



Joint Select Committee on End of Life Choices: WACHS Submission

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WACHS welcomes the opportunity to provide a submission to the Joint Select committee on End of Life Choices. WACHS submission is based on feedback and consultation with the Medical and Nursing workforce.

1. Introduction

WA Country Health Service (WACHS) serves a population of almost 560,000 people dispersed over an area covering 2.55 million square kilometres, 21 per cent of Western Australia's (WA) total population. WACHS is the major provider of hospital, health and aged care services across country WA, working in partnership with other service providers to improve service access and effectiveness. Access to services close to home is challenged by the geographical vastness of WA and access to a consistently skilled and available workforce.

WACHS comprises seven regions: Kimberley, Pilbara, Midwest, Goldfields, Wheatbelt, South West and the Great Southern. In 2004 the Reid Report endorsed the implementation of the regional network model with Albany, Broome, Bunbury, Geraldton, Kalgoorlie and Hedland Health Campuses forming the resource hubs for regional services. Their role is to connect services across the region and support staff located at the smaller sites optimising the best possible health services for consumers so they are able to access the right service, in the right place, to meet their needs. The regional support and resource hubs also lead coordination of services with other regional health and related providers.

WACHS is the biggest provider of residential aged care in rural WA and operates two Commonwealth funded aged care facilities and over 550 flexible aged care places in Multi-Purpose Service sites and a range of non-admitted community care services.

In WA the growth in the older population is greatest in country areas and is growing disproportionately to the younger population. The prevalence of chronic conditions and health issues increases as people get older and the need for palliative and end of life care across all care settings is increasing. It is important that people are supported to receive high quality end of life care in the setting of their choice.

2. Current Services

Life expectancy for country people is approximately two years less than for metropolitan people and the rates of death for country people are significantly greater than that of metropolitan people, particularly for heart disease, diabetes, some cancers and long term respiratory diseases. Aboriginal Western Australians experience poorer health, with lower life expectancy and experience disability greater than non-Aboriginal Western Australians.

WACHS is committed to working with other providers to improve access to support for those approaching their end of life, as well as supporting their families and carers.

Life limiting illnesses with long, unpredictable courses can create situations where a person's ability to communicate and their capacity to make decisions changes over time. Provision should be made to ensure that family and carers are engaged in care decisions and are encouraged to participate in the ongoing decisions about palliative care.



Nursing

WACHS provides Palliative Care Services (PCS) in each of the seven regions led by a Senior Registered Nurse with expert skills in the area of palliative care.

These coordinating nurses work closely with the WA Cancer and Palliative Care Network, provide links to tertiary services and facilitate the best use of local resources inclusive of other care providers including General Practitioners and/or Aboriginal Medical Services. Some regional services include other health disciplines within PCS including Social Workers and or Aboriginal Health Workers and administrative personnel.

WACHS PCS are based in the Regional Centres with outreach provided across the region. End of Life Care is one element of palliative care provision and the referral to PCS for non-cancer related disease has increased significantly in the last two years.

The Service

- Provides support to patients and families who are in the palliative phase of care this may be for children, youth, adult or the elderly
- Coordinates services, personnel and equipment to optimise care and management plans.
- Provides information to patients and relatives in a culturally sensitive manner.
- Provides education and support to those caring for patients in the palliative care setting
- Works with local medical practitioners, and metropolitan based specialists to ensure best practice care delivery is provided
- Collects and collates local data to contribute to State-wide monitoring of service provision; undertakes analysis to inform future service planning

Challenges in providing End of Life Choices

- Limited infrastructure in rural and remote communities to support death at home, solo health practitioners must risk assess home visiting in circumstances where large groups may be in attendance
- Facilitating planning inclusive of Advance Health Directives (AHD) with cultural sensitivity
- PCS is an in hours service with patients and carers required to contact nearest health facility for after-hours support or input. Funding for the provision of a 24 hour specialist service would ensure the right care, in the right place, at the right time for patients.

Aged Care

WA has an ageing population, many people frequently experiencing multiple health issues, including loss of cognition, particularly by the time residential care is required. Advance care planning and the opportunity to make an AHD are important components of routine care for those with chronic illness.

The Service

Advanced care planning is widely facilitated in WACHS residential aged care facilities and when residents are unable to express their own views regarding treatment, families and carers are involved in all decisions about ongoing care, including the acceptance or refusal of certain treatments. An advance care planning discussion allows an individual's



values, beliefs and preferences to guide future decision making regarding their care and treatment. Residents are empowered to direct their own care, whenever possible and this includes providing for their cultural, spiritual and psychosocial needs and for those of their families and carers.

Ongoing discussion and updating of decisions related to advanced care planning is encouraged to help ensure that communication on these matters remain current.

As part of this discussion, information regarding AHDs and Enduring Power of Guardianship is discussed with residents and their families and carers on admission to WACHS aged care facilities. Information is also made available to aged persons and their families and carers of these arrangements, in other settings eg community care, acute care environments.

“Care Plan for the Dying Person” is part of a new suite of WACHS tools that aids the delivery of safe, quality patient-centred care during the last days of life. It provides an outline of care that a patient is able to expect in the final days and hours of life, and also becomes a structured record of the actions and outcomes that occur. It facilitates doctors and nurses to provide end of life care and aims to guide members of the multi-disciplinary team in both continuing or discontinuing medical treatment and outlines comfort measures during the last days and hours of a patient’s life.

All residents are offered the opportunity to make an Advance Health Directive as part of their routine admission assessment. The end of life needs of residents in WACHS residential aged care facilities are assessed documented and regularly reviewed on a routine basis. In consultation with families and carers changes in resident’s health status are recognised and changing needs are documented and met; access to a specialist palliative care team is available and referral will be timely.

Challenges in providing End of Life Choices

- Establishing the resident’s cultural values and background is an important part of the advance care planning discussion. Many residents of minority cultural and language backgrounds are less likely to complete Advance Health Directives than the majority population and for some cultures, the principles of individual decision making are quite foreign.
- The issue of raising Advance Care Planning and its subsequent documentation is a difficult one, particularly in Residential aged Care Facilities where new residents and their families are often not ready to consider or discuss such options. Training and education both for consumers and staff would facilitate improved use of documentation and ensure better quality care for residents.
- Advance care planning documents vary and include a variety of legal documents as well as less formal documents for ascertaining a resident’s end of life wishes – a more standardised approach would make it easier for consumers and WACHS employees to navigate through them.
- Currently referrals to the State Administrative Tribunal (SAT) for Guardianship Orders (when there is no one in the hierarchy of treatment decision orders to provide consent) for a person who has not got the capacity to provide consent, may lead to delays of up to eight weeks. Under the SAT Act 2004, a health professional can only provide confidential patient information to the SAT in



response to an order or subpoena. Changes in legislation allowing disclosure of confidential patient information between government agencies would facilitate a more patient-centred philosophy and approach to care and make the process more timely and efficient.

Medical

General Practitioners (GPs) provide a substantial proportion of the palliative care provision in WACHS and also engage in end of life conversations with patients and carers. There is limited support from Palliative Care medical specialists and this gap is filled to some extent by the senior palliative care nurses. There is no medical oversight, coordination or governance of medical palliative care services across WACHS and a state-wide approach would be of some benefit coupled with a comprehensive auditing program to ensure that contemporary standards are maintained. Policy is also somewhat lacking and developing strong policy approaches is a pre-requisite for improving and maintaining standards.

Oncologists also have input into end of life conversations and again improved coordination and communication with GPs would be of some benefit to facilitate arrangements. The Cancer Network has a role to play here.

The current legislative arrangements appear to be satisfactory. Forms such as "Not for resuscitation" are widely used in addition to AHDs. Some jurisdictions have changed the name of the forms to "Allow natural death" to clarify the intent with patients and carers and perhaps this could also be considered.

3. Telehealth

Due to the geographical vastness of WA, Telehealth is able to provide an important role in maintaining/supporting terminally ill patients and their families and carers, offering an option to remain at home with the aid of technology.

In the Wheatbelt the Telepalliative Care in the Home program has piloted the use of tablets for patients enabling them and their carers stay in contact with the palliative care staff through existing Telehealth services for appointments and for support. During the trial 75 per cent of participants were able to remain at home while receiving palliative care treatment. Without this specialist palliative support, carers reported that they usually revert to hospital options even when it was not what the patient wanted.

4. Conclusion

A systematic method for the practice of Advance Health/Care Planning, is required for person-centred care to ensure the resident's wishes are known and respected.

End of Life care should be considered a core competency for aged care workers with staff trained and supported to recognise when end of life care is required and implemented with planned managements that will meet the change in a person's needs. The effective use of AHDs is dependent upon the aged care team's knowledge of the legal status of these documents. The effective use of Advance Health Directives is dependent on knowledge of the process underpinning the person's wishes, medical input and the legalities pertaining to the situation.



An important consideration is the Aboriginal preference to be on country. Travelling long distances and the separation from family is able to be minimised through the expanded use of telehealth technology. WACHS strives to provide high quality palliative and end of life services in the persons preferred location whether it is in aged care facilities or in their own homes. Dying, death and the bereavement process is a time of vulnerability and can be eased and supported to overcome barriers and challenges and allow patients and their families to have some control during a period where they have no control over the outcome.

Advance Health/Care Planning can lead to avoidance of non-essential hospital transfers and their inherent risks and is more likely to facilitate a dignified, peaceful death in familiar surroundings whilst averting medical interventions which may result in prolonged suffering. Improved infrastructure including the expansion of in-home Telehealth consultations and support would ensure improved access to services.

WACHS welcomes patients, their families and carers to be partners in their health care decisions whenever possible and endeavours to provide for cultural, spiritual and psychosocial as much as physical needs.