Annual report
2017-2018
All people with a life limiting illness and their families are supported to live, die and grieve well.

Palliative Care

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

Specially trained palliative care staff assist with complex needs, which may be physical, emotional, social, cultural and spiritual. They work alongside the person’s usual GP and other healthcare providers.

Challenges

Around 40,000 Victorians die each year; at least 10,000 miss out on needed palliative care.

56% Victorians have a poor understanding of palliative care.

Health professionals need more education about palliative care.

Opportunities

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 accessible locally.

Victoria’s end of life and palliative care framework, 2016

Benefits

Palliative care improves the quality of life, as well as how people die.

Early introduction of palliative care is beneficial.

Investment in palliative care is money well spent.

NATSEM, University of Canberra, The economic value of palliative care and end of life care, 2017.

About Palliative Care Victoria

Through collaborative leadership we facilitate access to quality palliative care. We provide services to the community and palliative care providers, facilitating access and responsiveness.

Our volunteer Board members were: Dr. Barbara Hayes (Chair), Michael Corry (Treasurer), Shannon Thompson (Vice-Chair), Rachel Bovenizer, Dr. David Brumley, Karen Conte, Dr. Judi Greaves, Dr. Claire Hepper and Jade Odgers.

Our membership comprised 96 organisations and 78 individuals. Our staff of four expanded to five at the end of the year and was supported by 7 part-time volunteers.
2017-18 at a glance

Informed
3.4 million people through our awareness campaign and media coverage.
45,325 people who visited our website and downloaded 40,628 resources.
2,680 people through events, education and information sessions.

Advocated
PCV sought an extra $65 million a year to improve access to palliative care.
We engaged with all Victorian MPs, including: 33 meetings, briefings on 12 issues, and 344 letters.
PCV contributed to 10 national policy matters as a member of Palliative Care Australia.

Supported
We provided assistance to 686 people.
We engaged with 32 non-member organisations to support our work.
82 PCV members reported 89% overall satisfaction with our work.

Achieved
The Victorian Labor Government allocated an extra $55.65 million over 5 years in response to our advocacy to improve access to palliative care in regional and rural Victoria.
The Liberals-National Coalition announced its palliative care election commitment to invest an extra $140 million over 4 years to implement seven recommendations by PCV.

A Family’s Lifeline
The stress for Rachelle started with her husband’s diagnosis of a serious life-threatening heart condition. “Simon was only forty three and it changed our life. My best mate had gone down, the grief and loss for our old life kicked in. I started to get sick and our household needed help,” said Rachelle.

“Daddy’s day care’ - as our 3-year-old son Elijah calls the couple of days Simon spends each week - has made all the difference to us,” says Rachelle.

“The focus there is not on what’s wrong with you, but on how to enjoy today,” said Simon. “It has brought the cheekiness back for me. I make things there for Elijah and I help them out with new activities using modern technologies. That gives me a sense of purpose. I don’t feel like I’m in palliative care. As long as I’m still breathing, there are opportunities to be doing things and enjoying the life that I’ve got.”

“As someone with a terminal illness, I know how important good palliative care is."

“The palliative care team was the reason I could bring my husband home to die.”

Rachelle, Simon & Elijah
Equity of access to culturally responsive palliative care

Changes in aged care and disability funding have created widening disparities in the resource capacity of ethnic community organisations. These changes limited the capacity of some of our 16 ethnic community organisation partners to participate actively in this strategy this year.

Given the increasing numbers of ageing people within these communities and new waves of ethnic migration, there is a need to support and sustain the social capital that resides in ethnic community organisations and their vital contributions to the goals of Victoria’s end of life and palliative care framework.

During 2017-18, PCV provided training about palliative care to 55 staff and volunteers of ethnic organisations. Our strategy supported the Serbian, Chinese, Spanish, Jewish and Polish communities to provide a total of 22 community information sessions to 534 participants.

Karen community

Karen refugees fled to Victoria from a decades-long civil war and persecution by the Burmese military. Although a small community, it has complex needs for palliative care associated with past trauma and a younger profile of people with life limiting illnesses. We worked with the Karen community to develop bi-lingual information about palliative care for use in community information sessions.

Friendship helps with grief

“The palliative care people did everything they could for Maureen. I was there holding her hand at the end. It’s been a pretty hard run since and I was on the verge of going nowhere,” said Jimmy after the death of his wife of 48 years.

“I don’t think you ever get over it. But the friendship of Margo and Christine, volunteers from South West Healthcare’s Palliative Care Team, has made a big difference for me on the good and bad days. They’re both locals. Margo takes me for drives and we take fresh flowers to the cemetery. Christine gardens with me and we sometimes play bingo. Maureen and I were great bingo fans! I don’t think I would have got through without them,” said Jimmy.

“Palliative care should be an unquestioned human right.”

“People are waiting for palliative care services when waiting is the very last thing they can do.”
Community experiences

The key concerns raised in hundreds of calls from the public to PCV included:

- Quality concerns about palliative care and end of life care in residential aged care facilities.
- Failure to receive early referrals to needed palliative care.
- Poor communication, discharge planning and care transition experiences.
- Inadequate support for carers.
- Failure to meet the need for aged and palliative care services.

Real case examples

A man with advanced lung cancer was hospitalised after an unsuccessful suicide attempt due to uncontrolled pain. He had a young family and had not been referred to palliative care at any stage.

A husband called PCV seeking support to care for his wife who was expected to die within weeks. She was discharged home from hospital with no palliative care or other support in place.

A son called PCV concerned about his mother in a residential aged care facility who had unmanaged pain, end stage kidney disease and emphysema.

Supporting quality end of life care in aged care

Mrs Smith was living in a residential aged care facility. Aged 90 years, she had advanced dementia and aspiration pneumonia. Her family were unhappy with the care she was receiving and had requested a palliative care assessment. At this stage, her family had advised that if her condition deteriorated they wanted resuscitation and admission to hospital.

Eastern Palliative Care (EPC) received the referral and organised an assessment of Mrs Smith by their specialist consultancy team for residents with complex needs in aged and disability care facilities.

The EPC nurse and family social worker visited and assessed Mrs Smith. They then met with her family and discussed the likely progression of her disease, other complementary services available (such as in-reach and locum services) and provided printed information. They also showed the family how to feed their mother safely and provided much reassurance and support.

The EPC team members also met with the manager, the Director of Nursing and the clinical care coordinator of the aged care facility. This revealed that the family had been perceived as difficult and staff had avoided them. They discussed ways to improve communication with the family and the appropriate use of medication prescribed on an ‘as needed’ basis to manage Mrs Smith’s symptoms at the end of life.

The staff of the aged care facility responded very well to education about symptom management and provided very good end of life care to Mrs Smith. Mrs Smith died comfortably at the aged care facility 2 weeks later.
Maddie is part of our family

Marco is 13 years-old and lives with a very rare, life-threatening condition that has caused severe epilepsy and intellectual disability.

“It was hard recognising that we needed help. But Maddie, a volunteer from Very Special Kids has been a part of our family now for two wonderful years and it has changed our lives for the better,” said Caterina, Marco’s mother.

“We go on outings and have great fun together. You should see Marco’s face shining with excitement! I also spend time with Lucas doing things he enjoys and might not be able to do otherwise,” said Maddie.

When Maddie takes the boys out, Caterina can enjoy time with her husband, Matthew. “We are very grateful. Trust is a big thing. We surround Marco with people who are supportive and loving, so he reaches his full potential, and we make sure Lucas doesn’t miss out,” said Caterina.

Strengthen palliative care volunteering

The PCV Managers of Volunteers Network members reflect the diversity in the size and needs of palliative care volunteer programs across metro, regional and rural Victoria. It met at metro and regional locations and included teleconferenced participants. Three working groups of the Network considered support for small rural programs, professional development of managers of volunteers, and volunteer development.

Two workshops on the A to Z of Volunteer Management were well-received by 23 participants. We also organised a risk management workshop and scholarships for ten people from rural and regional palliative care volunteer programs to attend EPC’s intensive biography training workshop.

PCV’s popular Volunteering Newsflash was sent to an average of 760 people on a monthly basis from February to November.

The PCV Volunteers Conference held on 23 May 2018 generated a very positive response from the 220 participants, of whom 85% were volunteers. Stimulating plenary sessions included storytelling and health communication, compassionate communities in action, spirituality and self-care, and partnerships in palliative care volunteering. The breakout sessions included person-centred care, community engagement, biography, supporting volunteers, and a speed talks session. Almost half of the presenters were volunteers.

“I was inspired by the variety of work volunteers are doing to assist clients and their families to live, die and grieve well.”
**Strategic Plan 2018-2022**

Our strategic plan 2018-2022 identifies four strategic objectives that will provide the focus of our work in advancing our vision and the goals of Victoria’s end of life care and palliative care framework. It is available at bit.ly/PCVSP18-22 and a summary at bit.ly/PCVSP18-22-Short.

**Financial Information**

Our financial report as at 30th June 2018 compared with 30th June 2017

<table>
<thead>
<tr>
<th>INCOME</th>
<th>2018</th>
<th>%</th>
<th>2017</th>
<th>%</th>
</tr>
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<tbody>
<tr>
<td>Grant &amp; project income</td>
<td>619,674</td>
<td>72%</td>
<td>659,011</td>
<td>75%</td>
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<tr>
<td>Membership fees</td>
<td>81,033</td>
<td>9%</td>
<td>74,748</td>
<td>8%</td>
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<tr>
<td>Products &amp; services</td>
<td>11,548</td>
<td>1%</td>
<td>16,253</td>
<td>2%</td>
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<tr>
<td>Donations</td>
<td>6,659</td>
<td>1%</td>
<td>16,225</td>
<td>2%</td>
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<tr>
<td>Investment income</td>
<td>138,481</td>
<td>16%</td>
<td>115,139</td>
<td>13%</td>
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<tr>
<td><strong>Total Income</strong></td>
<td>857,395</td>
<td>100%</td>
<td>881,376</td>
<td>100%</td>
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**EXPENDITURE**

<table>
<thead>
<tr>
<th></th>
<th>2018</th>
<th>%</th>
<th>2017</th>
<th>%</th>
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<tbody>
<tr>
<td>Projects</td>
<td>313,289</td>
<td>41%</td>
<td>227,709</td>
<td>28%</td>
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<tr>
<td>Products &amp; services</td>
<td>0</td>
<td>0%</td>
<td>96,157</td>
<td>12%</td>
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<tr>
<td>Salary costs (excl. projects)</td>
<td>292,903</td>
<td>38%</td>
<td>297,492</td>
<td>37%</td>
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<td>Occupancy, office &amp; other costs</td>
<td>163,773</td>
<td>21%</td>
<td>192,937</td>
<td>24%</td>
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<tr>
<td><strong>Total Expenditure</strong></td>
<td>769,965</td>
<td>100%</td>
<td>814,295</td>
<td>100%</td>
</tr>
</tbody>
</table>

- Other comprehensive income: 32,905 (2018), 12,552 (2017)
- **Total comprehensive income**: 120,335 (2018), 79,633 (2017)

**Net assets**: 1,375,503 (2018), 1,255,168 (2017)


**Grants & Donations**

We greatly appreciate the financial support received during 2017-2018.

We received a bequest of $5,000 from the estate of Mrs Irene Kazimiera Maria Gumolka and ten other donations.

**Appreciation**

We wish to thank the Victorian Government, the Department of Health and Human Services, our members, partners, volunteers, staff and all who supported our work this year.

"From personal experience, palliative care makes such a difference to those who are dying and those who are sharing the journey with them."
A special moment in the Tullamarine wind ...

“I can’t believe it’s September again. I’m going to have to prepare for another Christmas and plant tomatoes for the summer,” says Betty, a 78-year-old lady who receives palliative care at home from Melbourne City Mission.

Betty’s says this with astonishment.

For many years, she has lived with chronic obstructive pulmonary disease (COPD). Betty says this terminal lung disease “makes it very hard to breathe and can be really scary.”

“People find it difficult to accept that I’m not going to get better. Friends phone but visits are rare, except from my family.”

Fortunately, Betty’s life has improved and she no longer feels so lonely since the Melbourne City Mission Community Palliative Care Team became involved 18 months ago.

Trained palliative care nurses visit Betty regularly and help to manage her symptoms and pain.

“When I’m very unwell, I think that must be how dying feels. But after the palliative care nurse visits and there is no need to admit me to hospital, I’m very relieved. I realise I’m not going to die just yet,” explains Betty.

Palliative care counsellors have helped Betty to manage her anxiety and to discuss her end of life wishes.

Chris is a trained volunteer member of the team who visits Betty each week. She has helped Betty to get her affairs in order. They also garden, shop and go on outings together.

“Because I was afraid of going to hospital in the future, Chris took me to visit the Northern Hospital Palliative Care Unit. I now feel less afraid of that possibility,” Betty says with relief.

Betty told Chris she would like to have her ashes scattered in the wind, so Chris organised a special tour of the Woodlands Homestead in Tullamarine by Paul, a Parks Victoria ranger. Paul drove them around the park and to the highest point.

“I was struck by the beauty of the landscape and up there I felt I was floating in the breeze. It made me feel free. I haven’t felt that way for years due to my illness. It was marvellous,” says Betty.

“I don’t think I would have lived as long as I have without the palliative care and support provided by the staff and volunteers at Melbourne City Mission. They help me to enjoy my life more and keep my sanity. I know someone is keeping an eye on me and they’ll get help if I need it,” concludes Betty.