



PalliativeCare
WESTERN AUSTRALIA



Annual Report 2018/19

About us

Palliative Care WA is the peak body for the palliative care sector across the State. Operating for 33 years, we are a not for profit organisation that represents palliative care service providers and professionals in Western Australia. Our membership includes professionals working in the palliative care sector, organisations providing palliative care services and members of the community who support our vision.

Our mission is to work collaboratively with our members, key stakeholders and the community to ensure awareness of, and access to, quality palliative care for all Western Australians.

To achieve this mission, we work across five key focus areas:

- Raising awareness and understanding of palliative care in the community.
- Improving access to palliative care services for all people across the State.
- Improving the quality of care and support available to Western Australians at the end of life.
- Enabling meaningful relationships between government and the palliative care sector.
- Encouraging, recognising and rewarding excellence in the palliative care sector.

Our vision is quality palliative care for all.

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We acknowledge the traditional owners of country throughout Western Australia and recognise their continuing connection to land, waters and community. We pay our respect to their Elders, past, present and emerging.



President's report

Looking back over what has been a very successful year for Palliative Care WA I am immensely proud to present this Annual Report to you.

This year saw some exciting new initiatives as we developed our inaugural Palliative Care WA Awards and Gala dinner, created Australia's first consumer awareness campaign for Advance Care Planning, worked with co-host Palliative Care Australia on the planning and organisation of the inaugural Oceanic Palliative Care Conference, and ran a series of forums to consider the recommendations from WA Parliament's Joint Select Committee on End of Life Choices. Details on these and many other activities are included in this report.

I would like to acknowledge the hard work and dedication of the Palliative Care WA team, ably led by CEO Lana Glogowski, in successfully delivering such a wide range of projects in addition to our annual program of events and activities.

Growth and sustainability are a continuing focus, both for us as an organisation and for the broader sector. It is therefore extremely pleasing to see our member numbers continue to grow. Our individual and organisational members are vital to us remaining a strong, independent and representative voice for the sector, and in our ability to encourage and celebrate excellence in the sector while delivering a range of community education activities. With our funding largely project-based, the income from membership subscriptions enables us to continue working towards our mission of ensuring awareness of, and access to, quality palliative care for all Western Australians.

Working in partnership within the sector and across the community is vitally important to how we operate. Only by collaborating, innovating and empowering will we enable our vision of 'quality palliative care for all.' This year we welcomed a new partnership with Lotterywest as they supported the development of our consumer awareness campaign for Advance Care Planning. We are very grateful to them and to all of our partners for their support.

One of Palliative Care WA's strengths is the depth of knowledge, experience, skills and expertise brought to our Board table each month. I thank all Board members for their continuing support and hard work this year and for their insight and wise counsel at all meetings.

This coming year will see us undertaking further strategic planning to accommodate the many State and Federal initiatives in the area of palliative care. Our attention will also be given to growing and diversifying our income, increasing our personnel and therefore our ability to offer more membership services, and continuing to grow our profile within the WA community.

Dr Elissa Campbell



CEO's report

This year has been extremely busy for Palliative Care WA as we continue to prioritise our work in sector advocacy and development, as well as increase the understanding of palliative care within the community.

To some extent our work this year has been guided by the *Sustainable Health Review*, the WA Parliament's Joint Select Committee of End of Life Choices report *My Life, My Choice*, and the WA Government's 10 year *End of Life and Palliative Care Strategy*. There is no doubt these documents have created an increase in conversations in the public domain around palliative care and end of life issues. Despite this however, WA is still a long way from ensuring all Western Australians have equitable access to palliative care and a better understanding about the importance of early referral to palliative and supportive care. Unfortunately, this lack of understanding equally applies to many health professionals, including those working in aged care settings, and we have much work to do in this area.

Highlights for the year have included delivering five well attended forums in response to the *My Life, My Choice* report; the planning and development for the State-wide consumer awareness campaign for Advance Care Planning called *You Only Die Once*; facilitating well-attended Advance Care Planning community workshops across WA; and receiving statistically significant results from a Curtin University evaluation of these workshops. Our inaugural Gala Annual Awards dinner was a watershed moment for the sector in WA.

I highly value the consistent levels of attendance at Board meetings across the year, the high-quality discussions and debates and an increasingly clear strategic direction for the organisation. In particular I'd like to acknowledge the leadership of Dr Elissa Campbell as our President who provides such a strong commitment to our organisation both in our meetings as well as across the sector.

It has been such a privilege to lead our team of four highly skilled professionals, as they continue to support me in the delivery of a broad range of projects and events. I sincerely thank Cait Calcutt, Vicki Barry, Helen Greenham and Robyn Richmond for their dedication, energy and commitment. I'd also like to welcome Pippa Worthington who joined the team at the end of the year, as we farewelled Robyn.

I am more committed to this work as each year passes and I look forward to the coming year with optimism and enthusiasm.

Lana Glogowski



Our work this year

COMMUNITY EDUCATION

A key focus for Palliative Care WA is to increase both the awareness and understanding of palliative care in the community.

Our community education activities aim to encourage discussions about death and dying, explain and promote the value of advance care planning, and increase understanding about the process of, and access to, palliative care.

The number of people making enquiries by telephone continues to rise each year with 85% of calls coming from members of the community. A large majority are family members seeking services and supports for their loved ones.

Palliative Caring booklet

- 5,785 booklets distributed
- 2,678 booklets downloaded
- 130 requests for booklet, 30% community members

This year we undertook an extensive review and update of the highly popular Palliative Caring booklet, which was launched in February 2019. This review has been the most extensive since the booklet's first release fifteen years ago and couldn't have happened without the significant contribution made by our advisory group and expert reviewers who devoted many hours rewriting content, sourcing information and providing feedback.

Written to support families and carers as they negotiate the often-uncharted waters of caring for a loved one with a life limiting illness, the booklet covers all aspects of the palliative caring journey including planning and decision-making, the role of the carer, providing care, medicine safety, respite, death and bereavement.

Requests for copies of the booklet come from organisations and services wanting to provide copies to their palliative care clients as well as individual carers and family members. The booklet is also downloadable from our website.



Compassionate communities

Compassionate Communities is an international movement which aims to build capacity within individual communities to support people approaching the end of their lives. This approach not only applies to palliative care, but also ageing and all those living with a disability or a life-limiting condition.

In WA there are two national trial sites for the development of Compassionate Communities:

- Compassionate Communities Great Southern, an initiative of the WA Primary Health Alliance; and
- South West Compassionate Communities Network, an initiative of the GroundSwell Project.

There is growing interest in the development of Compassionate Communities and in the past year we have presented the model to:

- Avon Regional Organisation of Councils,
- St James Settlement, Hong Kong by special request while here on a local visit, and
- City of Mandurah and the Peel Development Commission.

In partnership with The Australian Centre for Social Innovation (TACSI) we delivered local connector training to support the implementation of the Weavers program at the Albany Community Hospice. Weavers is a peer to peer model supporting carers to manage the ongoing challenges of caring by connecting them to a volunteer with lived experience of caring who is trained to walk alongside them on their journey.

Advance Care Planning Community workshops

- 44 workshops
- 32% in regional WA
- 1,682 attendees

Palliative Care WA is continuing to deliver our highly successful community workshops across WA aiming to encourage Advance Care Planning conversations, increase engagement in the Advance Care Planning process and improve death literacy within our communities. In total 44 workshops have been delivered this year, 30 in the Perth metropolitan area and 14 in regional WA.

Customised workshops were delivered to general carers groups, dementia carers, people from culturally and linguistically diverse backgrounds, and women living with metastatic cancer.

These workshops are funded by the WA Health Department. Please note the statistics cover the period of the grant which is March 2018 to June 2019.



25,840

visitors to our website



1,102

social media followers



462

phone enquiries





You only die once.

Consumer awareness campaign

The need for a consumer awareness campaign on Advance Care Planning was identified by the CEO Roundtable and over 2018/19 the campaign took shape. It was launched in August 2019.

Over the last year Palliative Care WA undertook the following planning and development activities to progress the campaign.

- Additional funding from Lotterywest and WA Health was sourced to supplement the funds provided by members of the CEO Roundtable.
- The campaign concept was developed by the agency chosen as our creative partner for the campaign.
- Workshops were held for consumers and health professionals to understand the target groups and assess tone, sentiment and imagery in order to develop suitable key campaign messaging.
- A pre-campaign evaluation was undertaken to set the benchmarks to assist in assessing the effectiveness of the campaign.
- A media program was developed including radio, television, social media and sponsored partner articles.
- The script for the television advertisement was developed and filming commenced.

Development work scheduled for 2019/20 included the content and build for a website, scripts and recording for the radio advertisements, imagery for social media and sponsored content and the launch.

You only die once

The campaign name *You only die once* was deliberately chosen to challenge people to see death as an important part of life and worthy of consideration and planning. It aims to help consumers be more comfortable with the subject of death and make the conversation around Advance Care Planning more approachable.

The premise of the campaign is simple – have the conversation early because once someone's gone, it's too late.



SECTOR DEVELOPMENT

We encouraged and promoted service commitment in WA by recognising and rewarding excellence in the palliative care sector. Opportunities for networking and professional development were provided to members and the broader sector through our forums and other events.

National Palliative Care Week breakfast

- 150 attendees

In addition to raising awareness of palliative care in our community, each year National Palliative Care Week provides opportunities for us to come together as a sector. Our annual breakfast proved extremely popular again this year with 150 members of the sector attending. The guest speaker was Professor Kathy Eagar, lead Chief Investigator of the Palliative Care Outcomes Collaboration and a Chief Investigator on the NHMRC Centre of Research Excellence in End of Life Care.

Palliative Care WA Forums

- 134 attendees

We hold a series of forums each year to provide informal learning, allow local professionals and organisations to share and showcase new programs and innovations, and provide networking opportunities. Attendance is free for members, however all are welcome.

Spotlight on Paediatric and Adolescent Palliative Care highlighted the range of services that offer holistic and compassionate care to children and their families who live in WA with a life-limiting condition. Presenters from the Perth Children's Hospital, Hannah's House and Lion Heart Camp for Kids covered every aspect from diagnosis, support services, respite and bereavement.

Palliative Caring Booklet Launch was a special event to launch the revised booklet and hear about the changing landscape for carers in WA. At a time when more and more people are expressing the desire to be cared for and die at home we heard about the importance of the contribution carers make in our community. Presenters included Tish Morrison, Director of Clinical Operations at Silver Chain; Teresa Coburn, Hospital Program Coordinator at Carers Australia WA; and Kelly McIntyre, Manager Inclusion, Policy and Service Design at the Department for Communities.

The Dignity Model and Dignity Interventions covered the development of the internationally recognised Dignity Therapy Model, by Dr Brenda Bentley, a registered clinical counsellor who has worked in palliative care settings in the US and Australia. Dr Bentley facilitates Dignity Therapy training workshops throughout Australia as well as providing clinical supervision for Dignity Therapists and others working with dying people and their families. Attendees learned how to use the model to identify people who may be experiencing dignity-related distress and practice simple interventions to assist them.



Emerging leader network

Launched at the Palliative Care WA Awards and Gala Dinner, the Emerging Leaders Network aims to develop a peer platform to facilitate career development and inter-disciplinary collaboration for the next generation of palliative care practitioners. Designed to support professionals with less than ten years experience working in palliative care, we hope to encourage future leaders to emerge from the health, aged and disability sectors. The Network will be peer-led and meet periodically to facilitate opportunities for networking, information sharing and professional development including mentorship.

ACP Consortium

Palliative Care WA coordinates and supports the WA Advance Care Planning Consortium, a network of agencies committed to jointly promoting the development and delivery of information, educational opportunities and promotional strategies on Advance Care Planning in WA.

Over 2018/2019 the Consortium's held four meetings that focussed on:

- Advance Care Planning developments in WA;
- Findings and recommendations on Advance Care Planning from Parliament's Joint Select Committee on End of Life Choices;
- Progress of the planned Advance Care Planning consumer awareness campaign; and
- Update on the objectives and deliberations on the Expert Panel on Advance Health Directives.

Palliative Care WA Awards

- 160 attendees

This year we held the inaugural Palliative Care WA Awards and Gala dinner to acknowledge, celebrate and showcase the achievements of organisations, teams and individuals providing quality palliative care. Following a nomination and assessment process, four awards were presented at the dinner.

The winners were:

- Outstanding Professional was awarded to Ingrid Plug, Clinical Nurse from Albany Community Hospice.
- Outstanding Volunteer was awarded to Alison Phipps, Meet and Greet Volunteer at Albany Community Hospice.
- Outstanding Team was awarded to WA Paediatric Palliative Care Service, Perth Children's Hospital.
- Outstanding Organisation (Douglas MacAdam Perpetual Trophy for Excellence in Palliative Care) was awarded to Busselton Hospice Care Inc.

Congratulations to not only the winners but all our finalists, other nominees and everyone who works in the palliative care sector and is so committed to improving the end of life experience for all Western Australians.



A highlight of the Awards Ceremony was the induction of Dr Douglas Bridge as an honorary life member of Palliative Care WA to a standing ovation. This well-deserved accolade recognised Doug's work at Fremantle Hospital, as past head of the Palliative Care Service at Royal Perth Hospital and his indelible contribution as a pioneer of the development of palliative care in Australia.



ADVOCACY

Our advocacy work prioritises improvement of both access to and delivery of quality palliative care services across the State. This has been achieved by enabling meaningful relationships between government and the palliative care sector, providing submissions to appropriate reviews and inquiries, involvement in panels and committees and promotion of standards and guidelines.

CEO Roundtable for Palliative Care

Each year Palliative Care WA facilitates the CEO Roundtable on Palliative Care, a group that provides high level advice to State and Federal Government on palliative care issues in WA.

Two meetings of the CEO Roundtable were held in 2018/19, one with the Hon. Ken Wyatt Federal Minister for Senior Australians and Aged Care and Indigenous Health and one with the Hon. Roger Cook, Minister for Health. Topics discussed during the year included the report and recommendations from the Joint Select Committee on End of Life Choices *My Life My Choice*; the Sustainable Health Review final report; WA End of Life and Palliative Care Strategy 2018–2028; National Palliative Care Strategy; the evaluation of Palliative Care WA's Advance Care Planning community workshops; Palliative Care Outcomes Collaboration; and the progress and development of the Advance Care Planning consumer awareness campaign.

End of Life Choices forums

Palliative Care WA ran five forums following the release of the report and recommendations from WA Parliament's Joint Select Committee on End of Life Choices. The forums explored the findings in detail and identified sector priorities and recommendations which were presented to the WA Government.

Open to members, palliative care service providers, health and allied health practitioners, aged care providers, carers and consumers, the forums attracted over 450 attendees.

With the assistance of Rural Health West's webinar facilities one forum was aimed at health professionals located in regional, rural and remote areas of WA.

Panels

- WA Health End of Life and Palliative Care Advisory Committee – Lana Glogowski and Elissa Campbell
- Sustainable Health Review Consumer and Carer Reference Group – Vicki Barry
- Ministerial Expert Panel on Voluntary Assisted Dying – Elissa Campbell
- Advance Health Directives Expert Panel – Lana Glogowski
- University of Notre Dame Australia panel on end-of-life issues – Lana Glogowski
- Palliative Care Australia National Policy Advisory Committee – Elissa Campbell
- Palliative Care Australia Voluntary Assisted Dying Symposium and Guiding Principles – Elissa Campbell, Moira O'Connor and Shannon Calvert
- Oceanic Palliative Care Conference Executive Committee – Lana Glogowski, Elissa Campbell and Moira O'Connor
- Oceanic Palliative Care Conference Program Committee Co-chair – Elissa Campbell

Submissions

- Sustainable Health Review
- Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper

Members

Our members are our strongest asset. A committed and diverse membership is vitally important to ensure we have a strong, independent and collective voice to advocate for sector development and improvements in access to quality palliative care for all Western Australians.

In 2018/19 we had 154 individual members drawn from aged care, hospitals, community services, education and research spheres. This represents a 36% increase in individual memberships from 2017/18.

We continue to focus on growing our membership base and exploring new ways to maximise the potential value of our membership package.

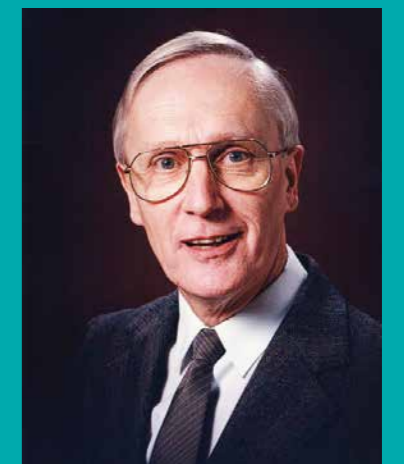
Membership developments this year included:

- Palliative Care WA awards and gala dinner aiming to celebrate excellence in our sector, and
- Emerging Leaders Network aiming to nurture career development and inter-disciplinary collaboration for the next generation of palliative care practitioners.

VALE Douglas MacAdam

It was with great sadness in October 2018 we acknowledged the passing of one of Palliative Care WA's Life Members Dr Douglas MacAdam, a pioneer of palliative care medicine in Western Australia. He was a remarkable man – a general practitioner, teacher, innovator and pioneer. He was instrumental in the development of the Cottage Hospice in Shenton Park, the Silver Chain Hospice Care Service and the first home care service in the Claremont region.

To honour his contribution to our sector we named the Palliative Care WA Award for the Outstanding Organisation, the Douglas MacAdam Perpetual Trophy for Excellence in Palliative Care.



154

individual members



3

life members



36%

increase in individual membership



19

organisational members

Our people







BOARD

President	Dr Elissa Campbell
Vice President	Ms Shannon Calvert
Treasurer	Mr Hiren Mehta
Hon Secretary	Mr David Smeeton
Members	Dr Samar Aoun Ms Zoe Clarke Dr Ashwini Davray Ms Magda Dudek Ms Carmel Markham Ms Yasmin Naglazas Associate Professor Moira O'Connor Dr Alison Parr Dr Alison White Mr Desmond Williams





STAFF

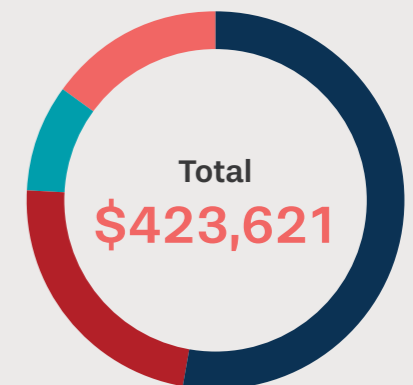
CEO	Lana Glogowski
Business Development	Vicki Barry
Project Officer	Cait Culcutt
Finance Officer	Helen Greenham
Marketing and Communications	Robyn Richmond (resigned)
Marketing and Communications	Pippa Worthington

Finances

	Income	\$	%
	Government grants	249,019	47.7%
	Event sponsorship	93,749	18%
	Donations and bequests	47,314	9.1%
	Membership fees	46,591	8.9%
	Event registrations	34,649	6.6%
	Other	50,496	9.7%



	Expenditure	\$	%
	Staffing	226,033	53.4%
	Project costs	97,266	23%
	Event costs	34,585	8.2%
	Other expenses	65,737	15.5%



SUPPORTERS

Our thanks go to these organisations for their generous support over the last year.



- Avivo
- Bethanie on Pier
- Bethesda Health Care
- Brightwater Care Group
- Cancer Council of WA
- Carers WA
- Genisis Care
- HESTA
- Menarini Australia
- Platinum Health care
- Ramsay health Care
- Seqirus
- Silver Chain Group
- Southcare
- St John of God Health Care
- The University Club of WA

We also gratefully acknowledge several bequests and private donations we received this year from people wishing to remain anonymous.



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