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Human Services Inquiry
Productivity Commission
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Introducing Competition and Informed User Choice into Human Services: Second Stage of Inquiry

Thank you for the opportunity to comment on the second stage of the abovementioned inquiry. Herein, you will find my response. As a privately employed Palliative Care Nurse working in Rural Victoria, I believe that with particularly scarce access to appropriate care, my patients both past, present and future are less able to achieve their End of Life (EOL) outcomes, and to me this is less than satisfactory. Wherever possible, I believe that maintaining my patient's autonomy is paramount because everyone deserves to have their needs met and their choices validated.

In Section 5 of the report (page 9), you mention that a huge number of those who die annually in Australia, are doing so in the 2 least preferred places, and that a core reason for this happening is the lack of 'clinically qualified staff' (p12) in such facilities. You also state on page 10, that 80 % of residents in these facilities are dying with inadequate pain relief which is incomprehensible when the solution seems so straightforward to me.

Your own data suggests that in home palliative care would be more cost effective than having our aged/ailing population dying in hospitals and/or Residential Aged Care Facilities (RACFs), and that "without significant policy reform, tens of thousands of people will die in a way, and in a place, that does not reflect their values or their choices". Indeed, you acknowledge that this is unacceptable.

It is an absolute disgrace that anyone should die in pain when we have the medical and pharmaceutical capacity to avoid such traumatic circumstances. Furthermore, we are wasting available funds on the provision of "unwanted medical intervention" (p10) which disregards the importance of both patient empowerment and autonomy. In the case of the cognitively impaired patient who is deemed by the report incapable of making appropriate informed decisions – "Some of these choices will be dependent (only certain types of providers can offer a specific service), and some will not be feasible for an individual user (a person with late-stage dementia, for example, may not be well-placed to choose a medical specialist)" p5 - the family and medical professionals such as myself should be able to advocate on their behalf for what we may know to be their personal preferences.

I firmly believe that looking to increase funding and therefore staff in hospitals and RACFs in order to cope with the influx of palliative and EOL care patients is the wrong decision. Your report clearly identifies on page 12 that these locations are not suitable at present to meet these needs. I would argue that if in home palliative care is both more cost effective ("While data on the costs of care at the end of life are scarce, community-based care can cost less to provide than hospital-based care, and so care that better aligns with patients' preferences may be delivered at lower overall cost to governments than the current model." P11), and more closely aligned with the patient's values and choices (indeed "70% of Australians would prefer to die at home" p10) then the funding should be focused on addressing the issue of how we train and subsequently place palliative and EOL care nurses (skilled professionals) in the home within the community. It is true that family and patient knowledge of how to gain access to such services is currently very limited. I believe this can be appropriately addressed in the following manner:

- Health professionals should be advocating for their patients in accordance with the patient and family wishes as this is paramount to ensuring appropriate care is both sought and received
- Hospitals should be viewed as an opportunity following an acute admission to implement the appropriate home support and EOL care, by way of consultation between patient/family and medical team. This would allow for the engagement of necessary services and appropriately skilled professionals so that they would be ready to step in as per the arrangements made between all invested parties with minimal disruption to ongoing care as soon as the patient returns home.
- Funding needs to be available through Medicare to access palliative and EOL care services at home with no assets testing to ensure that all Australians, irrespective of age and financial circumstances have equal and unbiased access to high quality health care at home. This would mean less aged and ailing filling hospital beds for prolonged periods because there is nowhere else to go and the same goes for RACFs. This would also ensure that access to appropriate services would be widespread rather than determined by geographical location.
- Educate the community on the out of pocket cost of these services so that patients are informed and empowered to make the best choices for their unique situation.
- Work closely with both hospital based palliative outreach services and community based palliative care professionals such as myself to ensure that all patients who require these services are able to access them in a timely and cost effective manner.

Finally, I believe that the implementation of compulsory Advance Care Planning (ACP) should be strongly considered. Many individuals are adverse to thinking about their future with regards to illness and certainly death. For this reason, ACP needs to be shown for the important role that it has. It isn't about focusing on the negative but rather on dying well and in a way that is aligned with personal wishes. It is designed to be undertaken during the fit and healthy stage of the lifespan and is only implemented in very specific circumstances. I believe that we need to eliminate the misconceptions surrounding ACP and encourage Australians to be proactive in choosing how they wish to undertake their medical and other related care in the event that they no longer have the capacity to voice these preferences. By making ACP compulsory or in some way incentive based, we can achieve an Australia with informed, empowered individuals who aren't afraid of EOL because they remain in full control. Perhaps a nationwide, publicly accessible database of palliative and end of life care providers would be useful tool. I would be more than happy to be able to reach and assist a broader community through such a database than I can do on a singular level.

I am a Registered Nurse of 12 years with a long history or working in both RACFs and in the community with the aged and ailing. I have witnessed first hand the heartache of families when they realise they can no longer fulfil their loved one’s wish to die at home because they believe they can’t afford it and/or that such services are not available. I welcome you to look at my Palliative Care page on Facebook and decide for yourself the true importance of this much needed health care reform.

Yours Sincerely,

Sarah Jane Marlow

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