

Friends of Northern Hospice,

PO Box 233

Launceston. 7250

The Chair,

House of Assembly Standing Committee on Community Development

Inquiry into Palliative Care,

Parliament of Tasmania,

Parliament House,

Hobart. 7000.

Dear Chair and Members of the Committee,

Friends of Northern Hospice (FONH), wish to make the following submission to the Inquiry into Palliative Care.

- 1) We support the principle of Advanced Care Directives (ACDs) for all Tasmanians. With regard to the preparation of individual Advanced Care Directives, we believe that they are best managed by General Medical Practitioners (GPs) who already have opportunities to discuss these with their patients, given their close medical and professional relationships. GPs are well-placed to raise, as routine, ACDs for patients of all ages with a life limiting illness, and all patients over the age of 75 years who receive an annual health assessment. E-health records can then hold this information so it can be accessed by appropriate care-givers. This can be reinforced through public advertisements encouraging people to discuss their ACD with their doctors. Advertising would also serve the purpose of raising end of life choices with the broader family unit. It may be possible for ACDs to be routinely promoted through solicitors when individuals are making their Will.
- 2) FONH also support community-based initiatives to raise general public awareness of the need for, and advantages of, everyone preparing an ACD. However, it is not the role of these community organisations to work directly with a specific individual to help them prepare their personal ACD. For example, there may be clinical and /or personal factors to be

considered, knowledge of which should remain a private matter protected by the ethics of the doctor- patient relationship.

- 3) The key factors in an ACD are: (1) what kind of palliative and end of life care a person would envisage for themselves; (2) where they wish to die; and (3) ensuring that a patient's wishes, as may be embodied in their ACD, are respected and implemented- even where they may be at odds with the views of family members or the institution that is caring for the patient. It must be remembered that while an ACD may have been documented, it is up to others to respect the wishes as stated .
- 4) The most popular option is to die at home, but in the large majority of cases this becomes impossible. As definitive disease treatment for a patient's illness transitions to palliative care and then finally to end-of-life care, there is usually a strong preference to avoid any further contact with hospitals. Palliative care can often be home based care which can be provided by family and /or services for weeks or months, but as the process progresses to end-of-life, care is more likely to move from home to 24 hour institutional care. The preferred model for this is a dedicated, home-like, non-clinical environment within a hospice.
- 5) We have been informed that the Department of Emergency Medicine (DEM) at Launceston General Hospital receives palliative patients on a regular basis. By its very nature this results in inappropriate tests, treatments and admissions to the acute hospital. These patients have been unable to successfully receive end-of-life care at home. This has been confirmed by canvassing the observations of Nurse Unit Managers of various departments within the LGH.

We all appreciate how overextended the resources are at the LGH Emergency Department. However, we also know that dying patients taken to ED by their families, often spend their last days and hours on a trolley or in an ED bay. This is inappropriate and immensely distressing for the dying person and their family.

- 6) Palliative care is an established medical treatment for paediatric patients and many hospices dedicate a section to care specifically for children. Further information regarding paediatric palliative care research can be found in the *"Australian Government Response to the Senate Community Affairs References Committee Report: Palliative Care in Australia"* released in May 2016.
- 7) Please find enclosed the following documentation in support of our submission:
 - (i) our previous submission to the "Department of Health and Human Services on the Delivering Safe and Sustainable Clinical Services – Green Paper";
 - (ii) Friends of Northern Hospice's proposal for a Northern Community Hospice, titled "Hospice Proposal for Launceston". This is 10 bed, community hospice designed specifically to provide end-of-life care as well as respite care, for terminally ill patients who can no longer be fully managed within their own home.

- (iii) An architectural plan to re-purpose the DHHS, former health care building, 'Allambie'.

NOTE: This does not exclude the possibility of, instead, establishing a purpose-built hospice on a green field site.

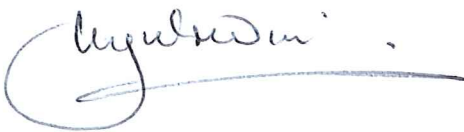
- (iv) Enclosed also is our public notice outlining our intention to establish a Northern community hospice and it summarises our case. It should also be noted that a hospice is part of the usual model of palliative care in other parts of Tasmania and Australia e.g. Whittle Ward in Hobart; Clare Holland House in the A.C.T.; and in other countries such as the Keech Hospice in Luton, U.K.

Should it be required, we are able to supply numerous examples of where the current system has been insufficient to provide adequate end-of-life care. Please feel free to contact me for clarification of any issue raised hitherto.

Finally, representatives of Friends of Northern Hospice would like to attend and present our case at any hearings that the Committee may hold. We would very much appreciate if you could notify us of when and where these hearings will be held.

Thank you for the opportunity to comment.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'Lyn Irwin', with a long horizontal flourish extending to the right.

Lyn Irwin.

Chairperson

Friends of Northern Hospice.