

From: [Joske, David](#)
To: [Joint Select Committee on Palliative Care](#)
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To The Joint Select Committee on Palliative Care in Western Australia.

To the Members of the Committee

I am writing to make a submission on a number of clinical levels. I am an experienced clinical Haematologist at SCGH having been Head of Department from 1994 to 2012 and I initiated the SCGH Bone Marrow Transplant Program in 1996. I am a UWA Clinical Professor of Medicine; and I am a Medical Co-Director for the Medical Specialties Division, including the cancer-related Departments and Services (Haematology, Medical Oncology, Radiation Oncology, Palliative Care, Adolescent and Young Adult Cancer Service, WA Psycho-Oncology Service and a large number of other medical speciality departments). I also founded Solaris Cancer Care in 2001, which has grown to provide complementary therapies in 5 centres to assist in managing cancer symptoms and treatment side effects, and aid patient empowerment, during the cancer journey. So I have clinical, managerial, so-called “integrative oncology” and leadership experience to call upon in this over 25 years of service here. I am also very passionate about improving our cancer care in WA. I have held an NHMRC Grant looking at Palliative Care in Haematology and in that we defined three models or levels of service, the ideal being one that includes early referral, inclusion of palliative care in the oncology team, and adequate out-patient and in-patient resources. I also published a paper with Dr Kirsten Auret, now in Albany, that showed remarkable variation in when (at what point in the illness) Australian Haematologists would chose to refer a number of hypothetical (or rather, true but anonymised) cases to a palliative care service. Sadly, across Australia, access to good palliative care for resource and prejudicial reasons is often late and denies patients access to good symptom control.

I make my comments as a private clinician and they are not intended to be critical of any of my peers in WA Health, nor to reflect SCGH or NMHS policies or operational matters.

Modern palliative care is a very dynamic service that incorporates patient review and monitoring, high-level pharmacological and clinical skills, supportive care and allied health, transfusion support for blood cancer patients and others with bone marrow failure (and many nursing and respite homes cannot manage blood transfusions), and occasionally interventional procedures to assist with pain and other symptom control. IT is a true tertiary specialty and at the same time we wish for our dying patients, access to a private, quiet and peaceful place and pleasant outdoor environment. Often though, an intensive in-patient management period allows the patient to go home to be with family in the terminal stages of illness. It is a statement of fact that a majority of Australians want to die at home and that a majority do not. It should be a national health performance indicator that we achieve more patients being able to die at home. So outreach palliative care services are also crucial and (in my view) inadequately resourced. That said, the model of GPs self-selecting as having a special interest in, and access to, post-graduate training has worked well and these GPs tend to accumulate, appropriately, patients for whom such expertise is beneficial.

In-patient services

In my view Palliative Care in the Northern Suburbs took a hit with the closure of their Lodge

some years ago. The beds available at Bethesda Hospital do not geographically suit a large number of the North Metropolitan Area Health Service community and of course nor do they suit our regional and rural catchment areas. There are beds planned at Joondalup. Putting beds onsite at SCGH is not the kind of environment we would wish for. There is an immediate need for more beds within the public system (and scope for a public-private partnership at a number of sites such as Joondalup, Glengarry and Hollywood Hospitals) with adequate medical and nursing resources. So there does not appear to have been much progress on the in-patient beds outlined in the 2019 report.

Out-patient services

My colleagues at SCGH do a fantastic job and often see my out-patient referrals within 48 hours and even on the same day if I ring from clinic. These patients often take more than an hour to fully assess, build rapport, educate on their (new) treatment and then they will need close follow up and support. I am unclear how well my palliative care colleagues feel out-patients and patients in the primary care sector have access to good palliative care services and won't comment on that. Community based services would be best delivered by skilled nurse practitioners with some prescribing rights of practice.

Equity of access

I have lost count of the number of time we have tried to cobble together something for dying rural and regional patients that brings them at least closer to home and loved ones and avoids them dying in the middle of a very busy tertiary care ward such as my own. This will always be difficult but multi-skilled clinicians such as Dr Auret are increasingly needed at centres north of Perth such as Geraldton, and soon, Port Hedland. Indigenous patients are also a group we fail, as a generalisation. Some Aboriginal peoples did not have a word for cancer making communication very difficult from the outset, and will be shunned if returning to country when obviously unwell. Young adults are another group we fail to provide appropriate palliative (and rehab) settings for. Below, I propose a model for mobile services that could be workable to improve rural regional access to palliative care expertise.

Impact of new legislation

The debate has been fierce and partisan and whatever one's personal views on end of life choices, the Victorian experience makes it clear introducing the practicalities of this was difficult and prolonged and needs to incorporate the strongly held views of clinical staff and allow them choice in their degree of involvement. So I would ask for the learnings from Victoria to be brought here and 18 months be the planned timetable for implementation. I am aware of a Canadian Palliative Care physician who was against the legislation there but ultimately decided as she and her colleagues were often so intimately involved with end of life care, she was well placed to be a person to provide the service. I see no ethical problem with a Death Certificate being signed after an assisted death, with the preceding illness that lead to a poor quality of life, as the cause of death. My judgment is that this will not be needed often; modern palliative care is nearly always able to tread the line between analgesia and sedation, that preserves dignity and allows the individual to be with family meaningfully.

A Role for Integrative Therapies (Solaris Cancer Care)

Some years I was caring for a man who was dying from cerebral lymphoma. (In fact he was a retired surgeon.) We had no further treatment to offer him; he was extremely agitated, unable to sit still and unable to cope with the situation. I suggested he visit Solaris on a Thursday and he

did so the next day. I saw him on the Saturday and he was a changed man – somewhere during the hour of reiki therapy, he had realised that he was dying and that he needed to be at home and to spend as much time as possible with his children. (Reiki is a controversial therapy but in our hands we have found only evidence of benefit, even if I for one can't see how a no-touch massage could work. This is an anecdotal case, but there is good evidence that touch based therapies do relieve anxiety and music therapies reduce depression scores in cancer patients cohorts (and I could list a lot more evidence for a number of complementary therapies we provide). So as Founder and in effect medical advisor to Solaris, we will be initiating conversations with the WA Palliative care Service to look at pilot and collaborative studies providing our service to their patients (as we have done with a number of institutions and groups already). I believe this could be of enormous benefit. Solaris has treated over 10,000 Western Australians with cancer safely and effectively since 2001, with no medical misadventure. With the pandemic, we have switched a lot of its supportive care services to an online format. The uptake of these has been so dramatic that it does tell us that the cancer population in WA, even if elderly, is ready for digital/virtual and telehealth interventions (I can provide data on this). We are contemplating adopting a mobile service model, consisting of a clinical psychologist and clinical nurse, who can visit the NorthWest (or the South-west) for face to face and individual support, links to local community support groups, and then assisting with linkage to our online services. Perhaps this mobile model could work in palliative care as well.

Advance Care Directives

We continue to have a problem with ready access to these once they have been formulated and of course the individual's wishes can rapidly change with progression of their illness. I think the hope was that MyHealth as a widely available electronic Health Record would solve this, but as yet, if a patient arrives delirious or comatose we may have no way of knowing what their wishes are regarding ceiling of care.

I hope these comments are helpful. I would be happy to provide more information, source data, and further discussion if desired.

Yours sincerely
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See my TED talk "Re-Humanising Cancer Care" ([Google Joske Ted Talk](#))