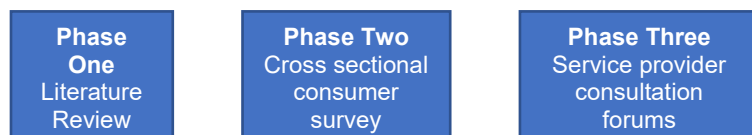


Independent review – Consumer perspectives of palliative care service models



In response to Recommendation Nine of the Joint Select Committee, the WA Department of Health commissioned this independent review of consumer perspectives of palliative care service models. The independent review was completed in three phases and findings documented in three separate reports.



Below are the **key improvements identified by consumers and service providers** within each priority area of the WA End of Life and Palliative Care Strategy.

“Palliative care is so important and when you’ve had good palliative care it makes a huge difference to your experience. Cancer patients that I’ve spoken with who have palliative care seem to have a much better experience than those who go without. But it’s not just the patient .. the family too cope better when there’s a pall care team involved. They have someone to call and they have a plan - there is support.” (Cancer patient).

Priority one: care accessible to everyone, everywhere

Improvements suggested by consumers	Improvements suggested by service providers
<ul style="list-style-type: none"> • Accessing care earlier/when required. • Increasing staffing levels in existing services. • Increasing number of services (in both rural and metropolitan areas). • Better after-hours care, support and access. • Providing sufficient support to stay in the setting of choice (e.g. home). • Better information and support at the initial diagnosis of a life limiting illness. • Better palliative care delivery for neurological conditions. • Navigation of referral and access-admission process • More adequate pain relief/reduce delays in achieving pain relief. • Information on how to manage changes in medication as the patient’s ability to swallow deteriorates. • Streamline and improve access to NDIS services. • Increase regional services: 24- hour care at home/ community palliative care. 	<ul style="list-style-type: none"> • Increase staff numbers/funding for services. • Simplify referral criteria and reduce wait times, particularly those related to Aged Care Assessment Team (ACAT) and National Disability Insurance Scheme (NDIS). • Introduce a directory of services. Knowing where to look for information about community providers. • Move towards shared models of care, with incentivised funding to ensure collaboration and integration across the continuum of care. • Improve equity of care both across regions (funding and staff numbers) and across different disease groups (cancer vs non-cancer conditions). • Improve health and death literacy of consumers • Improve staff retention in rural areas. • Explore ways to improve timely delivery of pain relief and other support to remote patients. • Reduce burden of chronic disease in rural areas. • Introduce funding options for EOL care for people < 65 years ineligible for NDIS.

Priority two: care is person-centred

Improvements suggested by consumers	Improvements suggested by service providers
<ul style="list-style-type: none"> • Improving their knowledge and education and making it easier to complete EOL wishes documents: Advance Care plans, Advance Health Directives, Goals of Care. • Flexibility to accommodate individual wishes of patients (e.g. day release, engaging activities, visiting access). • Patients and family/carers more involved in decisions (and given sufficient information). • Improve services' physical environment to be more sensitive. • Improve consumer knowledge: Flow chart for families – who's who and contact details. • More weekend services (doctor, spiritual needs, counselling and grief support). • More in-home support (not just personal care) for people wishing to stay in their home. • Tailored mental health support services for dementia patients. 	<ul style="list-style-type: none"> • Improve the ACAT/ NDIS interfaces. • Improve the access, processes and systems for patients that don't have access to ACAT funding. • Ensure clear pathways between different settings and within metropolitan/rural transfers. • Explore how technology can support patients isolated by distance (e.g. iPads in the home program). • Improve health literacy and death literacy to change perceptions of palliative care and promote the value of palliative care to consumers.

Priority three: care is coordinated

Improvements suggested by consumers	Improvements suggested by service providers
<ul style="list-style-type: none"> • Better coordination of care across different providers and teams. • Single professional responsible for the overall care of each patient – who can coordinate all the other agencies. • Utilising other disciplines in care planning. • Short-term support for medical treatment (at home) that does not require hospital admission. 	<ul style="list-style-type: none"> • Care coordination linked to the client and their support network, independent of any single provider. Palliative care should not become the default case manager. • Better communication between services and greater understanding of the limitations and value of services and between professionals (e.g., GPs, palliative care services, specialists).

Priority four: families and carers are supported

Improvements suggested by consumers	Improvements suggested by service providers
<ul style="list-style-type: none"> Information at the time of diagnosis (illness trajectory; how palliative care can help). Increase the level of family carer support. Grief and bereavement support. Respect for the role of the enduring guardian. Regular case reviews/communication with family about day to day care delivered. 	<ul style="list-style-type: none"> Routine assessment of carers' needs should be undertaken separately to patients to reduce carer strain during the caregiving period and for better bereavement outcomes. The use of an 'app' where users can complete some standard information (e.g., location, illness, existing supports/networks) as a filter which then provides them with a list of services and supports applicable to their circumstances. Increase personal care funding and improve out of home respite options. Improve symptom control over the illness trajectory to enable people to remain at home longer. Provision of bereavement support is better provided by other specialist organisations. improving knowledge/information/ health literacy on disease trajectories, services, and the benefits of palliative care.

Priority five: all staff are prepared to care

Improvements suggested by consumers	Improvements suggested by service providers
<ul style="list-style-type: none"> Staff knowledge and training including: swallowing, Specific diseases (e.g. MND, dementia), Basics of death and dying, Communication skills, Wound care management, Empathy, Catheter care. Staffing levels: Palliative care teams needing more staff on weekends and after hours. 	<ul style="list-style-type: none"> Provide training on palliative care to non-palliative care services- the palliative approach to care. Disease specific specialists could provide training on disease specific information to general palliative care providers and the upskilling of health staff in non-cancer disease groups (e.g., MND education workshops delivered by the MND Association to all health professionals). Improve the support/caring of frontline staff, in terms of debriefing opportunities and professional supervision. Improve GP knowledge and capacity of palliative care, including the use of Health Pathways.

Priority six: the community is aware and able to care

Improvements suggested by consumers	Improvements suggested by service providers
<ul style="list-style-type: none">• Community understanding of the benefits of timely end-of-life and palliative care.• Public awareness on how to informally support others within their own community.• Formal services need to work in partnership with informal networks to maximise capacity of support.• Clear and concise information and assistance to complete Advance Health Directives.• Use of completed Goals of Patient Care more widely.	<ul style="list-style-type: none">• Continue community programs to educate and empower consumers, carers, and families on advance care planning and the range of services available.• Community education on how to support others within their community through life limiting illnesses as well as grief support for families and their carers, before and after death.• Better publicity for existing services, such as the recently introduced palliative care support line, and the role of not for profit organisations.

Further information from Professor Samar Aoun (Samar.aoun@perron.uwa.edu.au)