

... too many people are dying in a way they wouldn't choose, and too many of their loved ones are left feeling bereaved, guilty, and uncertain. The care most Australians receive at the end of life often does not reflect their values, goals, or informed choices.

Australian Centre for Health Research

Our community based palliative care services / hospices offer a solution which both increases people's welfare and decreases healthcare costs. Community based services with a true connection to their community are best placed to identify gaps and evolve their care to best respond to the needs of the community that supports them.

Thank you for the opportunity to add my voice to this Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying.

I make my submission as CEO of Little Haven Cooloola / Sunshine Coast Palliative Care Inc with the full support of the Little Haven Board. I am also the Board Secretary of Palliative Care Qld, a Foundation member of the Hospices Services Network Qld and importantly a past carer for my terminally ill mum. I wish to speak specifically around the issue of Palliative Care and End of Life Care.

For many years I have been a staunch advocate for

- Recognition of the benefits of our model of care in providing end of life care options for all who need it in our regional community.
- An equitable sustainable model of funding for Little Haven Palliative Care and our Qld Hospice models delivering gold standard Community Based Palliative Care Service.
- The intrinsic benefits this model of care would offer for other Australian

I refer you to our timeline for advocacy here [\(Refer Advocacy Timeline\)](#)

I hope you will take the time to read through this timeline demonstrating my passionate stance on the benefits of our community driven models of palliative care and the benefits they offer to the terminally ill and the health system in relieving the burden on families and providing end of life care in the right place at the right time with all the societal and economic benefits it offers.

As a Palliative Care Practitioner and Business Manager for 17 years in a service that has never turned away a patient in need, at any stage of their disease trajectory, combining the clinical skills to manage symptoms and providing the 24/7 nurturing and carer support needed, it was in trying to access this level of palliative care for my dying mum I gained a heightened perspective as a carer, a consumer and advocate for community based Palliative care.

Despite mum living in the Metro South Palliative Care area of Brisbane accessing services proved difficult, arduous, an endless round of assessments with very little relief provided to lighten the burden of care. Services were more focused on what they couldn't provide than what they could. Given I was about to hand over some of the care of my mum, 79, physically vulnerable and living alone, to strangers, I thought it reasonable to enquire as to who would have access to her key safe code, what sort of training or security checks they had? But instead my questions were met defensively.

If the system was hard for me to access how must it be for others and I was infuriated on behalf of every lay person being subjected to the endless stream of acronyms, assessments and random questions about packages and prognosis and basically refusing to provide palliative care to someone who had less than a 3

month prognosis. It lacked the warmth, the cloak of Palliative Care I'd come to expect and I'd assumed those facing these tough decisions at the end of life would be afforded.

To give a comparison of how a community driven model compares to the HHS system I share this story. In my professional opinion mum could have benefited from an electric lift chair to assist her with standing and decrease her falls risk as the steroids she was taking to manage her brain swelling were impacting the strength in her legs. Over the course of a couple of weeks 3 separate health care professionals were dispatched from Metro South to do a needs assessment. In the house they agreed it would be helpful but when they ran the numbers through whatever program they use mum missed out "by 6 points on meeting the criteria" ??? An expensive and time consuming exercise to deliver nothing.

By comparison if a family member requests a piece of equipment from Little Haven we will do all we can to have that equipment delivered to their home in a timely fashion – at no cost to the client. This is how you build a trusting relationship and acknowledge we will do all we can to ease their burden.

I refer you here to Page 4 and 5 of the submission provided by Little Haven's Clinical Coordinator Bronwyn McFarlane which provides detailed information of Little Haven's history and model of care.

I refer you to the online submission by one of Little Haven's Clinical Nurses Carolyn Mandersloot which provides details of what is needed to fully support a family to care for their loved one at home.

The Productivity Commission's Human Services Review

And so when The Productivity Commission's Human Services Review was announced prioritising end of life care as one of the six areas where outcomes could be improved both for people who use human services, and the community as a whole, it was my experiences in caring for my mum that empowered me to make 3 lengthy submissions and to appear before the Commissioners at their public hearings in Melbourne. Subsequently at their request I provided additional documents including statistical, performance and financial reports.

The report identifies more can be done to ensure patients at the end of their life receive the right care, in the right place, and at the right with the final report from the Productivity Commission recommendation being Community Based Palliative Care - utilising our services model as the blue print :

Table 4.1 Overview of proposed reforms to end-of-life care

<i>Proposed reforms</i>	<i>Timeframe</i>	<i>Potential costs and benefits</i>
Community-based palliative care		
Recommendation 4.1 State and Territory Governments to increase the availability of community-based palliative care so that people with a preference to die at home can access support to do so.	Assess needs as soon as practicable. Implementation timeframe depends on assessed needs.	Community-based palliative care could cost less than its hospital equivalent. Patients would be able to access community-based palliative care that supports them to die at home if they choose.

Needs for Community based palliative care in Queensland

- There has been a 22% increase in the numbers of deaths in Queensland in the last 10 years
- In 2017 31,555 deaths in Queensland- 5,754 more deaths than 2007.
- An incredible growth in the number of deaths in 2017 of 6.3% - three and a half times the rate of population growth in the same period
- That is 1,865 more deaths between 2016 and 2017 – an additional 5 people dying every day in Queensland in just a single year.
- The ABS says the number of deaths will double over the next 40 years.
- Around 50-90% of people who die could benefit from end-of-life care – that is around 16,000 to 28,000 Queenslanders

In its report the Productivity Commission quoted our submission: “end-of-life care providers will face a ‘tsunami of palliative care admissions ... as our baby boomers move through the system’ (Little Haven Palliative Care, sub. 458, p. 2).

We know this puts a huge strain on the Queensland healthcare system and will continue to grow as Queensland’s population ages

And people are living longer with life expectancy increasing by almost a year in that same period.

Our community driven models of care at home in a home like environment offer a model for the state government – a proven model which improves patient welfare and decreases costs

The Productivity Commission Report notes:

Up to 70 per cent of Australians would prefer to die at home (PCA, sub. PFR329), but most end up dying in hospital instead (box 3.1). But only around 10% die at home.

PC report: “This leads to a situation where ‘almost two-thirds of terminally ill people for whom home or hospice palliative care would be appropriate die in hospital, often receiving heroic interventions”

Again, the Productivity Commission pulled out our service as an example of good practise:

“In some locations, hospices and community-based palliative care services largely succeed in supporting those who wish to die at home to die at home or in home-like environments. For example, Little Haven Palliative Care said that it supports 60 per cent of its patients to remain at home to die, and a further 24 per cent die with less than five days in hospital”

The health system imperative

Spending on the last year of life are increasing but the spending is not delivering the outcomes that people facing end-of-life choices want.

The clinical direction palliative care is taking in Australia is the wrong one ~ for the patient and for the health care system. Clinically driven services, laden with assessments, eligibility criteria, administrative costs are failing to deliver the “how can we ease your burden” approach needed to support peoples advanced health wishes.

Giving patients the choice of home end-of-life care represents value for money for end-of-life care and is preferred by patients and would allow health spending to be directed to other areas (like prevention)

- studies show that at least 13% of healthcare spending is spent in the last year of life
 - that is equivalent to \$2.4 billion in 2017-18 in Queensland

- 30 to 40 per cent of costs incurred in the last year incurred in the last month of life
 - that is equivalent to \$720m to \$960m in 2017-18 in Queensland
- Hospitals account for 70% of these costs
- Number of deaths in Queensland rose over 6% in 2017 (over triple the population rate) and will double in next 40 years
- Most importantly this spending is giving outcomes that do not reflect individual advanced care preferences for dying at home (or remaining at home for as long as able)

The Economic Imperative

Community based palliative care would better meet users' needs and could cost less than its hospital equivalent

- The Commission examined the financial and annual reports of 12 not for profit providers of community based palliative care (which were required by the Australian Charities and Not for profits Commission to publish information about their finances and activities). Across these organisations, the average total cost of providing community based palliative care ranged between \$6000 and \$10 000 per person, with a mean of just under \$8000.
- The commission goes on to compare that to the cost for caring for those same people in the Hospital system.

Palliative care in hospitals (Page 145)

- The Independent Hospital Pricing Authority (IHPA) reported that the average cost per palliative care separation in sub-acute care was \$10 750 in 2014 / 15, with some patients visiting hospital multiple times in the weeks and months leading up to death (IHPA 2017). Similar costs were found in a recent database study, using data from the Department of Veterans' Affairs, of 20 000 hospital episodes ending in death. The study found the mean total cost per separation was \$10 800 if the patient was in a designated palliative care bed (about one third of patients in the study) or \$16 200 for those with no recorded palliative care access (Ireland 2017, p. 549).
- The Commission concludes that funding community based Palliative Care would not lead to an increase in costs and may well be less expensive.
- Taken together, all of these sources of information suggest that reducing the proportion of people who die in hospital, and supporting more people to die at home or to stay at home for longer, would not lead to an increase in costs, and may be less expensive. It would also help people to avoid the stress and disruption of hospital admissions, which can be substantial.

The welfare imperative

Little Haven has a long history in Qld of enabling people in our community to

- Receive health and social care that supports their wellbeing, irrespective of their diagnosis, sex, gender, age, socio-economic background or proximity to death.
- People have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and are supported to retain independence for as long as possible.
- People in our community know their advanced care wishes will be respected and will be supported to live the best possible quality of life until death is inevitable
- People retain a sense of control of their end of life journey and with that comes dignity

- People know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.

The political imperative

- The families of people who are supported by our service become strong advocates for the service
- They often donate money or their time as volunteers for the continuation of the service and the ripple of compassion permeates into our community
- Any government who made this issue their own would benefit from a high degree of good will

In Conclusion

- Our Community based palliative care services / hospice models offers better societal outcomes and lower cost
- In Qld we have 7 of the best community driven models of Hospice / Palliative Care services in Australia
- Little Haven Palliative Care is recognised nationally as a best-practice provider and we welcome the opportunity to work with the Qld Government to improve access to our proven model of high quality efficient end of life care in other communities
- Providing Quality care has promoted a virtuous circle where patients families and local medical practitioners recommend our services and trust them and their loved ones will have their advanced care wishes met
- When a community engages with the vision “it takes a village to care for their dying” the ripples of this vision spread out into the community. Community services with a history of volunteering, support and fundraising not only bear a responsibility to deliver exceptional care, but help shape compassion in that community.

I am encouraged that after years of advocacy for better end of life care, the current Qld Government has turned its attention to the looming crises in healthcare of dealing with the coming tsunami of baby boomers into the system.

I am hopeful this enquiry, in partnership with the Qld Health Departments Palliative Care Policy review will provide the leadership to implement the cost neutral recommendations of the Productivity Commission, thus improving access to home based care for all Queenslanders with all the societal and political goodwill this will engender.

Because to quote Commissioner Stephen King in recent correspondence, “When a conservative economic body considers the shortage of end-of-life care to be a problem for both the economy and for society, it is time to take action.”

Additional Comments:

In my capacity with Little Haven and Palliative Care Qld I have provided information and support to many people over the years looking to replicate our model and also advocated to QHealth on trialling our community supported model of care in other regions who do not have access to Palliative Care services currently. There are some wonderful groups hoping to improve access for their local people including some ATSI communities eg. Coen, who wish to bring care of their dying back to country. I wish to be a part of the solution and to this end have requested to speak as a witness at the Public Hearings to be held in Caloundra on May 3rd.

On VAD, with approx 80% of Australians quoted as wanting this as a human right I support that it will provide comfort to many – knowing they will have control of their end of life. Statistically in countries with access to VAD this is only be accessed by approx 4% of the population and it is my experience that such is the human spirit that most people cling to life for as long as they possibly can. It is our role as Palliative Care providers to provide all the care and comfort to enable the terminally ill to have quality of life free from pain and suffering until the burden of disease is inevitable. With a focus on developing a relationship with the terminally ill to be able to educate them fully on what lies ahead and prepare them for how to best manage this without futile medical interventions which increase their health burden and often see them die in a way they would not wish to. At the core of Palliative Care should always be to quote Hypocrites “getting to know the patient who has the disease and not just the disease the patient has”.

To quote, with his permission, Ben Phipps - Officer in Charge | Critical Care Paramedic | Cooroy Station, whose young partner Little Haven recently cared for; “I think Leah would have found comfort in knowing VAD was available, but in the end through the care provided by Little Haven she wouldn’t have needed it.” Ben was “blown away” by the support provided.

Last month Ben was instrumental in organising a session attended by 80 Paramedics from all over Qld to discuss how Paramedics can improve end of life care for the patients they are called to see in the home. Little Haven was invited to speak at this event and emphasised the importance of providing patients with knowledge of what a transfer to hospital would achieve enabling families to make informed health care decisions without the intervention of futile medical treatments.

On ACP

We also discussed at this session our joint frustration at not having access to the QHealth Viewer for Advanced Care Planning. I note Liz Reymonds response that they are working to rectify this situation for QAS and community providers, however the 12 month timeframe is disappointing. Currently Little Haven uploads our patients Advanced Care Plans to the Office of Advanced Care Planning but are unable to access them once they are uploaded.

I have read through every submission currently posted on the Inquiry website and the horror end of life stories shared there break my heart. Last month I received a call from the family of a man recently diagnosed with Pancreatic Cancer who had no doubt gone to the site looking to see if the laws were likely to be changed in his time. Unfortunately the first submission he read was of the horrific painful death of a man also with Pancreatic Cancer. It broke his spirit and compounded his fear. It is my hope people know dying does not have to look like that and for many families there is no greater expression of love than to care for those who once cared for us. I append here a story written by one of our nurses Kelly King (with the permission of the family involved) which I hope will provide some comfort and an alternate view to what dying may look like.

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