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Because everybody deserves a peaceful ending

Submission to Senate Committee:
"Palliative Care in Australia"
Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

23rd March 2012

Dear Committee,

Thank you for the opportunity to provide input to your deliberations on palliative care in Australia. YourLastRight.com is the peak body for aid-in-dying law reform in Australia. It is the national alliance of State and Territory *Dying With Dignity* and *Voluntary Euthanasia* societies.

YourLastRight.com actively supports well-funded and well-developed palliative care (and integrated related services) in Australia. We congratulate palliative care specialists for a history of improvement that has resulted in Australians enjoying world-standard palliative care. Nevertheless, we also recognise that delivery of palliative care continues to raise many challenges for practitioners, clients, legislators, regulators and other constituencies, and that improvements can be made.

We maintain respectful and constructive dialogue with peak body *Palliative Care Australia* (PCA).

In this submission we intend to address the following terms of reference:

(a) factors influencing … choice of appropriate palliative care; and
(d) effectiveness of a range of palliative care arrangements.

We welcome and encourage comprehensive discussion about the principles of care under an overall deteriorating health trajectory, the transition from medical care to palliative care, the practices within palliative care and related services, *but* we notice generally a silence and blindness to an individual's trajectory *out of* palliative care: that is, the death. In reviews and discussions, if it is mentioned at all, it is often assumed that individuals just "slip away" and that's the end of it.

In some cases this is not so. It is imperative that conversations around the exit from palliative care are as thorough, comprehensive and robust as those for transition to and within palliative care. Failure to adequately consider the full range of exit trajectories that occur in real life amounts at best to an inadequate and inconsistent standard. This conduct does not reflect well on the principles and practice of affording Australians a death which *that individual* and their family feel is congruent with their own beliefs, values and wishes (not those of healthcare providers) for a dignified death.

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Limitations of palliative care treatment

It is well accepted that the general standard of palliative care practice in Australia is world-class. However, limitations of treatment, and the fact that some individuals prefer to decline a treatment which they may feel is ineffective, burdensome, objectionable or otherwise unwanted, mean that some individuals die an undignified and to them horrific death. Just as there is medical futility (which is not a criticism of medical practice, just a reality), so there can be palliative futility (which is not a criticism of palliative care).

Peak body Palliative Care Australia (1999) acknowledges that "*while pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care.*" AMA President Dr Steve Hambleton (2011) agrees that not everyone can be helped.

It is often assumed that pain is the main factor in preventing a peaceful and dignified death. Peer-reviewed research in the medical literature does indicate for example that about one in five late-stage cancer patients have intractable pain which can only be "treated" by rendering the individual unconscious. This may or may not be in line with the dying individual's preferences.

Part of that process is for the Federal Parliament to understand especially during its deliberations about palliative care in Australia (which I again emphasise we strongly support), that palliative care is not and cannot be perfect. A small but important percentage of Australians die in what to them are distressing and undignified circumstances because of a blindness towards the full range of exit trajectories from palliative care.

Full and honest consideration of palliative care in Australia can only occur if the Committee, in addition to drawing together the best of submissions and recommendations about palliative care funding and practice (and synergies with related services), examines, recognises and *acknowledges in its report* that palliative futility can occur

Conclusion

We strongly commend to the Committee that it specifically and explicitly recognises in its report:

1. That the exit trajectory *from* palliative care (nature of death) deserves as much attention, scrutiny and examination, discussion and expression of informed choices as the transition *from* medical care into and *through* palliative care.
2. That limitations of treatment means palliative futility can and does occur, regardless of funding and practice arrangements, and experts agree that this is so.

I also request that the Committee extends an invitation for me to address it in person to further explain this submission and to answer any questions it may have.

Yours sincerely

Neil Francis
Chairman and CEO

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