

# Annual Report 2015–2016

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# From the President and Executive Officer

2015/16 was a significant year for Palliative Care New South Wales and the palliative care community in general. In a year full of activity and highlights, three stand out - the second full financial year of the Volunteer Support Project, National Palliative Care Week and planning for the much anticipated PCNSW Biennial State Conference: Transforming the Landscape, hosted by our palliative care colleagues in Broken Hill.

During 2015/16, the business of dying was launched into the public arena in an unprecedented way. Euthanasia and assisted dying has received public prominence with national debate and state government legislation discussed in South Australia, Victoria and Tasmania.

The challenge that we accept is to reinforce the focus of palliative care, to continue the care for those with life limiting illness and to strive to improve access to palliative and end of life care.

### **Volunteer Support Project**

This was the second full year of the Volunteer Support Project with much being achieved in a relatively short time. The highlight of the year was the partnership built between PCNSW and Western Sydney LHD to establish a Volunteer Hub at Mt Druitt Hospital. The Hub will become a 'centre of excellence' for palliative care volunteering in NSW.

We also launched *Palliare: A Handbook* for *Palliative Care Volunteers in NSW* in October with Minister for Health Jillian Skinner at the NSW Parliament House.

Alex Huntir, Project Manager also developed a comprehensive website for the project and for all things palliative care volunteering.

# National Palliative Care Week 2016

This year PCNSW took an innovative approach during National Palliative Care week and engaged in partnership with Jewish House, a non-denominational self-funded charity and crisis centre in Sydney to present a week long art exhibition, 'Reflections of Care', featuring works by five artists touched by the journey toward death.

We support the potential for the arts to make a difference in the journeys of those with life limiting illness, their carers and all professionals and volunteers working in palliative care. Below: The crowd at the launch of NPCW in May. 2016. Bottom right: Minister Skinner at the Launch of Volunteer Handbook Palliare.





Below: Dr BJ Miller, invited guest speaker for the Biennial State Conference. Right: Megan Burke, Linda Hansen and Bron Heron at a meeting of the Palliative Aged Care Network in Dec 2015.



## Biennial State Conference 'Transforming our Landscape'

Much of the work of the year was allocated to organising our biennial state conference – this time in Broken Hill. We were successful in securing the services of an international guest speaker, Dr BJ Miller, who attracted significant interest from sponsors and from media. We were successful in obtaining a number of grants and sponsorship agreements that made it possible to offer an extremely good value for money conference to offset the additional costs associated with travelling to a remote location.

### Aged Care

We have increased out engagement with the Aged Care sector through our support of the Palliative Care in Aged Care Nurses group in their advocacy for improved access to palliative care and end of life care for those in residential facilities. We also participated in the parliamentary enquiry into 24/7 RNs in RACFs.

### **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.



### Grants

We gratefully acknowledge special funding granted from the Ministry of Health and the Ian Potter Foundation that assisted us in attracting Dr BJ Miller, Specialist Hospice and Palliative Care Physician from San Francisco as a Keynote Speaker for our Biennial State Conference to be held in October 2016.

### Donors

We receive regular donations from workplace giving arrangements and thank all donors most sincerely for your support.

### Acknowledgements

We acknowledge with grateful thanks all of our supporters over the last year.

We especially thank our Management Committee for their unflinching commitment and acknowledge their significant role in enabling us to achieve beyond our Strategic Objectives.

Linda Hansen Executive Officer, Palliative Care NSW

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Therese Smeal President, Palliative Care NSW



# Highlights

Quality Palliative Care is realised when strong networks exist between specialist Palliative Care providers, primary generalist and primary specialist and support care providers and the community, enabling them to work together to promote an optimal quality of life and a good death.

# Communication

500+

Phone enquiries from the public

1245

Facebook likes since November 2015

300

Database of people receiving our Member Update email

# **Publications**

1500 Copies of *Palliare* distributed in NSW

Copies of *Palliare* 

downloaded online

Downloads of all publications



### **Events**

# May 2016

Launch of NPCW Five Artists exhibition. Professional Education Forum.

# Oct 2017

Launch of Volunteer Handbook *Palliare* 

# Oct 2015

Professional Education Forum focusing on medicinal cannabis and chronic illness

# 10

Countries reading our work (by downloads)

# 39

Downloads of our most popular research report Palliative Care Volunteering in Residential Aged Care Facilities in NSW: A sample study in Western Sydney LHD 2015



# Strategic objectives

Provide professional support services to our members and raise awareness amongst health professionals and the public 02

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

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

### **PCNSW Bursary Program**

We have designed a Bursary Program to support members who wish to undertake further study and plan to formally launch the Program in December 2016. Bursaries of up to \$1500 will be available to current members who undertake a course that leads to an accredited post graduate qualification in palliative care.

### Professional Development Education Forums

Palliative Care NSW participates in National Palliative Care Week each year by supporting our members with their events and our Professional Development Education Forum. During 2015/16 an additional event was held in October as part of the World Hospice and Palliative Care Day celebrations. Member feedback tells us that these education days are both important and much anticipated. We will continue to schedule one education day per calendar year in locations that maximise access for members across the state.

### Palliative Care NSW Biennial State Conference 2016 in Broken Hill

Plans are well under way for the Biennial PCNSW State Conference, Transforming the Landscape to be held in Broken Hill in October 2016, generously co-hosted by the Far West Local Health District (FWLHD)

We are encouraged by the innovative conference program that has been developed and the keen interest in joining us in Broken Hill for what promises to be a dynamic conference. We thank the community of Broken Hill for embracing us warmly as we approach the October conference dates.

### Email newsletter updates

Palliative Care Victoria partner with us to provide a regular email Member Update. We have a very high opening rate for each issue and will continue to provide this service for members.

#### Website

Most people visiting the website were looking for services and heading for the Service Directory – or information on palliative care, looking for that information. Our website unfortunately encountered some serious issues as the year progressed and we were unable to attend to its upgrade as quickly as we would have liked.

Our website is currently under redevelopment to provide an increased range of resources and links that will be helpful both to the professional community and to the public.

### **Social Media**

During 2015/16 Palliative Care NSW continued to grow our social media and digital communications profile. Our Facebook page has had consistent growth and attraction for those interested in palliative care, hospice, and end of life. Those on the consumer and professional side are engaging with this type of medium on a daily basis with constant growth.

We have been able to reach and engage our immediate and local stakeholders in ways not possible before.

In terms of inter-media connectivity, the website and Facebook pages are leading visitors to each other respectively.

Social media is helping to take a challenging subject within the community and make the conversation about death and dying part of everyday conversation.

Professional Education Day, May 2016. Top: Dr Maria Cigolini talks about Cannabinoid Therapeutics. Right: Joan Ryan, Minister Skinner, Linda Hansen and Therese Smeal at the Professional Education Day.





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

A full review of existing resources about palliative care, end of life care, aged care, planning ahead as well as dementia specific and other disease specific resources was conducted during the year.

As a result the website is being redeveloped to increase public access to a wider range of resources and related links. We have developed printed information resources specific to NSW including an information brochure on Palliative Care in NSW and these are available free of charge to members and at a cost recovery basis to non-members.

PCNSW has continued with plans to roll out the Compassionate Cities Charter where resources allow.



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# Volunteers

The Volunteer Support Services Programme is an initiative of The NSW Government plan to increase access to palliative care 2012-2016 and intended to increase the number of palliative care volunteers in NSW, particularly those available to carers at home.

The Volunteer Support Services Programme continued to champion and provide support for palliative care volunteer services across NSW during the 2015-2016 financial year. Within this period two new volunteer services commenced in NSW: Cancer Council Hunter and Northwest Church Tamworth, and the Volunteer Support Services Programme was variously involved in the development phase.

In the 2015-2016 financial year the Volunteer Support Services Programme produced a number of reports and publications, most notably Palliare: A Handbook for Palliative Care Volunteers in NSW which was launched by Minister Skinner on World Hospice and Palliative Care Day 2015 at the NSW Parliament House. Palliare is a learning resource for volunteers who work in palliative and end of life care. The content of the book was developed by the Volunteer Support Services Programme based on the popular Volunteer Training Resource Kit produced by Palliative Care Victoria. Some 1,500 copies of Palliare have been distributed across NSW, with another 130 downloaded from the website. It is also available as an eBook for \$2.

The Volunteer Hub website www.volunteerhub.com.au is the electronic face of the *Volunteer Support Services Programme*. The website offers access to resources, reports and books as well as a regular eNews service. Visitors can also find an interactive service finder to locate and contact palliative care volunteer services within NSW. In this financial year we have tracked subscribers and users to the UK, USA, Canada, Malaysia, Denmark, Germany, and Estonia as well as to other states in Australia.



The Volunteer Hub website is the electronic face of the Volunteer Support Services Programme.





Launch of Volunteer Handbook Palliare. Left: Alex Huntir, Manager of the Volunteer Support Project. Right: President of PCNSW Therese Smeal. Below: Palliare, A Handbook for Palliative Care Volunteers in NSW.





The Volunteer Support Services Programme has helped respond to the high turnover of Volunteer Managers in NSW by networking new managers, hosting a legal issues workshop in conjunction with the NSW Network of Managers of Palliative Care Volunteer Services, and meeting with and teleconferencing new Volunteer Managers. Resources and support have also been provided to senior managers who are preparing to employ new Volunteer Managers and/or commence new service initiatives.

One of the outputs from the Volunteer Support Services Programme is the development of a Statewide Framework for Palliative Care Volunteering in NSW in 2017.

To ensure that the Statewide Framework is properly informed by experiences of volunteers and volunteer services we have been studying various aspects of volunteering across NSW. These include the role of volunteers in contributing to palliative care in residential aged care (Burke, 2015) and in other volunteer groups like meals on wheels (Bowman, 2016), and the role of community hospice as a volunteer-led initiative (Huntir, 2016). In order to learn from past mistakes we studied the failure of implementation of a palliative care volunteer initiative in the bush (Huntir, 2016). We also sought the views of Service Development Officers across NSW about palliative care volunteers (Flood & Huntir, 2016) to see if they could offer a different perspective or new insights into the future.

During the financial year staff members presented on the work of the *Volunteer Support Services Programme* at conferences and workshops in NSW and Victoria.

The Volunteer Support Services Programme is overseen by Palliative Care NSW Executive Officer Linda Hansen, and managed by Alex Huntir. Megan Burke and Kate Bowman are both involved in research and publications, having first been involved with the Programme as interns from Macquarie University. Julie Flood is an experienced palliative care clinician and led the recent study of Service Development Officers in relation to palliative care volunteers. To date some six Interns have contributed to the Programme through University placements.

The 2016–2017 financial year represents the final year of funding for the *Volunteer Support Services Programme*. Given the success of the work to date and the soon-to-be-released Statewide Framework for Palliative Care Volunteering in NSW we are hopeful of continuing our work with volunteers and volunteer services in NSW with renewed funding beyond June 2017.



# Membership

We have a goal of increasing our membership numbers and improving the services provided to members. Limited resources make this a challenging goal however we have secured such member benefits as free subscription to the International Journal of Palliative Care Nursing as well as significant discounts to the October conference.

At 30 June 2016, our membership numbers were 250, with around 300 on our email update database.

### **Member Survey**

To ensure that focus is aligned with members a Member Survey is scheduled for December 2016. The survey will include a range of questions on a variety of issues.

#### Pallium

Pallium is the tri-annual printed newsletter of PCNSW. It is only available for members and is a much valued member benefit.



# Input to policy development

PCNSW is represented on a range of government and non-government committees and groups including the Agency for Clinical Innovation, NSW Ministry of Health End of Life Advisory Committee and Palliative Care Australia National Policy Advisory Committee.

Reflecting the changing climate for palliative care NSW, the PCNSW Policy Statement 2012 has been reviewed and will be launched in 2017.

PCNSW provided a written submission and our Executive Officer was selected to present before the NSW Legislative Council Health Inquiry into Registered Nurses in Residential Aged Care Facilities in NSW. PCNSW supported the case for the Registered Nurses to be employed 24 hours a day in residential aged care without which equity of access to end of life care for residents would be compromised.

PCNSW develops an election strategy 'call to action' for every state election and a budget statement every year. The Executive Officer also meets regularly with representatives from the Ministry of Health and the Minister for Health and her advisors.

#### What is needed in the future

- An ongoing commitment to supporting real growth in the Palliative Care service system, including Specialist Palliative Care services in metro and rural/remote areas.
- Increased funding so that capacity growth is ahead of the ageing and chronic disease curve – not behind it.
- Government policy that encourages professional development programs incorporating end of life care so that hospital clinicians, General Practitioners and other care providers feel more confident in providing appropriate end of life care. GPs for example can feel confident and supported in starting end of life conversations with the growing number of patients and their families.

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# Strive for excellence in the governance of our Association

PCNSW seeks to expand its funding base each year as part of its excellence in governance work. This work can take the form of grant applications as well as increasing the membership base and seeking corporate and community partners. We also seek to continually improve our quality standards – this year we commenced the very long and challenging task of pursuing a paperless office, as part of our work to increase our efficiency within our very limited resources. We have also sought to improve and streamline our membership renewal options and financial accounting. This work is ongoing into the 2016/17 financial year but will be completed by the end of that year.



# Treasurer's report

Income Statement for the year ended 30 June 2016	2015 \$	2016 \$
Income		
Grants	\$366,195	\$416,696
Interest Received	\$11,128	\$9,336
Donations	\$3,554	\$1,557
	\$380,877	\$427,589
Other income		
Education	\$-	\$656
Membership Fees	\$12,845	\$22,131
Conference Sponsorship	\$24,309	\$30,726
Sundry Income	\$2,681	\$610
	\$39,835	\$54,123
	\$420,712	\$481,712
Expenditure		
Accountancy	\$4,726	\$5,391
Advertising & Promotion	\$125	\$6,512
Auditors Remuneration - Fees	\$2,800	\$2,800
Bank Charges	\$1,238	\$2,253
Computing Expenses	\$13,009	\$14,271
Consulting Fees	\$5,345	\$44,564
Conference Expenses	\$39,904	\$11,991
Depreciation	\$1,124	\$4,022
General Expenses	\$1,976	\$6,840
Insurance	\$199	\$6,459
Interest	\$7	-
Postage	\$1,138	\$3,100
Printing & Stationery	\$24,427	\$31,791
Employee Provisions	\$16,691	\$14,857
Rent	\$9,709	\$11,630
Repairs & Maintenance	\$3,255	\$205
Subscriptions	\$1,032	\$2,488
Superannuation	\$18,547	\$23,219
Telephone	\$3,025	\$2,528
Travelling	\$37,757	\$36,694
Wages	\$195,235	\$244,406
	\$381,269	\$476,157
Profit (Loss) before income tax	\$39,443	\$5,555



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