



**Palliative Care**  
NEW SOUTH WALES

# Palliative Care Volunteer Services

**Guidance for Managers**



## **Acknowledgements**

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## **The Volunteer Support Services Program**

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## What, why and who is this for?

### What is the purpose of this resource?

This resource has been prepared in order to share ideas and resources relevant to the management of palliative care volunteer services.

### Who is the target audience?

People who have an interest in the management of palliative care volunteer services.

This includes but is not limited to Volunteer Managers, Volunteer Coordinators, Supports Coordinators, Health Service Executives, Directors and Clinicians. They might be an employee of a local health district, or of a private hospital or health service, or an employee of a not-for-profit organisation with or without recurrent state government grant funding, or they may be an unpaid manager of volunteers.

**This resource is for managers of volunteers.**

Other people include palliative care volunteers, people receiving palliative care, their families and loved ones, managers of volunteers of services other than palliative care volunteer services who may benefit from the approaches of palliative care volunteer services, and members of the public.

### Is this a policy and procedure manual?

No. This is a discussion about the different contexts within which volunteer services operate and the challenges that they face. This is not a prescriptive list of *dos and don'ts*. If you are seeking specific instructions for managing your service you should refer to your organisation's policies and procedures.

### Key messages

The key messages include:

- This resource is for managers of volunteers.
- Palliative care volunteers are regarded as non-clinical members of the palliative care team.
- As manager you should check your organisation's policies and procedures for specific instructions in relation to volunteer and program management.

# Chapter 1 Managing your palliative care volunteer service

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## Palliative care volunteer services in NSW

In 2014 Palliative Care NSW undertook a survey of palliative care volunteering in the state and found 38 palliative care services with about 1,242 people engaged as volunteers. Across the 38 services there were 22 full-time equivalence roles held by managers. Only 8 services reported having full-time managers with the average across all services being 0.71 FTE. About 29% of managers were located in Metro LHDs, 60% in Regional LHDs and the balance in State-wide Networks. About 33% of managers indicated that they had been in their role for less than 1 year<sup>1</sup>.

The 38 services could be differentiated into 4 different service types including (1) Government health service (15 services) typically the local hospital which has inpatient palliative care service (beds, or a ward or unit); (2) Clinician-lead service (4 services) typically managed by a clinician with designated hours to oversee palliative care volunteer activities; (3) Not for Profit organisation (11 services) independent organisations, with or without recurrent funding from NSW Health, that receive referrals from the local palliative care team; and (4) faith-based private hospital provider (8 services) attached to a faith-based hospital or service organisation.

Volunteers perform different roles depending on local need. These may include inpatient support, community visiting and respite, equipment, bereavement support and biography. A paediatric service may deliver programs differently to a service which focuses on adults. An overview of the various volunteer roles typically found in NSW is included in this resource.

**Palliative care volunteers are regarded as non-clinical members of the palliative care team.**

## An overview of priorities in managing a service

Palliative care volunteer services aim to support the local palliative care team in providing care to clients and their family with compassion and dignity. In general the priorities for services are based on maintaining their relationships with:

- People in palliative care and their loved ones.
- The referring clinicians.
- Volunteers and the community.

### 1. Relationships with people in palliative care and their loved ones

The primary role of the volunteer service is to improve the patient-journey and contribute positively to the experience of people receiving palliative care, their family and loved ones. The manager, although (usually) not one of the volunteers, is expected to model this behaviour through interactions and behaviour around clients and family members.

Being relevant to and respectful of the people who are receiving palliative care, their families and loved ones includes customising the service's programs to the needs of the local catchment. For example a service might provide a local services guide, or acquire resources not otherwise available locally but which are of value to the individuals.

It also includes properly training, preparing, supporting and managing their volunteers so that the optimum quality of support is provided.

## 2. Relationship with the referring clinicians

The relationship between a palliative care volunteer service and the palliative care team is an important one. Ideally volunteers are included as part of the palliative care team wherever possible, through a process of referrals from clinicians to the volunteer service.

The flow of these referrals is essential, without which the work of the volunteer service may grind to a halt. Not all clinicians will be as supportive of volunteer involvement as others. Some will need more reassurance, or more evidence, or more awareness of the role of the volunteer.

The manager can make the most of the opportunity to obtain referrals by ensuring that the volunteer service has credibility with the palliative care service and has good working relationships with clinicians in the team. Having the support of senior management within the health service is also helpful.

The challenge of relationship management varies depending on the service context. About 70% of palliative care volunteers services in NSW are within larger health settings like hospitals, with about 26% are smaller not for profit services that are separate entities to the referring clinicians.

## 3. Relationships with the volunteers and the community

Maintaining faith with the volunteers is also an essential part of your role as a manager. This is important not only in terms of volunteers donating their time, but also in terms of the community donating their money and offering support through volunteering.

Acknowledging the contribution of volunteers as members of the health workforce is essential in attracting good quality and long serving volunteers and ensuring the best outcomes for the service.

Acknowledging the contribution of volunteers as members of the community is essential in maintaining the relationship with the local community. This is not only important in promoting opportunities for volunteering and to engender community confidence in the palliative care service, but in a pragmatic way is important for securing material contributions, donations and sponsorships.

Acknowledging the contribution of volunteers as members of the health workforce is essential in attracting good quality and long serving volunteers.



## Managing relevant issues and risks

As manager you will be involved in managing risks specific to your service, as well as risks generic to health and volunteer services.

Your organisation's **Policy and Procedures** should be the first point of reference. If your service is a not for profit organisation you might additionally be subject to the external requirements of the referring palliative care team, and/or to any agreement with funding bodies.

Additionally NSW Health has published the **Framework for Engaging, Supporting and Managing Volunteers** as a policy directive for all NSW Health services.

**As manager you should check your organisation's policies and procedures for specific instructions in relation to volunteer management.**

If your service is new then you should develop a set of policies as soon as possible. Some common areas for consideration include appropriate behaviour, privacy, confidentiality, workplace health and safety, driving and vehicle use, grievances and complaints, travelling with clients, safe community visiting, reimbursement, performance and disciplinary matters. Other risks associated with specific program areas will also need to be addressed. Palliative Care NSW publishes a **Sample Policy Manual for NGOs** on the VolunteerHub website as a starting point for your own manual.

Some organisations provide a summary of the organisation's policies and behavioural expectations in a **Volunteer Handbook**. Figure 1 lists suggested content for a volunteer handbook and serves as a checklist for reading your organisation's policies and procedures<sup>2</sup>.

**Figure 1: Suggested subjects for a volunteer manual**

- Welcome/overview of the service.
- Volunteer rights, responsibilities, authorities, delegations and scope of practice.
- Who to contact for support.
- How to claim for expenses.
- Declaring and managing conflicts of interests.
- Emergency procedures.
- Health and safety policy (alcohol and drug impairment policies).
- Acceptable workplace behaviour (antidiscrimination, sexual harassment, bullying).
- Working with vulnerable clients, working with children and families, police screening checks.
- Driving and vehicle use.
- Privacy and confidentiality.
- Property and intellectual property.
- Procedures for giving feedback, performance review, setting goals, ending the relationship.
- Complaints and grievances.
- Reporting and recording volunteer activity.
- The extent of insurance cover for volunteers, things to consider, scope of activities.
- Communication, social media, responsibility to fairly represent role and service, defamation.

The **National Standards for Volunteer Involvement** (2015) have been recently revised for use within an accreditation program. Published by Volunteering Australia they 'provide a framework for organisations to consider the role of volunteers within the organisation and the impact effective volunteer involvement can have on achieving the strategic goals and aims of the organisation'<sup>4</sup>.

The **Victorian Palliative Care Volunteer Standards** (2007) provide program standards and volunteer service standards for the Victorian palliative care sector, designed to; foster greater awareness of the role of volunteers in palliative care, support and promote volunteer engagement in palliative care, limit organisation legal liability with regard to volunteer engagement in palliative care services. A selection of resource documents are included to assist organisations compile volunteer policies and procedures<sup>5</sup>.

Palliative Care Australia publishes the National Palliative Care Standards (**Standards for Providing Palliative Care for all Australians**, 2005) which are generic to palliative care services. The standards identify service performance outcomes across 13 domains and are a guide for palliative care services to optimise and reflect on service delivery characteristics. Compliance with the standards is optional.

The Australian Commission on Safety and Quality in Health Care is the national oversight agency for health care standards and publish the **National Safety and Quality Health Service** (NSQHS) Standards. Compliance with the NSQHS is mandatory for continuation of funding for health services and may be achieved through the **Australian Council of Health Care Standards** (ACHS) programs including EQUiP National, EQUiP5 and others which include a planned inspection and accreditation cycle<sup>3</sup>.

Smaller, less complex and less diverse organisations require a commensurate accreditation system. The **Australian Service Excellence Standards**, the **Home Care Standards** and the **Health and Community Services Standards** are examples of accreditation systems measuring generic service characteristics and tailored to smaller organisations.

Performance data on palliative care services is also collected through the **Palliative Care Outcomes Collaboration** (PCOC) based at the University of Wollongong which is a national program measuring patient outcomes using standard clinical assessment tools.



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## Additional resources

A searchable map of palliative care volunteer services in NSW can be found on the VolunteerHub website [www.volunteerhub.com.au](http://www.volunteerhub.com.au).

Palliative Care NSW publishes *Palliare: A Handbook for Palliative Care Volunteers in NSW* (2015) as a learning resource for volunteers (available in print, pdf and eBook) [www.volunteerhub.com.au](http://www.volunteerhub.com.au).

The Centre for Volunteering in NSW published a report *Reimbursement and Value of Volunteer Effort* (2010) [www.volunteering.com.au/reimbursement-and-value-of-volunteer-effort](http://www.volunteering.com.au/reimbursement-and-value-of-volunteer-effort) which provides useful definitions and explanations of reimbursement concepts.

The Palliative Care NSW report into volunteering in NSW *A Snapshot of Palliative Care Volunteering in NSW 2014* is available at [www.volunteerhub.com.au](http://www.volunteerhub.com.au).

The NSW Agency for Clinical Innovation have published several reports describing the current service system in NSW and setting goals for future development (*Blueprint for Palliative and End of Life Care - A Blueprint for Improvement*) which are available online [www.aci.nsw.gov.au](http://www.aci.nsw.gov.au).

Volunteering Australia have a collection of management resources online [www.volunteeringaustralia.org](http://www.volunteeringaustralia.org).

The Fair Work Ombudsman has published about internships called *Fact Sheet on Student Placements* which is available online [www.fairwork.gov.au](http://www.fairwork.gov.au).

The Department of Human Services (Centrelink) has online information on opportunities for job seekers to undertake volunteering as an activity exemption [www.humanservices.gov.au/community/providing-volunteer-opportunities](http://www.humanservices.gov.au/community/providing-volunteer-opportunities).

## Chapter 2 Managing your volunteers

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Managing your volunteers includes:

- Understanding why people volunteer
- Recruiting and selecting
- Training
- Supporting and managing
- Valuing and recognising
- Farewelling

### Why do people volunteer?

It helps to think of two types of volunteers – let's call them Type 1 and Type 2:

**Type 1 volunteers** are mostly motivated by their altruistic values. They may have lost a loved one in palliative care. For example they might be a retired health professional wanting to continue their involvement as a volunteer; or they might be an artist, or art therapist, hairdresser, driver, chef, fundraiser or masseuse who can contribute time outside of their work commitments.

**Type 2 volunteers** are mostly motivated by achieving some sort of vocational goal including (1) Student Internships; (2) Student volunteers; (3) Centrelink volunteers; and (4) Job seekers:

**Student Internships** is a form of volunteering for work experience that is an accepted part of vocational preparation. Some universities are moving to make Student Internships mandatory for all undergraduate students. Vocational preparation is valuable, but there are limits to how much a person can be asked to contribute before it becomes exploitative<sup>7</sup>.

**Student volunteers** are people who are completing a course of study, which might be related (nursing, extended care, physiotherapy) or unrelated (law, business) to palliative care and who want to volunteer until the end of their studies as a way of fulfilling their own motivation to participate in a unique experiential opportunity. Their interest may be time-limited and opportunistic but nonetheless valuable.

**'Centrelink volunteers'** or 'Centrelink volunteering' is shorthand for the option of a person on unemployment benefits to undertake volunteering which will exempt them from Centrelink's unemployment-benefits activity test. Both the person and your service must be registered with Centrelink.

**Job seekers** are people looking for experience within a work setting to add value to their resume. While they may be genuinely interested in palliative care and volunteering their primary focus is on gaining experience to make them more attractive to an employer, and so their interest in volunteering is likely to be short term.

### Starting a new service, or adding a new program to an existing service

You may have determined a need for a volunteer program or service, and the time feels right to get underway. Spend some time making sure that the clinicians are supportive and that you have fully communicated the role of the volunteer and how they will be selected and supported. This is essential not only to provide a safe working environment but also to ensure that the volunteer is fully embraced as a team member.

If your service is new it is worth making sure that your volunteer support and management processes (policies, management systems) are sorted out before you start recruitment and training.

## Recruiting and selecting

A professional approach to the recruitment and selection of volunteers is essential to a volunteer service. Guides and resources on the recruitment and selection of volunteers have been published by Volunteering Australia and are available online.

**As manager you should check your organisation's policies and procedures for specific instructions about recruitment and selection of volunteers.**

Not all palliative care volunteer services advertise for volunteers. Some services find that word of mouth promotion in the health service and within the community brings adequate numbers of quality candidates.

Some services advertise on the *Go Volunteer* website (an initiative of Volunteering Australia) and others on Seek Volunteering and Ethical Jobs. There are many web-crawling job-boards that will promote volunteering jobs which are posted on reputable websites – so if possible post vacancies on the health services' website to improve exposure. Your local Volunteer Centre, Community Health Centre, Local council, newspaper or library are other possibilities.

Not all applicants will be suitable for a volunteer role. Managers generally ensure that all applicants are made aware, possibly at the time of their first enquiry, that a position is not guaranteed.

Many services start the recruitment approach by having an initial conversation with the candidate, possibly over the phone, to identify their strengths, motivations and interests. Taking short-cuts in the recruitment phase might result in the engagement of unsuitable candidates and consequent problems for the service. During our survey of volunteer services one clinician made the following comment about their early experiences in recruitment:

*"For our first recruitment program 25 years ago we ran an advert in the local paper, and took anyone off the street, and some people were there because of their own needs, so along the way we had to weed out people often around boundaries ... so now we ask them the reasons why they would like this work, they are told up front that acceptance of their application isn't a guarantee that they get a placement because they might be filtered out during the training program"*

A small number of candidates have maladaptive reasons for wanting to volunteer in palliative care. For example a person may want to 'set to rights' a wrong suffered, or they may want to assert their particular worldview about spirituality, pain management, alternative therapies or medical treatment which might be at odds with the policy position of the health service.

The manager should try to make sense of why the person wants to be involved in palliative care volunteering, identify if they have the potential to develop the skills and knowledges required of them, and briefly assess their interpersonal and communication skills.

A person who has experienced bereavement involving palliative care may bring excellent skills as a volunteer, but the accepted practice is that they be at least 12 months post bereavement before commencement.

All candidates should be made aware of the relevant organisation's policies particularly as they relate to identity and security checks such as the WCC (Working With Children Check) and Criminal Record Check.

Spend some time making sure that the clinicians are supportive and that you have fully communicated the role of the volunteer.



### Training

Of the candidates that are likely to be suitable, the next stage is to invite them to be involved in training. In most services the training must be successfully completed before volunteer status is confirmed.

**As manager you should check your organisation's policies and procedures for specific instructions about training volunteers.**

The training phase is critical to ensuring that the candidate is properly skilled before they engage with vulnerable members of the public, so consider carefully what you are aiming to achieve with training. Volunteering Australia<sup>9</sup> offers some points to consider:

- Decide if training is needed, and what kind of training is needed. For example, training is not always the best solution to a performance issue.
- Specify the learning outcome. Do you have a clear picture of what you want to achieve by the end of the training? How would you describe the skills and attributes of a competent volunteer?

- Focus on the learner learning, not the teacher teaching. Is there a different learning methodology that would be more suitable? Does the person have skills which could exempt them from parts of the training?
- Use assessment to deepen the learning experience. This is not only a chance to measure against the performance outcomes, but to receive feedback about what has been absorbed. How will you measure that the volunteers are competent to commence?
- Evaluate the effectiveness of training. Is there a strategy in place to evaluate outcomes from the program after an appropriate interval?

Trainers might use material from the **Palliative Care Volunteer Training Resource Kit 2012**<sup>10</sup> or they might develop their own resource material. **Palliare: A Handbook for Palliative Care Volunteers in NSW**<sup>11</sup> is designed for individual use by volunteers.

Each NSW palliative care volunteer service has developed their own training program to suit their own needs and resources. In many cases they engage local clinicians to provide the training. In smaller not for profit organisations the training may be delivered predominantly by one or two clinicians, or by the manager. Formats might be 1 or 2 days, up to 8 days in length. Sample training programs are shown in Figure 2.

### Figure 2: Sample training programs

#### Sample 2 Day Program (2 full days)

This format is intended to be used for volunteers who are experienced within the health service or a similar field to palliative care, and who need an orientation to volunteering within the palliative care setting. (With thanks to the John Hunter Children's Hospital).

Day 1: 0900 - 1030 What is Palliative Care? How does volunteering make a difference?  
1030 - 1045 Morning tea  
1045 - 1230 Communication and family dynamics  
1230 - 1300 Lunch  
1300 - 1400 Clinical/health and treatment issues  
1400 - 1500 The role of the volunteer  
1500 Close

Day 2: 0900 - 1030 Spirituality  
1030 - 1045 Morning tea  
1045 - 1230 Grief and bereavement, self-care and boundaries  
1230 - 1300 Lunch  
1300 - 1400 Practical care and support  
1400 - 1500 Next steps  
1500 Close

#### Sample 9 Day Program (9 part days)

This format is intended to be used for candidates who are new to the organisation and new to palliative care support. (With thanks to Tweed Palliative Support Inc).

Day 1: What is Palliative Care? The role of the clinical and support team  
Day 2: Communication, Volunteer Rights and Responsibilities  
Day 3: Family dynamics, Caring for the Dying (body and spirit), the Funeral Ritual  
Day 4: The Dying Process, Advance Care Directives  
Day 5: Grief and Loss, Massage for volunteers, Clinical knowledge  
Day 6: Spiritual care for the dying, the role of the Social Worker  
Day 7: Field visit, guest speaker with personal experience of loss  
Day 8: Palliative Care and the GP, Stress Management, Bereavement and Meditation  
Day 9: Patient care and contact, Letting-go and Completion

Whatever the format used the manager has an interest in knowing that the candidates have absorbed the material and have achieved the learning goals for the training program. This might include:

- Post-training interviews, serving as an opportunity for the manager and another (a clinician or experienced volunteer) to meet with each candidate and gauge their knowledge through questioning. This format might also serve to discretely raise any issues of concern with them.
- Competency-based approach, using one or more assessment processes to confirm competence (knowledge, skills and attitudes). This could be done using a written test each week or periodically.
- Buddy shifts, involving mentoring and observations by an experienced volunteer while the candidate is involved in practical experience.
- A combination of 2 or more of the above methods.

Some candidates may leave during the early stages of training having realised that it is just not for them, and others might simply be unsuitable. Schedule opportunities to discuss progress with each candidate. Some of the checkpoints for these discussions include:

- When the initial application is received
- At initial interview (telephone or face to face)
- Within the early part of the training
- During the mentoring phase at, or toward the end of, the training

This method provides several screening points at which candidates who perform poorly can be eased out of the program, and the best candidates selected to volunteer.

So far we have assumed that all candidates are equally skilled and require an equal amount of training. It might not be desirable or valuable for all candidates to be bought through the same pathway. Some exceptions might be:

- Services may choose to fast-track some candidates who have previous experience such as former health professionals.
- Some candidates might be in roles without direct contact such as fundraising, storage or administration.
- Candidates might be experienced former volunteers within the same service or a very similar one and are well known to the volunteer program, thus justifying their fast-tracking into a volunteer role.

There may be other examples. Managers should check their policy framework to ensure that fast-tracking is a possible option for them. A competency-based approach to training helps the manager collect information to justify their decision to by-pass the usual training obligations.

Successful completion of all elements (including the 'buddy-shift' or mentoring phase) usually confirms the candidate as being accepted as a volunteer. The formality of a 'graduation' celebration, witnessed if possible by members of the clinical team, should form an important rite of passage in confirming to the volunteers the gravity of their role and function within the palliative care team.

## Supporting and managing

The training period represents only the beginning of learning for the volunteer. In time they will experience situations not addressed or absorbed in their initial training and they may: experience complex illness conditions; be confronted by challenging family dynamics; lose their way with their boundaries; find themselves out of their depth spiritually; be emotionally invested beyond their resources; or experience the fatigue that sometimes comes with compassionate work.

The manager is the first point of contact for the volunteer to provide support, direction, correction and empathy.

**As manager you should check your organisation's policies and procedures for specific instructions about supporting and managing volunteers.**

Most managers say that a significant part of their role is helping their volunteers understand and maintain their 'boundaries'. 'Boundaries' refers to the acceptable range within which a volunteer may act. 'Maintaining their boundaries' refers to volunteers making appropriate decisions about how to act – such as knowing what to do if offered a gift, whether or not to share a phone number or what tasks are beyond their scope of practice.

Clinicians often find it challenging to measure their own performance. How well did I do that? Did I do well? It takes time for a clinician to gauge the adequacy of their empathy, compassion, listening and communication but over time they will become more adept at applying boundaries, seeking assistance, taking instruction and acting autonomously. The same is true for volunteers. As manager part of your role will be to guide the volunteers in understanding how well they are performing their roles. This might include:

- Responding to ad-hoc requests for support from the volunteer, or perhaps from a clinician who is working with the volunteer/s.
- Meetings and discussions with the volunteer, encouraging disclosure and providing a mentoring style support. This may be conducted by the manager or delegated to an experienced volunteer. Discussion may be initiated by asking the volunteer to bring with them responses to prompting questions on performance and communication.
- Seeking and collecting feedback from others who have been involved with the volunteer such as clinicians and clients.
- Meetings and discussions with volunteers in a group setting, usually on a monthly basis and sometimes in conjunction with an information or training session.

Most volunteers will do the right thing if they know what that is. So setting-out expectations clearly in a handbook or policy manual is essential for managing the performance of volunteers.

Typically managers of volunteers will offer opportunities to volunteers to learn, network and debrief through monthly volunteer meetings. The aim is to find topics of relevance and interest which will engage the volunteers and support their learning needs. Ongoing development might also be mandatory within the health service for the purposes of achieving quality accreditation.

Not all volunteer services manage to achieve a consistent professional development program. Some of the factors affecting consistency include:

- Whether or not the volunteers are community visiting. Some services report that arranging community visiting volunteers to attend training and networking events can be problematic if volunteers generally work away from the centre.
- The capacity of the service to offer a variety of interesting and topical subjects to volunteers. This is a particular issue for rural and regional volunteer services.

Regular meetings involving catering and learning opportunities are also a valuable form of recognition for volunteers.

### Valuing and recognising

Volunteers or not, everyone in the team wants to feel that they have value and are valued. Many services have developed ways to recognise the contribution of volunteers in the form of activities and events. Some of these activities are timed to coincide with events during the year such as:

- National Volunteer Week (May)
- National Palliative Care Week (May)
- National Student Volunteer Week (August)
- World Hospice and Palliative Care Day (October)
- NSW Health Awards (November)
- International Volunteer Day (December)
- NSW Volunteering Awards (culminating in December)

These specific events and activities are valuable and obvious ways to invest-in and encourage the volunteer group. There are also other more subtle contributors which are powerful predictors of how valued volunteers might feel within the service, some of which are outlined below (whilst these points are highlighted here they are not exclusive - in many ways the theme of this book is about valuing and recognising volunteers).

**As manager you should check your organisation's policies and procedures for specific instructions about valuing and recognising volunteers.**

Some other ways to value volunteers includes:

- **Valuing volunteers by acknowledging their learnings and ambitions.** A volunteer who wants to learn and contribute will want the service to value what they have learnt. Where learning is not mutually valued then it might result in dissatisfaction and frustration for the volunteer<sup>12</sup>.
- **Valuing volunteers by including them in the team.** Part of the role of the manager is to be actively involved in checking-in with volunteers to see how they are coping, but also in nurturing relationships with clinical staff so that volunteers are naturally accepted as a valuable part of the team.
- **Valuing volunteers by involving them in decision making and service development.** As appropriate, asking volunteers their views on the performance of the service, engaging experienced volunteers in reviewing the training program and material, and using volunteers to assist with interviewing new volunteer applicants are all valuable ways to recognise the value of your volunteers<sup>13</sup>.



## Farewelling

A change in personal circumstances (health, moving location, caring for a loved one, study, work) is the main reason for volunteers leaving their role. Research by Palliative Care NSW in 2014 found that on average some 22% of volunteers would be inactive at any given time about 10% of palliative care volunteers would leave a service during the year<sup>14</sup>.

Recognising the contribution of the volunteer not only validates their effort but tacitly affirms to the volunteer group how the service values them.

For performance or other reasons some volunteers may have to be dismissed, and this may be the end result of the manager following the organisation's performance management approach. Different legal obligations apply to volunteers than to paid staff and the manager should make themselves familiar with these.

**As manager you should check your organisation's policies and procedures for specific instructions about farewelling or terminating volunteers.**



### Additional resources

Palliative Care Victoria publishes the *Palliative Care Volunteer Training Resource Kit 2012* which can be ordered through their website [www.pallcarevic.asn.au](http://www.pallcarevic.asn.au). Also contact Palliative Care NSW for more information. The kit provides lesson plans and additional material for training and delivery.

Palliative Care NSW publishes *Palliare: A Handbook for Palliative Care Volunteers in NSW* (2015) as a learning resource for volunteers (available in print, pdf and eBook) [www.volunteerhub.com.au](http://www.volunteerhub.com.au).

Volunteering Australia publishes *A Guide for Training Volunteers (Part A)* (2006) and a *Toolkit for Training Volunteers (Part B)* (2007) [www.volunteeringaustralia.org/volunteering-resources/volunteer-managers](http://www.volunteeringaustralia.org/volunteering-resources/volunteer-managers). On their resources page you will also find a guide to *Working with Volunteers and Managing Volunteer Programs in Health Care Settings* (2003).

Palliative Care NSW publishes *A Sample Policy Manual for NGOs* (2014). This sample policy manual will be useful for non-government organisations and others as a basis for their own policy development [www.volunteerhub.com.au](http://www.volunteerhub.com.au).

Volunteering Australia publishes *Working with Volunteers and Managing Volunteer Programs in Health Care Settings* (2003) [www.volunteeringaustralia.org/volunteering-resources/volunteer-managers](http://www.volunteeringaustralia.org/volunteering-resources/volunteer-managers).

## Chapter 3 Inpatient support

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### Volunteers and inpatient support

In NSW about 29% of palliative care volunteer services have volunteers in inpatient settings only, and another 34% have volunteers in inpatient as well as other settings (such as community visiting)<sup>15</sup>. Their roles include:

- Companionship and psycho-social support.
- Meeting and greeting.
- Tea trolley, jolly trolley, hospitality.
- Assisting the clinical team in comfort care.

The inpatient setting provides an opportunity for the person's condition to be assessed by a team, for them to be supported, for their condition to be monitored and stabilised, and for their particular needs at end of life to be best met. Not everyone receiving palliative care will come to an inpatient setting.

Volunteers help to orientate the person and their loved ones and they have time to spend with the person which the clinicians may not have. In paediatric settings the volunteer will spend time interacting with family and siblings. They support, but not substitute for, the parents.

Time alone is part of the equation. The use of that time for reflection, discussion and silence is what people in palliative care often value the most. And not only with the person in palliative care but also their loved ones.

### Selecting and directing inpatient volunteers

As for all palliative care volunteers the inpatient volunteer should be confident to talk to people from all walks of life and to help bring peace and calm into their lives. This will involve competent interpersonal skills and sound emotional intelligence on the part of the volunteer.

Hospitality is a valuable gift for a volunteer, as catering is a practical way to express and share their humanity. Depending on the health service policies they may assist at meal times in unwrapping food items, they may walk with people, go on outings to the garden or grounds or coffee shop, and perhaps give light hand and foot massage.

**As manager you should check your organisation's policies and procedures for specific instructions about inpatient volunteers.**

A willingness to work in a team is also valuable for the inpatient volunteer, both within the clinical team and within the volunteer team. This highlights another important attribute of an inpatient volunteer, the need for them to understand the dynamics within a clinical setting between the various occupational specialities. Being teachable is a valuable quality of an inpatient volunteer.

Typically volunteers in an inpatient setting are rostered-on as a small group on a rotating roster with regular shifts or days. A small group might be one person, or as many as 4 or 5 people at a time. Shifts vary in length but generally are focussed around the needs of the patients and the service. For example if volunteers are used to assist with the morning routine then a shift might be timed for 0700-0900. In this way a volunteer who has committed themselves to giving 4 hours a week will fulfil their time in 2 shifts.

The needs of the service may vary and the demand for volunteer support may change accordingly. The routines of the ward, the familiarity of other staff and the habitual patterns of the roster and tasks can evoke a sense of loyalty and commitment for the inpatient volunteer. The flipside of these virtues is a sense of ownership which can manifest itself in resistance to change and direction, particularly for volunteers who have maintained the same pattern of attendance for some time.

Part of the role of the manager is to manage on the one hand the preferences of the volunteer for regularity, and on the other hand the needs of the service to manage their volunteers as and where needed (within reason).

In many services inpatient palliative care volunteers are managed day-to-day by staff on the ward. They continue to be supported by the manager of volunteers but the manager takes on a coordinator-type role, focussing on recruitment and background 'human resource' tasks.

At times the manager will need to be more closely involved. This is the case when the volunteers are new on the ward, or where there are particular performance issues or challenges in communication between clinical staff and volunteers. In general however the layers of supervision by the palliative care team for volunteers mean that they need less intensive support by the manager in an inpatient setting.

In any case the manager should clearly explain the lines of reporting for volunteers, clarifying to whom they report and from whom they take direction.

The inpatient setting makes for relatively easy recording of volunteer hours in a book on the ward, which are easily transferred to the manager's spreadsheet or database.



### Additional resources

For more resources on managing inpatient volunteers go to [www.volunteerhub.com.au](http://www.volunteerhub.com.au)

Palliative Care Victoria publishes the ***Palliative Care Volunteer Training Resource Kit 2012*** which can be ordered through their website [www.pallcarevic.asn.au](http://www.pallcarevic.asn.au). Also contact Palliative Care NSW for more information. The kit provides lesson plans and additional material for training and delivery.

Palliative Care NSW publishes ***Palliare: A Handbook for Palliative Care Volunteers in NSW*** (2015) as a learning resource for volunteers (available in print, pdf and eBook) [www.volunteerhub.com.au](http://www.volunteerhub.com.au).

The book ***Volunteers in hospice and palliative care: A resource for voluntary service managers***, Second Edition (2009) edited by Rosalind Scott, Steven Howlett and Derek Doyle by Oxford Scholarship Online (available in print and eBook) is a valuable resource for inpatient volunteering.

## Chapter 4 Community visiting and respite

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### Support in the community

Community visiting palliative care volunteers offer a valuable adjunct to the support given by community nursing and the palliative care team. They provide a number of important roles including assisting a person receiving palliative care, assisting and providing respite for the carer, and reducing social isolation after bereavement, and in children's services to assist parents and siblings.

**As manager you should check your organisation's policies and procedures for specific instructions about community visiting volunteers.**

Supporting people to live, and even to die, at home requires a good level of autonomy and emotional skills on behalf of the volunteer.

A robust sense of boundaries is also important. It is possible that the community visiting volunteer may spend more time with the family than do the palliative care team. There is the potential for inappropriate relationships to inadvertently develop. This can often place the volunteer 'on the spot' as family members grapple with changing roles, strong emotions, and the burden of caring for a loved one.

Being discrete and maintaining privacy are particularly important for community visiting volunteers who are given access to the most intimate settings of people's lives and homes. This is challenging in small communities such as rural towns where privacy can be quickly lost. Where the population is small and highly concentrated then not everyone wants 'Jack from up the road' coming into their house and knowing all their personal details.

### Creating a safety framework for home visiting

In brief summary, the challenges of managing community visiting volunteers includes: identifying and managing risk; keeping track of their whereabouts and planned visits to clients; keeping in contact with them as they may not be in proximity to visit the manager in their office; obtaining documented details of their activities (reports); and networking them, such as by having them attend the monthly meeting.

**As manager you should check your organisation's policies and procedures for specific instructions about community visiting volunteers.**

Remember that many other disciplines regularly visit people in their homes including 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 also have volunteers attending people at home.

These services may provide useful points of reference for developing policies on home visiting if your service is new or doesn't yet have appropriate policies in this area.

Some relevant points to consider in managing community visiting volunteers are:

1. **Preparing for a home visit:** Receiving referrals for home visits, site assessments and identifying safety issues, risk assessment, determining level of risk, managing risk;
2. **During a home visit:** On arrival, during, after, critical situations, when to leave and when to not visit, what and how to dress and present;

3. **Supporting volunteers:** Briefing and debriefing, instructions about equipment and dress, possible boundary and performance issues, reporting and recording home visits and contact; and
4. **Appropriate training:** In safe home visiting including how 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, working with difficult clients.
5. **Developing a policy for safe home visiting**

The task of managing and supporting community visiting volunteers is complicated by them operating away from a central base. This sense of being 'away from' the health service may result in an unintended sense of isolation for the volunteer.

A significant part of the role of the manager will be keeping in contact with volunteers who may easily feel disconnected, or who may stray from the boundaries set for them. The time taken to support, brief, debrief, and follow-up should not be underestimated by a service intending to create a home visiting volunteer program.

### Some key points about a home visiting program

- Identify features of the person's social situation, their home setting, and reason for referral to the volunteer service.
- Identify clear timeframes, site of care and care-tasks to be performed. This can be done at the time of referral and then again as visits commence.
- Punctuality by the volunteer is important as the person may have scheduled appointments with which the volunteer can assist.
- Where there are children involved ensure that the volunteer understands the scope of their involvement with the children (such as supporting the children with their chores or homework, assisting the parent to collect them from school) and that these are within the health service's policy requirements.
- Match the volunteer to the person as much as possible.
- Make sure the volunteer is briefed, and then debriefed particularly after their first visit. Also contact the person after the initial visit to check the suitability of the volunteer match.



#### Additional resources

For more resources on managing community visiting volunteers go to [www.volunteerhub.com.au](http://www.volunteerhub.com.au).

Palliative Care Victoria publishes the ***Palliative Care Volunteer Training Resource Kit 2012*** which can be ordered through their website [www.pallcarevic.asn.au](http://www.pallcarevic.asn.au). The kit provides lesson plans and additional material for training and delivery.

Palliative Care NSW publishes ***Palliare: A Handbook for Palliative Care Volunteers in NSW*** (2015) as a learning resource for volunteers (available in print, pdf and eBook) [www.volunteerhub.com.au](http://www.volunteerhub.com.au).

The National Palliative Care Program ***Guidelines for a Palliative Approach in Residential Aged Care*** (2006) are still a useful resource for material for visiting in a context away from acute care. Find them at [www.pcvlibrary.asn.au](http://www.pcvlibrary.asn.au) under Aged Care resources.

## Chapter 5 Complementary and alternative therapies

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Some volunteer services have introduced different modalities for the general health and wellbeing of people in palliative care. In some cases they require specialised practitioners to either perform the technique or to train volunteers, and in other cases volunteers can be effectively trained to perform specific techniques.

**Art Therapy:** Art Therapy is a vehicle for starting conversations, and for empowering people to express feelings and make sense of their situation. Although Art Therapy is a specialised discipline volunteers can be trained in different techniques designed to engage and communicate with people receiving palliative care. This might be of particular benefit to volunteers working with children, or people with limited communication skills.

**Bowen Therapy:** A specialised modality.

**Essential Oils:** Vaporising oil can provide a relaxing effect for people in palliative care. Small personal-use electrical-powered oil vaporisers are available which simply warm the oil sufficiently for the vapours to be released, and ultrasonic diffusers work

without heating the oils by creating a fine cool mist which is infused with water and oil droplets. In each case check with your inpatient unit to ensure these will meet the fire and safety requirements. Oil selection is a highly personal choice, and the more common ones for relaxation might include Lavender, Bergamot, Patchouli, Geranium and Orange. Extra money spent on quality oils will avoid the soapy-odours of cheaper products and result in a far more pleasant result.

**Jolley Trolley:** The Jolley Trolley provides a gratuitous drink (soft and hard) service usually in the middle of the day around lunch time as a vehicle for encouraging connection and conversation. Security is important for all stock, and refrigeration may be necessary for some beverages. It is particularly important that alcoholic stock is secured out of reach of persons under 18 years. Services with a Jolley Trolley report that they often receive donations of beverages from loved ones while the person is an inpatient, or even as a post-bereavement donation to the volunteer service. The regulator for liquor service and licencing in NSW is the Office for liquor Racing and Gaming [www.olgr.nsw.gov.au](http://www.olgr.nsw.gov.au) has additional information which may be relevant to services with Jolley Trolleys.

In some cases, volunteers can be effectively trained to perform specific techniques.



**Light exercise, Light touch:** Where it is offered, light touch is one of the most in-demand volunteer programs. It is widely used in the inpatient setting as a means of establishing connection without words, and provides a powerful means of communicating care and empathy between the volunteer and the recipient. The Australian Association of Massage Therapists recommends specialised training for some specialised modalities. The term light touch is used by volunteer services to describe hand and foot massage typically to assist relaxation and relief from stress. For example light touch is usually provided by volunteers who have been trained by a massage therapist, whereas massage is a specialised modality provided only by a massage therapist. Light exercise like walking is also a valuable way of supporting and engaging with people receiving palliative care.

**Hairdressing:** A specialised modality.

**Massage:** A specialised modality.

**Meditation:** Everyday meditation, or mindfulness, can be learnt and practiced by volunteers with the assistance of an experienced practitioner.

**Music:** Musical taste comes in many colours and shades. The easiest option is for people to bring their own music (CDs, iPod or music player) to the inpatient setting, consider headphones and even noise-cancelling headphones if people are sensitive to background noise or need additional help with stress relief. Alternatively you may have volunteers who are skilled in live music. Music is particularly valuable for people with dementia.

**Pets as Therapy:** Typically Pets as Therapy (PAT) programs involve the use of pets for visiting and companionship to people who are experiencing isolation due to illness or disability. Some programs allow for a person to own a PAT dog and take responsibility for the animal's exercise, grooming and general care and discipline ('residential pet'). For additional guidance contact one of the organisations in NSW operating PAT programs and training: Guide Dogs NSW/ACT, Velma's Pets as Therapy and the Delta Society.

**Qi Gong:** A specialised modality.

**Reflexology:** A specialised modality.

**Yoga:** A specialised modality.

### Final comments

These comments are intended to be helpful in seeing the scope of possible activities, and as a starting point for more research by you as the manager.

Check with your health services' policies for complementary modalities before introducing new programs, for example there may be particular insurance or scope of practice limitations. Guidelines for the delivery of programs should be clearly set out including the requirement for any specialised qualifications, the scope of the activities involved, resources, and responsibility for storage of equipment and materials.



### Additional resources

Check the references to the organisations listed above for their web addresses for more information about their activities and resources.

## Chapter 6 Bereavement support

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Grief is a universal experience and affects circles of people around the person who has died who are faced with the 'tasks' of realising their loss. Offering support to people who are bereaved can help people to accept their loss and adapt to their new reality without their loved one.

Bruce Rumbold and others studied the experience of bereaved care givers and identified opportunities for volunteer input into the post-bereavement period<sup>16</sup>:

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

The aim of a bereavement group is to create a socially-acceptable context within which recently bereaved persons can share their experience of loss. One approach considered here is a mail-campaign to engage directly with people post-bereavement.

### Bereavement follow-up cards

A follow-up program with scheduled correspondence is an effective method of providing unobtrusive contact and encouragement to people post-bereavement.

One program with the goal of providing non-intrusive support into the life of a carer post-bereavement is the follow-up program run by PACT from Clare Holland House<sup>17</sup>. The volunteers in the program receive referrals and are then active in preparing and scheduling the correspondence to be sent. Referrals take the form of the date of death and the contact details for the loved ones and family of people who have recently died. There may be more than one person to whom correspondence is sent. Details are provided by members of the clinical team to the manager.

The volunteers then prepare 3 letters which will be scheduled in advance for sending on a defined date. An initial card is scheduled to be sent 2 weeks post-bereavement. This is a 'with sympathy' message with appropriate wording:

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

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



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

*Dear <name>,*

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

*Kind regards, from the staff and volunteers of <name of service>*

The volunteers include 2 additional items of bereavement information with the letter; a brochure which outlines the common experiences of grief, and a list of grief and bereavement services and resources.

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

*Dear <name>,*

*We are remembering you on this first anniversary of <name's> death. Continuing support is available and you are welcome to contact <bereavement counsellors> on <phone number/s>.*

*Kind regards, from the staff and volunteers of <name of service>*

All the necessary preparation is done in advance. Once the cards (x2) and letter (x1) are prepared they are filed by date in a box-file and the date noted on the outside of the envelope where the stamp is being later affixed. Upon the date for postage the letters can be easily pulled and mailed.

Using more than one volunteer in preparing the letters helps confirm that the details of names and postal dates are correct. This highlights one of the qualities of volunteers in a follow-up program - their attention to detail and care in preparation of correspondence.

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

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



### Additional resources

If your service doesn't have a brochure on grief then the DL sized brochure from Palliative Care Australia **Now What? Understanding Grief** might be of interest see [www.pca.org.au](http://www.pca.org.au).

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

## Chapter 7 Memorial services

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A memorial service refers to an annual (or more frequent) group event which invites people to commemorate the life, death and memory of a loved-one in a supportive group setting.

Although they take many forms, memorial services are generally semi-formal in nature and are hosted in a respectful and peaceful setting that offers the opportunity for members of the group to reflect and recognise their loss. In general the aims might be to:

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

**Check with your service's policies for conducting memorial services.**

### Selecting invitees

When a person receives an invitation to attend a memorial service it will immediately recall memories of the person who has died and invoke emotions about the death and loss. So when sending out invitations think carefully about the wording and be accurate in the details, including the names of the names of the people represented on the invitation. Give people the option of sending an RSVP to attend, to withdraw the name of their loved-one from the list of commemorations, or to have the name included but not attend the event themselves.

A memorial service refers to an event which invites people to commemorate the life, death and memory of a loved-one.



Memorial services deliberately invoke memories of people who have died, and for some loved-ones there may be a period after bereavement within which the feelings about death might be too raw for them to attend a service. Some services assess on a person-by-person basis before sending out invitations, others recommend a period of at least 4 months to have passed before attending a memorial event.

The death of a person or people touches the staff and volunteers who have worked with the person. Inviting staff and volunteers to share in the event and to mark the deaths of people with whom they have worked is a healthy way of recognising their contribution to care and support.

There may be other people who are interested in attending as an act of support, and the invitation might be open to all. Think about the implications for the venue and for catering if a large number of people attend.

### Organising the service

A memorial service may be conducted by, or with the assistance of, palliative care volunteers. Grief and loss, pastoral care and/or social work staff typically attend to provide support for attendees if needed.

The format may vary but it is intended to be respectful, calm and unhurried. A typical format includes:

- Welcoming participants, perhaps by including the reading of a poem or passage to set the tone and to focus the participants on the reflective nature of the service.
- Honouring the persons who have died, perhaps with the lighting of a candle as names are read out-on.
- Pausing to recognise their significance in the lives of their loved ones, perhaps with a moment of silence, to invoke a sense of gratitude and love.
- Closing comments by the host which offer inspiration and encouragement to the living.
- A time for refreshments at the end of the service also serves as an opportunity for individuals to share and reflect with each other outside the formality of the service.

Attendees might be given a token gift to take home with them which resonates with the message shared by the host and that symbolises healthy acceptance of death and loss such as a paper butterfly (changes, release), a candle (light, spirit) or a rainbow (new beginning).

Services have many benefits which are secondary to simply remembering the loss of a loved one. It is an opportunity to share with others who have been through a similar experience, or for friends and relatives to stand with a loved one who has been closely touched by bereavement. It is an opportunity to reflect on one's humanity and mortality, and to mark the passing of time. It is an opportunity for an individual to be moved further toward healthy completion of their grieving, or to reach out for support if they feel stuck.

Individuals will find their own meaning through the service. Familiarity will do much to offer a sense of comfort particularly for people who have attended previously, and for this reason it is probably not necessary to be too creative or novel in format.

A service may be ecumenical in nature but need not be. The setting should offer calm and ease of access. If organising a non-denominational service say in a chapel the organisers might cover up the icons and elements of that particular faith tradition.



### Additional resources

If your service doesn't have a brochure on grief then the DL sized brochure from Palliative Care Australia ***Now What? Understanding Grief*** might be of interest see [www.pca.org.au](http://www.pca.org.au).

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

## Chapter 8 Biography and dignity narrative techniques

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Helping people make sense of their lives is consistent with the spiritual and holistic approach of palliative care. For example, bringing to conscious awareness those events in life that have been formative may help bring closure and improve the person's willingness to accept the inevitability of their own death. Reflecting on the care given can also help understand the person better.

Some volunteer services offer a biography program that offers one or both of these variations of narrative writing:

**1. Biography narratives:** Narratives with a whole of life interest.

**2. Dignity narratives:** Narratives recorded specifically to inform the care provided.

**As manager you should check your organisation's policies and procedures for specific instructions.**

### Biography (and life story) narratives

A patient 'biography' is much more intimate in nature than a public biography. It tends to focus exclusively on what the person wants to share and may skip elements or periods of their life. Life stories, or biography writing, involve a simplified recording of the person's life in written and/or photographic formats.

The aims and goals vary from service to service and might include:

- **Recording the experiences of the person for their family and friends.** A skilled biographer may create a valuable artefact and memento which can be enjoyed by family and friends. For parents who are dying and leaving behind young children a biographer can help capture the depth of love felt by the parent, and their hopes and aspirations for the lives of their children.

- **Validating the life of the person.** By spending time with the person, and by simply checking-off facts and events, the biographer can communicate a sense of acceptance and so validate the life of the person.
- **Creating awareness of maladaptive feelings.** Encouraging reflection on events which might eventually bring the person relief from feelings of bitterness and regret, directly or indirectly (perhaps as a trigger to seek counselling).

There is a particular skill in writing biography so managers and volunteers would benefit from training. Training costs are not insubstantial, and as manager you should weigh-up your own interest and skill in biography as an important element of the potential success of the program. You may well be the person best equipped to train future volunteer biographers in the service.

Some other considerations when creating a biography service:

- The volunteer is very present in the role of the story telling, and therefore they must be empathetic and interested by nature and involved in celebrating and reflecting when composing the story.
- Volunteers for biography writing will need good emotional intelligence and be able to draw-out a narrative from the person's account.
- As a manager you may not have the time to debrief the work of the biographer in detail, so ideally you would want to engage volunteers who are able to work quite autonomously and without intensive support.
- Biography requires time. Where referrals are being sent through to the volunteer service with insufficient time to engage with the person before their life ends then biography is unlikely to be successful.

Depending on the local catchment the manager may choose to trial the service with one volunteer to observe demand for the service before committing additional volunteers to the role.

## Dignity narratives

The ability to provide medical or nursing or allied health care requires the clinician to hear a person's story and to act on it. Dignity narratives are the result of a deliberate act of listening and interpreting what the person is telling them so as to identify meaning<sup>18</sup>:

*Not unlike acts of reading literature, acts of diagnostic listening enlist the listener's interior resources—memories, associations, curiosities, creativity, interpretive powers, allusions to other stories told by this teller and others—to identify meaning. Only then can the physician hear—and then attempt to face, if not to answer fully—the patient's narrative questions: "What is wrong with me?" "Why did this happen to me?" and "What will become of me?"*

Examples of therapeutic narratives include:

- **Patient/Carer Stories:** Represent a half-page story written by, or for, a patient or carer about an episode of care. The NSW Agency for Clinical Innovation has published 'Collecting Patient & Carer Stories: A Guide for Frontline Health Service Staff who wish to Understand and Improve Patient and Carer Experience' (2014) which offers extensive material on the subject of Patient/Carer Stories.
- **55 words stories:** A short reflection written by the clinician. 55 Word Stories could be performed by a volunteer in conjunction with their role in supporting people and carers, and shared with other members of the clinical team to help build a picture of the person and their care needs and concerns.
- **Dignity Therapy:** A form of brief-intervention psychotherapy in the existentialist tradition. Dignity therapy asks the patient 'what do I need to know about you as a person to give you the best care possible?' Dignity therapy is a psycho-therapeutic approach and one that should be conducted by or under the leadership of skilled and trained practitioners.



### Additional resources

There are learning programs for biography writing which are available through groups like The NSW Writers Centre [www.nswwc.org.au](http://www.nswwc.org.au) and Eastern Palliative Care (Melbourne) [www.eastpallcare.asn.au](http://www.eastpallcare.asn.au). Try your local community college or TAFE for short course offerings.

The Agency for Clinical Innovation's publication **Collecting Patient & Carer Stories: A Guide for Frontline Health Service Staff** who wish to Understand and Improve Patient and Carer Experience (2014) is available online at [www.aci.nsw.gov.au](http://www.aci.nsw.gov.au).

The book **Dignity Therapy: Final Words for Final Days** (2012) by Harvey Max Chochinov provides a more extensive explanation of the dignity therapy approach.

## Chapter 9 Equipment programs

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When people are accessing palliative care at home they may require equipment to support their progressive loss of function. Shower chairs, walking aids, mechanised beds, pressure-sensitive mattresses (Baer Huggers) and oxygen concentrators and respiratory supplies are some of the aids provided to people in palliative care.

In NSW several volunteer services purchase, store and/or distribute equipment to people who are living at home. They provide a delivery service and a collection service post-bereavement. The role of palliative care volunteers often relieves pressure on the community nursing service to distribute and collect, and can also provide valuable contact with family after bereavement.

### Before starting an equipment service

**As manager you should check your organisation's policies and procedures for specific instructions.**

If you are thinking about starting an equipment service ask the local community nursing staff and the palliative care service about how equipment is made available to locals.

Consider the possibility that another group is already offering equipment. You could contact the local service clubs, council, community centre, or community support services as part of your research. If people are accessing mainstream equipment services then they might be subject to extended waiting periods, or they are in a small community then the service might be dependent on supplies from a larger centre that could be intermittent.

The role of palliative care volunteers often relieves pressure on the community nursing service and can also provide valuable contact with family after bereavement.



Promptness is important in equipment supply. When you need support for mobility or breathing you don't want to find yourself on an extended waiting list. Likewise a family recently bereaved may want any equipment to be promptly removed from the home as part of their emotional stock-take post-bereavement. So in your research consider the possibility that volunteers could assist in delivering a more prompt version of an existing service.

Assuming you have identified a demand then you will probably also have started to develop a picture of some of the major costs and commitments involved.

As with other palliative care activities it will involve a healthy relationship with the local palliative care service. At a strategic level your service has to be committed to the long-term nature of the program, and consider:

- How will you identify the need for specific equipment (both initially and in the future)?
- How will the distribution of equipment be managed?
- Will the service be offered daily, only some days, only on demand?
- How will the equipment be stored, maintained (cleaned, checked, repaired)?

If your service can't commit to the full scope of activities perhaps there is another service in the local area that could collaborate with you. For example if a vehicle is needed for distribution and collection perhaps a local transport operator could offer assistance. Agreements for tasks that are critical to the success of your operation should be captured in a contract, or formal agreement or memorandum of understanding.

## **Sourcing and managing equipment**

Fundraising and small grants programs may provide a source of funds for equipment, particularly for larger items. In rural and regional centres volunteer services sometimes find support through a local service club or social group.

Storage is important and may represent one of the significant ongoing costs. Storage will include monitoring delivery and dispatch as well as archiving the equipment:

- For new equipment – ensuring that equipment complies with Australian standards, initial inspection, entering on the database (administration tasks), checking that any obligations of warranty are managed;
- For equipment that is dispatched – where, when, to whom, what condition it was in when it was dispatched;
- If equipment is overdue – who to contact and what follow-up has been undertaken;
- For incoming (returned) equipment – who will be responsible for the inspection, cleaning, repairs and administration of the received equipment; and
- If equipment needs repair or maintenance – who will do the repairs, what expertise is required for different equipment items, is there any maintenance that must be performed by approved technicians (as per warranty obligations).



A shipping container may provide the physical space to store equipment, but remember to provide for space to shuffle items around and access gear. Consider adequate ventilation. Depending on your equipment range you may need to clean and work on equipment, which of course means that you need to provide for electricity and water.

To record the movement and condition of equipment you will need a database (which might simply be a spread-sheet) and/or diary. The diary or log should allow volunteers to flag what activities occurred on which days, and is particularly important if more than one person is involved in managing the storage and maintenance tasks so that a reliable system of information sharing is established.

Supplying items for public use obliges a duty of care on the part of the service to ensure that the equipment is fit for purpose and the user is familiar with it's safe use. The manufacturer is required to provide instructions on safe use of their equipment and maintenance requirements. The local health service may have additional requirements, for example infection control guidelines regarding cleaning of equipment. This is particularly important if you are supplying equipment to patients prone to infection due to depleted immune systems.

The volunteers in an equipment program should be familiar with the use of the equipment for the purposes of stowing and securing the items in transit, such as the correct stowage of wheelchairs in transit.

Equipment should never be used in a way contrary to its intended use, or for a purpose that it was not intended to fulfil. The service's policy should specify lifting limits for staff, and these may already be in place in the workplace health and safety policy. Proper instructions also need to be left with the person receiving palliative care and their carer or family.



### **Additional resources**

The NSW Transport group provides policy input for transport for users of assistive devices and their material might be of value [www.spotond.org.au](http://www.spotond.org.au).

Roads and Maritime NSW have online guidance and instructions for drivers who are carrying loads and towing trailers [www.rms.nsw.gov.au](http://www.rms.nsw.gov.au).

Guidelines for preventing the transmission of infection can be found in NSW Health Infection Control Policy PD2007\_036 [http://www0.health.nsw.gov.au/policies/pd/2007/PD2007\\_036.html](http://www0.health.nsw.gov.au/policies/pd/2007/PD2007_036.html)

## Chapter 10 Other volunteer roles

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### Supporting the vision and mission of Palliative Care volunteer services

Not all volunteers want to be 'hands on' with people in palliative care and would be very happy to make a contribution by assisting the service in other ways. In NSW other roles for volunteers within palliative care services included:

- Administration including reception, database management or filing;
- Fundraising and marketing; and
- Community awareness-raising including information stalls in shopping malls and activism.

**As manager you should check your organisation's policies and procedures for specific instructions.**

### Fundraising, marketing and administration

Large fundraising and community awareness-raising campaigns have been run by volunteers. Managers may use a different pathway for recruiting volunteers for administration and fundraising, and different training provisions may apply.

For example in a paediatric service the child's grandparents sometimes become involved in fundraising and awareness-raising activities, for the simple reason that they are emotively attached to the needs of their grandchild and the parents may be too busy with the child to contribute.

Fundraising can be simple or complex depending on the aspirations of the organisation. A serious and long term fundraising strategy involves sophisticated relationships with donors and with groups who will run events for the service (sometimes called third party fundraisers).

If your organisation's plans are ambitious then you will need to consider whether or not your organisation will need an 'Authority to Fundraise' which is issued by the NSW Office of Liquor Gaming and Racing.

Fundraising involves a unique set of skills in marketing, administration and relationship-building. Volunteers with a fundraising background will be most valuable, and they might even have membership or recent involvement with groups like the Fundraising Institute of Australia (FIA).

Relationship-building takes time and effort and long term commitment. Good relationship-building can benefit your organisation in more ways than just fundraising. For example it might position you as influential within your community and win greater support for your advocacy and volunteer-recruitment efforts.

However if your fundraising efforts are detrimental to your relationships then the net result may in fact be counterproductive. For this reason fundraising staff, including volunteers, should be chosen carefully.

Working with databases requires a good understanding of how the data will be used and the various relationships that each stakeholder (contact) has with the organisation. Database work can be quite pedantic and is best suited to a person who will apply themselves diligently and intelligently to the fine detail.

Marketing in a human services context can be ethically quite challenging, particularly if you are constructing long-term fundraising programs. Constructing a message which is emotive and engaging, and that also respects the experience of the service user and their loved ones is part of the challenge. Having people who can proof-read and critique your material will be valuable.

Your fundraising aspirations might be more modest, involving small raffles or collection tins. In these cases the intensity of the effort is lesser, and you might find support from corporate or service club groups who can spend a set period of time assisting with a campaign in the community.

## Community awareness-raising including information stalls in shopping malls and activism

Increasingly members of the general community have been involved as activists in the interests of palliative care and the end-of-life experience. This includes lobbying funding bodies about service gaps, raising awareness of death and dying in the general community, using art and literature to express their experience of death and dying, and improving awareness of palliative care services.

Advance Care Directives have empowered the consumer in palliative care, and volunteers are well-placed to provide community education on the importance and benefits of planning ahead. Volunteers have also been involved in running death-cafes and hosting discussions about end of life issues in a way that attempts to normalise discussion about an otherwise sensitive issue for many people.

These activities offer great benefits for the service if the volunteers continue to work within their scope and boundaries. At a societal level the community is interested in claiming more control over their interactions with the health system, and in

reclaiming the social experience of death. The benefits for the health service is that the expectations of consumers is better clarified and the community is more willing to be empowered to care for people at end of life outside of the acute setting.

Volunteers may be involved in other and more political activism in palliative care which is at odds with the scope of their role as a volunteer. To be responsible they should declare this to the service or refrain from referring to their volunteering involvement with the service while engaged in activism. It is reasonable to ask a volunteer to declare any activity with which they are involved which might cause embarrassment to the service, so that the manager can be clear with them about the way in which they represent themselves. The focus here is not to prevent them from being involved, simply to guide them in how they represent their relationship to the service while they are involved.

**Your health service may have additional policies in relation to community activism with which the manager should be familiar.**

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### Additional resources

The regulator for charitable fundraising in NSW is the Office for liquor Racing and Gaming [www.olgr.nsw.gov.au](http://www.olgr.nsw.gov.au).

The Fundraising Institute of Australia (FIA) is the membership organisation which networks and provides professional development for fundraising professionals and they have resources and training opportunities at [www.fia.org.au](http://www.fia.org.au).

The Groundswell Project supports grass-roots activism as well as training and conferences on end of life care [www.thegroundswellproject.com](http://www.thegroundswellproject.com).

## Glossary

**Accreditation:** A process of evaluating the quality of care and services provided that involves self-assessment, review or assessment of performance against predetermined standards by an external independent body, and monitoring of ongoing performance against the standards by the accreditation body.

**Boundaries:** Limits which help to structure how a person should act in a specific context, situation or relationship.

**Competency:** The unique set of knowledge, skills and attitudes required to perform a role.

**Diagnosis:** The nature and cause of a disease or injury (and the process of determining the same).

**Existential:** Refers to a philosophical conceptualisation of human experience with authentic, moral and scientific domains.

**External environment:** Refers to the outside factors which influence how an organisation or system works, often factors over which management has little or no control.

**Governance:** The process of managing and controlling an organisation or system.

**Inpatient settings:** Includes hospital wards, palliative care units, hospices and residential aged care facilities.

**Internal environment:** Refers to the people and assets, the relational and tangible aspects of an organisation or system over which the management has control.

**Manager:** Refers to the role that provides day to day management of volunteers. Position titles may include Manager, Coordinator and Leader of volunteers.

**Prognosis:** The likely outcome of a disease or injury.

**Quality:** The degree to which a health service increases the likelihood of desired health outcomes and as consistent with current professional knowledge.

**Referral:** The process and act of requesting that another specialist service become involved in the care or support of a person.

**Spirituality:** The deep values and meanings by which people live.

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