



Annual Report

2016-2017



PalliativeCare
VICTORIA
Living, dying & grieving well

All people with a life limiting illness and their families are supported to live, die and grieve well.

Palliative Care Victoria seeks to achieve this vision through collaborative leadership that informs, supports and advocates for quality palliative care.

During 2016-17, we have focused on four strategic priorities:

- A strong palliative care sector in Victoria
- Increased community awareness and capacity
- Equity of access to culturally responsive palliative care
- Effective and sustainable volunteering.



Palliative Care

Palliative care helps people to live well until they die. It relieves pain and symptoms, improves quality of life, supports family members providing care, and helps with grief and loss.

Specially trained palliative care staff provide expert help alongside the person's usual doctors to assist with complex care needs and promote their emotional, spiritual and cultural wellbeing.



“I think people shy away from palliative care because they're scared of it – it makes them think they're going to die, they don't realise it's there to help them live.” Palliative care patient.

“From personal experience palliative care makes such a difference to those who are dying and those who are sharing the journey with them!” Palliative care patient.

About Palliative Care Victoria

In 1981, we were established by the pioneers of palliative care in Victoria as an incorporated association. We have deductible gift recipient and charity status with the Australian Tax Office.

In 2016-17, we had eighty-eight organisation members and seventy-nine individual members.

This year the following volunteer board members provided sound governance: Dr. Judi Greaves (Chair), Michael Corry (Treasurer), Rachel Bovenizer, Dr. David Brumley, Dr. Barbara Hayes (Vice Chair), and Jade Odgers. During the year: Chris Campbell, Maurice Cruz and Fiona Palmer were replaced by Karen Conte, Dr. Claire Hepper, and Shannon Thompson.

The staff during 2016-17 were: Maree Chilton (Accounts Manager part-time), Mike Kennedy (Projects Manager), Heather Stevens (Office Manager) & Odette Waanders (CEO).

Challenges

- Over 40,000 Victorians die each year.
- 70% wish to die at home but over half die in hospital.
- Less than half of people who died in hospital received palliative care.
- 56% Victorians have a poor understanding of palliative care.
- Health professionals need more education about palliative care.

Aspirations

- Everyone understands and can access needed services and bereavement support.
- Early discussion, referral, planning and coordination occurs.
- The right care is provided at the right time and in the right place for each person.
- Specialist palliative care is strengthened, used effectively and is accessible locally.

Victoria's end of life & palliative care framework released by the Victorian Minister for Health, Hon. Jill Hennessy, in July 2016

Benefits

- Palliative care improves the quality of life, as well as how people die.
- Early introduction of palliative care is beneficial.
- Palliative care contributes to more effective use of health resources.
- Investment in palliative care is money well spent.

The National Centre for Social and Economic Modelling, University of Canberra, Research notes on the economic value of palliative care and end of life care, 2017.



Muriel, a palliative care volunteer, with Beryl

End of life care at home

Mary, aged 85, had advanced heart disease and multiple health issues. A district nurse visited daily to provide wound treatment to extensive leg ulcers. When Mary's condition deteriorated the district nurse called the local community palliative care service. The next morning, the palliative care nurse practitioner visited Mary at home to assess her care needs and discuss her wishes. Mary was living with her daughter, Sarah, and said she did not want active treatment and wished to die at home. Mary's distressing symptoms were quickly relieved and equipment provided. Sarah received ongoing guidance and psychosocial support as the primary caregiver and the GP was kept informed. Mary died peacefully at home 6 days later.

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“It was rewarding to fulfil my mother's wish to die at home. The support of the community palliative care team helped to make this possible.”



Inform

- 1,110 people improved their understanding of palliative care at community information sessions
- 40,634 unique visitors accessed information & resources on our website.
- We reached up to 1.67 million people via media coverage of 8 media releases.
- We distributed 18,000 palliative care resources.
- 54 issues of newsflash kept people informed about latest news, events & resources.

Seniors benefit from peer-led discussions about palliative care

We continued our successful partnership with the Council on the Ageing Victoria thanks to the support of the Ian Potter Foundation. Highly motivated, trained COTA volunteer educators facilitated 38 community discussions involving 638 seniors from across Victoria. One third had no prior knowledge of palliative care and over 90% learned important new information. Feedback from participants confirmed the value of these discussions about palliative care, dying and death.



"I heard lots of stories about people who would have benefitted from palliative care but who were not referred by the health system."
COTA volunteer peer educator.

Equity of access to culturally responsive palliative care

This year, we commenced work with the Dutch, Jewish, Russian, Hindi and Serbian communities to improve their access to culturally responsive palliative care. Thirty-one staff and volunteers from these communities received training that enabled them to provide information sessions attended by 472 community members, using new bilingual resources about palliative care.

We continued our valued relationship with the eleven ethnic communities we have worked with in recent years. Among these, the Chinese, Greek and Polish community organisations delivered more community sessions about palliative care.

We also trained 91 staff and volunteers of ethnic organisations who were keen to assist with appropriate referrals to palliative care.

We appreciate the support from the Victorian Government and Gandel Philanthropy with this work.



"Many of our seniors didn't know about palliative care because it is not widely available back home." Polish Community Council of Victoria aged care worker.

"We want our community aged care workers to know about palliative care so they can discuss it and make referrals before the person and their family are in crisis." United Spanish Latin-American Welfare Centre General Manager.



John and Trevor speaking with Hon. Jill Hennessy, Minister for Health, at the Dreamers Exhibition in Parliament in August 2016.

Personal Encounters at Parliament

Victorian MPs had the opportunity to consider the personal experiences and reflections of people with a life limiting illness via the Dreamers Exhibition, which we held in Parliament in August. The Minister for Health, Hon. Jill Hennessy, opened the exhibition which was attended by several of the people featured in the exhibition, as well as their family members.



Trevor

Palliative care in aged care

The need to improve access to palliative care in aged care was the theme of National Palliative Care Week in 2017. We provided five articles about different aspects of palliative care in aged care in Victoria to the media and four of these were published online by Australian ageing agendas and one in the rural health magazine.

Advocate

- 78% Victorian palliative care services contributed to our Victorian policy and advocacy activities.
- We engaged with 30 community peak body, chronic disease, ethnic and consumer representative organisations to advance our vision.
- As a member of Palliative Care Australia, we contributed to 8 national policy submissions and 3 position statements.

Improve access to high quality palliative and end of life care

In July 2016, we welcomed the release by the Minister for Health, Hon. Jill Hennessy, of Victoria's end of life and palliative care framework.

During 2016-17 we sought and received valuable information from 50 (78%) palliative care services regarding their capacity to meet demand, barriers to supporting people to die at home and resources needed to improve access to palliative care.

Voluntary assisted dying legislation

We prepared a very considered submission to the Ministerial Advisory Panel. This was informed by extensive engagement with our members on the practical implications for palliative care services and safeguards for people in vulnerable situations.

Strengthening palliative care volunteering

The PCV Managers of Volunteers Network met quarterly and provided opportunities for peer support, education, problem solving and collaboration.

Opportunities to further strengthen palliative care volunteering were identified by forty-one palliative care volunteer programs in response to our survey. These include: greater promotion of palliative care volunteering; diversifying palliative care volunteering roles; strengthening volunteer input into multidisciplinary teams; and increasing flexibility in sharing volunteers across services to support individual clients.

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“I learned a lot from the dementia workshop. I’m sure we will be working with more clients with dementia and their families in the future.”

Community palliative care volunteer.

“We do a very good job in the ‘living well’ and ‘grieving well’ parts of palliative care but I wonder whether there is a bigger role for volunteers in the ‘dying well’ phase.”

Regional Coordinator of Volunteers.

We also conducted a census of palliative care volunteering in Victoria, which indicates that around 1,500 active palliative care volunteers contribute to the quality of life of people with a life limiting illness and their families.

Support

- We responded to 633 inquiries for information and support (excluding our project work).
- We held 19 education & networking events attended by 617 participants.
- Forty-one palliative care volunteer programs provided valuable input into priorities for our volunteering strategy.

*Kaye Hose, Austin Health, and
Dr. Judi Greaves, PCV Board Chair*

Conferences

Seventy palliative care volunteers and their managers participated in our one-day volunteer conference in July. The program included volunteering with clients with dementia, running biography and death café programs, best practice in recruiting and supporting volunteers, and expanding the roles of volunteers in caring for a person at home.

Our two-day biennial conference in July included thought provoking keynote presentations on compassion in action, integrating palliative care into social care, building compassionate communities and UK developments in palliative care. The 266 people attended a range of workshops and presentations relevant to the conference theme: Inside Outside Palliative Care. Half-day workshops covered clinical skills, communications, cultural responsiveness, and sustainability.

“

“It’s given me more knowledge, new perspectives. Good to hear different voices and thoughts.”

“I have come away inspired to face the challenges ahead.”

“Keynote speakers were exceptional. Providing insight and addressing challenges while remaining realistic and positive.”



Future Strategy

We commissioned The Australian Centre for Social Innovation to undertake field research, co-design and prototyping activities with key stakeholders. This will inform future strategies to advance our vision in ways that are effective, complementary and sustainable.

Financial Information

Our financial report as at 30th June 2017 compared with 30th June 2016

INCOME	2017		2016	
	\$	%	\$	%
Grant & project income	659,011	75%	404,057	68%
Membership fees	74,748	8%	73,286	12%
Products & services	16,253	2%	7,210	1%
Donations	16,225	2%	19,870	3%
Investment income	115,139	13%	91,925	15%
Total Income	881,376	100%	596,348	100%
EXPENDITURE				
Projects	227,709	28%	142,936	23%
Products & services	96,157	12%	25,590	4%
Salary costs (excl. projects)	297,492	37%	313,231	51%
Occupancy, office & other costs	192,937	24%	136,534	22%
Total Expenditure	814,295	100%	618,291	100%
Net operating surplus/deficit	67,081		-21,943	
Other comprehensive income	12,552		-48,470	
Total comprehensive income	79,633		-70,413	
Net assets	1,255,168		1,175,535	

The Audited Financial Report for 2016-17 is available at <http://bit.ly/PCV-Report>.

Grants & Donations

We appreciate the grants and valued support received during 2016-2017 from:

A bequest of \$12,724 from the estate of Mr Jacob Groenewald and \$2,000 from John de Bono.



Appreciation

We wish to thank all those who have supported and contributed to the work of Palliative Care Victoria in 2016-17. We greatly appreciate the support of the Victorian Government, Department of Health and Human Services, our members, partners, philanthropic supporters and volunteers.

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“With thanks and respect to palliative specialists and carers. Defining dignity by your professionalism and compassion.”

Member of the public.



Carole, a palliative care volunteer, with Shelley

What matters most

David had advanced cancer and was receiving support from the local community palliative care service, along with his partner and two children. His greatest wish was to accompany his daughter down the aisle on her wedding day. Shortly before the wedding his condition deteriorated. Fearful of not being able to attend the wedding, he refused admission to hospital for intravenous rehydration. The hospital and community palliative care teams worked together to provide the care he needed. David took leave from the hospital for a few hours and was able to proudly walk his daughter down the aisle, enjoy her wedding and achieve his greatest wish.



“We used palliative care for my dad and fulfilled his last wish to die at home... special memories made forever.”

“My family used palliative care services to help my mother to remain at home to die and provided much needed support to our whole family at a very traumatic time.”



Extended family care at end of life

A very supportive Samoan family wished to provide end of life care at home for a 67 year old Samoan gentleman. He lived with his wife, son, daughter-in-law and grandchildren. Five other adult children lived nearby and visited often. The local community palliative care service became involved when he was discharged home from hospital following a stroke. He was bedbound and required relief of symptoms due to advanced cancer, as well as tube feeding. A palliative care consultant visited to discuss his advance care wishes and to address pain issues. Suitable equipment was provided with the support and advice of an occupational therapist. Palliative care nurses visited daily, provided guidance to the family on his care and helped them to understand the dying process and what to expect. The family chose to attend to all his personal care and support needs. The gentleman died at home surrounded by his family ten weeks later.



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