Attachment One – Response Letter Productivity Commission Human Services Issue Paper

Thank you for the opportunity to add my strident voice to the very welcomed findings of the Human Services issues Paper – Section 6 - End of Life Care.

As Business Manager of Little Haven Cooloola / Sunshine Coast Palliative Care Inc, a board member of Palliative Care Qld and most importantly a carer for my terminally ill mother I presented at the Palliative Care Qld state conference in Nov 2016 on **Community Based Palliative Care in Regional Areas**. I have appended this presentation as **attachment Two**. This presentation whilst delivered prior to the findings of the Productivity Report were released, addresses many of the issues / questions raised in the report.

Empowered by the findings of this report I requested and attended a meeting with the Qhealth Community Funding Unit with the expressed objectives of:

- → **Recognition for true community based model of care –** the associated cost / benefits to the patient / health system and community. **(See attachment Two – Overview of Little Haven)**
- → **More equitable funding for community palliative care** – Currently receiving approx. 35% of annual budget in Government funding this funding gap as it widens is unsustainable- Hoping to balance the share with community and Govt funding to receive Greater than 50% of direct service costs (with increase annually in line with health budget / demonstrated growth (9%))
- → **Shaping policy direction to roll this demonstrated model out in other rural and regional communities** (5 pilot sites recommended – including into an indigenous communities in the far North)
- → **Extending the reach and support of palliative care** into more disadvantaged communities and bringing our care of the dying a little closer to that of other countries in the Western world.

Whilst I received a good hearing, I was extremely disappointed be informed "Community based Palliative Care is not on the QHealth radar at present". "Is freeing up hospital beds also not on the Health Care agenda?"

Currently Little Haven is caring for 78 palliative patients in the community at an approximate cost to QHealth of $700 / day (Total – not per patient). Should just one of these patients not have access to community based palliative support and end up in hospital the cost would be upwards of $1600 / day.

Little Haven's community based model of highly efficient and effective palliative care (funded by Qld Health at currently 35% of annual budget) has only ever seen our services expand to meet the increasing needs of the community.

Our community based palliative care model consistently sees 60% of patients at home for end of life and a further 24% with less than 5 days hospitalisation. Our model is highly regarded by referrers, patients, carers and the broader palliative care community.

And yet we are starved of funding – not on the "QHealth radar" and not eligible to apply for funding under National Palliative Care Projects Grants - currently available to projects and services deliverable on a national basis.

The Productivity Commission's Human Services Review *prioritised 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.* 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 time*

It seems counter intuitive whilst the rest of the civilised world moves towards empowering communities to care for their dying, we in Australia don't champion palliative care organisations deeply rooted in their communities, or provide seed funding for more regions to develop true community based care – born out of and nurtured in that community.

QHealth have provided special project funding for Little Haven and 5 other charitable Community based Palliative Care Services for 15 years and they have all the stats and all the reports demonstrating the effectiveness of this model. I'd hoped the community funding unit and policy unit would rejoice in the ongoing success of these true community based palliative care projects.

The clinical direction palliative care is taking in Australia is the wrong one ~ for the patient and for the health care system. Fully funded services, laden with assessments, eligibility criteria, administrative costs are failing to deliver the hands on care and "how can we ease your burden" approach will never meet the needs of the tsunami of palliative care admissions we are witnessing as our baby boomers move through the system.

I hope you will take the time to read my submission as an advocate for palliative care and a Business Manager of 15 years in a service that has never turned away a patient in need. We have only ever expanded our boundaries, added more nursing staff and services and just care for people. I wish to be part of the solution to improve access to quality end of life care for Australians through true connection with community.

In the week leading up to Christmas we received 8 new referrals, as the Private Hospital (which shut its doors for the holiday period) and Gympie General Hospital started emptying out their beds. When we said we were feeling overwhelmed we were told Blue Care was not taking new patients and they had to be discharged back to the community. This brought the number of patients in our care up to 80. Two of those patients passed away on New Years Eve and two on the 2nd Jan with 3 of those living 65 kms from our base. Consequently over the very expensive holiday period (when better funded facilities rationalised their costs) our on call nurses worked in excess of 12 hour days, which will have devastating effect on our already stretched budget.

Of course we had no obligation to take on these patients but what option would have been available for these poor families had we not been there. That's the value of community engaged care providers.

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.

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