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Submission to
Health and Community Services Committee Inquiry
“Palliative care services and home and community care services”
Queensland Parliament
Parliament House
Cnr George & Alice Streets
Brisbane 4000

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HEALTH AND COMMUNITY
SERVICES COMMITTEE

Submission 12

31st July 2012

Sent by email to: hscs@parliament.qld.gov.au

Dear Committee Secretary

Thank you for the opportunity to present a submission to the Committee conducting this inquiry into palliative care and HACC services in Queensland.

The organisation

Dying with Dignity Queensland Inc. is a long-standing State-based organisation whose object is to promote legislation giving effect to the widely held public opinion that any person suffering, through illness or disability, severe pain or distress for which no remedy is available, should be entitled by law to a pain free and dignified death in accordance with that person's expressed direction.

We also work to raise awareness of the existence of the Advance Health Directive (AHD) as a legal document that may assist people to plan for their future health care, especially end of life care, in a way that offers democratic choice, promotes dignity and quality of life. We assist in the formation of new Branches in all parts of Queensland.

We acknowledge the good fortune Australians enjoy in having access to one of the best palliative care systems in the world and quality standard home and community care services. Furthermore, we welcome any and all initiatives designed to allow patients to remain at home for as long as possible, to improve the care of the aged, the frail, the chronically ill and the terminally ill in our society and to bring aspects of that care more in line with societal expectations as time passes.

However, we also acknowledge that challenges still remain for all systems and jurisdictions associated with the provision of this care, particularly given possible fiscal limitations, the acknowledged ageing of the Australian population and the desire of many citizens to have a voice that will be heard when decisions need to be made on their behalf.

Addressing the Terms of Reference

We have read the issues paper and appreciate the scope of the inquiry.

We address only these terms of reference

- *the capacity and future needs of these services (including children and adolescents palliative care)*
- *the effectiveness, efficiency and adequacy of palliative, frail and chronic care services*
- *examine opportunities for reforms to improve collaboration and cooperation between chronic, disability and other health services*

Our comments focus largely but not exclusively on the inadequate role that AHDs currently play in assisting with the provision of quality care and the potential for this to improve.

1. The capacity of the services under review in this inquiry to expand and improve will depend on several factors:

- sufficient on-going, guaranteed funding to enable mid to long term planning and development for areas in greatest need
- increased funding for ambulance services to improve response times
- infrastructure is put in place to attract, train and deploy high quality administrators, registered nurses, enrolled nurses and carers in both low and high care institutions and particularly in sufficient numbers to improve the currently low ratio of carers to patients that exists in the vast majority of institutions
- increased incentive and assistance packages of sufficient scope through the HACC system are available so as to enable patients to be cared for longer in their own homes thus relieving pressure on low care institutions and later, where possible and appropriate, high care situations
- forthright acknowledgement of and planning for an ageing population that will place increased demand on existing services along with a demand for services not yet provided

2. A number of factors can influence the effectiveness, efficiency and adequacy of services.

Advance Health Directives

- Until such time as there may exist either State-based or national legislation that mandates democratic choice in how people may be treated in institutions or if they should suffer a condition for which there is no further effective treatment and that causes intolerable suffering, loss of dignity and loss of quality of life, DWDQ believes that the only currently available possibility for people in such a situation is to draw up an AHD that is reviewed on a regular basis.
- In researching for this submission, it proved impossible to locate information on the number of people in Qld who currently have an AHD. A phone call to the Office of the Adult Guardian clarified that because there is no register, it is not possible for them to provide a figure but it is likely that the percentage is very low.
- There is still considerable lack of awareness of the availability of an AHD and what it means in the general community.
- The effectiveness, efficiency and adequacy of services pertaining to AHDs can be compromised if institutional staff and home carers (who may or may not be family members) are unaware of and/or disagree with a patient's wishes, whether expressed in an AHD or not.
- It is reasonable to assume that persons in positions of responsibility and accountability for providing the services under review will be afforded greater confidence and professional indemnity in applying the AHD, thus improving the effectiveness, efficiency and adequacy of the services they provide.
- In 2004 the then President of the AMA, Dr Bill Glasson, in a radio interview on 24th September, indicated that issues relating to palliative and end of life care was not a debate that doctors should have, rather it was a debate the community must have. Current AMA President, Dr Steve Hambleton, in a press release of 21st July, made during AMA Family Doctor Week 16-22nd July 2012, said: "*Family doctors will review advanced health directives with their elderly patients and make sure that they discuss issues such as enduring power of attorney with their family and carers.*" (<http://ama.com.au>). With the AMA taking this position consistently over time, it is reasonable to assume that general practitioners should assist patients who want or already have an AHD in completing or modifying the document but considerable anecdotal evidence indicates that generally they do not promote them.
- It would greatly enhance public awareness about AHDs if the AMA at the policy level and GPs at the coalface were to take a more pro-active role in making **all** patients of **legal age** aware of the value of giving consideration to taking out an AHD.
- In a democratic society where people have the right of choice over so many aspects of their lives, any law reforms undertaken relating to the care of people in the home, the community or in

palliative situations need to be all encompassing, allowing choice for all, including those whose views are firmly secular. We deem it a medical and moral imperative that ALL patients in palliative care have, at one time or another, had the opportunity to complete an AHD in a way that accords with that person's wishes, values and beliefs, not those of relatives or family doctors.

- It should be mandatory that general practitioners assist patients to complete an AHD in depth as many of the tick box options require considerable medical knowledge. Funding should be made available to subsidise a longer consultation dedicated to this purpose or else the consultation should be bulk billed.
- AHDs as they currently exist should be redrafted to include more than just tick-the-box choices about what treatment is wanted and what is not. If some GPs are not prepared to assist patients in *understanding the consequences of the choices they make* in an AHD, then as a point of equity, the document itself needs to provide this information so all have access to it. This then would provide greater clarity to the patient about their choices and at the same time provide valuable information for other family members in their efforts to understand and respect the choices of a loved one.
- Unfortunately DWDQ continues to be made aware of situations in which the provisions in an AHD are ignored by the doctor because of his/her personal beliefs or because family members have pressured the doctor into doing so. Most of these patients are then reluctant to report these breaches to the authorities. Palliative care systems need to put in place mechanisms whereby in the case of a doctor who feels personally and professionally challenged by the directions in an AHD, that he/she has recourse to involve other colleagues who are not so challenged. In the end with a legal document in place, the patient's wishes must be respected.
- In cases where a doctor sees fit not to follow the directions in an AHD because of new treatments that have become available that the patient would have been unaware of, careful consideration must be given to the need for wider consultation on the case.
- In cases where a doctor overrides an AHD on the grounds of providing "best medical practice", decisions should be based on the consequences of any proposed "best medical practice". For example, applying best medical practice in order to prolong life where that treatment will still result in the patient ending up in a situation they have clearly indicated in their AHD they do not want to be in, does not reflect the best interest of that patient's stated wishes. In the end, the spirit, if not the letter of the AHD, should be respected.
- Research suggests² that physical suffering constitutes roughly half of the suffering of patients in palliative care. Other aspects of suffering include social, existential and psychological. Treatments and other services need to address the whole person for palliative care to be truly adequate.
- Overall, there is a need for a State-wide public education campaign about the availability and intent of AHDs and the need for people to appoint power of attorney *before* they become ill.

Suicide

- Since at least the 1920s, more males than females have died by suicide each year in Australia. In 2009, 1,633 males and 499 females died by suicide. Thus in 2009, 77% of people who died by suicide were males and 23% were females. In Australia suicide remains a major external cause of death, accounting for more deaths in Australia than transport accidents.¹ COTA, in its 2009 submission to the Senate Community Affairs References Committee Inquiry into Suicide in Australia, highlighted the problem of suicide in older men, a problem often overlooked and yet, despite some recent decline in number, the overall rate remains as high as that of younger men. The older men become, the more of a problem this becomes, with the suicide rate rising from 12.2 per 100,000 for men 65-71 to 17.6 for men 75-84 and 22.8 for men 85 years and over.
- Whilst the causes of this suicide rate are not clear, the factors of depression and terminal illness undoubtedly play a role. Where terminal illness or a condition offering no dignity or quality of life is the motivating factor, the tragedy is that many may have been helped by having an AHD. These situations speak to the fact that more funding and public education needs to be made available for mental health care and good palliative and end of life care and support.

3. In seeking opportunities for reforms to improve collaboration and the general synergy amongst the varied services provided
 - Consideration will need to be given as to how all care service providers at all stages of care, from GPs through to palliative care and including ambulance paramedics, can be informed as quickly as possible as to whether someone has an AHD or not. *This will be particularly important, if not critical, in the case of patients who have no other family members and particularly in the case of patients who have lost the capacity to express themselves.*
 - Thus, there is an argument for establishing an AHD REGISTER, similar to the organ donor and bone marrow registers or similar to the e-databases that exist in Oregon, West Virginia and New York State in the USA. With the recent advent in Australia of e-health record keeping, this would allow paramedical, clinical, nursing, administrative and other care providers quick and easy access, especially in emergency cases.

Recommendations

In view of the importance of this review and of AHDs in giving all citizens a voice and the need for all to be aware of their availability and their significance, DWDQ makes the following recommendations within the scope of this Inquiry:

- that an appropriate literature search be undertaken to ascertain any recent and relevant research pertaining to these issues eg.^{3,4}.
- that the experiences of other countries who have undertaken recent reforms in palliative care systems be taken into consideration (e.g. **Spain**,⁵ Belgium, the Netherlands, USA states of Oregon and Washington).
- that funding be put towards a comprehensive public education campaign about the role of AHDs and the importance of power of attorney being nominated *prior to serious illness or dementia* affecting the patient.
- that AHD's be updated to include a section outlining the consequences of the choices made in the document.
- that general practitioners, as the first port of call in community health care, be required to draw to the attention of all patients of legal age, the existence of the AHD and that this be driven at the level of AMA policy.
- that liaison between relevant government departments and the Law Reform Commission be established in order to (i) establish an AHD register and mechanisms that enable all people who wish to take out an AHD to become registered; (ii) expedite the drafting of legislation that recognises both the register and the legal force of AHDs.
- that the Committee access public submissions that were presented to last year's inquiry conducted by the then Health and Disabilities Committee into Guardianship laws subsequent to Queensland Law Reform Commission Recommendations as pertinent to this inquiry.
- that the Committee access public submissions that were presented in October 2010 to the Draft National Framework for Advance Care Directives put out by The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council as pertinent to this inquiry.
- that this Committee, in its final report, recognises and acknowledges that despite world-class palliative care in Queensland, there remain limitations on palliative treatments and that the next inevitable step for palliative care providers to embrace will be examination of and broadly-based discussion about how patients, who have explicit legally endorsed wishes, will die. Even the peak body, Palliative Care Australia, acknowledges that *'while pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care.'*⁶

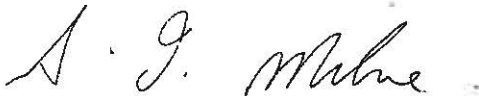
References:

1. <http://www.responseability.org/site/index.cfm?display=134569#old>
2. Wilson, K.G. et al., 2007 "Suffering with Advanced Cancer", Journal of Clinical Oncology, 25

(3).

3. Cartwright, C.M., 2003, 'Factors impacting on the lives of terminally ill older people, and requests for euthanasia', PhD thesis, University of Queensland, Brisbane, Qld.
4. <http://www.scu.edu.au/aslarc/>
5. **Please see attachment** re public lecture given in Brisbane on August 1st 2012 by Professor Xavier Gomez-Batiste, Head of the WHO Collaborating Centre for Public Health Palliative Care Programs, Director of the 'Qualy' Observatory Care and the Catalan Directory of Palliative Care Services, Barcelona, Spain. For further publications of Professor Batiste, go to <http://www.europall.eu/project-group-members/institut-catala-doncologia/xavier-gomez-batiste>
6. Palliative Care Australia, 1999 "Position Statement on Euthanasia" and 2011 "Position Statement on Voluntary Euthanasia".

Signed

A handwritten signature in cursive script, appearing to read 'S. J. Milne'.

Ms Sandra Milne
for and on behalf of the Committee