Palliative Care
NEW SOUTH WALES

Palliare

A Handbook for Palliative Care Volunteers in NSW

With the support of NSW Health through the Volunteer Support Services Programme

Palliative Care
Volunteering

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Chapter 1 Introduction to Palliative Care

What is Palliative Care?

'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 an team-based approach that includes symptom control and support for the patient and family – whatever the diagnosis.

Palliative Care is both a **medical specialty** and a **philosophy of care**. Both are discussed in this chapter.

Palliative Care is also known as **Hospice Care** in some countries. In Australia the word 'hospice' generally refers to a facility rather than a model of care.

The word 'hospice' has the same derivation as 'hospital' and 'hospitality', and dates back to the 4th century when pilgrims were cared for at an inn or hostel[1].

World Health Organisation (WHO) Definition of Palliative Care[2]

"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 that different organisations, states and countries may have different definitions of Palliative Care.

NSW Health endorses the WHO definitions of palliative care, and this forms the basis of the *NSW Government's Plan to increase access to Palliative Care 2012–2016*[3].

Specialist Palliative Care services

Most volunteer services are attached to, or have a close working relationship with, a specialist Palliative Care service.

People seeking the help of specialist palliative care can be referred by any doctor, including their own General Practitioner (GP). The referral will take into account the prognosis for the person, and the support from their loved ones.

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

A list of Palliative Care Services in NSW can be found on the Palliative Care NSW website at www.palliativecarensw.org.au.

Once a person is seen by Palliative Care they will receive support according to their need and prognosis. Assistance may be needed for short term symptom control, or they may be involved throughout their illness journey.

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

Curative vs Palliative Approaches

Curative (Traditional) Approach

The curative approach is the approach taken when all treatment and care is focused on ensuring the person will recover. In this approach the decision maker is usually the medical practitioner.

One of the challenges of clinical treatment is to find the greatest benefit for the person. Not all treatments result in beneficial outcomes for them – such treatment is described as ‘futile’[4].

On the other hand treatment may bring benefit, but be very burdensome for the patient, and therefore decisions about treatment has to consider the person’s distress and suffering which may result from the treatment[5].

This approach differs from the palliative approach in that the palliative approach focuses on the holistic care of the person, and does not include futile treatments which may be considered where the curative approach is used[6].

Palliative (Integrated) Approach

The contemporary approach to Palliative Care is to integrate Palliative Care into the ‘curative’ treatment of the person as it becomes necessary. 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 Palliative Care may become involved.

Underlying the philosophy of a palliative approach is a positive and open attitude toward death and dying. The promotion of a more open approach to discussions of death and dying between the Palliative Care team, clients, and their families, facilitates identification of their wishes regarding end-of-life care.

A palliative approach is not confined to the end stages. Instead, a palliative approach provides a focus on active comfort care, and a positive approach to reducing an individual's symptoms and distress. This assists clients and their families in understanding they are being actively supported through this process[7].

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 see *Chapter 7 Young People in Palliative Care*.

Standards for Providing Quality Palliative Care for all Australians (The National Palliative Care Standards)

Since the first edition in 1994 the National Palliative Care Standards have been guiding the delivery of specialist Palliative Care services[8].

These standards are set-out below.

Standard 1 – Care, decision making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patients, their caregiver/s and families' needs and wishes are acknowledged and guide decision making and care planning.

Standard 2 – The holistic needs of the patient, their caregiver/s and family are acknowledged in the assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes.

Standard 3 – Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family.

Standard 4 – Care is coordinated to minimise the burden on the patient, their caregiver/s and family.

Standard 5 – The primary caregiver/s is provided with information, support and guidance about their role according to their needs and wishes.

Standard 6 – The unique needs of dying patients are considered, their comfort maximised and their dignity preserved.

Standard 7 – The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.

Standard 8 – Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services.

Standard 9 – Community capacity to respond to the needs of people who have a life limiting illness, their caregiver/s and family is built through effective collaboration and partnerships.

Standard 10 – Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.

Standard 11 – The service is committed to quality improvement and research in clinical and management practices.

Standard 12 – Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.

Standard 13 – Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies.

The standards are under review as at the time of writing.

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.

The volunteer and the Palliative Care team

The 'team' is made up of everyone who is involved in the person's care. This includes specialist Palliative Care staff, physicians, GP, nursing, pharmacy, counselling and social work, clergy, nutritionists, occupational therapy, physiotherapy, speech pathology, home support workers, volunteers and volunteer managers, music and complementary therapy.

Not all teams will have a representative from each discipline. Some may involve staff from outside of their service in a 'consultant' role.

At the heart of the team is the group of clinicians who have regular or 'as needed' contact. This group will communicate regularly about the person's situation and revise and adapt the plan of care accordingly.

The team may decide to ask others to be involved by 'making a referral' on behalf of the person.

This is the formal way in which volunteers become involved in the support for an individual in Palliative Care.

The usual pathway of communication between the volunteer and the team is through the volunteer manager.

Palliative Care as philosophy – reclaiming death as a social experience

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.

Do we want to recapture this social experience of death? If so how would we honour death and dying, how would we talk about it, who would be involved to help people enact death in a non-medical setting, how can we mentor and empower people who are caring for the dying at home, should we and how do we value the non-expert voice in the end of life period?

This awakening to the social narrative of death has also been shaped by community empowerment in health care. 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 Directives** (see *Chapter 6*) 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.

This has supported the success of '**death cafés**' in which community members (as consumers) meet to share and discuss end of life. Although each event might differ, the general theme is information sharing and discussion to de-mystify and destigmatise 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, reevaluate, and reclaim their collective story about the end of life experience. **The Groundswell Project** (www.thegroundswellproject.com) is a community activist 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'.

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

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.

Another support role is performed by **death doulas** or **death midwifes** 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.

A **community hospice** is a clinically-supported home-style environment for people in their end of life. For example Tweed Palliative Support (www.tweedpalliativesupport.com.au) operates Wedgetail Retreat as a hospice and respite service, and there is interest in establishing similar hospices around the state.

Additional resources

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).

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.

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 includes:

- 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 the team, and **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 its 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 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.

Volunteer settings

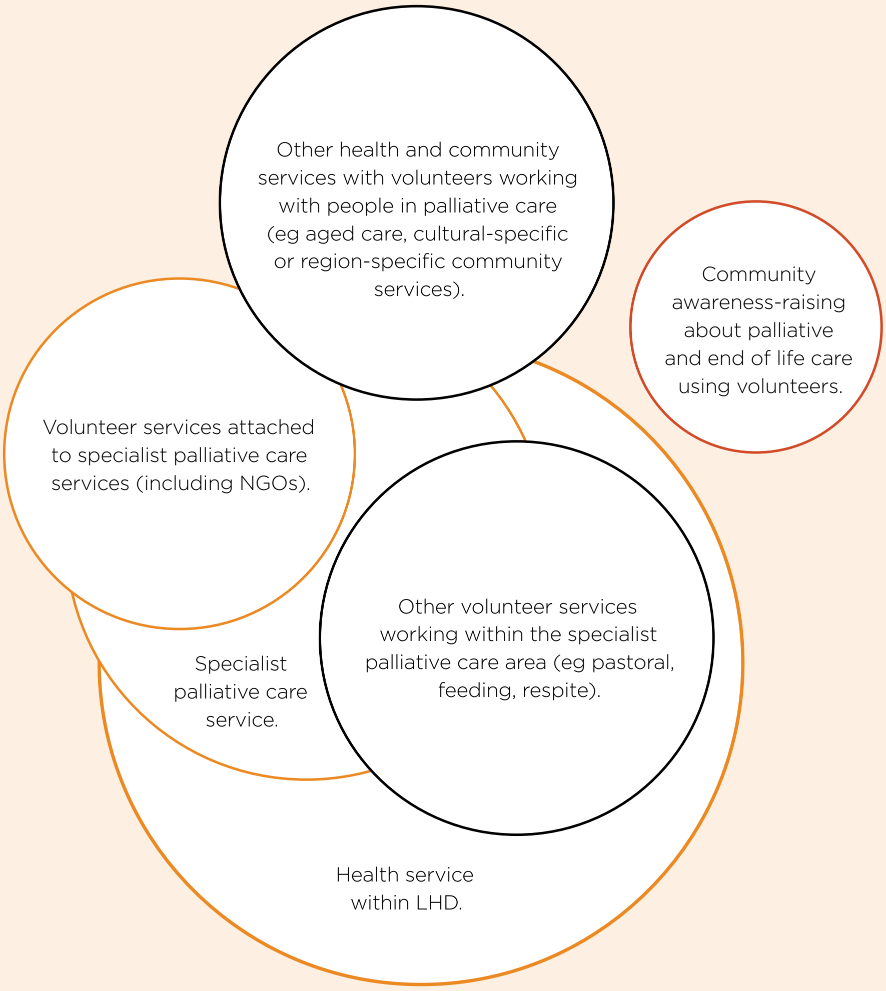
Inpatient: There are volunteers who work on hospital wards, Palliative Care units and in other inpatient or outpatient settings.

Community: There are volunteers who work in community settings, such as supporting people who are receiving Palliative Care at home, or in an aged care facility or in a day-respite centre.

Organisational support: There are volunteers who work behind the scenes, doing administration, fundraising, food preparation, driving, maintenance or other activities with Palliative Care services[1].

These settings reflect the various settings in which Palliative Care is delivered the activities which support service delivery.

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



Providing 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 Medicine[2]

One of the important goals of Palliative Care is to acknowledge the 'wholeness' of the person and to find ways to provide 'holistic' care. Volunteers can make an important contribution to holistic care within each of these domains[3]:

- **Physical** (concerning safety, nutrition and fluids) – Volunteers may prepare and serve snacks and beverages. They may not provide intimate personal care.
- **Psychological** (concerning fears and emotions) – All volunteers can reassure anxious clients with a calm and affirming presence.
- **Social** (concerning safety and supportive relationships) – Volunteers 'companion' the ill person, their carers and families. They can enhance existing relationships by creating comfort in an unfamiliar hospice or hospital setting, or support people at home or in aged care facilities. They can offer creative distractions such as working through a puzzle, playing chess, watching a video, or similar activities. If the client is mobile they may take them out for a coffee, drive, or other social outing.
- **Spiritual** (concerning meaning, values, and symbols) – Volunteers, through active listening, can give the ill person space to revisit old memories, enhance meaning, or bring the context of having done the best they could with what they had at the time.
- **Practical** (concerning assistance with tasks) – Volunteers may assist in getting the clients to medical appointments or checking community resources available to them. Volunteers provide respite so family caregivers can take a break or get much-needed rest.
- **Life closure** (concerning end-of-life legacies and ritual) – Volunteers, if requested, can help clients with closing tasks such as helping to complete a quilt, photo album, or bibliography. Such legacies can be great conversation stimulators.
- **Loss and grief** (bereavement and grief) – Volunteers assist with bereavement support groups. These can take many forms, such as walking/coffee groups, groups for widowers who feel lost in the kitchen, and bereavement support groups for weekly debriefing.

In **Paediatric Palliative Care** this includes special support to siblings to accompany or assist in the care of the child and to go on social outings. It may also include assistance with light domestic tasks around the home. Visits for loss and grief support continue to provide a listening ear for the carer following the death of child.

Sometimes a volunteer may feel that their visit is pretty low key. However, you should never underestimate the value of just being there and listening.

Getting started as a volunteer

In NSW each service manages their own recruitment process and induction training.

Based on their needs this might mean that there is an intake several times 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, 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 a 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 report[4]:

> *"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 minimise the likelihood of disputes or issues, and to be respectful of your time.

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 inclusiveness[5].

NSW Statement of Principles for the Recognition of Volunteers

The Department of Communities hosts the Statement of *Principles for the Recognition of Volunteers*[6] 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.

Chapter 3 Boundaries and Self-Care

Duty of Care

A service has an obligation to exercise reasonable care and diligence (Duty of Care) toward staff, volunteers, patients and visitors so as to avoid harming them and to protect them from foreseeable risk of injury.

By extension, volunteers have a Duty of Care toward their clients. For this reason volunteers are accountable for their actions and are expected to take reasonable steps to ensure client safety and welfare.

Under Duty of Care a service will provide to staff and volunteers a suite of expectations about how they must act. These include job descriptions, policies, procedures, instructions, guidelines and regulations.

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 have Policy and Guidelines[1] and these typically with system-wide issues of concern (such as the policies on infection control outlined in Chapter 12).

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.

State and commonwealth laws[2] permit a service to share information about an individual, but only if the shared information is provided to the responsible person 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 specialised 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 information about people with you 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. Breaking confidentiality is justified in cases 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
- Reasonable suspicions of abuse

If you hear or note any of the above, you must report it directly to your 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 where and how to say no and refer to other members of your team[3].

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.

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 supports[4].

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. One the one hand the genuiness 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 it 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 out[5].

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*[6].

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 waste of time, non-productive. 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, on the other hand, is staying healthy and doing something for yourself – allowing 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 for[7]:

> *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.*

Dealing with death and dying on a regular basis requires a lifestyle balance.

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.

Allow yourself to make mistakes and still feel okay as a person. Mistakes usually lead to new learning when you acknowledge them and review what actually happened.

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 their feelings of anger, hurt, sadness etc, 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.

Chapter 4 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 oncology[1]:

> *"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 would 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, to get a sense of who we are and to be assured that they will treat us with respect and consideration. We don't expect to be let into their emotional landscape in 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 Manual*[2]:

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*[3].

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 list[4] 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've caused your wife."

Avoid cliches: "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: Stories such as 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).

Chapter 5 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 who's partner has recently died. If the person is elderly then the challenges may include a profound sense of social isolation. So 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

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. Compared to Volunteers who work in an inpatient settings who need skills in team-work and who 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, or may 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 many of the cultural-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 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 safety[1]:

- 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 their 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.

Home visiting requires a different set of skills to, say, inpatient volunteering.

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, 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) recommends[2] that if a volunteer uses their personal vehicle for volunteering that they do the following:

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.

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.

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.

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.

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 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.

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 NSW[3]:

> *"... (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.

Chapter 6 Advance Care Directives

What is Advance Care Planning?

Advance Care Planning means planning your care in advance of your condition worsening to the point where you are unable to make decisions for yourself. It is how you take control of our future health care decisions and help you live more positively[1].

Why is this important to me as a volunteer?

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.

A properly prepared Advance Care Directive 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.

By being aware of Advance Care Directives you may be able to talk with people about preparing their own, or inform the team if you find that the person already has one.

Paediatric Palliative Care

Minors can't make Advance Care Directives. Advance Care Directives can only be made by competent adults. However depending on the age and maturity of a young person, they may wish to participate in the process so their views can be taken into consideration.

Some important terms

Advance Care Planning – Advance Care Planning involves thinking, discussing and documenting. It generally involves ongoing conversations between patients, their families and their treating health professionals introduced gradually over a period of time. These conversations enable planning ahead for potential deterioration in future health when that person becomes unable to make decisions about their own treatment and care.

Advance Care Plan – An Advance Care Planning discussion will often result in an Advance Care Plan. Advance Care Plans state preferences about health and personal care and preferred health outcomes. They may be made on the person's behalf, and should be prepared from the person's perspective to guide decisions about care.

Advance Care Directive – An Advance Care Directive is a type of written Advance Care Plan recognised by common law or authorised by legislation that is completed and signed by a competent adult. An Advance Care Directive can record the person's preferences for future care and appoint a substitute decision maker (an enduring guardian) to make decisions about health care and personal life management.

Enduring Guardianship – An enduring guardian is a person, over the age of 18 who agrees to be appointed by you to make personal and lifestyle decisions and/or medical treatment and healthcare decisions on your behalf only when you are no longer able to do so for yourself.

When is a good time to start planning?

The earlier the better. If a person has been diagnosed with a life-limiting illness then there is no time to lose. The person should make the most of the time they have before their ability to make their own decisions (their 'capacity') is lost. A person can always change their mind and re-write their Directive at any time.

Unless you have been specially trained or approved by your service your role as a volunteer is to simply to encourage people to seek the assistance of their family, their physician or their GP in the planning process.

Is it legal?

NSW currently has no legislation on Advance Care Directives or refusal of medical treatment. However an Advance Care Directive is legally binding in NSW, and functions as an extension of the common law right to determine one's own medical treatment.

Additional resources

NSW Health www.health.nsw.gov.au/patients/acp/Pages/more-info.aspx

The Advance Care Directives Association Inc www.advancecaredirectives.org.au

Advance Care Planning Australia www.advancecareplanning.org.au/resources/new-south-wales

My Wishes www.sswahs.nsw.gov.au/services/myWishes

Palliative Care NSW brochure ***Advance Care Planning***

Chapter 7 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 include[1]:

- 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 quantify[1], but we do know that in Australia in 2013 some 1344 children died at less than 15 years of age[2]. 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 year[3].

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 Network[4]

"Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- *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."*

World Health Organisation[5]

Paediatric Palliative Care in NSW

The 3 specialist children's hospitals in NSW are:

- The Children's Hospital at 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 Sydney Children's Hospital Randwick 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 include[7]:

- 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 can[8]:

- 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 understand[9].

Children may 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 guidelines[10]:

- 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 4 Communication Skills*).

Working in paediatric Palliative Care may be quite emotive and volunteers may form strong attachments to the family, siblings and child.

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 parents[11].

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 realise[12].

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 enjoy[13]. Sibling support and attending family-outings are activities with which volunteers in children's Palliative Care services are often involved.

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 who may feel isolated, as they struggle with the challenge of parenting and running a household with other children in addition to the intensive work involved in care of 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.

For this reason 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 (www.icpcn.org) 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.

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

Chapter 8 Spirituality and Palliative Care

Why spirituality?

Every human person has the capacity to resonate with and respond to another person who is facing such experiences and the questions that arise for them, at least to some extent.

As life comes to a close many reflect on the past, what life has meant to the person and, the choices one has made. The person or their loved ones may want to share this with trusted family members, friends, and Palliative Care volunteers.

Many Palliative Care volunteers rely on their own sense of spirituality and faith as support in this work, but this is not enough. This personal spirituality can be an important foundation, but the Palliative Care volunteer needs to understand his/her role in providing spiritual support to a diverse client base that may be in spiritual turmoil or may express spirituality in an unfamiliar way.

Volunteers are supported by professionals with advanced training in spiritual care, to whom they can refer those with special needs[1].

Commonly used terms

Spirituality

Spirituality is intrinsic to being human. It is the self-in-relationship with self, others, nature, environment, universe and the transcendent.

Spirituality may be experienced as a quest for meaning, purpose, connection, belonging, and hope. It can deepen with growing reflective capacities and self-awareness, and can become more conscious at major turning points in life. Spirituality is always embedded in the person's unique experience and story, and is essentially individual, subjective, and shaped by one's context.

Due to its subjectivity, each individual story needs to be heard, and the person's spirituality and unique reality discerned in each encounter and context.

Common themes or aspects may include:

Cognitive: A search for meaning, answers to life's deep questions, hope, a sense of purpose

Affective/relational: Connectedness to self, others, nature, the transcendent

Ethical: A moral sense of 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. It can also draw on the accumulated wisdom of traditions, and can be expressed communally. When this is the case, the individual's spirituality can be expressed within a tradition of faith or religion (see below). However, spirituality is more primordial than religion. All religious persons may at times explore other expressions of their spirituality beyond their particular religious tradition.

Religion and faith

Religion is understood as the organised, communal expression of spirituality. Religion has shared points of reference to charismatic figures, sacred texts, teachings, rituals and practices, and moral precepts, to express and make accessible the cognitive, affective/relational and ethical wisdom of a faith community for its members.

The words 'religion' and 'faith' are often used synonymously by people outside of a faith tradition, but for many people within faith traditions the meanings are quite different. Religion is a set of practices and/or gestures by which the person is reminded of important aspects of their tradition, whereas faith is the simple belief in divinity. For these people faith and relationship are often used interchangeably to describe their place in the divine, whereas religion is eschewed as artificial and 'missing the point' of the faith tradition.

For example, if you ask a person who attends church if they are religious they may say 'no, but I have a firm faith'.

Pastoral Care

Pastoral care encompasses all the ways in which attention is paid to spirituality and particularly in the healthcare environment, where spiritual issues arise within the experience of illness, suffering, life, and death. The terms pastoral care and spiritual care are very closely linked.

Bruce Rumbold from the La Trobe University School of Public Health has worked extensively in the area of spiritual and pastoral care, and palliative care, in Australia and offers the following definition of Pastoral Care[2]:

> *Pastoral care is a person-centred, holistic approach to care that complements the care offered by other helping disciplines while paying particular attention to spiritual care. The focus of pastoral care is upon the healing, guiding, supporting, reconciling, nurturing, liberating, and empowering of people in whatever situation they find themselves.*

Chaplaincy

Chaplains are found in a diverse range of settings including health care, education, prisons, emergency services and the armed forces. Chaplaincy is a professional role which draws people from diverse faith backgrounds. Usually the focus of the role is on support rather than proselytising. Chaplains may come with a specific faith background but are required to be sensitive to other people's view, values and beliefs. Endorsement from a faith community and/or minimum training is required[3].

Diversity in spirituality

Acknowledging cultural and linguistic diversity is of critical importance in spiritual support. This can be a specialised field as these comments from Spiritual Care Australia indicate[4]:

> *Where cultural and linguistic diversity is not acknowledged, valued and approached effectively, it can lead to profound misunderstanding, increased social isolation due to language difficulties, lack of empathy and discrimination. Pastoral/Spiritual Care practitioners understand the importance of non-verbal communication. Likewise, they encourage the use of professional interpreters for situations involving crisis, legal obligations and high-risk scenarios where cultural and or language issues are likely to impact the care offered. Pastoral/Spiritual Care workers make use of interpreters if necessary.*
>
> *It is important to note the spirituality and culture may significantly contribute to the meaning attributed to many aspects of life, from the natural environment, food, hygiene, traditions and art, to body embellishments, festivals, astrology, religious practices and relationships. Where people find Meaning is as diverse as the people themselves. Pastoral/Spiritual Care can assist people to find or reclaim or remember their own meaning and their own answers.*

Traditional Aboriginal spirituality

For Aboriginal people who follow their ancestors' traditions closely spirituality is all encompassing, and inseparable from every day events. We might talk about spirituality within Palliative Care, but they would talk about Palliative Care within spirituality.

The spirituality of the traditional members of the Aboriginal community is inseparable from their identity and their land.

Note that not all members of the Aboriginal community identify with the traditional beliefs. There are a range of secular, Christian and other beliefs within the community.

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-centred, 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 occur[5].

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 electing the person with whom they wish to share information[6].

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 Care[7]:

> *"…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.

Searching for meaning – some verbal sign posts

When someone is facing a terminal illness they tend to reflect on the **past** (possibly in an attempt to make sense of what's happened, of life experiences, successes, failures, and choices), the **present** (making sense of suffering, changes in body image, roles, independence, life-style, wanting to be needed and useful) and the **future** (what is in store for me?)

Often the questions asked by the person can give you an insight into their concerns:

- **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.
- **When will I die?** May indicate wanting to put their house in order.
- **How will I die?** A question like this may mean they are frightened and/or seeking reassurance.
- **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.

What might they really be asking? Possibly they simply want someone to be present with them in their reality. The person may wish for you, the volunteer, to be present with them in their reality. Possibly they simply want to talk with someone about death. It's possible they can't do this with family or community because it is regarded as a difficult and delicate issue[8].

How will you talk about the meaning of life?

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?

Each of us has searched for meaning in our own lives. Maybe 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 formed around not believing what other people believe.

Everyone believes something about what gives meaning to life. To be able to support other people in finding meaning it is critical that we have explored the important questions of life ourselves, that we have 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.

Your own search for meaning will make you more sensitive to the search that others may take.

Of course as a volunteer your role is not to 'sell' your own meaning of life, but to create an environment where the person can explore or express their unique meanings.

Volunteers can learn to recognise spiritual needs by developing excellent listening skills and being sensitive to tiny clues. A volunteer can support the terminally ill person and their carers in their spiritual quest, by being open and compassionate, listening carefully, and answering truthfully, even if that means saying "I don't know".

Remember:

- The experience of spirituality is a very individual experience.
- For some it is intimately tied to their religion or faith tradition.
- It is important in varying degrees to different people but is central to how a person deals with death.
- There is sometimes an urgency to attain spiritual peace when death is near.
- The experience of spirituality is based somewhat on individual life experience[9].

The practice of spiritual support

In practicing spiritual support you will be practicing communication and relationship building. These are some considerations as you embark on this role:

How do we converse with people asking unanswerable questions?

Don't try to find the problem, don't try and fix the problem, just be and don't do. It is your integrity and sincerity that will make 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, the past, present and their hopes for the future.

Listen with empathy and build a relationship based on trust and mutuality. Learn to be present to 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 specialised 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 pace, respect their selection of what they do and don't want to talk about, encourage and allow their autonomy.

Remind them that we won't always find all the answers, often the joy is in the questions. Ask the questions, enjoy the journey.

Additional resources

The **Palliative Bridge** has video resources on spirituality in Palliative Care
www.palliativecarebridge.com.au/resources-spiritual

Chapter 9 Grief and Bereavement

What is grief?

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 is a normal reaction. It is estimated that at least 5 close friends or loved ones are left behind for every person who dies[1]. This suggests that between 5 and 9% of the general population each year are affected by grief[2].

Grief, death and loss are inter-twined. The death of a loved one is a source of grief for everyone. There are other 'deaths' which you might experience along the way, such as 'social death' resulting from exclusion from one's familiar community for example through divorce or financial ruin, or 'physical death' resulting from a loss of physicality for example through acquired disability.

Everyone grieves in their own way according to gender, personality, family, cultural background, and life experiences. Most grieving people appreciate support and understanding.

This chapter focusses on the normal grief reaction that volunteers will come across in the Palliative Care setting.

In a small percentage of cases grief can become abnormal, protracted and unhealthy. In such cases people need additional and specialised support.

Some terms

Bereavement refers to the loss of a person in this case through death. **Grief** describes our feelings, thoughts and behaviours which result from our loss. The **grieving process** entails the changing feelings and behaviours that occur over time.

Mourning refers to the way in which we engage in social expressions of our grief and loss, such as through culture-specific rituals and behaviours.

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.

Complicated grief is being stuck in grief, unable to return to an emotional state of well-being[3].

Understanding the experience of grief – broken attachments

It is important to remember that the experience of grief is the same for everyone, and those who work in the area of grief and bereavement have conceptualized grief in different ways.

John Bowlby was a psychiatrist who conceptualised a way of understanding grief in terms of the person's experience of breaking the bonds of attachment[4]. His ideas have been developed over time and you will learn of other ways of understanding grief, but this is a useful starting point.

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

The phase of numbing and blunting

People experience a sense of disbelief, dismay and denial as they struggle to take-in the fullness of their loss. "I can't believe it", "it can't be true". They may describe themselves as being numb, or not experiencing any feeling at all. Being present at the death, or at the funeral, of a loved-one can help people to accept the reality of the loss.

The phase of pining and yearning

Intense feelings occur once the death is acknowledged both intellectually and emotionally, the 'pangs of grief'. These can be accompanied with other physical experiences like sighing, shortness of breath, and empty feelings in the abdomen. There may also be strong feelings of guilt or anger directed at the deceased, hostile reactions to anyone who offers consolation, and signs of disorganized thinking and activity (like wandering). Preoccupation, detailed recall, rumination and over-analysis of the relationship with the person may occur to the extent that the person may once have been diagnosed as sick or mad.

Phase of disorganisation and despair

Introversion and withdrawal follow once the intensity of the emotions subside. Appetites are diminished and people live day to day preferring to avoid the future. This marks a time of healthy healing, but it may equally mark a time when excessive rumination can lead to self-derogation and a slow decline into unhealthy grief can occur.

Phase of reorganisation and recovery

The attachments to the bereaved are eventually broken down and the individual begins to resume old roles, refresh old attachments and form new attachments. Although they still experience grief they start to shift their attention to the world around them.

Expressions of grief

Grief is a profound experience. Feelings, physical sensations, thoughts and marked changes in behaviour are all possible consequences for a person undergoing a grief response. These notes are from the Palliative Care Volunteer Training Resource Kit[5].

Feelings include sadness, anger, guilt and self-reproach, anxiety, loneliness, fatigue, helplessness, shock, yearning, emancipation, relief and numbness.

Physical sensations include hollowness in the stomach, tightness in the chest, tightness in the throat, oversensitivity to noise, a sense of depersonalisation ('I walk down the street and nothing seems real, including me'), breathlessness, weakness in the muscles, lack of energy and dry mouth.

Thoughts can include disbelief, confusion, preoccupation, sense of presence, hallucinations.

Behaviours can include sleep disturbances, appetite disturbances, absent minded behavior, social withdrawal, dreams of the deceased, avoiding reminders of the deceased, searching and calling out, sighing, restless hyperactivity, crying, visiting places or carrying objects that remind the survivor of the deceased, treasuring objects that belonged to the deceased.

These responses are listed here to alert you to the scope of experiences that someone might express. They may be unaware that the response might be part of a grief response – for example they might attribute it to some other stress in their life[5].

Severe grief can become unhealthy when it is prolonged, and in about 7% of cases individuals will need treatment for complicated grief[6].

While it could be said that all grief has it's complications, some people suffer prolonged, delayed, or absent grief reactions that adversely affect their functioning and their relationships.

For example, grief within a socially problematic context (such as deaths from HIV/AIDS, suicide, miscarriage, deaths of frail elderly people, and bereaved people with intellectual disabilities) can lead to a sense of disenfranchisement by the individual, invoking a sense that their grief is inappropriate. In particular this can occur in children if they are not given permission to be involved in death rituals.

Other factors include gender and culture. Even in normal grief experiences women tend to grieve longer than men. In recent research finding women took longer to recover from bereavement than men: on average it took women two years and four months to feel better, while men said that it took on average one year and nine months. It also took people aged 45–54 twice as long to feel better than those in the 16–24 age category[7].

Complications can also arise when people are overwhelmed by a number of losses, do not have access to support, or have had previous mental illness such as severe depression. Expert professional help is indicated in these circumstances.

Avoiding clichés about grieving

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."

Tips for supporting families and friends

> *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, UK*[8]

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.

Listen to the bereaved person. Allow him or her to repeat their story. Sharing memories of the person who died can be very comforting for you and the bereaved person.

Be willing to talk about the person who died. 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.

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 never goes away 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. Don't judge how long a person's grief appears to be taking.

Remember that there is no right way to grieve. Avoid criticising how someone is grieving; you cannot know 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 your own past.

Offer practical help. In the days after the death has occurred, help with answering the telephone, do errands and shopping, or take care of the children. Later, share a regular walk or outing and remember anniversaries, birthdays, and special holidays. When the bereaved person is ready, include him or her in social gatherings with new people, encourage the individual's growing independence, and continue to remember and talk about the person who died[9].

Children and bereavement

Statistics indicate that each year 2% of children are bereaved of a parent before the age of 18 years whether by sudden or progressive decline[10]. 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 periods[11].

Children benefit from sharing their feelings and exploring their thoughts about death and loss, although they must be allowed to instigate discussions[12].

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 response[13].

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 withdrawn[14].

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.

Siblings and Bereavement

A sibling's grief is often influenced by the parent's response to death, and this may affect the way in which they express their own grief.

Siblings can be the "forgotten grievers" as everyone focuses on the parents. Fear is the predominant emotion for siblings – they fear that parents may get sick and die, maybe other people will die, maybe there will be nobody to care for them. They may be of an age whether they believe that death is preventable and have "magical thinking" about it.

Siblings need to be able to talk about their sibling who is dying but also have the right not to talk about them if feelings are too raw. They need to be valued and made to feel important, and to have time to play loud games as a way of expressing feelings on the inside.

The role of the volunteer in the grief experience

Usually the person who is grieving will want to talk. By listening you may mean hearing 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; and remembering ... and saying goodbye.

We should encourage the person to talk about the past and their memories but in the role of supportive friend rather than counsellor. If the person doesn't want to talk about a topic that's fine. 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; the second implies they're not "recovering fast enough".

Show your emotions. If you're at ease showing how you feel it can make it easier for others. Recognise when to keep silent – and don't try and fill the spaces with words.

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 contact you – and they probably won't. If, on the other hand, you drop by with a meal, or offer to do their shopping when you're doing your own, you're helping to ease the burden.

Remember that grief may surface at significant times: birthdays, anniversaries, Christmas, holidays. These can be painful times. Knowing this, think about whether there is anything you can do to provide support. And avoid the clichés listed earlier[15].

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

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)

Chapter 10 Palliative Care, Multiculturalism and Families

What is culture?

Culture occurs with shared meanings. Culture describes an identity, and is itself an identity to which people ascribe or are assigned. One definition of culture is[1] '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.'

Culture is personal and communal. Definitions of culture are normative, that is to say that 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[2]:

> *"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 it's belief system and perceptions of health, illness and dying."*

Gender, sexuality, language, religion, nationality, ancestry, language and ethnicity each forms the basis for what we might describe as cultural identity. You might be part of one or more of these cultural groups. Within each cultural group there will be 'normal' ways of understanding and behaving into which you might or might not fall. Of course just because you have a particular identity doesn't prevent you from acting contrary to it. Therein is the complexity of understanding not only 'mainstream' culture but each cultural group in our community.

These notes focus on ethnicity as a basis for thinking about multiculturalism and culturally-sensitive Palliative Care, and then consider family as a dynamic within which volunteers will be involved.

Some terms

Ethnicity describes a group formed by common ancestry, cultural or national experience. Within an ethnic group there may be more than one **language group** of people speaking the same language. **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. **CALD** stands for 'culturally and linguistically diverse' and is a commonly used term in service delivery.

Multicultural groups in Australia

Data from the 2011 Census[3] indicates that almost a quarter (24.6 %) of Australia's population was born overseas and 43.1 per cent of people have at least one overseas-born parent. The United Kingdom is the leading country of birth for the overseas-born population (20.8 %). It is followed by New Zealand (9.1 %), China (6.0 %) and India (5.6 %). The number of people born in India has experienced the largest growth with an increase of 148,261 people since the 2006 Census, followed by China (112,379) and New Zealand (93,934). In 2011, 82% of the overseas-born population lived in capital cities compared with 66% of all people in Australia.

In terms of languages spoken, the Chinese languages of Cantonese and Mandarin are the most commonly spoken languages after English. Cantonese speakers represent 1.2% of the Australian population (2% of the NSW population) and Mandarin speakers represent 1.6% of the Australian population (2% of the NSW population). 76.8% of households in Australia speak only English, and 20.4% of households have two or more languages spoken.

Religious traditions are one defining feature of culture, and 61.1% of people in Australia indicated that they were Christian with 7.2% indicating a religion other than Christianity (including Buddhism 2.5% and Islam 2.2%)

and 22.3% indicating ‘no-religion’. Of the Christian traditions the most common were Roman Catholic (25.3% Australia, 27.5% NSW) and Anglican (17.1% Australia, 19.9% NSW).

These statistics go some way to painting a picture of 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?

Volunteers from the different cultural groups can provide a valuable source of community representation of their group for a service which will help to inform their service delivery.

Multiculturalism resources

Palliative Care Australia has a range of online and printable multicultural 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 clients[4].

Palliative Care Australia also publishes the *Multicultural Palliative Care Guidelines*[5] 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 which are free to access from their online library[6]

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[7].

Volunteering responses to multicultural service delivery

There are essentially three responses to providing volunteers within a multicultural catchment. If a service received referrals for Palliative Care volunteers then the service might:

- train existing volunteers in cultural awareness; and/or
- recruit volunteers from within the community, perhaps with English as their second language; and/or
- ask for assistance from a culturally-specific service to assist with guiding their volunteers, or to receive referrals for Palliative Care support.

Each of these strategies is in use by various volunteer services in NSW.

A culturally-specific service: Palliative Care Volunteers in the Chinese community

In 2015 *CanRevive Inc* celebrates 20 years of service to the Chinese community in metropolitan Sydney, working with Cantonese and Mandarin speaking Chinese as a cancer support group.

CanRevive engages Palliative Care volunteers in their work. Their hospital visiting program includes the RPA, Concord, Westmead, St George, Royal North Shore and Liverpool hospitals. Chinese people might register with CanRevive in advance so that a visit can be scheduled, or volunteers might just visit on the off-chance that they can be of assistance.

Many aspects of their volunteer work are shared with other volunteer services. Not each volunteer will be selected for Palliative Care work, instead during their training they are individually screened for their interests and communication skills. The ability to talk about difficult subjects with sensitivity is critical. Of the 100 or so volunteers on their register about 60–80 are active at any given time, comparable with other services. In general volunteers offer a half-day or full-day a week to their program area. Volunteers are also used to co-facilitate training and information sessions.

Interacting with families in a way that respects diversity

Families are at the centre of most multicultural traditions, and working with families is a useful context in understanding 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 (birth, marriage, choice, friendship, etc) 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'[8].

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 (family meetings, open sharing of all information, protection of vulnerable members, etc).
- External communication (who speaks for the client, the family etc).

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 Hospice*[9]

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 memories[10].

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 great a significant impact on the family.

Changing roles means that family members are faced with learning new skills, 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 reorganisation 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 illness[11].

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

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

Palliative Care Victoria have resources available online www.pcvlibrary.asn.au for working with families and multicultural groups.

Comfort at the end of life

Cure sometimes, treat often and comfort always.

– Hippocrates

A symptom is what a person feels or experiences. Any symptom that is uncomfortable, restricts activity, keeps patients awake, makes them anxious because they don't know what it means, or worries them is important

Some illnesses have unique symptoms, some share many similar symptoms, but as the end of life approaches these differences can slowly disappear. Consequently many of the symptoms at the end of life are similar.

Pain management

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;
- distraction or involvement in any activity.

Pain and fatigue are linked in terminal illness. Pain is exhausting. Fatigue increases the experience of pain.

It is worth noting that sleep does not indicate pain relief. Research indicates that some 66% of patients deal with pain by remaining calm, lying still, and trying not to show their feelings[1].

Common myths about pain management

Many people do not follow their pain management regimes due to misconceptions about tolerance, physical dependence, and addiction to their medications. These notes are from the Hospice & Palliative Care Volunteer Training Manual[2]:

Myth: "If the person takes narcotic medications, he/she will become addicted."

Fact: Addiction is characterised by the compulsive use of drugs for their psychological effects. It is rare for people with no history of substance abuse to become addicted to pain medication – including opioid drugs, such as morphine. Those taking medication for relief of pain or shortness of breath will not become psychologically addicted.

Myth: "If the person no longer needs the medication, he/she will go through severe withdrawal when trying to stop it."

Fact: Withdrawal is a physical phenomenon that means that the body has adapted to the drug in such a way that a 'rebound' occurs when the drug is suddenly stopped. Having withdrawal is not the same as being addicted, and is usually no problem at all.

Myth: "The person will develop tolerance to his/her medication and will have to keep taking more and more until he/she is immune to it, and it doesn't work anymore."

Fact: Tolerance to opioid drugs occurs but is seldom a problem. Tolerance means that taking the drug changes the body in such a way that the drug loses its effect over time. Most people's doses are gradually increased because pain increases, not because they develop tolerance.

Myth: "The person will not be him/herself on the medication and will become a zombie."

Fact: Although opioids can make people sleepy and cloud their thinking during the first few days of starting the drug or increasing the dose, this side effect is usually temporary.

Physical effects

These notes are from the Palliative Care Victoria *Palliative Care Volunteer Training Resource Kit*[3]:

Poor appetite

The gut is often very sensitive to medications. 'Drugs slow the gut'.

Poor appetite is a common symptom faced by people in medical treatment. It can be a result of illness, treatment, tiredness, an altered sense of taste, pain, lack of activity, depression, nausea, and vomiting.

The best we can do is to provide food that is appetising and appealing and is provided based on advice from the team including the dietician (nutritional aspects), doctor (drug interactions with certain food types), or nurse (comfort, gut motility).

Be encouraging if the meal is not consumed, perhaps next time a little more will be eaten.

The medical term for poor appetite is 'anorexia'. Note that the condition 'anorexia' is different to 'anorexia nervosa' which is an eating disorder psychological in origin.

Nausea and vomiting

Nausea can occur in 50–60% of all terminal ill people and vomiting in 30%. The consequences of uncontrolled vomiting and anorexia include:

- Poor fluid intake can cause frequent returns to hospital and much distress;
- A reluctance or refusal to take other medication, in particular analgesia, in a belief that this is the cause of the vomiting;
- Poor absorption of oral medications;
- Dehydration and deteriorating electrolyte in-balance (which in turn can increase low blood pressure and then vomiting);
- Weakness, exhaustion, misery, depression;
- Confusion; and
- Rapid weight loss, malnutrition, and cachexia (muscle breakdown).

In the same way that 'drugs slow the gut', nausea and vomiting can result from medication side-effects. Anti-nausea medications (anti-emetics) can act to ease symptoms. Emotional factors can exacerbate or cause nausea, and consequently relaxation techniques can be beneficial in reducing the discomfort associated with feelings of nausea.

Fatigue and exhaustion

Fatigue (extreme tiredness) is one of the most frequent symptoms in Palliative Care patients. It is reported in 80% of cancer patients, and up to 99% of patients following radiotherapy or chemotherapy[4]. 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.

Unfortunately, treating fatigue successfully is not as straightforward as treating some of the other symptoms.

Allow and encourage the person and carer to be as independent as possible.

Helpful things to do when the person is tired:

- Encourage them to talk about their tiredness: understanding how it feels will help everyone.
- Conserving energy for the things that really matter.
- Plan to do things at the time of day when tiredness is least severe. Morning is best for most people.
- Encourage short naps during the day.
- Set short achievable goals.
- Try and encourage a little dependence on others so as to maintain the client's level of independence.
- Encourage gentle exercises like walking to the letterbox or sitting out of bed for meals. This preserves muscle tone and a sense of normality.
- Provide high-calorie, high-protein drinks. This may slow weight-loss and help maintain muscle strength.

Difficulty breathing – breathlessness or shortness of breath

Affects approximately

- 55% of people in the terminal phase;
- 65% of people with lung cancer;
- 30% of people with cancer in the terminal phase.

Fear of choking and the emotional response to breathlessness can exacerbate the difficulty.

Volunteers may notice noisy respirations:

- A death rattle is a rattling noise in the hypo-pharynx as the person breathes
- Cheyne-Stokes breathing is a specific pattern of breathing in the terminal phase when the person is semi-conscious or unconscious.

The palliative care team can assist clients with their breathing if required. The latter two conditions (noisy respirations) are often not distressing to the person but can be very distressing to the family and the carers. As a volunteer, you may feel the need to talk with your manager for support and debriefing if you experience this situation.

Constipation

Everyone has a different bowel pattern. Some people only use their bowels twice a week and this is normal to them.

A common misconception is that if a person is not eating they do not have to use their bowels. The aim for comfort is a soft, easy to pass bowel action. The person should be comfortable with no abdominal pain.

Diagnosis, prognosis and 'how long will I live?'

Diagnosis is the act of distinguishing one disease from another e.g. dementia, liver cancer.

Prognosis is the prediction of the duration and outcome of a disease e.g. less than a year to live.

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

Prognosis includes a focus on duration and inevitably the question will be asked by a patient or their loved ones "how long do I have to live?" 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.

The volunteer and comfort care

As a volunteer you are in an invaluable position to be able to note changes in the person's symptoms, but your role is limited to reporting the observations and not providing advice to the person or their carer.

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.

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 hygiene[4]. 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 5 – 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 should[5]:

- cover the 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 us;
- 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 ***Pain*** (www.palliativecarensw.org.au)

Chapter 12 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 spirituality[1].

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 are 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 causes 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 Care[2]. 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).

One the other hand loved ones might appreciate someone giving them 'permission' to feel comfortable to retire from the bed side 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-arranged[3].

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 included elsewhere:

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 like 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 concerns – Dying and death brings out the best in some people and the worst in others. Most people though 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. 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.

Spiritual concerns – 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. 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.

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 Dying*[4].

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 patters 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, of softly play familiar music.

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

As a member of the team your role is to be supportive.

Questions for Review

Chapter 1: Introduction to Palliative Care

1. What is meant by the term ‘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 focusses 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.
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: 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 4 of the qualities looked-for in a Palliative Care volunteer.
3. Briefly outline 3 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 3 of the domains of ‘holistic care’.
5. List the clinicians or specialists that might be present in the Palliative Care team.

Chapter 3: 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.

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: 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 5: Home and Community Visiting

1. Why is it important that your 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 6: Advance Care Directives

1. What features give legal validity to an Advance Care Directive?
2. Describe the people with whom an Advance Care Directive should be shared in order for it to be available when needed.

Chapter 7: 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 8: Spirituality and Palliative Care

1. Which of these best describes 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
2. 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.
3. 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.
4. Which members of the team would you look-to for assistance with spiritual care?

Chapter 9: Grief and Bereavement

1. Which of the following is part of the process of mourning:
    a. Accepting that our loved-one is gone
    b. Processing the pain of grief
    c. Adjusting to our new world
    d. Working-out our new relationship with the person lost
    e. All of the above
2. List ten of the common physical, cognitive and emotional 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 10: Palliative Care, Multiculturalism and Families

1. Briefly describe why members of the same national group might have different language, ancestry and ethnic identity.
2. 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
3. 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 11: 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 12: 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.

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