The Statewide Framework for Palliative Care Volunteering in NSW

Palliative Care
NEW SOUTH WALES

Palliative Care
Volunteering

Contents

Introduction

From 2014 to 2017 Palliative Care NSW hosted the Volunteer Support Services Programme funded by NSW Health under the *NSW Government Plan to Increase Access to Palliative Care 2012–2016*.

Palliative Care NSW worked to increase the capacity of palliative care volunteer services, to stimulate and support new service development, as well as to raise public awareness about their work. Perhaps because volunteers complement, rather than determine, service delivery there had been little aggregated data on the experience of palliative care volunteer services prior to the commencement of the NSW Volunteer Support Services Programme in mid-2014. Consequently there was little existing knowledge on which to base recommendations for a statewide approach to palliative care volunteering.

A number of studies of the experience of palliative care volunteers and clinicians were undertaken. We mapped, networking and helped to develop new services. We looked in detail at the experience of paediatric volunteers, community visiting volunteers, multicultural community and volunteers, volunteers in regional NSW, a survey of Service Development Officers on palliative care volunteering, and aged care, palliative care and volunteers.

These research reports and other resources can be found on the VolunteerHub website www.volunteerhub.com.au and have informed the development of this Statewide Framework.

Identity and contested meanings in Palliative Care Volunteering

Health promoting palliative care and introducing 'community' into palliative care

The seminal *Alma Ata Declaration on Primary Health Care* (1978)[1] marked a revision of how health services worked with and for people. The health workforce was implicated as advocates and activists in the achievement of the 'health for all, health by all' primary health care goals.

Central to the primary health care narrative was valuing the empowerment and inclusion of people in decisions and actions relating to their own health. The

empowerment of 'health consumers' gave life to the idea that health was more than the 'mere absence of disease'[2] and would be achieved by a deliberate and organised effort at a societal level. In short, through public approaches to health.

Palliative care started life as a protest movement, one that denounced the bigotry of passive discrimination against people left to suffer at or near their end of life. Palliative care practitioners sought to reduce this suffering, however and wherever possible.

Thanks to the modern palliative care movement, volunteer involvement is a well-established feature of end of life care. Volunteering brings the community into palliative care. Volunteering bridges formal and informal care, clinical and non-clinical care and the expert-lay divide. Volunteer services are often more intimately focussed on private moments of health than public approaches to health. What were the origins of this involvement?

Activists, often clinicians, were well acquainted with the physical dimensions of suffering. They brought their clinical focus on end of life care and developed a unique body of clinical knowledge about pain management and other comfort measures.

Physical pain was not the only focus. Clinicians also recognised that suffering had spiritual, relational and social dimensions which were existential in nature. So they championed the need to embrace the collective wisdom and spiritual narratives that help us make sense of our existence, our social identity and our suffering. For this they co-opted 'others', members of the general public in voluntary roles who would usher in community-held wisdom to the spiritual, relational and social dimensions of end of life care.

Including volunteers in care settings was a deliberate statement by clinicians to their community that 'we are better together'. The effect was to accord palliative care volunteers with a status in the care setting that was unmatched by other volunteer roles. This welcoming and privileging of 'others-as-experts' is rare in the often fiercely territorial world of clinical practice, but grew from a desire to be as fully available to the dying patient as possible.

A blending of clinical and non-clinical knowledge is characteristic of palliative care today. This includes the privileging of teams in the multidisciplinary approach, the active inclusion of the views of families and carers into the epistemology of care, as well as the continued involvement of the community through volunteering.

But volunteers were more than kindly custodians of wisdom. In the UK, hospice volunteers led social action campaigns to lobby for new programs, to establish residential hospices, to institute training programs, and to support disadvantaged and marginalised groups. Volunteers represented a counter-cultural force for change. They railed against neglect, lassitude and rationalism in end of life care. The leader of the modern palliative care movement, Cecily Saunders, personified the tenacious and compassionate spirit of her cause.

That palliative care grew from revolutionary roots is reflected in a body of revolutionary language and rhetoric. Team-based, holistic, supportive, patient-centred, ensuring comfort, early identification, impeccable assessment.

Palliative care challenged medical-scientific reductionism, and this was reflected through contested sites and meanings. The construction of St Christopher's Hospice in 1967 was deliberately sited 'away from' hospitals, symbolically resisting the colonisation by scientism of the social ritual of dying. The ideological resistance to reductionism extended to resisting the legalisation of euthanasia, with Cecily Saunders acknowledged as a notably loud voice opposing the introduction of euthanasia laws in Britain in the 1980s[3].

Life experience was significant to those who volunteered and often the individuals had experienced bereavement and understood the very personal nature of grief and loss. They were also likely to be in a privileged financial and social position so as to have time for, and commitment to, their community.

Privilege, opportunity, compassion, community and conviction shaped the character of early palliative care volunteering. These attributes correlated to the capacity of volunteers to rally financial support, influence policy and funding decisions, and shape the development of formal care and information networks.

Consequently members of the community (as hospice volunteers) radicalised care and supplemented the efforts of paid staff. They came in increasing numbers, and their willingness to be involved reflected a groundswell of community interest in palliative care.

Slowly the roots of the modern palliative care movement spread under the foundations of the clinical edifice. Cracks appeared and change followed. No longer would the absence of a curative treatment mean the cessation of care. No longer would the community accept neglect of their dying by those entrusted to care for them.

Contested meanings and community visiting volunteers

Valuing the non-expert voice potentially challenges the dominance of clinical-knowledge in the formal care setting. Where clinicians feel challenged this contest is rarely confrontational but is given expression through more subtle forms of resistance, contest and points of difference.

One contest arises from the presence of multiplicity of volunteer groups and skills in health care. Today we estimate that some 6,000 people volunteer in palliative care across Australia, but this is only a small proportion of the 592,000 or so people who volunteer in health[4]. Pastoral care, visitor services, shop and trolley services, patient surveys, driving, wig and book libraries, cancer services, mental health, drug and alcohol, fundraising and administration may each utilise volunteers.

Clinicians who don't understand the difference between general and palliative care volunteers may harbour concerns about the suitability and gravitas of palliative care volunteers to work with their vulnerable patients. Thus the generic title 'volunteer' can negate the specific skills and focus of volunteers in palliative care.

Another contested meaning arises from the lack of a common identity for palliative care volunteer services. The variety of formal care settings for palliative care including dedicated wards, stand-alone units, consultancy and in-reach models is matched by a mosaic of volunteer service types. The diversity of models and the local focus of each service have made categorisation problematic and 'performance measurement' of volunteer services highly localised. Local clinicians with genuine concerns for the quality of the palliative care volunteer service have little if any agreed benchmark for reference, and likewise those who are sceptical of the relevance of volunteers can provoke an endless arc of improvement requests against the volunteer service.

The variables in the work, context and governance of a community visiting volunteer service potentially complicate agreement on identity and benchmarks. Each volunteer manager can attest to how their service is the same as but perhaps a little bit different to another service, whether in terms of the remoteness of location, the geographic range, the limitations imposed by mobile phone reception, the cost implications for volunteers driving to and from points of care and the supply of equipment to clients. In rural and regional areas the organisation may even be independent to the referring hospital or community clinicians, typically a not for profit organisation.

The establishment of not for profit groups in rural or regional locations typically aimed to supplement a lack of local end of life services, or to enhance the capacity of local community services to support people in palliative care "f*or as long as our volunteers have the strength and dedication to support our community*" (volunteer manager in personal communications with author, 2016). Their vigorous, local, parochial commitment to their people locates them in the narrative of rural resilience. If clinicians feel that there is a risk of the volunteers not being sufficiently compliant with guidelines and policies then they may be reluctant to refer patients.

Another point of difference for community visiting volunteers is the relationship with the referring nurses. Unlike an inpatient setting where the volunteer has a remit to talk to inpatients throughout the ward or unit, a community volunteer is attached (referred) to a particular client and their often plays out in the clients home, perhaps while the volunteer offers a respite visit for the carer. That this relationship, between vulnerable client and volunteer, occurs almost entirely out of sight of the volunteer manager and clinicians introduces a higher element of risk for the referring clinician. Will the volunteer be suitable? Will they stick to their scope (boundaries) of practice? Clinicians need reassurance that community visiting volunteers are both autonomous and compliant, a reassurance largely provided by their relationship with the volunteer manager. Where this relationship breaks down then the volunteer contribution can easily become devalued within the clinical team.

The brevity of the volunteer's acculturalisation to formal care, when compared to say a nurse or an allied health worker, can't be expected to adequately equip a lay person to respond as a clinician might to the various scenarios and emotions encountered in their role. Whereas in the inpatient setting the volunteers may receive mentoring from other clinicians, much emphasis is placed on the volunteer manager of a community visiting volunteer group to be insightful as to how each volunteer is responding to their role. A significant task for any volunteer manager is mentoring, colloquially known as 'boundary maintenance': briefing, debriefing, reiterating appropriate responses and behaviours, conciliating, deterring inappropriate behaviours and sometimes even exiting a volunteer who proves unwilling to comply.

Where the volunteer manager is aware of and insightful in how to manage 'non-compliant' volunteer behaviour the relationship with clinicians is more likely to flourish. Where the manager is less skilled, or unaware, or for some other reason there are gaps in management supervision, then clinicians may be less confident in volunteers.

For these reasons the relations between volunteers and clinicians can at times be fickle. Not surprisingly there was, and is still, a mixed reception amongst some clinicians to palliative care volunteers.

Brief insights into Palliative Care Volunteering in NSW

People and organisations in palliative care volunteering

In 2014 there were 1,242 palliative care volunteers in NSW attached to palliative care services and non-government organisations across NSW[5]. At the time of writing this number had increased to about 1,600 volunteers. Palliative care volunteers come from all walks of life and often list their motivations as reciprocating support that they have received in palliative care and the belief that they have something to contribute typically in their retirement years[6]. In paediatric palliative care, volunteers are often younger and more likely to be working-aged[7].
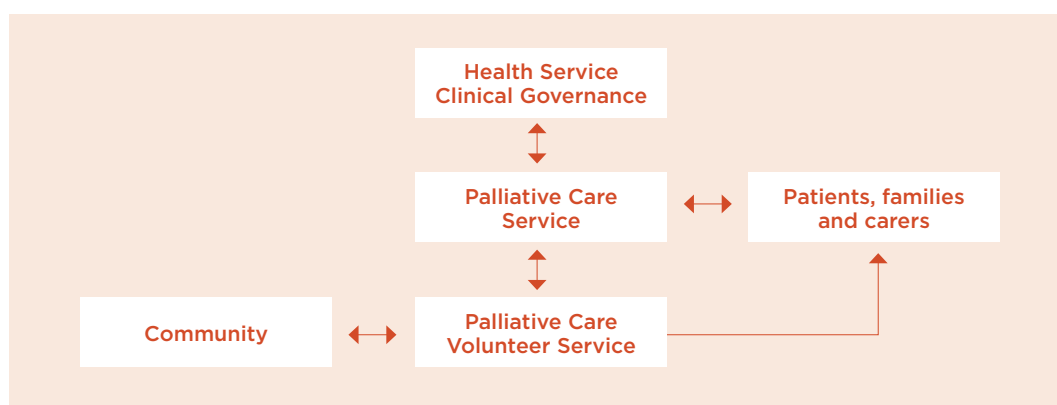
There are about 40 palliative care volunteer services in NSW[5]. Each volunteer manager can attest to how their service is the same as but perhaps a little bit different to another service, whether in terms of the nature or focus of the support offered, the setting or geographic range of support, the age of their clients, the mix of programs they offer, the relationships with clinicians, whether their service is part of or independent to the referring health service, or by the supply of equipment, biography or other specialist features. Typically palliative care volunteers are involved in inpatient settings,

and/or in community visiting volunteering. Bereavement support, respite, helping with memorial services and offering gentle massage are other roles for volunteers.

Most palliative care volunteer services are attached to large health services (70%) and the remainder are not-for-profit organisations. Typically each palliative care volunteer service has developed in response to the unique demands of the local population or palliative care team, championed by a local clinician or community member whose personal character has been influential in shaping the mission of the volunteer service. Palliative care volunteer services share many common elements but defy generalisation and in this way they often have unique governance challenges.

Governance of volunteer services

Palliative care volunteers represent not only a workforce component but also a form of community engagement. Volunteers offer the health service an important resource for informing their own communities about the philosophy of palliative care and have the potential to positively address issues like service access and health literacy. (See diagram below).

In some cases the health service's governance system suffers from a poor understanding of risk and performance in relation to the volunteer service, and the volunteer service suffers for lack of visibility and governance support within the LHD.

Typically palliative care volunteer services have grown around local need without centralised or coordinated input. Different services may have a different focus of service delivery, different volunteer training programs and outputs even within the same LHD.

Gauging a sense of how well any given volunteer service is performing can be problematic when comparisons are difficult to make. Services often face different operating contexts (not for profit, community centre and hospitals), catchments (paediatric, remote, rural, regional, metropolitan), quality (accredited as part of a health care facility, or under another quality framework, or none) and fiscal constraints (with or without regular income, with or without paid manager).
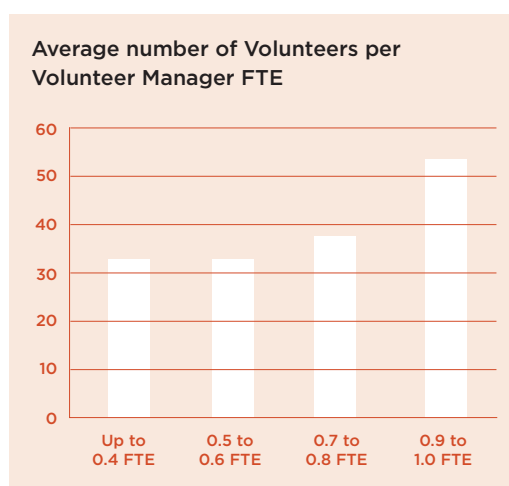
The willingness of people to volunteer for the health service is evidence of a positive relationship with their community. Poorly managed volunteer services have the potential to sour relationships with the community.

When surveyed in 2016, Palliative Care Service Development Officers in NSW endorsed the value of volunteers in palliative care, and noted several possible initiatives to support volunteering including statewide coordination or networking, agreed standards and outcomes as well as standardised data collection and reporting are initiatives that promote confidence amongst clinicians involved in volunteer referrals[8].

Service management and the role of the volunteer manager

Volunteer groups vary in size from 1 to 150 or more with no commonly agreed group size for one volunteer manager to manage. There is little agreement about how many volunteers can reasonably be supported by a volunteer manager although the yardstick of 1:40 was promoted by Palliative Care Australia[9] and an average of 1:56 was observed in NSW in 2014[5]. With larger group sizes the task of managing volunteers becomes increasing complex. Community visiting volunteers are more intensive to manage than inpatient volunteers by virtue of their geographic range of activities and their largely autonomous role. Studies have observed a turnover in volunteer manager positions in the order of 25–30% per annum across NSW[5]. Initiatives like peer support, networking and professional development opportunities help to reduce the high turnover of manager positions.

Volunteer managers come from diverse professional or technical backgrounds. They may work as little as 0.2FTE or as much as 1FTE, they may share a role in the community team, or in fundraising, or in another capacity, or they may have a stand-alone position. Consequently there is a practical limit to how many volunteers can be supported and a consequent correlation between the hours worked by the volunteer manager and the number of volunteers in their service.

Average number of Volunteers per Volunteer Manager FTE

Much emphasis is placed on the skill and competence of the volunteer manager to ensure the success of the service. Where palliative care volunteers are undifferentiated from general hospital volunteers there may be reluctance by clinicians to allow palliative care volunteers to engage with and directly support patients. Where volunteers are not well embraced by the health service there is added pressure on the volunteer manager to carry the philosophy of volunteer involvement in palliative care as well as the administrative and leadership roles of volunteer management.
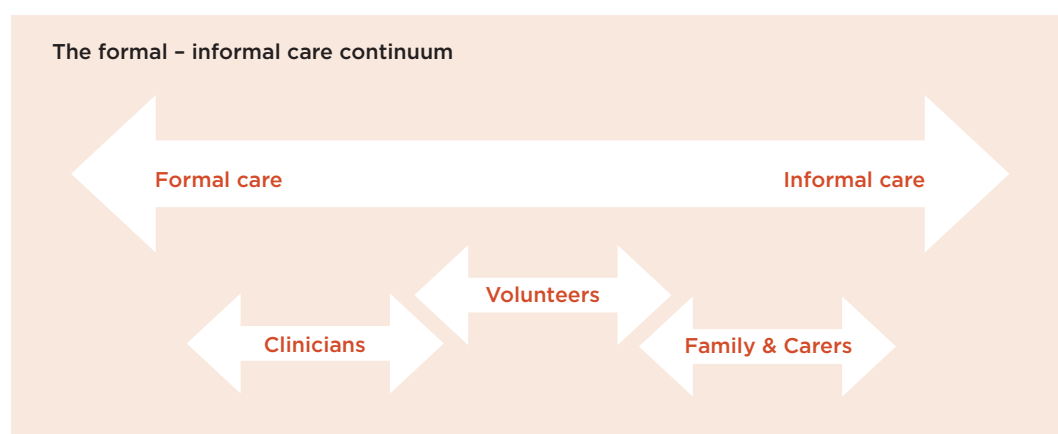
Approaches to recruiting and training volunteers

The concept of palliative care volunteers was motivated from a desire by clinicians to include members of the public in providing companionship to patients. Volunteers are valued for their participation in the health system but also for their non-expert voice and familial-like support. In this way palliative care volunteers sit 'in between' the formal and informal care 'systems'. (See diagram below).

Palliative care volunteers are required to complete induction training prior to confirmation with their service. Training is largely input based and uniquely designed by each service. Clinicians are generally involved in the course delivery although there is neither a core training 'syllabus' as such nor any 'core competencies 'for volunteers in NSW. Training is generally attendance based and delivered to small groups. There is typically little recognition of prior learning on commencement, or of competence on completion.

Training is not everything, but it is significant in establishing an essential body of knowledge skills and cultural attitudes amongst volunteers. It is also significant for creating common understandings of the role of the palliative care volunteer which can be easily understood by clinicians and carers.

Training must adapt as ideas change, and personal skills refreshed. Studies have shown opportunities to significantly expand palliative care volunteering into other community services[10] and aged care[11]. Introducing new ideas, creating new training materials, developing in-service material, measuring volunteer performance and skills are all part of an important ongoing role to improve clinician and public confidence in palliative care volunteers.

The formal – informal care continuum

Formal care   Informal care

Volunteers

Clinicians   Family & Carers

Acknowledging existing frameworks and guidance documents

The fields of volunteering and palliative care each have well-established frameworks and standards in place. These publications provide an insight into the defining elements of each discipline (volunteer management and palliative care service delivery).

The goals of the *NSW Health Framework for Engaging, Supporting and Managing Volunteers* (2011) [12] are intended to engender respect and dignity for volunteers, to strengthen and guide volunteer management and to optimize the experience of volunteering within NSW Health. They also aim to ensure that NSW Health's approach to volunteering aligns with State and Commonwealth priorities for inclusive social communities.

The *National Standards for Volunteer Involvement* (2015)[13] describe 8 domains of a 'best practice' systems-based approach for managing volunteers. These domains include leadership and management, commitment to volunteer involvement, volunteer roles, recruitment and selection, support and development, workplace safety and wellbeing, volunteer recognition, as well as quality management and continuous improvement.

In Victoria the *Palliative Care Volunteer Standards* (2007)[14] provide valuable guidance on aspects of volunteer management including establishing a volunteer program, volunteer recruitment and orientation, volunteer performance (including health and safety, grievances, discipline and dismissal), volunteer training and recognition as well as volunteer supervision and volunteer responsibilities.

The *National Standards for Palliative Care* (or more correctly the Standards for Providing Palliative Care for All Australians) published by Palliative Care Australia (2005)[15] is accepted as a key reference document in the ongoing planning and development of palliative care services in Australia.

The Standards embody the philosophy of palliative care and include references to the provision of care, the dignity and respect for patients, the values and culture of the organisation and the accessibility of services. Also valued is the development of a community capacity to care for patients and families through effective collaboration and partnerships (Standard 9).

In NSW the recommended approaches to palliative care service delivery have recently been articulated by the Agency for Clinical Innovation in the *Palliative and End of Life Care – A Blueprint for Improvement* (2014)[16]. The *Blueprint* notes 6 principles behind the model of palliative care service delivery in NSW, including the delivery of patient, carer and family centred care, that care is provided on the basis of need, that patients, carers and families have access to local and networked services to meet their needs, that care is evidence-based, safe and effective, that care is integrated and co-ordinated and also that the provision of care is equitable.

The *National Consensus Statement* published by the National Commission on Safety and Quality in Health Care (2015)[17] highlighted a number of principles to guide service delivery which included highlighting that dying is a normal part of life and a human experience, not just a biological or medical event, that safe and high-quality end-of-life care requires the availability of appropriately qualified, skilled and experienced interdisciplinary teams, and that providing for cultural, spiritual and psychosocial needs is as important as meeting physical needs.

The proposals embodied in these publications have been considered during the development of the *Statewide Framework for Palliative Care Volunteering in NSW.*

The Statewide Framework for Palliative Care Volunteering in NSW

What do we want for palliative care volunteering in NSW?

The Statewide Framework sets out three domains to guide the governance, management and development of palliative care volunteer services in NSW.

Nurture talent

Create a safe harbour

Adopt communities

The domains of Palliative Care Volunteering

Create a safe harbour

Palliative, supportive and end of life care has the intention of creating a safe harbour of hope and calm for patients and family – their partner, their children, their siblings, their mob, their friends, their neighbours, their community, their pet.

Clinicians should expect that palliative care volunteering will improve the delivery of palliative care. Clinicians should expect the palliative care volunteer service to be a vibrant hub of support for the work that they do. For this to occur we need governance systems that nurture the optimal conditions for the volunteer service to thrive.

What do we want for palliative care volunteering in NSW?

• Palliative care volunteering contributes to the optimal, safe and effective delivery of palliative care.

• Clinical governance and planning systems embrace the unique contribution of palliative care volunteering to create a safe harbour of hope and calm for patients and family.

• Systems for recruiting and supporting palliative care volunteers ensure the best outcomes for volunteers and palliative care services.

• The unique body of knowledge informing the practice of palliative care volunteering is curated and valued within palliative care.

Nurture talent

The inclusion of volunteers is radical in the sense they represent the progressive and innovative thinking inherent in palliative care philosophy. Yet the point of having volunteers in palliative care is that they offer something different. So much of what volunteers do is about responding on a purely personal level.

Volunteers bring a non-clinical and non-expert focus. They bridge the gap between the expert and the lay person. They sit in the middle of the formal – informal care continuum. As part of the formal care system volunteers must observe appropriate professional boundaries. And as part of the informal care system each volunteer is valued not because of their professional qualifications or skill-set but because of their unique personality and presence they bring to relationships.

The practice of managing and supporting volunteers requires skilled practitioners who can balance these tensions and instil confidence in referring clinicians.

What do we want for palliative care volunteering in NSW?

- Palliative care volunteers are celebrated for their empathy and sensitivity towards the patient and family

- The practice of palliative care volunteering embraces the uniqueness of the individual and their family

- The different interests and abilities of palliative care volunteers are nurtured in ways that benefit and develop the practice of palliative care

- Professional development opportunities nurture the abilities of managers and volunteers to respond to the needs of palliative care

Adopt communities

Community and identity are inseparable and interwoven. Aboriginal, European, Chinese, Christian, Gay, Buddhist, Post-modernist, Arab, Creole, Muslim, Wiradjuri, Celtic – the combinations and variations of community are endless. With different identities come different worldviews and spiritualities which inform the various ways that people understand illness, suffering, distress, dying and death.

Communities look to palliative care to be accepting of their traditions, rituals and beliefs. Palliative care looks to communities to share their wisdom about their end of life cultural practices, as well as to receive wisdom about clinical practices.

Palliative care services adopt volunteers, and in so doing the team values and embraces the unique cultural and language groups in their catchment. By donating their time, volunteers demonstrate the value that they place on the palliative care team by mutually adopting them into their community. In this way palliative care volunteers act as a bridge connecting palliative care and local community.

What do we want for palliative care volunteering in NSW?

- Palliative care volunteering seeks to develop a volunteer pool that reflects the diverse language and cultural needs of the local community.

- The practice of palliative care volunteering is informed by and accepting of diverse cultural, familial, spiritual, language and ideological views.

- Palliative care volunteering is celebrated as a vehicle of community engagement within the delivery of palliative care services.

- The diverse backgrounds of palliative care volunteers contribute to improved palliative care service delivery.

Concluding comments

The *Statewide Framework for Palliative Care Volunteering in NSW* is intended to provide a background to the challenges faced by palliative care volunteering in general, and in NSW in specific.

The domains of palliative care volunteering reflect the most valued and problematic area of service involvement for volunteers. These are not standards as such but rather guiding principles behind service involvement by volunteers.

The Statewide Framework is not intended as a stand-alone document, but when used in conjunction with other frameworks and guidance documents it seeks to develop a consistent approach to the development, governance and management of palliative care volunteering in NSW.

End notes

The Volunteer Support Services Program

This paper has been prepared as part of the Volunteer Support Services Programme which is hosted by Palliative Care NSW and funded by NSW Health. The Volunteer Support Services Programme seeks to champion the work and interests of Palliative Care Volunteer Services and volunteers in NSW (www.volunteerhub.com.au).

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Contributing author and contact

Alex Huntir, Manager Volunteer Support Services Programme, Palliative Care NSW
alex@palliativecarensw.org.au +61 2 9206 2097

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Contact Palliative Care NSW

Phone 02 9206 2094 **Email** info@palliativecarensw.org.au
Mail PO Box 487, Strawberry Hills NSW 2012 **Office** 414 Elizabeth Street Surry Hills NSW 2010

www.palliativecarensw.org.au | www.volunteerhub.com.au