

INQUIRY INTO END OF LIFE CHOICES

Submission from Busselton Hospice Care Incorporated

Background

The care of the dying in the City of Busselton region is represented by a partnership between the local community, the Busselton Hospice Care Inc. (BHCI) and WA Country Health Services – South West (WACHS - SW.)

BHCI (and the WACHS Busselton Health Campus) primarily provide services for the Busselton City Local Government region (Incorporating Dunsborough and Yallingup communities.) The 2016 Census deemed the population to be 36,686. The median age is 42 years with 19.7% over 65 years. 74.3% are born in Australia.

BHCI began in 1989 as a non- Government, not-for-profit organisation registered as a charitable institution. From 2000 – 2015 BHCI provided an inpatient palliative care service, in partnership with WACHS –SW and the Silver Chain Nursing Association, employing registered nurses and incorporating a team of 100 trained volunteers who provided emotional and social support at the end of life. All operational expenses were funded through the generosity of the local community.

In 2015 the model of palliative care in the City of Busselton changed. A four bed Hospice Unit was incorporated within the new Busselton Health Campus, and the nursing staff of BHCI were transitioned to employment by WACHS -SW, to provide a community palliative care nursing service.

BHCI has continued to be involved in palliative care in the Busselton Health Campus through (a) the supply and management of the team of 100 trained volunteers to enhance the palliative care and to provide emotional support of patients (and their families) admitted to the Hospice Unit and (b) providing furnishings and equipment to maintain an attractive and non-clinical atmosphere and other services essential to best practice in palliative care.

BHCI provides a range of programs in the Geographe Bay Centre – our Centre for Excellence in Palliative Care, including the palliative care volunteer services, bereavement support, carer education, community education, complementary therapies to support those dying in the community or hospital/hospice, workshops and professional education.

BHCI receives no government funding to sustain its services. It relies solely the funding provided through the generosity of local people which is an expression of community concern and inclusion and represents invaluable support at a time which for many can be isolating and overwhelming.

STATEMENT TO ADDRESS THE TERMS OF REFERENCE

We wish to contribute to the Inquiry by addressing the Terms of Reference Statement
(a) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care;

Palliative care in regional and rural settings is variable according to the interest and expertise of local health professionals. The City of Busselton and its people are fortunate to have access to quality

general practice medical facilities. Multiple General Practitioners (GPs) have practiced locally over many years thus building personal relationships with their patients. Many GPs also have a professional interest in palliative care and will continue to care for their patients until the end of life.

Patient referrals to palliative care services are channelled through the WACHS South West Regional Palliative Care team, based in Bunbury, to the Coastal Palliative Care Service operating in the City of Busselton community. Patients who require inpatient palliative care can be admitted to the Hospice Unit at Busselton Health Campus. Most palliative care patients admitted to the Hospice Unit will have their care needs met. If patients have more complex problems or when medical needs exceed the resources and expertise available locally, they can be referred to and/or transferred to Bunbury Health Campus (or Perth). Specialist palliative care medical advice and support can be received by referral to a Bunbury based Palliative Care Medical Specialist or by accessing the Palliative Medical Advisory 24/7days phone service.

It has been our unfortunate clinical experience that infrequently some patients will not achieve good symptom control despite best efforts locally, in Bunbury or in metropolitan Perth.

Local Issues

Inpatient End of Life Care

There is no dedicated palliative care staff position to provide a leadership role around contemporary end of life care best practice within the Busselton Health Campus. Care is provided by generalist health professionals who also have responsibility for all other patients within a general ward setting. The quality of palliative care relies on the palliative care knowledge and expertise of each individual health professional. The trained palliative care volunteers therefore play an important support role to ensure a consistent standard of holistic palliative care.

Training in palliative care and contemporary end of life programs is not high priority for hospital staff due to time constraints and competing work demands. State-wide end of life care initiatives such as the implementation of an End of Life Pathway and “CPR Decision–Making in the hospital setting” training programs have not been implemented at Busselton Health Campus.

Hospital funding for protracted terminal care encourages discharge from the hospice / hospital to a nursing home facility. This may be in a neighbouring town. This can be very distressing to family especially if death is imminent and / or carers are elderly and not mobile.

Community Services

WACHS- SW have allocated 1.0 FTE of palliative care nursing to provide community palliative care across the City of Busselton region. There is no on-call and weekend nursing support model and these services are currently being provided by the 1.0 FTE nursing component.

There has been additional clinical nursing support provided to this position from the Regional Palliative Care Team located in Bunbury with additional FTE in recent months although this is irregular in nature.

The quality and capacity of this service is solely dependent on the skill and commitment of the individual nursing staff who go far beyond the call of duty. The current funding and staffing of this service is insufficient to give every person requiring palliative care the option to be cared for and to exercise their choice to die at home.

There is no dedicated multi-disciplinary team for Palliative Care in the City of Busselton and the coastal area. Community service professionals for palliative clients are drawn from the generalist staff of the community service team. There is no capacity in this model to meet the palliative care standards that relate to the multidisciplinary coordination of assessment and planning of care.

Problems are compounded for younger patients in rural regions under the age of 65 years due to the limitations of Home and Community Care (HACC) services criteria. People under 65 with a palliative care diagnosis are not entitled to access any home care support as they do not meet the criteria for HACC or the disability scheme. There are no options for people under 65 and their families to access professional personal care or domestic support to enable them to exercise their choice to die at home. Any support provided to them is capped at limited time frames for only domestic help through Cancer Council and Red Cross. This is capped up to 6 visits. This is inconsistent and limited to certain geographical locations. People under 65 rely on their own informal networks to provide physical care and support a death at home.

Final Statement

The Board of BHCI wish to express concerns about any change to current end of life legislation in Western Australia that could be perceived to give people the 'option of choice' when rural and regional people do not yet have the option to receive a full range of end of life services in their local community including the option to receive full support to die at home.

Jenny Monson, Chairperson

On behalf of Busselton Hospice Care Inc

23rd October 2017