

TALK FOR PRODUCTIVITY COMMISSION 24.7.17

I have been a palliative care doctor for 40 years. Now retired, I am a full time advocate for **more** palliative care and **better** aged care.

For its first 30 years palliative care was not a specialty, but there were some doctors, like me, who worked **full time** looking after people who needed what we now call palliative care. It took those 30 years to build up enough knowledge to call palliative care a specialty, which since 1997 requires specialist academic training.

Palliative specialists now have both the knowledge and the means to relieve most pain and other symptoms and to relieve much of the suffering that attends the end of life for both patients and their loved-ones.

It was in my retirement, when I was leading a weekly support group for people with advanced cancer, that I began to realise that instead of governments enhancing and supporting palliative care services they were treating them as cash cows – convenient when the LHDs bottom line need propping up.

I think, sadly, this can happen because nobody is in a position to complain about palliative care when it is under-resourced. The dead can't speak, the weak are too sick to speak. The family want peace after the distress. And the employed professionals are forbidden to speak about the suffering they see but are sometimes too stretched to relieve. And so palliative care is seen across Australia as a 'quiet cut'.

But I can speak now, and I am really very grateful for this opportunity to comment on the Draft report.

I want to congratulate the Commission on its research and on the Draft. **Yet** it fills me with apprehension.

First, I want to stress that palliative care is not just needed for the last year of life. Both cancer and chronic conditions can progress slowly, and their course can play out over years, not just months. Personally I have been involved in the care of many people in their last five years of life. Timelines are not set in stone. So there can't be a time limit for when specialist palliative care is needed and can be brought in to provide pain, symptom relief and to give support.

My second concern is the Commission's recommendation 4.1 "to use competitive processes to select providers (or a single provider) to deliver **additional** community-based palliative care services". I agree that the palliative care services **DO** require enhancement, but the model we currently have of having specialist physicians, nurses and allied health, employed by the State Governments, is not a failed one of itself.

The only thing that's failed is that Governments and health bureaucrats, in State Health Departments and in Local Health Districts, haven't **grown** the workforce, instead, in some places they've **reduced** it! This is a failure of politics, not practice.

The Draft acknowledges that palliative care services are stretched. I see that across NSW. Much more is needed but why bring in another level of organisation needing more bureaucracy and increased difficulties of integration?

That's the thing that gets me. When we should be doubling down on the system that works, it seems we're going all-out on an outdated model, ignoring all that was learned over the last 50 years. In what other branch of medicine would this be tolerated? It's like asking the cabin crew to fly your airplane. Might have worked 100 years ago but planes and palliative management are a bit more sophisticated **today**.

What we are seeing playing out in Western Sydney right now is an NGO contracted to provide end-of-life services for only the last three months of life, based mainly on GPs, RNs and care assistants at an annual cost of \$1.72M. That would have paid for two additional palliative physicians and 10 additional palliative care nurses or allied health. That would have **brought** their existing service up to Gold Standard, providing much better care than anything the new service could possibly provide. And without the problems of how to deal with handing over dying people and their families from one service to the other.

What I fear is introduction of an outdated model of generalist-based community palliative care services using GPs, non-specialist nurses and assistants-in-nursing for personal care. This does risk turning the clock back 50 years to the time when there was no expert training in palliative medicine or nursing and when each clinician had to "learn on the job" at the expense of patients and their families. This model is outdated and not as good as is claimed by those promoting it. It has failed in Queensland and been rejected in much of NSW.

If Governments **MUST** use a **variety** of services to supplement the struggling specialist palliative care service it will be vitally important to give contracts to services which offer **adequate** numbers of specialist palliative physicians, nurses and allied health to meet the community's needs.

And don't expect families and patients in their last year of life to be in a position to make a choice between a range of services. It's hard enough for governments to choose.

The care available in aged care facilities is of particular concern in this regard - and this is my last point.

The fact that the Commonwealth does not mandate that there must be RNs

present 24/7 is a shame and a disgrace. For dying people not to have access to "as required" medications is unacceptable. How can we mandate staffing in child care and not in aged care?

There also needs to be, as your excellent draft states, much more access to, and integration with, specialist palliative care.

At this time in NSW some LHDs have employed specialist PC nurses to attend aged care facilities, when asked, advising and training staff. They are thin on the ground but they are a start.

I thought you'd like to know about one outstanding approach to providing expert care in RACFs which is delivered by the Palliative Care Aged Care Consultancy Service in Southern NSW.

They contract to RACFs which are visited by a specialist palliative care nurse at least once a week. She spends up to eight hours in each facility, seeing patients, meeting relatives, having discussions, making clinical recommendations, up-skilling staff in capacity and confidence, liaising with GPs and ensuring that the necessary medications are on hand. Advice is available 24/7. This service reduced transfers to hospital by two thirds in its first year of operation. It has changed the culture in all the facilities it covers. Payment for these services is directly from the facilities, but the service also saves the State Government squillions. Adjusting the ACFI funding rules to allow palliative care to be funded for a longer period as you recommend, will help more facilities to be able to afford such an excellent service.

We have a tried and tested specialist palliative care system, we know it works. It just needs more workforce, in the community, VISITING NURSING HOMES, and in acute hospitals. All this with a net saving to the public purse.

I ask the Commission to consider these points as they prepare the final report. Thank you.

Dr Yvonne McMaster