

annual report

2015 - 2016



PalliativeCare

VICTORIA

Living, dying & grieving well

Chair and CEO Report

Community need

The increasing need for high quality palliative care and end of life care due to population ageing and advanced chronic disease is well recognised. The implications of shortfalls in meeting need are experienced at a profoundly personal level.

This year around 400 people reached out to us by phone or in person for help in getting information, care and support for a person with a life limiting illness and their family. Their requests highlighted gaps and issues relating to: communication about prognosis, care options and what matters most; planning ahead, more timely referral to palliative care, and improved discharge planning; increased capacity to provide care at home (including emergency response and carer support); and improved access to palliative care in aged care.

Government priority

We were very pleased that the Victorian Government recognised these needs are a priority and undertook extensive community engagement to inform its new policy framework. We also appreciate the engagement of MPs who have taken the time to meet with us and to consider this in depth.

Supportive partnerships

We value the dedication of palliative care services across Victoria and their insights and contributions to our work, as their peak body.

Our cross-sector partnerships are also vital in building community capacity and expanding the impact of our work. This includes the Victorian Aboriginal Community Controlled Health Organisation, the Ethnic Communities' Council of Victoria, Council on the Ageing Victoria, many ethnic community organisations and the Health Issues Centre.

Our objectives to improve access to palliative care and to strengthen volunteering have been advanced through the Volunteer Ambassadors Project with COTA (Vic) and parallel work with palliative care volunteer programs, supported by the Ian Potter Foundation. A grant from Gandel Philanthropy has enabled us to extend our culturally responsive palliative care strategy to several smaller ethnic communities.

We also value the important relationship we have with the Department of Health and Human Services, our major funder.

Commitment and governance

The dedicated commitment and sound governance of the nine volunteer members of the Board and the small team of staff are important enablers of our mission and vision. We greatly appreciate the support of our members, funders, donors, partners, and many others who assist us to have a greater impact than would otherwise be possible.



Dr. Judi Greaves
Chairperson

Odette Waanders
CEO

Strategic Focus

Palliative Care Victoria's Strategic Plan 2013-2016 provides a clear focus on our purpose, priorities and desired outcomes.

Our Vision

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

Our Mission

To achieve our vision through leadership that informs, supports and advocates for quality palliative care.

Our Priorities

- A vibrant, strong and innovative palliative care sector in Victoria
- Increased community understanding of what to say and do when facing life-limiting illness, death, grief and loss
- Improved access by Aboriginal people and CALD communities to culturally responsive palliative care
- Growing innovative, effective and sustainable palliative care volunteering.

Action Areas

Our advocacy and engagement with the Victorian Parliament and a wide range of key stakeholders during 2015-16 has focused on 6 key action areas to improve access to high quality palliative care:

1. Increase community palliative care
2. Expand palliative care consultancy services
3. Improve access for diverse communities
4. End of life care a health care priority
5. Increase community awareness and capacity
6. Improve health care experience and performance.

Our Board Members

Full year

Dr. Judi Greaves, Chair (from 12/2015)
 Michael Corry, Treasurer
 Rachel Bovenizer
 Dr. David Brumley
 Maurice Cruz
 Jade Odgers
 Fiona Palmer

Part year

Michael Bramwell, Chair (to 12/2015)
 Dr. Brian Le (to 12/2015)
 Dr. Barbara Hayes (from 12/2015)
 Chris Campbell, (from 12/2015)

Our Patrons

Dame Beryl Beaurepaire AC DBE
 Sir James Gobbo AC CVI KStJ

Our Staff

Maree Chilton - Accounts (P/T)
 Mike Kennedy - Projects Manager
 Joyce Zhuang - Volunteer (P/T)
 Heather Stevens - Office & Member Services
 Odette Waanders - CEO

Palliative Care Australia

As a founding member of Palliative Care Australia, we value the opportunity to contribute to key national policy issues and initiatives to improve access to palliative care and end of life care. We also benefit from Palliative Care Australia's regular updates, insights and advocacy on relevant national reforms and policies.

Strategic Priority

Increased Community Understanding

Living well with chronic disease

Four out of five deaths in Australia are caused by advanced chronic illness. Although evidence shows that early access to palliative care is beneficial, there is a widely held misperception that palliative care is only for people with cancer and for the last days or weeks of life.

Living well with chronic disease was the focus of National Palliative Care Week in May 2016. Several people with chronic illnesses and their carers kindly agreed to share their stories to address this misperception.

Geoff and Faye



Geoff was hospitalised due to advanced diabetes, heart disease and an infection. Although he was discharged to a residential aged care facility his wish was to be cared for at home. This became possible when his wife, Faye, found out about the volunteer hospice service in Warrnambool. Hospice volunteers and district nurses assisted Faye to care for Geoff at home.

“It’s much better being at home. It wouldn’t have happened without the Hospice volunteers and the District Nurses.” Geoff

Per and Pamela



Per was diagnosed with Parkinson’s disease in 1993. His wife and carer, Pam says, “the specialist encouraged us to talk about the care he’d like when he gets worse, that’s terribly important. Per wants to be carried out of here. He feels very strongly about that, and so do I. We should be able to stay together in our home. Even so, I don’t believe that I would have been able to care for him at home as long as I have without the help from family, the aged care package, and the palliative care day respite service.”

New website launched

Best practice website design and user testing underpinned the development of our new website. Launched in December 2015, it is more engaging, easier to navigate, includes many stories and videos and integrates the previously separate online library. It also includes a member access area and the opportunity to list career and volunteer opportunities.



Strategic Priority

Improve access by Aboriginal people

A highlight this year was the inaugural *Cherie Waight Aboriginal Palliative Care Symposium* held on the 2nd December 2015. The Victorian Health Minister, Hon. Jill Hennessy, and over one hundred people paid tribute to Cherie Waight’s inspiring vision and legacy as the VACCHO Manager of the Victorian Aboriginal Palliative Care Program for 7 years, before her untimely death in 2014.

Aboriginal health and palliative care sector representatives discussed strengths and actions to further improve access to culturally responsive palliative care for Aboriginal people across Victoria.

Jointly hosted by Palliative Care Victoria and VACCHO, the symposium symbolized the importance of working together to address the gap in Aboriginal palliative care.



L-R Michael Bramwell, PCV Chair, Marcus Clarke, VACCHO Chairperson



Hon. Jill Hennessy, Minister for Health

Improve access for diverse communities

Our aim this year was to maintain the momentum and build on the success of the culturally responsive palliative care strategy undertaken in 2013-2015. Representatives from ethnic communities and palliative care services participated in two forums. We shared the successful outcomes as shown by the independent evaluation, discussed priorities for the next steps and provided opportunities to strengthen the relationships and understanding that underpin culturally responsive palliative care.

With the support of a grant from Gandel Philanthropy, we commenced work with five smaller communities to increase their awareness of palliative care, which includes bilingual information in Dutch, Hebrew, Hindi, Russian, Spanish and Yiddish.

Feedback from forum participants



"I found the group sessions were very beneficial because of the diverse skills and expertise that participants brought to the discussions and the range of views we needed to consider."

"Over the next year we will work on a diversity framework to be more inclusive, taking opportunities to meet with CALD communities and share what we do."



Strategic Priority

A Vibrant Palliative Care Sector

National voice

Advocacy and representation at the national level are vitally important given the major reforms in health, aged care, disability and primary care. During the year PCV participated in Palliative Care Australia's National Policy Advisory Committee and contributed to a range of position statements and submissions. These included the 2016 Federal budget and election, as well as inquiries into aged care and chronic disease.

At the state level, we participated in the 2040 Health Summit, contributed to the Dementia Action Plan and made representations to Government key decisions makers and MPs regarding the priorities for palliative care.

Information and education

Over 570 people working in palliative care received our weekly newsflash, which includes relevant news, information, links to resources and short reviews of journal articles.

Nine special interest group meetings covered interesting topics and provided opportunities for discussion and networking. We also planned our biennial conference to be held in July 2016.

Given the need to raise community awareness of palliative care, we organised and funded media training for 14 palliative care professionals and managers.

What Our Members Value Most About PCV from our 2016 Survey



"PCV is engaging, visible and pro-active in their work to improve the sector."

"Punch well above the weight of actual resources."

"As a peak body PCV provides useful information and leads debate to encourage informed discussion on pertinent issues."

"I've always found PCV to be full of initiative and always looking to do things better. Whenever I have contacted PCV, staff have always been very supportive and helpful, no matter what the issue."



L_R Odette Waanders, PCV CEO, Michael Bramwell, PCV Chair, Gabi Williams (centre), Parliamentary Secretary for Carers and Volunteers, Lina Hassan and Mesko Ayouz (VASS) at our 2015 AGM.

Strategic Priority

Strengthening Volunteering

Around 2,000 palliative care volunteers across Victoria contribute enormously to improving the quality of life of people with a life limiting illness and their families. The Victorian Government recognizes the importance of their contributions and funds Palliative Care Victoria to provide leadership, support and training to strengthen palliative care volunteering.

The Managers of Volunteers Network provides a valuable vehicle for networking, information sharing and peer support. The teleconference option facilitates participation by Managers of Volunteers from smaller rural and regional services.

Palliative Care Volunteer Ambassadors

With the support of the Ian Potter Foundation, we have developed resources and trained volunteer peer educators to deliver engaging information sessions about palliative care through their community networks. We engaged the Council on the Ageing (Victoria) to undertake the delivery of information sessions by their trained volunteer peer educators. These commenced in the second quarter of 2016 and 19 information sessions were delivered to a total of 273 participants (51% in regional Victoria). Forty-six percent of participants have provided feedback, which has been very positive.

These resources and 8 training sessions were also provided by Palliative Care Victoria to 120 palliative care volunteers interested in giving community information sessions about palliative care.



Palliative care volunteers from the Hume region who trained to be volunteer palliative care ambassadors.

Feedback

"As a part-time Volunteer Coordinator in a small rural palliative care service, I really value the opportunity to problem-solve and share strategies with other Volunteer Managers."

"I feel supported and affirmed and more confident to deal with the issues in our program."

"I now feel confident that with the Ambassador Kit I can go out and talk about palliative care in my community." Palliative care volunteer

"There has been a massive change since the start of the session in my knowledge about what palliative care does."
Information session participant

"I could see participants' perceptions about palliative care changing as the session progressed. Participants came up and thanked me, feeling very positive about palliative care."
COTA peer educator

Community Engagement

Website

www.pallcarevic.asn.au

Total Users 49,998

Page views 167,182

Website data below is for the new website from 17 December 2015 to 30 June 2016

Information for Families and Patients

- Symptom management 15,530 views
- About palliative care 12,035 views

Service Provider Search

14,630 views



12,162 views

Information for Health Professionals



Multicultural information:

5,085 views (70% Aboriginal)



PCV YouTube

4,591 views

19% increase on 2014-15



PCV Facebook

16,678 total reach

20% increase on 2014-15

Resources Distributed



11,633

Living, dying & grieving well
- a guide to palliative care



13,146

Other publications
and leaflets



2,894

Bilingual palliative
care leaflets



27,637
TOTAL

751

Inquiries & Referrals

(10% increase on 2014-15)



Presentations about our work

Community Events



5 exhibitions in metro and
regional areas.
Viewed by over 10,000 people

The Dreamers

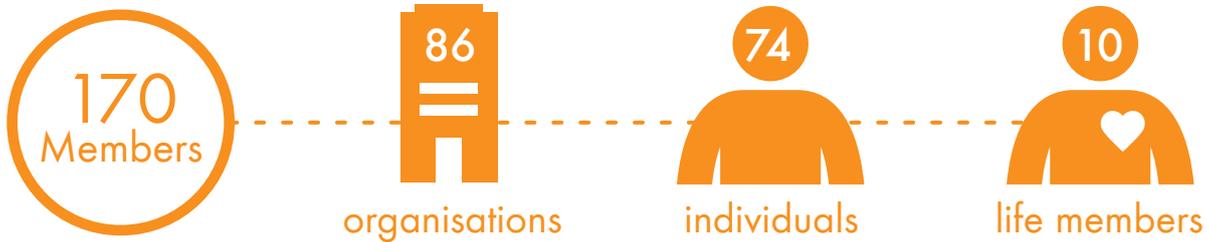


Information sessions about palliative care

19 sessions by COTA (Vic) for PCV
273 participants

Palliative Care Sector Engagement

PCV Membership



2016 Member Survey Feedback

51% organisation members responded

88% very satisfied/satisfied with our overall performance

Highest levels of satisfaction contribution to the sector, responsiveness to diverse communities, policy and advocacy, collaboration with other sectors

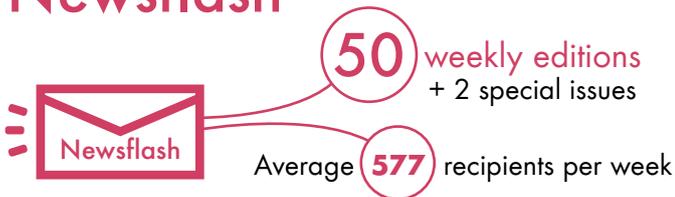
Education



Special Interest Groups



Newsflash



Member Events



Government Relations



2 communications to 128 Victorian MPs seeking support for palliative care priorities and funding

9 meetings with a total of:



11 MPs



5 advisors



Meeting with DHHS Secretary and visit to palliative care services



Participation in the Health Summit 2040 and submission to End of Life Choices Inquiry

End of life choice – care at home

Pat and Marg



Being cared for at home and making each day happy are what matter most to Pat, who has end stage kidney disease, and his wife, Marg.

“The palliative care is just A1, for me and for Marg. I’d describe it as most helpful and supportive... The nurses help me with everything they can. The palliative care volunteers provide company... get me out of this depression and help Marg too. We couldn’t do it without palliative care now,” says Pat. Marg agrees: “it’s not easy and I get tired sometimes, so they help me to get out and see friends. I know I can call them if I need them.”

John and Helen



Four years ago, at the age of 57, Helen was diagnosed with Alzheimer’s Disease. Her husband, John, has wound down his landscaping business to care for Helen at home with the support of a range of services including palliative care day respite.

“I’ve got to a point of acceptance,” says John, “but on the way there have been emotional hurdles. It’s going to be a progressive thing... We’ve decided that Helen will stay at home for as long as possible. To achieve this, we’ll increase the in-house services to assist Helen.”

Appreciation

Palliative Care Victoria greatly appreciates the financial support received in 2015-2016.

Grants



Donations

We greatly appreciate the ten donations we received totalling \$19,870, including:

Estate of Mr Jacob Groenewald	\$17,000
John de Bono	\$ 2,000

Legal and Taxation Status

Palliative Care Victoria is a not-for-profit association incorporated under section 8 of the Associations Incorporation Reform Act 2012. It is a health promotion charity endorsed by the Australian Taxation Office for charity concessions and as a deductible gift recipient. Donations of \$2.00 or more are tax deductible.

Treasurer's Report

2015-16 was a solid year for PCV, generating a small operating loss of \$24K.

Revenue dropped significantly as some funding was realigned, but expenses were constrained to a similar level. Project income in particular fell from \$254K to \$29K, and it is a priority of the Board to work with funders to demonstrate the value to the sector which flows from well-structured projects.

Negative movements in financial markets produced an unrealised loss on year-end revaluation of investments held, but this should be viewed in tandem with a strong growth in investment income through the year.

PCV closes the year with a healthy net asset position, with \$1.1 million in total reserves.

The Board continues to balance financial prudence - protecting the net assets - with the strategy of investing in activities to promote palliative care leadership, communication and projects throughout Victoria.

Michael Corry, Treasurer.

Financial Information for the Year ended 30th June 2016

	2016		2015	
	\$	%	\$	%
Revenue from Ordinary Activities				
Grants: Department of Health	369,647	62.0	623,011	46.8
Membership fees	73,286	12.3	72,371	5.5
Projects income - current year	29,410	4.9	253,938	19.1
Donations	19,870	3.3	115,994	8.7
State Conference	-	-	144,214	10.9
National Palliative Care Week	5,000	0.8	5,500	0.4
Products, resources	6,723	1.1	25,547	1.9
Other income	487	0.1	21,031	1.6
Investment income	91,925	15.4	68,621	5.1
Total income	596,348	100.00	1,330,227	100.00
Expenditure				
Project expenditure	137,175	22.1	702,232	56.9
National Palliative Care Week	5,761	0.9	5,093	0.4
Conferences, Seminars & Workshops	25,590	4.1	108,942	8.9
Salaries and on costs	395,148	63.7	530,700	43.0
Less amounts reflected in project expenditure	(81,917)	-13.2	(236,632)	-19.2
Communications	21,774	3.5	35,985	2.9
Occupancy costs	39,577	6.4	43,631	3.5
Administration	32,646	5.3	34,911	2.8
Consultancies	20,790	3.3	43,850	3.5
Depreciation	24,147	3.9	24,112	1.9
Less overheads to projects	-	-	(57,489)	-4.6
Total expenditure	620,691	100.00	1,235,335	100.00
Net surplus/(deficit) from ordinary activities	(24,343)		94,892	
Total other comprehensive income	(48,470)		5,151	
Total comprehensive income for the year	(72,813)		100,043	
Net assets	1,124,373		1,197,186	

The Audited Financial Report for 2015-16 is available at <http://bit.ly/PCV-Report>.

Positive community response to The Dreamers

Over 10,000 people experienced *The Dreamers* at five exhibitions in metro and regional Victoria this year. It demonstrates the power of personal stories in breaking through fears to consider our mortality.

It also demonstrates the valuable role of the arts in health promotion. Created by visual artist, Pippa Wischer, *The Dreamers* exhibition and book were developed with the support of palliative care services involved in caring for the people it features and Palliative Care Victoria.

The youngest dreamer, Cory, was proud to visit the exhibition at Ballarat. Relatives and friends have also viewed the exhibitions at the various art gallery and public library venues where it has been held, along with the many people frequenting those community spaces.



Cory was delighted to see his photo in the Dreamers Exhibition at the Ballarat Photo Biennale in August 2015.



Thousands of visitors to the Melbourne City Library in September 2015 viewed the Dreamers exhibition and read "The Two of Us" stories about palliative care volunteers and people with a life limiting illness.

Reflections on viewing the exhibition are overwhelmingly positive:

"Thank you for such a moving testament to the beauty hidden within our fleeting lives. Tears!"

"Beautiful! These people won't be forgotten. Some don't look close to death at all. Makes one realise how fragile we all can be."

"Intense. I am also struck by how 'well' even 'happy' some of these people appear. Oh the irony. Important work overall - particularly in our death phobic society. Well done."