

My apologies again for not getting back to you with a quick response as requested, it is the shortfall in our model that the burden of raising funds can be overwhelming and leave little time for the important work of advocacy for community based palliative care and sustainability of our model, as identified in the commissioner’s question to Liz Callaghan (CEO PCA)

“So what else might be needed? I hear the ground up story, but for something to really work the ground up has to meet something. So what should governments do?”

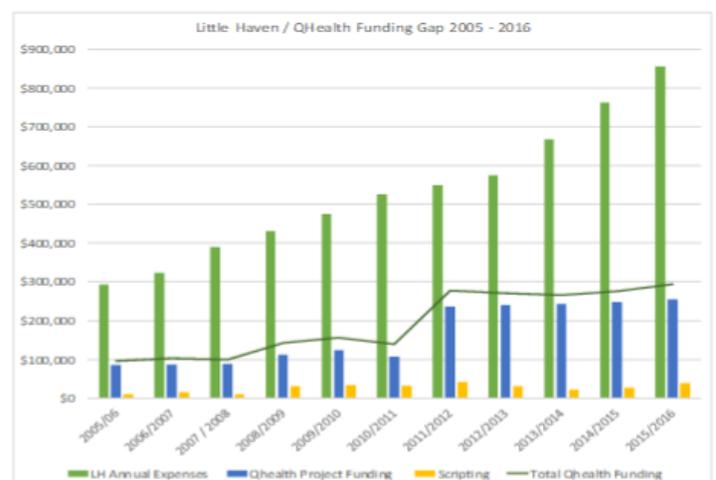
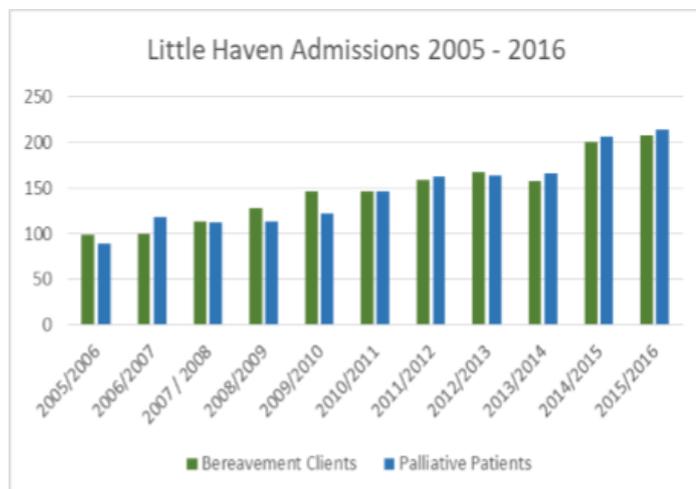
As I’m aware of the time pressures you now face and appreciate the Commissions recognition of Little Haven’s model of care, demonstrated in the draft report, please find attached:

- The Financial, Statistical and Performance reporting on LH’s Service Provision (2016 – 2017) provided to QHealth on a 1/4ly and 6 monthly basis, demonstrating the layer of accountability provided over our 18 years of partially contracted services.
- P&L April – June with YTD (2016 – 2017) to give an overview of costs of service delivery and funding sources. This is the first year we have posted a significant deficit. This tipping point, when demand for our services would exceed the ability of our community to fund the financial gap, had been identified in our Strategic plan and hence the increased advocacy to government for a better funding model. The reality is without a change in Government funding, our model is not sustainable.

In answer to the question “So what should Governments do”, recognising this funding unchanged for many years is now severely inadequate and needs improving..... I think this model of the QHealth Community Funding Unit administering and overseeing community based palliative care projects has proven to be a very effective model (in terms of Palliative Care Standards, excellence of care, care provided at the right time in the right place) over many years now.

The 6 Qld NGO palliative projects receiving funding under the community funding unit since 1999, continue to grow and succeed in the end of life care for 1000’s of patients in their local communities. This funding contract enables services to set their service delivery direction and mission in line with the QHealth contract and the Standards of Palliative Care, whilst having the flexibility to engage with and mould that model to meet the specific needs of their community.

There’s no need to reinvent the wheel – this model already works, however the amount of funding has not grown as the demand on service grows.



I know the enormous value we provide in terms of quality of life and the positive impact we have on the end of life for the families we care for, and also how cost effective our model of end of life care is for Governments.

Measures must be in place to ensure as service needs increase, so too does the funding - providing services are meeting performance and quality indicators.

However QHealth has no current vision to increase funding to community driven models, despite Federal funding being given to the states for this purpose. I cite Minister Dick below from a recent article into end of life care

Queensland Government in 2015-16 gave \$87m to the state's 16 hospital and health services for palliative care, \$1.88 million over three years to helpline Pallassist; and \$5.5m - over seven years - to paediatric hospice, Hummingbird House.

The Health Department also contributes to the state's eight hospices.

Prof Swerissen said the formula for a good death was "dignity, choice, privacy and support".

"Good deaths are where people can have control over where they die, the care that they get and who they are supported by and that they get their symptoms well managed," he said.

"People also say that they would like to have the opportunity to say goodbye to people and to settle their relationships as well as put their affairs in order.

"People often will talk about having a friendly environment where they're comfortable and which is familiar to them."

Health Minister Cameron Dick said each hospital and health service was best placed to determine how their share of the palliative care funding was spent.

"It is important that decisions regarding models of care and distribution of funding are made by local clinicians - and administrators ensure services best address the needs of their community," Mr Dick said.

With \$87m allocated to the state's 16 hospital and health services for palliative care in 2016 – 2017 the responsibility for allocating those funds has been given to QHealth local clinicians and administrators whose interest is being served by building their own resources at the exclusion of non QHealth organisations, who have served the Health system so well. It is these decision makers and clinicians that are driving people into hospitals instead of keeping them out of them. To give you just one example.

Whilst we have been repeatedly told by the SCSPCS there is no money for scripting the patients they refer to us, we have seen them recently employ and deploy 2 Nurse Practitioners to the SC Health District at considerable cost – on par with our entire funding. When I've enquired what their role would be and where did they see the gap in services here? Their response "they can write scripts" – (why when the GP's already do this?) and "we are still working on a position description"

These positions offer no after-hours support, instead divert people to Dove House or the Gympie Hospital. It is Little Haven's nurses who are there at all hours to support these patients, managing complex clinical symptoms under the direction of the GP or the specialist, keeping patients out of hospital.

If in purely economic terms Commissioner Stephen King agrees community driven models have economic benefits to the health system, I hope the final report will ensure the support and sustainability of our service model through a sustainable stream of funding. I would also like the final report to champion the roll out of our proven model to other communities, who indicate a desire and a drive to develop the compassion we know exists in all communities, into a quality provider of end of life care.

Susan, you mentioned successful rollout would depend on the need for "a champion" to spruik the model to other communities. Whilst I'm no champion, I'm certainly passionate and recognise that Little Haven's only real chance of long term funding comes from acknowledgement of our model (And I'm grateful to the commission for this) and uptake on a broader scale.

To this end I have been pushing over the past 4 years, in my role on the Palliative Care Qld (PCQ) board for recognition of the services providing exceptional care and ways to extend this care. I believe this advocacy to be a fundamental role of our Peak bodies and I also believe they should be doing more to promote the services providing such wonderful standards of care. With a commitment from Government - Federal Govt funding, provided to and administered by the State & Territory Govt's for Community Based Palliative Care services, with grass roots connection to the communities they serve, uptake of our model of care would be easy.

In my position on the board of PCQ, we have formed a working group of NGO Specialist Palliative Care providers who in time I hope will be positioned to share their knowledge and network with other communities to enable greater access to palliative care and end of life care for all Qld's

QLD NGO SPECIALIST PALLIATIVE CARE PUBLIC SERVICES NETWORK - Purpose of this network:

QLD has 7 unique specialist palliative care services that have been identified as vulnerable services due to their service funding model. They are particularly good at community engagement and currently they have no overarching network to bring them together.

Identified 7 Services:

- 1. Toowoomba Hospice*
- 2. Ipswich Hospice*
- 3. Hummingbird House*
- 4. Karuna Hospice Service*
- 5. Hopewell Hospice / Paradise Kids*
- 6. Little Haven Palliative Care*
- 7. Cittimani Hospice Service*

As I said at the commission hearing, with a commitment from Government to provide seed funding we could roll our model out in at least 3 rural communities in Qld, who I know have skilled professionals and a supportive community, chomping at the bit to address their lack of access to quality end of life care.

In closing I hope the commission will learn from the current state of the My Aged Care System which is

- Almost impossible to navigate
- Has in our area an 8 week waiting list just for urgent ACAT assessments – Let alone package availability.
- On average administration costs of 45% being charged by providers

And has added enormously to our burden of care, with our nurses spending so much time trying to cobble together services to keep people supported at home. Patients at the end of life do not have the time or capacity to deal with this level of complexity in accessing support.

Kind Regards

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