

Thank you for the opportunity to provide further comment on the draft report released in June 2017 specifically around reforms to End of Life Care.

My apologies for the late submission as I was caring for my mum, who passed away on June 16th, subsequently grieving her loss and on returning to work have had a lot to catch up on. Thankfully I was able to draw on everything I'd gleaned over 15 years working in an exceptional community-based palliative care service to fulfil Mum's wish to remain in her home of 60 years until the end.

As business manager of Little Haven Palliative Care, a NFP community based palliative care service with a long history of providing quality end of life care to all who seek our support in the Gympie / Sunshine Coast region, I welcome the commissions acknowledgement of the value of community based palliative care services. Here in rural Qld, our organisation ticks all the boxes for what important service specifications for community based palliative care could include (Page 121 Draft Report) and we hope with the recommendations of your inquiry one day we will also see adequate funding for our service.

I offer the following comments for discussion / clarification on the relevant 5 draft recommendations set out in this report.

DRAFT Recommendation 4.1

State and Territory Governments should ensure that people with a preference to die at home are able to access support from community-based palliative care services to enable them to do so. To achieve this, State and Territory Governments should:

- assess the need for additional community-based palliative care services

Comment:

For as long as I have been involved in Palliative Care I have been frustrated that our community based models, demonstrated to work, are overlooked and we continue to spend so much of the scarce State and Federal Govt palliative funding, assessing and scoping need for services. Surely the gaps in access to community based palliative care services are well documented by now and funding should be utilised to ensure the sustainability of current providers and focused on rolling out these proven effective and efficient models of community care .

- design services to address identified gaps in service provision

Comment:

Community based services with a true connection to their community are best placed to identify gaps and to respond to the needs of the community that supports them.

- use competitive processes to select providers (or a single provider) to deliver additional community-based palliative care services

Comment:

I agree with previous commentary that competitive tender processes advantage larger scale providers with capacity to deliver services on a national basis. Having the administrative support and a greater understanding of the tender process they may present very well on paper. Smaller organisations can be disadvantaged in the process. This happened in Metro North Hospital and Health Service District. Karuna Hospice (a very highly regarded and compassionate service) which had served QHealth and the Windsor community so well, was unsuccessful, with the tender awarded to a National provider, who at the time had no presence in Qld healthcare landscape.

Despite Little Haven successfully tendering and having a service agreement in place with the Sunshine Coast Specialist Palliative Care Service (SCSPCS) for provision of palliative care services, we are consistently sent new admissions without any scripted funding. Unless the patient is in the last week of life, where daily visits are required, we are told there is no funding available.

We are told the overall scripting budget for community based palliative care for the Gympie region is approx. \$40,000. This seems incredible, given the older demographic and low socio economic status of the region. It's also extremely inadequate ~ given 60% of our referrals come from the SCHHS (Hospital and Specialists) and only 2 of our current patient load of 68 have any scripted funding attached.

- monitor and evaluate the performance of community-based palliative care services to ensure that those services deliver integrated and coordinated nursing, medical and personal care, and provide access to care and support on a 24 hours a day, 7 days a week basis

Comment:

Under Little Haven Palliative Cares funding agreement with QHealth, care is provided by specialist RN's, which is appropriate given the complexity of clinical issues nurses may be dealing with in the home, often after hours.

If patients are eligible for increased services through aged care packages, Little Haven works in with aged care providers to give the palliative support /symptom and medication management, whilst they provide the personal care, domestic services. To this end we participated in the Decision Assist project, developing shared care tools and communication pathways for the benefit of our shared patients. With our Palliative Care component not funded under aged care packages, often despite being principally the coordinators of care and on call 24/7, we are the only service visiting the patient without compensation for our visits.

We provide genuine 24/7 support to enable patients and carers to be maintained in the community. Care provided at the right place in the right time. Too often (as was the case with my mum) phone calls after hours see patients immediately triaged into hospital, with no after home visits carried out.

DRAFT Recommendation 4.3

The Australian Government should promote advance care planning in primary care by:

- including the initiation of an advance care planning conversation as one of the actions that must be undertaken to claim the '75 plus' health check Medicare item numbers. At a minimum, this would require the general practitioner to introduce the concept of advance care planning and provide written material on the purpose and content of an advance care plan introducing a new Medicare item number to enable practice nurses to facilitate advance care planning.

Comment:

These are not always easy conversations to introduce and need to be dealt with sensitively and with the due amount of respect and time they deserve, once a relationship between health care professional and patient is established.

Introducing a medicare item for Palliative Care services who are often instrumental in initiating these conversations would also be advantageous.

In the absence of access to quality end of life care in many communities, advanced care wishes, if they include remaining at home to die, may be irrelevant.

DRAFT RECOMMENDATION 4.5

The Australian, State and Territory Governments should ensure that there are sufficient data to enable governments to fulfil their stewardship functions by monitoring how well end-of-life care services are meeting users' needs across all settings of care.

Governments should work together to develop and implement an end-of-life care data strategy that leads to the provision of, at a minimum, linked information on:

- place of death
- primary and secondary diagnoses
- details of service provision at time of death (what, if any, health or aged care did they receive, at what level and for how long)
- whether they had an advance care plan.

Comment:

Little Haven Palliative Care under our service contract with QHealth collects, collates and reports this statistical data on a 1/4rly basis to the Community funding unit. From the data collected they can see the consistent growth of 14 + % annually in admission numbers for both our palliative and bereavement support services. Stats are also supplied for our rate of deaths at home (approx. 60% with 24% requiring less than 5 days admission to hospital, age, gender, diversity etc and an increasing number of non-cancer related admissions to our care. The level of information being collated from NFP providers is far more extensive than from QHealth driven facilities.

In closing I wish to mention the value we see in the professional relationship Little Haven has with the Gp's, local hospitals and Specialist Medical services. We see this collaborative approach to health care in the community, along with early access to our support as being key to presenting the best option to palliative patients to remain at home as long as they are able and to choose their EoL space. Our history and stats confirm it truly is the ideal trilogy of care; Specialist Palliative Nursing Service, GP and access to Palliative Care Specialist for management of complex clinical needs.

We continue to lobby for equitable funding and we are also keen to see the Palliative Care Service Delivery Model, we as a team have built over many years, continue to grow and succeed in the lives and deaths of our consumers. We certainly see great value in our adherence to the best practices in palliative care of early access, 24/7 in home support and providing clinical support through active treatments and know we are highly regarded for our care by the health professionals and general community in our region.

However these are insecure times for Little Haven as the palliative funding becomes more and more elusive and our patient list becomes more and more dynamic.

With the draft report

- *recognising the work community based palliative care services are providing,*
- *validating our model of care,*
- *acknowledging the financial and societal benefits,*

perhaps we will also see pressure on Governments to fund us accordingly

I share with the commission the letter below, sent unsolicited to the Qld Minister for Health yesterday in response to recent media around our push for equity of funding for the work we do. I have the permission of the author to share it with you. How fantastic that 5 years on family's still feel moved to come out in support of our work.

Sue Manton OAM

Little Haven Palliative Care

Office of the Minister for Health and
Minister for Ambulance Services

Dear Sir/Madam,

23/07/2017

I am writing in support of Little Haven Palliative Care in Gympie and the critical importance of keeping this valuable service operating, and the need to provide it with adequate funding to continue to operate at its best.

In 2012, they assisted me to care for my dying mother who was 86 and had Multiple Myeloma (numerous bone tumors, pneumonia, atrial fibrillation, and osteonecrosis of the jawbone.) They respectfully came into my home and provided my mother with a hospital bed and air mattress, plus a movable shower and toilet chair, plus numerous other pieces of equipment that allowed me to manage my mother with dignity at home in the last few weeks of her life. They also came in and managed the syringe driver (under doctor's instructions) to provide my mother's pain medication in her final days. They also provided valuable support and encouragement to all members of the family to allow my mother to pass away with dignity in our home where I had been looking after her full-time for the last 3 years of her life.

All the services offered were provided free of charge the whole time they were helping us, and after my mother died I was able to make a proper donation to thank them for their assistance and I continue to support them as best I can even now, 5 years later.

Had there been a charge for their services during the period of support needed, I would not have been able to afford it and hence my mother would have ended up in the public health system for numerous health events, and also for the dying process.

You should also know that we had actually moved specifically to Gympie (from a western town which had little to no services for the dying) because it had this service..... Little Haven Palliative Care.

This service was invaluable to us and also saved Qld Health significant costs.

Death is a journey we will ALL have to take, and to have a valuable service like Little Haven Palliative Care is beyond measure.

Please help them to continue to operate satisfactorily by funding them appropriately, as the cost savings to Qld Health and the Federal Government are considerable.

If you need to contact me for further clarification, please feel comfortable to do so by email or phone

Yours sincerely,
Lucy Ritchie

Southside. Qld 4570