



Submission to the Joint Select Committee on Palliative Care in Western Australia by East Pilbara Independence Support (EPIS) Incorporated

July 2020

This submission response has been developed with input from experienced aged care, nursing and management staff from EPIS.

Background of EPIS

EPIS provides aged, respite and disability care services for people living in communities located in the Shires of East Pilbara and Ashburton. The primary role of EPIS is to provide a person centred care by delivering services based upon understanding and assisting clients to live according to their own abilities, specific needs and family and community support. In addition, EPIS works in creating conditions where an appropriate degree of independence is achieved and provides advocacy support for clients in need of care. A major gap encountered by EPIS experienced staff is the lack of palliative care services in the region, especially among the Aboriginal population. Consequently, the lack of palliative care services disturbs the provision of person centred care and deleteriously affects the well-being of the client, his or her family and community.

Response to Terms of Reference

- **(2) (c) Delivery of palliative care into regional and remote areas**

Access to quality palliative care is limited for the communities of the Shires of East Pilbara and Ashburton. The only palliative care service provided in the region is Nursing Consultation to the Newman, Tom Price and Onslow Hospitals by the Pilbara Palliative Care Service and a single room on the general ward of the hospitals for palliative care patients¹. The Pilbara Palliative Care Service is based in Karratha, 600 kilometres away from Newman and as mentioned, with very limited capacity for service delivery to Newman and the remote Western Desert Communities.

There is no palliative care service for residential aged care facilities and home care. In fact, there is no residential aged care homes in the Shires of East Pilbara and Ashburton. Nonetheless, there is a critical need for palliative care in home and residential settings. Numerous examples exist of clients in need of palliative care with unfortunate outcomes. For instance, Aboriginal and non-Aboriginal clients at the end-of-life stage being relocated to nursing homes located hundreds of kilometres away from home and family and in different Aboriginal Country land. This practise brings hardships not only to the client in need of palliative services, but also to his or her family and wider community.

An experienced aged care team leader answered the following when questioned about her experience with clients in end-of-life situations:

“Having the ability to end their life in their land is a privilege that most Aboriginal people don’t have in our region.”

The lack of palliative care and residential aged care is not the only limitation in the Shires of East Pilbara and Ashburton. There are no in-home palliative services available for clients with terminal conditions who wish to remain at home with family. As a consequence, clients and their families are



faced with the difficult decision of going to residential aged care facilities hundreds of kilometres away or having limited assistance with end-of-life care at their homes. The last option is often sub-optimal.

- **(2) (d) The progress of ensuring greater equity of access to palliative care services between metropolitan and regional areas.**

As a service provider, EPIS has not seen progress on ensuring greater equity of access to palliative care services between metropolitan and regional areas. In the Eastern Pilbara region, people in need of palliative care do not have the option of palliative care in a residential facility; or palliative care provided at their homes by a nursing service; or comprehensive medical, nursing and allied health care based on their unique needs, when facing a life limiting prognosis. Furthermore, there are no culturally appropriate services for the Aboriginal community and many times Aboriginal family members of clients with a life limiting prognosis are left with feelings of guilt and shame when making the decision of transferring their loved ones to residential facilities located outside our region.

Having a palliative nurse 600 kilometres away does not translate to equity access to palliative care for the people of the Shires of the East Pilbara and Ashburton.

Recommendations

- According to the OECD Health Statistics 2017ⁱⁱ, Australia designates 52.2 nursing and residential care beds per 1000 people aged 65 years or older. The Shires of East Pilbara and Ashburton have a combined population of 945ⁱⁱⁱ iv people aged 65 years or more, which translates to a need for 49 residential long-term care beds. Currently there are 0 (zero) beds. EPIS Inc. recommends the select committee consider funding a residential aged care facility in Newman that has included at least 2 palliative beds for people with life limiting prognosis to provide quality residential aged care and palliative care.
- EPIS Inc. consider there is a need to fund in-home palliative care service based here in Newman that could outreach to the Shire of Ashburton and into the Western Desert communities. EPIS Inc. is experienced in providing in-home care for frail clients and has the capacity to deliver palliative care if provided with the necessary funding.
- EPIS Inc. recommends that palliative care is done in a culturally safe and appropriate manner in collaboration with the Aboriginal community and the Puntukurnu Aboriginal Medical Service.

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- ⁱ Palliative Care Western Australia. Pilbara Palliative Care Service. [website].
<https://palliativecarewa.asn.au/locations/pilbara-palliative-care-service/> (accessed July 2020)
- ⁱⁱ OECDiLibrary. OECD Health Statistics 2017. Long-term care beds in institutions and hospitals. [website]
https://www.oecd-ilibrary.org/sites/health_glance-2017-80-en/index.html?itemId=/content/component/health_glance-2017-80-en (accessed July 2020)
- ⁱⁱⁱ Australian Bureau of Statistics. 2016 Census QuickStats. East Pilbara (S) [website].
https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/LGA53220
(accessed July 2020)
- ^{iv} Australian Bureau of Statistics. 2016 Census QuickStats. Ashburton WA. [website].
https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/510031271?opendocument (accessed July 2020)