Palliative Care Volunteering Strategy
2013 - 2016
Acknowledgements

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Volunteers are essential to the ongoing sustainability of quality palliative care services in Victoria. With close to 2,000 trained volunteers providing practical care, compassionate support and awareness raising, volunteers make a valuable contribution to people with a life-threatening illness and their families.

The palliative care sector faces three key challenges in attracting and retaining volunteers: meeting the diverse needs of an ageing volunteer population, a shift in how people are choosing to engage in volunteer activities and demand for flexible and short-term volunteer opportunities. As the demand for palliative care in Victoria increases, supporting existing volunteers and identifying strategies to engage new volunteers is critical. A whole of sector approach is required to keep our volunteer communities resilient and strong.

The Victorian Government is committed to working with the palliative care sector to achieve this goal. Strengthening palliative care: Policy and strategic directions 2011-2015 has a key action area focusing on ‘strengthening the capacity of palliative care services to recruit, train and support volunteers’.

The Victorian Palliative Care Volunteering Strategy sets out a vision for the future of volunteering within the palliative care sector. Informed by emerging issues and challenges, and developed as a result of extensive research and consultation, the strategy outlines the priorities, actions and impacts.

I would like to thank everyone who contributed to the development of this strategy. I am confident that by working together to achieve the strategy’s outcomes, the significant role that volunteers play in palliative care will continue to be valued, supported, and sustained.

The Hon. David Davis MP
Minister for Health
Acknowledgements

Volunteers make a huge contribution to palliative care services. They embody the spirit of community, caring, and compassion that makes such an important difference to the quality of life experienced by people living with a life limiting illness and those who love and care for them.

Victoria is fortunate to have almost 2,000 volunteers contributing on a regular basis to the provision of palliative care services. They outnumber our paid workforce and strengthen the community support available to people at a very vulnerable and important time in their lives.

We express our appreciation and pay tribute to the inspiring support, friendship and compassion so generously donated by palliative care volunteers across Victoria.

Our thanks to Don, Claire, Helen, Marjorie, Pam, Philippa, Robert and Thomas who kindly agreed to allow us to share some of their experiences as palliative care volunteers. Their stories demonstrate the difference they make and hence the importance of this strategy.

Managers and coordinators of volunteers play a vital role, which impacts on the growth, effectiveness and sustainability of palliative care volunteering. We are very grateful for their participation and other key stakeholders in the development of this strategy and acknowledge the importance of their support in its implementation.

Sue Salau, former Manager of Volunteer Strategy at Palliative Care Victoria, provided leadership and expertise in the consultative process of developing this strategy. Sue’s passion and professionalism have been instrumental in producing a visionary strategy that will guide our work in the coming years.

We greatly appreciate the leadership and support of the Victorian Government and the Department of Health in funding the development of this strategy and its ongoing implementation. It is a comprehensive, evidence-based and practical strategy that will enable us to work together to achieve our shared vision of volunteering as a vibrant, valuable and sustainable dimension of Victorian palliative care service provision.

Odette Waanders
CEO Palliative Care Victoria
Executive summary

Volunteering has always been fundamental to the specialist palliative care movement and it is vital to the future of palliative care in Victoria. Volunteers make up a large portion of the Victorian palliative care workforce and they bring a diverse mix of cultural and life experiences and expertise from the community. Volunteers allow palliative care services to extend compassion and expand the range of services on offer to those living with a life limiting illness and their carers within the hospital, hospice and community settings.

Both nationally and internationally palliative care volunteering is currently being challenged by increasing demands for palliative care, changing patterns of volunteering and disease, increasing demands for quality care and regulation, system-wide shortages of health care professionals and reforms to health care. This is putting pressure on palliative care volunteer programs. Evidence suggests that the number of palliative care volunteers directly supporting clients and carers in Victoria is not growing but actually declining, and the participation of volunteers does not reflect the diversity within our communities or the settings in which care is required.

The Palliative Care Volunteering Strategy 2013-2016 aims to foster, promote and influence good practice in palliative care volunteerism across Victoria and expand the capacity of palliative care volunteer programs to address gaps in service and increase access to skilled palliative care volunteers. The key strategic directions within the strategy are:

1. Ensure effective leadership and management of palliative care volunteer programs
2. Enhance volunteer recruitment, retention, recognition and retirement strategies
3. Provide quality training and education
4. Extend volunteering opportunities and reach
5. Provide quality care supported by evidence.

These strategic directions are consistent with the Strengthening Palliative Care: Policy and Strategic Directions 2011-2015, the Victorian Palliative Care Service Capability Framework, the Victorian Palliative Care Volunteer Standards, Victoria’s Volunteering Strategy and Victoria’s Supportive Care Policy.

The Palliative Care Volunteering Strategy 2013-2016 has been informed by detailed research and broad consultation in 2011 and 2012. In particular this strategy was developed through:

- Surveying palliative care volunteers
- Extensive consultation with the broad palliative care sector
- Expert advice and practice wisdom from the Victorian Managers of Volunteers Network
- Consultation with key stakeholders such as Volunteering Victoria, CALD and indigenous peak bodies, aged care organisations and research institutes
- Reviewing the evidence to ensure the actions are supported by research and best practice
- Insights gained by Sue Salau during her Churchill Fellowship in 2011, which examined international palliative care volunteer models.

The Palliative Care Volunteering Strategy 2013-2016 is expected to produce the following key outcomes:
For people living with a life limiting illness and their families and carers:

- Access to highly trained palliative care volunteers wherever they live in Victoria
- Seamless, quality, palliative care volunteer support
- Support from their communities.

For palliative care services and volunteers:

- A shared, consistent, best practice approach to palliative care volunteering
- Adequate numbers of diverse, skilled, culturally appropriate volunteers to support client and carer needs
- Palliative care services can extend their service provision and innovation
- Increased retention rates for volunteers and those who manage palliative care volunteers
- Future palliative care volunteer program planning and service development is informed by best practice evidence and research.

Creating and sustaining a stronger palliative care volunteering sector will require a whole-of-sector effort. Strong partnerships will be required between the Victorian Department of Health, Palliative Care Victoria, Volunteering Victoria, palliative care services, palliative care consortia and a broad range of primary care organisations and research centres.
I had decided on another volunteering role, when I found myself attracted to volunteering with Peninsula Home Hospice through my wife’s involvement and her stories about her role there.

A number of friends have said to me that they couldn’t do what I do, but my reply is always that they would be surprised at the difference they could make. But the motive has to be genuine, not just a ‘feel good’ throw-away line at a dinner party. From the many letters and cards I have received, I know I am making a difference. People are just so grateful for what we do, and that is the tremendous upside of what volunteers do - the privilege it is to go into someone’s home, with no prior contact (other than a confirming telephone call before the visit). I have met some truly inspirational people who, despite their dire predicament, share their life-stories with you. Three such people come to mind:

- A man who was a tail-gunner on a Lancaster bomber when the Allies bombed the German city of Dresden. When he found out the devastation it caused, it affected him deeply for a very long time.

- Another gent was a ‘Wallaby’ and first grade cricketer. Coming from NZ we had many good talks about the pros and cons of the All Blacks and the Wallabies in relation to the rest of world rugby, and listening to stories of the many countries he visited was so good.

- Another man was part of the inaugural committee that led to the founding of the Australian Democrats. Some of his stories about the politicians of yesteryear were quite fascinating.

Essentially, volunteers respond to a wide variety of needs relating to people at home in the palliative stage of their illness. This can range from sitting with a client while the primary carer takes care of other things outside the home, to occasional transport to medical appointments, or to group programs held by Peninsula Home Hospice Service. Visits are usually two to three hours; most times it is one-on-one with the client, but often the carer needs support also. I can remember being very apprehensive about my first visit to a client - but it soon became apparent that by simply being there in a non-judgemental role with an empathetic attitude, the conversation just flowed. Sometimes if the client is well enough, an outing for a coffee or a trip to the seaside can be arranged.

My message to any male who is thinking about becoming a volunteer, but feels that he doesn’t have the ‘qualifications’ is - don’t be shy! You will be surprised at the difference you can make to a client and their family, and you will be amply rewarded by their warmth and heartfelt thanks for simply giving your time.

“You will be surprised at the difference you can make…”

Don George

My name is Don George, I am seventy years old, and I started volunteering when I retired at sixty five. I always wanted to do ‘something’ as I’m fit and healthy, and I know that the most vulnerable in our community are the young, the elderly and the sick.
Introduction

Vision
All Victorians living with a life limiting illness and their families and carers have access to volunteers that are trained and supported by high quality, integrated, innovative palliative care volunteer programs that are founded on best practice evidence.

Purpose
The Palliative Care Volunteering Strategy 2013-2016 aims to foster, promote and influence good practice in palliative care volunteerism across Victoria and expand the capacity of palliative care volunteer programs to address gaps in service and increase access to palliative care volunteers. The strategy explores emerging issues and challenges for the palliative care volunteering sector and provides a set of strategic directions and actions for the future. The key strategic directions are:

1. Ensure effective leadership and management of palliative care volunteer programs
2. Enhance volunteer recruitment, retention, recognition and retirement strategies
3. Provide quality training and education
4. Extend volunteering opportunities and reach
5. Provide quality care supported by evidence.

Audience
The primary audience for this strategy is the Victorian specialist palliative care sector; Palliative Care Victoria, palliative care consortia, palliative care services and the fifty-six palliative care volunteer programs in Victoria. The directions and actions are also relevant to hospitals and other health and aged care organisations that may auspice palliative care volunteers.

Context
The Palliative Care Volunteering Strategy 2013-2016 provides guidance to palliative care services and other organisations who auspice palliative care volunteers.

These strategic directions are consistent with the Strengthening Palliative Care: Policy and Strategic Directions 2011-2015, the Victorian Palliative Care Service Capability Framework, the Victorian Palliative Care Volunteer Standards, the Victoria’s Volunteering Strategy, and Victoria’s Supportive Care Policy.

Victoria has been very innovative in the area of palliative care volunteering in the past. The Victorian Department of Health has included palliative care volunteering in their palliative care workforce surveys, and, together with Volunteering Victoria, developed the Victorian Palliative Care Volunteer Standards and Templates (the only ones of their kind in Australia). Palliative Care Victoria has developed, evaluated, and recently updated, a Palliative Care Volunteer Training Resource Kit that is being used not only state-wide, but also in many other states of Australia and overseas.
Creating and sustaining a stronger palliative care volunteering sector will require a whole-of-sector effort. Strong partnerships will be required between the Victorian Department of Health, Palliative Care Victoria, Volunteering Victoria, palliative care services, palliative care consortia and a broad range of primary care organisations and research institutions.

The Victorian government is providing Palliative Care Victoria with $130,000 annually to assist with strengthening palliative care volunteering in Victoria; $30,000 of this is specifically targeted for training. Other funds from palliative care services, consortia and other stakeholders will be required to implement some of the recommended actions.

**Who are palliative care volunteers?**
Volunteers have long been an integral part of palliative care with some services owing their very origins to volunteers. These volunteers are people from local communities who give their time freely to provide compassionate support and practical care to those living with a life limiting illness and their carers. Palliative care volunteers provide respite, emotional and social support to some of the most vulnerable people in our society. They also assist with the governance of palliative care organisations, fundraising, projects and promotion of palliative care principles. Palliative care volunteers are constantly interacting with their wider community and influence public attitudes to palliative care, death and loss.19

**Palliative care volunteer leadership**
Every successful team needs effective leadership. Management of volunteers has evolved from an unpaid role taken on by a willing volunteer to fast becoming a profession in its own right with competencies and standards.20 There are a number of titles applied to the person who manage volunteers in palliative care. The most frequently used in Victoria has been ‘Coordinator of Volunteers’. All are required to act as managers and internationally they are becoming increasingly recognised as Managers of Volunteer Services.21
“Feedback comes in different ways; for example, a niece comments ‘I was speaking with ....and she said how helpful you were when her husband died’, or recently one of the nurses said to another: ‘Marjorie was a great help at the weekend.’”

“I don’t know what I did except be there, and I listened. Part of my work is the ‘presence of being’.

“I have conducted funerals for patients who have died on the palliative care program, at the request of the family, who I have got to know by being there and sitting with them.

“I have been volunteering with palliative care for over 20 years. I do it two or three days a week around my job which is two days a week, and fortunately both are flexible.

“I check to see who has come into the palliative care unit and then work out the most suitable time to introduce myself to the patient - of whatever denomination or faith - and their family. I am there for support as and when they want.

“It can take a while to build up a relationship, but you can then be called on at any time by them to come in. One farmer asked me to come in to see his wife in her last few days. I just sat there and talked. Sometimes it was meaningful conversation, sometimes we just laughed.

“It was a laughing family and the wife was from Scotland, like me, so we exchanged stories about what our grannies used to say.

“I also help nurses who may have had a tough time.”
Why we need to strengthen palliative care volunteering

No volunteer program lives within a vacuum. It is influenced by the world in which it resides. Society is undergoing rapid change that is bringing with it new challenges to the way that we habitually do things within palliative care volunteering.

The traditional palliative care volunteer role has mainly offered companionship, respite, transport, loss and grief support, fundraising, administration and ancillary services within hospitals, hospices and within people’s homes. The expectation has been for long-term volunteer commitment of a year or more. The management of volunteers has in the main been a top down affair with volunteers having little input into the running of their programs. Volunteers are so much a feature of palliative care that we can, and do at times, take them for granted, as well as the skills needed for the person who manages the volunteer program22.

The management and role of palliative care volunteers is being challenged by changing patterns of volunteering and disease, increasing demands for quality care and regulation, system-wide shortages of health care professionals and reforms to health care. Programs that wish to flourish must continually investigate new ways to engage, train, support and manage volunteers so that they can ensure the effectiveness and sustainability of their programs.

There are three key challenges facing palliative care volunteerism. These are:

Challenge 1    Emerging trends in volunteering
Challenge 2    Victoria’s population is growing and ageing
Challenge 3    Addressing unmet needs

These challenges justify the need for an urgent strengthening of the palliative care volunteer sector in Victoria.

Challenge 1
Emerging trends in volunteering

Volunteering is an ever-adapting movement affected by social, economic and technological changes. The issues and challenges this creates crosses organisational boundaries and affects volunteers in all sectors and all settings including palliative care.

The emerging volunteer trends that will affect palliative care volunteering23 now and into the future are:

- Volunteer numbers in the traditional community services sector is on the gradual decline despite the overall numbers of volunteers increasing24.

- Governments are interested in encouraging more people to volunteer. The Victorian and the national governments have introduced state25 and national26 volunteer strategies to support the evolving nature of volunteering. With this increasing recognition has come increasing accountability. There is now increased regulation around managing volunteer risk and legal liability. The complexity of requirements means that some organisations risk being underinsured, being unaware of regulations and standards that apply to them, or investing scarce resources in duplicate insurance or police checks. In addition, many organisations feel that the cost of obtaining appropriate insurance prevents them from using volunteers27. There is a need to find a balance between risk management, quality care and clients’ needs.

- People are more mobile than in the past, making it less likely that a volunteer will stay for many years in a single role28.
Over the next 10 years, the proportion of the population in retirement or semi-retirement will increase. There is an opportunity to engage more of these baby boomers (those born between 1946 and 1964) in volunteering activity as they approach retirement. ‘Baby boomers’ have a higher average education and skill level than the previous generation and as a consequence, they have high expectations of their volunteer experience. They will want interesting, challenging and meaningful, work with strong support structures within a well organised organisation.

Victorians are volunteering for shorter periods of time as volunteering activities compete with greater work and caring responsibilities. People are now looking for volunteer roles that are flexible, or require shorter hours or a shorter-term commitment. This is particularly true of younger people and the large ‘baby boomer’ population. The young want flexible, project-based roles, meaningful work with room for autonomy, innovative use of technology and rewarding social connections. Baby boomers want much the same as the young but they also have external influences impacting on their availability, such as caring for grandchildren and/or ageing parents, possibly working part-time and wanting time out for travel and leisure activities.

Volunteers are now more discriminating, both in their choice of volunteering opportunities and in the organisations with which they become involved; this is often displayed in choosing to volunteer for a particular social or community cause.

Younger people and new migrants are paying increased attention to the value of volunteering as a pathway to developing new skills and finding employment.

The for-profit sector is becoming increasingly involved in volunteering. This is where businesses can ‘honour their community obligations’ and volunteering organisations can receive meaningful expert assistance to build their capacity. An emerging trend in corporate volunteering is virtual volunteering where staff does online volunteering in their time of work for organisations that they may have no face-to-face contact with. Services supplied can include assistance with administration, strategic planning, financial advice, etc.

Specialist volunteering, such as volunteer complementary therapists in palliative care, is gaining a higher profile. Involving volunteers that are highly skilled, often in areas that are not economically viable to attract funding, gives unique opportunities to extend the quality and range of care on offer.

People expect high levels of management and support systems to be available to them if they volunteer. On the other hand they expect volunteering to be fun and not overly regulated. The effective recruitment, placement, protection and recognition of volunteers require effective and flexible management, as well as excellent planning capabilities. Volunteer managers must have the right knowledge and skills to ensure the effectiveness of volunteers.

People are increasingly connecting online and the way they use technology is changing. Greater use of information technology can enhance volunteer involvement, training and management. For example virtual volunteering can mean volunteer projects or tasks can be completed, in whole or in part, via the internet and home or work computer. The number of online volunteer matching services has grown and this can expand the reach of volunteer recruitment. Some volunteer organisations are now making innovative use of social media such as Twitter, Facebook, LinkedIn and YouTube for recruitment, staying in touch and training.

There is increasing competition for volunteers. Australia has around 700,000 not-for-profits, 95% of whom rely largely on volunteers. There will be an increasing need for volunteers as greater levels of services are required and funding via other sources is cut. Increasing competition for people prepared to volunteer is a factor making it important to have quality recruitment and excellent volunteer program frameworks in place.
Rising costs of living and fuel costs will have an impact on volunteerism. Reimbursement for out-of-pocket expenses, particularly in rural areas, will become increasingly important as the involvement in volunteering can cost individuals on average $300-$600 per annum.  

### Challenge 2

**Victoria’s population is growing and ageing**

The population of Victoria is now over five and a half million. Between 2011 and 2022 it is predicted to increase to 6.5 million. Between 2011 and 2022 the percentage of the population aged 60+ will be higher than in the last 40 years. The percentage of the population aged 70-84 will increase by 127 per cent. The percentage of the population aged 85+ is projected to increase by 236 per cent. This growing ageing population is likely to have a threefold impact on palliative care volunteering:

#### 1 Increasing demands for volunteer services

In Victoria demand for palliative care is growing at 4.6 per cent per annum. This demand is affected by the increasing incidence of cancer and other non-malignant chronic illnesses in the ageing population and a wider recognition of the benefits of palliative care for those with a non-cancer diagnosis.

There are limits to the available health resources and the number of professionals and carers available. The ageing population and a changing social structure means many clients will not live with a family carer nearby and may require support and assistance of volunteers if they are to remain in their preferred site of care. To provide the appropriate level of psychological, social and respite services the numbers of palliative care volunteers will need to match the increasing demand.

#### 2 The way we live in old age, and die, has changed

More serious life limiting illnesses and chronic conditions such as dementia, cardiovascular and respiratory diseases, and cancers are increasing and have changed the pattern of death. With the increasing number of clients with a range of complex disease patterns and an increase in the number of cancer clients, new approaches to palliative volunteer care, education and service models are required.

Palliative care services are now caring for people with illnesses that result in three types of end-of-life trajectory. Unlike cancer clients who experience considerable decline in a shorter period of time prior to death and where the need for palliative care services may be more obvious, clients with chronic conditions have a much longer disease trajectory with difficult prognostication. Additionally, a larger number of clients exist with more complex chronic conditions involving multiple co-morbidities. The need for palliative care may not be as obvious and may involve multiple, shorter encounters.
The trajectory of various disease types is depicted in this diagram.52

Anecdotal evidence suggests that palliative care volunteer programs have mainly been providing short term care in response to the shorter period of decline seen mainly in cancer patients. As they care for more people with non-cancer diagnosis, within and external to their services, palliative care volunteer program models will need to change to accommodate a variety of volunteer placement options (increasing and variable length of time with clients and various sites of care). Volunteer programs will also need to ensure their palliative care volunteers have an understanding of a variety of chronic illnesses, particularly dementia, if they are to provide appropriate support.

3 Palliative care volunteers are ageing

Palliative care volunteers make up the largest number of staff of palliative care services across Victoria53 and they are ageing54. In 2006, 72 per cent of volunteers were aged over 60 years55. Most female volunteers were aged between 60 and 69 and males were slightly older and aged between 70-79 years56. A recent survey of volunteers indicated that these volunteers would like to give another 3-5 years to palliative care but they qualified this by saying this was dependent on their physical and mental health57. Palliative care services will not only need more volunteers to replace an ageing volunteer workforce but also to meet rising demands. Strategies will need to be in place to ensure volunteers are able to perform their roles as they age.
**Challenge 3**
**Addressing unmet needs**

As part of providing equitable access to palliative care it is important to ensure palliative care volunteer models are responsive to the diversity of future clients, carers and their needs.

Palliative care volunteers mainly work in the specialist palliative care sector with the majority working in the community setting and in particular the home\(^58\). The remainder work within inpatient, hospice and day hospice services.

International research demonstrates that up to 90 per cent of people living with a life-threatening illness would prefer to die at home, or in a home-like environment. However this research also shows that only 26.5 percent of people died at home, while 56 per cent died in hospital\(^60\). This research is consistent with the proportion of Victorians who die in hospital\(^61\). The majority of those nearing the very end of their life are cared for in the generalist sector not the specialist palliative care sector, where there is limited access to palliative care trained volunteers. Anecdotal evidence suggests that very few volunteers follow their clients into an acute or aged care setting. The skills of palliative care volunteers could benefit the wider community as demonstrated in the “Palliative care service picture”.

*Source: Aspex Consulting 2010\(^59\)*
Formal shared care arrangements or assistance with training volunteers in the palliative care approach in the primary care, acute, aged care and disability services will become increasingly important if we are to ensure equitable access to the psychological, social, and respite supports palliative care trained volunteers offer.

There is a need to promote the role of the palliative care volunteer, their skills and training and referral pathways - both internally (within palliative care organisations) and externally (possible referral organisations) - if their care and community capacity building is to be maximised.

To ensure equity of access to volunteers across all of Victoria, rural palliative care volunteer programs require strengthening. The larger sizes of rural regions require multiple smaller palliative care volunteer programs than those of Melbourne. Four rural palliative care volunteer programs have closed over the past five years.

The profile of palliative care volunteers does not currently reflect the level of diversity in our communities. Palliative care volunteers in Victoria are mainly white Anglo-Saxon and aged over 60 years; however, palliative care services care for people of all ages and backgrounds. Under-represented in palliative care volunteering are young people, men, people with disabilities, people from Aboriginal communities, people from culturally and linguistically diverse backgrounds, people who are gay, lesbian, bi-sexual and transgender, and pro bono and corporate volunteers.
In 2011, 26.2 percent of Victoria’s population were born overseas and 46.8 percent of Victorians were either born overseas, or have a parent who was born overseas. Victorians came from more than 200 countries, spoke more than 230 languages and dialects and followed more than 130 religious faiths. Most overseas-born Victorians came as migrants or refugees. Victoria’s older culturally diverse population is ageing more rapidly than the average population. By 2026 one in four people aged 80+ will be from culturally and linguistically diverse (CALD) backgrounds.

No palliative care volunteers identified themselves as Aboriginal in the 2007 palliative care volunteer survey. In the next 13 years the Victorian Aboriginal population eligible for aged care (and thus in the demographic group most likely to need palliative care) is expected to grow by 70%.

There is a need to engage more with Aboriginal, CALD, gay, lesbian, bi-sexual and transgender communities and people with disabilities to identify how the role of the palliative care volunteer may be promoted and integrated into these communities, acknowledging that informal ‘volunteering’ does occur within their extended family and support networks.

Children and young people receiving palliative care require a different service response, often delivered by a range of services not required by adults receiving palliative care. Volunteers skilled in the particular needs of children and young people with a life limiting illness are essential.
She had been a pre-school teacher in the area for 30 years and, with her family, was involved in many community activities.

“When I retired, I took a while to decide what to do in the community that would be fulfilling rather than bits and pieces. About six years ago I chose palliative care and have worked voluntarily ever since, usually one full day a week.

“I’ve always been one of those people lending an ear here and there, and I wanted to be helping people who were less fortunate. A friend worked in the centre and when they advertised for volunteers I did the training session to understand and help.

“Even though all the people we assist are going to die, you don’t look at it in that vein - you focus on making their life better now.

“I found you get really involved with people and you have to learn to distance yourself a little bit sometimes. That was a hard thing for me to do, and still is.”

“Helen is a ‘jockey’ on the bus, driven by another volunteer, which picks up and returns home those coming to the Fernlea Palliative Care Centre.

“The clients meet with others here, usually on the same day, and have morning tea. We chat, do quizzes, things like that. What they do varies with the abilities, capacities and interests of those in the group.

Helen has completed a couple of memoirs with clients as well as her group work and these have taken additional time going to the person’s home, recording, editing and compiling them over a six week period.

“Families have said they used the document at the funeral, and many in the family didn’t know the things we’d recorded.”

Other volunteers provide hand and foot massages and reiki. After the morning’s activities they all have lunch in the sun-filled dining room.

“My family knows I won’t do any babysitting on my volunteering day. I don’t treat it like a job, it’s something I want to do.

“It’s very rewarding, and a privilege because these people allow you to be fairly closely involved in their lives, even if for just a few hours. And even though they may only be here for a short time, we have lots of fun.”
Strategic direction 1: Ensure effective leadership and management of palliative care volunteer programs

Priorities
1. Promote volunteering as part of core business in all services providing palliative care.
2. Ensure palliative care volunteering programs are well resourced, managed and supported.

Effective support of palliative care volunteers improves psychological and social outcomes for clients and carers, as well as organisational capacity

Volunteers are vital core members of interdisciplinary palliative care teams.70,71. The ability of palliative care services to provide the extent and range of services they do is dependent on the efforts of volunteers.72 They provide much of the respite, emotional and social supports to those living with life limiting illnesses and their carers.73 Palliative care volunteers can also assist with the governance of palliative care organisations, fundraising, projects and promotion of palliative care principles. Victorian palliative care services on average have approximately two to three volunteers for every paid staff member.74 In Australia, the essential role of the volunteer in the palliative care team is acknowledged through such policies as the National Palliative Care Strategy,75 the Australian National Palliative Care Standards (Standards 12 and 13),76 the Health System Reform and Care at the End of Life Guidance Document and the Productivity Commission Inquiry into Caring for Older Australians.77 Volunteers are acknowledged in 3 of the 7 strategic directions in the current Victorian palliative care policy and are mentioned in all levels within the Victorian Palliative Care Service Capability Framework.80

In Canada, volunteers are promoted as a ‘discipline’ in palliative care analogous to the other disciplines such as medicine, nursing, allied health, pastoral care etc.81

Some Victorian palliative care volunteer programs report reducing numbers of volunteers, no funds or inadequate funds to support their management, coordination, training and support, low referrals and trained volunteers waiting some time to be placed with a client or carer.82 Many things may contribute to this. One is a lack of understanding of the palliative care volunteer’s essential role and the referral pathway internally (within palliative care organisations) and externally (possible referral organisations).

There has been a reduction in palliative care volunteer programs over the five years during which Palliative Care Victoria has been keeping records. In 2007/08, there were 60 palliative care volunteer services in Victoria. Now there are 56 as four rural programs have closed. The larger sizes of rural regions require multiple smaller palliative care volunteers programs to cater to all their sub communities and reduce volunteer travel time. How rural palliative care volunteer programs are auspiced and financially supported and managed varies. Some are attached to rural hospitals or community health centres where there is no specialist palliative care service. In some rural areas those who manage and coordinate palliative care volunteers are unfunded or have this role added onto another role with no extra time allowed to cover the added work load.84
The tyranny of distance can result in inequitable support as not all people who wish to have a palliative care volunteer can access one. Recent anecdotal evidence suggests many rural regions are currently struggling to maintain their palliative care volunteer programs. Until recently the Hume region had a part time regional position that assisted the smaller palliative care volunteer programs and the organisations that hosted them with best practice evidence, training and regional networking. This was very beneficial in supporting sustainability.

Palliative care volunteers are not used widely within hospitals within Victoria. Those that are working in the inpatient environment report the need for clear duty statements and a more organised approach to placement and support.

**Strong management and leadership leads to quality outcomes**

Various studies and volunteering standards indicate that for volunteer contributions to be effective and best practice, high quality management, recruitment, supervision, support and training is essential. Volunteers must be managed within a defined system and by capable personnel with the authority and resources to achieve identified goals. The palliative care volunteer program should be owned and valued by all paid staff and the volunteer voice represented at both the organisational executive and board level.

United Kingdom research promotes the integration of the management and strategic development of volunteer programs into the management structure of palliative care organisations. A designated, funded, experienced Manager of Volunteers and/or Coordinator of Volunteers is essential to ensure best practice and the growth of palliative care volunteer services. Opportunities for networking with other Managers/Coordinators of palliative care volunteers and access to continuing education are essential to support volunteer program best practice, innovation and staff retention.

**Strategic direction 1 priorities: Actions and impacts**

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<th>Strategy 1 Priorities</th>
<th>Actions</th>
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<tbody>
<tr>
<td>Promote volunteering as part of core business in all services providing palliative care</td>
<td>1:1 Adopt, implement and evaluate the Palliative Care Volunteering Strategy under the leadership of a Victorian Manager of Palliative Care Volunteering Strategy based at Palliative Care Victoria.</td>
<td>Improved consistency of best practice palliative care volunteering across Victoria. Collaborative approach to the implementation of the strategy. Expert leadership and support is available to assist Palliative Care Consortia, palliative care services and palliative care volunteer programs with regional and local volunteering planning throughout the introduction and life of the strategy.</td>
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| Promote volunteering as part of core business in all services providing palliative care (contd.) | 1:2 Review organisational volunteer management frameworks to:  
a) ensure that palliative care volunteering management and strategic development is situated within the management structure of organisations; and  
b) where possible, devolve some volunteer management roles to various organisational departmental managers. | Palliative care volunteering is integrated into organisational governance, planning, community and consumer participation, communications, training and development, service delivery, and quality improvement processes.  
Quality of life of the client and carer health is maximised by the strengthened provision of emotional and practical support and respite.  
Palliative care volunteer programs can extend their service provision and innovation.  
Strengthened respect, relationships and communications between paid staff and volunteers.  
Strengthened holistic care as volunteers are included in care planning and review, relevant organisational communications, committees, clinical advisory groups and working groups. |
| | 1:3 Promote palliative care volunteering as a ‘discipline’ within palliative care. | The volunteer role is more visible within the community and health and palliative care services.  
Volunteers are respected as interdisciplinary palliative care team members. |
| | 1:4 Develop and implement strategies to support the strengthening of hospital palliative care volunteer programs. | Patients and carers within hospital palliative care programs have access to skilled palliative care volunteers.  
Palliative care volunteer skills are well utilised and their roles understood and respected. |
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<tr>
<td>Promote volunteering as part of core business in all services providing palliative care (contd.)</td>
<td>1:5 Strengthen the role of the Victorian Palliative Care Managers of Volunteers Network.</td>
<td>The Network supports, implements and promotes best practice in palliative care volunteering. Information and advice is provided to relevant bodies, including the Department of Health and the National Managers of Volunteers Network, on matters of palliative care volunteer best practice. The profile of palliative care volunteering is raised both within palliative care services and the community.</td>
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<td>Ensure palliative care volunteer programs are well resourced, managed and supported</td>
<td>1:6 Ensure funding for services that engage palliative care volunteers takes into account the costs associated with: • volunteer management, administration and regulation • appropriate training and support for volunteers and managers/ coordinators of volunteers; and • innovation.</td>
<td>Palliative care volunteer programs have a dedicated budget and funded Manager/ Coordinator of Volunteers at an FTE level that will ensure quality training, skilled coordination, management and supervision of all palliative care volunteers as well as volunteer program innovation. Palliative care services have an adequate number of skilled, supported volunteers to support client and carer needs. Volunteers are reimbursed for their out of pocket expenses.</td>
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<td>1:7 In partnership with Volunteering Victoria develop core competencies for Palliative Care Managers of Volunteers and Coordinators of Volunteers.</td>
<td>1:7 In partnership with Volunteering Victoria develop core competencies for Palliative Care Managers of Volunteers and Coordinators of Volunteers.</td>
<td>Volunteers are expertly managed, trained and supported and are confident in performing their role/s. Increased retention rates for Managers of Volunteers and Coordinators of Volunteers working in palliative care.</td>
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<td>Ensure palliative care volunteer programs are well resourced, managed and supported (contd.)</td>
<td>1:8 Establish a regional palliative care volunteer program leadership function in each rural region and provide resources to support this.</td>
<td>Rural gaps are identified and actions are taken to address this.</td>
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<td>Increased access to volunteers supports equity of access to needs based service provision.</td>
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<td>All services providing palliative care have access to best practice palliative care volunteering expertise, regional networking and training/educational opportunities.</td>
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Thomas Fong, a 79 year old Chinese Malaysian survived his own cancer challenge to help others facing their final journey in palliative care. In 2006, after three years' treatment at the Alfred he was declared to be in permanent remission from bladder cancer. He wanted to 'give back' and surprised staff by choosing palliative care.
Gentle touch therapy – a volunteer’s gift

Thomas Fong
Thomas Fong, a 79 year old Chinese Malaysian survived his own cancer challenge to help others facing their final journey in palliative care. In 2006, after three years’ treatment at the Alfred he was declared to be in permanent remission from bladder cancer. He wanted to ‘give back’ and surprised staff by choosing palliative care.

“I was always curious about the ‘twilight zone’- the transitional phase from life to death, and thought I might learn more by volunteering in palliative care. Besides, if I worked with younger patients, they might think they had to look after me, an older man, rather than me helping them,” he said during a break from his work at Calvary Health Care’s Bethlehem Centre in Caulfield.

Thomas was born in Borneo and educated in NSW where he matriculated and obtained a degree as a biochemist before qualifying as a dietician in WA. Returning to Borneo he managed the blood bank and blood laboratory for thalassemia - a major problem in the region. He returned with his family to Australia in 1982.

He undertook general volunteer activities at Bethlehem before finding his métier – therapeutic touch, or gentle massage. His foreign accent and hearing disability sometimes made communication difficult, until a patient said ‘you have magic hands’ after Thomas had held his hands. Thomas saw this as a ‘message’ that this is what he should concentrate on, and he now massages up to 14 patients (and some staff) on each of his thrice weekly visits.

He remembers and was thankful that the first time he responded to a patient’s request for a foot massage, a nurse gave him a towel to reduce the pain on his knees from the cold hard ward floor. He links his foot massages to humility and to the examples of Christ and the Pope washing the feet of disciples.

“I am deeply and emotionally rewarded by the response of the patients to my touch,” he said. “They show this by their sweet, contented, grateful and graceful smiling faces, even though they are suffering from pain or other discomfort. Those who can thank me with words also, but some who can’t smile through their tears or touch me back. Many say that in that time, the pain has gone.”

“I believe that sympathetic and empathetic feelings can be transmitted from the massage practitioner to the patients, and that patients can feel the emotional mood of the practitioner.”

He develops bonds of friendship with some of the patients before they either die or move to a nursing home. Referring to the patients he massages in the neurological day centre, he says “I learn so much; how lucky I am to be able to look after them and how grateful they are to me.”

While Thomas was initially unfamiliar with the term ‘volunteer’ he had undertaken such work in Borneo, starting a Blood Donors’ Association and co-founding a Thalassemia Association. Both activities sought to educate and change cultural views about blood, and he hopes that his palliative care volunteering has helped to promote multiculturalism amongst Australia’s culturally diverse communities.

Thomas volunteered for over 3000 hours at Bethlehem and recently retired to return to Borneo where he is working again as a volunteer to run a youth-focused obesity prevention program.
Strategic direction 2
Enhance volunteer recruitment, retention, recognition and retirement

Priorities
1. Increase the visibility of palliative care volunteerism and ensure recruitment of volunteers is anti-discriminatory and reflects palliative care and cultural and social profiles.
2. Ensure all volunteers are well supported throughout their whole palliative care volunteering experience.

Increase the number and diversity of palliative care volunteers to meet future demand

Volunteers make up a large portion of the Victorian palliative care workforce (60% of the combined palliative care labour workforce head count\(^94\)). Evidence suggests that the number of palliative care volunteers directly supporting clients and carers is not growing but actually declining and that the volunteer base does not reflect the diversity within our communities.

In 2005\(^95\) there were approximately 1,460 palliative care volunteers directly supporting clients and carers in Victoria whereas in 2011\(^96\) there were 1,342. In 2011, the number of palliative care volunteers performing other organisational duties as well as direct client and carer support was counted for the first time\(^97\). There were 1,973 palliative care volunteers and of these 1,342 (or 68%) were directly supporting clients and carers. It is of great concern that the number of volunteers directly supporting clients and carers is not keeping pace with the expected 4.6% growth in palliative care per year\(^98\).

Palliative care volunteers are predominately female and are born in Australia\(^99\). The least represented place of origin is Asia\(^100\). While there is significant informal support within aboriginal communities, there were no palliative care volunteers who identified themselves as Aboriginal in the 2007 palliative care volunteer survey\(^101\).

72% of volunteers are aged over 60 years\(^102\) and many will only be available for the next 3-5 years and only then if their mental and physical health permits\(^103\).

A planned, systematic and targeted approach to recruiting and selecting palliative care volunteers is required to address future requirements. This approach will provide organisations with the best possible basis for attracting and retaining the optimum number of effective volunteers and increasing the diversity of volunteer programs.

Volunteer recruitment must reflect the new volunteering landscape, societal trends and predicted growth of palliative care. A multi modal marketing and recruitment approach, increased diversity of volunteer roles and greater recognition and support will increase the chance of the engagement of those previously underrepresented in palliative care volunteering: young people, men, people with disabilities, people from culturally and linguistically diverse backgrounds and Aboriginal communities, people who are gay, lesbian, bi-sexual and transgender, the homeless, those in prisons and pro bono and corporate volunteers.
Organisations can use information on what motivates volunteers to tailor recruitment messages and volunteering experiences\textsuperscript{104}. In assessing the motivational needs of new volunteers, organisations can ensure effective placement of volunteers into activities that meet their needs. This can result in improved volunteer satisfaction and retention as motivations are fulfilled\textsuperscript{105}.

**A clear volunteer support system and exit strategy leads to better outcomes for volunteers and the organisation**

Quality measures should ensure volunteers are able to access advice and be supported while they are working. Anecdotal evidence suggests that in the main Victorian palliative care volunteers are provided with advice and support during volunteer program operational hours, which are usually between 9-5pm weekdays. As the face of volunteering changes and more volunteers wish to volunteer out of hours due to work commitments, it will become increasingly important for palliative care services to look at how they support volunteers after hours. In Ottawa (Canada) for example a few palliative care services provide support through their clinical home support managers with the use of pagers. Volunteers were able to contact them 24/7 if required\textsuperscript{106}.

As the palliative care volunteer workforce is ageing it is important to ensure that there are strategies in place to ensure volunteers can competently perform their designated role/s to their physical and mental capabilities. If they are unable to do this other volunteer role options and/or support to exit the organisation should be provided.

**Strategic direction 2 priorities: Actions and impacts**

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<tr>
<td>Increase the visibility of palliative care volunteerism and ensure recruitment of volunteers is anti-discriminatory and reflects palliative care and cultural and social profiles</td>
<td>2:1 Develop recruitment approaches to support the engagement of those previously under-represented in palliative care volunteering.</td>
<td>Clients and carers have access to palliative care volunteers who can assist in meeting their emotional, social, spiritual, cultural and respite needs. Other sectors provide opportunities for volunteers to be involved in supporting clients receiving palliative care and their carers. Palliative care volunteering is anti-discriminatory.</td>
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<td>2:2 Use a multi modal promotional approach to recruitment including social media, professional journals, newsletters, websites, university and community centres and volunteer resource bureau volunteering systems</td>
<td>The volunteer profile is more diverse. It is easier for people to find out about volunteering opportunities</td>
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<tr>
<td>Increase the visibility of palliative care volunteerism and ensure recruitment of volunteers is anti-discriminatory and reflects palliative care and cultural and social profiles (contd.)</td>
<td>2:3 Target volunteer recruitment according to geographic need and the social and cultural profile of regional and local palliative care service catchments.</td>
<td>Clients and carers have equitable needs-based access to palliative care volunteers who assist in meeting their emotional, social, spiritual, cultural and respite needs.</td>
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<td>Ensure all volunteers are well supported throughout their whole palliative care volunteering experience</td>
<td>2:4 Investigate and implement organisational strategies and processes to provide situational support to palliative care volunteers out of hours.</td>
<td>Clients and carers can receive quality volunteer support out of hours. Volunteers can provide support to clients and carers and receive support from palliative care services during and outside standard business hours.</td>
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<td>2:5 Ensure volunteers are well supported to change roles or retire from service if their physical and mental capabilities decline.</td>
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<td>Volunteers are supported to meet existing or new role requirements or are supported through a clear compassionate exit strategy.</td>
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<td>2:6 Strengthen organisational volunteer recognition strategies in an enduring, formal and tangible way.</td>
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<td>Volunteers feel their input is valued and retention rates are high.</td>
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<td>2:7 Investigate the feasibility of Victorian Excellence Awards for palliative care volunteer projects, programs, services that involve, manage and deploy volunteers according to excellence criteria.</td>
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<td>Volunteer programs are recognised for innovation and excellence.</td>
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Enhancing quality of life

Philippa Wetherall
Retired Anglican priest, Philippa Wetherall, was inspired to learn more about palliative care when ministering to those with terminal cancer in her pastoral ministry in South Australia.

“I had done a short training course for volunteers in palliative care in Port Lincoln and organised a seminar on preparing for death and dying before moving to Melbourne,” she said.

“I knew a little of the hospice movement and felt I would like to be involved with a faith tradition outside my own. Since October 2011, I have volunteered one day a week at Caritas Christi Hospice day centre in Kew.

“I really enjoy being a part of the centre as it is a very caring and hospitable space. Many people come to the day centre on the same day each week and I appreciate the opportunity to engage with them. Others come from the hospice wards to spend part of each day seeing new faces.

“One has to realise that though they may appear to be well, their lives are tenuous.

“Eating together and having food to share with anyone who drops in, is an important aspect of the family life in the day centre.

“There is no sense of compulsion for anyone present - patients, clients, staff and families - to join in a specific activity. As a volunteer I try to discover what our clients would like to do: they may need simply to sit and rest.

“If it seems appropriate I ask a question about how someone is feeling, but it is more important to listen well and to respond to their need - a cup of tea or coffee just how they like it, or a cushion for their back.

“Together staff and volunteers challenge each other to solve the 9 letter word game from the paper, and in the early afternoon we often play a board or card game which can involve clients, volunteers and visitors.

“Sometimes someone comes to play a musical instrument or we help Catherine, our wonderful artist in residence, make paper flowers for her forthcoming exhibition in the hospice. With her colourful outfits and adorable ‘Hairy McLarey’ dog, Archie, she is very much part of the hospice life.

“I don’t mention my role as a priest unless a client has heard whispers and asks about it, so it was all the more surprising when a long term client, out of the blue, asked me if I would take his funeral. I was very touched by this, by his trust in me and replied that I would be honoured.

“I do feel some anxiety when a regular client is unable to attend because of therapy and sad when someone leaves or dies. But I accept the nature of palliative care and indeed my own mortality.

“I really enjoy being part of something and a centre that is people centred, holistic, and concerned with enhancing quality of life for those in the last stage of their journey.”
Strategic direction 3
Provide quality training and education

Priorities:
1. Ensure all volunteers working in palliative care have common core competencies and knowledge, as well as access to continuing education.
2. Ensure palliative care volunteers can access volunteer training easily and quickly.
3. Develop partnerships with key organisations, where palliative care is likely to be an issue, to ensure they have access to competency based palliative care volunteer training.
4. Ensure people with late-stage dementia are supported by volunteers knowledgeable in palliative care as well as dementia care.
5. Strengthen access to appropriate educational opportunities on offer for those who manage, coordinate and support palliative care volunteers.

Volunteers and their leaders are skilled in their service provision

Training and education must be provided to volunteers to enable appropriate support of clients and carers, to ensure standards of care and safe practice and to ensure appropriate public representation of the organisation. It is important that all Managers/Coordinators of Volunteers and volunteers have a common minimum knowledge base and a universal understanding of the philosophy, work, values and role of palliative care and the organisation in which they work.

Volunteer training and education is a continuous process of formal, structured and experiential on-the-job learning. Formal training is required to ensure that Victorian palliative care volunteer minimum standards are recognised and met. The modules within Palliative Care Victoria’s Palliative Care Volunteer Training Resource Kit meet both the national standards for palliative care and the Victorian Palliative Care Volunteer Standards and, if delivered as prescribed, meet the minimum competencies required for volunteers who work face to face with clients and their carers. Following induction, experiential on-the-job learning allows volunteers to acquire new skills and knowledge as they respond to service delivery. Volunteers must be regularly supervised, and refresher and continuing education must be provided to ensure volunteer skills are maintained to meet required roles. Anecdotal evidence suggests that currently most metropolitan palliative care volunteer programs are performing their own induction training once or twice a year usually within normal work hours. Rural palliative care volunteer programs offer training less often.

Those who manage and coordinate volunteers, including team leaders who are volunteers, also require regular supervision and continuing education opportunities. Their training must reflect their complex human resource and leadership function. Managers of volunteer programs must also be skilled in the provision of adult education, supervision and strategic planning. Education for those who manage or lead volunteers is available through Volunteering Victoria. Anecdotal evidence obtained from the Victorian Managers of Volunteers Network suggests that those who manage and support volunteers are often unable to access education due to their heavy workload and limited budgets. Many fund continuing education from their own pocket and within their own private time.
Organisations providing services where palliative care is likely to be a need, can benefit from volunteers trained in a palliative approach

Palliative care volunteers primarily work within the specialist palliative care area. Few are utilised in the generalist health sector where palliative care and end of life care is predominately required. Specialist palliative care volunteer programs have the expertise to educate volunteers and their volunteer managers/coordinators on a palliative volunteering approach, within CALD services, Aboriginal services, aged care services, HACC services, community visiting programs, disability programs, volunteer resource bureaus, etc.

The Productivity Commission Inquiry into Caring for Older Australians\textsuperscript{111} and national research\textsuperscript{112} recommends the use of volunteers trained in a palliative approach working in residential\textsuperscript{113} and community\textsuperscript{114} aged care settings. The rapidly growing ageing population will place increasing demands on palliative care volunteer programs to support care within the aged care setting. Innovative ways of supporting this are required.

In Australia, deaths from dementia related illness are rapidly increasing. The number of deaths due to this cause has increased 140.7\% from 3,740 in 2001 to 9,003 in 2010\textsuperscript{115}. It is now the third leading cause of death and is projected to increase to 465,000 in 2030 and to over 730,000 in 2050\textsuperscript{116}. Palliative care services will be caring for many clients and/or their carers with dementia and palliative care volunteers will require specific education and support to be able to adequately support this population.

The role of specialist palliative care volunteer programs to support palliative care volunteer training for other organisations where palliative care is likely to be a need will be dependent on their resourcing capability.

### Strategic direction 3 priorities: Actions and impacts

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<tr>
<td>Ensure all volunteers working in palliative care have common core competency based knowledge and access to continuing education</td>
<td>3:1 Perform a Palliative Care Volunteer Training Needs Analysis to identify training gaps and priorities.</td>
<td>Volunteer training is targeted to requirements. Volunteers are confident and skilled in their roles.</td>
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<td>3:2 Develop a Victorian Palliative Care Volunteer Training/Education Framework that outlines the minimum training, education and support requirements and competencies for volunteers. (Include induction, continuing education and refresher training).</td>
<td>There is a sustainable best practice foundation for the ongoing contribution of volunteers in palliative care in Victoria.</td>
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<tr>
<td>Ensure all volunteers working in palliative care have common core competency based knowledge and access to continuing education (contd.)</td>
<td>3:3 Further investigate and develop state volunteer training resources; a) such as continuing education modules, Train the Trainer workshops and refresher training; and b) investigate the use of technology to strengthen volunteer access to training opportunities (e.g. podcasts, webinars, online education etc).</td>
<td>Quality volunteer training resources can be shared across organisations. Managers/Coordinators of volunteers can spend more time on other aspects of their roles. Volunteers have ready access to training opportunities.</td>
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<td>Ensure volunteers can access volunteer training easily and quickly</td>
<td>3:4 Develop strategies for shared volunteer training opportunities with other palliative care and volunteer organisations across metropolitan and regional Victoria.</td>
<td>Volunteers have access to timely and flexible training options. Increased number of trained volunteers due to increased number of induction training opportunities for prospective volunteers. More cost-effective approaches to training that enable the better use of staff time.</td>
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<td>3:5 Develop strategies to strengthen residential and community aged care services’ access to palliative care trained volunteers.</td>
<td>Enhanced capacity of residential aged care, HACC services and community visiting programs to provide support to those living with a life limiting illness. Less demand on palliative care specialist programs for the use of their volunteers in the aged care sector. Palliative care services are working closely in partnership with aged care services.</td>
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<td>3:6 Investigate the possibility of accredited qualifications for palliative care volunteers.</td>
<td>Promotes consistency in the training and recognition of the competencies of volunteers.</td>
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<tr>
<td>Develop partnerships with key organisations, where palliative care is likely to be an issue, to ensure they have access to competency based palliative care volunteer training</td>
<td>3:7 In partnership with the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) and the Aboriginal Palliative Care Project design and implement a culturally appropriate palliative care volunteer service model that includes training.</td>
<td>Aboriginal people have access to culturally appropriate palliative care volunteer support.</td>
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<td>3:8 Work in partnership with ethno-specific organisations to design and implement culturally appropriate palliative care volunteer models and training.</td>
<td>Ensure people from CALD backgrounds have access to palliative care volunteer training and support. People from CALD backgrounds are available to facilitate links between their communities and their palliative care service. Clients and carers from non-English speaking backgrounds (NESB) have the opportunity to receive support from palliative care trained volunteers in their preferred community language.</td>
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<td>3:9 Partner with the disability sector to develop strategies to improve access to palliative care trained volunteers.</td>
<td>Disabled palliative care consumers have access to palliative care trained volunteers.</td>
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<td>Ensure people with late-stage dementia are supported by volunteers knowledgeable in both palliative care and dementia care</td>
<td>3:10 Partner with Alzheimer’s Victoria to ensure all palliative care volunteer programs receive training in dementia care and all volunteer programs working with people with dementia have access to palliative care volunteer training.</td>
<td>Volunteers have the appropriate training to support people with dementia requiring palliative care.</td>
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<td>Strengthen access to appropriate educational opportunities on offer for those who manage, coordinate and support palliative care volunteers</td>
<td>3:12 Provide management and leadership training and networking opportunities.</td>
<td>Managers/Coordinators and volunteer team leaders are confident in their leadership skills and retention rates are high. Managers/Coordinators of Volunteers network with other volunteer services (both within and external to palliative care) to learn and share innovations in volunteer program management. Managers/Coordinators of palliative care volunteers participate in the Victorian Postgraduate Palliative Care Scholarship program. Strengthened partnerships with Volunteering Victoria and the Volunteer Resource Centres.</td>
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Claire is also co-ordinator of Friends of Palliative Care in Warrnambool.

"We have done a huge amount of fundraising - Easter luncheons, garden parties, Relay For Life every year. I try to attend all meetings and workshops.

"I get a lot of satisfaction in knowing I am helping, even in some small way."
“I helped a man two weeks ago who owned one of the two grocery shops I went to as a child, depending on which had the best lolly display. He came from Scotland and lived above the shop and we talked about those days.

“Living in a country town you can’t help but know people. You tell them your name and they ask if you were related to so and so who was my uncle or my cousin or whoever. You make connections straight away and it helps them reminisce about the past.

“We can have lots of lively conversations if they want to. But some just want you to be there without necessarily saying or doing anything.

“It is not all doom and gloom; most look forward to her coming, especially the ones with the sweet tooth.

“One elderly man loved ‘snowballs’ but he couldn’t understand that they were not always in season. I kept a lot of packets at home to give to him when I couldn’t buy them. He would say: ‘I told you so, there’s no such thing as out of season.’”

Claire works one on one as a volunteer and her co-ordinator, Marita, rings her to see if she is ready for the next client. She is happy to take on whoever is next but finds it sad when young children are involved.

“I was always interested in doing something in the community, helping people less fortunate than me.”

“Palliative care was always close to my heart. I had two cousins who died of cancer years before palliative care was even known or talked about, and my sister had breast cancer five years ago.

“I first heard about palliative care when our local Dr Fairbank started palliative care training and services 20 years ago, and it was written up in the paper. That’s when I did the training and started as a volunteer.

“Over the years I have been a one on one volunteer with many clients in their homes, sometimes taking them to appointments, or social events, or just being in their home while their carer has a break. One man I helped who was caring for his wife just had to get out and have a game of bowls every week.”

Claire is also co-ordinator of Friends of Palliative Care in Warrnambool.

“We have done a huge amount of fundraising - Easter luncheons, garden parties, Relay For Life every year. I try to attend all meetings and workshops.

“I get a lot of satisfaction in knowing I am helping, even in some small way.”
Strategic direction 4
Extend volunteering opportunities and reach

Priorities
1. Develop and implement a wide range of diverse, flexible volunteering opportunities that utilise volunteers’ individual skills to address client, carer and organisational needs.
2. Enable palliative care volunteers to assist in strengthening Victorians’ awareness, capacity and resilience in relation to palliative care, dying, death, loss and bereavement and their ability to support people living with a life limiting illness and their carers.

Extending palliative care volunteer opportunities, roles and program innovation ensures client and carer needs, organisational requirements and volunteer interests are met and existing volunteer skills are utilised.

Research demonstrates that one of the highest motivations for becoming a palliative care volunteer is the opportunity for the individual to use their skills and give back to their community\textsuperscript{117,118,119}. Palliative care service volunteer roles should be varied and flexible in response to changing needs, opportunities and best practice; innovative approaches are limited only by the available skills, resources and needs\textsuperscript{120,121}. Palliative care volunteers can provide face to face client and carer support, assist in income generation, mobilise community support and deliver innovative cost effective responses to need. Volunteers can ensure diverse community representation and promote community resilience around death, dying and bereavement\textsuperscript{122,123,124}. As community members, palliative care volunteers can influence public attitudes and contribute to general community well-being and cohesion\textsuperscript{125}.

The latest volunteering trends demonstrate that some volunteers have an interest in short-term high impact volunteering opportunities rather than longer-term volunteering commitments upon which palliative care services depend\textsuperscript{126}. We are moving to a situation in which there are two distinct types of volunteers: (1) the long-term volunteer, who lives locally and has been trained in-house to provide a specific support task, and (2) the specialist ‘professional’ volunteer bringing externally acquired expertise to the palliative care service\textsuperscript{127}. Mostly, but not exclusively, the specialist ‘professional’ volunteer, such as complementary therapists, enhance the quality of physical care that is provided to the client and carer and extend the quality and range of care that can be offered. Pro bono and corporate volunteering is also increasing\textsuperscript{128}. This is where people donate their professional skill for a few hours a month perhaps for a specific project or to sit on committees.

One of the recommendations from the Churchill Fellowship investigating international palliative care volunteering models was that resources were required to allow for innovations that would increase the usage and roles of palliative care and end-of-life care volunteers within the community, hospital and aged care systems\textsuperscript{129}. Providing palliative care training to pastoral care volunteers, aged care volunteers, volunteers who assist in strengthening community resilience around death and loss, volunteers who support advance care planning and provide guidance throughout the hospital cancer continuum are but a few examples that could be taken up to strengthen supports to palliative care clients and carers.
Research by the Healthcare Chaplaincy Council of Victoria (HCCVI)\textsuperscript{130} and the La Trobe University Palliative Care Unit\textsuperscript{131} demonstrate that skilled pastoral care volunteers can extend the provision of pastoral care where pastoral care services are limited. Pastoral care volunteers can provide the basic level of care, allowing professional staff to tend to those who need a higher level of care\textsuperscript{132}. This model could support strengthened palliative care pastoral care provision.

Palliative care volunteers can take up ambassador roles and thus assist in raising awareness of palliative care, promote the local palliative care service, assist in volunteer recruitment and build community resilience around death and dying. The Southern Metropolitan Palliative Care Consortium’s Promoting Quality of Life: Speakers Kit\textsuperscript{133}, La Trobe University Palliative Care Units’ health promoting resources\textsuperscript{134} and Palliative Care Victoria’s Community Resilience Volunteer Training module\textsuperscript{135} have been developed to support this. These resource are slowly been taking up by palliative care services.

La Trobe University has recently developed an Entrust-U Program\textsuperscript{136} which is designed for the volunteer and involves talking to participating older people in their homes or at their services about their life story and values as a starting point for exploring their future health care wishes. This program enhances Advance Care Planning before a ‘crisis’ in people’s health. This program has volunteer training resources that could be utilised to provide education that enables palliative care volunteers to assist in this role.

In Montreal, Canada, volunteer cancer survivors are providing support and guiding patients through all points along the cancer continuum within hospitals with palliative care wards, oncology outpatient clinics and radiotherapy\textsuperscript{137}. This could be of benefit to Victorian cancer patients.

In America, San Diego Hospice offers a broad range of palliative care volunteer roles such as pet therapy, spiritual support volunteers, constant companions (volunteer sitters who watch delirious or agitated patients in the hospice units), Notary Volunteers (volunteers who certify signatures on forms associated with advance care planning), energy therapists (e.g. reiki and massage practitioners), and promotional volunteers (volunteers, who have received speakers bureau training from the hospices marketing department, speak to local groups upon request). A Vet to Vet project is also being rolled out to offer veterans with palliative care trained volunteers who are also veterans\textsuperscript{138}.

Many international palliative care services are utilising experienced palliative care volunteers who demonstrate educational and/or leadership qualities as team leaders of groups of volunteers, educational assistants in training volunteers and as mentors who buddy new volunteers\textsuperscript{139}.

Leadership, strategic planning, time and resources are required to meet the changing volunteer landscape, good practice requirements and support innovation and increased volunteering opportunities. This will ensure the variety of supports to clients and carers are enhanced and sustainable and more volunteers are recruited and retained.

**Support continuity of care**

Palliative care volunteers often develop strong relationships with clients and their carers. It is common within the community palliative care setting for one volunteer to support one client and their carer throughout their journey. Currently this volunteer role is contained within the specialist palliative care service and their support is often discontinued when the client moves to a hospital, aged care setting or another palliative care service (e.g. community palliative care to hospice and vice versa). Social and emotional supports for the client and the carer could be strengthened by identifying ways volunteers can follow and support their clients and carers if all agree.
This could be particularly important for those clients who are socially isolated. The capacity for community palliative care services to extend their volunteer programs outside of their speciality area will be contingent on their resources.

## Strategic direction 4 priorities: Actions and impacts

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<th>Strategy 4 Priorities</th>
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<tr>
<td>Develop and implement a wide range of diverse, flexible volunteering opportunities that utilise individual skills to address client, carer and organisational needs</td>
<td><strong>4:1</strong> Encourage palliative care services to perform a skills audit of all volunteers and identify role opportunities for their organisations.</td>
<td>The organisation has access to a volunteer pool with diverse skills. High rates of volunteer satisfaction and extended periods of service.</td>
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<td><strong>4:2</strong> Develop, train and support palliative care ‘volunteer team leaders’.</td>
<td>Managers/Coordinators of volunteers are able to become increasingly involved in strategic development and innovation.</td>
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<td><strong>4:3</strong> Undertake a needs assessment in partnership with the Cancer Council of Victoria to determine the need for a Victorian model where volunteer cancer survivors provide support and guide patients through all points along the cancer continuum within hospitals that have palliative care wards, oncology outpatient clinics and radiotherapy department under one roof.</td>
<td>Determine the need for increased support available to people in palliative care hospital environments.</td>
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<td><strong>4:4</strong> Investigate the feasibility of increasing the number of ‘professional’ volunteer roles within palliative care organisations.</td>
<td>The range of contributions by volunteers to clients and carers and the organisation is extended in a cost-effective way.</td>
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<td>Develop and implement a wide range of diverse, flexible volunteering opportunities that utilise individual skills to address client, carer and organisational needs (contd.)</td>
<td>4:5 In partnership with the Health Care Chaplaincy Council of Victoria and palliative care services develop the palliative pastoral care volunteers’ role and training requirements.</td>
<td>Palliative care services have access to volunteers trained in pastoral care.</td>
</tr>
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| Ensure palliative care volunteers can assist in strengthening Victorians’ awareness, capacity and resilience in relation to palliative care and death, dying, loss and bereavement and their ability to support people living with a life limiting illness and their carers. | 4:6 Enhance opportunities for palliative care service volunteers to engage with their communities by:  
   a) Encouraging the take up of programs that support palliative care volunteer ambassadors and strengthen community resilience in death and loss; and  
   b) Support the resourcing of a Train the Trainer program for the EntrustU Program. | Palliative care services have volunteers who assist in building community resilience in relation to death, dying, loss and bereavement.  
Victorians are better able to support people living with a life limiting illness and to deal with issues of loss and grief.  
Consumers are more informed about the need for advance care plans and how to prepare them. |
| Support continuity of care | 4:7 Develop strategies to support volunteers who have formed a strong relationship with the client and carer moving with their client (if practically possible) if they are transferred to another organisation or new location. | Continuity of care for the client and carer.  
Hospital and residential aged care staff have increased knowledge of the role of the palliative care volunteer.  
Increased volunteer satisfaction. |
Volunteering highlights what’s important in life

Robert Lasky Davidson
A wish to help others following the Black Saturday bushfires encouraged 42 year old Robert Lasky Davidson to respond to an Eastern Palliative Care advertisement for palliative care biographer volunteers a year ago.

“It was just by chance I picked up the local paper and saw the ad. When I talked to them and did the course, it was a real eye opener as to how impressive their services were and the good they were doing,” Robert said.

“Before starting, I went on the road with one of the nurses, which was a fantastic experience to see that the people they were visiting were just like you and me but in an unfortunate position of needing palliative care.”

Robert assists people with a life limiting illness to remember, record and organise their life story and resources (papers, photos etc.) in biographical form for their families.

“When EPC lets me know that one of their clients would like to record their life story, I call them and introduce myself, make sure they’re comfortable with the process, and organise a convenient time for our first meeting.

“I say to them before we start: ‘it’s your story, however you say it, so it will be in your words and what you want the people your life story is for to hear.’ I always use a recorder so I don’t miss anything.

“My first client was an elderly Irish gentleman who would start and end with ‘and that’, and I put that in because that’s the way he spoke. He had a beautiful way of speaking but often I had to clarify things because of his accent. He couldn’t stop talking and although his health was declining from week to week he was determined to finish it before he died. When he looked at you, you knew he really meant it, eyes half shut, telling it from memory.

“He thanked me for really listening. I said little - my visits are saying ‘good on you you’re worth hearing, and have something to share.’”

Robert’s first biography took six weeks, and was finished in time to show his client before he died. His second took six months and is finished now except for the photos. This client is a woman the same age as him, who developed secondary cancer following the birth of her two young sons born after the first cancer occurred.

“For her, it’s about fighting as long as possible for her kids and recording things for her boys to remember. She wants them to know that they were meant to.

“I have pride in what I do. I like going into their homes and seeing the benefit they’re getting. It gives me a purpose - giving value to someone even if they won’t live long - and a great appreciation of how precious and short life can be.

“It made me ask what’s really important in life, which is why I now work flexibly to be with my kids.”

“I like going into their homes and seeing the benefit they’re getting.”
Strategic direction 5
Provide quality care supported by evidence

Priorities
1. Ensure all palliative care services assess the quality of care provided by volunteers with reference to the Victorian Palliative Care Volunteer Standards and that the quality of services they provide is supported by a quality improvement culture.
2. Identify the feasibility of minimum Victorian data collection requirements for all palliative care volunteer programs.
3. Support and build palliative care volunteering research capability across academic and palliative care services and its translation into continuous improvement practices.

Applying consistent volunteer standards and quality measures leads to better outcomes

Applying consistent palliative care volunteer standards leads to better psychological, social and spiritual support for clients and their carers, volunteer satisfaction and retention. It also manages organisational legal liability and compliance obligations with regard to volunteer engagement in palliative care services.

In 2007, the Department of Human Services partnered with Volunteering Victoria to develop the Victorian Palliative Care Volunteer Standards. The only ones of their kind in Australia, these standards provide guiding principles that support quality care provision in palliative care volunteer services in Victoria. They have been informed by the Volunteer Australia Standards and the national palliative care standards. Leadership that ensures a pro-active and planned continuous improvement process which assesses the effectiveness of volunteer programs and ensures they are part of the organisations’ accreditation process, is crucial to strengthening the quality and effectiveness of palliative care volunteer services in Victoria.

The National Standards Assessment Program (NSAP), funded by the Australia Government’s Department of Health and Ageing through the National Palliative Care Program, aims to support palliative care to move towards best practice, as set out in the Palliative Care Australia national standards. NSAP’s quality elements mention volunteers in 8.7, 12.6, 12.7, 13.2, 13.3 and 13.4.

All organisations with volunteers must also comply with national and state regulatory requirements covering a range of areas including working with children, police checks, food handling, privacy, occupational health and safety, and equal opportunity and protection from sexual harassment. The new national model on Work Health and Safety affords the same rights and responsibilities to volunteers as to paid staff. Increasing regulation and demands for quality care can change the experience of clients and their carers and the experience of the volunteers themselves as organisations struggle with risk mitigation. It is important to balance potential risks and opportunities to improve the quality of life of clients and carers, with reference also to the organisation’s risk appetite, so that the contributions that volunteers can make are optimised and the rights of clients and carers are respected.
It is also important to keep abreast of good practice. Active membership of Palliative Care Victoria’s Victorian Managers of Volunteers Network will assist in this.

**Volunteer program evidence**

Victorian palliative care volunteer program evidence, such as data collection and research, can provide fundamental information for quality improvement activities and evidence based resource allocation\(^{149}\). The effectiveness of programs is measured by weighing qualitative and quantitative data against service delivery and standard benchmarks. Currently within Victoria there is very little state wide palliative care volunteer program data collection that can be used to inform the government, palliative care services and researchers about palliative care volunteering.

Currently, palliative care services are collecting a wide variety of volunteer program data which is used in-house. Palliative Care Victoria periodically surveys volunteer programs and maintains minimal data such as location of programs and numbers of volunteers. VINAH, the minimum palliative care data set used by the Department of Health\(^{150}\), monitors palliative care services, supports service planning, policy formulation, equitable distribution of funding and epidemiological research. Volunteer programs are not included in VINAH data collection; however, the Department has recently undertaken a palliative care workforce study and this will give some more information about palliative care volunteers. National palliative care performance indicators collected between 2004 -2008\(^{151}\) were the only national palliative care volunteer measurement. These indicators collected whether a palliative care service employed a coordinator of volunteers in either an unpaid or paid capacity. This was not broken down into state data.

To support the expansion and resourcing of palliative care volunteer programs in Victoria there is a need to explore and identify the minimum common palliative care volunteer data requirements required to support service development, resource allocation and to provide research evidence. Representatives from the Department of Health, Palliative Care Victoria, Victorian Managers of Volunteers Network, palliative care consortiums, palliative care volunteer services and palliative care researchers\(^{152}\) should be some of the key stakeholders who undertake this work. How this evidence is collected at a Victorian level without a huge impact on volunteers and volunteer programs will also need to be identified.

Research, and publishing of good practice, is required to guide future policy, planning and evaluation and ensure services share innovations. The Victorian palliative care research collaborative between La Trobe University and Monash University is working to establish evidence about the use of volunteers in palliative care. This team has recently completed a Cochrane review of ‘Training and supportive programs for palliative care volunteers in community settings’ which will be published shortly. The protocol was published last year\(^{153}\). Further research is required to progress this. As previously mentioned in Strategic Direction 4, Victorian research has also been undertaken in the areas of utilising palliative care volunteers in the areas of pastoral care, building community resilience around death and loss and in early advance care planning. The take up of the opportunities identified in this research by palliative care volunteer programs has not been widespread in Victoria as yet.

CareSearch, the national online resource of palliative care information and evidence, contains some palliative care volunteer program evidence\(^{154}\). Victorian palliative care volunteer program managers require encouragement and support to ensure their innovations are captured and shared across Victoria and on CareSearch. Currently these managers have limited time for research and reading of best practice literature let alone writing up their innovations\(^{155}\).
Anecdotal evidence gathered from the Victorian Managers of Volunteer Network suggests that many services are struggling with volunteer bereavement support protocols as palliative care volunteers provide bereavement support across the state in a variety of ways. Some volunteers receive more specialist training around loss and grief and others do not. Some programs introduce a new volunteer once a client has died while others continue to offer the services of a volunteer that has already been in place. Volunteer bereavement support can range from letters to phone calls to visits. The Victoria Bereavement Support Standards for Palliative Care Services should assist in providing overarching best practice in this regard. Recent discussions with the Australian Centre for Grief and Bereavement suggest a clear guiding position statement specifically on the role of the palliative care volunteer in the bereavement phase would assist in the translation of these standards into best practice.

### Strategic direction 5 priorities: Actions and impacts

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<td>Ensure all palliative care services assess the quality of care provided by volunteers with reference to the Victorian Palliative Care Volunteer Standards and that the quality of services they provide is supported by a quality improvement culture</td>
<td>5:1 Palliative care services will ensure their volunteer programs meet the Victorian Palliative Care Volunteer Standards, and are part of their national palliative care outcomes and standards self assessment (NSAP) and accreditation processes.</td>
<td>All palliative care volunteer programs are monitored under their organisation’s continuous quality improvement and accreditation processes. Palliative care volunteer data contributes to monitoring and measuring quality care.</td>
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<td>5:2 Review the 2007 Victorian Palliative Care Volunteer Standards in partnership with Volunteering Victoria, Volunteering Australia and Palliative Care Australia.</td>
<td>The Victorian Palliative Care Volunteer Standards are updated and inform the provision of high quality care by volunteers supporting people who are receiving palliative care.</td>
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<td>5:3 Organisations identify the level of risk they are prepared to accept to ensure the rights of clients and carers and volunteers’ roles in enhancing quality of life are maintained.</td>
<td>Risk assessment and management is appropriately cognisant of the rights of clients and families and the aim to enhance quality of life.</td>
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<td>Ensure all palliative care services assess the quality of care provided by volunteers with reference to the Victorian Palliative Care Volunteer Standards and that the quality of services they provide is supported by a quality improvement culture (contd.)</td>
<td>5:4 Consult and partner with both the Victorian and National Managers of Volunteers Networks to strengthen the palliative care volunteer sector.</td>
<td>Sharing of palliative care volunteer program innovation and best practice across Victoria and Australia.</td>
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<td>Investigate the feasibility of minimum Victorian data requirements for all palliative care volunteer programs</td>
<td>5:5 In partnership with the Australian Centre for Grief and Bereavement develop best practice guidelines or position statement specifically for the role of the palliative care volunteer in the bereavement phase.</td>
<td>The involvement of palliative care volunteers in providing bereavement support is consistent with evidence-based best practice.</td>
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<td>Support and build future palliative care volunteering research capability across academic and palliative care services and its translation into practice</td>
<td>5:6 Develop a state working party of key stakeholders to investigate the feasibility of the development of minimum volunteer program data requirements. Develop strategies to progress recommendations.</td>
<td>Supports future planning, service development and research, and enables evidence based volunteer program funding allocation.</td>
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| 5:7  
  a) Identify gaps, fund and undertake research in the area of palliative care volunteering.  
  b) Encourage and enable those who manage volunteer programs to participate in research as part of their work.  
  c) Develop strategies to ensure current evidence is published and communicated into practice and action. | Evidence supports palliative care volunteering practice.  
  Increased research capacity of managers/coordinator of volunteers.  
  Palliative care volunteer research is published and communicated through means such as CareSearch and presentations at Conferences. |
What a help a volunteer would have been for my mum

Pam Sierak
Pam Sierak added one day a week as a Melbourne City Mission (MCM) palliative care volunteer to her busy retirement after talking to a friend who described the work she did for MCM.

“I realised what a difference it would have made to my mother, when she died 30 years ago, if there had been a volunteer around to provide a break from the care,” she said.

Pam and her husband already volunteer one morning a week at a homeless persons’ breakfast, regularly transport people to church services and wrap Christmas presents for Vision Australia, on top of their family responsibilities, cycling, exercise and travel activities.

After ‘some wonderful training with MCM’ she provides respite and comfort for one client one day a week, and is now with her 28th client in 9 years. Some links last for a year, others for just a week. She takes a break between each client depending on how she feels.

“I go into their homes and give the carer a break, and just do what they want me to. Sometimes I take them for treatment, or shopping or just coffee. I used to take one lady to opportunity shops - she loved them and had a house full of her finds.

“I learnt massage as part of my training, and can just sit doing their hands and feet and sharing the silence. It’s humbling to sit at their feet.

“I never go in with an agenda for visiting. Every person is different – and it’s for the doctors and nurses to be specific.

“One woman I visited when her husband went off to sing in a choir. I would sit and knit as she dozed, and she said she knew I was there by the click of needles.

“Another Italian man loved to talk. His family thought they knew the story of his life, but he told me all about his life – he was an amazing person.

“You do go to a lot of funerals; I have usually met the family and need to go for closure. You don’t have clients living nearby as you don’t want to be bumping into people, but some you lose your heart to.

“I read to people and often come home and google things that I think they would like to talk about.”

Pam keeps a journal to record her contacts and, if she’s worried about something that’s been done or said, she contacts MCM ‘rather than stewing over it’. They are very valuing and supportive of their volunteers.

“I’m always overwhelmed how I’m trusted and accepted when I go into strangers’ homes. I would never do anything to break that trust.

“When you’re there for someone else you empty your head of yourself.

“I have met beautiful people that I connect with. Everyone is different but they are all lovely. Volunteering has enriched my life and my sense of being.”

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