visitors; Pink Ladies and members of the auxiliary groups.

Bear in mind that other staff might not be familiar with the specific role of palliative care volunteers and might confuse you with a volunteer with another group that has a different focus. This is another of the benefits of wearing the designated identification (polo shirt, badge, vest, lanyard) provided by your health service.

Not one but many – the diversity of volunteer services related to Palliative Care



Residential Aged Care Facilities

End of life care is also provided in **residential aged care facilities** (RACF). In NSW the 875 residential aged care facilities have an average of 75 beds per facility⁴ with about 20,000 deaths each year. Residential aged care facilities provide support to 1 in every 13 Australians over the age of 65 with an average age of 85.8 for women and 81.6 for men (in 2013–14)⁵, so responding to the palliative care needs of residents is a big part of the work of facility staff.

The federal government funds the Community Visitor Scheme that supports volunteers visiting individuals who are in aged care (at home or in residential settings). Some residential aged care services have their own volunteers, and some invite volunteers from outside organisations, to support residents – usually to relieve social isolation or to engage them in activities. Residential aged care facilities are operated by either for-profit or not-for-profit providers, with the latter more likely to include volunteers in the support of their residents.

As a volunteer in a residential aged care facility you will be working closely with the facility's direct patient care staff. The staffing arrangements in a residential aged care facility largely comprise Extended Care Attendants. You may also work with Enrolled Nurses and some facilities employ Registered Nurses. Depending on the size of the facility there may be other roles for lifestyle, diversional therapy and facility management.

As a volunteer you'll need to be inducted into the service. Some of the questions to be answered include:

- who do you report to, who do you ask when you need guidance or when you have questions to be answered;
- the daily routine for checking in, reviewing your role for the day, and what to do if and when you are leaving the facility;
- the scope of your role and the expectations about how you interact with the other staff;
- what to do if you have concerns or observations that you feel should be reported; and
- any particular workplace health and safety or patient care considerations within the facility.

It is mandatory for all staff and volunteers to have a current criminal safety check, and within aged care settings for this check to be renewed every 3 years.

At commencement you should be inducted into the facilities premises and policies. Given that the focus of your role is on aged persons you might find that you are included in professional development in important areas of knowledge including advance care planning, elder abuse, privacy and confidentiality, infection control as well as personal planning and support.

Other settings

There are other respite and end of life accommodation settings that include volunteers in their models of care:

A **hospice** is a term that usually refers to a stand-alone facility dedicated to offering accommodation to people at end of life. The term hospice might be used interchangeably with a palliative care unit, although it is generally taken to mean a facility with a more general and less specialised suite of care. Hospices that are owned and managed by a volunteer-governed not for profit organisation rely on volunteer involvement to provide support services, fundraising and governance. These are sometimes referred to as community hospices, and might have between 2-8 beds for end of life or respite care. Depending on their availability of funding a community hospice might have Registered Nurses on duty 24 x 7. The volunteer is inseparable from the care team when it comes to resident support. As a volunteer you will probably be rostered on as part of a team of volunteers.

A **Multipurpose Service** (MPS) is a mixed service funding model managed by the local hospital network (in NSW the Local Health Districts) with funding through the state and federal government. Not unlike a small hospital, the MPS is typically found in rural towns with a range of services that might include emergency, rehabilitation and residential aged care as a 'flexible care' service⁶. In NSW there are 60 MPSs representing about 990 beds for aged care. The MPS will have a mixture of nursing and other care staff, often working flexibly across the various services offered by the facility. As a volunteer you may be supporting people who come into the service as part of short term carer respite. The inpatient volunteer role may be combined with a community visiting role, as patients and their carers may also benefit from support in the home environment.



Additional resources

In addition to the resources within the health service the following resources might be useful to volunteers.

Palliative Care Online is a free online course developed to help everyone who is involved in the care of an older person receiving or needing palliative care, head to www.ahha.asn.au/pallcareonline.

End of Life Essentials is an online learning resource for people working in acute settings (hospitals, health services). You can register and learn here: www.caresearch.com.au/caresearch/tabid/3866/Default.aspx.

An older resource **Volunteers Contributing to a Palliative Approach in Aged Care: Toolkit** published in 2005 by the National Palliative Care Program offers a range of resources and guidelines for volunteers in aged care. The Toolkit can be found online.



In some ways home
visiting requires a different
set of skills to, say,
inpatient volunteering.

Chapter 11

Home and Community Visiting

Improving support for people to live and die at home

Community nursing plays a central role in the delivery of palliative care in most Local Health Districts in NSW. In some cases, the team has a 'consultancy' role visiting hospitals and providing input and support on the care of people in palliative care. In all cases they visit people at home. Palliative care volunteers may be coordinated by one of the community nursing team.

The support of children and young people in palliative care is often provided within the home setting. Volunteers often feature prominently in this support, which characteristically goes on for months to years given the nature of diagnosis and disability experienced by the young person.

Bereavement brings with it a new set of challenges to a person whose partner has recently died. If the person is elderly then the challenges may include a profound sense of social isolation. Palliative care volunteers may also be involved in home visiting as part of their health service's bereavement follow-up.

Volunteers for a home-visiting service

In some ways home visiting requires a different set of skills to, say, inpatient volunteering.

Home visiting requires volunteers who are more autonomous, are willing to work with less supervision and are willing and able to identify their own limitations and ask for help. This is in contrast to volunteers who work in inpatient settings that need to be skilled in team-work and are happy working in a more formal and procedural environment.

Reflect on your own skills and preferences. Would you be confident entering someone's house and responding to the various situations that might arise? You may, or may not feel confident in time with training and support.

Remember that health care workers are travelling and visiting in the community every day. Community Nursing, Child and Maternal Health, Mental Health, Disability Support, Housing, Aged Care in the home and Child Protection are just some of the disciplines that regularly visit people in their own homes. In addition, Meals on Wheels, Home Maintenance services, Patient Transport and culture-specific support groups routinely send volunteers into people's homes.

Creating a safety framework for home visiting

Some of the considerations for home visiting (whether paid staff or volunteers) are:

- identifying safety issues, determining when it is safe to visit, how to make it safer and what to do if the visit gets tricky;
- practical safety tips and strategies for home visiting;
- approaches to work with clients that will keep you safer;
- good risk assessment practice in home visiting and strategies for safe home visiting;
- developing/supporting agency policies and your home visiting practices; and
- supporting you to maintain client-centred practice, your boundaries and your emotional and physical wellbeing.

Preparing for a home visit

Gather as much information as you can about the visit and location. Talk to your manager about the client and what is known about the home setting. Think about your personal safety and make an assessment of the risk.

Some services will routinely complete a risk assessment on the home before visiting commences. For example, if Community Nursing is involved they will have completed a risk assessment before involving other services.

For some health services the geographic size of the catchment and distance to travel means that a pre-assessment by the manager is just not possible. Think about services like the Ambulance – they routinely visit people's homes without pre-assessment. If you are in this situation then the same principals apply – gather, talk, think, assess.

Contact the manager or delegated contact person if your schedule changes.

Carry a mobile phone with you.

Make sure that you are appropriately dressed and in particular wearing appropriate footwear.

Check with your health service about identification when home visiting. Volunteers working in an inpatient setting may have a vest or name badge, this may not be appropriate in the community where some effort is taken to not draw the attention of neighbours to a service visit.

Be aware of what support and roles you are performing. Any requests from the person or their loved ones to perform activities outside the agreed role needs to be referred to the manager for consideration.

Also, be wary of agreeing to excessively long commitments. Most services will limit a volunteer's contact with a family to about 4 hours a week except at end of life when more hours might be permitted as desirable and beneficial. In particular staying overnight is fraught with social, ethical and safety complexities and would almost certainly be ruled-out by the manager.

Be wary of giving out your personal contact details like phone number. Not everyone shares equally a respect for other's privacy and confidentiality. Check with your manager and consult the health services policy.

During a home visit

Some of these may pose hazards for visiting staff and volunteers, and you should be familiar with your health service's policies. Take alcohol for example. Some home visiting services may have a strict no alcohol policy, if the person or others in the house are drinking then you are required to withdraw.

Assess before entering

Remember it may be necessary to abandon the visit if you have any concerns for your safety¹:

- Be cautious when entering the home. Check-out the general state of the property. Is it well kept, are the curtains open or closed, are there signs of dogs around the yard, can you hear noise from inside or reflecting off the neighbours walls or fences? If the property is difficult to find? Stop and look back at the way you have come from time to time to make sure you can identify landmarks when you are leaving.
- If an unfamiliar person opens the door, make sure the client is home. Ask whether there are other people at home. Be aware of the presence of others, and the signals that they are giving off – do they look calm, or agitated, or intoxicated, or uneasy? Be aware that the person might be alone but want you to think that there is someone else there – some people will leave a shower running to give the sense that they are not alone, and this might indicate that they are uncomfortable with you being there.

Be alert to your own safety when inside the home

Be aware of house layout and your exit routes. Can the exit doors be opened from the inside or are they capable of being deadlocked? Where is the nearest toilet – almost everyone's toilet has a privacy latch on the inside and if you need to shelter somewhere this might be the best option.

Dogs should be restrained or in another room.

If people are smoking inside you should leave the premises.

Keep your keys and mobile phone on you and avoid taking too many personal effects with you. You can always excuse yourself and go back out to the car to collect them later.

Health workers who regularly visit clients develop a sense of when things are ok and when they are not. Intuition develops over time and until then you should make a habit of being cautious until you get to know your clients.

Some health services routinely conduct home visits with 2 volunteers present. For example, CanRevive Inc (the Chinese community support group) routinely assign a husband and wife team to home visits. This is not only culturally appropriate, but it helps with collecting information about the person's home situation and for providing support to loved ones.

Summary

Conduct a quick assessment by asking yourself:

- Is the client coherent? Is there anything different in their demeanour?
- Are they exhibiting signs of agitation or aggression?
- Is there any evidence of alcohol or drug use?
- Are other people present? Is anyone arguing?
- Are there any weapons?
- Is the home in disarray or different than usual?

Using vehicles to travel to and from a client's home

If you are travelling in your own vehicle to visit clients in the community then there are a few sensible things to consider. Naturally the vehicle should be in good condition, roadworthy and registered.

The New South Wales Council of Social Services (NCOSS) recommends² that if a volunteer uses their personal vehicle for volunteering that they do the following:

1. Check that their registration and Compulsory Third Party (CTP) insurance is up to date

CTP insurance is paid separately to your registration but is invalid if the vehicle is unregistered. CTP provides compensation for people killed or injured when the driver is at fault in an accident and, in certain circumstances, regardless of who was at fault. CTP doesn't cover property damage or damage to other vehicles.

2. Check to see if they have Third Party Property Damage insurance

Third Party Property Damage insurance provides cover for the damage done to the car and other property in an accident. It doesn't cover the driver's vehicle. Comprehensive insurance includes Third Party Property Damage cover and is a preferable alternative.

3. Check to see whether the CTP insurance has Driver-at-Fault add-on cover

Driver at Fault cover is only provided by some of the CTP insurers. This additional benefit provides for injuries which are sustained in an accident where the driver is at fault. There are several green slip comparison websites available to help in making the choice of provider.

4. Check with the insurer that any volunteering activities do not affect the insurance cover

Driving their own car as part of volunteer work may affect the volunteer's car insurances. There are a few variables which are relevant, such as how many times a year, how far they drive and what compensations they are given. Volunteers need to check with their insurers to see if the activities affect their insurances. It is possible that a volunteer needs to upgrade their car insurance from private to business and it may be possible for an organisation to make a policy to enable them to compensate a volunteer if this happens.

5. Notify your Manager about your intention to use your vehicle as part of volunteering role, if they aren't already aware

You should expect that the health service will ask to:

- Sight a current valid NSW driver's licence
- Sight current NSW registration papers for the vehicle being used
- Check that the vehicle is roadworthy
- Sight current CTP insurance
- Sight proof of comprehensive or, at the very least third-party property insurance

The vehicle-use policies of the health service may apply even though the car is owned by you. Bear in mind that you will be responsible for traffic and parking fines. After all, the health service can't be seen to be reimbursing you for breaking the law.

Using vehicles to transport a client

Some volunteers drive clients in the volunteer's vehicle to and from medical appointments, to shopping and just out for respite. If the distance travelled is quite long, say in country areas, it's possible that the client may be asked to pay a small fee or contribution.

To transport a friend or relative is different to transporting a person attached to your health service, primarily because by transporting them in your vehicle it looks as if you are providing a service to them of commercial value. This is reinforced if the client is asked to pay a small fee or contribution.

In NSW, cars used to transport clients usually come under the regulations for Community Transport Providers which are contracted to provide transport services, but clearly this doesn't include the sort of work done by volunteers.

In 2014, PCNSW was given the following advice from Transport for NSW³:

"... (in the scenarios you provided) responsibility would rest with the hospital or funding agency as to how they manage their volunteers/insurances/training practices/licensing requirements/vehicles/standards in delivering these services. All drivers must meet minimum standards – in the case of our funded community transport providers (at present) they need to meet a Driver Safety Framework which involves a medical assessment, RMS demerit points check and Police Check prior to driving..."

Rather than transporting the client can they be reimbursed for costs? Instead of driving can you share a bus ride with them? Is there an alternative to driving?

Reporting requirements

Each individual service will have their own policies and procedures relating to reporting requirements for visiting volunteers. The following is an example from one Victorian service:

- As a volunteer, you will need to report to your manager after the initial visit and then according to your own local communication arrangements
- Please remember, any information that shows any changes in condition or needs must be reported immediately. If the manager is not available, contact the nurse in the team
- You are also required to record the details of the visit on the Volunteer Contact form, which is usually then forwarded to the Palliative Care team via the manager of volunteers. This data is essential evidence for the volunteer program's reporting and future funding/resourcing.



Additional resources

Training on Safe Home Visiting: Training for home care workers is available on the subject of Safe Home Visiting and you may benefit from undertaking a more detailed training course. Costs vary, but some of the services offer very reasonable rates for volunteers.



In palliative care volunteers will meet children who are terminally ill, their siblings, or children of a parent who is dying.

Chapter 12

Young People in Palliative Care

Children and death

Palliative Care for children (generally 0–16 years but may be up to 18 years) can often be quite different to adults given that the prognosis for many of the genetic and neurological conditions of childhood are poorly understood.

The Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) and The Royal College of Paediatrics and Child Health (RCPCH) explain that children with life-limiting conditions include¹:

- Those with cancer and other potentially curable conditions (about 40% of total);
- Those in which inevitable death is preceded by a period of normality such as Duchene muscular dystrophy;
- Those characterised by relentless deterioration from diagnosis such as Batten's disease; and
- Those non-progressive conditions whose cumulative complications nevertheless result in premature death such as cerebral palsy.

How many children use Palliative Care? This is difficult to quantify¹, but we do know that in Australia in 2013 some 1344 children died at less than 15 years of age². In the UK the Royal College of Paediatrics and Child Health (RCPCH) estimate that 10 children in 10,000 will suffer from a life-limiting condition, of whom 5 will need active Palliative Care and 1 will die each year³.

What is Palliative Care for children?

Each of these definitions, one from the International Children's Palliative Care Network and the other from the World Health Organisation, give us insight into the understanding and priorities of paediatric Palliative Care:

"It is an active and total approach to care embracing physical, emotional, social and spiritual elements. It focuses on an enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement."

– International Children's Palliative Care Network⁴

"Palliative care for children represents a special, albeit closely related field to adult palliative care. The World Health Organisation's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (5):

- *Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.*
- *It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.*
- *Health providers must evaluate and alleviate a child's physical, psychological, and social distress.*
- *Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.*
- *It can be provided in tertiary care facilities, in community health centres and even in children's homes."*

Paediatric Palliative Care in NSW

The 3 specialist children's hospitals in NSW are:

- The Children's Hospital, Westmead
- Sydney Children's Hospital, Randwick
- The John Hunter Children's Hospital, Newcastle

Each service provides a multidisciplinary range of supports for children and their families referred to Palliative Care living in NSW, including rural and remote areas. They offer a 'consultancy service' to other hospitals and practitioners to provide advice and support in issues relating to paediatric Palliative Care.

The *Children's Hospital at Westmead* and the Sydney Children's Hospital are both part of the Sydney Children's Hospital Network.

Bear Cottage is a special project of *The Children's Hospital at Westmead* and provides respite and Palliative Care to children from all over Australia. There is no charge to stay at Bear Cottage.

The *NSW Paediatric Palliative Care Programme*⁶ brings together the combined resources of the 3 specialist hospitals and provides resources for health professionals and family members.

When would a child be referred to Palliative Care?

When there has been a diagnosis of a life-limiting illness the reasons for a referral to paediatric palliative care include⁷:

- An uncertain disease prognosis;
- The disease has become unresponsive to interventions or the disease process is worsening;
- Pain or symptom management has become complicated; or
- The family is in need of support to manage complex care needs.

The treating team will determine the goals of care for managing the child's condition. These goals of care may include managing difficult symptoms (for example pain) in addition to helping all members of the family to maintain their activities of daily living in as normal routine as possible.

To achieve this goal, families may choose to care for their child at home. To enable this palliative care can⁸:

- Provide home visits by the palliative care team. This may include medical, nursing, social work, physiotherapy, occupational therapy or play therapy. This can be provided via telehealth for those families living in rural and regional area.
- Coordinate home care by linking families with available hospital and community services.
- Provide information for available respite options (for example Bear Cottage in Manly) www.bearcottage.chw.edu.au.
- Provide school visits to help teachers and other staff facilitate and understand the support that is needed to allow a child with a life limiting illness attend school. These visits can also encompass the support that may be required for siblings.

Are all children in Palliative Care managed in specialist hospitals?

No, although many may come and go during their lifetime.

All children who are not expected to live to adulthood may well be considered for a referral to paediatric palliative care. This will ensure that appropriate care is provided at the right time and in the right place.

The specialist paediatric palliative care services based at the 3 specialist hospitals are available to provide education, advice and support to a child's primary medical team and the other health practitioners involved in the child's care. After hours medical advice is available for health professionals if needed.

Generally, families can choose where they would like to care for their child and in most cases care is provided at home. However, as the illness progresses more frequent admissions to hospital may be necessary which can make life for families quite tumultuous.

Respite is an option, to give the family a break from the tasks associated with caring. Inpatient respite and end-of-life care is an available option for children and their families at Bear Cottage located in Manly, Sydney.

Volunteer support in the home is also an option.

Communicating with children

'I guess one of the major differences in a volunteer role is that there is another layer so to speak with the parent/carers. It is not volunteer-to-adult. Our volunteers are often working with children but must step back from parental styles and opinions, their choices in information given etc and always respect those decisions and be very sensitive in how they handle situations in not conflicting with parental wishes. We encourage them to alert us to any issues that professional members can help with.'

– Volunteer manager, paediatrics

In palliative care volunteers will meet children who are terminally ill, their siblings, or children of a parent who is dying.

Questions from children can be confronting; 'am I dying?', 'is there a heaven?', 'what happens when you die?' These questions must be answered in the context of the child's culture and capacity to understand⁹.

Children have the capacity to understand more than they are generally given credit for, and are very sensitive to non-verbal communication. It is quite likely that they know when adults are avoiding questions, or answering them dishonestly. Ineffective communication may lead to anxiety and feelings of isolation in the child. Effective communication has the potential to considerably reduce this.

As a volunteer you should try to find out what the child has been told by their parent about their (or their sibling's) illness and don't say anything that conflicts with this.

If you are concerned about the questions then you should talk to your manager. They might ask the social worker or bereavement counsellor to follow-up.

Never try to force conversation. Pay attention to the child's non-verbal cues and communicate these to your manager. Some guidelines¹⁰:

- Be flexible
- Recognise that children communicate best through non-verbal means such as artwork, music and play.
- Respect the need for children to be alone, as well as their desire to share. Be there to provide support, but do not force communication
- Be receptive when children initiate a conversation. They often take great care in choosing the person to whom they will direct questions
- Remember that euphemisms about death such as 'going to sleep' can be confusing for children
- Acknowledge that a child's life can be complete even if it is brief, and that he or she will always be loved and remembered
- Empower each child as much as possible regarding the circumstances of his or her own death. Involve the child in decision-making whenever possible

Some children in palliative care will have significant communication challenges by virtue of their disability (see also *Chapter 5 Communication Skills*).

Communicating with parents

Many of the needs of the family and the child are similar to those of adults in similar circumstances.

You will find that the child in palliative care will generally have a more extended circle of family around them. Parents sometimes talk of the added pressure from family who 'want to be helpful' and also want to 'put things right' with helpful information about the latest miracle cure or with constant queries about the 'latest update' on the child's condition. Having the support of someone who will support the normality of their family life and who understands what is happening without needing explanation is highly valued by parents¹¹.

Within the team the social worker plays an important role in addressing the questions that parents have about the care of their child, including 'will it be sudden?', 'will he/she be in pain?', 'how long do we have?', 'how do we know when to tell our child that they are dying?', 'what do we tell him/her?', 'what do we tell our other children?'

The research indicates that most children with a life-limiting condition have a better understanding of death than their peers and that they are more aware of their condition than parents and carers realise¹².

Communicating with siblings

When a child is sick or has a disability inevitably that child becomes the focus of the parents' attention and siblings may feel left out, unimportant or isolated. Consequently, they may become more clingy, rebellious, attention-seeking or withdrawn.

Many parents will struggle to know how to share information with the child's siblings for the best. They might be anxious about saying too much, too soon, or of leaving things too late. Some siblings will need and want to ask questions and have the answer given more than once, others will avoid conversations whether or not they want to know.

The recommended approach is to answer questions honestly as they arise, to include siblings in care-giving to encourage communication and to plan treats and events for the whole family to enjoy¹³. Sibling support and attending family-outings are activities with which volunteers in children's Palliative Care services are often involved.

Children and spirituality

Spirituality and the search for meaning are not unique to adults. Like adults, children explore meaning through stories, nature and art.

The concept of 'death' as a permanent event may not be well developed, or developed at all, before the age of about 6 years. Beyond the age of 6 years the child's concept of death expands and may be thought of as a 'ghost' like event, or being 'bad'. Their understanding is often highly self-centered, and they may perceive events as being the result of their own 'wishing' or thinking and as such they might believe that is it their 'thoughts' that have made death occur¹⁴.

Children readily absorb from their environment and many are highly sensitive to the cues given off by those around them, and the sincerity with which others share information and feelings. Parents may chew-over what to say and how to say it for fear of saying the wrong thing while the child picks up on their desire to withhold information, reading it as secrecy and insincerity. It is not unusual for children to elect the person with whom they wish to share information¹⁵.

This suggests that we approach children with a willingness to listen, but we allow them to choose to share with us. Dr Joan Marston is a palliative care specialist from South Africa who's experience with children in palliative care¹⁶:

"...showed that spirituality is often misunderstood or ignored in children but they often express their spirituality through true stories. She spoke of one young child, often withdrawn and alone, who connected spirituality to the night sky using the stars as a way of expressing his inner self. She advised that when talking to children about spirituality – we wait for them to talk to us."

The spirituality of the family should also be considered within the context of the child's spirituality. Children will have absorbed ideas from family members which they may or may not have adopted themselves.

Many young people have the task of untangling themselves from childhood influences before they can resolve on their own belief systems. The volunteer can support the expression of beliefs and values, and the reconciliation of ideas, by a thoughtful and reflective approach to communicating.

What roles do volunteers play?

Several features of paediatric palliative care make for unique volunteer roles:

Firstly, depending on the nature of their condition and how early the referral is made, children may live for many years under palliative care, and this means that the volunteer may have months or years of involvement in the child's life. Compare this to adult palliative care in which the volunteer might have days or weeks of involvement in the person's life (hopefully longer, depending on how early the referral is made).

Secondly, volunteers that spend time in the family home often may become very involved in the life of the family in a way that volunteers working with adults may not. They may be involved in supporting siblings, helping around the home, going on outings to the park or shopping centre. Play is very important for children and volunteers can play with the ill child or with siblings. They may become a listening ear for parents as they struggle with the challenge of parenting and running a household with other children in addition to the intensive work involved in the care of a seriously ill child.

Thirdly, it's about kids. They can evoke our rawest and most heartfelt emotions. For anyone working in paediatric palliative care the experience may be quite emotive and volunteers may form strong attachments to the family, siblings and child. For this reason, post-bereavement periods can be prolonged for the volunteer and the experience of detachment more complex.

In this situation the volunteer must be attentive to their self-care, involve themselves in regular debriefing with the manager, and monitor their emotions throughout the placement.

Volunteers are also involved in the inpatient setting of *Bear Cottage*, the children's hospice at Manly. Roles include reception, play therapy, art and music therapy, housekeeping, kitchen, administration, fundraising, junior siblings camp, driving and dog-walking.



Additional resources

The **International Children's Palliative Care Network** offers an eLearning program suitable for health care professionals and lay people. They also have a video series called Little Stars each of which tells the story of a child and their Palliative Care. www.icpcn.org

The **NSW Paediatric Palliative Care Programme** has resources for family members and health professionals including online training resources. www.nswppcprogramme.com.au



One of the features of palliative care which distinguishes it from other models of care is the palliative care focus on prognosis rather than diagnosis.

Chapter 13

The Volunteer and Comfort Care

Principles of good end-of-life care

'We know from research what's most important to people who are closer to death: comfort, feeling unburdened and unburdening to those they love; existential peace; and a sense of wonderment and spirituality.'

– BJ Miller

One of the features of palliative care which distinguishes it from other models of care is the palliative care focus on prognosis (the likely trajectory of the disease) rather than diagnosis (the cause of the disease). This means that the focus of support is on comforting the person in terms of their diagnosis.

A good end-of-life period and death might mean different things to different people. One person might want to know when death is near so that they can have final discussions with the people they love and finish off unfinished business, whereas another might want to die quickly without lingering. One person might want to be at home when they die, whereas another might want to be in hospital where they feel like they can easily receive specialist support. One person might want to be surrounded by friends and family, whereas another might want to be alone¹.

CareSearch² explains that good end-of-life care is based on the understanding that death is inevitable, and a natural part of life. The goals of end-of-life care are: to maintain the comfort, choices, and quality of life of a person who is recognised to be dying (in the terminal phase); to support their individuality; and to care for the psychosocial and spiritual needs of themselves and their families.

Support for families, if needed, continues after death as bereavement care. End-of-life care also aims to reduce treatment and healthcare interventions that might be considered unnecessary given the person's prognosis, and to offer a choice of place of care when possible.

Remember the guiding principles of volunteer care are:

- Unconditional acceptance;
- Supportive presence; and
- Active listening.

Allow and encourage the person and carer to be as independent as possible. Allow them to do what they can, do not rush to assist unless asked. Ask them how things are usually done, what works best or is most comforting – offer choices. Pay attention to the person and carer's need to look nice. Just because someone is ill or they are busy caring does not mean they do not care about their personal appearance. Help to keep the environment around the person neat and tidy. This will also help to avoid tripping accidents, etc. Avoid suggesting home remedies. There may be particular allergies, or even religious and cultural traditions, that need to be taken into account.

Your organisation's volunteer role description and policies will give you clear direction on your specific comfort care role. This is particularly relevant when answering questions that people might ask you at end of life. Some of these are discussed below.

When the person is actively dying: Symptoms and experiences

The symptoms and experiences of people at end of life might include:

- Pain
- Distress and anxiety
- Breathing problems
- Skin irritation
- Digestive problems
- Temperature sensitivity
- Fatigue
- Grief and loss

Pain: For clinicians, good pain management requires an understanding not only of the medications used, but also understanding what the person is saying about their pain, understanding their disease process, and knowledge of their social circumstances and stressors.

A lack of trust by health professional of the patient's self-assessment, and a lack of trust by the patient of the health professional of their competence and interest can hamper the sharing of critical information. Misinformed attitudes and fears between the health professional/s and the patient or carer may lead to the same adverse outcomes for pain management.

In some cultures, it is seen as weak to acknowledge physical pain. In general, we all find it easier to tolerate pain if we have plenty of sleep and rest, the sympathy and understanding of others, laughter, support, interesting discussions, companionship and distraction or involvement in any activity.

Distress and anxiety: In Chapter 6 we considered pain vs total pain; that total pain referred to a combination of the physical experience of pain and the painful sense of distress that is so common at end of life.

The experience and effect of distress at end of life should not be underestimated, not only as experienced by the patient but as experienced by the family and carers. Always think about how the people are experiencing emotional pain and suffering. A person at end of life might well experience depressing or anxious thoughts. They might be fueled by specific concerns about those who will be left behind, or by the reactions of loved ones. A family member who is grieving for the dying person may feel emotional, angry, frustrated or emotionally dull and withdrawn.

Dying can be confronting. Family members and friends may avoid visiting when they know that the person is dying. Even health care professionals might feel a sense of helplessness and avoid contact. The result is that the person might feel increasingly isolated. Simple companionship and light touch massage on the hands or feet can be simple acts of physical contact that add greatly to comfort care. Think about how to create a comforting atmosphere by using fragrance or music. Use music sparingly and only if you know the person's preference. Talking and sharing memories about the good times in their life can bring comfort. It is commonly believed that even if a person is unconscious they might still be able to hear you.

It is never too late to talk to the person and share encouragement, thoughts and memories to soothe them. Research shows that relationships around the dying person intensify at end of life³. These social networks are important in creating support not only for the person but for their carers and family members. By getting to know the nature of the person's extended social network the volunteer will be better able to support the person. Often just being present can be a comforting presence for a person who is dying.

Breathing problems: At end of life patients might experience difficulty in breathing. A person who is worried about their next breath may struggle to talk or connect with others. Sometimes nursing staff will use a fan, offer oxygen support or raise the head of the bed to assist with breathlessness. Shortness of breath may also leave the person with little energy add to their experience of fatigue.

At end of life people may also experience noisy breathing or so-called death rattles. This sort of noisy breathing usually doesn't upset the person who is dying, but it may well upset family and friends who are with them.

Skin irritations: Skin, lips, eyes and mouth are all prone to dryness and discomfort at end of life. Skin and face moisturiser can be applied, and make for a form of light touch that can be soothing for the person. A lip balm can ease lip dryness; a damp cloth placed over closed eyes might relieve dryness around the eyes.

Sucking on ice chips (if the person is conscious) or else wiping inside the mouth with a damp cloth or swab stick dipped in water can help. People who are sedentary for periods of time can develop skin irritations and tears, and benefit from being moved every couple of hours. Pillows and foam pads can relieve pressure points.

Digestive problems: It is common for people to experience nausea, vomiting and constipation, especially if they are on medication. 'Drugs slow the gut'. Loss of appetite at end of life can be normal and a sign that death is near. Reduced food intake can result in reduced energy and fatigue. Swallowing might be a problem for people, such as people with dementia. A person might prefer many smaller snacks than several large meals in a day.

Temperature sensitivity: People may lose the ability to regulate their body temperature. They might lose the strength to manage bedding when they overheat or get cold. Watch for cues that they are uncomfortable and avoid artificial heating like electric blankets.

Fatigue: Fatigue (extreme tiredness) is one of the most frequent symptoms in palliative care patients. Fatigue has physical, emotional and cognitive implications for patients⁴. Simplify activities and conserve energy: a commode can relieve a person from walking to the bathroom; a shower stool can save a person's energy as can switching to sponging off in bed; setting short achievable goals will encourage; consider dietary needs.

Pain and fatigue are linked in terminal illness. Pain is exhausting. Fatigue increases the experience of pain. Fatigue also plays a major role in palliative care for non-cancer patients, with many patients with HIV, Multiple Sclerosis, Chronic Obstructive Pulmonary Disease or heart failure reporting fatigue. It is worth noting that just because a person is lying quietly doesn't mean that they are tired, as research indicates some 66% of patients deal with pain by remaining calm, lying still, and trying not to show their feelings⁵.

How long will I live?

Inevitably the question will be asked by a patient (or their loved ones) “how long do I have to live?”

In truth it is very difficult to measure how long a person will live. Some people appear to be actively dying, only to rally and live for years more. Others can deteriorate very quickly. Generally, people appreciate having some guide as to how much time they might have left and to organise themselves for the end of their life. For these reasons doctors may provide a broad guide as to how long a person may have to live however the medical team will probably avoid giving more specific timeframes as sometimes this creates a false sense of certainty. On the one-hand a person may outlive these dates and be bewildered, or on the other-hand families may become distressed if their loved one dies before the nominated time.

As a volunteer you may well be asked the same or a similar question: “how long do you think I have to live?” or “how long do other people in my situation go on for?” You should always refer them back to the information that has already been given (clarify with the team if the patient can’t remember) or suggest that they discuss it with their doctor.

Infection control precautions

Health services and their staff and volunteers have a common law duty of care to take all reasonable steps to safeguard patients, staff and the general public from infection. Here are some typical features of infection control (from the NSW Health Policy Directives):

Hand hygiene

NSW Health offers specific advice on hand hygiene⁶. The most commonly available hand hygiene techniques are scrubbing with liquid soap under running water (for 15–20 seconds) or the application of alcohol-based hand rub until dry (for 15–20 seconds).

When do you clean your hands? These are the ‘5 Moments for Hand Hygiene’:

Moment 1: Before touching the patient or the patient’s surroundings (on entering the patient zone).

Moment 2: Before performing an aseptic procedure.

Moment 3: After a body fluid exposure risk.

Moment 4: After touching the patient (if leaving the patient zone).

Moment 4: After touching the patient’s surroundings (if leaving the patient zone)

You must also perform hand hygiene:

- After going to the toilet
- After sneezing or coughing into hands
- After handling contaminated material
- After handling waste
- Before handling patient food

Wearing gloves does not eliminate the need for hand hygiene:

- Wear gloves when contact with body fluids is anticipated
- Change gloves during patient care if moving from a contaminated body site to a clean body site
- Remove gloves after caring for a patient. Do not wear the same pair of gloves for the care of more than one patient
- Change and discard gloves if they become torn, punctured or compromised in any way
- Gloves must not be sanitized, washed or reused.

Refer to the current infection control policy on personal protective equipment for further information about glove use.

Cover your mouth

If you have signs or symptoms of a respiratory infection you should⁶:

- cover your nose/mouth when coughing or sneezing with a tissue
- use tissues to contain respiratory secretions
- spit into tissue, if spitting is necessary
- dispose of tissues in the nearest rubbish bin after use
- perform hand hygiene after contact with respiratory secretions and contaminated objects or materials
- wear a surgical mask (if coughing or sneezing, when being transported, or to protect other persons in a waiting area).



Additional resources

Palliative Care Australia brochure **Asking Questions Can Help** www.palliativecare.org.au

Palliative Care NSW brochure **Learn More about Pain Management**
www.palliativecarensw.org.au.

NSW Health **Infection Prevention and Control Policy** (June 2017).



Volunteers need to be aware that their role at the time of death will vary from client to client.

Chapter 14

About Dying

Death is a process

'How people die remains in the memories of those who live on.'

– Dame Cicely Saunders

If you have never seen someone die you may be afraid of what will happen.

Death is the great unknown. Carers in particular are often concerned that death will be a painful experience for the person. The moment of death is usually peaceful. There is a gradual winding-down that might take several days, as if the body is 'letting-go' of life.

This is described as the process of dying. This chapter considers the signs which may occur during this period. These physical signs are part of the normal, natural processes of the person's body gradually slowing down.

Not all signs will occur in all people. Nor is there a particular sequence in which they will occur. They are best thought of as 'changes' that occur at the end of life. You may see changes that are not described here. Remember that as a volunteer you are part of a team of people and you should feel free to discuss your experience and needs with your manager or other members of the team.

Our personal response to dying and death

Illness, dying and death are among the most sacred and significant experiences of all human societies. If we are to share our client's journey, it is important that we have considered our own beliefs and attitudes about dying and death. For example, is a death always sad or inevitable? Is it a 'tragedy' if the person is a child, just 'bad luck' if the person is in their 60s, or 'a fact of life' if the person is in their 90s? Our responses will depend on our personal values, cultural influences and spirituality¹.

In one way this is part of how we answer the bigger question of 'is there such a thing as a 'good death?' As death is the great unknown, most people value having a sense of control. That is, an insight into how long they have to live, how the process will take place, how discomfort will be relieved, how my personal wishes will be respected, to know when to say my last good-byes to loved ones. These sorts of concerns affect how we measure a good death.

The impact of dying and death on loved ones

Caring for a person during the last few weeks and days of life can be intensive and particularly so when you are in a close relationship with the person. Apart from their concern for the comfort of their dying loved one, a carer will be experiencing their own emotional reactions.

Other family members may be involved at this time, and this can add a new layer of intensity for the team. Sometimes family members who suddenly gather at the time of dying may feel a 'disconnect' from the person's recent progressive decline. This disconnect might result in them being more reactive, more animated and even more assertive than usual.

It is not unusual for some concern or even drama to emerge at the bedside at such times. This event might be based on legitimate concerns which need to be addressed by the team. Perhaps they have been projected from some unresolved relationship pain, misunderstandings about prognosis, sibling rivalry or ancient family antagonisms. There is a myriad of possible reasons that might exacerbate the already emotionally charged experience of dying for family members.

The carer of a person who chooses to die at home may need particular support. Sometimes the final stages of their loved one's life cause such intense distress for the person's carer that they need to reach out for support at the last minute. We know that the statistics show that about half of people in residential aged care die in hospital, probably whilst accessing Palliative Care². Does this suggest that staff in the residential aged care facility feel inadequate or uncomfortable about working with the dying person? If so then imagine how a loved one would feel.

As a member of the team your role is to be supportive. Don't underestimate the value of simple things. 'Being with' can be more important than 'doing for'. Prepare yourself by asking 'what is likely to happen?' Be prepared for questions and know when to refer people to the specialists in the team. Find ways to bring peace into the situation, but as usual don't try and control or script conversations. Are family members agitated? Maybe suggest a chat and engage them in conversation, maybe outside the room, or even take them down the corridor to sit or have a cuppa.

Encourage the relatives to stay with the dying person as much as they wish. Encourage the relatives to speak to the dying person if they wish, particularly if the dying person is in a coma. Encourage 'loving' messages and touch, if this is appropriate. Encourage the relatives to participate in providing 'physical care' if they wish (whether at home or in hospital).

On the other hand loved ones might appreciate someone giving them 'permission' to feel comfortable to retire from the bedside to achieve adequate rest.

The awareness that death will be soon conflicts with not being ready to let go. Carers may want the death to occur, yet hold on; want the suffering to be over, yet not want the person to die. They may be feeling angry, or relieved about the death, yet guilty about wanting the death to come soon. Some may have feelings of fear and anxiety about being present at the time of death. As death approaches, family that are aligned with what is happening may experience a profound sense of peacefulness. At the time of death, feelings of relief are common, accompanied by feelings of sadness and loss.

You will probably find that your focus is now on the person's family and loved ones. Experienced clinicians often say the same thing – 'we spend a lot of time with the dying person, and a lot more time with the family and loved ones.'

Site of care concerns

There may be established expectations of where death should occur, and deciding when it is time to implement a change in the site of care is influenced by many factors. These include:

- The equipment, medications, and care requirements
- The wishes of the client
- The wishes of the carers

Admission to hospital should not be seen as a failure; it may be essential if clients' needs are overwhelming, if carers are exhausted and stressed, or if the carer doesn't want the death to occur in the home.

Dying at home is best supported by Palliative Care services, domiciliary nurses, and General Practitioners who know the client and carer, and who are available 24 hours a day. Appropriate equipment, medications, and support must be pre-arranged³.

Planning ahead

Death signals a time of great change for many people. It is worth being aware of some possible client and carer concerns which might be significant to the person or their loved ones. Some of these are:

Practical concerns: This involves wills, funeral planning, and wishes around the type of care the person desires. Hopefully Advance Care Plans are already in place and these will need review. A Palliative Care social worker or other staff member can assist the client or carer if they are concerned about medical or legal matters, such as 'medical power of attorney', 'enduring power of attorney', and 'refusal of treatment'. It is important to remember that some people also like to write down their medical care choices. For example, they may not wish to be resuscitated. Some clients wish to be involved in their own funeral planning, while others will avoid the issue. Some carers commence funeral planning prior to the death. Palliative Care staff can assist in identifying the questions clients/ carers may be likely to ask when choosing a funeral service, etc.

Adjustments to lifestyle: Time spent conversing with the client will need to be managed according to their energy levels. This is the time for 'being there', touch therapies, guided imagery, and relaxation.

Carer burden increases at this time as the client becomes more dependent and less mobile. The carer may be operating on 'auto pilot' as they are exhausted physically and emotionally. They can experience increasing difficulties with sleep, relaxation, and time out as they may prefer to be continually by their loved one's bedside.

Relationship and spiritual concerns: Dying and death brings out the best in some people and the worst in others. Most people muddle along, coping as best they can. As death draws closer, clients often have a desire to set things right; to not only express love to their nearest and dearest, but to also seek or offer forgiveness and to deal with any regrets.

Discussions about family visiting or attendance during the time remaining are important. The family may struggle when the client begins the process of letting go, as they may perceive this as giving up or giving in. Family may want a prognosis or time frame as they shift from long-term hopes to wanting the client to live until a particular day or event, or until the arrival of certain family members. This is not always possible. The family may require help to deal with misunderstandings and issues as they arise.

Children: Parents and other family members may need to be reminded of the needs of children. Children should be included in ways that are comfortable for them and have their questions answered. Their presence should be encouraged and they should have the space to play if they wish. Children's behaviour may change at this time.

The client and carer may wish to explore the meaning of life and death through expressing their thoughts and feelings about dying, death, and spirituality. This is an important time for the volunteer to 'be' and listen and refer when necessary.

Changes you may notice at end of life (the process of dying)

This information is taken from a brochure by Palliative Care Australia called About the Process of Dying⁴.

Appetite and thirst: The person's appetite and thirst may decrease, and they may have little desire to eat or drink.

Sleep and alertness: Changes occurring in the person's body mean that they may spend a lot of time asleep, may be drowsy and difficult to wake up.

Temperature: The body's temperature may change. At one time the person's hands, feet and legs may be increasingly cool to the touch, and at others they may be hot and clammy.

Incontinence: The amount of urine that the body is producing decreases due to the reduced amount of fluid the person is drinking. The urine may become stronger and darker in colour.

Secretions: As coughing and swallowing reflexes slow down, saliva and mucus may collect in the back of the person's throat, causing a gurgling, bubbling or other noise. This noise can be a concern to carers, but does not usually cause distress to the person.

Breathing: Regular breathing patterns may change. Sometimes the breathing may be fast, and at other times there may be long gaps between breaths. Breathing may be shallow or noisy.

Restlessness: Due to the decrease in circulation of blood to the brain and to other changes happening in the body the person may become restless or agitated. To have a calming effect, speak with quiet calm, lightly massage the person's hand or forehead, or softly play familiar music.

How will you know when death has occurred?

- Breathing stops
- No heartbeat or pulse can be felt
- The person cannot be woken-up
- Eyelids may be half open
- Sometimes their mouth may also be open
- Pupils are fixed.

The volunteer role at the time of death

Volunteers need to be aware that their role at the time of death will vary from client to client.

This can be the result of the length of time they have been with the family, their relationship with the relatives, and their understanding of any specific cultural and religious needs. Sometimes the volunteer may not be aware of the death until later. If the volunteer is present, their main role is one of quiet, gentle, empathic support.

It is important to remember to be sensitive to cultural and religious beliefs in the final hours.

The family may need to be prepared for the procedures that the staff will follow after the death (e.g. washing and dressing the body, closing the eyes and mouth, putting dentures back in).

Families may have special requests for the treatment of the body after death (e.g. some families may not wish the person to be moved as there may be specific religious and cultural requirements for the preparation of the body for burial and cremation).

Volunteers may need to pass these messages on to staff if not already known, or if the family is grieving and unable to adequately portray their wishes.

Some concluding thoughts

Those who have the strength and the love to sit with a dying patient in the silence that goes beyond words, will know that this moment is neither frightening nor painful, but a peaceful cessation of the functioning of the body. Watching a peaceful death of a human being reminds me of a falling star – one of the million lights in a vast sky that flares up for a brief moment only to disappear into the endless night. To be with a dying patient makes us conscious of the uniqueness of the individual in this vast sea of humanity, aware of our finiteness, our limited lifespan.

– Elizabeth Kubler-Ross



Remember that as a volunteer you are part of a team of people and you should feel free to discuss your experience and needs with your manager or other members of the team.

Questions for Review

Chapter 1: Introduction to Palliative Care

1. What is meant by the term 'philosophy of palliative care' or 'palliative approach'?
 - a. A specialty qualification for Palliative Care physicians
 - b. A set of beliefs and values about chronic disease treatment
 - c. A way of treating people which focuses on their comfort
 - d. A focus on diagnosis instead of prognosis
 - e. None of the above.
2. According to the World Health Organisation, Palliative Care involves:
 - a. prolonging death
 - b. relief of suffering
 - c. careful treatment of pain
 - d. all of the above
 - e. b and c above.
3. Briefly describe the main difference between the Curative and the Palliative approaches in the integrated model of care.
4. What is the significance of the '12 month' question to Palliative Care?
5. Where would you find information about the location of Palliative Care Services in NSW?

Chapter 2: Health Promoting Palliative Care

1. A good death:
 - a. can only be achieved if a person dies at home
 - b. can only be achieved if a person dies in a hospital
 - c. is when a person dies quickly
 - d. is an aspirational goal that guides the provision of palliative care
 - e. none of the above.
2. Consider the setting in which you would prefer to die. What factors would make you prefer dying at home over dying in a hospital intensive care unit, and vice versa?
3. Name four social determinants that would predict a poor health or death experience.

4. Poor health literacy might result from:
 - a. inadequate language or reading skills
 - b. inadequate cognitive capacity
 - c. unavailability of information in an appropriate format or language
 - d. inability to absorb and assimilate health care information
 - e. inability to interact with the professionalised workforce of the health care system
 - f. All of the above.
5. The goals of health promoting palliative care include:
 - a. Building public policies that support dying, death, loss and grief
 - b. Creating supportive environments (in particular social supports)
 - c. Reviewing clinical pathways
 - d. a & b above
 - e. None of the above.

Chapter 3: The Volunteer's Role

1. Reflect on what has prompted you to consider being a palliative care volunteer. If you have been influenced by a personal experience of bereavement, reflect on how this might benefit you as a volunteer and also ways in which it could hamper you.
2. List four of the qualities looked-for in a Palliative Care volunteer.
3. Briefly outline three sorts of roles that are performed by palliative care volunteers in your service. How would you rate your capacity to perform each role, on a scale from 1 (not at all) to 10 (highly)?
4. Briefly describe three of the domains of 'holistic care'.
5. List the clinicians or specialists that might be present in the palliative care team.
6. Which of the following factors might contribute to your experience of stress as a volunteer:
 - a. Dealing with the complexities of the health care system
 - b. Communicating with the other members of the Palliative Care team
 - c. Working intimately with dying patients and grieving relatives
 - d. Confronting your own mortality
 - e. All of the above.
7. "Humans are not hardwired for long-term stress". Reflect on your own experiences of stress and what strategies you adopted (successfully or unsuccessfully) to cope and heal.
8. "To spend unhurried, quality time with the dying, volunteers need other outlets that are active and exuberant to rejuvenate their soul and avoid burning out". Outline some of the other activities that you will include in your life during your time as a Palliative Care volunteer that will help to avoid burn-out.

Chapter 4: Boundaries and Self-Care

1. What does 'Duty of Care' mean? Give an example of how it relates to a Palliative Care volunteer.
2. What is meant by the term 'role boundaries'?
 - a. A statement of my duties as a volunteer
 - b. A scope of tasks and responsibilities within which I perform my role
 - c. What I can and can't do within the Palliative Care team
 - d. The geographical limits of the Palliative Care service
 - e. None of the above.
3. What sorts of guidance is likely to be found in a policy relating to privacy?
4. In what ways does your service's Workplace Health and Safety Policy apply to volunteers?
 - a. Not at all – it only applies to paid employees
 - b. It applies to people whether they are paid or unpaid
 - c. It's up to the volunteer manager to tell us whether the policy applies to volunteers
 - d. It's only for volunteers on hospital grounds, not for volunteers in the community
 - e. None of the above.
5. Briefly describe how the practice of self-reflection and self-care are beneficial in coping with the emotions of volunteering in Palliative Care.

Chapter 5: Communications (aka Relationship) Skills

1. Reflect on your own communications skills and style. What skills would you like to improve in yourself?
2. Briefly describe three important communication tasks that a Palliative Care volunteer might perform on a regular basis.
3. Which of the following techniques will make your listening more effective:
 - a. Don't ever break eye contact
 - b. Try and feel what the speaker is feeling
 - c. Help the speaker finish the sentence
 - d. Try and interpret what the speaker is saying
 - e. All of the above.
4. You have been asked to visit a young man who has been angry and hostile since learning about his prognosis. Describe how you might try to open a conversation with him.
5. You have been asked to assist a person with an intellectual disability who is attending a clinic. Describe some tips for establishing communication with the person.

Chapter 6: Spirituality and Palliative Care

1. The relief of suffering is best achieved
 - a. With psychological intervention focused on PTSD
 - b. By spiritual care staff
 - c. With support, hopefulness and a peaceful presence
 - d. With a stimulus-response approach
 - e. None of the above.
2. Which of these best describe what is meant by the term 'Spiritual Care'?
 - a. Offering religious rites to people from their church
 - b. Helping people make sense of their life's journey
 - c. Instructing people in the way they should believe in God
 - d. Baptising and proselytising
 - e. None of the above.
3. A Muslim person asks you if you think that Allah is angry with her, and questions 'is that why I am sick?' Describe how you might respond to her.
4. A person with no religion might be very spiritual, and a person who is very religious might have little spirituality. Explain whether or not you agree with this statement.
5. Which members of the team would you look-to for assistance with spiritual care?

Chapter 7: Palliative Care, Multiculturalism and Families

1. In descending order, the most likely countries of birth for new immigrants is
 - a. UK, China, Philippines, India
 - b. UK, NZ, China, India
 - c. China, Korea, UK, Somalia
 - d. India, China, UK, NZ
 - e. NZ, UK, Vietnam, Germany.
2. Briefly describe why members of the same national group might have different language, ancestry and ethnic identity.
3. What are some of the key points in working with families in Palliative Care?
 - a. Assume that the family is coping the best they can, support don't judge.
 - b. Each family member has their own way of dealing with difficulties in their lives.
 - c. Everyone has a different experience of the same situation, and appearances are not always what they seem. It is not our job to take sides.
 - d. One of the most beneficial things we can do for families is to be present with them.
 - e. All of the above
 - f. Only b and c above.
4. You have been asked to work with a person and their family of a non-English speaking background. What sorts of information will be useful to you to help you support both the person and their family during their time in Palliative Care?

Chapter 8: Grief and Bereavement

1. Which of the following is part of the process of grief?
 - a. Accepting that our loved-one is gone
 - b. Processing the pain of grief
 - c. Adjusting to a 'new world'
 - d. Working-out our new relationship with the person lost
 - e. All of the above.
2. List 6 possible responses to grief.
3. What are some practical things that can be done for a person who is recently bereaved?
4. Reflect on an experience of grief that you have had. What surprised you about that experience, if anything? What do you remember most about it?
5. "Death ends a life but not a relationship." Describe how this understanding might affect the way in which you communicate with a person who is recently bereaved.

Chapter 9: Grief and Bereavement Support

1. The goal of a bereavement support program is to:
 - a. Reconstruct the final days of the patient's life before they died.
 - b. Create a socially-acceptable context within which to approach recently bereaved persons and encourage or invite them to share their experience of loss and their feelings.
 - c. Introduce the family member to a person who can help them with their complex grief when they need it.
 - d. Identify people who no longer need help from the health service and can be exited from the health service's records.
 - e. None of the above.
2. Not everyone will respond to an invitation to a memorial service, and some may attend with great apprehension. Describe 3 of the apprehensions that a person might bring to a memorial service, that a volunteer should be aware of and attentive to.

Chapter 10: Inpatient and Residential Settings

1. Patients who are dying will be happy to be admitted to a hospital bed. Discuss whether you agree or not with this statement.
2. Typically, as a volunteer you should ensure that you know:
 - a. Who you report to and who to ask when you need guidance or when you have questions to be answered.
 - b. The daily routine for checking in, reviewing your role for the day, and what to do if and when you are leaving the setting.
 - c. The scope of your role and the expectations about how you interact with the other multidisciplinary team members.
 - d. All of the above.
 - e. None of the above.
3. In what ways do you think that the experience of a volunteer in a hospital setting might be different to that of a volunteer in a residential aged care facility?

Chapter 11: Home and Community Visiting

1. Why is it important that you update your manager with your home visiting schedule when changes occur?
2. List some precautions that you would expect to take upon arriving at a person's home and before entering the house.
3. You have arrived at a home that you are visiting for the first time. What sorts of things might you consider before you step through the front door?
4. What checks are volunteers recommended to perform before using their own vehicle for volunteering activities?
5. What are the recommended checks if you are involved in carrying clients in your own vehicles?

Chapter 12: Young People in Palliative Care

1. Conditions affecting children with life-limiting conditions are grouped into 4 categories. What are they?
2. Name the 4 criteria which are considered before a child is referred to Palliative Care.
3. How might you approach a discussion about spirituality with a child?
4. Briefly describe 4 of the key points for consideration when communicating with children.
5. What are some of the challenges for adolescents in Palliative Care?
6. Being involved in paediatrics provides a unique experience for volunteers. Why?

Chapter 13: The Volunteer and Comfort Care

1. Some people with chronic or terminal illness can experience their symptoms to in a more profound way than others. List six factors that can increase the person's perception of their symptoms.
2. "Pain is whatever the patient says it is." Briefly describe how this understanding might affect the way in which you communicate with a person who is experiencing pain.
3. "If a person takes narcotic medication they will become addicted." What are the implications of this belief for your role as a volunteer?
4. You are at home with a person who is ill and they are distressed. Describe how you might work with the person to provide comfort and support and what you might do if their distress becomes more elevated.
5. List the 'Five Moments for Hand Hygiene' promoted by NSW Health.

Chapter 14: About Dying

1. What would you describe as a 'good death'? You might like to reflect on what you think a 'good death' would mean for you.
2. Describe six of the common indicators of an approaching death.
3. Describe some of the indicators that death has occurred.
4. As a volunteer, at the time of death your role is to:
 - a. Be sensitive to the needs of the family
 - b. Provide gentle and empathetic support
 - c. Indicate to the family members what they should do next
 - d. Answers a and b only
 - e. None of the above
5. "Your role may be to act as a 'mentor' to those sharing the vigil." What are the implications of this statement for your role as a volunteer?
6. Describe how you will care for yourself after providing support to a person at their end of life.



As a member of the team
your role is to be supportive.
Don't underestimate the value
of simple things. 'Being with'
can be more important than
'doing for'.

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