



Snapshot 2018: A review of Palliative Care Volunteering in NSW

A report on the activities and experiences of palliative care volunteer services in NSW

Palliative Care NSW *Volunteer Support Services Programme* funded by NSW Health

Acknowledgements

Palliative Care NSW would like to acknowledge and thank the NSW Health for the funding that made this report possible.

Thanks to the coordinators, managers and leaders of palliative care volunteer groups in NSW for their contribution to the findings in this report.

Palliative Care NSW

Level 5, 414 Elizabeth Street

Surry Hills NSW 2010

PO Box 487

Strawberry Hills NSW 2012

Tel +61 2 9206 2097

info@palliativecarensw.org.au

www.palliativecarensw.org.au

ABN 67 231 950 900

Registered number NSW Y2782305

© State of NSW (through the Ministry of Health) 2014

Suggested citation:

Bowman, K. and Huntir, A. (2018) *Snapshot 2018: A review of Palliative Care Volunteering in NSW*. Surry Hills, Australia: Palliative Care NSW.



Foreword

Few clinical specialities are as inclusive of volunteers as specialist palliative care.

Volunteers contribute hours of support to people in palliative care, and yet they are not simply a workforce asset. Volunteers are called on to demonstrate insight and emotional awareness in the way that many clinicians do, and yet they are not clinical. Volunteers bring both friendship and formality into the often distressing world of the person and family at end of life.

Recognising the importance of carers as significant contributors to care, NSW Health funded the *Volunteer Support Services Programme* in 2014 to improve access to palliative care volunteer support by families and to enhance palliative care volunteer services across the state.

One of the first tasks of the *Volunteer Support Services Programme* was to report on the activities and experiences of palliative care volunteer services by documenting *A Snapshot of Palliative Care Volunteering in NSW 2014* (Hansen & Huntir 2014). As well as providing insight into the variety of management models for palliative care volunteer service delivery, it was an opportunity to take account of the number and spread of palliative care volunteers across the state.

Four years on, there was a need to update this information. This report provides that update but also expands on it by including more information about volunteer management, service provision and the enterprises of the *Volunteer Support Services Programme*.

Since 2014 we have seen a significant increase in funding for palliative care in NSW. My hope is that the positive contribution of carers will be continued to be recognised in coming years through initiatives that nurture volunteer involvement in palliative care.

I commend this report to you.

Therese Smeal

President, Palliative Care NSW

Executive Summary

This report is based on an interview survey of palliative care volunteer managers across NSW. The study found that there are 1,610 active palliative care volunteers in NSW with 615 volunteers in hospital or inpatient settings, 352 in community settings and 270 volunteers working in both. 373 volunteers operate within residential aged care facilities.

The Sydney Children's Hospital Network and St Vincent's Health Network are both specialty networks. Between them have 209 active volunteers.

The volunteers are supported across 44 palliative care volunteer services in NSW. Of these 13 are within Metropolitan Local Health Districts and 27 within Regional Local Health Districts, 3 within Specialty Networks and 1 within Residential Aged Care.

This report found that 3 services were dedicated to the support of paediatric patients and their families.

The survey focussed on volunteer involvement in inpatient and community visiting roles and found that 7 services have volunteers within inpatient settings only, 15 services have volunteers only within community settings only, 21 services have volunteers in both settings with an additional service supporting residents in aged care.

This report asked managers about changes in their volunteer groups over the preceding 12 months and found that some 594 new volunteers had been commenced, with 391 of these in inpatient or aged care settings, 143 in community visiting roles and 60 volunteers in both inpatient and community visiting.

This means that the number of volunteers engaged in palliative care has increased by 33% over the last four years.

The majority of palliative care volunteers are aged between 50 and 85 years of age and are 4 times more likely to be female than male. Their main activities are companionship and psychosocial support but they are also active in grief and bereavement support and carer respite. Each service requires their volunteers to undergo training before commencing in their role.

Managers spend on average 17.75 hours per week managing volunteers. Some 30% of managers have been in their role for more than 10 years and some 10% of managers having been employed over the last 6 months.

Whilst managers may work full or part time in their roles there are 7 volunteer services in NSW that are managed or coordinated by unpaid managers.

When asked about plans for service development 37% of services indicated they were planning to increase their number of volunteers. 15% of services either just have, or are just about to, expand into new areas and 37% of services have new projects planned such as adding biography services, complementary therapies, or bereavement supports.

Table of Contents

Foreword	3
Executive Summary	4
Table of Contents	5
Part 1 Exploring Palliative Care Volunteering in NSW	6
Part 2 Key Findings - Palliative Care Volunteers	8
A. Palliative Care volunteers in NSW	8
B. Activities of Palliative Care volunteers	8
C. Volunteer induction training and development	12
D. Volunteer supervision	13
Part 3 Key Findings - Service Characteristics	14
A. Number of palliative care volunteer services in NSW	14
B. Supporting and supervising volunteers	17
C. Participation in networking and development	19
D. Feedback on the <i>Volunteer Support Services Programme</i>	20
E. Plans for the future	21
Part 4 Concluding Comments	23
End Notes	24
References	26

Part 1 Exploring palliative care volunteering in NSW

A. What our 2014 mapping survey told us about palliative care volunteering in NSW

In July 2014 Palliative Care NSW was provided with funding to undertake a 3-year Palliative Care *Volunteer Support Services Programme* to improve access to palliative care volunteers in NSW for people approaching their end of life and their carers.

This had resulted from a commitment to improving palliative care by the NSW Government in 2012 under the *NSW Government Plan to Increase Access to Palliative Care 2012 – 2016* (NSW Ministry of Health 2012).

The first stage of the *Volunteer Support Services Programme* in late 2014 was to map the existing activities of palliative care volunteer services in NSW in part to help establish a framework for championing their ongoing work.

The 2014 mapping study was subsequently published as the *Snapshot of Palliative Care Volunteering in NSW 2014* (Hansen & Huntir 2014) and is available on the VolunteerHub website www.volunteerhub.com.au.

This 2018 survey is a shortened version of the 2014 mapping study and includes new questions to respondents such as those seeking feedback on the role of the *Volunteer Support Services Programme*.

B. How we conducted this 2018 services survey

Between February and June 2018 Palliative Care NSW contacted all volunteer services that had previously been identified as having volunteers involved with formal palliative care services across NSW. Using a mixed-methods approach we questioned the managers of these services about their levels of volunteer activity over the last twelve months, enquired into their volunteer management and asked for feedback on Palliative Care NSW's *Volunteer Support Services Programme*.

Several identified services were discounted from this research as they were not yet operational or were still in the recruitment phase. Another 4 services were excluded when we found them to no longer have palliative care volunteers.

The remaining 44 service managers were then surveyed. The majority were able to participate in the survey via a structured telephone interview. The 2 services that were unable to do so gave written responses via email to the same set of questions.

The research instrument consisted of 28 questions. It included a mix of open-ended, closed, probing and scaled questions. Some questions were designed to provide a comparison to data collected in *A Snapshot of Palliative Care Volunteering in NSW 2014* (Hansen & Huntir 2014) and potentially with data collected from any future surveys of this kind.

Inductive coding was used and the data subjected to thematic analysis in order to identify common threads, make comparisons and relate these findings to the existing knowledge in the field.

C. How we will use these results

The results represent the aggregated and de-identified responses to the survey questions and will be used in the work of Palliative Care NSW and the *Volunteer Support Services Programme* to better inform their approaches with volunteer services.

This report is also a deliverable under the terms of funding for the *Volunteer Support Services Programme* in the 2017-2018 financial year.

Part 2 Key Findings - Palliative Care Volunteers

A. Palliative Care volunteers in NSW

The study found that there are 1,610 active palliative care volunteers in NSW with 615 volunteers in hospital settings, 352 in community settings and 270 volunteers working in both. 373 volunteers operate within residential aged care facilities.

This report asked managers about changes in their volunteer groups over the preceding 12 months and found that some 594 new volunteers had been commenced, with 391 of these in hospital or residential settings, 143 in community visiting roles and 60 volunteers in both inpatient and community visiting.

Larger services tend to offer a more diverse range of programs (inpatient, community, bereavement, biography etc) so their volunteers may get to choose how they are used. Volunteers in inpatient settings need a particular skillset in team work, while those in community visiting need to be confident in more autonomous roles. The volunteer's skills are likely to mature as the volunteer becomes more experienced.

“New people tend to do inpatient first until they get the hang of it before they are sent into the community.”

“New volunteers will eventually specialise in one or the other.”

During the same period, 280 volunteers ceased or retired from their roles, perhaps due to a change in work or family commitments, illness or injury or advancing age.

Despite a loss rate of 14.8% which is up on the 2014 loss rate of 9.6%, there has still been a net increase of 315 volunteers across NSW just within the last year.

In 2014 the *Volunteer Support Services Programme* (Hansen & Huntir 2014) reported a total of 1,242 palliative care volunteers but from that number only 965 of them were currently active. Now in 2018, we can report 1,610 active volunteers which represents an increase of 645 volunteers (33%) over the last four years.

The volunteer services we surveyed had volunteers ranging in age from as young as 18 up to 93 years of age. About 32% of services had volunteers aged in their teens or twenties, typically within inpatient settings. Over half of all volunteer services reported that their volunteers were over 50 years and 83% of services had no volunteers aged under 60 years.

Volunteers are 4 times more likely to be female than male. This reflects a significant gender imbalance amongst palliative care volunteers given that the ratio reported in aggregated volunteering statistics in Australia is 8:7 (Volunteering Australia 2015).

For more information about the services that support volunteers see *Part 3 Service Characteristics* in this report.

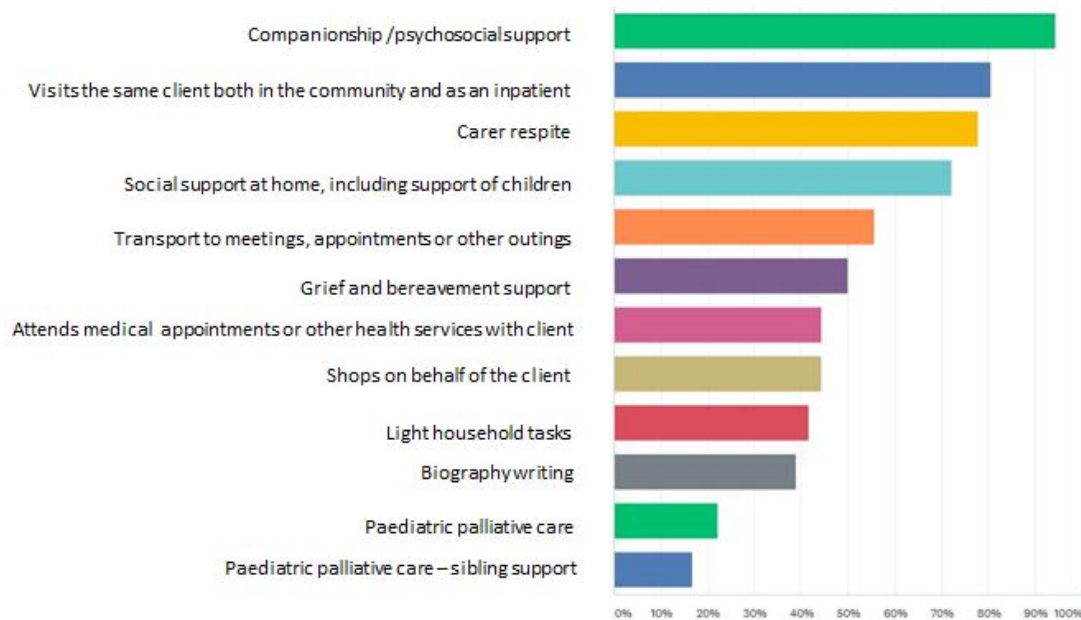
B. Activities of palliative care volunteers

Community visiting volunteers

Community volunteers typically visit palliative care patients in their own homes. Their main role is providing companionship and psycho-social support to not just the patient but also their family and

carers. Figure 1 below maps the variety of activities community volunteers engages in. Not all volunteer services are able to offer all services.

Figure 1– Responses to the survey question ‘What type of activities do your community visiting volunteers perform?’ (n = 36)



Other types of community visiting activities include following their client into a residential aged care facility, yard maintenance/gardening, participating in hobbies, assisting with IT needs, and other home administration such as making appointments and filling in paperwork.

Grief and Bereavement Support

Only half of the respondents noted that they offered ‘grief and bereavement support’ as a part of their service. This figure may not accurately represent the amount of support of this type given because there seemed to be a difference in how people answered the question. Some managers judged grief and bereavement support to be such an intrinsic part of the psychosocial support their volunteers provide that unless they had a more structured grief and bereavement program, they may not have noted it as such.

Even so, for those services who did include it, there is a broad spectrum of grief and bereavement services offered. Some services may only offer a follow-up phone call to check in on the bereaved and refer to further services if required. Others have more dedicated grief and bereavement programs such as walking groups. In some cases, rather than providing support themselves volunteers assist qualified counsellors to run groups.

“Grief and bereavement support is a casual monthly group luncheon for widows of people that have died. They are a strong group and often go on trips together.”

“Volunteers help professional staff to run a walking group. Sometimes they provide basic assistance for example following up with someone who leaves the group to check they are ok and inviting them to come back to the group.”

Biography program

Some organisations do have dedicated and trained biography volunteers who aim to capture life stories. Others have included digital storytelling, making photobooks or helping to collate and label photographs on a computer, or just writing down narrated stories or anecdotes under the biography banner.

39% of services indicated that they offered a biography program.

Biography activity is three times more likely to happen in community settings than in hospital or residential settings. This could be because patients and volunteers are often paired together for longer periods of time, and home is where all the photos and memories are, providing the impetus. Patients may also be less unwell and so more able to participate in such an activity.

Paediatric support

Volunteer organisations that offer paediatric palliative care services typically focus more on supporting the entire family including siblings. Volunteers are involved in a range of age appropriate activities as part of their repertoire such as playing video games or assisting with homework. They are more likely to help out around the house doing light household chores like folding laundry or making snacks.

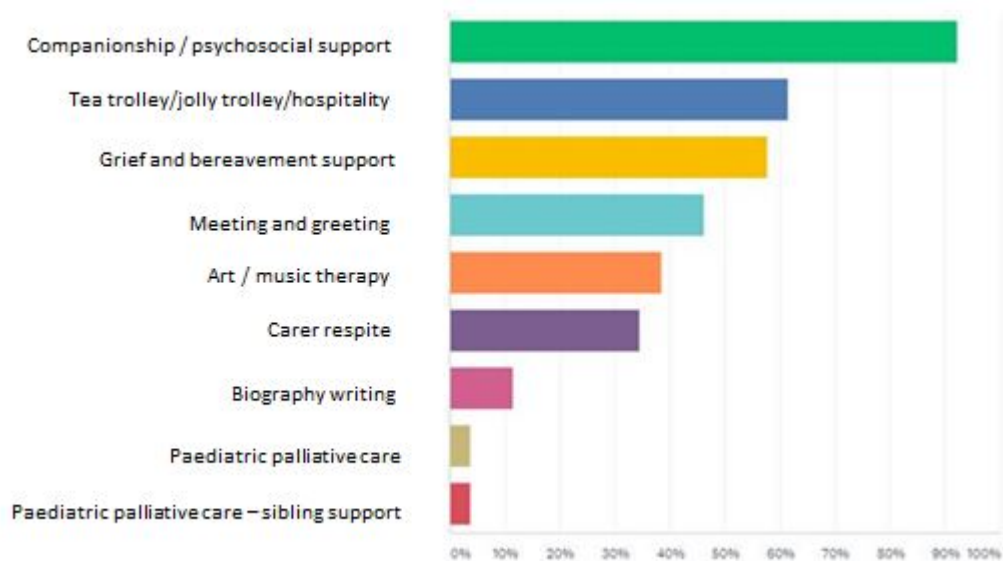
Sibling support is important and might include volunteers taking them to their regular sporting activities, doing a craft or reading with them. Parents are supported with massages and a friendly ear or carer respite, for example, babysitting siblings while they take their sick child to a medical appointment.

Inpatient support

The inpatient setting, with the constancy of regime, environment and clinical support, allows for a broader swathe of engagement by volunteers with patients and their families. Volunteers tend to meet with multiple patients throughout the inpatient facility rather than being referred to specific patient/s. Volunteers interact more often with clinical staff, are more embedded in the inpatient team and are more focussed on being hospitable to patients and their families by meeting and greeting them or operating a tea or jolly trolley. Offering hospitality is a useful tool that facilitates conversations and connections between volunteers, patients and carers providing support in an informal and relaxed way.

Figure 2 below shows volunteer activities for those working in a hospital or residential setting.

Figure 2 – Responses to survey question ‘What type of activities do your volunteers working in an inpatient setting perform?’ (n=26)



Palliative care inpatients often have access to art, music and other diversional therapies. Volunteers may assist a professional to deliver such programs (for example, taking a patient in a wheelchair to their hydrotherapy session). Alternatively, they might themselves take the lead, for example, a volunteer might set up art and craft supplies in a common room where anyone can come by and join in the activity, perhaps the sibling or child of a patient who needs a bit of ‘time out’.

Complementary therapies such as aromatherapy, reflexology, yoga or pet therapy may be on offer and possibly facilitated by volunteers. Sometimes the volunteers are trained professional themselves. In a 2018 study of volunteers and complementary therapies showed volunteers may offer massage not just to patients and their families or carers but also to stressed staff (Petrocitto & Bowman 2018).

Figure 3 shows the diverse types of activities volunteers in inpatient settings perform. Clearly, volunteers are integral to not just providing important services such as equipment hire but also play a large part in providing patients and families with a more comfortable and caring environment at what can be a very distressing time.

Figure 3 - Volunteer activity in inpatient settings – Other.

Puzzles/crosswords/cards/games to relieve boredom	Floral carers e.g. getting vases, arranging and disposing of flowers
Equipment maintenance and loan service e.g. wheelchairs	Pastoral care/Bible reading/catholic communion
Crafts e.g. knitting, crochet	Helping patients get around the facility
Hairdressing/shaving/manicures/beauty	Resident feeding support
Making fruit platters/sandwiches/baking	Washing/labelling clothes
Tidying/maintaining the visiting room	Operating a wig library
Play the piano or other instruments	Manage mobile library trolley
Running errands e.g. buying a newspaper	Storytelling/singalongs
Community language conversation	Photography
Friday afternoon cheese, wine and biscuits	In-house movie nights

Other volunteer duties

About half (n=20) of services have volunteers involved in administration, fundraising or marketing. Examples include helping the doctors and nurses by making appointments, filing or doing data entry, reporting on their own activity, helping with volunteer recruitment drives, re-stocking stationery in offices, writing and delivering birthday cards for clients, making up bereavement packs or producing a newsletter. In some instances, the entire service including the management is run by volunteers.

41% of services also use volunteers to help with community awareness raising/media liaison or health promotion and advocacy. For example, they might run Advance Care Planning forums, promote National Palliative Care Week (held each year in May) or send ambassadors out into the community to speak at events held by community clubs such as Probus Clubs or the Country Women's Association.

Volunteer support within residential aged care facilities

Recognising that many residents in aged care facilities are suffering from chronic and/or terminal illnesses and that many others would benefit from the palliative approach, Christadelphian Aged Care Homes have chosen to include information on palliative care as a standard part of their volunteer training. They have 373 volunteers spaced across 9 residential aged care facilities in Sydney and the Central Coast. The activities performed by their volunteers are very similar to activities undertaken by palliative care volunteers operating in hospital inpatient settings.

C. Volunteer induction training and development

The *Palliative Care Service Development Guidelines, Workforce support in palliative care* (Palliative Care Australia 2018) acknowledges that palliative care is a complex and demanding area of work that has its own specific set of stressors. The palliative care workforce, whether paid or volunteer, encounters deaths on a regular basis. Learning how to navigate the feelings of despair, anger and grief expressed by patients, carers, family members, staff and themselves is an essential part of the role.

To equip them with this knowledge and the skills to safely and effectively carry out their roles all services require their volunteers to undergo mandatory induction training. In addition, many organisations have monthly volunteer meetings wherein further training is delivered.

In the last twelve months, 448 training sessions have been delivered to 3197 volunteers (Note: if an attendee went to more than one session they were counted each time). 91% of services delivered a minimum of 10 training sessions over the year.

95% of respondents agreed that the training and support provided to their volunteers is of a high standard. Large organisations such as HammondCare have developed their own comprehensive in-house training resource. Others make use of existing training resources such as *Palliare: A Handbook for Palliative Care Volunteers in NSW* (Palliative Care NSW 2015), or the Palliative Care Victoria Volunteer Resource Training Kit (2012).

A number of other useful training resources are utilised by services (see End Notes in this report for more details):

- **Accidental Counsellor Training.** This equips individuals who are not qualified counsellors to be able to recognise when other people are in distress, respond appropriately to them and refer them on to someone who can help.

- Dying2Learn MOOC (Massive Open Online Course). This MOOC provided by CareSearch helps people overcome the awkwardness when talking about death and dying.
- The Safe Home Visiting Workshop. This provides strategies for staying safe while visiting in the community.
- Last Aid. This course provided by Amitayus Home Hospice service teaches caring for the dying at home.
- Midwifing Death. This course facilitated by Michael Barbato provides a deeper appreciation of the profound human experience which is death.

In addition to the mandatory induction training, further education is delivered during monthly volunteer meetings. This education is aimed at reinforcing, enhancing or expanding on the basic induction training given and is often facilitated by nurses or other allied health workers relevant to that area of expertise. Topics might include privacy and confidentiality, hand hygiene, manual handling, fire safety, Advance Care Planning, spirituality, grief and bereavement, art therapy, dementia, mental health, cultural intelligence, self-care or stress management.

Another important component of volunteer training is learning about health and safety in the workplace. 93% of managers either agreed or strongly agreed that their service clearly specifies and controls the work of volunteers and actively manages workplace health and safety considerations.

Volunteers also find attending conferences a helpful pathway to professional development. They provide an invaluable opportunity for volunteers from other services to get together to learn and share experiences. Specifically mentioned in this study was the biennial *NSW Palliative Care Volunteer Conference* held in Maitland in 2017, the *Pain is More than Pills* conference held by the Parkes Neighbourhood & Community Information Centre Palliative Care Volunteers, and events like the *Nepean Blue Mountains Annual Supportive and Palliative Care Conference* which feature presentations inclusive of volunteers.

D. Volunteer supervision

We asked managers if they felt their organisation's commitment to providing proper management and supervision negatively impacted on volunteer activity.

The 6 respondents who agreed with this statement were all from large inpatient settings which have strict policies and procedures regarding recruitment protocols and prescribed restrictions to volunteer activities e.g. a maximum number of weekly volunteer hours.

One respondent mentioned her volunteers must attend at least 50% of the monthly volunteer meetings and they have mandatory review and development meetings annually to enforce this. She believes this is too onerous for volunteers who are often very busy people, some working full-time as well as volunteering and that maintaining a significant connection via face-to-face contact with them should be enough.

Smaller community run organisations have a little more freedom to operate as they see fit to meet their demand for service.

Part 3 Key Findings - Service Characteristics

A. Number of palliative care volunteer services in NSW

Palliative care volunteers are supported across 44 palliative care volunteer services in NSW.

A palliative care volunteer service is identified as a service that is embedded within or receives referrals from a specialist palliative care practitioner. With a growing awareness of the value of palliative care volunteers in Residential Aged Care Facilities, we have first the first time recorded volunteers who support aged residents.

Of these 44 services, 13 are within Metropolitan Local Health Districts and 27 within Regional Local Health Districts, 2 within Specialty Networks and 1 within Residential Aged Care.

This report found that 3 services were dedicated to the support of paediatric patients and their families.

The survey focussed on volunteer involvement in inpatient and community visiting roles and found that 7 services have volunteers within inpatient settings only, 15 services have volunteers only within community settings only, 21 services have volunteers in both settings with an additional service supporting residents in aged care.

The important function of a palliative care volunteer is to support the work of palliative care teams by helping to ease distress and anxiety at or near the end of life. Palliative care teams may have either an adult or a children's focus.

Volunteer services may be administered by the Local Health Districts (LHDs), non-government hospital providers, aged care providers and community organisations. While there are volunteer services in each local health district there are many places, especially in rural and regional NSW, where volunteer services do not reach.

Figure 4 – Volunteer Contribution by Local Health District

LHD	Service	Volunteers	Population*	Total Volunteers
Central Coast	Central Coast Palliative Care Volunteers	NR	339,696	0
Far West			29,908	10
	Broken Hill Health Service	10		
	Broken Hill Community Volunteers	0		
Hunter New England			922,363	191
	Palliative Care Program Cancer Council NSW Hunter (Charlestown)	8		
	Mid Hunter Palliative Care Volunteers	22		
	Dungog Shire Palliative Care Volunteers	35		
	Taree Community Health	32		
	Port Stephens Palliative Care Volunteers	28		
	Volunteers for Palliative Care (Maitland)	30		
	NorthWest Church Tamworth	12		
	Palliative Care Program Cancer Council NSW Hunter (Muswellbrook)	7		
	Tamworth Hospital Palliative Care Service	2		

	Calvary Mater Health Care Newcastle	10		
	John Hunter Children's Hospital	5		
Illawarra Shoalhaven			409,052	86
	Illawarra region	35		
	Shoalhaven region	51		
Mid North Coast			218,725	30
	Port Macquarie-Hastings Palliative Care Volunteer Service	19		
	Coffs Palliative Care Volunteer Service	11		
Murrumbidgee			241,749	56
	Wagga Wagga Palliative Care Volunteers	6		
	Mercy Health Albury Palliative Care	50		
Nepean Blue Mountains			373,577	47
	Blue Mountains Palliative Support Service	26		
	Nepean Blue Mountains LHD Lemongrove	21		
Northern NSW			299,989	170
	Amitayus Hospice Service	60		
	Palliative Support Group (Lismore)	19		
	Tweed Palliative Support	75		
	Clarence Valley Palliative Care Volunteer Support Service	16		
	St Vincents (Lismore)	NR		
Northern Sydney			924,658	134
	HammondCare Northern Beaches Palliative Care	35		
	HammondCare Greenwich Hospital	65		
	HammondCare Neringah Hospital	34		
South Eastern Sydney			925,290	99
	Calvary Health Care (Sacred Heart)	99		
South Western Sydney			982,886	77
	South Western Sydney LHD Palliative Care Service	49		
	HammondCare Braeside Hospital	28		
Southern NSW			208,228	8
	Goulburn Health Service Volunteer Program	2		
	Eurobodalla Community Palliative Care Service	6		
Sydney			666,537	29
	Concord Palliative Care Service	29		
Western NSW			280,820	32
	Parkes Neighbourhood & Community Information Centre Palliative Care	11		

	Volunteers			
	Orange Health Service Palliative Care Volunteers	14		
	Bathurst Volunteer Palliative Care Group Daffodil Cottage	7		
Western Sydney			974,797	59
	Western Sydney LHD	59		
	TOTAL		7,861,068	1,028
*Australian Bureau of Statistics estimated resident populations based on projections from the 2016 Census.				

Figure 5 – Other Volunteers

Organisation type	Service	Volunteers	Total volunteers
Specialty networks			209
	Sydney Children’s Hospital Network – Sydney Children’s Westmead	12	
	Sydney Children’s Hospital Network – Bear Cottage	127	
	St Vincent’s Health Network	70	
Residential Aged Care Facilities			373
	Christadelphian Aged Care Homes	373	
	TOTAL		582

Figure 6 – Volunteers by organisation

Volunteers by LHD and non-government organisations	1,028
Volunteers by Specialty Networks	209
Volunteers by Residential Aged Care Facilities	<u>373</u>
TOTAL	1,610

Figure 7 – Volunteer effort by Service Type

Service type	Number of services	Range of active volunteers per service	Number of active volunteers
Inpatient	7	2 – 108 volunteers	615
Community visiting only	15	1 – 36 volunteers	352
Both inpatient and community visiting	21	1 – 75 volunteers	270
Residential aged care facilities	1	373	<u>373</u>
Total	44		1,610

Organising health in NSW

The NSW Ministry of Health organises the funding of health services through service agreements with 15 Local Health Districts (LHDs) of which 8 cover the metropolitan regions and 7 cover rural and regional NSW.

In addition, there are 2 specialty networks namely the Sydney Children's Hospital Network (Bear Cottage, Manly and The Children's Hospital Westmead) and the St Vincent's Health Network (St Vincent's and St Joseph's Hospitals).

LHDs and Networks have their own governance arrangements and in some cases enter into subsequent arrangements with other health providers such as private and not-for-profit services.

The geographical area of each LHD is essentially an aggregation of more than one Local Government Areas (LGAs), although some LGAs cross LHD boundaries.

Each LHD is responsible for developing local strategies for health service delivery (such as a Clinical Services Plan).

B. Supporting and supervising volunteers

Most palliative care volunteers are being overseen by someone specifically tasked with the management of volunteers. The most popular job title is Volunteer Coordinator (n=19) followed by Volunteer Manager (n=5). There are 2 of both Volunteer Leader and Manager, Volunteer Services.

Some managers revealed they are also in charge of volunteers in areas other than palliative care such as cancer care or all hospital volunteers. Palliative care is only specified in 4 of the titles.

Almost 20% of managers are also employed to do other work for their organisation. Mostly their other role is clinical (n=6) in nursing, social work, diversional/occupational therapies or bereavement care and they are required to manage volunteers in addition to these duties. One manager's role also included responsibility for fundraising and human resources at their organisation.

When asking managers how many hours per week they spent managing palliative care volunteers, many had difficulty answering accurately. Some managers are also employed to manage volunteers working in other capacities so it was hard for them to separate out exactly how many hours are spent just on palliative care volunteers. Others were not employed but in voluntary positions and so spread their work in a very ad-hoc manner across the week making it difficult to estimate the actual time spent.

Those splitting their work time between their volunteer management role and other roles such as nursing and had the same problem. Often the volunteer management workload varies quite a lot from week to week and this was another factor contributing to the difficulty of deciding exactly how much time they spent at the task.

The time spent managing volunteers ranged between 1 and 38 hours per week.

16% of services employ volunteer managers on a full time basis and 30% of managers work 3 days per week. Only 7 respondents were employed to manage volunteers on a full-time basis, this is one less than reported in 2014.

Interestingly only 7 services employed managers on a full-time equivalent (1 FTE) basis and another 7 services had managers in unpaid roles.

In total managers spent 745.2 hours per week managing volunteers or 2 hours per volunteer. This equates to 19.6 FTE positions, a reduction of 2.4 FTE positions since 2014. On average, each manager spent a total of 17.75 hours per week at this task.

The types of positions that managers' report to reflects differences in organisational size and structure. Only 10% work in organisations with a dedicated volunteer arm and as such have a dedicated volunteer executive to report to, while the majority of services (57%) report to general management positions. 33% of services report to positions in a clinical stream, with slightly more reporting to palliative care clinicians (n=8) than other clinicians (n=6).

There is a wealth of experience that managers bring to the table. 30% have been in their role for over 10 years, with 24% having between 3 and 9 years of experience. 10 (23%) manager positions have turned over in the last 12 months and several managers are very new to their role having been employed over the last six months.

Reflecting on their experience, some managers did not feel they were much in need of professional development. Others mentioned that they would like some but there is no provision for it allocated in their budgets, either to reimburse training expenses such as enrolment or to allow enough time away from their work to attend training. For managers in regional areas, distance is another problem for the budget as training expenses might also include the costs of travel and accommodation.

"Being regional it is often difficult to get to places courses are offered. Online stuff would be really useful"

From those that did want professional development, there were calls for exposure to information about workplace assessment and training, group supervision skills training, mentoring and professional development for volunteers, service development, policy writing and review, how to write applications for funding, and reflective practice. Knowledge about how to "de-brief" volunteers would be of benefit as well.

"Some sort of counselling course in grief and bereavement would be good but any general counselling knowledge would help me assist my volunteers with their worries."

"I'm interested in finding out what drives a volunteer psychologically and emotionally to volunteer with this type of work so I can learn to better meet their needs and know how to attract the 'right' type of volunteer."

A new palliative care volunteer service for Western Sydney LHD

In the 2014 *Volunteer Support Services Programme* report identified that Western Sydney Local Health District (LHD) was found to be the only district health service in NSW without palliative care volunteer involvement.

Following a commitment from the Western Sydney LHD Executive, a volunteer presence was developed from early 2016 at the Mount Drutt Supportive and Palliative Care Unit. The aim of the service was to provide inpatient support for people in palliative care and their families, and since then the service has expanded into Blacktown and Westmead Hospitals.

A later development has been the introduction of community visiting volunteers into the western Sydney community, a service that was recently supplemented by the introduction of volunteers by the non-government organisation Silverchain Group.

Silverchain Group has been contracted to provide support to people in the western Sydney community for the last 3 months of life. In this way, people in supportive and palliative care will access volunteers from Silverchain Group and possibly also from Western Sydney LHD depending on the duration of their referral to supportive and palliative care.

C. Participation in networking and development

Often volunteer management issues are common across services and managers who have been in their roles for longer are able to help those newer to their role by dispensing advice or potential solutions.

Some 60% of respondents said that they had participated in the NSW Network of Managers of Palliative Care Volunteer Services. The Network was established to provide support to and a community of practice for managers of palliative care volunteers across the state. Comments included the sense for some managers that having more opportunity to participate in the Network would help with their professional development as this facilitates access to all the experience and knowledge of other managers. Their attendance is typically restricted by time, distance and available resources.

Almost three-quarters of managers have professional involvement with one or more other organisations, for example, the NSW Centre for Volunteering and the Leaders of Health Volunteer Engagement (LoHVE) Network which are dedicated to supporting volunteering.

Managers are also involved with community strengthening organisations such as 3 Bridges, SCOPE club or LEEP. Connections are maintained at a local level with some managers attending inter-agency meetings (n=5).

“Being part of the Network is gold and it is great that we can all support and share with each other - very valuable.”

“It is very good at providing support to managers especially in rural areas.”

When asking the other 40% why they didn't participate in the NSW Network of Managers of Palliative Care Volunteer Services, 3 respondents said they did not because they haven't felt the need - their particular circumstance didn't warrant it or it was not a priority for them. 4 managers were new to their role and didn't know of the network's existence. For the most part, it is time constraints that stop people from participating.

Many managers are only employed part-time and might not work on Mondays when the meetings are scheduled, or they might have other more pressing matters to attend to at those times.

“I'm a very busy NUM (Nurse Unit Manager) looking after three different areas”

Often managers who are unable to participate in the meetings still make sure to keep abreast of the network happenings.

“I can't make the meetings but I always read the minutes and have been involved with organising the volunteer conference.”

D. Feedback on the *Volunteer Support Services Programme*

Respondents were asked to comment on the activities and resources of the *Volunteer Support Services Programme*.

The *Volunteer Support Services Programme* has aimed to support managers of services by publishing studies on various aspects of palliative care volunteering in NSW, a volunteer training manual (*Palliare: A Handbook for Palliative Care Volunteers*), a guide to managing palliative care volunteer services and other material to support volunteer and service development. Resources for both managers and volunteers are made available through their VolunteerHub website www.volunteerhub.com.au. The *Volunteer Support Services Programme* posts news about volunteering on the website, distributes a monthly eNews and host conferences and other events across NSW.

Respondents indicated the *Volunteer Support Services eNews* is a popular source of information, with over three-quarters of respondents saying they always or usually read it. Quite a few managers said they also shared it with their volunteers or used articles from it for their own newsletters.

Generally, the respondents indicated that the resources and support offered by the *Volunteer Support Services Programme* have been very well received:

“All the resources are great and really useful.”

“Great to have a central place to get information from, really good to have a coordinating body to host that information.”

“I always find you to be very approachable and appreciate that you are here providing your service.”

A list of all publications by the *Volunteer Support Services Programme* is included in the End Notes to this report. The *Palliare: A Handbook for Palliative Care Volunteers* was singled out for praise by more than half of the respondents. *Palliare* is a 72-page handbook that is aimed at the lay reader with subject matter relevant to volunteers in palliative care. Since its release in 2015, Palliative Care NSW has distributed 1,750 copies of *Palliare* free of charge to palliative care volunteers across NSW. The online (pdf) version has been downloaded 530 times and can also be found uploaded on the websites of other services for download by their volunteers. Comments from respondents included:

“Palliare is fantastic and made training so much easier.”

“It's terrific. The Palliare Handbook is one of the best ever written. Extremely well received. An excellent document for all involved in pc volunteering.”

54% of respondents mentioned they really appreciated the Volunteers Conference and the Managers' Conference.

“The conference really makes a big difference to our volunteers. They really look forward to being involved in that.”

“I love the volunteer conference and so do my volunteers. It's really the only opportunity they have to get together with volunteers from outside the service and they always find it a really valuable opportunity to share experiences with other vols, especially if they are in different settings.”

We acknowledge that the nature of the survey required respondents to speak directly to the researcher in the *Volunteer Support Services Programme* and that this may have led to some observational bias in the feedback provided.

E. Plans for the future

Of all services in NSW, 37% say they have plans to increase the number of volunteers in order to meet service demand or volunteer attrition. 15% of services either just have, or are just about to, expand into new areas. These new areas may be geographical or a new area of service provision such as adding a community visiting component, community transport component or including clients living in residential aged care facilities in their community visits.

43% currently have palliative care volunteers available that they are unable to engage in volunteering as much as they would like. Volunteer services may find that the number of volunteers needed at a service is subject to fluctuation depending on, for example, how many referrals the service receives, their client's individual needs and the availability of a suitable 'matching' volunteer, and on what days their existing volunteers are available. Some comments from respondents included:

"Volunteers are offered many different tasks but they might not be willing to do all of them which means they might end up dissatisfied with the narrow availability of their choice. They might only be available on certain days or they might only want to do community visiting but we might need people in impatient."

"Sometimes we need to wait until we have the best personality match."

When questioning if services were losing volunteers because they lacked sufficient referrals, only 2 services agreed:

"Referrals have tapered off a bit because it is a small rural area and there are not enough sick people - this is unpredictable over time."

"Communicating openly with volunteers helps them understand if there are delays in engagement and keeps volunteers happy while waiting."

When asking services whether they need to do a lot more with their clinical staff to convince them of the value of volunteers, responses were mixed. Only just over half (53%) of respondents disagreed showing that clearly there is much room for improvement in this area.

"It has taken a bit to get them (clinical staff and GP's) on board but they are now recognising the benefits and sending referrals. Palliative Care specialists are not as likely to refer because they don't think of it as much as the nurses or admin staff."

"If the nurses were not so busy they would refer more."

"A portion of the staff come and go and they might not understand what a volunteer does. The regular staff certainly do know and appreciate the volunteers."

“The culture is set by the existing staff so when new staff come on board they follow along.”

We note that there is a different dynamic between service managers and clinicians in the different settings of inpatient support and community visiting volunteers. Services with community visiting volunteers are dependent on clinical staff referring specific clients to them, whereas in inpatient settings the extent to which volunteers are utilised is often based on how much their input is valued by clinical staff generally.

To explain further, where a community visiting volunteer service has excellent support from referring clinician/s they may find a high uptake of volunteers and vice-versa if the relationship with the referring clinician/s is not robust. In an inpatient setting volunteers might be embraced by some clinicians and perhaps only tolerated by others but the volunteers will still be actively involved within the setting to some extent. We note that the different experiences of volunteer managers may inform their responses to this survey question.

37% of services have new projects planned such as adding biography services, complementary therapies, bereavement support or adding an Advance Care Planning group. 22% of services plan to increase training for existing volunteers, two of which will focus specifically on spiritual or pastoral care training.

5 services intend to improve on their existing policies and procedures to ensure better support for their existing volunteers, for example, having a counselling and advice service available for anytime their volunteers might need to de-brief.

Whether or not a service is able to expand or improve is often down to whether the manager has enough time to orchestrate any changes. With many in part-time employment and a busy volunteer management load, many managers just do not have the time available to devote to anything beyond their current capabilities.

Developing a district wide palliative care volunteer response within Western NSW LHD

The largest health district in NSW, Western NSW, has commenced rolling out a program to introduce palliative care volunteer support for people in the diverse catchments of their rural and regional population base.

Using a coordinator in the northern area and one in the southern area, the approach taken involves linking clinicians in palliative care with volunteers who belong to local community or service groups.

When an interested party is identified within the clinical community the coordinator then seeks to match their needs with volunteers from one of the local community or service groups. Where a match can be made the coordinator then connects the two groups and provides support for the referral of patients to volunteers.

The service aims to provide coverage across the entire Western NSW LHD catchment within a few years.

This brings to 3 the number of health districts that have adopted an area-wide approach to palliative care volunteer coordination and development.

Part 4 Concluding comments

This report has highlighted the diversity and challenges associated with palliative care volunteering in NSW.

In addition to the many different types and structures of services, the sheer diversity of volunteer roles and contexts makes it challenging to identify the single best or most effective way to manage or support volunteers to ensure that they do their job to the best of their ability and meet the needs of carers, patients and families.

If anything has been made obvious through this report the limited time to manage volunteers by managers and the range of services on offer contribute to stress on the manager position and this helps to explain the high turnover of manager positions in the state. In the 2018 survey the number of managers who changed over represented 23% of all positions in the state. This is an improvement on the findings of the 2014 survey which indicated that 33% of all positions had changed over but there is still more work to be done to improve the conditions and context of volunteer management in NSW.

End Notes

About the *Volunteer Support Services Programme*

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).

Contributing authors and contacts

Kate Bowman, Policy Officer, Volunteer Support Services Programme, Palliative Care NSW
health@palliativecarensw.org.au +61 2 9206 2048.

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

Resources

Volunteer Support Services Programme www.volunteerhub.com.au

Palliare: A Handbook for Palliative Care Volunteers in NSW <http://volunteerhub.com.au/palliare-a-handbook-for-palliative-care-volunteers-in-nsw/>

Dying2Learn MOOC <https://www.caresearch.com.au/caresearch/tabid/2868/Default.aspx>

Accidental Counsellor Training <https://humanconnections.com.au/accidental-counsellor-training/>

Safe Home Visiting <https://3bridges.org.au/training/safe-home-visiting-2/>

Last Aid Course <http://byronhospice.org.au/trainings/>

Midwifing Death <http://www.midwifingdeath.com.au/>

LEEP <https://leep.ngo/>

3 Bridges <https://3bridges.org.au/>

NSW Centre for Volunteering <https://www.volunteering.com.au/>

Studies, reports and publications (2014-2018)

Over the last four years, the Volunteer Support Services Programme has been developing a body of knowledge about palliative care volunteering by conducting small scale studies into the experiences of Volunteers, Volunteer Managers, Nurses and Service Development Officers in various contexts within NSW. These studies have generated 14 separate papers and through them we attempted to reveal the dynamics and narratives that shape palliative care volunteering. They, along with our other reports and publications, are available to read and download through our website (see www.volunteerhub.com.au/our-publications.)

A Snapshot of Palliative Care Volunteering in NSW 2014 by Linda Hansen and Alex Huntir.

Palliare: A Handbook for Palliative Care Volunteers in NSW (2015) by Alex Huntir.

Palliative Care Volunteering in Residential Aged Care Facilities in NSW: A sample study in Western Sydney LHD (2015) by Megan Burke.

Palliative Care Volunteer Services: Guidance for managers (2016) by Alex Huntir.

Investigating Understandings of Palliative Care within Community Volunteer Groups (2016) by Kate Bowman.

Towards a framework for community hospice in NSW (Part 1): A background paper (2016) by Alex Huntir.

Towards a framework for community hospice in NSW (Part 2): Accommodation at the end of life, an overview of the local service context (2016) by Alex Huntir.

Faded away: The life and death of a district volunteer initiative in the bush and lessons for the future of palliative care volunteering (2016) by Alex Huntir.

Where-to with our volunteers? Results of a survey of Palliative Care Service Development Officers in NSW (2016) by Julie Flood and Alex Huntir.

Paediatric Palliative Care: A survey of a hospice volunteer service (2016) by Megan Burke.

The Statewide Framework for Palliative Care Volunteering in NSW (2017) by Palliative Care NSW.

Collecting stories from Palliative Care Volunteers: Narratives, empathy and insight (2017) by Alex Huntir and Ros Bradley.

It Takes A Village: Discussing the challenges of managing cultural diversity and volunteering in palliative care services (2017) by Megan Burke.

People I have known: The experiences of rural and regional community visiting palliative care volunteers in NSW (2017) by Kate Bowman, Megan Burke and Alex Huntir.

A space of caring: NSW nurses' experiences of Palliative Care Volunteers in inpatient settings (2017) by Jessica Marsden, Kate Bowman, Megan Burke and Alex Huntir.

Investigating involvement in bereavement support by palliative care volunteers (2017) by Kate Bowman and Alex Huntir.

Perspectives on the value of complementary therapies within palliative care volunteering (2018) by Austyn Petrocchio and Kate Bowman.

References

- Centre for Epidemiology and Evidence. *HealthStats NSW*. Sydney: NSW Ministry of Health. Available at: www.healthstats.nsw.gov.au. Accessed 16 July 2018.
- Hansen, L. and Huntir, A. (2014) *A Snapshot of Palliative Care Volunteering in NSW 2014*. Surry Hills: Palliative Care NSW.
- Huntir, A. (2015) *Palliare: A Handbook for Palliative Care Volunteers in NSW*. Surry Hills: Palliative Care NSW.
- NSW Ministry of Health (2012) *The NSW Government plan to increase access to palliative care 2012-2016*. Sydney NSW: Ministry of Health.
- Palliative Care Australia (2018) *Palliative Care Service Development Guidelines*. January. Canberra, ACT: Palliative Care Australia.
- Palliative Care Victoria (2012) *Palliative Care Victoria Volunteer Resource Training Kit*. East Melbourne: Palliative Care Victoria.
- Petrocitto, A & Bowman, K. (2018) *Perspectives on the value of complementary therapies within palliative care volunteering*. Unpublished. Surry Hills: Palliative Care NSW.
- Volunteering Australia (2015) *Key facts and statistics about volunteering in Australia*. Available at: <https://www.volunteeringaustralia.org/research/fact-sheets/>. Accessed 20 June 2018.