WAPHA
WA Primary Health Alliance

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PERTH NORTH, PERTH SOUTH, COUNTRY WA
An Australian Government Initiative

WA End of Life and Specialist Palliative Care Strategy 2018-2028

December 2017

Rate the extent to which you agree/disagree with the following statements.

When rating the statements, please be aware that:

- End-of-life care is provided by all health services that care for people with life-limiting illness
- Specialist palliative care is provided by health professional teams with recognised qualifications or accredited training in palliative care.

The Strategy….	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree	Don't know / Not Applicable
The strategy is applicable to the end-of-life care sector				✓		
The strategy is applicable to the specialist palliative care sector				✓		
The VISION in the strategy will inform the end-of-life care sector to 2028				✓		
The VISION in the strategy will inform the specialist palliative care sector to 2028				✓		
The PRIORITIES outlined in the Strategy are clear				✓		
The strategy provides direction for future initiatives and service provision				✓		
Overall, the strategy is achievable in the defined time frame 2018-2028				✓		

PROVIDE ANY RATIONALE, COMMENTS OR SUGGESTIONS YOU HAVE RELATED TO THE ABOVE

WAPHA is pleased to provide our submission on the WA End-of-life and Specialist Palliative Care Strategy 2018-2028 (The Strategy) to inform the development of strategic priorities to support people living with life-limiting illness, their families, and the vast range of health, community and aged care professionals who care for them.

WAPHA is the organisation that oversights the commissioning activities of WA's three Primary Health Networks – Perth North, Perth South and Country WA. Primary Health Networks (PHNs) that were established by the Australian Government in 2015 with the key objectives of increasing the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes, and improving coordination of care to ensure patients receive the right care in the right place at the right time.

The alignment of WA's three PHNs under one organisation (WAPHA) affords a once in a generation opportunity to place primary care at the heart of the WA health system and create the mechanism for integrating services across organisations and across boundaries. WAPHA's vision is improved health equity in WA and our mission is to build a robust and responsive primary health care system through innovative and meaningful partnerships at the local and state-wide level.

WA Primary Health Alliance (WAPHA) believes strongly in an integrated health care system; with capacity to deliver patient-centred, best practice care for all those in need. An integrated system requires a collective focus on delivering care in the most appropriate setting through a better relationship between primary care and the hospital system, and integrated hospital services to enhance a person's journey through the system. The Department of Health WA (DoHWA) strategic priorities are focused on a continuum of care and aim to support and guide health care through integrated service delivery from prevention and health promotion, early intervention, and primary care through to diagnosis, treatment, rehabilitation and palliation.

One of WAPHA's principal roles is to commission services that provide the best care and support to people. These should augment and enhance existing services and resources as well as better respond to identified gaps in the health of people in later years. The workshop conversations will continue to ensure best care is provided in the peri-end-of-life service environment.

On 30 November 2016, WAPHA partnered with Silver Chain and McKinsey & Company to host a workshop titled "*Designing a world leading peri-end-of-life health and social care service*"[1]. This workshop which included representatives from DoHWA, St John Ambulance and other health related organisations, collaborated to identify gaps in the existing service environment for peri-end-of life. As a result, Silver Chain is now conducting a pre-trial of Integrum Aged Care + to support older people with chronic health conditions to stay out of hospital and nursing homes and live their lives as they choose.[2]

Integrum is an alternative, holistic primary care and community model, based in a dedicated general practice, for people with complex care needs and chronic conditions. It will provide a one-stop-shop approach to health and aged care, integrating all the services a client is likely to need. The service involves:

- Aged care services and home nursing
- Rapid response care and family support
- General practice with a transport option to and from the clinic
- Case management
- Hospital admission and discharge coordination
- Remote monitoring and digital tools

WAPHA recently supported training for GPs promoting the Palliative Care Approach and worked with Palliative Care WA and the Cancer Council to provide Advance Care Planning Workshops. In addition, WAPHA has provided funding for a regional GP studying part-time towards a Clinical Diploma of Palliative Medicine provided through the Rural Clinical School of WA within The University of Western Australia, and awarded through RACGP.

WAPHA is currently working on community development models to provide greater choice for at home palliative care. This work is underpinned by a compassionate community approach, that sees health as the responsibility of society, including death, dying and end of life care. [3]

WAPHA initiatives such as Comprehensive Primary Care, Integrated Team Care and GP Shared Care, are also relevant in terms their capacity to help improve the lives of all Western Australians through quality end-of-life and specialist palliative care. In addition, the Perth North PHN is an

[1] WAPHA hosts peri-end-of-life workshop. Available at: http://www.wapha.org.au/wapha-hosts-peri-end-of-life-workshops
[2] Integrum Aged Care +, Silver Chain. Available at: https://www.silverchain.org.au/news/integrum-aged-care/
[3] Kellehear, A., 2005. Compassionate Cities: Public health and end-of-life care, London, Routledge.

implementation site for the Commonwealth's Health Care Homes initiative to provide Australians with improved co-ordination, management and support for their chronic conditions[4].

Importantly, WAHPA is committed to facilitating the primary health perspective in the development of the WA End-of-life and Specialist Palliative Care Strategy, including contributing to the development of the priority plans that will support the implementation of the Strategy.

WAPHA has a newly established Strategy and Health Planning Unit that would be keen to strengthen its relationship with DoHWA to facilitate action, implementation, monitoring and evaluation where possible and appropriate. This could be beneficial during the development of the priority plans that will support the implementation of the Strategy. WAPHA would appreciate the opportunity to facilitate input of the primary health care perspective and contribute through initiatives to improve GP capacity and capability to help reduce end-of-life care gaps and challenges in a united, collaborative manner.

WAPHA appreciates the Department's consideration of our submission. If you wish to discuss our recommendations in more detail, contact Mrs Christine Kane, General Manager Strategy and Health Planning, on 08 6272 4966 or chris.kane@wapha.org.au

IDENTIFIED WEAKNESSES AND SUGGESTIONS ON HOW THESE COULD BE ADDRESSED

WAPHA is committed to supporting the effective implementation of the Strategy and suggests that consideration be given to the following:

Priority Area 1: Access to care

WAPHA acknowledges that equity of access to end-of-life and specialist palliative care services is an issue for Aboriginal people, CaLD communities, people with specific diseases and marginalised groups, such as homeless people, refugees and the LGBTI community. These population cohorts all require specific consideration.

People living in regional, remote and rural WA also experience issues accessing end-of-life and specialist palliative care services. So that this important issue is separately addressed, it is suggested that a specific outcome statement be included to improve equity of access in regional, remote and rural WA. This will ensure that dedicated attention is given to addressing the access issues experienced by people living in these communities.

WAPHA is exploring options in parts of regional WA for new ways of delivering after-hours general practice palliative care services to people living at home and in residential aged care facilities to support greater choice for end of life care within the community.

There are additional community health providers that could provide innovative ways to provide end-of-life care in regional areas, such as St John Ambulance. For example, the New South Wales (NSW) paramedic palliative model enables GPs involved in palliative care to close the after-hours gap for their palliative care patients. In consultation with the patient and their family, the GP may elect to complete a NSW Ambulance Authorised Palliative Care Plan. This plan authorises NSW Ambulance paramedics to deliver individually tailored treatment based on the GP's advice.[5][6]

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[4] Health Care Homes The Department of Health. Available at: http://www.health.gov.au/internet/main/publishing.nsf/Content/health-care-homes

[5] Ambulance Service of New South Ways, Authorised Palliative Care Plans, General Practitioner Information Kit. Available at: https://www.google.com.au/url?sa=t&rct=j&q=&esrc=s&source=web&cd=4&cad=rja&uact=8&ved=0ahUKEwj5x-jEm_LXAhWLErwKHRhvBAcQFgg9MAM&url=https%3A%2F%2Fwww.slhd.nsw.gov.au%2Fbtf%2Fpdfs%2FAmb%2FGP_Booklet.pdf&usg=AOvVaw33uT0nadhjm_fq3MN0vgKm

[6] NSW Ambulance Instruction Sheet, Authorised Adult Palliative Care Plan. Available at: https://www.google.com.au/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKEwij9b2cnPLXAhWKS7wKHaUBBBYQFggqMAA&url=https%3A%2F%2Fwww.slhd.nsw.gov.au%2Fbtf%2Fpdfs%2FAmb%2FAdult_Palliative_Care_Plan.pdf&usg=AOvVaw1elDWPnVec8Fd5IE2WNJuV

Recently Martin Laverty, CEO, Royal Flying Doctor Service (RFDS), announced the Dying to Talk in the Bush research project being undertaken in partnership with Palliative Care Australia (PCA) and funded by the Commonwealth. The project stemmed from concerns about access to palliative care services in remote Australia and will inform how RFDS can form deeper partnerships with others to be able to extend palliative care services in regional Australia. RFDS staff will use Palliative Care Australia's Dying to Talk resources in its clinics in Victoria, NSW, Queensland and South Australia (SA), focussing on people who are over 65 and those with a chronic illness. The outcomes of this project could inform end-of-life and specialist palliative care service provision throughout regional WA.[7]

Priority Area 2: Person centred care

Outcome: Patients and families co-designing care with health teams, to include culturally respectful and comprehensive care, and opportunities to talk about and plan for death, including Advance Care Planning (ACP).

- GPs would benefit from having more information available so they are aware of the relevant legislation and have easy access to the forms and documents needed to facilitate effective discussions and actions around Advance Care Directives (ACD) and ACP.

Priority Area 3: Connected Care

General practice should play an increasingly important role in delivering services in the community that could positively contribute to the quality-of-life for patients and their families approaching end-of-life. The role of practice nurses and nurse practitioners working under the auspices of GPs should also be considered within the Strategy.

Outcome: Strengthened referral pathways between end-of-life and specialist palliative care teams.

- Case conferences are important to promote the sharing of knowledge across all members of the end-of-life and specialist palliative care team. Communication needs to improve more generally across all services providers, including hospitals, GPs, locums, palliative care specialists, allied health professions, ambulance services and Silver Chain – particularly at the point of hospital discharge.
- GPs being actively involved in decision-making around the care provided in hospital and hospice settings would promote greater continuity of care. GPs have ongoing relationships with their patients and can provide a whole person perspective that is integral to good palliative and end of life care.
- WAPHA supports examination and trial of an expanded scope for physiotherapists, pharmacist, dieticians, practice nurses and other allied health professionals in end-of-life care and specialist palliative care. This would form part of the multidisciplinary, GP led, team approach.

Outcome: Adequate resources to support health, community and aged care providers delivering end-of-life and specialist palliative care.

- There is a gap in training, resources and processes to support GPs and hospital emergency staff to have effective discussions with patients and families on decisions around ACD and ACP. Resources and systems, including medical software packages and shared care planning tools, could be better designed to provide local clinical pathways and to prompt GPs and Hospital Emergency staff to include ACD and ACP discussions at relevant times. For GPs, these relevant times would include when undertaking health assessments and care plans, including

[7] Royal Flying Doctor Service is dying to talk in the bush and map gaps in palliative care services, Heather Wiseman, 20 October 2017. Available at: http://palliativecare.org.au/palliative-matters/royal-flying-doctor-service/

as part of the age 75+ health check, when chronic health conditions are first diagnosed and other clinical triggers. Greater use of the 'surprise question' "Would you be surprised if your patient died in the next year?" should also be encouraged.

- WAPHA could take a leadership role in co-ordinating and disseminating local information on end-of-life and specialist palliative care services available by locality and take responsibility for keeping this information current.
- Promoting the use of My Health Record would support greater sharing of relevant health information across all end-of-life and Specialist Palliative Care clinicians who are part of the patient's care team. Importantly, it is also an avenue for people to share their documented wishes for future medical treatment (Advance Care Planning) and make that information available to healthcare providers at the time and place it is needed.[8]
- There is also an opportunity to explore the use of electronic shared care planning tools for use across the end-of-life and specialist palliative care team, such as the list of software programs that meet the Commonwealth's minimum requirements for Health Care Homes.[9]
- Within the WA context, consideration could also be given to using tools such as the palliAGED app that provides nurses and GPs with easy and convenient access to information to help them care for people approaching the end of their life. Timely access to palliative care information can support the clinical care being provided. An online-offline capacity means they can use the apps anywhere in Australia. As the app is web-based, it can be updated as new evidence and resources are released.[10]

Priority Area 4: Family and carer support

Outcome: Improved awareness by health, community and aged care providers regarding family access to bereavement support

- Providing families and carers with the information and skills to understand end-of-life choices and services options could avoid unnecessary hospitalisations.
- Consideration could be given to enhancing the Patient Assisted Travel Scheme (PATS) to provide access to appropriate transport and accommodation for regional WA families accompanying a family member who needs to be relocated to Perth to receive appropriate end-of-life and specialist palliative care services.
- Building on the Great Southern Compassionate Communities approach, WAPHA could support the development of community and other support mechanisms involving families and carers in design and delivery of services.

Priority Area 5: Workforce capacity

Outcome: Improved health, community and aged care provider understanding of end-of-life care, and appropriate referrals to specialist palliative care.

- GP remuneration for end-of-life care is challenging. Some key activities that contribute to effective end-of-life care do not attract a payment within the Medicare Benefit Schedule, such as service co-ordination, family consultations, after-hours support provided via telephone, consultations with practice nurses, and case conferences. Alternative funding models to address this gap require consideration.

[8] MyHealthRecord, My Wishes, My Plan – Advance Care Planning. Available at: https://myhealthrecord.gov.au/internet/mhr/publishing.nsf/Content/acp
[9] Medical Software Industry Association. Available at: https://www.msia.com.au/healthcare-homes/
[10] palliAGED Apps Available at: https://www.palliaged.com.au/tabid/4351/Default.aspx

- GPs have said that they would benefit from having greater access to specialist palliative care services.
- HealthPathways is as an enabler that can increase the capacity across the primary, secondary and tertiary health sectors related to end-of-life and specialist palliative care management and appropriate referral pathways with GPs, practice nurses and allied health professionals.
- Some General Practitioners have expressed concern around the medico-legal implications around palliative care. This could be a barrier to GPs taking on further training that could improve the end-of-life care they provide for their patients. WAPHA recommends that further discussions be held with MDA National and other Indemnity providers to seek their advice on this important issue.

Outcome: The generalist healthcare workforce is supported to increase capacity, knowledge and skills, improved succession planning for an ageing workforce, the workforce is better equipped to support an ageing population.

- Dr Angus Cook, School of Population and Global Health, University of Western Australia, is conducting research to improve the quality of end of life care in the community. An initial study is being conducted to determine what care is currently provided for people dying an expected death, how general practitioners contribute to that care, and how general practitioners can be supported to be more effective in providing end-of-life care in the community setting.
- Knowledge about end-of-life care and specialist palliative care is fragmented across the GP workforce. Demands on GPs can vary depending on where they are required to provide services. In-home care is the most demanding and requires substantial skills and knowledge about end-of-life care.
- There is an opportunity for WAPHA, he royal College of General Practitioners (RACGP), the Australian College of Rural and Remote Medicine (ACRRM) and Western Australian General Practice Education and Graining (WAGPET) to work in partnership with DoHWA on initiatives to address knowledge gaps and build GP capacity on end-of-life care and appropriate referral pathways for specialist palliative care. This could require strengthening of the general practice core curriculum and professional development programs. Greater emphasis is needed on symptom management, pre-emptive prescribing and the use of ACD and ACP. More understanding around effective assessment of unnecessary care and treatment is also required.
- Providing more information on the use of MBS items to GPs to support effective end-of-life care for patients would be beneficial. WAPHA can coordinate the development and distribution of relevant information and resources. An example of the type of information that could be made available is the guide for health professionals working in general practice and residential aged care prepared the North-Western Melbourne Primary Health Network [11]

Priority Area 6: Public awareness

In this area, it is suggested consideration be given to providing greater public awareness around decision-making at the point of transition from active treatment to end-of-life palliative care.

[11] MBS remuneration to support planned palliative care for patients: A guide for health professionals working in general practice and residential aged care. North Western Melbourne PHN, available at: https://northwestpalliative.com.au/wp-content/uploads/2017/08/MBS-remuneration-to-support-planned-palliative-care-for-patients-NWMPHN.pdf

IDENTIFIED STRENGTHS

WAPHA supports the development of the WA End-of-life and Specialist Palliative Care Strategy and acknowledges the focus on patient centred care incorporating patients and families co-designing care with health teams, strengthening of referral pathways between end of life and specialist care teams, increasing the capacity of the generalist healthcare workforce, improving practical advice and support for families, and community awareness.

In developing the priority plans that will accompany the Strategy, it will be important to seek input and advice from consumers and carers on their needs to ensure the Strategy is easy to use, action and understand in terms of what the implementation will mean from their perspective.

ANY OTHER COMMENTS

General practice has a key role in delivering end-of-life care in the community and referral pathways to specialist palliative care services. WAPHA can facilitate engagement with, and capacity building in, primary care, including general practice, engagement and involvement in developing and implementing the Strategy and the accompanying priority plans.