Fighting for *quality of life*

While doctors are fighting for a patient's life, palliative care doctors are fighting for a patient's quality of life. At the CHA National Conference, palliative care specialist, Associate Professor Mark Boughey made a simple plea for the future – to ensure patients feel safe, valued, understood and heard. But dying in peace is not so simple.

A/Prof Mark Boughey

"What would you want, if you can't get better?"
— A/Prof Mark Boughey

Dr Ellen Marks

"The Aged Care Funding Instrument does not cater for palliative care or end-of-life."
— Dr Ellen Marks

"What would you want, if you can't get better?"
A/Prof Mark Boughey posed this seemingly uncomplicated question.
Broadly Australians would expect and hope that everyone gets to live and die with their wishes and dignity honoured, but it can be a long road dealing with the complexities and uncertainties that a loved one's life-limiting condition brings.

The majority of patients want to die at home but only 14 percent achieve this according to Australian health reports. While 90 percent of cancer patients, and 50 percent of non-cancer patients, are thought to derive benefit from palliative care, half of them don't receive it. Why?

Preliminary findings of a report on palliative care commissioned by Catholic Health Australia, conducted by researcher and health policy consultant Dr Ellen Marks, show that palliative care improves the chances for people to die in the setting of their preference, but that there are still major barriers to access.

A/Prof Boughey and panel members working in, and researching the sector agree that palliative care is frustratingly misunderstood, too often equated with giving up, or 'diminished care'.

"So why would a clinician refer a patient if we are perceived as less than what should be good care?" A/Prof Boughey shrugs.

"What needs to be understood is that palliative care can promote and does produce longevity. The earlier we integrate palliative care into our chronic life limiting, and life threatening space, the greater the likelihood that we will gain these benefits from that connection.

"Palliative care teams bring about consistency and congruity in care. The fragmentation of the traditional system gets pulled together when palliative care gets involved.

"I now see colleagues adopting innovations which have been common palliative care practices. St Vincent's Renal Services are now providing of a real multidisciplinary team and case discussion approach to chronic renal care with a variety of renal health care workers and palliative care involve. Similarly, how great it is to see our many different pain services having multi-disciplinary meetings that bring people together to work out problems together. I believe this is the palliative care model having a broader positive impact."

"We are the navigators of the healthcare system – palliative care pulls all the threads into a place of understanding.

"The likelihood of a good death and a death at home goes up four-fold if palliative care is involved in your care... the innovation is palliative care," A/Prof Boughey said.

Why then, for all of Australia's wealth do people still experience bad deaths and are unable to exercise their preference for treatment at the end of their lives?

Research points to 'funding' as the number one barrier to palliative care. A/Prof Boughey said despite palliative care consultation services being the fastest growing area in hospitals, out-patients, and in the community, it is very poorly served by activity based funding in the public sector. "There is no funding model to support it and there is no key to unlock the costing of consultation - we rely on historical data to argue for any funding increase. The system requires a national approach," he said.

"It's not just the level of remuneration, it's also the models used for funding. The Aged Care Funding Instrument does not adequately cater for palliative care which needs a separate funding category with its own set of rules," Dr Marks told the conference.

She said equipment and medications are not readily available and nursing and medical support is not commonly available 24/7, which limits the ability of community services to respond rapidly to changing needs of the patient.

Researcher Zoe Austin-Crowe from the Health Issues Centre said her research shows that most people in support of Voluntary Assisted Dying see it through a civil rights lens, however the law is designed in a medical context, which means most people will not be eligible.

Her investigations reveal that loss of identity and loneliness, more so than loss of independence is what drives people to disengage with life and descend into severe depression. "We can do a lot more to support them," she said.

Critical workforce shortages, lack of palliative care literacy amongst staff, and poor use of advance-care planning are also blockages for palliative care.

"Within the Catholic sector, there are home-grown strategies in place where good nurses are being employed and trained in palliative care and end-of-life care. A recommendation from the report will be to improve end-of-life training for all staff, and will acknowledge that staff training and engagement is a huge resourcing challenge," Dr Marks said.

With an ageing population the pressure is only going to increase. The ABS predicts the number of deaths will double by 2061 over the next 100 years due to growth in chronic disease and ageing population.

There is concern that any introduction of voluntary assisted suicide without adequate palliative care resourcing is akin to 'shuffling the deck-chairs on the Titantic'.

A/Prof Boughey recalled the long tradition of Catholic services in palliative care, opening Australia's first dedicated hospice in 1890 at Sacred Heart in Sydney, a commitment carried forward to the 21st century.

"My plea is that we step back and look 100 years, 50, 40, 30 years at our very strong advocacy for palliative care as part of our mission, and reaffirm our care for those with dying on their horizon.

"We must urge governments, and work with them, to help to deliver palliative care as we expect it to be delivered and would want for ourselves – we want safe, consistent, valued care where we are heard and understood, and are able die peacefully."

Hm

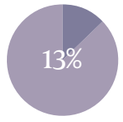
At a Glance

WHAT IS PALLIATIVE CARE

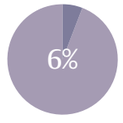
"An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering... of pain and other problems, physical, psychological and spiritual."
(World Health Organisation)

Associate Professor Mark Boughey is the co-deputy director of the Centre of Palliative Care and Director of Palliative Care Medicine at St Vincent's Hospital Melbourne, and Associate Professor at the University of Melbourne.

The Catholic sector is a major provider of palliative care

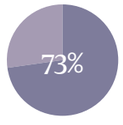


13% of all palliative care related hospitalisations occurred in a CHA hospital



6% of palliative care related hospitalisations were in a CHA Public hospital

53% of private palliative care related hospitalisations were in a CHA private hospital



CHA members have 73% of private inpatient beds

Most people want to die at home or in the community but most die in hospital