

Progressing quality end-of-life planning in WA

Palliative Care WA is planning to develop and manage another Australian-first project here in Western Australia.

This project presents the opportunity for WA to once again lead the way in increasing both community awareness of, and engagement in, ***Advance Care Planning***.



PalliativeCare
WESTERN AUSTRALIA

This proposal

Palliative Care WA will develop and manage another Australian-first project that has the potential to be a game changer for the people of Western Australia.

The project also presents an opportunity for WA to once again lead the way in Australia in increasing community engagement in *Advance Care Planning* (ACP).

In addition to a consumer awareness campaign, a follow-up to the hugely successful *You only die once* campaign run in 2019, we will deliver 'train-the-trainer' style workshops across WA. By working in collaboration with a range of community service partners, we aim to enable them to increase their knowledge and understanding of ACP. Using co-design we will explore nuanced approaches to education and engagement to suit the needs of their communities, many of whom experience vulnerability and exclusion including:

- people with disabilities;
- residents in aged care;
- members of the LGBTIQ+ community; and
- people with culturally diverse backgrounds.

The current context

The timing is ripe for this project in WA.

- **COVID** – has created an increased awareness of our mortality and the value of planning ahead; increased stress for those not able to be with loved ones at end-of-life; and an increased commitment from the aged care sector to ACP processes.
- **Joint Select Committee on End-of-Life Choices** – included a recommendation on the need for community education on ACP.
- **Sustainable Health Review** – included a recommendation on achieving respectful and appropriate end-of-life care and choices.
- **Introduction of Voluntary Assisted Dying** – is creating more conversations in the community on what people want for their end-of-life.
- **We have an aging population**
 - By 2032 Western Australians aged 65+ will make up 16% of our population.
 - In WA regional areas this age group is expected to more than triple by 2026.
 - Between 2000 and 2030, the ABS has projected an 139% increase of people aged 65+.

Palliative Care WA

As the peak body for palliative care and end-of-life issues in the State, Palliative Care WA is uniquely positioned to deliver this project.

- We have a diverse, engaged and growing membership that can support this project.
- We have a demonstrated capacity to work successfully with the sector and community.
- We have a strong track record of success in engaging the community in *Advance Care Planning* through our highly rated and independently evaluated community education program and the extremely successful consumer awareness campaign *You only die once*.

Please note: A separate project to engage Aboriginal and Torres Strait Islander peoples in *Advance Care Planning* conversations is being planned.





Benefits of Advance Care Planning

- Assists people to clarify their values and priorities and make decisions about their wishes for end-of-life
- Lessens the decision-making burden on family members during what can be a distressing time
- Decision makers are nominated to act when people lose capacity
- Prepare for Goals of Patient Care discussions in hospital

Benefits of this project

- Increased awareness, understanding and uptake of Advance Care Planning (currently less than 5% in WA)
- Collaboration with not-for-profit agencies which work with people who are often marginalised and vulnerable, including those with disabilities; residents in aged care; members of the LGBTIQ+ community, and people with culturally diverse backgrounds
- Cost-efficient and evidence-based approach that will reduce hospital admissions and lessen unwanted medical procedures
- Opportunity to educate community on the benefits of early access to palliative care

Sarah's story

I'm the manager of an aged care facility. I have seen too many residents and families go through the trauma and distress of unwanted medical care at the end-of-life. This trauma could have been prevented by having conversations about end-of-life wishes and recording them.

A recent example is Vincent, who was having treatment for bowel cancer. Vincent's wife Joan was visiting when Vincent became unconscious. An ambulance was called. As Joan didn't know her husband's end-of-life wishes, CPR was started and continued for a considerable time. Vincent was taken to hospital but died in intensive care. Joan told me afterwards she felt traumatised by the attempted resuscitation and that she wished that she could have held Vincent's hand and comforted him as he died.

We now have regular advance care planning education sessions for staff, residents and family members. The feedback I often hear after these sessions is "It's giving me peace of mind".

Project Plan

STAGE 1 - 6 months	STAGE 2 - 12 months	STAGE 3 - 6 months
<ul style="list-style-type: none"> • Develop a community awareness campaign on <i>Advance Care Planning</i> as a follow-up to the Australian-first 2019 You Only Die Once campaign www.youonlydieonce.com.au www.palliativecarewa.asn.au/consumer-awareness-campaign-proven-effective/ • Develop a train-the-trainer package for delivery to the aged care, culturally diverse, disability and LGBTIQ+ sectors based on our highly successful community education workshops <i>PCWA ACP workshops evaluation report July 2019 (parliament.wa.gov.au)</i> 	<ul style="list-style-type: none"> • Deliver a state-wide community awareness campaign on <i>Advance Care Planning</i> via TV, radio, newspaper and social media • Deliver train-the-trainer workshops across WA to both staff and volunteers in collaboration with our sector partners, to increase their knowledge and understanding of <i>Advance Care Planning</i> and explore nuanced approaches to reflect the needs of their vulnerable communities 	<ul style="list-style-type: none"> • Facilitate a free-of-charge conference where all sector partners are invited to share the successes and challenges of the project. The conference approach will be based on the highly successful Palliative Care Summit held in November 2020 www.palliativecarewa.asn.au/joining-the-dots/

Sector partners



Bethesda Health Care	St John of God Health Care
Brightwater Care Group	St John Ambulance WA
Cancer Council WA	Alzheimer's WA
Carers WA	Health Consumers' Council
Silver Chain Group	WA Department of Health

Budget

Total project cost	\$580K
less Sector and Palliative Care WA contribution	\$120K
Sub total	\$460K
Funding support required	\$460K

To illustrate why this project is needed in WA we have included some stories, each representative of many real conversations we have had with members of the WA community.

James' story

Graham and I had been together for thirty years. We both came from conservative families, so over the years we found our way through situations by not talking about our same-sex relationship – that seemed to work best. However when Graham became unwell with Parkinson's Disease, things got harder. First we faced issues of what to say to carers who came into our home to care for Graham. Then when Graham went into hospice care, we again had to consider what to say to whom and how.

It was a stressful time and we didn't want to upset family. What that meant, though, was that clinicians talked to Graham's family rather than me. I was shut out from sharing my thoughts on what Graham would want for his care. And who knew him better than me? After he died, Graham's family organised a religious funeral that he would have hated and that I wasn't a part of.

Graham and I loved each other dearly and talked about everything. However I deeply regret that we didn't complete forms around guardianship and care decisions for the end of Graham's life ... that would have saved us both so much unnecessary anguish and distress.

Palliative Care WA

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Gemma's story

I'm an advocate for advance care planning. I support people living with neurological conditions and their families to have conversations about their values and end-of-life wishes.

I've taken this role because of what our family went through when my son Brett was diagnosed with Motor Neurone Disease at 32. Brett was always full of life. He surfed and played AFL at a state level. He and his wife Clare had two young children when he was diagnosed. Brett was determined to beat his disease and refused to talk about his end of life wishes.

Eventually Brett lost more and more function. Towards the end, Clare was asked if/when the medical staff should turn off the machine that was keeping Brett alive. Six years on, Clare still feels haunted about having to make that decision without knowing what he wanted.

Hafsah's story

My name is Hafsah. My husband Aabir and I were born in Iran and have lived in Australia for only a few years. Our world fell apart when our 2 year old daughter Pakiza became very ill and was dying. We were alone here. We were so very blessed when the palliative care nurses helped us, they became our family. They talked with us about what we wanted for Pakiza at the end of her life, and our cultural practises around death and funerals. They helped us write all this down. This was a very big blessing. As we didn't have much English, we wouldn't have been able to ask for these things if we didn't have them written down. And I don't know if I would have been brave enough to ask for these things. Now I tell all my friends to talk about what's important to you and get help to write it down.