

Palliative Care in Victoria – The Facts

In Victoria the State Government launched *Strengthening palliative care: Policy and strategic directions 2011-2015* last year. This policy aims to ensure that Victorians with a life-threatening illness and their families and carers have access to a high-quality palliative care service system that fosters innovation, promotes evidence-based practice and provides coordinated care and support that is responsive to their needs. The strategic directions in this policy are consistent with the Victorian Health Priorities Framework 2012–2022: Metropolitan Health Plan, which sets out the priorities for metropolitan, rural and regional and health capital planning into the future.

This document responds to a range of challenges in meeting growing and changing demand for palliative care. It aims to provide palliative care for people with all types of life-threatening illnesses – not only cancer – and to ensure that people’s wishes about how they are cared for and where they die are understood and met.

Need for Palliative Care

Demand for palliative care in Victoria is expected to grow by at least 4.6 % each year.ⁱ An ageing and diverse population, increasing incidence of chronic illnesses and cancer will put increasing pressure on palliative care service provision as the following evidence indicates:

- About 36,000 people in Victoria die each year; of these people, 50 per cent die following a period of chronic illness, such as heart disease, cancer, stroke or a neurological illness that would have benefited from palliative care.ⁱⁱ
- When asked, most people indicate they would prefer to die at home.ⁱⁱⁱ In 2010/11, of the recipients of community palliative care services who died, 24% died at home, 34% died in a designated palliative care bed, 27% died in an acute hospital and 13% died in a residential aged care facility.^{iv}
- Up to 90% of people in the terminal phase of a life-threatening illness spend the majority of their time at home^v and 83% are cared for by family and friends.^{vi}
- In Australia, deaths from dementia related illness have increased 138% since 1999.^{vii} The proportion of people with dementia is projected to increase from about 230,000 in 2008, to 465,000 in 2030 and to over 730,000 in 2050.^{viii} This will put increased demands on palliative care services.
- Cancer incidence will increase by up to 40% over the next 10 years.^{ix} This will put increased demand on all palliative care services.

- In Victoria, 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% and the percentage of the population aged 85+ is projected to increase by 236%.^x
- By 2011, one in every five people aged 80+ in Australia will be from culturally and linguistically diverse backgrounds; this will increase to one in four people by 2026.^{xi} Currently, there is a low uptake of palliative care services among CALD communities in Victoria.^{xii}
- The demand for residential aged care in Australia is anticipated to increase more than threefold by 2045.^{xiii} Currently, almost one third of people who are admitted to a residential aged care facility as high care residents die within six months of admission^{xiv} and 61% will die within one year.^{xv} Many of these people would benefit from palliative care. American research shows that by 2020 half of all deaths are expected to occur in residential aged care facilities^{xvi} and a similar trend could occur in Australia.
- There is evidence to suggest that a range of groups have unmet palliative care needs, including:
 - People who live in an aged care facility or other institutions
 - People who have a non-malignant illness
 - Aboriginal people
 - People who live in remote areas
 - People from CALD and other diverse backgrounds
 - People from a low socio economic background including people who are homeless
 - People who have a physical or intellectual disability and a life threatening illness^{xvii}

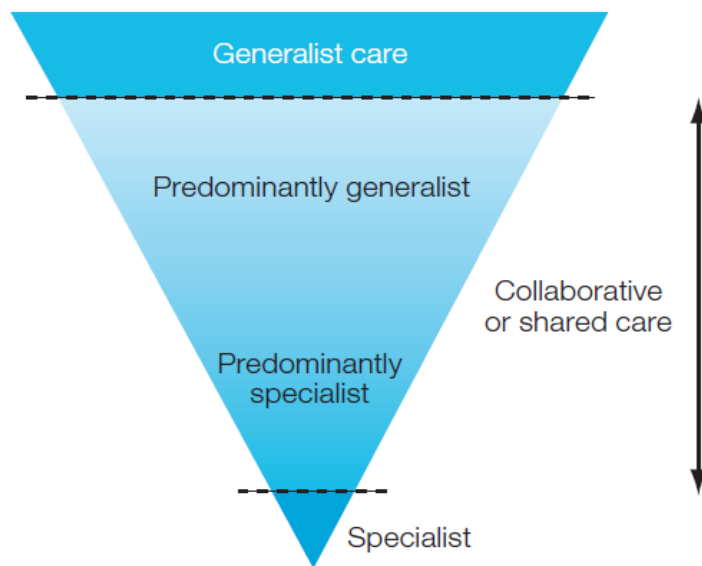
Palliative Care Service Provision in Victoria

Victoria has a service delivery framework that was designed to:

- provide a clear framework for assessing service capability
- reduce unexplained variation in services across the state
- articulate the roles and responsibilities of each service level to support client treatment and care, linkages, education and research in and across regions
- establish statewide structures that support best practice.

Effective integration and co-ordination of services is an indicator of services operating efficiently. For example, clients of community palliative care services who require an inpatient admission for pain and symptom management or end-of-life care are 5 times more likely to be admitted directly to a palliative care bed than those with a life threatening illness not registered with a palliative care service.^{xviii}

The following captures the service planning model diagrammatically.



Specifically in Victoria;

- 10,638 people^{xxix} received community palliative care (primarily in the home) from 39 community palliative care services in 2009/10^{xx}. The average length of stay on a community program was 110 days.^{xxi} 4 day hospices provided assessments, respite and activities.^{xxii}
- There are 264 designated palliative care beds located across 30 health services. In 2010/11 86,000 specialist palliative care bed days were provided.^{xxiii}
- 16 specialist palliative care consultancy services provide expert advice and education to community, hospital and aged care providers.^{xxiv}
- There are 6 funded state-wide services:
 - Australian Centre for Grief & Bereavement Counselling
 - HIV Aids Consultancy Service
 - Motor Neurone Disease Association of Victoria
 - Palliative Care Victoria
 - Very Special Kids
 - Victorian Paediatric Palliative Care Program.
- Approximately 1,490 trained palliative care volunteers provide companionship, respite for carers, transport and emotional support.^{xxv}
- The State Government established the Palliative Care Clinical Network in 2010 to oversee the clinical elements and implementation of:
 - Strengthening palliative care: policy and strategic directions 2010-2015
 - Service Delivery Framework and Service Capability Framework
 - Clinical Service Improvement Program

Funding of Palliative Care in Victoria

The State Government committed new funding of \$34.4m in the 2011 budget as part of the implementation of its statewide policy and this raised its investment in palliative care to \$108m as detailed below.

	Total Funding in 2011-2012	Funding & Activity
Community palliative care (including flexible funding to meet needs at home plus day hospices)	\$38m	Community palliative care services have a target for the number of contacts to be provided with the funding received. Funded via historical block grant and since 2005 new funding allocated via the PCRAM (see below). No set unit price
Inpatient palliative care	\$55m	Health Services authorised by the Department to provide inpatient specialist palliative care are set a target number of palliative care bed days to provide. Unit price for a palliative care bed day is \$566 metro & \$571 rural (against a hospital bed cost of \$1,117 per day)
Consultancy services	\$5m	Provided in all metro health regions and all rural regions. Funded via block grant. No set unit price or activity target.
Research, education & training	\$3.55m	Funded via block grant
Palliative care consortia	\$1.57	Funded via block grant – includes nurse practitioner, aged care link nurse positions and new disability funding
Statewide services (paediatric, diagnosis specific services and peak body)	\$5.2m	Funded via block grant

The Palliative Care Resource Allocation Model (PCRAM) allocates funding based on the needs of the population within defined geographical catchment areas – it takes account of population growth, ageing, rurality and low socioeconomic status.

Workforce

The Strengthening palliative care policy includes a number of initiatives around sustainability and skills development. There are a couple of programs worth mentioning:

- The Victorian Palliative Medicine Training Program (VPMT) is operated by the Centre for Palliative Care and the University of Melbourne. It aims to develop a sustainable palliative medicine workforce at a variety of levels, particularly in rural/regional Victoria. The program has grown the number of palliative care trainees to 35 in 2011-2012.
- Support has been provided to develop and implement nurse practitioner models since 1998.

Research

Recurrent government funding is provided to the following sites for the purposes of research in palliative care, however other sites state wide conduct research through competitive grant funding and clinical trials research.

Academic centre	Auspiced by	Research focus
Centre for Palliative Care	A collaborative centre between the University of Melbourne & auspiced by St Vincent's Health	<ul style="list-style-type: none"> • Family centred palliative care • Psychosocial care • Symptom management • Service delivery
Chair in Palliative medicine	Monash University & Southern Health	<ul style="list-style-type: none"> • Palliative care policy • Service delivery • Symptom management
Palliative Care Unit Research in Supportive Care (RISC) program	La Trobe University	<ul style="list-style-type: none"> • Public health • Pastoral care • Sociological studies • Supportive care
Vivian Bullwinkel Chair in Palliative Care Nursing	<p>Financially supported by Monash University to undertake research to that improves the quality of life of the sick and dying.</p> <p>Clinical partners with Peninsula Hospice Service, RDNS & Peninsula Health</p>	<ul style="list-style-type: none"> • Service evaluation • Palliative care policy • Cultural issues • education
Department of Pain & Palliative Care Department of Nursing and Supportive Care	Peter MacCallum Cancer Centre	<ul style="list-style-type: none"> • supportive care • pain management

Palliative care academic centres in Victoria are members of the Victorian Palliative Care Research Network (PCRNV) and it receives funding to collaborate on research that will benefit services, carers and clients. Research is recognised as a critical part of strengthening the provision of palliative care with a particular emphasis on translating evidence into practice.

ⁱ Department of Health, Victorian Integrated non-admitted Health Minimum Data Set (VINAH), 2010/11

ⁱⁱ Department of Health, Strengthening palliative care: Policy & strategic directions 2011-2015 p27

ⁱⁱⁱ Davies, E. & Higginson, I. 2004, *Better Palliative Care for Older People*, World Health Organisation, Geneva

^{iv} Department of Health, Victorian Integrated non-admitted Health Minimum Data Set (VINAH), 2010/11

^v Palliative Care Australia 1999, *State of the nation 1998- Report of the national census of palliative care services*, PCA, Canberra, p12

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- ^{vi} Aspex Consulting, 2009, *Department of Human Services Palliative Care Service Delivery Framework and Funding Model Service Mapping Report*, p106
- ^{vii} ABS 2010, 2008, Causes of Death,
<http://www.abs.gov.au/ausstats/abs@.nsf/0/7472F4976D5DC022CA2576F600122927?opendocument>
- ^{viii} Access Economics, 2009, *Alzheimer's Australia, Making choices. Future dementia care: projections, problems and preferences, Executive Summary*, p6
- ^{ix} Department of Human Services, 2008, *Victoria's Cancer Action Plan 2008-2011*, p5
- ^x Department of Planning & Community Development, 2009 *Victoria in Future 2008: Victorian State Government population and household projections 2006-2036*
- ^{xi} Australian Institute of Health & Welfare 2001, Projections of immigrants, People from culturally and linguistically diverse backgrounds, 1996-2026, AIHW, Canberra, p18
- ^{xii} Department of Human Services, 2009, *Strengthening Palliative Care Policy 2004-2009 Evaluation Report*, p40
- ^{xiii} <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-iar-review-framework.htm~ageing-iar-review-framework-2.htm>
- ^{xiv} AIHW 2008, Residential Aged Care in Australia 2006-07: A Statistical Overview, p31
- ^{xv} Hudson, R and O'Connor, M, 2007, Palliative Care and Aged Care: A Guide to Practice, Ausmed Publications:
- ^{xvi} Sheenan, D and Schirm, V 2003, 'End of Life Care of Older Adults', *American Journal of Nursing*, Vol 103, pp48-58
- ^{xvii} Department of Health, Strengthening palliative care: Policy & strategic directions 2011-2015 p31
- ^{xviii} Department of Health, VINAH community palliative care data 2008-9, Internal Report, 2009, State government of Victoria
- ^{xix} Department of Human Services, 2009, *Strengthening Palliative Care Policy 2004- 2009 Evaluation Report*, p11
- ^{xx} Ibid, p39
- ^{xxi} Department of Health, 2009, General Practice Victoria Palliative Care Workshop Powerpoint,
www.gpv.org.au/.../Programs/Palliative%20Care/.../20090806_prs_%20DHS%20Update_%20jh.ppt
- ^{xxii} Ibid, p59
- ^{xxiii} Department of Health, internal VAED reports
- ^{xxiv} Aspex Consulting, July 2009, op.cit. p24
- ^{xxv} Department of Human Services, 2006, Palliative Care Workforce, A supply and demand study, p43



The Benefits of Palliative Care

Population ageing and the increasing incidence of deaths from chronic disease and age-related frailty present significant challenges for our health and aged care services.

A high proportion of health costs are incurred in providing care for a small proportion of patients at the end of life. Yet too many patients suffer pain and die in hospital having undergone futile interventions.

Palliative care provides an alternative approach that is centred on the needs and wishes of patients and their families. It ensures the relief of pain and suffering, as well as addressing the social, spiritual, psychological and cultural needs of the patient and their family.

This paper provides a short summary of the growing body of evidence on the benefits of palliative care from research studies. This demonstrates that palliative care not only improves the quality of life of people with a terminal illness and their families, it also contributes to more efficient use of limited health resources.

The evidence that palliative care delivers quality of life benefits and better use of limited health resources provides a strong case for increased funding of palliative care as an integral part of our health and aged care services.

Improves Quality of Life

- A study conducted in 2008 of 33 high quality systematic literature reviews and 89 intervention studies concluded that there is strong to moderate evidence that palliative care improves important aspects of end of life care, such as reduction in distressing symptoms and relief of caregiver burden.¹
- Studies of a range of palliative care interventions from Europe, Canada, Australia and the US demonstrate consistent improvement in pain and other symptoms, patient and family satisfaction, and likelihood of receiving care in the place of choice.²
- Hospital palliative care consultation programs have been associated with reductions in symptoms and higher family satisfaction with overall care, and greater emotional support as compared with usual care.³
- A multi-method study at the Royal Melbourne Hospital involving a retrospective audit of 171 deaths during 2007 found that referral within the hospital to the palliative care service resulted in key improvements in the care of the dying patients, including

implementation of appropriate end-of-life medication orders, cessation of futile treatment and interventions, and improved communication with families. However, the majority of dying patients in the hospital were not referred to palliative care, with concerning evidence found for deficiencies in quality of care, such as: mouth care, lack of communication with GPs and the assessment of religious and spiritual needs.⁴

- Results of a randomised trial of in-home palliative care in two US health organisations found that patients reported greater satisfaction with care at 30 and 90 days after enrolment and were more likely to die at home, their preferred location, than those receiving usual care. They were also less likely to visit emergency departments or to be admitted to hospital than those receiving usual care. The study provided strong clinical and cost saving evidence supporting the provision of palliative care in the home of terminally ill patients with cancer, chronic heart failure and chronic obstructive lung disease with a life expectancy of approximately 1 year.⁵

Improves Health Resource Use

- According to a review conducted by the UK National Audit Office of 36 research studies on the costs of palliative care, there were average cost savings of around 30% for cancer patients receiving palliative care in the last year of life. Consistent savings result primarily from fewer hospitalisations and, when hospitalisation occurs, savings are from less utilisation of acute hospital care resources.⁶ The study concludes that palliative care is cost-saving – this was true for the various types of provision, including inpatient hospice and home-based care. The evidence is most clear for cancer patients.⁷
- A study examining 2004-07 data to determine the effect on hospital costs of palliative care consultations for patients enrolled in Medicaid at four New York state hospitals found that patients who received palliative care incurred \$6,900 less in hospital costs during a given admission on average than a matched group of patients who received usual care.⁸
- A recent inter-institutional comparative analysis found that the total mean charges per admission to the Cleveland Inpatient Palliative Care Medicine Unit (CCPIM) were \$7,800 lower than at other peer institutions despite an equivalent severity of illness, longer length of stay and higher mortality in the CCPIM unit. The lower charges were due primarily to lower laboratory and pharmaceutical charges.⁹
- A study comparing the daily costs of 123 patients prior to and following admission to the St Thomas Palliative Care Unit in Virginia found a 66% reduction in overall costs (including a 74% reduction on expenditure on medications and diagnostics). Reasons cited include a change in the goals of care once people are clearly identified as dying and associated changes in care patterns. The authors found evidence of intensive and expensive interventions for patients receiving care outside the palliative care unit, even when the patient and family were accepting death. They suggest that the most likely reason was that the medical care team did not know how to change care patterns.¹⁰
- Hospital palliative care consultation teams are associated with significant hospital cost savings. This was the finding of a US study involving analysis of data from 8 hospitals with established palliative care programs. Patients receiving palliative care were matched by propensity score to patients receiving usual care. The study found the average total direct

cost per admission for palliative care patients discharged alive was around US\$1700 less than for matched patients who received usual care. For palliative care patients who died the net savings per admission were almost US\$5000 compared with matched patients receiving usual care who died.¹¹

- A 2009 US study found that patients with advanced cancer who reported having end of life discussions with their doctors had on average 35% lower health costs (\$US1041) in the final week of life compared with similar advanced cancer patients who had not had those discussions. Higher costs among those advanced cancer patients who had not had end of life discussions with their doctors were associated with more physical distress in the last week of life and worse overall quality of death as reported by the caregiver. There was no survival difference associated with higher healthcare expenditures.¹²
- A 2006 Spanish study found that the provision of palliative care services to advanced cancer patients generated savings of 61% in the cost of care during the last 6 weeks of life compared with conventional medical care provided to similar patients in a 1992 study. The cost savings from palliative care were due to reduced use of emergency rooms, a shift from conventional acute care beds to palliative care beds, reduced average lengths of hospital stay and associated use of home-based care.¹³

Endnotes

¹ Lorenz et al, 2008, reported in Rand Europe and the National Audit Office, 2008, *The Potential Cost Savings of Greater Use of Home- and Hospice- Based End of Life Care in England*, National Audit Office, 2008.

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³ Morrison, R S; Penrod, J D; Cassel, B; Litke, Ann; Spragens, L; Meier, D E, 2008, "Cost Savings Associated with US Hospital Palliative Care Consultation Programs", *Archives of Internal Medicine* 168, No 16 (2008) p1786

⁴ Le, B; Watt, J, 2010, "Care of the Dying in Australia's Busiest Hospital: Benefits of Palliative Care Consultation and Methods to Enhance Access", *Journal of Palliative Medicine* Vol 13, No 7, 2010, pp855-860.

⁵ Brumley, R; Enguidanos, S; Jamison, P; Seitz, R; Morgenstern, N; Saito, S; McIlwane, J; Hillary, K; Gonzalez, J; "Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of In-Home Palliative Care", *Journal of the American Geriatric Society*, 2007, Vol 55 No 7 pp993-1000

⁶ Hatziandreu, E; Fragiskos, A; Daly, A, UK National Audit Office, 2008, *The Potential Cost Savings of Greater Use of Home- and Hospice- Based End of Life Care in England*, Rand Corporation, 2008, www.rand.org, p19

⁷ Ibid. P 20

⁸ Morrison, R, Sean et al, 2011, *Health Affairs March 2011* vol 30 no.3 454-463, p454

⁹ Davis, M; Walsh, D; LeGrand, S; Lagman, R; Rybicki, M; 2005, "The Financial Benefits of Acute Inpatient Palliative Medicine", *The Journal of Supportive Oncology*, Vol 3, No 4 July/August 2005, pp313-316.

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¹¹ Morrison, R S; Penrod, J D; Cassel, B; Litke, Ann; Spragens, L; Meier, D E, 2008, "Cost Savings Associated with US Hospital Palliative Care Consultation Programs", *Archives of Internal Medicine* 168, no 16 (2008) p1783-1790

¹² Zhang, Baohui; Wright, Alexi A; Huskamp, Haiden A; Nilson; Maciejewski, Matthew L; Earle, Craig C; Block, Susan D; Maciejewski, Paul K; Prigerson, Holly G; 2009) "Health Care Costs in the Last Week of Life: Associations with End of Life Conversations", *Archives of Internal Medicine* (2009) March, 9; 169(5): 480-488

¹³ Gomez-Batiste, X; Corrales, E; Porta-Sales, J; Amor, M; Espinosa, J; Borrás, J de la Mata, I; Castellsague, X, 2006, "Resource Consumption and Costs of Palliative Care Services in Spain: A Multicentre Prospective Study, *Journal of Pain and Symptom Management*, Vol 31 No 6, pp522-532

Volunteers in Victorian Palliative Care

Fact Sheet

Volunteers in palliative care

Volunteers in palliative care play a significant and often under-estimated role in caring for patients, families and carers who are facing the end-of life. Following extensive training, volunteers increase and enhance the range of supports palliative care services can offer to their clients. They can offer constancy for patients and families amidst the busy-ness of caring. Trained volunteers in palliative care make a difference in keeping someone in the home and in sustaining carers in their complex and demanding role.

In Victoria, 56 palliative care services reported in June 2011ⁱ that they involved:

- active volunteers working in a range of capacities = 1,973, and
- the number of these active volunteers involved in directly supporting patients, families and carers = 1,342 or 68% of all volunteers

The majority of palliative care volunteers commit 2-5 hours per week to their palliative care roleⁱⁱ. These volunteers are predominately female, and born in Australia. The majority (72%) are aged 60 years or more.

What do volunteers in palliative care do?

72% of Victorian palliative care volunteers carry out their roles in the homes of patients and their local communityⁱⁱⁱ. The others work within inpatient, hospice and day hospice services. Many palliative care volunteers choose this role because of their own direct experience with losing a loved one.

Direct care palliative care volunteer roles

Direct care provided by trained volunteers is any care or activity that involves contact with clients. This can include:

- **Companionship** - Accompanying to appointments or making regular scheduled visits (i.e. weekly or fortnightly) to clients in their home, hospital or hospice for companionship, e.g. having a cuppa, playing board games; helping with meal time of inpatients; etc.

- **Respite** – Enabling respite for carers by caring for the patient in their home while the carer rests, or makes social outings, or keeps appointments. Can be up to 4 hours at a time.
- **Transport** – Volunteers provide valued support by assisting with transport for patients and their families. It is more than the physical task of driving a car to appointments or on outings - there is a measure of emotional support, companionship & reassurance involved in most transport jobs. Volunteers are asked because taxis are not able to give the same type of flexibility, care or sensitivity to client needs.
- **Special Programs** – Special programs can include: recording life stories in memoir or biography programs; sibling and family weekends; dog walking or re-homing animals; massage, reflexology & reiki by qualified volunteers; walking groups; art & music therapy; etc.
- **Bereavement Support** – Bereavement support can include: annual remembrance services; bereavement follow up; assist paid staff at 'Bereavement Education' sessions (meet and greet, hospitality, address group); 'Walking Through Grief' sessions (support paid staff with group walks/coffee for bereaved carers); preparing mail-out packs for bereaved carers; Christmas Tree remembrance programs; etc
- **Equipment pick-up and delivery** - The volunteers meet and interact with patients and families.

Volunteers must be able leave their own emotional issues outside their role yet at the same time accept being a mirror in which carers and the bereaved can see themselves. Their task is to resist trying to fix what is broken and to 'go with the flow' of what patients and carers wish and need as things change.

Other palliative care volunteer roles

Other volunteer roles generally fall into three main areas that do not involve having regular contact with patients and carers:

- **Health Promotion** – For example through "ambassador programs" where volunteers are trained to give presentations to groups about the services of the palliative care service; organising and taking part in community death education e.g. Café Conversations around end-of-life topics; etc
- **Encouraging local community support** – for example through fundraising such as: opportunity shop; sausage sizzles; Christmas card charity shops; annual community door-knocks/letterbox drop collections; charity auctions; film nights; golf days, etc
- **Administration** - Cataloguing for music therapist; preparing client home-folders; mail-outs; preparing info packs for prospective volunteers; preparing data packs for volunteer biographers; making up blank client files; assisting with admin requirements for Volunteer Training (i.e. volunteers may help photocopy training slides, help with set up of training room, etc.)
- **Research** - Participating in research on end-of-life issues

Palliative care volunteers have a critical role in sustaining carers and patients in the home. This means trained palliative care volunteers have a primary rather than an ancillary role in palliative care – they respond to the social dimension of many of the issues faced by patients and those close to them increasing the social, emotional and practical supports that families and communities need if caring is to be sustained.

Training Palliative Care Volunteers

- **Initial training** - Initially, palliative care volunteers receive around 30 hours of training based on the Palliative Care Volunteer Training Resource Kit developed by Palliative Care Victoria in 2008.
- **Refresher & in-service seminars** - Depending on their duties, services offer volunteers one-day refresher courses annually and regular half-day in-service seminars covering topics such as 'chronic illness trends in palliative care'; role of music and art therapy in symptom management; Alzheimer's Australia (VIC) strategies for communication; etc.
- **Standard workplace training** - Volunteers are invited to the same courses as paid staff including – service orientation programs; computer training; food handling; driver training; etc.

Some of the challenges facing the volunteering role in palliative care

- ***Increasing need for volunteers trained in palliative care by the generalist sector*** - Volunteers involved in palliative care require special training and supervision which may not be readily available in the generalist sector yet the generalist sector is where palliative care is predominantly provided. The growing expectation and demand for end-of-life support in the home means that the use of volunteers by generalist services to support patients and families needing end-of-life care is of increasing importance.
- ***Limited service infrastructure and support for volunteers*** - A designated manager of volunteers role is essential to the development of volunteer services and the recruitment, induction and training, supervision and support of volunteers.^{iv} They provide a diverse human resource management role often supporting large numbers of volunteers^v who require close care/supervision given the nature of their roles in dealing with death and dying. Currently many of these managers work in isolation and some are un-funded. This is a risk for the sector given the primary role volunteers have in delivering palliative care.
- ***Sustaining and growing the palliative care volunteer workforce*** - Like the palliative care paid workforce, regular palliative care volunteers are ageing. The nature of working with people and families facing the end-of-life means that volunteers move on after a period of time. They may also need training and guidance to assist them in providing culturally inclusive, responsive and competent support to patients and families from culturally and linguistically diverse backgrounds. While the profile of palliative care volunteers may not reflect the level of cultural and linguistic diversity in our

communities, more informal 'volunteering' occurs within the extended family and support networks within many CALD communities and Aboriginal communities. Sustaining and adapting our current palliative care volunteering model in the face of changing work/life patterns and the increasing expectations of services is a challenge that needs to be acknowledged in policy, service development and resourcing.

- ***How best to ensure that funding and service development models include palliative care volunteers*** - Collection of baseline data that e.g. measures the number of clients who are receiving palliative care volunteer support and the numbers of hours volunteers provide is essential to adequately defining the model, funding and resource needs for delivering palliative care in the community.

ⁱ Palliative Care Victoria and Managers of Volunteers SIG update May & June 2011

ⁱⁱ Department of Human Services, (2006) *Palliative Care Workforce- A Supply and Demand Study*, p 2

ⁱⁱⁱ Department of Human Services, (2009) *2007 Palliative Care Volunteer Survey Findings*, p14

^{iv} Ibid, p 119

^v Commonwealth of Australia and Volunteering Australia, 2003, *Working with Volunteers and Managing Volunteer Programs in the Health Care Setting*, p9.

The Victorian Aboriginal Palliative Care Project

In Victoria the number of people accessing palliative care services from an Aboriginal and Torres Strait islander (ATSI) background was much smaller than the state's demographics would suggest. The numbers were particularly low given that ATSI people have a lower life expectancy, higher infant mortality rate and high levels of chronic disease.

In 2007 the Victorian Government made funding available for 3 years to the Victorian Aboriginal Community Controlled Health Organisations (VACCHO). The aims of this project were to:

- Increase AHW's awareness of palliative care
- Increase the cultural appropriateness of palliative care service delivery
- Increase the number of ATSI people accessing palliative care services

Employing a statewide project officer was integral to the success of the project. Being placed at VACCHO gave her immediate access to aboriginal communities, ACCHOs and other experts. She followed the cultural protocol when introducing the project and she was the conduit between the ACCHOs and the consortia managers.

Collaborative support was garnered by bringing all key stakeholders onto an advisory body. Regional forums built links at a local level, particularly between local ACCHOs, community members and the palliative care consortia and services.

The most significant demonstration of the success of the project was the progressive increase in utilisation of ATSI people of palliative care services.

Number of ATSI people using palliative care services

	Community based palliative care	*Specialist palliative care beds	*Other beds	Total inpatient separations
2006 – 7		11	22	33
2007 – 8	82	12	29	41
2008 – 9	99	21	45	66
2009 – 10	61	27	7	34
2010 – 11	45**	20	6	26

* Separations not clients

** Data validity may be unreliable

In 2010 - 11 the State Government funded this project on an ongoing basis and additional funding was allocated in the 2011 budget for the next 4 years. Ongoing funding is important given the staff turnover in AHW and palliative care roles and vigilance is necessary in continuing to promote palliative care in the ATSI communities and in improving the cultural responsiveness of services.

Since 2007 the program has:

- Facilitated PEPA palliative approach workshops for 141 AHWs and Aboriginal Health Liaison Officers
- Facilitated PEPA supervised clinical placement for 21 AHWs in specialist palliative care services
- Provided cultural awareness training to staff of palliative care services
- Co-ordinated the inaugural 2007 national aboriginal palliative care workshop that was attended by 153 people
- Developed resources (such as artwork, podcasts, message sticks and an Aboriginal palliative care guide)

Case Study 1 - Bethany's Story

David and Lyn's beautiful daughter Bethany was diagnosed with brain cancer just after her 15th birthday and was given only 1 to 2 months to live. While the doctors recommended active treatment they told the family that they had only known of one other case like Bethany's where the person had survived.

Bethany was in the Children's Hospital for nearly 4 months receiving radiotherapy amongst other treatments. Her cancer was particularly aggressive and she was in considerable pain from both the condition and the treatments. While she was in hospital the Palliative Care team was called in. Doctors explained to the family that they were not giving up but they needed specialist assistance particularly with pain management.

The family decided that Bethany's father David would give up his job and become her full time carer while Lyn would run the house and manage the other 3 children. The arrangement started while Bethany was still in hospital and the staff supported David to learn about the medication regime. He said that he felt trusted by the medical staff who were very busy and appreciated his contribution. At times David needed to be Bethany's advocate.

Bethany's condition continued to deteriorate and she was bedridden when she came home. She needed 24 hour care and it could take three people to move her. Much of the time she had a naso-gastric tube and required oxygen on site. David designed a medication chart and managed her drug regime closely because he knew that if her medication was late then she could get severe break through pain that was hard to bring under control. In a 24 hour period Bethany needed medication on 13 separate occasions. He was trained by the nurses to undertake many nursing tasks including replacing the naso-gastric tube as Bethany would often expel it.

The formal support they received in the 8 months that Bethany was at home was considerable including district nursing daily, assistance with showering 3 times a week, music and massage therapy, overnight support two nights per week, grief counselling and more. However it was the support from their church and friends that made it possible to have Bethany at home. The church provided financial support and friends gave David respite that allowed him to sleep.

Bethany died peacefully at home after a 12 month illness with her family at her side – just as she had wanted.

Policy Issues

David and Lyn are extremely grateful for the support and love their family received during Bethany's illness. They felt it was a privilege to have her at home. However there are some lessons that can be learned from their experience that could improve the situation for families who are faced by a similar tragedy in the future. While the Governments should welcome and encourage community support and caring of its fellow members there are times when the State needs also to step forward and provide services where this is not available.

Factors that enabled Bethany to stay at home

- Her Father becoming her full time carer
- External financial support
- Community support with caring and respite

Financial Costs – The family not only lost a salary when David gave up work to care for Bethany but they also attracted a raft of additional costs. These included:

- Medication costs - while they received subsidised scripts they were at the Chemist daily and the costs mounted
- Much inflated heating and electricity bills due to all the additional people in the house and the electric bed
- Some equipment like the bed were provided while other equipment had to be rented

The Church provided regular financial support but for families without this a full time carer would not be possible and the result would be greater periods of hospitalisation. Alternatively families could face financial ruin when the length of time required for caring is unknown.

Out of hours Support – Bethany needed someone with her 24 hours per day and many of the overnight shifts were covered by friends. While the family received up to 2 nights per week of professional overnight support at times families without the network of friends would not necessarily be eligible for more professional support due to funding limitations. Given the savings to the health system with a child being cared for at home rather than in hospital there should be greater flexibility to provide higher levels of support on a case by case basis.

Co-ordination & Continuity – In essence David was the case manager and Bethany's advocate. While the GP was an active member of the care team locums had to be called out of hours, particularly when Bethany had trouble breathing. David knew from experience that with a quick response and anti-biotics Bethany's condition would improve but she was hospitalised a few times unnecessarily because locums were not available and not familiar with her case. Also the district nurses who came were often different and not familiar with Bethany's needs. Once Bethany could no longer talk she could not explain if she had pain and how to handle her without hurting her further. Greater co-ordination and information sharing with health professionals and continuity of care givers would improve the quality of care.

Grief Counselling – David and Lyn had grief counselling which they found very helpful but they understand that not all people have access to this service. They firmly believe that counselling should be automatically available to those who have lost a child to assist with an understanding of what is ahead of them.

Ben & Nicole's Story - Case study 2

- A sibling's story
- Paediatric services

Ben is a 22 year old young man who had an older sister Nicole with Rett Syndrome which is a neurodevelopmental disorder that affects girls almost exclusively. It is characterized by normal early growth and development followed by a slowing of development, loss of purposeful use of the hands, distinctive hand movements, slowed brain and head growth, problems with walking, seizures, and intellectual disability.

Nicole had learned to walk with assistance but she regressed to the stage where she was bedridden by the age of 12. Her epilepsy was severe. Nicole received services and respite through Very Special Kids and Ben got involved with their sibling program while he was still at primary school.

As a young boy Ben experienced mixed emotions about his sister. He was always asking why this was happening to his family. While he loved her he sometimes felt resentment towards her for all the things the family could not do – no family holidays, not enough attention on him and his younger brother. This resentment often turned into guilt because he understood that Nicole had very complex and immediate needs that just had to come first.

The family regularly used the family house at Very Special Kids while Nicole was in respite. Ben loved staying there – playing pool and games in the huge grounds. He particularly liked the sibling groups and camps where he could mix with other kids who had a disabled sibling. He found they understood how he felt and did not make him feel guilty – he could relax in their company.

Nicole died when she was 16 at Very Special Kids. The family stayed in the family house for the 3 weeks leading up to her death. They were all shattered and their home felt empty. Ben knew his mum was grieving and he did not want to put additional pressure on her so he lent on his friends in the sibling group, some of whom are still friends today.

Ben was able to keep going to the sibling group activities for as long as he needed because Nicole had died there at the age of 16. However if she had lived to over 18 then he would not have been eligible.

Ben cannot sing the praises of Very Special Kids loud enough. He believes that all states in Australia should benefit from the respite and family house, but for him, the sibling program was critical for him coming to terms with his family life that included a very special young woman.

Giulia's Story – Case study 3

Transition from the Paediatric to the Adult System

Giulia is an 18 year old young woman with Rett Syndrome who lives at home with her mother, Ursula, and her sister. Rett syndrome is a neurodevelopmental disorder that affects girls almost exclusively. It is characterized by normal early growth and development followed by a slowing of development, loss of purposeful use of the hands, distinctive hand movements, slowed brain and head growth, problems with walking, seizures, and intellectual disability.

In Giulia's case she never learned to crawl or walk, she has no self help skills, has epilepsy and has suffered from numerous bouts of pneumonia that have seen her hospitalised in ICU and close to death.

While Giulia was under 18 she attended the Glenallen Special School and she and her family received support and services through Very Special Kids and a state government program called Family Choices. Turning 18 meant that she had to transition from the paediatric system to the adult service system and she and her family could no longer access the respite they had been receiving through Very Special Kids, the special school which had been her daily activity for 13 years or the services through the Family Choices program.

When Giulia was 16 her mother began the search for comparable respite in the adult system and placed her name on a waiting list; she also looked for an adult day activity centre; she had to apply for an Individual Support Package (ISP) to replace the Family Choices program and there was no guarantee that there would a package available when Giulia turned 18. Ursula wonders how people who are not as familiar with the system cope.

Giulia's mother believes that they were lucky in that the ISP came through in time; a place opened up in the respite and day centre. They were also able to use the same carers that had worked with Giulia under Family Choices. However Ursula describes this transitional period as very stressful and difficult. Not only did they need to go back to the beginning and apply for support but the nature of the services they were able to receive were different to those in the paediatric system. For example the respite service was staffed by disability support workers while the paediatric respite had nurses on around the clock. Giulia required regular suctioning and some feeding via a tube. She has no speech and a high pain threshold so she is not able to indicate when things are wrong. Ursula was concerned that the disability support workers would not have the medical skills required. An ISP is only allocated if there is one available – what would she have done if the quota was full? She was afraid that she would need to give up work to look after Giulia.

Giulia spends her days at the day centre with many people in their 40s to 60s and Ursula has found that the day centre communicates less with her than the special school as most of their participants live in group homes not with families. Therefore Ursula designed a simple form that the staff could tick the boxes that would tell Ursula what had happened with Giulia at the centre that day.

Ursula knows a number of other families who are in the throes of making the transition from the paediatric to the adult system. For some, the child's high support needs have meant that they have not been able to find a respite or a day activity centre that is able to provide the care required. In these cases the task of caring is left with the families without relief.

Ursula would like to see a system where transition from one system to another is seamless and does not place additional strains on families when their day to day lives are difficult enough. It does not matter to her if the funding comes from one program or another; from one Government or another. The system just needs to work.