

17 July 2017

Human Services Inquiry  
Productivity Commission  
Locked Bag 2, Collins Street East  
Melbourne Vic 8003

Dear Commissioners,

**Submission to the: Reforms to Human Services Inquiry - End-of-Life Care Services**

Thank you for the opportunity to make a submission to this inquiry.

In April this year, my father passed away in a public hospital bed in the Australian Capital Territory. He was receiving palliative care from early February 2017 until the time of his death.

Based on my family's experience with the palliative care and aged care sector during this time, I believe that there are systemic failings that need to be addressed. I was pleased to see that some of these have been noted in the Productivity Commission's (PC's) draft report.

I have set out below:

- a summary of our experiences with end-of-life care; and
- my comments on the PC's draft recommendations 4.1 – 4.5.

I hope that this submission will provide a useful case study and help to further inform the PC's recommendations for the purpose of your final report.

**Experiences with End-of-Life Care**

My father had advanced prostate cancer, and suffered a series of strokes and associated complications. He ceased cancer treatment in February 2017 and became a palliative care patient. At that time his Oncologist (accurately) gave him a maximum of 6 to 8 weeks to live.

Our initial experiences with the palliative care team were positive. They visited the house and organised some in-home resources and support, including a hospital bed, walking aid, and showering assistance. We were informed about the range of wonderful support options available, including additional in-home support, and the specialist palliative care facility, Clare Holland House (CHH) for respite care and in-patient care if required. Our desire was to keep my father at home for as long as possible in accordance with his wishes.

However, as my father deteriorated, it became obvious that we would no longer be able to adequately care for him at home with the level of in-home support available. At that time, we

reluctantly sought to avail ourselves of the respite care or in-patient support offered through CHH, only to discover that the support was largely illusory. CHH had very limited beds (15 at that stage) and could only keep people for a limited period. My father was not yet close enough to death to qualify, despite only having a predicted 4-6 weeks to live.

In hindsight, it would have been preferable if the palliative care staff who initially attended us, had given a more realistic presentation of what was available, rather than trying to present a comforting picture that only resulted in confusion and disappointment. I feel that being informed early may have given us more time to explore other options.

My father remained at home for longer than he should have with the available support, and started having falls. The only option when he fell during the night was to call an ambulance for assistance. After two visits two emergency in the one week, he was admitted to hospital. We learnt that in the absence of viable, alternative palliative care options, the public hospital system is forced to fill the gap.

He remained in hospital for close to a month and, despite the clinical setting, we were reasonably satisfied with the standard of care provided. While he was there, the hospital organised an Aged Care Assessment Team (ACAT) needs assessment to determine his eligibility for a bed in an aged care facility.

Given that CHH was still not an option, we were then required by the hospital to seek a vacancy in an aged care facility. My family spent considerable time: educating ourselves on the aged care sector, visiting facilities, and completing application forms, as well as the extensive assets and income assessment forms required by the Department of Human Services. This diverted valuable time away from my father. We were also acutely aware that we were going through this process, and seeking a 'permanent aged care bed' for what was likely to be a matter of weeks. The required approach felt like a terrible fit for our situation.

We did our due diligence on aged care facilities as best we could, but found it very difficult to get an accurate picture of the quality of care at the different facilities. I would say that it didn't feel like we were in a position to make an informed choice. Add to this, the fact that aged care beds are hard to come by - which means the hospital strongly encourages families to take the first available bed and then to move your relative if you are dissatisfied with the standard of care. This seems a poor solution.

We accepted an aged care bed at a facility which was reportedly of a reasonable standard and with higher than average staffing ratios. The reality of our experience was that, while the management and most individual staff members seemed well intentioned, the facility was poorly organised, understaffed, and poorly equipped for the care required. Our list of complaints (collected over only a week and a half) was extensive, and related both to concerns for my father's physical welfare as the result of his care, and to issues of personal dignity. On his final day at the aged care facility he suffered a major, incapacitating, stroke, which rendered him non-verbal. The staff at the facility failed to notice this until it was drawn to their attention by my mother.

As a result of his stroke my father was taken to hospital emergency, and later readmitted to the hospital ward. During his final week, we received conflicting advice from hospital staff regarding the location of his ongoing care. This was confusing and distressing.

Initially, doctors suggested that an aged care facility would not be able to adequately deal with my father in his condition, and that he would probably need to go to CHH. However, we were subsequently told that a bed CHH would not be available, and that my father would need to return to the aged care facility to receive palliative care. We expressed very serious concerns about his return given the standard of care we had experienced at the aged care facility.

Despite this, in the days immediately prior to my father's death, hospital administrative staff exerted considerable pressure on my family in an effort to get us to agree to return him to the aged care facility. We were told the hospital was experiencing a shortage of beds. Our dealings with the hospital on this issue added considerably to our distress at an already very difficult time.

### **Comments on the Draft Recommendations**

#### Draft recommendation 4.1

I strongly support all aspects of this recommendation. Giving palliative care patients the option of coordinated, quality, in-home care, 24 hour 7 days a week in accordance with their requirements, is surely be the ultimate goal if it can be funded.

I would emphasise though, that in attempting to provide such a service, quality and reliability are absolutely paramount. If it cannot be delivered well, I would rather it not be presented as an option.

Our family experienced in-home care providers who were variously unreliable with timing, or did not turn up at all. This kind of 'support' in a palliative care setting is almost worse than none, as it creates the reliance without meeting the need. In situations where the need may be immediate and critical, patients and their carers waiting at home for help are disempowered and have few options available to them other than a disruptive trip to hospital.

Ultimately, in my view, the responsiveness and quality of the care being provided is more important than the location.

#### Draft recommendation 4.2

I support improving the duration and quality of palliative care for those people who are already residing in residential aged care facilities. My experience (whether fairly representative of the sector or not), is that the standard of care in aged care facilities is woefully inadequate.

Further, it seems there is little information and little choice available to individuals requiring an aged care facility with any urgency. If there had been a high-end, high quality aged care facility available at the time we were looking, we would have been willing to pay extra for the peace of mind that offered. In my experience there seemed to be a real gap in the market in this space.

However, in my view residential aged care facilities (even if improved) are an inappropriate fit for palliative care patients with a short life expectancy. Given that in-home care was not an option, we would rather have transitioned my father to a quality, specialist palliative care facility (such as CHH), rather than having to go through the involved process of seeking a 'permanent' place in an aged care facility. I can only conclude from what I have seen, that the need and demand for such palliative care facilities clearly exist in the community. I would like to see greater focus and funding given to providing this type of care as an option to palliative care patients, rather than trying to offer aged care facilities as a solution.

Draft recommendation 4.3 and 4.4

While I support the promotion of advance care planning, from my experience this is something that is already done well by the sector. My father had an advance care plan in place from before he became a palliative care patient, and we subsequently had a number of health care professionals mention it to us in their dealings with him, including palliative care providers, hospital staff and the manager of the aged care facility.

Draft recommendation 4.5

I strongly support this recommendation. I believe that there is a real need for increased focus and scrutiny of end-of-life care services with the aim of prompting improvements in the sector.

The VOICES survey from the UK, as described in the PC's draft report at Box 4.10, sounds to me like an excellent initiative. Not only could it inform government policy decisions but, but I believe it would also be constructive for those families and carers, with raw, first-hand experience of the sector, to be able to relate their experiences – both good and bad.

Yours sincerely,

S. Coburn