

# A Snapshot of Palliative Care Volunteering in NSW 2014

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

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

#### **Acknowledgements**

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

Thanks to the Steering Committee members Carolyn Walsh (Chair), Peter Birmingham, Peter Cleasby, Therese Smeal and Helen Moore who provided direction to the report.

Thanks also to 3 willing specialists from the palliative care community Coral Marks (Murrumbidgee LHD), Kay Cope (Illawarra Shoalhaven LHD) and Alison Dawes (Western LHD) who assisted in shaping the survey tool.

Linda Hansen, Executive Officer, Palliative Care NSW

Alex Huntir, Manager Volunteer Support Services Program, Palliative Care NSW

#### **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**

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



#### **Foreword**

Palliative care volunteers. They feature in our newspapers, at our local hospital, in our family. They appear in our shopping malls raising funds, at our service clubs raising awareness, and in our homes raising spirits. We have seen and celebrated their contribution to the heart of our community.

This report for the first time attempts to map the activity of volunteers through palliative care services in NSW.

Palliative care represents an increasingly significant part of our health delivery system. Last year the NSW Government reported an expenditure of more than \$86 million a year on specialist palliative care in public and private hospitals, hospices, community clinics, residential aged care facilities and in at-home support.

This report shows that there are some 1,242 volunteers across 38 palliative care services in NSW. Volunteers are supported by some 22 FTE Volunteer Coordinator roles state-wide, not including services in which clinicians manage volunteers as an add-on to their role. In some rural non-government organisations considerable voluntary effort is contributed by committee members, including at least 3 organisations with unpaid Volunteer Coordinator roles.

Each of the respondents to our survey indicated that the future for palliative care volunteering is positive. We must now ensure that our volunteers and their coordinators are properly resourced to do their roles and build a healthy basis for future service delivery in NSW.

We greatly appreciate the leadership and support of the NSW Government and NSW Health in funding the Volunteer Support Services Project. This funding has given life to this report, and provides the means for further capacity-building and awareness-raising of volunteer services.

Thank you also to the volunteers Elizabeth, Jenny, Julie, Gypsy, Shona, Yvonne and Leanne who shared their stories in the making of this report.

They put a human face to the experiences and ambitions of our volunteers, and remind us that we will be remembered not for the reports that we produce but for the relationships that we build and the hope we inspire.

I commend this report to you.

Carolyn Walsh, President PCNSW October 2014

### **Executive Summary**

The survey found that a total of 38 palliative care services involve 1,242 volunteers with 965 volunteers (77.7%) actively involved at any given time.

Volunteers are supported by some 22 FTE Volunteer Coordinator roles state-wide, not including services in which clinicians manage volunteers as an add-on to their role, with an average of 56.4 volunteers per 1 FTE Volunteer Coordinator. The survey found that 33% of Volunteer Coordinators have been in their roles for less than 1 year. In some rural non-government organisations considerable voluntary effort is contributed by committee members, including at least 3 organisations with unpaid Volunteer Coordinator roles. The 4 largest volunteer services collectively accounted for 32.4% of all palliative care volunteers in NSW, 3 of these were non-government services and organisations. In addition 1 LHD and 1 Network expressed plans to introduce volunteers whilst having none currently.

Active palliative care volunteers contribute some 110,400 hours per year to their services.

About 63% of services involve volunteers within community settings, and about 63% involve volunteers within inpatient settings (not necessarily the same services). About 23% of services indicated that volunteers were involved in other roles within the palliative care service such as community awareness raising, fundraising or general advocacy.

When asked to rate themselves against the *National Standards for involving Volunteers in Not for Profit Organisations* the respondents consistently indicated lower levels of confidence in relation to service planning and management system integrity.

Respondents expressed a high level of confidence that the reputation of their service was no barrier in volunteer recruitment (91%) and similarly refuted the suggestion that volunteers are lost because they can't be properly trained and supported (81%).

Some 62% of respondents indicated that demand for volunteers was generally greater than they could supply, but equally that increasing supply would be problematic without increased capacity to supervise and manage them.

In comparison to other services in NSW about 72% of services rated themselves as average or above average although some 38% of respondents indicated that they had no basis for comparison nor of knowing 'what the other services are up to'.

Respondents indicated that their plans for the immediate future included review the scope of their volunteer activities and the quality of their management system (67%), to increase the number of volunteers (55%) and expand the geographical opportunities for volunteers (22%).

### **Contents**

Foreword		3
Executive S	Summary	4
How did th	is report come about?	6
Overview o	of Volunteer management and support	8
Mapping V	olunteer services in NSW	12
Findings		13
	A. Palliative Care volunteers in NSW	13
	B. Volunteer contribution in figures	14
	C. Management and supervision	17
	D. Recruitment and training	20
	E. Activities performed by volunteers	22
	F. How do you rate?	25
	G. About our service	28
	H. Compared to other services?	32
	I. Plans for the future	33
Concluding	comments	36

### How did this report come about?

In 2012 the NSW Government launched the Plan to Increase Access to Palliative Care 2012-2016 which committed an additional \$35 million over the 4 years to improve access to care and support for people who are dying, their families and their carers.

The **Plan** articulated goals for enhancing the involvement of volunteers in palliative care, and noted the significance of volunteers within the delivery of palliative care services:

Volunteers provide a range of support for patients and/or their carers and families. These services may range from direct practical assistance through to telephone support and counselling. Volunteers may be members of NGOs or operate as part of local palliative care service networks. Most LHDs have volunteer programs and employ at least a part-time dedicated volunteer coordinator. These programs vary in size and can fluctuate in activity.

There is a need to support volunteers working in this area.

The **Plan** recommended two actions for Local Health Districts (LHDs) in relation to palliative care volunteering:

- In the context of expanding community-based palliative care services particularly in rural areas -Support the ongoing training of volunteer palliative care workers and carers; and
- In the context of expanding support for families and carers - Establish linkage programs between local carers and palliative care volunteers

Additional information from the *Request for Tender* documentation for the *Volunteer Support Services Project* (NSW Health, 2013) expands the government's vision on volunteering in palliative care:

The NSW Government Plan to increase access to palliative care 2012-20161 identifies volunteer activities as an integral component of care networks for people who are dying and their families and carers.

Palliative care volunteers provide very important personal care for patients and their families and carers. This personal care may take the form of companionship, practical assistance, provision of respite for everyday carers and other activities and supports known to make it more feasible for a person to receive care and to die at home.

Indeed the potential contribution of palliative care volunteer services can be identified as advancing each of the Plan's key strategic objectives for palliative care in NSW.

#### These are:

- Expanded community based palliative care services especially in rural areas and for special populations
- Greater cooperation between specialist palliative care services and existing primary and aged care services across the state
- Expanded support for families and carers
- Extended capacity of palliative care services in NSW

#### The commentary concluded:

The vision for NSW specialist palliative care services sees volunteers featuring consistently and prominently within local community support networks for people who are dying and their families and carers.

Palliative Care NSW received funding through NSW Health for 3 years to develop the capacity of palliative care volunteer services, to raise awareness of the importance of palliative care volunteering in NSW and ultimately to develop a statewide framework for palliative care volunteer services.

This report documents what we found in mapping the current activity of palliative care volunteer services in NSW.

### Plan to Increase Access to Palliative Care 2012-2016

In 2013 the NSW Government committed to additional \$35M in funding under the Plan to Increase Access to Palliative Care 2012-2016.

This included funding for the Volunteer Support Services Project by Palliative Care NSW; home support packages offering personal care, domestic assistance and service co-ordination to ensure safe and comfortable end of life care at home (up to 1545 packages in 2013/14 increasing up to 2863 packages in 2015/16) by Silver Chain and HammondCare; and an after-hours telephone service.

#### What is a palliative care volunteer?

A palliative care volunteer provides some aspects of compassion, support and comfort to people who receiving palliative care services.

They function in a supernumerary way to the specialist palliative care team typically in inpatient settings, or in community-based settings. Their work can include providing some respite for carers or family members, attending to chores or simply sitting with a patient.

Some volunteers work as ambassadors or educators or activists, providing an awareness raising role of palliative care, end-of-life issues, and death and dying to the community. Others provide support to the health service, assisting with administration, fundraising, and possibly in the coordination of volunteers.

Some non-government organisations use the term 'volunteer carer' to describe the role of a palliative care volunteer within their service. Here the term 'carer' is used in the vocational sense, and may help to distinguish them from other volunteers (eg administration or fundraising) within the service.

The *Carer's Recognition Act 2010* notes that the term 'carer' is a person who is not paid for their work, not a volunteer attached to an organisation, and not a student on work experience.

Carers often have a familial connection to the person receiving palliative care, whereas volunteers share the professional detachment of other members of the clinical team.

In some cases a volunteer may once have been a carer for a person receiving palliative care. For these people most services recommend an adequate effluxion of time (usually 12 months) to allow them time to adjust to their own loss before they can commence a role as a palliative care volunteer.

# Overview of volunteer management and support

## Volunteer management and supervision

Typically the management of volunteers is undertaken by a Volunteer Coordinator. This position is tasked with recruiting, training and supporting the volunteers, with the assistance as appropriate of clinical staff who help with specific training and support needs. In a community organisation the Volunteer Coordinator role might be an addition to the task of running the organisation (for example as the Executive Officer's role).

In NSW palliative care volunteer services have historically been fostered within services attached to public health services or nongovernment hospital operators, or community organisations which provide volunteers to local health services.

Typically the public health services or non-government hospital operators fund the costs associated with volunteers out of their operational budget. In some cases community organisations have received recurrent operational funding for their volunteer management. This funding is established through the centralised functions of NSW Health, but operationally they interact with relevant health services under a formal arrangement or Memorandum of Understanding through the localised function of the Local Health District.

In other cases community organisations exist to support local palliative care services (such as by fundraising) but do not provide palliative care volunteers in interpersonal or psychosocial roles.

#### **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 region, and (7) cover rural and regional NSW.

In addition there are (3) Networks namely the Sydney Children's Hospital Network, the St Vincent's Health network (including St Vincent's Hospital and the Sacred Heart Hospice at Darlinghurst and St Joseph's at Auburn) and the state-wide Forensic Health network.

LHDs and Network 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.

National statistics are collected at the LGA level on demographic and economic issues which in turn provide input into health service planning and delivery. Each LHD is responsible for developing local strategies for health service delivery (such as a *Clinical Services Plan*).

Under a 2010 NSW Government *Palliative Care Strategic Framework 2010-2013* each LHD was required to develop a *Palliative Care Service Plan* supported through established funding for a Palliative Care Service Development Officer position within each LHD.

#### Parkes, a local community partnership

The Parkes palliative care service receives about 110 referrals a year from a local catchment of about 10,000 people. Over the last year local CNC Bernadette Orange has been the energy behind developing a new palliative care volunteer initiative and now has a team of 10 volunteers.

Volunteer roles include direct support to people living in the community. Bernadette added that "the volunteers have been active in health promotion and advocacy as part of an effort to destigmatise palliative care during the month of May. Their efforts included presentations to seven local service clubs, and an information stall at the local supermarket."

In addition the volunteers have been involved in music therapy, massage, and organising a celebration of life event.

"We are also looking at setting up a prostate cancer support group in Parkes."

The volunteer program operates as a partnership between the local Community Health Centre and the Parkes Neighbourhood & Community Information Centre, or PINC for short. The volunteer coordinator role is voluntary and home-based, jointly managed by Bernadette (with a clinical focus) and PINC.

The partnership resulted in some initial funding, largely thanks to the *Foundation for Rural and Regional Renewal*. "We received grant seeding of \$12,000 in total, and part of that was used to send volunteers to the biennial conference in Canberra last September."

Interest in starting the program arose after the service reviewed their delivery against the National Palliative Care Standards. The service operates under the accreditation of the HACC requirements of PINC and the Community Health Centre's accreditation.

Within these three types of organisations (public, non-government hospitals and community organisation) each service typically offers volunteers to provide support

in the inpatient setting or community (for example at home or in a residential aged care service) setting, or will have volunteers who work within both inpatient and community settings.

Volunteers may take on other roles such as fundraising, community awareness raising, administration or education.

#### Standards of service delivery

Typically health services are accredited through Standards frameworks such as the *Australian Council of Healthcare Standards* and associated tools. Satisfactory compliance with these standards is essential for operational status for the service. Funded community organisations are required to comply with contractual performance provisions with NSW Health.

The National Palliative Care Standards (or more correctly the Standards for Providing Palliative Care for All Australians) published by Palliative Care Australia provides an optional measurement device for palliative care services. Within this there are two standards explicitly relating to palliative care volunteers (Standards 12 and 13):

- Standard 12 Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.
- Standard 13 Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies.

The National Standards Assessment Program enables palliative care services to optionally participate in continuous quality improvement through self-assessment against the National Palliative Care Standards. NSAP includes a 2 yearly review of the service to tighten their focus on quality, offers peer

mentorship visits, and provides feedback to funding and oversight bodies on the key quality issues the palliative care sector is facing.

# Bega activists for palliative care volunteering



Julie Roberts is part of the Bega Valley Hospice Group, a meeting of activists lobbying for improved palliative care services in the Bega Valley, and in particular for quality end-of-life care in a home environment.

With a long history of volunteering between the members of her group, they understand the significant value that volunteers can bring to palliative care if properly trained and supported. "You can't really have volunteers without a paid coordinator. I mean, no one has the time to volunteer (to perform the role as a volunteer coordinator) and take on all the training and (clinical) support of the volunteers, I mean it's a huge thing."

The South East Regional Hospital, due to open in the Bega Valley in 2016, will have dedicated palliative care beds, creating an opportunity for volunteer involvement.

"Palliative Care beds in hospital are good, but support to die at home is vital, and trained volunteers can really add value in this area too."

The Bega LGA has a population of about 33,000 people of which in 2012 about 22% were over 64 years of age (compared to the state average of 14%). There are currently no palliative care volunteers in the Southern LHD.

"You really need someone at the top who understands the value of volunteering."

More specific standards on volunteering within community (not-for-profit) organisations are provided by the *National Standards for involving Volunteers in Not for Profit Organisations* (*Volunteering Australia*, 2001).

These describe eight domains for the management of volunteers and volunteer services including quality review which 'describe what elements should be part of a 'best practice' system for managing volunteers.

In 2006 Volunteering Victoria published standard specifically for palliative care Strengthening Palliative Care: Palliative Care Volunteer Engagement Standards under the Victorian Government's initiative Strengthening Palliative Care: a Policy for Health and Community Care Providers 2004-2009.

Although the Victorian standards are intended for the *palliative care sector* the document acknowledges that volunteering *traditionally takes place in a not-for-profit organisation*. The document explains that volunteers are to be engaged in the context of interdisciplinary team service delivery to a multicultural society utilising primary care services and community resources.

#### **Training**

Each service is responsible for the design and delivery of an appropriate volunteer training program.

In 2012 Palliative Care Victoria developed the Palliative Care Volunteer Training and Resource Kit as a training and development resource for palliative care volunteers. The kit is sectioned into nine modules, with multimedia presentations, and a nominal delivery time of 30 hours.

# **Exploring Palliative Care Volunteering** in Europe/UK

The palliative care volunteering activities of the EU member nations are currently the subject of a study by a working group of the European Association for Palliative Care (EAPC).

Their work will include surveying national palliative care associations, volunteer managers, and volunteers. The working group is planning a volunteering symposium at the EAPC Conference in Copenhagen May 2015.

A recent report by UK researchers Volunteers in Specialist Palliative Care: A Survey of Adult Services in the United Kingdom (2014) across 290 services found that about 33% of services used volunteers in community-based roles mostly in home support and transport; about 50% of services involved volunteers to sit with patients in the last few hours; and about 68% of services involved volunteers in counselling. They identified the most likely role for palliative care volunteers as day care and bereavement services.

UK academic Ros Scott reports that recently in the UK there has been a lot of interest in volunteering in hospice and palliative care.

"It seems to go through peaks and troughs but the recent interest has been sparked by out comes from the volunteering work stream of *Commission into the Future of Hospice Care*. The Commission stated very clearly that hospices would need to develop volunteering further if they were to meet future demands."

A subsequent working group subsequently published *Volunteers: Vital to Our Future* which aims to assist hospices to develop volunteering.

#### **Jenny Furney**



Jenny worked for 20 years as a registered nurse in Palliative Care in Dubbo before becoming a volunteer in the local bereavement service. The one-day-a-week role involves contacting people who have requested follow-up after bereavement.

"We ask the family early-on if they want to be contacted, and if they do then we book a time for a follow-up call about 4 or 5 weeks after the death." Not everyone wants to be contacted. "We make it easy for them not to continue with the calls if they don't want it."

In a small community Jenny often knows the people that she is calling. "A lot of the people I am ringing, I remember their mother, or their father, or I know them from golf, or something, it does concern me that they might think 'Oh there is that Jenny Furney ringing again, I don't want to talk to her, she knows me personally' – I don't know if people do feel like that but I am conscious that they might have that in the back of their mind."

"I'll be in touch with about 15 or so people at a time, some are long conversations, and sometimes it's just a message. If they aren't responding then we don't continue to call them.

"Part of the role is to screen people, to see who is not coping, and a very small percentage will need referral on to a counsellor or psychologist."

"I leave work feeling quite tired, because you put an effort into it and you're careful of what you say. It's quite exhausting, without doing anything physical, the emotional side of things is very tiring."

### **Mapping Volunteer services in NSW**

#### Method

In August-October 2014 *Palliative Care NSW* surveyed relevant palliative care services in NSW to identify various specific aspects of their volunteer activity.

The survey consisted of 21 questions. A total of 45 respondents were involved across 38 services either by telephone (n=29), face-to-face meetings (n=15) or email only (n=1). Of the respondents 50% were Volunteer Coordinators, 30% were supervisors of Volunteer Coordinators, and 20% were other palliative care clinicians.

See list of all services in the Appendix, and figures on involvement by LHD and Network in part B.

In instances where contact was not made with a service (n=2) reliable data about them from a nominated contact person within the Local Health District has been used in these results.

During the interviews some respondents were unable to provide all the data required. This may have been because the service did not have volunteer involvement, or due to one or more self-identified limitations (lack of knowledge, experience or expertise), or lack of time. In each case the number of respondents is indicated.

In addition a number of interviews with volunteers actively involved in different regions, and performing different functions, were undertaken to supplement the data.

#### Elizabeth Allen



Elizabeth became involved in palliative care volunteering after her husband was diagnosed with prostate cancer about 19 years ago. "It never ceases to amaze me the number of people who don't know much about palliative care".

"We need to get away from the idea of palliative care being the last 48 hours. It's the prior support, I see prior support as months before end of life. It's the support role that's important."

Elizabeth is well acquainted with volunteering. She has been instrumental helping form a number of prostate cancer support groups including her own, providing community information sessions throughout the Western area, speaking with men in clubs, men's sheds, underground mines, between halves in football games, and to service clubs.

She was involved in instigating a cardiac support group last year, is an advocate for people in the aged care system, helps people to navigate the health system, and currently serves on the local health council.

She is particularly aware of the challenge facing families with a loved one who has dementia. "Dementia is very hard on carers and families, it's the everyday coping that people need support with, the everyday repetitiveness of dealing with it, coping with things that are just not normal. It's a hard thing to deal with."

### **Findings**

#### A. Palliative care volunteers in NSW

This research indicates that there are currently about 1,242 people engaged as palliative care volunteers in NSW. Of these about 965 are actively involved (77.7%).

Inactive volunteers may or may not become active again after a period of inactivity.

The annual loss rate of volunteers is about 93 or about 9.6% of the total volunteer population.

"We have a good retention rate, we did a report early this year which showed, of those who started in 2009, over 50% are still with families, a couple of them dropped off recently because of family changes and death" (Volunteer Coordinator, metropolitan)

"(We lose) only a few volunteers a year, there is an awful lot who have been here since the beginning" (Volunteer Coordinator, metropolitan)

"We lose around 6 to 8 volunteers per year, and we do twice a year training, with about 6 in each intake" (Volunteer Coordinator, metropolitan)

"The majority of volunteers seem to stay for 2-3 years, then a change of family situation or employment means that they change their involvement" (Volunteer Coordinator, metropolitan)

"Palliative care for young people is quite different in as much as the prognosis is more poorly understood for some conditions...so volunteers tend to be attached to families for longer periods of time" (Volunteer Coordinator, metropolitan)

"Some (volunteers) are just hanging in there, they'll come back when (their personal situation) gets better" (Volunteer Coordinator, metropolitan)

# The delivery of palliative care services in Northern Sydney LHD

Karen Gill, Palliative Care Development Officer Northern Sydney LHD

"The LHD outsources palliative care services to Hammond Care, and Hammond Care delivers inpatient services at Greenwich Hospital and Neringah Hospital. In addition Hammond Care delivers community services within the LHD and these services are based at the Greenwich Hospital and Neringah Hospital, and at the Mona Vale site in the Northern Beaches.

Hammond Care also delivers a medical consult service to the Royal North Shore Hospital, and medical and nursing in-reach service to Ryde Hospital, Hornsby Hospital, Manly Hospital and Mona Vale Hospital.

In addition the Northern Sydney Home Nursing Service (which is a LHD organisation with a governing structure through the primary and community health portfolio) are delivering athome services, they have 160 FTE in the service providing home nursing, with 2.5 FTE specialist palliative care nurses providing end-of-life palliative care services in the home.

At the Royal North Shore Hospital there is a specialist palliative care department with a CNC and a CNS who are full-time Monday-Friday (and that is supported by Hammond Care delivering the medical consult service at Royal North Shore Hospital).

In addition we have a palliative care network (with a Director, Cancer and Palliative Care Network) and that looks at coordinating and facilitating palliative care services across the district bringing all those organisations and teams together."

#### **B. Volunteer contribution in figures**

Also see alphabetical list of all services in the Appendix.

#### In summary the number of volunteers<sup>1</sup> in NSW is as follows:

Volunteers within Local Health District boundaries (volunteers in service)			Total volunteers
Central Coast LHI	Central Coast LHD		35
	Central Coast LHD (35)		
	Central Coast Hospice and Palliative Care Foundation		
Far West LHD		31,000	8
	Broken Hill Health Service (8)		
Hunter New Engl	and LHD	885,060	195
	Hunter New England Health - Tamworth Hospital (7)		
	Hunter New England Health - Taree Health Centre (35)		
	Dungog Shire Palliative Care Volunteers (32)		
	Make Today Count (15)		
	Mid Hunter Palliative Care Volunteers (40)		
	Muswellbrook Carelink (16)		
	Volunteers for Palliative Care (35)		
	Westlakes Palliative Volunteers Group (15)		
Illawarra Shoalha	ven LHD	387,605	79
	Illawarra region (29)		
	Shoalhaven region (50)		
Mid North Coast LHD		208,331	108
	Coffs clinical network (35)		
	Hastings-Macleay clinical network (73)		
Murrumbidgee LI	HD	287,865 <sup>2</sup>	85
	Murrumbidgee LHD (15)		
	Albury Mercy Hospital (70)		
Nepean Blue Mo	untains LHD	351,223	73
	Nepean Blue Mountains LHD Lemongrove CH (28)		
	Blue Mountains Palliative Support Service (45)		
Northern NSW LF	HD	289,371	140
	Tweed Palliative Support (100)		
	St Vincent's Hospital Lismore (20)		
	Palliative Care Volunteer Support Service (20)		
Northern Sydney LHD		864,380	95
	HammondCare Greenwich Hospital (50)		
	HammondCare Neringah Hospital (20)		

	HammondCare Northern Beaches PCS (25)		
South Eastern Sydney LHD		858,300	120
	Calvary Health Care (120)		
South Western Sy	dney LHD	887,902	45
	South Western Sydney LHD (30)		
	HammondCare Braeside Hospital (15)		
Southern NSW LF	HD	198,342	21
	Southern NSW LHD Eurobodalla CHS (6)		
	Southern NSW LHD Burke St HS Goulburn (15)		
Sydney LHD		590,504	45
	Sydney LHD Concord Hospital (45)		
Western NSW LH	D	273,173	53
	Western NSW LHD Orange HS (14)		
	Western NSW LHD Dubbo HS (4)		
	Bathurst Voluntary Palliative Care Group (Daffodil Cottage) (25)		
	Parkes Neighbourhood & Community Information Centre (10)		
Western Sydney LHD		862,783	0
TOTAL		7,301,134	1102

#### Notes:

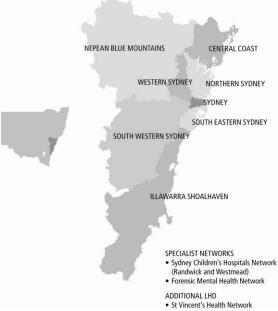
- 1 The number of volunteers is indicative rather than exact, it may reflect volunteers who are currently inactive, and the actual number may fluctuate depending on demand, availability and turnover.
- 2 The catchment for Murrumbidgee here includes the Albury Residents LGA figure of 49,733

Volunteers by state-wide Network		
Justice Health & Forensic Mental Health Network		0
St Vincent's Health Network (28)		28
Sydney Children's Hospitals Network		112
	Bear Cottage (90)	
The Children's Hospital at Westmead (22)		
TOTAL		140

Total volunteers	Total
Volunteers by LHD and non-government organisations	1102
Volunteers by state-wide Network	140
TOTAL	1242



Map of regional Local Health Districts in NSW



Map of metropolitan Local Health Districts in NSW

### Hours and other measures of contribution by volunteers:

Typically the contribution by volunteers is recorded by each service as hours per volunteer.

Depending on the service other data may be collected such as occasions of service,

distance travelled or number of calls (such as for a bereavement service).

In many services the contribution by any one volunteer is nominally capped at 4 hours per week, although this may be flexible. As one Volunteer Coordinator put it:

I would count one visit even if they turn up at the person's house and they don't do anything, because we have actually been available to provide a service. As far as actual hours we try and keep it under 4 hours per week, but then a volunteer might do 8 hours a week over a few days or they might just go once a fortnight for a few hours, but it can be very different depending on what the needs are.

Some people want more than is reasonable, we teach the volunteers to say no, and in some ways that comes to their motivation for doing it, if they just want to please everyone then ultimately they are going to over-extend and burn-out" (Volunteer Coordinator, regional)

Reported contribution per month was indicated within a range of 3 to 20 hours per volunteer, although an average figure of 10 hours per month was expressed by some of the larger services and is used for the purposes of this report.

Hence the average contribution by volunteers is estimated at 10 hours per month per volunteer, or an average of 110,400 hours per year.

#### C. Management and supervision

In NSW there are currently 22 FTE roles held by volunteer coordinators.

- 6.3 FTE in metropolitan services
- 13.1 FTE in regional services
- 2.6 FTE in 2 Networks

This included 4.1 FTE in non-government services which are hospital providers, 5.9 FTE in non-government services other than hospital providers, and 3 FTE in unpaid roles in non-government services

In-lieu of a Volunteer Coordinator supervision of volunteers may be provided by clinical and allied health staff coincident-to and in addition-to their usual duties.

For all services the number of volunteers managed is 56.4 volunteers per 1 FTE Volunteer Coordinator.

For non-government services which are hospital providers this figure is 59.1 volunteers per 1 FTE Volunteer Coordinator, and for non-government services other than hospital providers it is 41.5 volunteers per 1 FTE Volunteer Coordinator.

Within these results were 4 services which reported 75 or more volunteers. Of these 3 were non-government services and organisations.

These collectively accounted for 31% of all palliative care volunteers in NSW. They also collectively represent an average of 113.2 volunteers per 1 FTE Volunteer Coordinator position.

- Calvary Health Care 1 FTE Volunteer Coordinator, 120 volunteers
- Tweed Palliative Support 1 FTE Volunteer Coordinator (voluntary position), 100 volunteers

- The Sydney Children's Hospital Network (Bear Cottage) – 0.6 FTE, 90 volunteers
- Mercy Hospital (Albury) 0.8 FTE, 75 volunteers

Only 8 services reported having a full-time Volunteer Coordinators. The average Volunteer Coordinator position for all services was 0.71 FTE.

About 33% of Volunteer Coordinators indicated that they had been in their role for less than 1 year.

Volunteer coordinators who worked 0.8 FTE or more were more likely to express confidence in the quality of their service and in their future plans to develop volunteers.

Those volunteer coordinators of 0.6 FTE or less with community-based volunteers were more likely to indicate concerns about capacity and service development.

The respondents' commented on the role of a Volunteer Coordinator:

"Some (volunteer coordinators) are supported better than other, some supervisors are more supportive than others, some services are more engaged than others...(in other places) volunteers are just another service, no-one takes any notice of it (volunteering), it's an afterthought." (Clinician, regional service)

"I took over a full time position that was made part time, so more hours are needed, more training and more volunteers and it's all so time consuming" (Volunteer Coordinator, metropolitan service)

#### **Service Review Chats**



Paul Colyer coordinates a group of about 50 volunteers attached to the palliative care service at David Berry Hospital in Illawarra Shoalhaven LHD. With volunteers working across the inpatient and community areas he is exploring ways to efficiently and effectively conduct performance and development processes.

"After discussing the idea at a monthly volunteer meeting it was agreed to trial a process where I meet with a small group (4 or 5) volunteers at a time over a cup of coffee. This is held at a local café, we meet the cost in appreciation for their time and input."

Paul explains that smaller groups allow for a freedom of speech that is inhibited in a large group, and is more time effective than individual conversations which are difficult to organise and not particularly popular.

The agenda topics include any achievements of the service over the last few months, what has been most satisfying, difficulties/ frustrations that have arisen, areas for future development (personally and the service), suggestions for change/improvement and evaluation of the role of the coordinator.

Paul is upbeat about the success of the approach, "to date these coffee chats are working well and are really appreciated by the volunteers."

"Another advantage is that it also provides an opportunity for social interaction and bonding between all of us. This helps create an atmosphere of appreciation for their service, and collegiality."

"I don't even think (local clinical staff) would be aware of volunteers in palliative care, my immediate supervisor knows, but there are no dedicated resources or allocated time for their support. Having said that I don't feel like it's a

big issue in supporting them, but it's a big issue if you look forward to look at how you might develop the service. We have formal procedures for recruitment, we are well supported as to how to recruit, but not beyond that, there are no policies in how volunteers are to be supported and so on" (Clinician, regional service)

"Where you have a specialist palliative care service the volunteer service is well supported and the service delivery is good, but in other sites the services are placed in community health centres and they are managed by community health centre managers who don't understand a lot about palliative care volunteers, and they don't (recruit) well, consequently volunteers don't have high skills level and the services don't develop at all. I mean, the way you manage a volunteer to change the flowers in the hospital is very different to the way you support a palliative care volunteer in the community" (Clinician, regional service)

Respondents also indicated a variety of lines of support and direction for volunteers:

"(Apart from the volunteer manager) each volunteer program has a program manager... according to the program the volunteers report to staff on the ward usually the CNE or Ward Clerk" (Volunteer Coordinator, metropolitan service)

"I go daily to the ward, I rotate my work days to make sure that I can get there every day...for community volunteers I'm the first point of contact, but they can also contact the nurse, or if things escalated then I would go and meet with them" (Volunteer Coordinator, metropolitan service)

"At the moment they are all supported through me, but in the (biography service) it could be me or a staff counsellor" (Clinician, regional)

"(My role) includes debriefing with volunteers and families...in the team there is a bereavement coordinator and social worker that I can call on if I need to...volunteers can also access the employee assistance program" (Volunteer Coordinator, metropolitan service)

"Volunteers in (name of town) are not being utilised ... they are coordinated by local clinical staff and it's not working well. In (name of different town) they are being placed with patients but its ad-hoc for example there is no assessment done on the suitability of the match with the volunteer etc ... in (name of centre) volunteers are not utilised well. So we need to highlight the value of paid coordination and best practice standards, emphasise that need for an annual volunteer recommitment agreement, the importance of treating volunteers like paid employees ... (In summary) it's a combination of a funded coordination position and then maintaining a standard of support for volunteers (through accreditation)." (Clinician, regional)

"In the past we've had supposedly a lot of volunteers on the books but not supported, or not properly supported, and that's not a good look for palliative care volunteering" (Clinician, regional)

"(Name of Volunteer Coordinator) is a really hard worker and she has done a sterling job, she has come as a non-clinician to do the role, and what we tried to develop in her in the beginning was that she needed to have some experience with dying patients within the team" (Clinician, metropolitan)

"That why it works well for us here, because I sit in the same office as the palliative care nurses, I am totally in the loop with it all, and I'm included as part of the bigger team...(after all) the volunteer role is only one part of the larger system" (Volunteer Coordinator, regional)

"Volunteer Co-ordinator only works 8 hours/week" (Volunteer Coordinator, regional)

### Volunteering in NSW - who's doing what

According to Health Statistics NSW the estimated residential population of NSW in 2012 was 7,301,134, which was just under one-third (32%) of Australia's population. The population of NSW in 2031 is projected to be approximately 9,228,362.

The NSW population is predominantly urban. In 2012 approximately 74% of the NSW population lived in metropolitan areas, 20% lived in inner regional areas, and 7% in outer regional and remote areas.

The Australian Bureau of Statistics publication *Voluntary Work, Australia 2010* reported that approximately 163,600 people volunteered in *health* organisations in NSW (health care services and health support services) representing about 8.1% of all volunteers in the state, and approximately 433,500 people indicated that they volunteered in welfare/community organisations (community transport, community centres, residential aged care) representing about 21.6% of all volunteers in the state.

A resident of NSW was more likely to volunteer if they lived outside the capital city (41.7%) than in the capital city (33.6%), more likely to be female (40%) than male (33.1%), and more likely to be within the 55-64 age bracket (46% of residents - compared to 36.6% for the state).

ABS (2010) 44410DO001\_2010 Voluntary Work,
Australia, 2010
http://www.healthstats.nsw.gov.au/Indicator/dem\_pop\_Ihnmap

#### D. Recruitment and training

This report did not attempt to investigate the details of training programs used by individual services, as this was regarded as outside of the scope of this initial mapping exercise. Instead the training and development of volunteers will be the focus of a future study.

Respondents did comment on the process of recruiting and engaging volunteers for their services, in some cases highlighting the protracted nature of the recruitment process and the policy emphasis on recruitment to the expense of ongoing support.

"We lose around 6 to 8 volunteers per year, and we do twice a year training, with about 6 in each intake" (Volunteer Coordinator, metropolitan)

"We have formal procedures for recruitment so we are well supported as to how to recruit, but not beyond that" (Clinician, regional)

"I wonder if some (volunteer cohorts in)
services don't have a magic maximum
number, it's as if you can try and try to attract
more volunteers and for a while you have
more but then the number slowly returns to
where it was" (Volunteer coordinator,
metropolitan)

"My referrals come through Volunteering NSW unless they walk in through the street, but (if they walk-into) the hospital they can be swallowed up in other volunteering in the hospital ie oncology." (Volunteer coordinator, metropolitan)

"The process of application can be quite long. The initial application, police checks, the mandatory one day general orientation training and referee checks can take 8-9 weeks or longer to complete. By that time they might have given up." (Volunteer coordinator, metropolitan)

"There has been no (development) training for them for quite a while, (the volunteers) are begging for training, they had some bereavement training in the recent past, but we really need to commit to ongoing (training and development)" (Clinician, regional)

"An awful long process getting them started, immunisations, criminal checks, referee checks, time to come to training. I recently had a woman who started the process in May, she had done everything but then she had some family circumstances and so she is only just trained and ready to go (in October), some people drop out in the process, and then some people start with a big ideals but find the reality is something different" (Volunteer Coordinator, metropolitan)

"We do our training using the Palliative Care Victoria material, and (the local Palliative Care CNC) comes in for those 4 days, and its fairly involved, all the (information) on boundaries and death and loss, it's quite invasive to some people, (but we soon) work out who is there for the long haul and who isn't" (Volunteer Coordinator, metropolitan)

"I send a job spec to Volunteering NSW and the applicants get interviewed by them initially and then their referral comes to me, and then I send them the job description and criterion, and application form. About a third actually get (through the process and are) interviewed by me." (Volunteer coordinator, metropolitan)

"About once a year we put adverts in the local paper to recruit new volunteers, and we encourage media stories to get people interested in volunteering, we aim to recruit people with a vested interest in people who have a life limiting illness" (Volunteer coordinator, regional)

"The biggest issue when you start to recruit, you get quite a few people who need 15 hours a week on Newstart (job seeker activity) - that concerns us greatly, how do you find out the true motive of the person." (Volunteer coordinator, regional)

"(...in summary) I want to stress web-based training, and that you can't organise volunteers without dedicated support" (Volunteer coordinator, regional)

"You have to be very clear in your own mind about the requirements for a volunteer, some of those things are about having good boundaries, not carrying their own agenda, common sense, and their motivation...you need a good interviewing processes and a good training program... appreciate your volunteers and give them meaningful work if you want to retain them" (Volunteer Coordinator, regional)

"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 eg not giving out your home phone or rushing out at 2 in the morning if they call you - 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" (Clinician, metropolitan)

"People often say 'I'd like to volunteer in palliative care' but what does that mean, what am I going to do with you, I don't know what your skills are what your motivation is, if only there was some type of tool to gauge motivation and skills" (Clinician, regional)

#### **Leanne Blaker**



Leanne joined the South West Sydney LHD Palliative Care Volunteer Service a year ago to "give back" to the team that gave invaluable care to her mother-in-law when she was at the end of her life.

She now travels across the Macarthur district offering community-based support to families accessing palliative care. "I had such a positive experience with the palliative care team, they made such a difference to my mother-in-law that I wanted to give back."

Leanne provides respite support and assistance to attend appointments for two hours a week.

"Long term illness places such a strain on families and carers, financially and emotionally. We can come in and give carers some respite and give the patient companionship and alleviate some of the stress that families face."

"You start as strangers but you very quickly become an intimate part of their life. Illness can be socially isolating so it's the little things you can offer that make a difference and when you receive thanks you realise this why you do this work," she said.

"It's a privilege to be there for them and offer that support."

(With thanks to the Campbelltown Macarthur Advertiser)

#### E. Activities performed by volunteers

Respondents (n=30) indicated that volunteers performed a range of activities and roles within the palliative care service.

About 63% (n=19) of services involve volunteers within community settings, and about 63% (n=19) involve volunteers within inpatient settings (not necessarily the same services). About 23% (n=7) of services indicated that volunteers were involved in other roles within the palliative care service such as community awareness raising, fundraising or general advocacy.

Respondents indicated a diversity of possible activities. Not all roles were performed or endorsed by all services:

Roles performed in community settings included:

- Visiting the home to provide companionship and psycho-social support
- Assistance in interacting with medical staff and General Practitioners in the community, co-attending appointments, accessing services
- Transporting the person and/or their family such as to/from appointments, shopping or meetings
- Shopping on behalf of the person receiving care, if the person lives alone and can't go shopping themselves
- Social support at home including assistance with the support of children
- Respite support, by attending the home while the carer is away or on break
- Assistance where socio-demographic or cultural barriers exist

- Visits to the person when they attended hospital as an inpatient
- For paediatric patients Sibling support, respite support, light household tasks to assist the parent, psychosocial support to parents and children
- Bereavement support

Roles performed in inpatient settings included:

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

Other roles within palliative care services included:

- Health promotion and advocacy including small-group presentations and information distribution
- General community awareness raising including information stalls in shopping malls or media liaison
- Fundraising and marketing
- Administration

Respondents described the diversity of the roles of volunteers, and the context of those roles:

"(A community volunteer) can help with outings, shopping centres or parks, be a listening ear and share some light household chores" (Volunteer Coordinator, metropolitan)

"(Volunteers in our inpatient service help with) reception, general in-house roles which include play therapist, art and music therapy, housekeeping, volunteers work in the kitchen, volunteers help out in the admin side and

fundraising, morning afternoon and evening shifts, assist the social worker, also volunteers sit on committees for big events, dog walking, driving" (Volunteer Coordinator, metropolitan)

"Palliative care for children is quite different, our children are diagnosed with life limiting illness but the prognosis is poorly understood... the ones that have genetic or neuro problems can access palliative care, they can be in the service a lot longer than adults are in palliative care, so the volunteers can have long term attachment to families" (Volunteer Coordinator, metropolitan)

"(We have inpatient volunteers) rostered to be there supporting patients when they come for their clinics, and the volunteers are basically handing out cups of tea and chatting with them (and happy to do that), but some volunteers want to be extended and we are losing them because they are bored, so I've (got one volunteer helping with) filing and administration, one volunteer that runs 2 support groups, one volunteer does bereavement follow-up and prepares information packages, as well as preparing clinical oncology information folder, someone to fill up the medical oncology trays with supplies, and two volunteers doing life stories" (Clinician, regional)

"The bulk of the community referrals for volunteers are for respite or companionship, in inpatients they do emotional support, carers coffee break, carer support, jolly trolley, art and craft trolley diversional therapy, then special events for Mother's Day etc, (all volunteers) do the same training and can opt to do one or both roles" (Volunteer Coordinator, metropolitan)

"We have rehab and dementia volunteers, they are all inpatient, also we have the happy hour trolley, pastoral care conversations, administration support, in community the volunteers are companions only" (Volunteer Coordinator, metropolitan)

"There is hands-on personal care and community heath, respite, showering, free transport to and from medical/oncology appointments, companionship, shopping, hospital massage (if clients come into hospital)" (Volunteer Coordinator, regional)

"Community visiting, health promotion and advocacy, de-stigmatising talks at the local service clubs, also an information stall at the local supermarket, flyer and things, music therapy, bereavement, there are interested volunteers helping me organise the bereavement 'Celebration of Life' event, one of our volunteers also works in the leukaemia foundation support group" (Clinician, regional)

"There are no community palliative care clients, in inpatient we have pet therapy volunteers, diversional therapies, sensory garden, uni students if they are studying they can volunteer eg physio, OT, we also organise events and do fundraising, social visitors, manicure trolley, it's about social engagement" (Volunteer Coordinator, metropolitan)

"(Mostly) supporting patients in the community, but at (name of service) they have (inpatient) volunteers who run a day care centre, do massage and aromatherapy, serve high tea in the inpatient unit, volunteers to do biographies, and are developing volunteers to do advanced care planning forums in the community" (Clinician, regional)

"At home they can do in-house respite for up to 4 hours per week, also provide company for the patient, in some situations where the patient may live alone they might assist with shopping etc" (Volunteer Coordinator, metropolitan)

"Respite social support and transporting clients as far as (major hospital), also some bereavement support for up to 12 months, and in (local hospitals) volunteers are rostered-on in inpatient roles" (Volunteer Coordinator, regional)

"Inpatient volunteers arrange flowers, cups of tea, jolly trolley, it's like happy hour with grog and they give them a drink of choice, there are volunteers who do the wig library, on the palliative care ward the volunteers assist with breakfast, then they bake daily, garden maintenance in the palliative care garden, other volunteers assist with laundry, massage, visiting, talking, others get involved with fundraising, we used to have community volunteers but these have dropped away, we need to rebuild the support" (Volunteer Coordinator, regional)

"Mostly volunteer support in-home, transport, social support, with some inpatient but not as much as in (other hospital). The inpatient volunteers attend on a rostered basis, mostly they do social support, talking and walking, cups of tea, wig library, and they do presentations at the cancer care centre. The community volunteers do a lot of respite support in the community, they also transport clients out for occasional appointments to the cancer care centre" (Volunteer Coordinator, regional)

"Respite care, they do some work with paediatrics in palliative care, mainly community based, they have a mutual support group, they do adult bereavement support and education" (Volunteer Coordinator, regional)

"About half of our volunteers do bereavement, then in-home respite, transportation, hand arm massage, biography, historically the bereavement and palliative care volunteers were separate, but then about 10 years ago they went to a single point of entry into the service but their working patterns are quite different" (Volunteer Coordinator, regional)

#### **Dr Yvonne McMaster OAM**



Yvonne worked as a Palliative Care Specialist for 23 years, and she believes that she was one of the first to work full time in palliative care long before it was recognised as a speciality. She now describes a new role for herself as an advocate for the palliative care system, a volunteering and activist task that fully occupies her time.

Yvonne spends a lot of time travelling around the state attending meetings and speaking to policy makers. "The main thing really is to have enough clinicians to meet the need in community as well as inpatients, we really need to get specialist palliative are doctors in the regional areas, fly-in fly-out is ok but it doesn't really give any governance to the system."

Her energy has attracted the support of members of the community who have joined her as Ambassadors for Palliative Care. "There is a lot of interest and excitement in being an Ambassador, with about 25 people now on the books. Just the other day as I was getting on the train from Dubbo I received an email from a woman wanting to be an ambassador. I wasn't sure how she found me, but in the end I worked out that she must have seen something in the local CWA magazine and decided to make contact."

Yvonne admits that being an advocate for the palliative care system and lobbying policy makers "doesn't always make you a lot of friends", but is committed to the cause for the benefit of the patients and clinicians.

#### F. How do you rate?

Respondents (n=20) were asked to rate themselves against each of the eight (8) Standards from the *Volunteering Australia*  publication *National Standards for involving Volunteers in Not for Profit Organisations* as follows:

Standard	Indicator	Aggregated result	Low/ High
1	Policies and procedures for volunteer involvement are defined, documented, understood and implemented within the service where volunteers are involved	8.2	4/9
2	Volunteers are managed within a defined system by capable personnel with the authority and resources to achieve the service's policy goals	8.7	4/10
3	The procedures for volunteer recruitment, selection, and orientation are consistently applied	9.3	4/10
4	The service clearly specifies and controls the work of volunteers and actively manages workplace health and safety considerations	8.6	3/10
5	Volunteers obtain the necessary knowledge, skills and feedback on work, and the recognition needed to effectively carry out their responsibilities	8.1	4/10
6	Procedures are established and followed for the effective planning, control, and review of all activities relating to the delivery of services by volunteers.	7.7	4/9
7	A system of procedures control all documentation and personnel records that relate to the management of volunteers	8.0	3/9
8	The service plans and routinely reviews it's volunteer management system to ensure that opportunities to improve the quality of the system are identified and actively pursued	7.6	3/9

In general the respondents expressed more confidence in their service's procedures and management functions than in service planning and review, although the range of responses (high/low) suggests that a diverse range of confidence existed within each indicator.

Some comments associated with higher ratings:

"I do a lot of work around policies, I'm so fortunate to have such a solid set of policies in the hospital to back me up" (Volunteer Coordinator, metropolitan)

"Well, I don't know if the volunteers actually read (our policies) but they certainly have access to them" (Volunteer Coordinator, metropolitan) "Yes (our policies are consistently applied) but this can be a very lengthy process and long winded, plus there is training and other commitments before they begin" (Volunteer Coordinator, metropolitan)

"When I started here my manager kept saying 'Keep thinking outside the box for patients, keep open to the possibilities'" (Volunteer Coordinator, metropolitan)

"The volunteer is seen as part of the overall system" (Volunteer Coordinator, metropolitan)

"(The Volunteer Coordinator) and I meet monthly with an agenda to go over quality, OHS, projects etc and from that we involve other teams" (Clinician, metropolitan) Some comments associated with lower ratings:

"Because of the geographical diversity (visiting and doing a risk assessment on each client's home setting) can be hard" (Volunteer Coordinator, metropolitan)

"(Actively managing workplace health and safety considerations) can be difficult because the volunteers are out in the community, and after the initial interview at the client's home you don't know what changes. And even though the volunteers are told 'no lifting, no physical' once they've been working for a while they start to say 'Oh its ok I'll just help them', sometimes the clients ask them to stay overnight!" (Volunteer Coordinator, metropolitan)

"Within the hospital system when you go into a ward it seems like everyone is so busy with their own jobs that it's hard to get staff to recognise (and acknowledge) volunteers, I understand it's busy, but that's one of the most difficult challenges" (Volunteer Coordinator, metropolitan)

"(Acknowledging and supporting volunteers is) a bit varied, some volunteers you see every month some once a year, you can't make them come to meetings especially if they work or whatever" (Volunteer Coordinator, regional)

"I have some naughty volunteers at times who think that because they have been here for ever they can get away with anything" (Volunteer Coordinator, metropolitan)

#### **Gypsy Artemis**



Gypsy's involvement with the Central Coast LHD bereavement program followed a personal experience with the death of her mother.

Volunteering in bereavement has confirmed her interest in end of life support. "I had one client whose husband had the most amazing death, she wanted to celebrate it, so I said let's make a film and tell the story and you can pass it on down the family. So that's what we did".

A young energetic woman, the bereavement program alone is not likely to hold her interest for the long term. "I really want to develop relationships with people at end of life, that's my passion, direct support for people around end of life."

Community engagement is something that also is of interest to her. "I'd love to train in the end of life area, and to get young people involved in palliative care around Australia. Whilst I want to do bedside stuff, I am a trainer and have worked in the community, and so community training is a way that my skills could be utilised. The palliative care workers and volunteers are such a valuable resource in the community, how can we do capacity building in the community?"

Proving that volunteers come from all walks of life, Gypsy is actively involved in running her own business and feels the tension of being committed to both volunteering and building her business. "I'm time poor, so for every hour I spend time in volunteering then my business misses out, so (the nature of the volunteering) has to hold my interest".

"(Our system of procedures that controls all personnel records) is not as process driven and not available to everyone who needs to have that information. There should be a requirement that volunteer information is put through (central) HR, confidential details could rest with the volunteer coordinator, I think the process of recruitment of volunteers needs to be bought into line with recruitment generally" (Volunteer Coordinator, metropolitan)

"The (volunteer personnel) records are still paper based, on excel, kept in a locked filing cabinet" (Volunteer Coordinator, metropolitan)

"(A management system?) No not really, I lost access to my database and (shrugs shoulders) 'oh well it's just volunteers' you know, it's just that mindset (that volunteers aren't important)" (Volunteer Coordinator, metropolitan)

# Palliative care volunteers at Long Bay Hospital?

Long Bay Hospital is an 85 bed inpatient unit located on the Long Bay Complex in Malabar. The hospital consists of 3 units; 40 bed acute Mental Health Unit, 30 bed Medical Subacute and 15 bed Aged Care and Rehabilitation Unit.

Long bay Hospital provides Palliative and End of Life care for all patients in correctional centres throughout NSW.

Shirley O'Keeffe Service Director Long Bay Hospital sees that there is a great potential to work with Palliative Care NSW and commence a volunteer program for palliative patients in Long Bay Hospital. This program would have to be done in collaboration with Corrective Services NSW and Shirley is keen to start exploring possibilities for introducing a volunteer program in this unique setting.

# Volunteering at the Royal North Shore Hospital



Lorena Aziz is responsible for overseeing the engagement of the 450 volunteers who work across 69 different programs within the Royal North Shore Hospital.

"Our volunteers are placed in many different areas in many different roles. I'm involved in the recruitment process, and making sure the volunteers are navigated through various steps of the process." The volunteering programs fall under several activity areas; patient contact, administration, customer service and driving. Each program has a program manager.

If a volunteer requests to work in a new area where they have not previously had volunteers then the process can be extended by 2-8 weeks while checks are made by the hospital to ensure that no paid positions are being displaced by volunteers. "Of course if a department hasn't requested volunteers then I can't place them."

Supervision of volunteers is provided by staff on the ward, usually the CNE or Ward Clerk, and they might oversee as many as 2 - 3 volunteers in a day.

To alleviate the cost of parking at the hospital all volunteers receive free parking tickets.

At the moment there are no volunteer positions specifically within Palliative Care at the RNSH. At the Royal North Shore Hospital the specialist palliative care department is supported by Hammond Care (see Box - Delivery of Palliative Care Services within Northern Sydney LHD).

#### G. About our service

Respondents (n=21) were asked to respond to each of the following statements using 'strongly agree, agree, neither agree nor disagree, disagree, strongly disagree'.

- 1. We have more than enough volunteers involved in our service
- Our training and support for volunteers is of a high standard
- We need to do a lot more work with our clinical staff to convince them of the value of volunteers
- 4. We easily attract appropriate people to volunteer in our service
- 5. Our volunteer activity is negatively impacted by our organisation's capacity to provide proper management and supervision
- 6. Our volunteer activity is affected by transport issues for volunteers
- Our volunteer activity is affected by a negative perception of our organisation in the community
- 8. We are losing volunteers because we can't properly train, support or develop them

In response to 'we have more than enough volunteers involved in our service' about 62% of respondents disagreed, indicating that the demand was generally greater than they could supply. Those who agreed (38%) tended to indicate that their service was at capacity in terms of supporting volunteers:

"Yes, for now, but we will need more volunteers if we expand into the community" (Volunteer Coordinator, regional)

"I could certainly have more volunteers (to meet demand), I've just had the clinical services manager wanting me to do more than I can, but all the time I have to be putting the brakes on myself, but I won't cope with things if I push it any further" (Volunteer Coordinator, metro)

"No, we would need more infrastructure ie management of volunteers" (Clinician, regional)

In response to 'our training and support for volunteers is of a high standard' respondents were in strong agreement (95.3%), indicating some of their practices and indicating some identified strategies for the future.

"My concern is about mandatory training around OHS and infection control...training in these areas is now moving toward online training, I received an email that volunteers may not have access to computers, and so if mandatory training goes online it will be a problem for some of our older volunteers" (Clinician, regional)

"We have a great team of in-house trainers, and they don't like us going off to other places (to source training for volunteers) we're not go off and have just any old training!" (Volunteer Coordinator, metro)

When prompted 'we need to do a lot more work with our clinical staff to convince them of the value of volunteers' about 54% of respondents disagreed and 38% agreed (and of these about 19% were in strong agreement).

"No, I think all staff are overwhelmed, they might be really happy with the work of volunteers, but I don't think the staff have the time to acknowledge volunteers, and (in light of some internal workforce issues) I think a some staff are feeling that this isn't a time to be generous to other people, I think some might even fear being replaced by a volunteer" (Volunteer Coordinator, metro)

"No, but I think we are certainly well on the way, the medical staff are fantastic for example if they see the volunteer massaging

someone's feet they say 'it's ok we'll come back' they can see that what the volunteer is doing is of more benefit that what they can do at that time, so right through I would say they are well respected especially by the allied health...with the nurses, well they appreciate what the volunteers do but it's not a team, they wouldn't think to do something special for them, the OTs and Physios buy them a gift, so a lot of work to do with nurses still" (Volunteer Coordinator, metro)

"It's just something that you need to keep working on, I need to find ways to reinvigorate relationships every month" (Volunteer Coordinator, metro)

"We really have to push the role of the volunteers and integrate their service, the specialist nurses are just off doing their thing, and I don't think they care much at all about the volunteers" (Clinician, regional)

"The clinicians here are very supportive" (Volunteer Coordinator, metro)

In relation to 'we easily attract appropriate people to volunteer in our service' about 57% were in agreement and about 38% in disagreement.

"I don't know how to interpret that question, yes we've attracted appropriate people but (it hasn't) been easy" (Volunteer Coordinator, regional)

"The ones we have are great, we have often advertised and we had suitable applications, but some of the others were just looking to have Centrelink signed off, sometimes there have been talks at community groups to generate interest but we don't necessarily get applications" (Volunteer Coordinator, metro)

"We get very high quality people here, I mean professional, about half are nurses, doctors, lawyers, engineers, massage therapists, uni students, we get quite a lot of ethnic volunteers too, Cantonese, Arabic" (Volunteer Coordinator, metro)

#### **Shona Bridge**



Shona became interested in the world of palliative care volunteering after a near death experience a few years ago. As a result of that experience she lost the fear of death and dying, a loss that she describes as a gift.

"So many people in our community are afraid of death and dying, and if I'm not afraid then that's a gift that I can give to others. I feel strongly called in this area, and being a volunteer gives me the opportunity for a stronger and deeper experience of death and dying. For me it feels like a second career."

In the 3 years or so she has been volunteering on the Central Coast she says there is no such thing as a typical day. Shona works as community-based volunteer in homes, and every day is different. "You just have to be prepared for the unexpected".

"We work with people from such diverse backgrounds, part of the experience for me is having to work through my own layers of response to their situations. You are walking into people's worlds and they are showing life as it really is, it can be wonderful and messy and gentle.

What next? Shona hopes that her volunteering experience will be part of something bigger and more integrated into the clinical care system, saying "I feel very isolated as a volunteer in a vocational sense. The support from the health service is really great, but there is a sense that vocationally we are tagged-on and not part of the bigger palliative care team."

"A lot of people want to work for our brand there an inbuilt horror around palliative, especially in paediatrics" (Volunteer Coordinator, metro)

"We don't attract many people but they are excellent" (Volunteer Coordinator, metro)

"No, we did more advertising in local radio, unis, newspapers to attract the right people" (Volunteer Coordinator, regional)

"The volunteers I have virtually came to me, I didn't have to look for volunteers, I'm just getting calls, might be geographical too because in (name of city) the population is more concentrated (than in other parts of the LHD)" (Volunteer Coordinator, regional)

In response to 'our volunteer activity is negatively impacted by our organisation's capacity to provide proper management and supervision' about 57% of the respondents disagreed with about 33% in agreement.

"(Name of Volunteer Coordinator) is doing a great job but having one FTE across such a big area, it's not enough, we really need another person so we can have a Volunteer Coordinator to cover (each part) of the LHD" (Clinician, metropolitan)

"No, it's good here, the volunteers feel supported don't ask me why! But they do, (yes I work hard but) I think it's because the system is so supportive of them" (Volunteer Coordinator, metropolitan)

In response to 'our volunteer activity is affected by transport issues for volunteers' about 52% of respondents disagreed with 33% in agreement.

"We have an MOU with the local hospital so that volunteers can use hospital cars if they are available" (Volunteer Coordinator, metropolitan) "I think consideration has to be given to at least pay for the volunteer's mileage, petrol is now quite expensive. Mind you when we ask some of them if they want to be paid for mileage they say 'no I would give the cash back to you', even though they are travelling 70kms or catching 3 buses. At (name of hospital) the parking is really expensive and management provided parking vouchers, if we are serious about volunteers in the community we need to do something about the cost of mileage" (Volunteer Coordinator, metropolitan)

"The hospital gives them free parking vouchers" (Volunteer Coordinator, metropolitan)

"It's an interesting question because one service has a budget to assist with transport but not the other (in the same LHD)" (Volunteer Coordinator, regional)

"Our volunteers put in travel claims and get reimbursed for their travel at 40 cents per kilometre, some volunteers will take patients in their own cars and others won't, if they drive to and from (the inpatient unit) they can claim it back from us" (Volunteer Coordinator, regional)

"We assist with parking on a monthly basis for meetings and sometimes with travel to homes if they are out of area" (Volunteer Coordinator, metropolitan)

In relation to 'our volunteer activity is affected by a negative perception of our organisation in the community' some 91% of respondents disagreed.

Likewise there was strong disagreement with 'we are losing volunteers because we can't properly train, support or develop them', for which some 81% disagreed.

"That's not the reason, we have a lot of transitional volunteers, they move onto once they have gained employment, there is the core that stay and then the transitional ones who move on" (Volunteer Coordinator, metropolitan)

"If we lose volunteers it's because they are aging, aging and health issues are the primary reason volunteers have resigned" (Volunteer Coordinator, metropolitan)

### Palliative care volunteers within aged care services?

Where do palliative care volunteers fit into the model of care for our aged people?

Bronwyn Heron shares some experiences from when she started working as a Clinical Nurse Consultant Palliative Care with Anglican Retirement Villages (ARV) nearly 4 years ago, joining Palliative Care CNC colleague Christine Lancaster.

"For us coming from a Specialist Palliative Care background volunteers were an integral part of the palliative care team in supporting people at the end of their lives." So we thought 'let's establish a volunteer service in aged care."

Christine joined the organisation as its first Palliative Care CNC in 2009 and saw a need for volunteers to be available to those who were dying, who had no family or friends available to sit with them to offer support and comfort.

"Often our residents have families who can't visit, because of distance or family commitments. Some families particularly struggle to continue to visit over a long illness journey of many years, if for instance their elderly family member is living with dementia, the journey can be a protracted and difficult one to end of life."

A palliative care volunteer service was established about 6 years ago, and in the early days volunteers were specially selected and offered specific education and training in palliative care. A program of ongoing support was also provided. This service ran successfully for 3 years.

We became aware over time that the role of the volunteer in aged care differs from that of the volunteer in a specialist palliative care services. In part I think, due to a difference in illness trajectories and needs of the frail aged, and a different volunteer base. Our palliative care volunteers were of advanced age themselves and over time we saw a natural attrition of these volunteers due to their own health issues.

Rather than specific palliative care volunteers in our aged care organisation we now believe that all ARV volunteers should be provided with information to prepare them for giving comfort to the dying and to have an appreciation of the palliative approach in aged care.

"We are trying to open-up thinking about palliative care in aged care, which is so much more than the dying. In aged care I think there is a need for greater awareness of the importance of the provision of a palliative approach. More than that, I think improving access to palliative care is a real issue of equity particularly for elderly residents in care."

"We are really keen on raising the profile of palliative care in aged care and volunteers can be a key member of the care team toward provision of support and comfort to the frail aged and their families requiring palliative care support as they approach and reach the end of their lives."

#### H. Compared to other services?

Respondents (n=21) were prompted "Overall, when compared to other palliative care volunteer services in NSW, our service is probably ..." and asked to rate themselves as 'well above average, above average, average, below average, well below average, don't know'.

No services rated themselves as **well above average**. About 43% (n=9) of services rated themselves as **above average**, 29% (n=6) rated themselves as **average** and only 1 service self-rated as **below average**.

About 38% (n=8) of respondents either responded **don't know** or indicated that they felt unsure about the basis for their response, for example adding '...but I really don't know what the other services are up to'.

About 19% (n=4) of respondents from the same Local Health District indicated significantly different ratings between different service areas within their LHD.

# Tweed Palliative Support – Volunteers caring for our community



With sixteen years of home hospice care experience, the not-for-profit organisation *Tweed* 

Palliative Support is a key palliative care support provider in the Northern Rivers area.

Tweed Palliative Support has supported thousands of palliative clients and their families through the provision of their free palliative support services including the delivery of TPS equipment for clients (wheelchairs, hospital-style beds, walking frames etc.), transport to appointments, carer respite and personal care.

They work closely with local hospitals and community health staff to coordinate their hospice care, cancer support, bereavement courses, and Sunshine 'Pamper' days.

The activities of the 100 or so volunteers are coordinated by Meredith Dennis, who is also President of the organisation and performs her volunteer coordinator role unpaid.

"Our volunteers provide a total of some 31,000 hours of their time each year across the organisation's activities. Without government funding we rely on community and corporate donations, bequests, and the proceeds from our Murwillumbah-based Op Shops to continue our free service."

A ten-week training course is run annually for volunteers working in the organisation's palliative care support services. Local GPs, nurses, community workers and therapists take part in the training days (see pic).

"Besides home hospice support, our Volunteer Carers also have a role at the Wedgetail Retreat hospice. The hospice currently accepts palliative clients for respite or end-of-life care if they have their own carer or full-time nurse. While our volunteers have an important presence, we are fundraising for the funds to employ the muchneeded nurses to enable 24-hour nursing care at the hospice."

#### I. Plans for the future

Respondents (n=28) indicated the following future intentions (total exceeds 100% because of multiple intentions):

- 1 LHD and 1 Network indicated that they don't have a palliative care volunteer program but would like to commence one in the near future
- 67% of services indicated that they intend to review the scope of their volunteer activities and the quality of their management system
- 55% of services indicated that they intend to increase the number of volunteers
- 22% of services indicated that they intend to expand the geographical opportunities for volunteers

The respondents also indicated a range of operational tasks and aspirational strategies to improve the value of their volunteer service:

"We are doing an audit at the moment to identify the specific skills-sets of our volunteers, to see how we can make better use of them" (Volunteer coordinator, metropolitan)

"Another plan down the track is addressing the needs of our rural patients. I was thinking about exploring working with community palliative care services in rural areas in some way to provide volunteers for our patients in rural areas. Again this is something that I would consider exploring in the future in an attempt to address equity of service for all palliative care patients and their families across NSW. Obviously this is a big exercise with lots of issues but one definitely worth exploring I think" (Volunteer coordinator, metropolitan)

"I would like to increase the number of volunteers in the community service with

different multicultural skills - Arabic, Greek, Italian" (Volunteer coordinator, metropolitan)

"If I was doing anything to develop our volunteer service I would be looking at collaboration with an NGO" (Clinician / service manager, regional)

"We've definitely had to meet the need for transport to (treatment centre), we will probably be looking at some funding to keep that going, so that could be something that needs to be addressed in the future, as far as the rest of it goes I don't see many changes" (Volunteer Coordinator, regional)

"To involve volunteers in planning and ongoing professional development, to spend more time reinforcing boundaries, giving encouragement & feedback as to their value to the community & palliative care staff" (Volunteer Coordinator, regional)

"The question of what we do with volunteers is a bit of a 'cart and horse' - there is a capacity to use volunteers more in at-home or patient-transport roles, but it depends on whether we have more volunteer coordination roles, not even a half time position, but just enough to make sure that standards are met, to be the go-to person for volunteers when they need direction, provide support especially for in-home situations" (Clinician, regional)

"Develop-up services particularly the role of respite for carers, going into people's homes and providing companionship say 2 hours a week, one of the things is now that there is a plethora of services available and the specialists are saying that there are just too many people visiting people in their homes, people can get tired of getting different people in their homes" (Clinician, regional)

"I guess for us its more about promotion and letting the community know that we are there, if we had people accept a volunteer (in their home) then our volunteers would be fully utilised, whereas they can wait for quite a while" (Volunteer Coordinator, regional)

"We just have to focus on promoting ourselves more in the area, getting the referrals up, keeping our volunteers with work to keep them happy with" (Volunteer Coordinator, regional)

Some of the respondents gave insights into the tension between volunteering and the realities of the service delivery system:

"In terms of growth, it's a Catch 22 really, where we are (number of volunteers) is probably our capacity limit in supporting them, so unless we can address the capacity issue then we probably can't grow in number or scope of activities" (Clinician, regional)

"We have done a lot of development (of our volunteer support system) now the task is maintaining a service for them to work in" (Volunteer coordinator, regional)

"Volunteering is not cost neutral and not cheap" (Clinician / service manager, metropolitan)

"... (to justify funding for a volunteer support program we have to able to gauge) client satisfaction, not just around outcomes for the patients and carers but also around the experience of volunteer involvement by specialists and clinicians ... we would start looking at the patient journey and asking 'has it improved the journey?'" (Clinician / service manager, regional)

"We want to expand the service to (name of another town nearby) but I don't know ... there is definitely a demand, but we have limited resources ... there is only one of me." (Clinician / volunteer support, regional)

## Hunter New England LHD in collaboration with local NGOs

Within the Hunter New England Local Health
District are 5 non-government organisations (NGO)
which organise and supervise palliative care
volunteers: Make Today Count, Mid Hunter
Palliative Care Volunteers, Volunteers for Palliative
Care, Muswellbrook Carelink, and Dungog Shire
Palliative Care Volunteers.

Each organisation receives central funding through NSW Health, and their relationship at a service-delivery level involves interaction with the Hunter New England LHD.

They each also enter into a Memorandum of Understanding with the Hunter New England LHD which sets out responsibilities in relation to matters such as service quality, key processes, referrals and data collection.

The Hunter New England LHD provides a coordination function through their NGO Program Unit which employs 2 part time managers and Tarika Rivers, HNE Palliative Care Program Coordinator.

"We have been working to improve collaboration between LHD and NGO, and to improve integration between NGO and their palliative care service. This has been driven by a desire to improve on health outcomes for the service user."

We would love to do more development work with volunteers in the top of the Hunter New England LHD, around Armidale, Tamworth and Narribri. We are also mindful of the need and benefit of engaging with Aboriginal communities in terms of improving their access to services.

The Hunter New England LHD is the second largest LHD in NSW by population (at about 885,000 people) and one of the largest in terms of land area.

"(Name of service) is looking to expand their services to capture advance care planning, so they are really active, but the others are not active, are not integrating into their other

services, so for me it's about raising the profile of volunteers and getting people to know that volunteers need support, and also for people to understand the scope of roles that volunteers can perform. At an exec level they need to understand what the volunteer role is ... volunteer services are rarely mentioned within our exec" (Clinician / service manager, regional)

"The thing with volunteer services is that they don't come free ... what it does is more than just providing volunteers it also educates the community about what volunteering does and enhances the community to understand death and dying, and there are intangible benefits to just providing a volunteer, and how you value that I don't know" (Clinician, metropolitan)

"I don't know how to answer that, I don't have a huge vision for the future that is different from what I am doing know, as things manifest themselves I respond to them in the moment...I don't have this big vision, except to get some help (for my role)!" (Volunteer Coordinator, regional)

"It's a little bit tricky, the hospital is quite small I feel we are close to capacity, my boss would like more volunteers but I don't want to bring in a volunteer and given them nothing to do, so there are a few new roles that I'm hoping to develop next year" (Volunteer Coordinator, metropolitan)

"It's all dependant on the new funding model (through NSW Health), we need to have more detail about that, all the palliative care NGOs in the region are in the same boat, we just keep going as we are at the moment and see how it pans out" (Volunteer Coordinator, regional)

#### A commitment to volunteering by HammondCare

Barry Costello is a wealth of information about the ways in which volunteers have changed the lives of people receiving services through *HammondCare*.

As Head of Volunteer Services he oversees the activity of the organisation's 14 volunteer leaders and in turn the 600 active volunteers engaged with their aged care dementia and palliative care services.

"About 3 years ago the senior executive was identifying where volunteering was at, and they decided to develop-up the role of the volunteering service by creating a dedicated position to provide leadership."

HammondCare are aiming to have about 1000 volunteers by the end of 2016, and then about 1250 volunteers by the end of 2018.

Why does volunteering feature in their future plans? "HammondCare's foundational mission is about improving the quality of life for people in need. So the specific role of a volunteer is to provide TLC care."

"We are careful to make sure that our volunteers are engaged for the social enrichment of the people we care for. We have made a conscious decision to attract people with a passion for the elderly, with a passion for the satisfaction of caring for people."

"It's really important to us that our volunteers are not engaged as unpaid workers, they are deliberately engaged as TLC volunteers."

"The growth in volunteering has taken place because it is supported by the Chief Executive and the executive team, it's gathered some great momentum thanks to their commitment."

### **Concluding comments**

### **Embedding volunteers in communities of practice**

The field of palliative care is adapting to changing social narratives about death, pressure on the health care system and increasing user-demand for autonomy in decisions relating to palliative care treatment.

Clinicians and policy makers readily recognise the complexity of these shifts and problems, as evidenced by reports and policy initiatives in the recent past. One of the problem solving responses within this emergent system is to create networks or communities of practice within which problems can be addressed and acceptable solutions negotiated.

At a strategic level communities of practice can be seen at work, for example, in the *Agency for Clinical Innovation* in NSW. At a more operational level these are seen within hospital and health-service as clinical and multidisciplinary groups.

At the nexus of the problem solving approach, these communities of practice provide tacit recognition of those represented within their ranks. That is to say, their inclusion recognises not only the importance of their function within the system but also the willingness of the other members to invest influence with them.

Although the recent reports and policy documents acknowledge the presence of the palliative care volunteer in the system, and a few services are very successful at inclusion, it is fair to say that the volunteer is generally underrepresented in communities of practice.

Training is a more traditional problem solving response, and training is highly effective in environments of simple or complex problem solving. In more complex or chaotic

environment the employment of training alone, embracing as it does the transference of past learnings onto future problems, must be supplemented by other strategies which include all participants in real-time problems solving.

One Volunteer Coordinator described how over a long period of time their health service had systematically included volunteers within the clinical practice team, in particular by embedding the Volunteer Coordinator within those teams. Although the number of volunteers managed by the role was very high there was a clear sense that the volunteers felt 'part of the system':

"...it's good here, the volunteers feel supported, don't ask me why! But they do, (yes I work hard but) I think it's because the system is so supportive of them" (Volunteer Coordinator, metropolitan)

Another Volunteer Coordinator expressed a similar sentiment, emphasising the physical as well as professional integration of her role with the clinical team:

"That why it works well for us here, because I sit in the same office as the palliative care nurses, I am totally in the loop with it all, and I'm included as part of the bigger team...(after all) the volunteer role is only one part of the larger system" (Volunteer Coordinator, regional)

This proved the exception rather than the rule. Within the discussion arising during the survey it was not unusual for the Volunteer Coordinator to express a sense of being ancillary to the service, tagged-on, and consequently with a foreshortened vision for the future of the service or the scope of their work. One respondent gave this example:

"(A management system?) No not really, I lost access to my database and (shrugs shoulders) 'oh well it's just volunteers' you know, it's just that mindset (that volunteers aren't important)" (Volunteer Coordinator, metropolitan)

This Volunteer Coordinator was employed 0.6FTE. Another Volunteer Coordinator, with 61 active volunteers, when asked about service risk-management simply replied:

"Volunteer Co-ordinator only works 8 hours/week" (Volunteer Coordinator, regional)

It is possible that frustration with efforts to embed themselves within the service system might explain the survey finding that some 33% of Volunteer Coordinators had been in their role for less than 1 year.

Therefore it is essential that future efforts to build the capacity of palliative care volunteer services including the volunteer more fully as a participant in communities of practice. It is equally important that training, as valuable as it is, is not substituted for inclusion.

Some of the expressed concerns about service planning and quality are complicated by information sharing between services and the limited availability of Volunteer Coordinators (with an average FTE of 0.71). The spread of services across rural, regional and metropolitan settings creates a diversity of challenges for networking and communications, as well as a diversity of contexts within which services are delivered. Networking within these contexts will be important in developing beneficial communities of practice through which services will flourish.

#### **Training and recruitment**

Nevertheless training is essential to building the knowledge and skills of palliative care volunteers, and more work needs to be done in identifying the attributes of successful induction training and professional development of volunteers.

#### Volunteers and service equity

If we believe that volunteers are of significant importance to the function of a palliative care service, then it follows that access to volunteers by service users is an issue of equity.

In particular the people within the enormous catchment of the Western Sydney LHD, with their cultural diversity and socio-economic disadvantage, stand out as a population deserving of palliative care volunteer support.

Similarly the prisoner population of the Justice and Forensic Health Network, characterised by high levels of disadvantage, should be prioritised for volunteer involvement.

This report also flags the risk associated with services under-committing to volunteer support, in particular for those services which currently engage Volunteer Coordinators on less than 0.6 FTE. These services now have the basis to review their commitment in order to continue to achieve equitable service delivery for their catchment.

From this early research we can see some of the features of the Statewide Framework for Palliative Care Volunteer Services which will be delivered within this program.



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