Annual Report 2017–2018

Palliative Care
NEW SOUTH WALES

This report prepared by Linda Hansen, Executive Officer and
Alex Huntir, Manager Volunteer Support Project Palliative Care NSW Inc

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02

From the President and Executive Officer

Throughout the year 2017/18, Palliative Care NSW has been involved in numerous events and activities across NSW to achieve our strategic objectives

National Palliative Care Week

PCNSW launched National Palliative Care Week on a Sunday morning over a cup of tea at the iconic Art Gallery of New South Wales in May this year. It was a wonderful opportunity to launch the innovative new arts program that is being developed in conjunction with the AGNSW and UTS, designed to support palliative care patients, carers and palliative care workers. We were fortunate to have the Hon. Bronnie Taylor attend this function in support of PCNSW, and officially launch National Palliative Care Week.

During National Palliative Care Week for 2018 the annual Palliative Care NSW Professional Education Day was held at Rooty Hill RSL. As in past years the day was a great success thanks to the hard work of the organising committee.

Left: Julie Flood, Linda Hansen, Kate Bowman and Alex Huntir at Rooty Hill RSL for Professional Education Day.
Right: Linda Hansen at the launch of NPCW at the Art Gallery of NSW.

03

Website launch NSW, Parliament House

Membership

As a membership-based organisation, our support base of palliative care professionals and others with an interest in palliative care is fundamental to us.

We welcome new members and thank all members for your ongoing support and we continue our commitment to making your membership fruitful and professionally supportive.

Leading into the new financial year we sent regular reminders to our current members that it was time to renew their membership. We had several gifts generously donated from local businesses that also allowed us to offer an incentive for our members to renew during the month of July, and go in the prize draw.

In July 2017, Palliative Care New South Wales hosted a member only event at NSW Parliament House to officially launch our new and updated website.

As we move forward, we are developing a new database system for our members that will automatically renew memberships and provide a more interactive experience you.

Voluntary Assisted Dying

On the 21st September, 2017 the Voluntary Assisted Dying Bill was introduced into NSW Parliament by the Hon. Trevor Khan. The Bill was defeated in the Legislative Council by 20 votes to 19. However, with the recent success of a similar Bill in Victoria we are certain that after the next NSW State Election Voluntary Assisted Dying will again be at the forefront of NSW politics. We will continue to monitor new developments and remain engaged in the debate.

Community Engagement – Art Appreciation Program

Still in the early stages, the art and palliative care program that has been developed in collaboration with UTS and AGNSW can assist the community in gaining a better understanding of palliative care and end-of-life care. Increasing their resilience in talking about issues associated with life-limiting illnesses, dying and death.

And although arts engagement has been carried out in the palliative care environment in the past, this will be the first program of its kind. This program will build on from the work of Dr Gail Kenning and Danielle Gullotta, that has seen the Art Gallery of NSW offering art access programs similar to this for people living with dementia and their carers since 2009, with great success.

A specially curated tour will see trained art guides select 2 or 3 art works for viewing by the group.

All of the artworks that are chosen will be different in their style and subject matter, and can be used to start a discussion about what matters most to people – be it ritual, reflection or materiality?

Everyone who participates in this will almost certainly have a different experience whether physically, emotionally or spiritually. And while this can make evaluating a program like this challenging, we are expecting as many positive experiences and outcomes as the Dementia and Art Program has achieved.

Acknowledgements

We acknowledge with grateful thanks all of our supporters over the last year. We also thank our Management Committee for their steadfast commitment and acknowledge their significant role in enabling us to achieve beyond our Strategic Objectives.

Linda Hansen
Executive Officer, Palliative Care NSW

Therese Smeal
President, Palliative Care NSW

Our People

Management Committee

Therese Smeal
President

Deborah Parker
Vice President and President Elect

Peter Cleasby
Secretary

Michael Edgar
Treasurer

Melissa Cumming

Peter McVey

Gerry Dixon

Joan Ryan

Colleen Carter

Janelle Chruszcz

PCNSW Staff

Linda Hansen
Executive Officer

Alex Huntir
Manager Volunteer Support Services Programme

Megan Burke
Policy Officer

Kate Bowman
Policy Officer

Julie Flood
Policy Officer

Highlights

Attendance

NSW Volunteering Conference
21 July 2017, Parkes

PCNSW Website launch
27 July 2017, Parliament house

Euthanasia Symposium
August 2017, Westmead

National Health Innovation and Research Symposium
August 2017, Coffs Harbour

Palliative Care Australia National Conference
September 2017, Adelaide

2nd International Conference on End of Life Law, Ethics, Policy and Practice
September 2017, Halifax, Canada

Public Health and Palliative Care International Conference
September 2017, Ottowa, Canada

Voluntary Assisted Dying Forum
September 2017, Parliament House, Sydney

Hosted a film screening of Hippocratic, joined by Dr Raj
September 2017, George St Cinemas

Running Volunteer Programs for Culturally and Linguistically Diverse (CALD) backgrounds
30 November 2017

Community Forum: Helping people with intellectual disabilities understand dying and death
November 2017, Surry Hills

NSW Network of Managers of Palliative Care Volunteer Services
11 December 2017, Surry Hills

NSW Network of Managers of Palliative Care Volunteer Service
5 March 2018, Surry Hills

Spirituality and Reflective Practice and Palliative Care Forum
7 March 2018, Wagga Wagga

NCOSS and NSW Legislative Council Workshop on Parliamentary Inquiries
14 March 2018

Aboriginal Cancer Network Forum
20–21 March 2018, Sydney

Patient Experience Symposium
9–10 April 2018, Sydney

Spirituality and Reflective Practice in Palliative Care Forum
16 April 2018, Mt Druitt

Being Present: Spirituality, Art, and Experience in Palliative Care
2 May 2018, Port Macquarie

The NSW Managers of Palliative Care Volunteer Services Managers Conference
7–8 May 2018. Coolangatta Estate

National Palliative Care Week
20 May 2018, Art Gallery of NSW

Volunteers Conference Palliative Care Vic 23 May 2018, Melbourne

PCNSW Professional Education Forum
25 May 2018, Rooty Hill

10 Things to Know Before you Go Workshop
29 May 2018, Mt Druitt

NSW Community Pharmacy & Palliative Care Workshop (CEC)
May 2018, North Sydney

NSW Network of Managers of Palliative Care Volunteer Services
4 June 2018, Surry Hills

Death Literacy Conference
7–8 June 2018, Homebush

Being Present: Spirituality, Disruption and Reflection in Palliative Care
19 June 2018, Warilla

NCOSS 2018-19 NSW Budget Breakfast
26 June 2018, Sydney

Highlights

Media & Communications

587
new facebook followers

260
individual Facebook posts

2000+
number of Facebook users we reached

1592
downloads of our research and documents

21
countries reading our work by downloads

270+
phone enquiries from the public

Australia
New Zealand
Canada
US
UK
Lithuania
France
Belgium
Switzerland
Turkey
Jordan
India
Pakistan
Afghanistan
The Philippines
Indonesia
South Africa
Uganda
Nigeria
Kenya
Egypt

Five areas of focus

AWARENESS

Raise awareness about palliative care through the ongoing provision of relevant and up to date information and education.

PARTNERSHIPS

Increase the membership base to strengthen the core group of those engaged with palliative care. Build partnerships with related sectors, strengthen relationships with other relevant organisations.

LEADERSHIP

Increasingly position PCNSW as a thought leader in the area of palliative care. Influencing the discussion, shaping policy, informing the agenda etc.

GOVERNANCE

Strengthen the management committee through increasing the skill mix and diversity of it, including people with different areas of expertise.

FUNDING

Ensure financial success, increase funding through growing membership base and through seeking government funding. We developed Strategic Objectives to address the focus areas.

STRATEGIC OBJECTIVE 1

Provide professional support services to our members and raise awareness amongst health professionals and the public

The annual Professional Education Forum was held in Rooty Hill this year. Attendance at this forum was free for PCNSW members, and is targeted to palliative care professionals. The goal of this forum was to increase the level of specialist palliative care knowledge for attendees.

There have been several other forums throughout the year including Community Forums. Working with a range of community organisations and consumers to explore important issues in palliative care, gain a community perspective on programs and initiatives, inform policy submissions and advocate on behalf of people with life-limiting illnesses, their family members and carers.

These included:

- Spirituality and Reflective Practice and Palliative Care Forum
- Being Present: Spirituality, Art, and Experience in Palliative Care Forum
- PCNSW Professional Education Forum
- Community Forum "Helping people with intellectual disabilities understand dying and death"

Events we have hosted such as our website launch at NSW Parliament House and the film premiere of Hippocratic (co-hosted with PCA) have given us opportunities to meet our members face-to-face and engage with the public around the topic of death and dying.

Communication with members and the public has increased steadily over the year. Facebook continues to be the most effective platform on which to link to our own original content as well as current news events in the palliative care world. With over 500 new followers on Facebook it is an increasingly popular medium. Kate Bowman has incorporated the first podcast into our social media repertoire, utilising this emerging platform we hope to engage with a more diverse audience now and in the future.

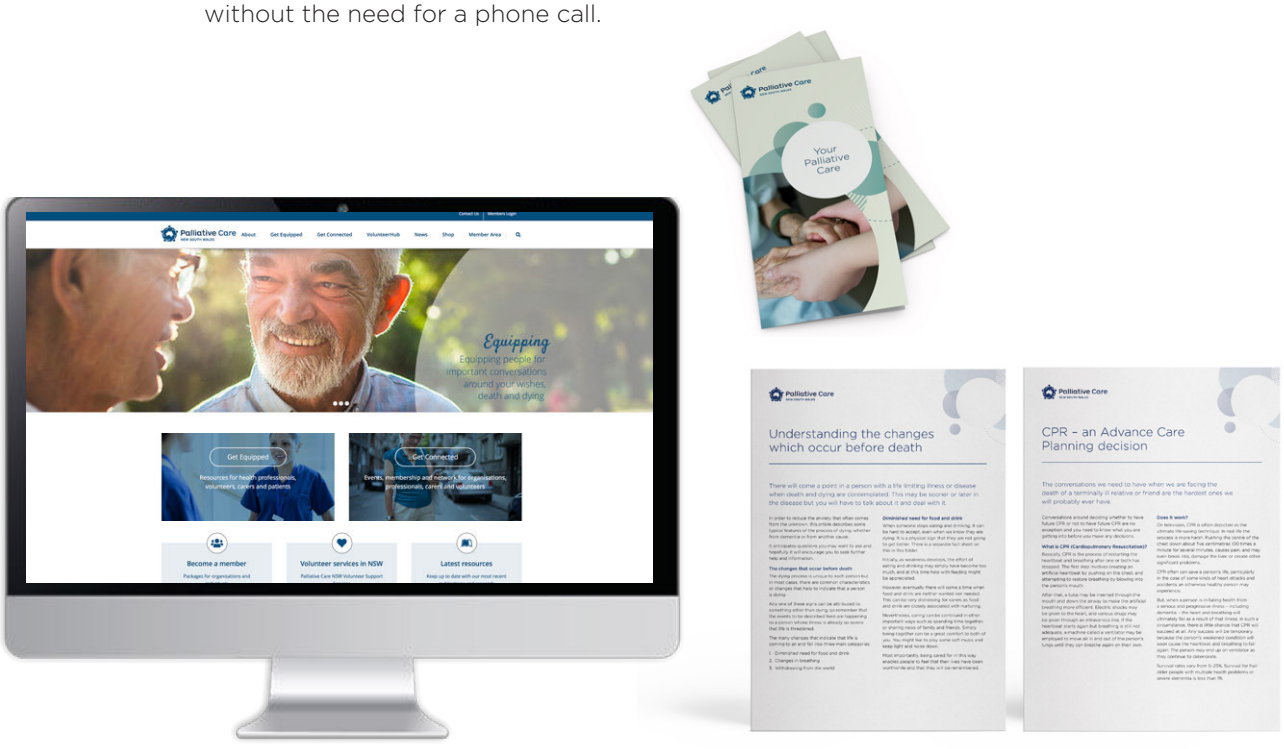
Regular newsletters throughout the year have provided our members with palliative care news, stories, job opportunities and research. Complemented by the now online Pallium, released quarterly.

STRATEGIC OBJECTIVE 2

Provide a range of information services to patients, their families and/or carers

We continue to respond to the frequent telephone enquiries from members of the public, GPs and RACFs, in search of information and guidance about access and referral to palliative care services across NSW. There has been a small decrease in phone enquiries since 2016. This could perhaps be due to the newly designed and more comprehensive website format and content effectively addressing some general enquiries that patients, families and carers may have without the need for a phone call.

All existing resources about palliative care, end of life care, aged care, planning ahead as well as dementia specific and other disease specific resources are available for download via the website. Printed resources are also available free of charge to members and at a cost recovery basis to non-members.



STRATEGIC OBJECTIVE 3

Volunteers

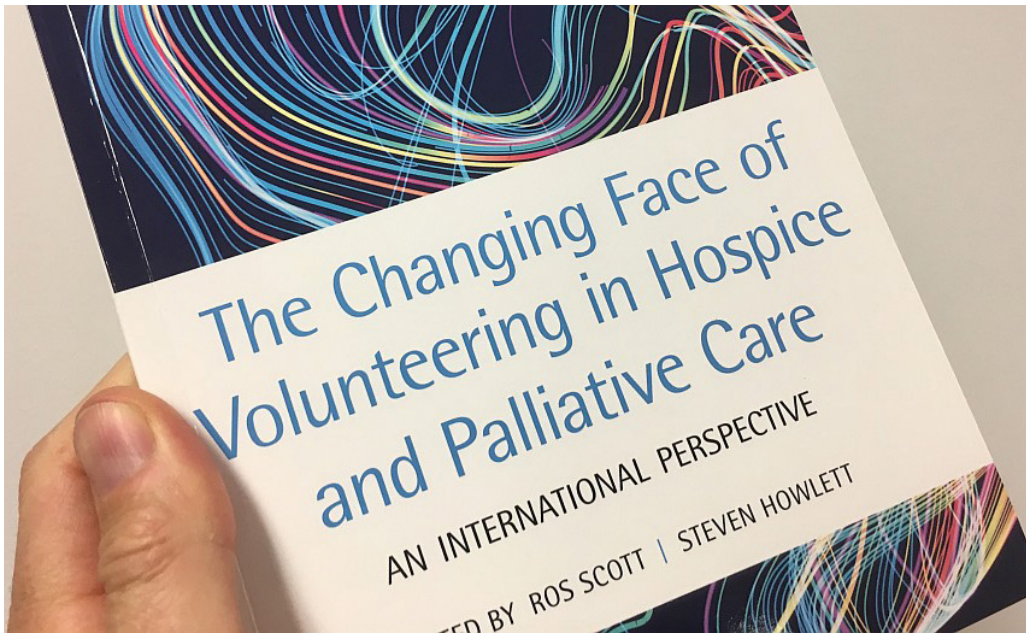
The *Volunteer Support Services Programme* continued to champion and to provide support for palliative care volunteer services across NSW during the 2017–2018 financial year. The Volunteer Support Services Programme is run by Alex Huntir and Kate Bowman.

In the second half of 2017 Kate Bowman continued her involvement with the Western NSW LHD Volunteer Project. Using a health promoting palliative care approach the project aims to form, facilitate and support local collaborations between clinicians and volunteers from a partner organisation. Kate was involved in a large scale stakeholder mapping and reporting exercise. In 2018 we have continued our involvement through report writing and attending values workshops with the Volunteer Project team.

Alex and Linda spoke about the work of the Volunteer Support Services Programme at the 5th Public Health Palliative Care International Conference in Ottawa in September 2017.

In the first half of 2018 we hosted a series of forums around the state with the aim of bringing together clinicians and volunteers on a subject of common interest to palliative care. These were held in Wagga Wagga (March), Mt Druitt (April), Port Macquarie (May), Warilla (June). We are grateful to Kate Englebrecht for her presentations on Spirituality and Palliative Care, as well as Dr Pippa Blackburn and Bernadette Orange for their presentations at the Warilla forum.

L-R: Kate Englebrecht, Bernadette Orange and Dr Pippa Blackburn



Above: New publication by Oxford University Press.

In May 2018 we hosted the inaugural Managers of Palliative Care Volunteers Conference at Shoalhaven Estate, near Berry. The conference bought together managers from around the state to learn and share information about recruiting, supporting, mentoring and managing palliative care volunteers, as well as self-care and fundraising. Thank you to our sponsors and presenters, including Michael and Ann Barbato.

In June we were published in a new release by Oxford University Press *The Changing Face of Volunteering in Hospice and Palliative Care: An international perspective* after Ros Scott, Volunteering Researcher & Consultant and Honorary Research Fellow at the University of Dundee, asked Alex to write a chapter on palliative care volunteering in Australia. Also included was a story about life as a palliative care volunteer by Heidi Hodder and a poem by palliative care volunteer Donna Mckenzie, each volunteer from NSW.

Also in 2018 Kate finished work on the Snapshot 2018 report, the result of an extensive telephone survey of palliative care volunteer managers about their service, their volunteers and their plans for the future.

The 2017–2018 financial year represented the end of the 4th year of funding for the *Volunteer Support Services Programme* by NSW Health. We are grateful for their continued support of palliative care volunteering in NSW!

STRATEGIC OBJECTIVE 4

Membership

Representing and serving our members is an important goal for Palliative Care NSW. Our limited resources make this challenging, however with some generous sponsors we were able to offer incentives for people to join and renew their membership for 2018. Combined with the discounted registration fees offered to members for the November conference we have seen our membership increase by 40% for the year. The development of a new database will hopefully support further increases in our membership base, as well as opportunities for better engagement.

STRATEGIC OBJECTIVE 5

Input to policy development

The Voluntary Assisted Dying Bill was introduced into NSW Parliament in September 2017, and was defeated in a vote of 19 to 20.

Prior to this, Palliative Care NSW provided a submission to the working group based on the draft Bill, primarily noting the lack of consultation with the palliative care sector and health sector more broadly.

Palliative Care NSW wrote to all members of NSW Parliament to highlight a range of shortcomings, deficiencies and gaps within the Bill and advised Ministers that the position of PCNSW was that the Bill should not be supported.

STRATEGIC OBJECTIVE 6

Strive for excellence in the governance of our Association

We acknowledge and thank the members who retired in 2017-18 for their significant commitment and generous contribution to the Management Committee. To achieve excellence in governance the Management Committee is committed to nurturing and sustaining a talented leadership group. The collective diversity of expertise and experience, held by individuals who bring to the organisation a broad range of skills acquired within different roles, is valued by Palliative Care NSW in enabling it to remain responsive to the current and impending issues affecting palliative care in NSW.

To support the Management Committee a subcommittee structure has continued so that the Five Areas of Focus of the organisation (Awareness, Partnerships, Leadership, Governance and Funding) can be implemented, monitored and evaluated by committee members. The subcommittees have been provided with secretariat support from staff member Julie Flood and have met second monthly.

In order to undertake and sustain new projects PCNSW seeks to expand its funding base each year as part of its excellence in governance work. This work includes making applications for philanthropic grants and seeking corporate and community partners and sponsors, in addition to continuing to grow the membership.

Treasurer's report

Income Statement for the year ended 30 June 2018	2018 $	2017 $
Income		
Grants	427,900	547,592
Interest Received	7,678	8,934
Donations	735	16,663
	436,313	**573,189**
Other income		
Administration Charges	-	81,250
Education	1,018	-
Membership Fees	11,825	14,073
Managers of Volunteers	7,011	-
Conference Registrations	(354)	91,175
Conference Sponsorship	1,364	89,842
NPCW Week	5,080	5,436
Sundry Income	-	200
	25,944	**281,976**
	462,257	**855,165**
Expenses		
Accountancy	4,083	12,939
Administration Charges	84,636	86,388
Advertising & Promotion	18	260
Auditors Remuneration - Fees	300	2,600
Bank Charges	643	1,340
Computing Expenses	10,368	23,305
Consulting Fees	-	160,963
Conference Expenses	10,903	85,952
Courier	-	14
Depreciation	3,759	6,124
Education Expenses	6,778	15,710
General Expenses	824	418
Insurance	4,397	3,404
Postage	1,661	6,234
Printing & Stationery	9,174	37,840
Employee Provisions	(18,687)	36,400
Rent	2,961	13,595
Subscriptions	1,200	109
Superannuation	27,699	27,312
Telephone	1,061	2,598
Travelling	39,720	58,572
Wages	294,316	287,498
	485,814	**869,575**
(Loss) profit before income tax	**(23,557)**	**(14,410)**

Palliative Care
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