Marie McLnerney reported on the Australian Palliative Care Conference held in Adelaide from 6 – 8 September, 2017, for the Croakey Conference News Service.

#17APCC

Croakey is a social journalism project for public health based in Australia.
http://croakey.org
Contents

Conference to spotlight gaps and inequities in palliative care ........................................ 3

What song would you like at your funeral? And other death-changing questions to kick off #17APCC ................................................................. 10

Working with difference in grief and loss: insights from a “wounded healer” ................................................................. 22

Some big questions about life and death: challenging “conveyor belt” of Western medicine and wishing for a loving end ........................................ 29

Maggie Beer calls for “revolution” in quality of food in aged care, hospitals and palliative care ................................................................. 40

Stunning art exhibition gives glimpses of beauty and humanity amongst death and dying ............................................................................. 48

“Please don’t let this happen to me” – too much medicine at the end of life ................................................................. 52

Laying down the euthanasia challenge to the palliative care field: are you ready? ................................................................. 62

Westernised systems of palliative care can be problematic, conference is told ............................................................................. 70

Share this intimate conversation about death, dying and caring ................. 75

Wrapping some “life-changing conversations” from palliative care conference. Plus #17APCC selfies ................................................................. 80
Conference to spotlight gaps and inequities in palliative care

Implications of the likely introduction of voluntary euthanasia in Australia will be a focus at the biennial Australian Palliative Care Conference in Adelaide.

Victoria looks on track to allow people suffering with an advanced and incurable illness, disease or medical condition to be able to seek a medically assisted death from 2019. New South Wales is expected to follow with similar legislation.

The dramatic shift poses important questions for palliative care which, according to the World Health Organisation aims to improve the quality of life of patients with life threatening illness, and their families, through the prevention and relief of suffering and pain and other problems, physical, psychosocial and spiritual.

But, as journalist Marie McInerney outlines in the story below, there is much else on the agenda in palliative care beyond the momentum towards voluntary euthanasia in Australia – from “foundational” policy reviews underway through to grassroots innovations like Death Cafes to boost “death literacy”.

Among the priorities is a lack of adequate palliative care support in aged care services, which the Productivity Commission warns is exposing vulnerable patients and their families to “ridiculous, costly, traumatic and inefficient” hospital care instead.

Marie McInerney writes:

It’s a rare media interview or political meeting for Palliative Care Australia’s chief executive Liz Callaghan when euthanasia is not high on the agenda.

“It’s what happens all the time, with every interview I do, every politician I go and see,” she tells Croakey in the lead-up to the Australian Palliative Care Conference in Adelaide.
“Some people think palliative care is euthanasia, others think palliative care (means) you’re never allowed to die,” she says. “Both of which are wrong.”

“It’s about care of the whole person, the family, it’s about psychosocial support, spiritual support, about really exquisite pain and symptom management, about unfinished business – it’s about a whole range of things.”

But Callaghan says assisted dying will rightly be a big focus for the 800 delegates at this year’s conference, with moves in New South Wales and Victoria to become the first jurisdictions to legalise voluntary assisted death, or euthanasia as it is also known, since the Northern Territory’s laws were overturned in 1997.

One of the plenary sessions at the three-day biennial event will be a panel discussion to explore the ‘complex, difficult and emotional” implications for the sector if and when these new laws come in, from what happens to practitioners who are conscientious objectors through to questions of liabilities when there are “unintended consequences”.

“We want to explore this in a safe environment, while acknowledging that voluntary assisted death is still illegal across the country, and there are lots of diverse views, (around a) complex and emotional subject,” Callaghan said.

“It will be really good for the sector to be engaged in that discussion.”

But she said there are many other important issues to consider for the majority of Australians who will not choose assisted death but need a palliative care service system that can respond to their end of life needs and wishes.

That is particularly important for those who are currently “dying poorly” in residential aged care and for those groups who are currently missing out – for cultural, geographic, socio-economic and other reasons – on proper access to palliative care services.

All this comes at a time of “foundational” changes in the palliative care policy landscape, with the Federal Government’s National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End of Life now being updated.

Palliative Care Australia is also conducting a review of the Standards for Providing Quality Palliative Care for all Australians. Conference delegates will be asked to feed into both processes.

Heart-breaking gaps

Few might have predicted the Productivity Commission as the agency to highlight big gaps in end of life or palliative care – defined as services for people who are likely to die within the next 12 months – much less to say that the funds to be saved on better care should not be the major consideration.

But in June it shone a bright light on failures and inequities in the system, particularly in aged care and hospitals, in its draft report on human services reform.
It found that:

- The quality, availability and affordability of end of life care in Australia is among the best in the world, but only a small proportion of the 160,000 people who die each year receive such care.

- More than 80,000 Australians die in hospitals each year and about 60,000 die in residential aged care — two of the least preferred places to die.

- People approaching the end of life in hospitals can find it hard to access care that is responsive to their preferences, and sometimes receive medical interventions that are not beneficial to them.

- About 70 per cent of Australians would prefer to die at home but few are able to do so because demand for community based palliative care would far exceed availability, particularly for those with illnesses other than cancer, and because access is too often determined by where they live.

And in what will be another important focus at the conference, the Commission found that residential aged care is generally “ill equipped” to meet end of life care needs.

It reported that while four out of five residents of aged care facilities die in them, a lack of palliative care expertise and qualified staff to administer pain relief means residents often make “traumatic (and costly) trips to hospital to receive medical care that could have been provided in surroundings that are familiar to them.”

It said: “Some aged care residents die in unnecessary pain causing distress to themselves and the people who care for them.”
It concludes that:

- **Without significant policy reform, tens of thousands of people will die in a way, and in a place, that does not reflect their values or their choices.**

- **Their end of life journey will likely be punctuated with avoidable, or unwanted, admissions to hospital with the confusion, loss of dignity and loss of control that comes with it.**

- **This is not acceptable.**

Lack of data is a big issue for the sector, but research analysis commissioned by Palliative Care Australia from the National Centre for Social and Economic Modelling (NATSEM) this year found that less than half of the 77,000 people who died in hospital in 2014-15 received palliative care during their final hospitalisation.

It also found that only four per cent of residents in aged care had a formal appraisal for palliative care and only 1 in 1,000 aged care patient encounters with GPs was palliative care-related.

In response, Palliative Care Australia and other peak bodies have produced a set of **guiding principles**, with the overriding message that palliative care “is absolutely core business” for aged care providers.

It’s also developed 10 questions for patients and their families or carers to ask of aged care services (see image at the bottom of the post).

Meanwhile the PCA is drafting a new chapter for the Federal Government’s **Aged Care Roadmap**, which astoundingly does not mention either end of life care or palliative care.

A plenary session at the conference on Friday will examine the issue.

**Driving ‘bottom up’ change**

With the theme ‘connecting with community’, the National Palliative Care Conference will urge both “top down and bottom up” approaches to palliative care reform.

It aims to capture some of the exciting grassroots work going on to promote “death literacy” like death cafes, death doulas, and a growing movement around natural burials in a session featuring “The Deathtalker” Molly Carlile, **Groundswell Project** director Kerrie Noonan and Dr Leah Kaminsky, author of **The Waiting Room**.

Keynote speakers at the conference include Canadian physician and academic Dr Alex Jadad, who describes his mission as to **“unleash a pandemic of health”**, New Zealand based grief therapist Liese Groot-Alberts and Australian chef Maggie Beer on ‘creating an appetite for life’.

Other plenary and keynote sessions will focus on pain and symptom management, including the use of medicinal cannabis and on “clinically futile” treatment.

Concurrent sessions will look at palliative care developments for people with motor neurone, end-stage kidney disease and chronic obstructive pulmonary disease, new technology, telehealth, paediatric palliative care, education, the role of the arts, clinical practice, and advanced care planning.
A number of sessions will look at cultural issues particularly for Aboriginal and Torres Strait Islander people, where there is growing concern about the needs of the ageing Stolen Generations.

“Overall we’re trying to build connections with community and ways to integrate care in our community, whether that’s through technology or research or exploring innovative models of care,” Callaghan said.

The aim is to “take a public health approach to palliative care: community driven, bottom up, trying to create a movement in the community to say ‘this is the care we want, you need to respond with these service models’.”

---

10 questions to ask about palliative care in residential aged care

1. Are you able to provide a palliative approach to care?
2. Do I need an advance care plan?
3. What palliative care training do staff receive?
4. How will staff recognise when I’m close to dying and what processes are in place for this?
5. What support will there be for my loved ones when I’m close to dying?
6. What arrangements are in place for my spiritual and cultural needs?
7. Will I be able to have specialist palliative care if I need it?
8. Will I get the medicines I need if things change suddenly, and how long will it take?
9. How many staff are present on evening and night duty?
10. If I need equipment to help with my comfort or problems, will the facility provide it?
#17APCC tweets have begun

Liz Callaghan @PCACEO · 7h
@janefischer @Pall_Care_Aus President learning the ins and outs of the fabulous #17APCC app from conf organiser Jacquie Murkins

Liz Callaghan @PCACEO · 23h
Congratulations Margaret Ambridge on a deeply heartfelt exhibition 'til death. If yr in #Adelaide pay a visit at the Hawke Centre #17APCC

Read more about the exhibition [here](#).
Further reading

Palliative Care Australia’s Palliative Matters website for excellent stories about living, dying and palliative care, including this story with Professor Gregory Crawford from the University of Adelaide, Distinguishing sadness and depression at end-of-life.
What song would you like at your funeral? And other death-changing questions to kick off #17APCC

Conversation - a powerful intervention

Who do you want by your side when you die?

These and other such questions about death and dying were asked of participants during a #DeathOverDrinks event in Adelaide on Tuesday night, ahead of the opening of the Australian Palliative Care Conference on Kaurna country in Adelaide.

The exercise illustrated the power of conversation in improving end of life experiences.

Marie McInerney writes:

These were not the polite and often stilted conversations of your usual pre-conference drinks event.

First everyone gathered in little groups, and we were invited to “bring a loved one to the table”, someone close to us who had died.
Colleagues and strangers toasted each one, many tearing up as groups lifted their glasses to parents, partners, friends and other important losses.

The questions began a bit lightly: What music or song would you like played at your funeral?

The night’s playlist included Leonard Cohen’s Hallelujah of course, Amazing Grace, and the ever-hopeful Staying Alive by the Bee Gees.

Then the questions got a little tougher.

Where would you like to die?

Who would you call if you only had one more call to make?

Other than pain, what scares you most about dying?

How would you like to die?

Who do you want with you when you die?

The Deakin #DeathOverDrinks is a variation of #DeathOverDinner, a movement launched in the United States by chef Michael Hebb to encourage people to talk to their loved ones about their end of life plans, in the knowledge that it can help to bring a good death.

It was an apt and effective curtain raiser for the National Palliative Care Conference. It was led by Rebecca Bartel, now Executive Lead at the Institute for Healthcare Transformation at Deakin University’s Faculty of Health, who was instrumental in the launch of the Australian #DeathOverDinner last year.
Bartel opened the event by introducing her mum, Jan, through a series of photos.

“She was pretty fabulous,” she says. “Very Sydney, very Double Bay, on a good day she was like Patsy from AbFab (Absolutely Fabulous).”

But this “glamorous, amazing woman just had a really terrible death,” she told delegates.

Diagnosed with acute myeloid leukaemia, Bartel’s mother underwent “too many rounds of chemo, a lot of futile medical treatment”.

“She was shuffled in and out of hospital, never offered any palliative care, never asked what she wanted and she died a really textbook horrible death. And it really haunted me,” she later told Croakey.
Bartel comes from a medical family that includes GPs and professors of medicine, and has worked in a range of health organisations.

She thought if she couldn’t make things better for a loved one, then what would be the experience of people with no health background?

Working as executive director of the Australian Centre of Health Research, she led a “deep dive” research project on end of life care that examined the evidence to investigate, “if we could make one intervention, what would make the difference”?

The answer was end of life conversations with loved ones, in time to influence how death comes – that is, conversations over fundamental choices “with family and loved ones at the kitchen table – not in the intensive care unit when it’s too late”.

“When people have end of life conversations, they actually get much better care, they are more likely die at home not surrounded by doctors and machines, and their families don’t suffer,” she said.

Sadly, Bartel says, too many people die in a manner they would not choose and too many of their loved ones are left feeling bereaved, guilty, and uncertain.

Around 70 per cent of Australians would prefer to die at home but less than 20 per cent do, according to her paper, Conversations: Creating Choice in End of Life Care.

Most, she says, will die in a care institution, such as a hospital intensive care unit, where there is a “significant mismatch between what people most often say they want (supportive services) and the services they actually get (acute care)”.

That’s not always within the individual person’s control, with access to care largely determined by age, diagnosis and geography, rather than individual need.

Most doctors try to do their best, she says, but many people get caught up in the system, often resuscitated or given futile treatments whether they want them or not.

“Unfortunately now death is so medicalised and institutionalised that it’s the default,” Bartel said.

Too many people die in a manner they would not choose and too many of their loved ones are left feeling bereaved, guilty, and uncertain.
Death Over Dinner in the US claims to have inspired more than half a million people to sit down to a meal and discuss end of life, helped shift policy and funding for advance care conversations.

In Australia, Bartel says it has started off small but with big backing, a list of influential ambassadors who include media leader Arianna Huffington (Huffington Post founder), musician Ben Lee and a host of medical heavyweights.

One high profile Death Over Dinner brought together actors Michael Caton and Nakkiah Lui, comedian Denise Scott, writer Alex Lee, and intensive care specialist Neil Orford with US founder Michael Hebb, broadcast on ABC TV’s Lateline.

There was almost a #DeathOverDinner on The Bachelor, Bartel laughs.

But these conversations are also being hosted in aged care homes, Indigenous communities, and at private homes seeking to encourage people to take more control over how their lives will end.

Bartel says “It’s ultimately about people taking control… If they want to die at home, surrounded by family, it’s about giving them the tools and the processes so they can have conversations with family and doctors and die on their own terms.”

Find out more: www.deathoverdinner.org.au

Watch this interview with Rebecca Bartel

Find out more: www.deathoverdinner.org.au

Watch this interview with Rebecca Bartel
Watch these vox pops on funeral songs

Also watch Michael Hebb’s TEDMED talks: What happens when death is what’s for dinner?
https://www.youtube.com/watch?v=4DT0aMfFtuw

Tweets and selfies from the first day of the conference
What song would you like at your funeral? And other death-changing questions to kick off #17APCC
You can track Croakey's coverage of the conference here.

What song would you like at your funeral?
And other death-changing questions to kick off #17APCC
What song would you like at your funeral?
And other death-changing questions to kick off #17APCC
You can track Croakey’s coverage of the conference here.

What song would you like at your funeral? And other death-changing questions to kick off #17APCC
What song would you like at your funeral? And other death-changing questions to kick off #17APCC

Croakey
"Conference News Service"
You can track Croakey's coverage of the conference here.

What song would you like at your funeral?
And other death-changing questions to kick off #17APCC

Opening video
Working with difference in grief and loss: insights from a “wounded healer”

Keynote speaker Liese Groot-Alberts talked about the importance of self-awareness and reflection practices to ongoing personal and professional development.

How do we make sure that all communities in Australia, including Aboriginal and Torres Strait Islander people, can access the palliative care and grief support they need so that they experience healing rather than “new hurts” during death and dying?

This is a challenge posed by New Zealand-based grief specialist Liese Groot-Alberts, who has worked with Holocaust and major disaster survivors and many communities across the Asia Pacific since the sudden death of her young daughter led her to becoming a “wounded healer”, as she describes herself.

A keynote speaker at this week’s Australian Palliative Care Conference in Adelaide, Groot-Alberts says her main passion is in “working with difference” – across cultures, as well as in families, workplaces and communities.

This report is based upon an interview with Groot-Alberts ahead of her presentation.
Marie McInerney writes:

International grief specialist Liese Groot-Alberts recalls working as a facilitator at a workshop on “life, death and transition” soon after she emigrated from the Netherlands to New Zealand in the 1980s.

As was the widely accepted practice adopted from a US model, participants were asked to introduce themselves before the facilitators, who then made their own more in-depth introductions.

Maori participants in the room challenged the sequence, asking how could they introduce themselves to her, when they didn’t know who she was.

In a journal article titled *The lament of a broken heart: mourning and grieving in different cultures*, she quotes them as saying:

“You ask me to reveal myself while I don’t know anything about you: who you are, who do you belong to and where are you from?”

It was a wake-up call, and now she tells her own story first, one steeped in her own deep loss.

Groot-Alberts talks of being born in Friesland in the Netherlands, growing up in her early years with her grandparents, marrying, and then suffering the devastating loss of her nearly three years old daughter Nana, two days after her son Aiko was born.

She describes a time of polar emotions: “Hope and despair at the same time, and pain and joy”.

Friends and acquaintances didn’t know how to respond to the birth of a new baby at the same time as needing to acknowledge such sharp loss. “I didn’t either,” she says.

She threw herself into work, becoming a therapist and thinking, “if I can fix everyone else, then I’ll feel much better myself,” she told Croakey.

But it didn’t work out that way, and she burnt out. Over time, Groot-Alberts learnt that she needed to deal with her grief in her own way and to make her pain “a school, not a prison”.

In her workshops, in her writing and in conversation, she talks freely and deliberately about what her daughter’s loss has meant to her, how it’s not something she will ever “get over”, about how, for her, death has ended a life but not a relationship.

“In that way, I’m a wounded healer. I think most of us are,” she says.

Building bridges, not silos

Groot-Alberts went on to work with and for Dr Elisabeth Kübler-Ross, the Swiss-American psychiatrist who was a pioneer in end of life studies and the author of the groundbreaking book *On Death and Dying*, which outlined her theory of the five stages of grief.

Since then Groot-Alberts has been teaching health-care professionals as well as working with people with terminal illnesses and those affected by loss, trauma and grief – among them Holocaust and tsunami survivors – in Europe, Asia, the Pacific, and Africa.

It’s brought her up close to different experiences and expressions around death and dying, grief and loss, and to the issues that arise when one culture or group does not recognise and honour those differences, “creating new hurts, instead of healing”.

Working with difference in grief and loss: insights from a “wounded healer”

#17APCC
Those differences can be seen across families, workplaces and communities, and of course within cultures, but it’s particularly an issue, she says, where mainstream culture or orthodoxy “fails to honour difference”. For some it can risk “psychological colonisation” all over again.

Groot-Alberts has written of repeatedly encountering in Africa, Asia and Pacific the practice of transplanting Western palliative care models onto cultures where the community, not the individual, is the central focus.

“My main passion has been for a long time in working with difference,” she says. “How can we connect together and how can we make sure that we don’t create silos? How can we build those bridges, especially in grief and loss?”

It’s an important issue in Australia and one explored in a number of conference sessions focused on the experiences of end of life care for people from culturally and linguistically diverse backgrounds and for Aboriginal and Torres Strait Islander people, including in remote regions.

Some of the work being done in palliative care remains “a bit paternalist”, says Palliative Care Australia CEO Liz Callaghan, who sees particular issues emerging for the now ageing members of the Stolen Generations.

Their need for trauma informed aged care has been highlighted in recent reports by the Healing Foundation, including its report marking the 20th anniversary of the Bringing Them Home report.

‘My experience is not your experience’

Groot-Alberts says the challenge for palliative care practitioners and others dealing with grief and loss is to be more aware of their own beliefs when working cross-culturally, and to be aware how that can play out in fear or judgments of anything different.

She gives a personal example of how ingrained her own customs and beliefs were when she was working in Samoa after the 2009 earthquake triggered a tsunami in which nearly 200 people died, including many children.

One extended family she worked with lost 14 members, and included a mother who lost all three of her children. They were all buried together, in one big grave, on family land.

After the ceremony, the mother of three beckoned the therapist over to join her sitting on the grave, to show her their individual headstones and to sit and talk, for some time.

Groot-Alberts admits to it being a total shock to her own upbringing, in the Netherlands, where from an early age she learnt “to never step on a grave, that was so taboo”.

Her reaction, as she went to join the Samoan mother on the grave, was almost visceral, she remembers. “It was like I heard all my ancestors yelling ‘Don’t you dare!’ It was a total body response, so ingrained…The whole time I sat on the grave, my body kept screaming “get off!””

The lesson for her was for self-awareness and reflection practices to be “an essential part” of continuing personal and professional development. She says:

“What is important is to be aware that my experience is not your experience.

“(It’s about) being aware of the judgments and stereotypes and dogmatic thinking that has come into the culture about another culture. It is about waking up to all that, becoming aware of our biased thinking and a willingness and openness to be curious about the other.”
 Asked how difficult it is for palliative care practitioners and other health professionals to take the time to honour the needs of each patient and family, Groot-Alberts says she thinks of time as neither linear nor about quantity but about quality.

“When we can be totally present with a person, then at times five minutes are a whole lot more for both of us than an hour or two hours of half distracted and half disconnected,” she says.

She talks in her journal article about the need to be in a space of “openness, awareness, silence, listening and curiosity” to be able to facilitate a person’s healing, rather than to follow prescriptive models.

She describes how that was beautifully put into action in the pulmonary TB ward of a hospital in the Philippines, which was understaffed and under-resourced, with 50 beds in the men’s ward and often 100 patients and where families were counted on to help with care.

There was, she said, terrible depression, hopelessness and despair among those patients whose families were too scared of infection to help.

But one 15-year-old boy who had also been left alone by family was in “very good spirits”.

The difference, she said, was that he had bonded with one of his nurses who made sure to take a short time in every busy shift to give him her full attention and let him know he mattered to her.

“It taught me to never underestimate the healing that can happen in a very limited time, if we stay present and truly connected,” she said.

Conference tweets

[Image of tweets]
Working with difference in grief and loss: insights from a “wounded healer”

You can track Croakey’s coverage of the conference here.
You can track Croakey's coverage of the conference here.

#17APCC @WePublicHealth - 2h
The most difficult thing about majorities is not they cannot see minorities, but cannot see themselves. Dr Glen Colquhoun. #17APCC

#17APCC @WePublicHealth - 2h
We need to be awake and aware of our own belief systems, judgements, dogmas, then less inclined to push down others’ throats. #17APCC

Palliative Care Tas @PallCareTas - 2h
#17APCC Liese Groot Alberts Self awareness is the key to connection and compassion

Palliative Care Qld @PalliativeCareQ - 2h
What is it that facilitate hope? meaningful relationships; a sense of humour; clear goals & courage” Liese Groot-Alberts #17APCC

Palliverse @palliverse - 2h
When community closes a circle around an energy of love, we can heal together - Groot-Alberts #17apcc #hpm Love that image!
You can track Croakey's coverage of the conference here.

Working with difference in grief and loss: insights from a "wounded healer" #17APCC

---

#17APCC @WePublicHealth · 2h
When we form a circle around an energy of love, not to keep anyone out, we are much stronger, healing can happen. Groot-Alberts #17APCC

Liz Callaghan @PCACEO · 4h
And a way to combat gossip is to say "why r u telling me this?" #17APCC

#17APCC @WePublicHealth
Liese Groot-Alberts: lot of workplace toxicity created by gossip: “creates a false sense of intimacy, a sense of ‘I belong with you’” #17APCC

#17APCC @WePublicHealth · 4h
Liese Groot-Alberts urges palliative care/health self/team awareness, to challenge practice, “to be a healer, not a fixer”. #17APCC

#17APCC @WePublicHealth · 4h
Groot-Alberts: When work silos are formed, we disconnect, then we start to be in competition - the $ are part of that of course. #17APCC

#17APCC @WePublicHealth · 2h
Great to see Lieze Groot-Alberts keynote at #17APCC trending nationally @Pall_Care_Aus

---

Australia trends · Change
#ThreatenedSpeciesDay
@GuardianAus, @pauldutton1968 and 2 more are Tweeting about this

Peter Luck
Journalist Peter Luck dies aged 73

Mitch Wallis
Liese Groot-Alberts
#TSL2017
Anthony Seibold
#HungryForSport
#WOINZ
Stringer
1,283 Tweets
#GarryTimAndHamish
Some big questions about life and death: challenging “conveyor belt” of Western medicine and wishing for a loving end

Marie McInerney writes:

Should “bad deaths”, where people suffer unnecessary pain and distress or needless and harmful medical interventions, be pursued in the courts as violations of human rights?

Is palliative care failing its mission if it doesn’t go far beyond supporting those dying in our hospitals, homes and hospices to challenge the staggering number of deaths caused by hunger, environmental injustice, and female infanticide?

Does humanity itself need palliative care in an era where the planet’s health is in crisis?

And when we talk about ‘good deaths’, what do we mean?

These were some of the challenges put to the Australian Palliative Care Conference in Adelaide this week, in a powerful and provocative keynote address by Dr Alex Jadad, Professor at the Institute for Global Health Equity and Innovation at the University of Toronto.
The Colombian-born physician and educator had already made a splash at an earlier conference event, describing in glorious and gory detail how last month he helped his 25-year-old daughter give birth – “unexpectedly with bare hands” – in the corridor of a building.

He despaired at the “over-medicalisation of everything” that has led to an 80 percent Caesarean rate in the Colombian region where his daughter lives and helped breed a “myth of immortality” in Western nations that are losing community connections, separating body from soul, and fearful of death.

“If we brought someone here from 100 years ago, they would say ‘What have you done to yourselves!’” he said. “I think we need to be embarrassed.”

As he roamed the stage for an hour during his keynote, inviting questions, comment and coaching from the floor, Jadad did a quick poll.

Raise your hand, he invited the 800 delegates in the convention hall, if you would like to die as your patients are now.

Just four did.

“Wow,” he said. “I could stop here.”

**The final assault**

The result echoed a conference discussion on Wednesday led by Ken Hillman, Professor of Intensive Care at Liverpool Hospital in Sydney, who has recently published a book, ‘*A Good Life to the End*’, on taking control of our inevitable journey through ageing and death.

Hillman despaired of a “conveyor belt” that is pouring frail, elderly people with multiple problems into intensive care units in the last few weeks of their lives, where they are more likely to be overtreated and face death without dignity.

“Hardly a ward round goes by that one of our team doesn’t say ‘please don’t let this happen to me’, so it’s extraordinary that we’re doing it to other people,” Hillman said.

He quoted leading US geriatrician James Goodwin, who said:

> Overtreatment of 50-year-olds is mostly a matter of inconvenience and waste, whereas overtreatment of 80-year-olds borders on assault.

In his keynote, Jadad proposed that “a bad death be considered a violation of human rights”.

While he didn’t expect health professionals to march governments off to court or The Hague, he said they should consider whether they should rightly sue governments for continuing poor treatment of people in the final hours or days of their lives.

Around the world, he said, about 80 percent of people are dying in institutions like hospitals and aged care facilities when the same number would like to die at home.

A “huge proportion” are dying unnecessarily in pain in countries like Canada and Australia, where vets get three times the training on pain management than doctors or nurses, or elsewhere where government regulations make it difficult to access painkillers. He said:

> I’m not saying we should do it (go to court) but I’m wondering, because I think we are too nice and we have become accomplices most of the time.
We keep witnessing bad deaths, (and we blame) ‘the system’, ‘the government’, ‘the perverse incentives under which I operate’....

What happens if we start thinking in those (human rights violations) terms instead of how I’m going to deal with this case in front of me, or the community that I have committed to support.”

**Broaden the discussions about death**

Just as powerful was Jadad’s challenge to the health and palliative care sector to think more globally about its concept of a ‘bad death’.

He showed a slide with the World Health Organisation’s list of the top ten causes of death of the 56 million people who died worldwide in 2015, led by heart disease, stroke, and lower respiratory conditions, describing it as “one of the greatest expressions of medicalisation of death. We die with a label given by medicine.”

What would happen, he asked, if we looked through a different lens, and looked at other data sets about death?

Nearly 13 million are linked to the environment, through air, water and soil pollution, chemical exposures, climate change, and ultraviolet radiation which the WHO says **contribute to more than 100 diseases and injuries.**

“What do we do with this?” he asked delegates. “What’s our role, and there’s a lot of greed involved here and a lot of government complicity to allow this to happen.”
Eight million die each year of hunger, including 21,000 children every day, in a world with an abundance of food, he said.

“Isn’t that a bad death that can be prevented?” he asked, quoting former United Nations Special Rapporteur on the right to food as declaring in 2002: “Anyone dying from hunger was dying from murder.”

“Is that part of our scope?” he asked.

And what of those millions who die through medical error?

He pointed to a 2012 documentary ‘It’s a girl’ – “the three deadliest words in the world” – about millions of girls who are killed, aborted, and abandoned in India, China and many other parts of the world simply because they are girls.

Should that trouble palliative care professionals when they come to conferences, he asked, just as much as finding out how to relieve pain, or improving the efficiencies of their team, to learning how to advocate change to governments?

And then what of the renewed nuclear threat? He said:

We are the people who know more about death and dying than anyone in the world. What kind of provisions are we making (about that), what kind of statements are we issuing?

If there is one group of people that has legitimacy to talk about death and good death and how to avoid bad deaths it is us.

What are we doing, (are we) looking at our navels, (asking) how many milligrams of this do we need, how many beds do we need, are nurses valued enough? How can we advocate to the politicians around us when the world is falling apart around us?”

These questions are the underlying focus of a (paywalled) article he recently published in the European Journal of Palliative Care, after it was knocked back by many other journals.

Co-authored with Canadian Professor Murray Enkin, the article asks whether hunger, disease and poverty are really only symptoms that our “human world is terminally sick”. It says of the world:

We have reluctantly come to accept our individual mortality and to embrace palliative care when cure is beyond reach.

What if it is time to think of palliative care for our collective humanity?”

(Access to the article, Does humanity need palliative care, can be requested via ResearchGate.)

Aspirations for a good death

Jadad told delegates that a survey of healthcare workers in a network of Colombian facilities has asked: how would you like to die?

The main responses were: to die in my place of choice, receive pain relief, and have friends and family around me.

He says that raises a number of questions: such as why do we need a specialised health system to deliver that and why doesn’t it already happen?
But it begged a bigger question for him: “Should we have higher aspirations for the biggest event of our life?”

Jadad certainly has, and he put some into practice for his 50th birthday, “curating” his own funeral and receiving a coffin as a surprise gift from his family.

He wanted to consider what palliative care might look like if we had no fear about dying: “how much closer could we get to enabling everyone in the world to experience a good death?”

In his practice run, in an effort to remove fear and regret from his last days, Jadad sent letters of apology to people he had hurt, thanked those who had helped him, and spent intense time with his wife and children, dealing with “a lot of issues in a very explicit way, dealing with our fears about hurting each other.”

At his ‘funeral’, they closed the casket and carried him off, with his funeral music playing. That music is now set as his alarm, “so I remember, when I wake up, that I could have been dead, and I need to experience whatever the day is going to show me in the most intense way, without fear.”

What if, he said, we were able to view death as a work of art, to go out with a bang instead of a whimper, to die happy, health and in love?

- **How about an institution for creative dying, a hospital for delightful dying... how about music, great food, massage, smoothies with opioids, and poetry?**

- **What if we died in style, on our own terms, and we enabled each other to do it? What if we viewed death as a work of art? That’s a conversation I hope we can have.”**

There’s much more to watch and consider.
Some big questions about life and death: challenging “conveyor belt” of Western medicine and wishing for a loving end

Watch his full presentation at this link.

The views from Twitter
Presentation by Professor Alex Jadad

Watch his full presentation at this link.
Some big questions about life and death: challenging “conveyor belt” of Western medicine and wishing for a loving end
Some big questions about life and death: challenging “conveyor belt” of Western medicine and wishing for a loving end

You can track Croakey's coverage of the conference here.

@alexjadad thinks this is a very sad list for the most important event of our life! Let's have higher aspirations #17apcc

What do clinicians want at the end of their own life, for a good death? Dying in place of choice, without pain, with loved ones #17apcc

Iatrogenesis was a bigger killer than cancer or heart disease in the US in 2001 - is that a good death? @alexjadad #17apcc

Alex Jadad: We have become prey as a community to the ‘merchants of immortality’. We are fighting big forces, incl big pharma #17apcc

Jadad: i am afraid of falling into the hands of colleagues. Biggest fear to have condition that makes me vulnerable to cruel trtment #17apcc
Some big questions about life and death: challenging “conveyor belt” of Western medicine and wishing for a loving end

You can track Croakey’s coverage of the conference here.
Some big questions about life and death:
challenging “conveyor belt” of Western medicine and wishing for a loving end
You can track Croakey's coverage of the conference here.

Some big questions about life and death: challenging "conveyor belt" of Western medicine and wishing for a loving end

Presentation by Professor Ken Hillman

@WePublicHealth

Hillman: Most elderly frail ppl know are coming to end, 2nd to know are carers, 3rd nurses. Last are doctors, "programmed to cure" #17APCC

@palliverse

Hillman: doctors are trained only to cure, not to talk about dying. Doesn’t have hope that this will change in his lifetime #17apcc

@palliverse

Hillman: Single organ specialists are not ideal to care for the frail older person #17apcc

@Elissa_Campbell

In my experience, sad lack of access to palliative care (specialist & generalist) for frail older people #17APCC #hpm

@palliverse

Hillman asks: What’s the role of palliative care in the final year of life of a frail older person? #17apcc #hpm #pallanz

@palliverse

Hillman: ICU beds cost $4000/night. We could provide the Rolls Royce of care in the community for that amount #17apcc

@soniaif

Hillman: need more appropriate KPIs for evaluating quality of care. eg. honesty, community resources, inappropriate admissions #17APCC
Maggie Beer calls for “revolutions” in quality of food in aged care, hospitals and palliative care

Marie McInerney writes:

Australian chef and food guru Maggie Beer is determined that food can and must be a pleasure to the very end of life – from the meals served in aged care homes and hospitals through to the taste of mouth swabs for dying patients who can no longer swallow.

“Food is medicine, the fuel of life. It’s what fires our appetite for life, no matter what age,” she said in a keynote speech to the Australian Palliative Care Conference.

One of Australia’s best known food personalities, Beer is on a mission to encourage aged care homes to serve food “full of flavour and nutrients”, where residents look forward to meals, and cooks and chef can take pride and joy in their work.

Food is, she says, one of the last things in our lives over which we get to exercise choice and receive enjoyment, so to serve meals that don’t taste or look good and aren’t good for you is an insult both to those who have to cook and serve it, and those who have to eat it.
You can track Croakey’s coverage of the conference here.

Maggie Beer calls for “revolution” in quality of food in aged care, hospitals and palliative care

“You might think it a utopian ideal but there is no place for institutionalised food anywhere, not just aged care, but hospitals, organisations, schools, mental health facilities,” she said.

“We need equal measures of pleasure and nutrition (from our food),” she says. “Pleasure has such a bearing on wellbeing.”

Beer is deliberately positive in her speech and on the website of the Maggie Beer Foundation which she established in 2014 with the motto ‘Creating an appetite for life’, showcasing and fostering innovation in recipes and in making good food available to those who can no longer chew or swallow.

She may not focus on the negatives, but they came through loud and clear in questions from the floor at the conference, packed with health professionals working in aged care, hospitals and in community palliative care, as well as having their own relatives in care.

Delegates talked of tasteless, overcooked mush served to those who can no longer chew, of inflexible eating hours for those undergoing treatments that affect their appetite, and of families on blacklists for bringing in their own home-cooked food.

Then there are the bigger challenges, among them what might be possible for patients who are fed through a percutaneous endoscopic gastrostomy (PEG) tube placed through the abdominal wall and into the stomach to bypass the mouth and oesophagus.

Sue Pieters-Hawke, who has become an Alzheimer’s Australia ambassador following the death of her mother Hazel Hawke, urged Beer to do something about the “bloody dreadful” mouth hydration products used for many dying patients in their final days or hours.

“Given these are the last things that many people taste, can you come up with something delightful?” she asked.

Beer accepted the challenge with alacrity, confessing she had not thought of that before. “It’s on my list,” she promised.

Hearing about one facility that served white toast and tomatoes for dinner one night, prompting protest action from a delegate’s 82-year-old aunt, Beer urged more uprisings, saying cooks and chefs are hamstrung by management, and residents often are reluctant to speak up.

She said:

*The revolts are really important. A lot of residents in aged care now had such tough lives that they’re not demanding people, they’re accepting.*

*[Revolts] give the cook and chef something to work with, even if it’s to shame the CEO.*

Who are the champions?

Beer has long been a champion of good food, but her “turning point”, she says, came when she was appointed Senior Australian of the Year in 2010.

One of the 700 speaking invitations she received that year was to a conference for 1,000 chief executive officers of aged care facilities. In preparation, she visited many facilities, finding some good, some bad, and some very bad.

Her address to the CEOs did not go down well.
“I thought I had a pile of solutions but it wasn’t the right time and most of them hated me,” she laughs now.

But that conference led to her forming the Maggie Beer Foundation and to meetings with HammondCare Chief Executive Dr Stephen Judd.

Beer’s advice to Judd was to find a restaurant chef with a passion for food and people, so the aged care group appointed, as Executive Chef and Food Ambassador, Peter Morgan-Jones, a former chef at Sydney’s Berowra Waters Inn, Bennelong and MG Garage, who had famously cooked for the British royal family and catered at Wimbledon.

The Foundation also launched regular workshops and masterclasses for cooks and chefs from aged care homes across Australia, to give them inspiration, listen to their problems, help to find solutions and build connections and respect.

The masterclasses bring in auditing experts who “debunk” what chefs and cooks are wrongly told by management about what they can or can’t do. Astoundingly, Beer said, there are safety standards for food in aged care “but not one for quality”.

And on the final day the CEOs are brought in to the masterclasses, to show what can be done and “to advocate on the chef’s behalf”.

“The cooks and chefs are considered the lowest of the low in many (aged care) places and in the food industry – the very reverse of what it should be because these are the people who can make such a difference in the lives of the people they cook for,” Beer said.

To effect change in aged care, she says, requires “two champions for good food: the chef and the CEO, and it needs to be a concerted effort with everyone (in the facility) involved, from the carers to the nursing staff to the ground staff, and changing the culture.”

Flavour and fragrance

As all those with elderly or ill relatives or who work in aged care and palliative care know, eating can involve complex food and digestion needs.

Beer is almost licking her lips as she reads about one of Morgan-Jones’ innovations to the conference. You would swear from her tone that she was reviewing the work of a five star chef in a gourmet restaurant.
“First, he created a liquid, blending fresh strawberries and ice-cream,” she begins. “Then it’s passed through a sieve, with a binding agent added to help the formation of bubbles.”

So far so good, but then the hint of something different.

“Using a small clean battery powered fish pump, plastic tubing and a pipette, he frothed the liquid into delicate foam,” Beer continues. “You spoon it off, and you can actually smell the fresh strawberries and the ice-cream. You can put it on the tongue, and it just disappears into nothing, like a flavoured water bubble.”

She is referring to something known as “molecular air”, designed by Morgan-Jones, who was moved by the story of a friend’s 14-year-old son who has been fed through a PEG tube in his stomach for eight years.

It’s “a way of delivering flavour and fragrance through tiny bubbles that the boy could safely savour on his tongue”, Beer says.

Morgan-Jones has written two cookbooks for people who find it difficult to chew and swallow, or use cutlery – maybe because of dementia or a physical limitation like arthritis or a stroke. See some recipes and find out more here.

He is now working on a cookbook for people receiving palliative care – in collaboration with Professor Roderick MacLeod, a senior staff specialist in palliative care and conjoint professor of the University of Sydney, who is based at HammondCare’s Greenwich Hospital, and other professionals – an occupational therapist, dietitian and speech pathologist.

It’s due to be published in Palliative Care Week in 2018. Beer said:

- **This is really important stuff. There are also issues with appetite loss, a metallic taste often caused by chemotherapy, which can impact on people’s enjoyment.**

- **While they may not be able to eat a meal in the same way as they used to, we have to find ways to enable them to get pleasure from food again.”**

**Providing pleasure**

Like so many at the conference, Beer talked in presentations and the lunch and dinner breaks about her own experiences with death and dying, including her distress at having her mother die interstate, “without me at her side”.

“That will be with me forever,” she said.

Happier experiences were the around the death of her mother-in-law, who was cared for closely at home by two daughters, both nurses, and an aunt who had a most beautiful funeral, buried in a cardboard coffin, upon which all her grandchildren had drawn, and with most of the service delivered in song. “So our spirits soared,” she remembered.

For her own dying days, Beer talked about wanting to have speakers beneath her pillows so she can listen to music and podcasts, “of all the things I wish I had known about in life”.

Asked whether it is time for the hipsters to take over the kitchens of nursing homes and hospices, to bring on menus of “smashed avocado”, Beer said there were complications other than tight operational finances and feeding issues.
Many of this generation’s residents have had “quite ordinary food lives”, she said, so cooks and chefs need to learn to trick them to make food both comforting and nutritional. “We put kale in the minestrone, lentils into the patties,” she said.

But she said, at the risk of being crude, the pending tsunami of the demanding baby boomers into aged care may lead aged care facilities into seeing good food as “a competitive advantage”.

It should also be an intrinsic part of palliative care. She said:

- *We all know that palliative care seeks to neither shorten nor prolong life but to improve the quality of life and manage symptoms so people can enjoy to the full the time they have left.*

- *We need to look to ways to meet the social, emotional and spiritual needs as well as the physical symptoms.*

To provide relief from pain is a given, but so should be the pleasure of food and eating, she said. “In palliative care, we can still provide pleasure in food.”

---

**Tweet reports**

- Meera agar @meera_agar · Sep 8
  We need to ban the frozen meals which are defrosted and reheated in hospitals too @mbeerfoundation #17APCC

- #17APCC @WePublicHealth · Sep 8
  Hearing about ‘blacklists’ in aged care for families who bring in their own home cooked food for loved ones: #17apcc

- You Retweeted
  #HelloynameisElissa @Elissa_Campbell · Sep 8
  @pmorganjones is working on a tasty PEG feed! @mbeerfoundation @maggie_beer #hpm #17apcc
Maggie Beer calls for “revolution” in quality of food in aged care, hospitals and palliative care

You can track Croakey’s coverage of the conference here.

Maggie Beer calls for “revolution” in quality of food in aged care, hospitals and palliative care
Maggie Beer calls for “revolution” in quality of food in aged care, hospitals and palliative care.
Maggie Beer calls for “revolution” in quality of food in aged care, hospitals and palliative care

#17APCC
Stunning art exhibition gives glimpses of beauty and humanity amongst death and dying

Marie McInerney writes:

A pillow shows the indent of a dying patient’s resting head, capturing the traces of life after it has left.

More than 1,000 images of flowers bloom, wilt and die, mirroring our own cycles through life and journeys taken in a hospital or hospice.

A woman shares her partner’s death bed. They are wrapped together tightly, with a pump line delivering medication as he keeps a frail hold on life.

These are raw, powerful glimpses of death and dying, provided through the art of Margaret Ambridge. They are among the stunning and moving works in her ‘til death exhibition, which was staged in Adelaide in association with the Australian Palliative Care Conference last week.

Working primarily with charcoal, “because it provides so many shades of grey”, Ambridge has been a finalist in many major Australian art prizes including the Waterhouse and the Kedumba Drawing Award.
But she is also a physiotherapist at a palliative care facility in Adelaide. Each of the 50 or so works in the exhibition aim to “capture the strength I see in humanity”, to explore the process of dying and the effect it can have on palliative care and other health workers.

“We are all human, we are affected by what we do,” she told Croakey.

“Palliative care is a very special and private work and health professionals are deeply affected by the work they do,” she said. “But they have very little opportunity to show or discuss their work.”

**Floral metaphor**

The exhibition was first inspired by one of her patients, an elderly woman who in her early days at the hospice was dressed beautifully, in full make-up, and surrounded by people and a ‘florist shop’ worth of flowers all around her room.

At the woman’s request, Ambridge cleared away some of the flowers that had died, but found a little group of bud roses that hadn’t been in water and had shriveled. They both agreed they looked rather beautiful and she asked if she could take them home to draw.

“When I went back a couple of days later to treat her, she was in a side room, dying, with no make-up, no friends, just the flowers. She was alone and I found this terribly sad. After all this entourage…when it came to the crucial moment, they were gone,” she said.

“I saw from that that flowers have a parallel journey with the people who come through the hospice… They age, they deteriorate, sometimes they outlive the people, sometimes they (don’t). I saw them as a very strong metaphor.”

Another series of works, titled ‘What remains’, (see image below) emerged from a conversation with a friend who had become distraught when her mother’s body being taken away after she had died.

“She was so traumatised to see the pillow start to raise up and lose the shape of her mother’s head, that she lay down on it herself to hold on to that last impression of what remained.”
Her friend’s husband had not known about his wife’s distress at the time and had been very moved to hear it when he saw the exhibition.

“That’s happened multiple times with me over the past few days, where people have come and shared the stories of losing their loved ones, it’s been incredibly moving stuff, and also allowed a lot of people to talk about themselves.”

**Art and practice**

Another of the poignant pieces – of a couple sharing a death bed, after which the exhibition is named – sparked comment at the conference from international keynote speaker Dr Alex Jadad, struck that it had come from Ambridge’s efforts at the hospice to introduce double beds for patients who were dying.

“It came from many conversations we had in the palliative care unit about patients (whose) loved ones had to sit next to the bed and hold hands through the bed rail,” she said.

“You’ve been lying together for 50 years: why just a hold a hand through a bed rail,” she says.

It took three years to work through the proposal for a double bed with staff and the service. Some of the concerns were practical – it can be harder for nurses to lean across a double bed and there can be issues with pressure sores, but Ambridge thinks a double bed also challenged an accepted medicalisation of death.

Since double beds were introduced, couples have been able to lie together, before and after death, as well as letting children tuck in closely with a dying parent.

Ambridge says she loves to be able to go into a creative space to explore these issues after a day at work.

But the driver for her is to use art to provide a glimpse into someone else’s world, and one we will all eventually enter, to prompt thinking about how we want our last days, hours or minutes to be.

“We’re all going to die,” she says, “and sometimes we don’t want to have those conversations at the end of the bed about where we want to die and who we want to be there.
"If we can start those conversations earlier, and art can be useful for that, then I think I’ve done something good."

With thanks to Mark Fitz-Gerald for the photos used in the article.

Do make sure to watch this interview

Read more about her work and the exhibition here.

Dying for a cuppa

In more moving explorations of art and death, Palliative Care Australia awarded its art prize for this fantastic dress crafted from tea bags used by grieving families.

The work, titled ‘Dying For A Cuppa’ was made by Karen Benjamin who works at a funeral home, where she makes a lot of cups of tea for people who are planning a funeral or grieving the death of a loved one.

“At times, the grief seems overwhelming,” she told Palliative Matters, the news site hosted by Palliative Care Australia.

“The gesture of a cup of tea and the chance to speak openly about death and dying soothes the soul.”
“Please don’t let this happen to me” – too much medicine at the end of life

Marie McInerney writes:

A clinical prediction tool is being trialed in a Sydney hospital to give doctors and families the confidence to stop “heroic” interventions like cardiopulmonary resuscitation (CPR) on frail elderly people approaching the natural end of their lives.

The aim is to try to halt the “conveyer belt” that is pouring frail, elderly people with multiple problems into intensive care units in the last few weeks of their lives, and to remind health professionals and families that death is both natural and inevitable.

It was outlined at the Australian Palliative Care Conference, along with other innovations to improve end of life care, including the development of a palliative care triage tool by Melbourne’s Centre for Palliative Care (see tweets beneath this article).

UNSW researcher Dr Magnolia Cardona-Morrell, working with Liverpool Hospital’s senior intensive care physician Dr Ken Hillman, has developed a 29-point checklist – dubbed CriSTAL (Criteria for Screening and Triaging to Appropriate alternative care), partly to reflect the transparency it seeks to bring to end of life.

“We know they have poor prognosis, but we keep on treating them,” Cardona-Morrell told Croakey. “They are having a difficult time in hospital, they are suffering, their families are being given false hope, but we’re still giving them these treatments,” she said.
“It’s time for a change. We want to get back to the concept of accepting death as a natural part of the life cycle.”

Cardona-Morrell presented to the conference on ‘Clinically futile treatment: how significant is the problem, who drives it, and how to minimise it?’.

She talked about the changing profile of hospitals in recent decades, with older people now making up more than half of patients, presenting at emergency departments with “multiple advanced chronic illnesses, unaddressed frailty and high social expectation of longevity.”

Family pressure, doctors bent on cure, and high tech possibilities mean they experience harmful overdiagnosis and overtreatment and risk ending their days in intensive care or emergency department beds instead of going home to die in peace.

Earlier at the conference Hillman gave a graphic insight into their fate, saying:

Hardly a ward round goes by that one of our team doesn’t say ‘please don’t let this happen to me’, so it’s extraordinary that we’re doing it to other people.”

Defining non-beneficial treatment

Cardona-Morrell said her research began with thinking about futile, or ‘non-beneficial’ treatment as medical or surgical activity like CPR or life support.

But literature and experience soon expanded the definition to include all management like chemotherapy, intensive monitoring, imaging – including X-rays – and blood tests for patients who do not have a prospect of survival.

The UNSW researchers now define non-beneficial treatment as:

Any treatments, procedures or tests administered to elderly patients who are naturally dying and which will not make a difference to their survival, will probably impair their remaining quality of life and can potentially cause them pain or prolonged suffering or leave them in a worse state of health than they were before admission.”

Cardona-Morrell’s team conducted a systematic review of 38 studies in 10 countries over 20 years, mapping the experiences of 1.2 million research subjects (patients, relatives, care-givers, doctors, nurses etc).

They were shocked to find that one in three patients over 60 years admitted to hospital towards the end of life were subject to invasive and potentially harmful medical treatments.

According to the study, which attracted international media attention, 33 per cent of elderly patients with advanced, irreversible chronic conditions were given non-beneficial interventions such as admission to intensive care or chemotherapy in the last two weeks of life. Others who had orders for limitation of treatment or not-for-resuscitation orders were still admitted to ICU or given CPR.
The researchers reported that they also found evidence of concurrent treatment of other multiple acute conditions in the last few days of life with complex medications that made little or no difference to the outcome, but which could prevent a comfortable death.

**Why?**

Given the harm and distress these can cause, and the unnecessary costs, the question arises: ‘Why?’

There is a range of different motivations, Cardona-Morrell said. In the United States, these include financial incentives to doctors and hospitals to over-diagnose and overtreat.

In Australia, it seems to be more a reluctance by families and hospital clinicians to recognise that a patient is not just approaching end of life in the final hours, when they are no longer able to get out of bed, but that dying “is a process, a journey” over time.

There is family pressure on doctors to do “everything they can”, she said. In turn, patients can feel the pressure from their families not to give up, “for the grandchildren or the wife of 50 years who doesn’t want to let go”.

TV medical shows also have a lot to answer for, she said, feeding the belief that CPR is pretty much always successful and quite a simple procedure.

In fact the CPR success rate is about 15 per cent, and the prognosis and outcomes are very different for a 25 year old versus an 85 year old who can suffer complications like broken ribs, stroke, and loss of consciousness, she said.

There’s also the issue of medical mission. For doctors in acute settings, end of life is a “critical” matter, unlike for those working in aged care or palliative care where death may be expected.

“We need to harmonise the definition of what’s the end of life, how long it goes for, and how we recognise it,” she said.

**Take a step back**

That’s what the CriSTAL tool is doing, providing a prognostic checklist – with items such as frailty, advanced chronic illness and frequency of hospital admissions – so that doctors and nurses can come up with a number to estimate the probability of a patient dying in the next three months.

“It tells us that person is dying by definition, but maybe the doctor doesn’t know, maybe the family doesn’t know, maybe the patients themselves don’t know,” she said.

Notwithstanding better end of life care for patients, you might think there would be big system support in the trial, given that an intensive care bed can cost $5,000 a day. The same amount could support the same patient in the community for two months.
But Cardona-Morrell says the research is struggling to attract funding, despite international attention and awards. The current randomised trial of the tool followed by a one-hour end-of-life discussion relies on the work of two part-time nurses, who have been barely able to keep up in with the flood of elderly patients over winter into Liverpool Hospital.

She thinks that the lack of enthusiasm for funding is due to a number of reasons: the project does not involve an exciting new medicine or technology, nor high profile diseases or conditions, and is about a “neglected population”. “This is very non rocket science, but is a growing problem that will not go away,” she said.

It’s also about more appropriate care, not less care, she says, though the tool got caught up in the fraught US “Death Test” debate, led by former Republican presidential campaigner Sarah Palin, when Cardona-Morrell unveiled details at a US medical conference.

Neither, she says, is it a further medicalising of health care, but rather an objective tool to help doctors reduce their prognostic uncertainty and start important conversations with patients about where and how they would like to die. She said:

- **One of the reasons doctors claim not to have conversations is that they are uncertain about the time the patient has to live: they don’t want to have the conversation too early, don’t want to upset the patient, or don’t want to be wrong.**

- **Doctors are trained to cure illness and save lives, but we have to remember the ‘do no harm’ principle. If we’re doing things that are unnecessary and aren’t going to be of benefit we need to take a step back. By doing everything that is available just because the technology is there we could be harming the patient.**

- **Our job is now not to do everything but to do what is in the best interests of the patient, and what is in line with patient preferences.**

- **This may include sending them home with pain relief, a community nursing service that comes to provide symptom relief and other support, training the family in administering some medicines, and letting older patients die in peace at a place of their choice.”**

---

**Tweet reports**

*Liz Callaghan @PCACEO · Sep 7*

> Only a small proportion of non beneficial tx is justifiable - Magnolia

---

**Conclusions on NBT**

- NBTs leads to:
  - Unnecessary suffering/prolonged death
  - Stress, false hope and regret for families
  - Poor job satisfaction to doctors/nurses
  - Unsustainable costs of care to the health system

Hope findings prompt wider social engagement in EOL discussion

The justification and reduction of NBT
- Is multifactorial and complex
- Culture change at social and health system
You can track Croakey’s coverage of the conference here.

Please don’t let this happen to me – too much medicine at the end of life

Liz Callaghan@PCACEO • Sep 7
Magnolia - potential solutions after identifying dying #17APCC

Australian Palliative Care Conference
Possible Solutions (2)
Concerted healthcare provider response after identification of dying
- Minimise prognostic uncertainty
- Use of prognostic tools in ED and wards to trigger the EOL discussion rather than admissions/MET calls
- GP involvement in EOL discussions with older chronically ill clients
- Nursing home EOL discussions on ‘Not for hospital transfer’ forms

#hellomynameisElissa @Elissa_Campbell • Sep 7
Specialties like Emergency & surgeons (!) have engaged with Cardona-Morrell to improve care of older people #17APCC @acemonline @ANZSCTS

“Please don’t let this happen to me” – too much medicine at the end of life

#17APCC
Development of a tool for defining and identifying t...
Objective To develop a screening tool to identify elderly patients at the end of life and quantify the risk of death in hospital or soon after discharge for to minimise progrn...
spcare.bmj.com

Older people want to be involved in discussions about their prognosis & treatment, despite what doctors think - MCM #17apcc
Triage in palliative care

Palliative care physician Dr Beth Russell, from the Centre for Palliative Care in Melbourne, delivered the Ian Maddocks Guest Lecture at the conference, selected as the best palliative care submission by an author under the age of 40.

She outlined the development of a **palliative care triage tool**.
You can track Croakey’s coverage of the conference here.

"Please don’t let this happen to me" – too much medicine at the end of life

More tweet-reporting
“Please don’t let this happen to me” – too much medicine at the end of life
Further reading

National Consensus Statement: Essential elements for safe high quality end of life care
Laying down the euthanasia challenge to the palliative care field: are you ready?

Marie McInerney writes:

It’s time for palliative care specialists and services to grapple with the reality of voluntary euthanasia and to consider what they would do when a terminally ill patient asked to be given lethal medication to relieve their suffering, according to experts.

The Australian Palliative Care Conference was told there is a potential implementation “void”, where non-specialists such as “fertility doctors or sports physicians” or physician advocates will step up to assist and encourage voluntary euthanasia, rather than palliative care specialists who are most equipped to provide end-of-life care.

The conference, hosted by Palliative Care Australia, staged a landmark panel discussion on voluntary euthanasia – believed to be the first it’s had at a national conference – as Victoria looks set to introduce enabling legislation.
If the Victorian legislation is passed, voluntary assisted death, as it is called there, is expected to be introduced in 2019. New South Wales legislation is also expected this year.

It would be the first time such laws were in place since the Northern Territory’s short-lived euthanasia laws were overturned in 1997.

Implementation issues

Many in the palliative care sector are opposed to voluntary euthanasia and are, the conference was told, reluctant to engage on the issue.

Conference participants also heard many other concerns about the implementation of voluntary euthanasia, related to “the devil in the detail” – worries about process, training, support, funding, ethical guidelines, litigation, and regulation.

However, some panelists believe the move towards voluntary euthanasia could benefit the palliative care field by increasing its profile and resourcing. Others feared it may divert attention and support for other palliative care patients.

According to the World Health Organisation definition, palliative care seeks to improve the quality of life of patients (and their families) with life-threatening illness, through the prevention and relief of suffering by early treatment of pain and other physical, psychosocial and spiritual problems.

The field of palliative care has traditionally opposed voluntary euthanasia, with many in the sector believing that better access to good palliative care would mean no-one needs to die in unbearable pain.

At the same time, there is confusion in the community about the difference between the two.

Some at the conference said they worry the introduction of voluntary assisted death will compound existing misconceptions of palliative care, where physicians are dubbed “Dr Death” and patients and their families fear that it involves interventions that might hasten death.
There’s also tension around the practice of palliative sedation in the last days or hours of life. For practitioners, it’s a nuanced approach involving careful prescription of a range of medications to ease pain and other symptoms, while many in the community believe that it “amounts to euthanasia”.

**Where to draw the line?**

As she opened the discussion on what Palliative Care Australia warned was “a complex, difficult and emotional issue” for the sector, panel facilitator Dr Karin Myhill urged presenters and delegates to “engage in respectful and open exchange of views”.

It was not, she said, to be a discussion about the pros and cons of voluntary euthanasia, but of the implications for the sector of its introduction.

The panel was largely medical, but medico-legal representative Georgie Haysom, from indemnity insurer Avant, cut through many of the concerns with a challenge to practitioners to think deeply about what they would do if asked to assist a patient to die.

How far would they be prepared to go, she asked, warning that miscommunication within teams and with families are “main drivers” of medico-legal action. She asked:

- *Are you prepared to give them information? Are you prepared to prescribe the medication? Are you prepared to administer the medication?*

- *Where do you draw the line and what will you do if someone asks you to step over the line? How is that going to work in terms of teamwork? How is that going to work in terms of referral?*

**Get ready**

In a recent New York Times article, US palliative care physician Jessica Nutik Zitter describes how her stomach lurched when she faced her first request for assisted death after legislation was introduced to California last year. She wrote:

- *Our hospital, like many others at that time, was still in the early stages of creating a policy and procedure.*

- *To me and many of my colleagues in California, it felt as if the law had passed so quickly that we weren’t fully prepared to deal with it.*

It chimed with an earlier admission from Myhill, a psychiatrist at the Repatriation General Hospital in Adelaide, about how unprepared she was when a private member’s bill on voluntary euthanasia in South Australia last year came within one vote of passing. She said she realised it was suddenly “one minute before midnight” on the issue.

The lessons from Zitter’s article, according to clinical service coordinator Helen Walker, from Adelaide’s Daw House Hospice, are that a highly trained workforce and strong ethical guidance system will be needed when voluntary assisted death is introduced.

But she sensed a reluctance within her own professional network to engage on the issue. She said:

- *I look at my hospice team and wonder: are we ready? Have we really thought this through?*
We need to prepare ourselves, we need to be knowledgeable and really understand the ethical framework that we work in (where) every case we will come across will be different,” she said.

If we take ourselves out of the picture, I’m worried there’s a void, and I’m worried there’s a void also within our own sector until we do some more work.”

Why now?

Other speakers saw it as important to keep palliative care as “quite distinct” from voluntary assisted dying, and to ask the urgent questions if patients express a wish to die.

Professor Jennifer Philip, chair of Palliative Medicine at the Victorian Comprehensive Cancer Centre, said overseas research showed that 70 per cent of people wanting to access an early death changed their mind after receiving good palliative care.

When faced with a patient seeking assisted death, palliative care specialists should take the opportunity to ask “why now?”, she said.

“In the past, maybe some of us have just batted back, said it’s not legal, really shut down the conversation.

“Instead I think we really need to frame this as... an opportunity to engage in some very deep reflection and exploration for that person who is clearly suffering.”

Unanswered questions

Dr Peter Allcroft, a respiratory physician and palliative care senior consultant at the Repatriation General Hospital, said he was wrestling with multiple nuances, complexities and details that he felt had yet to be addressed.

Topmost, he said, was his concern over who might respond to voluntary assisted death requests if it was not palliative care, one of the few specialties with multi-disciplinary teams able to provide complete assessments of patients at the end of life.

“If not us, who then?” he said, adding that it “may scare you to know that the first doctor to utilise medical assistance in dying in Canada was a fertility specialist”.

 Asked later by Croakey where that was reported, Allcroft said he had heard it personally from a palliative care leader in Canada – there was no formal register to “track who is doing what”.

He said he had been reassured in some of his concerns by the work of the Victorian Voluntary Assisted Dying Ministerial Advisory Panel, which recently handed down recommendations on how best to create a “safe and compassionate” voluntary assisted dying framework.

But he said much still remained to be spelt out in detail in the legislation, regulations, and training. It was one thing to be able to have the legislation and policy for voluntary assisted death, he said, and another to establish what to do at the service level. “We haven’t got that sorted yet”.

Some of his “as yet unanswered” questions included:

• How will legislation and guidelines protect patients who are seeking voluntary assisted death from clinicians who have standards “that are not as rigorous as ours”?

• What will be the minimal clinical skill set, experience or qualifications?
• From a practical perspective, where will voluntary assisted death be performed? Can it take place in a four bed bay in a public hospital or only in a patient’s home?

• How will we ensure pharmacists are adequately trained to understand medications?

• Does the Federal Government need a specific Medicare item number to keep track?

• How do we support a single-doctor town where a patient may request assisted death?

And warning that the assessment and management of patients requesting voluntary assisted death will be “time consuming and need to be repeated”, he asked:

“How will we ensure fair and equitable resources for all our palliative care patients?”

That was an issue for others. One delegate was concerned that public discourse on voluntary assisted death has been “too narrow”, led by a handful of “charismatic” advocates. She didn’t mention names but they no doubt include voluntary euthanasia champion Andrew Denton.

It was, she said, focused on the very small number of people who might opt to hasten their deaths versus the broader impact on society and on vulnerable communities, particularly the frail elderly, diverse cultural communities, and Indigenous people, who often already delayed seeking palliative care because they feared it involved euthanasia or hastening death.

“We’re living in a society where all lives are not regarded as equal,” she said to applause.

Her comments prompted a warning from panel member Dr Roger Hunt, a palliative care physician who supports voluntary assisted death.

There has been a history of “fear mongering” around the issue, he said, including where Aboriginal communities were warned of a “second Holocaust” when the laws were in place in the NT.

**Implications for palliative care field**

Hunt was a member of the Victorian Voluntary Assisted Dying Ministerial Advisory Panel whose recommendations were described by the Victorian Government as among the most conservative in the world, with strong protections for conscientious objectors that go beyond those for abortion.

The panel’s report says enabling legislation will need to “clearly step out the request and assessment process in order to provide health practitioners with clarity about their obligations”.

It recommends that assessment of the eligibility criteria and conversations about voluntary assisted dying and end of life will require “specific experience” from medical practitioners involved.

Hunt later told Croakey that he believes opposition to voluntary assisted death in palliative care stems from its faith-based origins, and had “tended to overstate what could be achieved in relieving suffering”, plus an element of “this is our turf”.

But he said that having it discussed at a national palliative care conference meant there had been “some evolution and some maturity developing” in the sector, which would benefit it.

“The profile of palliative care will be incredibly boosted by this debate,” he said.

Fellow panellist Michael Moore, CEO of the Public Health Association of Australia, also expects assisted death law reform to lead to greater funding and resources for palliative care.
“People want to know that when someone does choose to have assistance to die, that every other option has been explored,” he said. “You can’t do that in an equitable way unless there is adequate funding.”

When he was Health Minister in the Australian Capital Territory, Moore introduced a euthanasia bill in 1997 that was overruled by the Federal Government.

He said Allcroft’s warning that a fertility doctor had led the way on voluntary assisted death in Canada was for him “the most telling comment” in the panel discussion. He said:

- **The people in Australia who have the most skills to assist people in their dying are palliative care specialists. What they don’t, of course, want to do is actually assist people to die...**
- **But if they step away from the decision altogether, it will be left to the fertility doctors or the sports physicians or others who don’t have the level of skills there.**
- **If we leave it in the hands of someone who doesn’t understand palliative care, then they will be encouraging assisted dying instead of taking people through an appropriate palliative care process.”**

Warning that voluntary assisted death legislation would need a serious lead time to discuss such issues – an 18 month implementation period is proposed in Victoria’s case – Moore imagined the questions to be put to a Health Minister in an Estimates review:

“Minister, you’ve given huge new responsibility to health professionals: how are you going to pay for it and how are you supporting them? How have you ensured equity of access?”

Moore told the panel that big issues will include funding, including likely cost shifting between states and territories and the Commonwealth (already signalled in this Guardian article, and training – ensuring that support, education, programs and guidelines are in place for clinicians).

He quoted Machiavelli that there is “nothing more difficult to take in hand, more perilous to conduct or more uncertain in its success than to take the lead in the introduction of a new order of things”. Moore added:

“What could be more challenging when we talk about change than being about ending the life of a person?”
Tweet reports

#helloymameisElissa @Elissa_Campbell · Sep 6
Dr Jenny Philip: important to make distinction btwn Pall Care & #VAD - ppl already fear #Palliativecare due to fear of hastened death #17APCC

Palliative Care Aus @Pall_Care_Aus · Sep 6
Helen Walker, if we take palliative care out of the VAD picture, I’m worried there’d be a void in care #17APCC

#helloymameisElissa @Elissa_Campbell · Sep 6
Helen Walker - most doctors lack the communication skills to have the conversations described by Dr Philip. #VAD #17APCC

#helloymameisElissa @Elissa_Campbell · Sep 7
This is very doctor-centric discussion. Would love to hear more from Helen Walker & @mmore501 #17APCC #VAD

Palliative Care Aus @Pall_Care_Aus · Sep 7
Georgie Haysom: Legal implications - practitioners have a lot of gaps in their knowledge about the current end-of-life laws ACP/ACD #17APCC
Watch these interviews

Michael Moore, CEO of the Public Health Association of Australia

Dr Roger Hunt, palliative care physician and member of Victoria’s Ministerial Advisory Committee on voluntary assisted death
Westernised systems of palliative care can be problematic, conference is told

Marie McInerney writes:

A palliative care doctor working in the Northern Territory has urged major changes to end of life care for Aboriginal and Torres Strait Islander people, particularly in remote areas, saying the system of care itself is an “immense barrier” to equitable access.

Dr James Ricciardone, a registrar with the Australian College of Rural and Remote Health, graphically illustrated the inequities in access to palliative care in a presentation at the Australian Palliative Care Conference about one of his patients, a man in his 30s.

The man’s care was already limited by his late presentation to the health service with cancer, and his difficulty tolerating palliative chemotherapy, Ricciardone said.

But it was also compromised by having to live a huge distance from his community and to deal with a Western system of care, in his third language, where practice even by Aboriginal health workers was not able to meet his cultural needs.

Ricciardone said:

- Despite all the effort of all the people involved, the system itself is incredibly Westernised and that is an immense barrier at the outset.
- Regardless of how much cultural training you have, it’s the system itself that is a barrier.
- It’s quite crushing to see someone who’s so isolated from their family and culture, just having to somehow cope with their situation.”
Concerns about prisons

Ricciardone said there was an “ethical minefield” around palliative care and prisons.

He said there was not a lot of evidence about end of life outcomes for prisoners in Australia, but evidence from the United States showed that people with terminal illnesses in prisons felt isolated and lacking control, with challenges in accessing medication and appropriate equipment, all of which exacerbated pain and reduced quality of life.

In the Northern Territory, he said, it was “safe to say” that Correctional Services had an “antiquated approach” to compassionate release for dying prisoners.

(The issue of palliative care for prisoners also emerged in other sessions of the conference, prompting Palliative Care Australia to put it on the agenda for the next conference in 2019).

Return to country

Ricciardone said another big and complex issue was in assisting his patient to return to country to die, which involved weeks of wrangling over early parole and then problems with being able to provide proper support in a remote location when he got there. He said:

I often feel when I work in the Northern Territory that return to country happens in spite of the system, not because of it.

When we develop policy and when we develop ways to help people die at home, Indigenous people, particularly in remote Australia, deserve to have the same consideration as those of us who live in the city.

His experiences underscored research into palliative care for Aboriginal and Torres Strait Islander people, which has urged a greater role for Aboriginal community controlled health organisations as a starting point.

As well as different understandings of death and dying, autonomy and community, research into service provider perspectives has found that the broader context of Aboriginal history and historical distrust of mainstream services also impinges on Indigenous people’s willingness and ability to accept care and support from palliative care services.

And the recent report to mark the 20th anniversary of the Bringing Them Home report into the Stolen Generations sounded a warning to the aged care sector.

“In all but a handful of cases, the trauma of being forcibly taken under government policy is not recognised in the design of Australian aged care,” Healing Foundation CEO Richard Weston wrote in a challenge to the health, community and aged sectors.

There were a number of other presentations at the conference about improving delivery of palliative care services to remote communities, including work by the Far West Local Health District that was said to be transforming the palliative approach in rural residential aged care in far west New South Wales.
The specialist palliative care team from that service featured in one of the conference poster presentations, showcasing a photographic study (‘Melorites’) by celebrity photographer (and Broken Hill local) Robin Sellick, aiming to explore the balance between life and death.

**Other gaps in care**

As well as lower access to both inpatient and outpatient end of life care for Indigenous Australians, the recent draft Productivity Commission report on human services identified gaps in access to other people from culturally and linguistically diverse backgrounds.

A conference session on palliative care in aged care talked about the “rich tapestry” brought by cultural diversity in aged care, with an estimated 31 per cent of residents and 32 per cent of staff born overseas.

But a presentation on cross-cultural training by Flinders University associate professor Dr Lily Xiao highlighted that the majority of overseas-born residents come from Europe while the majority of overseas-born staff come from Asian and African regions.

Her work found that this diversity generates many opportunities for aged care organisations to address equitable and culturally appropriate care for residents but can also be a challenge, particularly as her research found that:

- most staff interviewed did not attend education programs in cross-cultural care services
- staff were not aware of normative approaches when delivering care services to residents or working with co-workers in cross-cultural interactions
- educational programs and resources in cross-cultural care services for aged care staff are scarce, and
- there is a lack of organisational structure to enable and sustain high-quality care for residents and workforce cohesion in cross-cultural interactions.
Westernised systems of palliative care can be problematic, conference is told

#17APCC

The most common non-English speaking countries of birth

- Residents
  - Other Groups: 50%
  - China: 1%
  - Poland: 1%
  - The Netherlands: 1%
  - Greece: 1%
  - Germany: 1%
  - Italy: 19%

- Personal care attendants
  - Other Groups: 9%
  - Chinese: 1%
  - African: 1%
  - Arabic: 1%
  - Italian: 1%

Source: references 1, 2

Country of birth of recent hires from the three census data

<table>
<thead>
<tr>
<th>Year</th>
<th>Australia-born</th>
<th>Overseas-born</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007</td>
<td>54%</td>
<td>46%</td>
</tr>
<tr>
<td>2012</td>
<td>37%</td>
<td>63%</td>
</tr>
<tr>
<td>2016</td>
<td>40%</td>
<td>60%</td>
</tr>
</tbody>
</table>

Source: reference 2

You can track Croakey's coverage of the conference here.
Conference keynote speaker, grief specialist Liese Groot-Alberts talked about “honouring difference”, including between mainstream western cultures that focus on the individual and those where the community is paramount.

No one place has all the answers, said Marcus Riley, chair of the Global Ageing Network and BallyCara CEO when asked about international best practice. But he said Australian palliative care “can learn, particularly from some of the less developed nations”.

“There are a lot of cultural learnings we can take from many places to benefit our society”.

Mary Schumacher, Chief Executive of Hospice New Zealand, said her sector had an explicit commitment to align standards with the principles of the Treaty of Waitangi with Māori people.

Care guidelines were based around the Māori Health Model, Te Whare Tapa Wha (a four sided house) with a focus on spiritual, emotional and social needs.

“There is a very strong alignment with Māori beliefs and palliative care,” she said. “When we get it right for Maori, we tend to get it right for everyone else. We are learning that.”
Share this intimate conversation about death, dying and caring

Julie Morgan (L), in conversation with her friend and carer Robyn Horner. Behind them is Liz Callaghan, CEO of Palliative Care Australia

Julie Morgan is a former lecturer in ethical leadership and senior consultant on organisational development for Australian Catholic University.

In February 2016 she was diagnosed with metastatic breast cancer, which has spread to her bones and lungs.

It’s not her first encounter with terminal illness: originally diagnosed five years ago with breast cancer, she was cared for by her best friend and housemate Cath – only to become Cath’s carer when she was soon after diagnosed with lung cancer and died 14 months later.

Now Julie gets much loving care from her friend and former colleague, Robyn Horner, who is Associate Professor at the Institute for Religion and Critical Inquiry at the ACU, as well as from her beloved family. She also continues to care for others, including her elderly parents.
At the **Australian Palliative Care Conference**, Julie and Robyn spoke about their roles, about accessing good care, how health professionals sometimes see patterns more than people, and the risks for patients and carers where “the host becomes the hostage”.

They continued the conversation with Marie McInerney; here’s an edited transcript.

---

Marie McInerney: How did you come to be both a carer and one who is cared for?

**Julie Morgan:** I lived in Sydney for 16 years and shared a house with my best friend Cath. In 2012 I was diagnosed with breast cancer. Many years before that Cath had had ovarian cancer so she had a real sense of what was needed in looking after someone with cancer. For example, when I was on chemo she would often turn up at my doorway in the middle of night; when I was too sick to call out for her, she would somehow know. We put that knowing down to her having experienced much of that shadow side of treatment, particularly chemo. Chemo keeps you alive but it’s a very blunt instrument.

Towards the end of my treatment, we noticed she had a very bad cough. She worked for Mary MacKillop International so would often travel backwards and forwards to East Timor. One of the staff members up there had TB. She went away for tests and we were hoping it was TB but unfortunately it wasn’t, it was very significant primary lung cancer. Cath died after 14 months, aged only 49. She was pretty keen to get to 50 but she didn’t quite make it. Caring for her was an intense experience, partly because I was still recovering from my own treatment, but it really was a privilege, I wouldn’t trade it for a second.

I then moved back to Melbourne to be with family and friends. One morning I tripped over my little dog and fell quite heavily on my chest: I thought I might have broken my ribs. After a few months of not being able to fix the pain with my chiropractor, I went to my doctor to order a chest x-ray. She said that given my history she should also do a bone scan. She did and it lit up like a proverbial Christmas tree. I counted at least 16-17 different tumour sites on my spine and ribs, while the lung x-ray showed hundreds of tiny tumours.

Eighteen months on, I think I’m pretty lucky in that I’ve had longer than they thought I would. It is what it is. It’s not going to get better. The chemo has done as much as it can do. I have radiation on spots where I think it will help to ease the pain on the spine. Really they are just treating me palliatively now, and I’m happy with that. I have got very very good care at the Peter Mac (Peter MacCallum Cancer Centre) and Melbourne City Mission.

I’m surrounded by love and prayer and support and positive energy from all over the world, from Jewish friends in New York and Buddhist friends in Bangkok and people who don’t know what they are in Geneva! I feel I have a universe of support around me, but in particular I’m really touched by the support I have from Robyn, and my brother and sister.

**Robyn Horner:** I’ve known Julie for over 30 years. I shared a house with her in Melbourne before she moved to Sydney, and she’s the godmother of my (13 year old) daughter. She is very close to my two kids. I count it as a privilege to be her friend. She’s much more extroverted than I am and she’s taught me such a lot.

You can kind of imagine, then, how shocking it is for this to be happening, unfolding, but given that it is, I wouldn’t want to be anywhere else (than providing close support), so I, too, would describe it as a privilege to be in this moment in Julie’s life...

I struggle to be a carer. I’m not as intuitively observant as many others, I live in my head, so sometimes I won’t think of doing something till I’ve noticed someone else do it.
But there are other areas where I’m better. For example, I knew that the people from around the world who love Julie, and they are legion, would want to know what is happening, so I’ve set up an email distribution list of 100 or more people. It’s a lot of work for her to address all the texts and emails coming in from friends, so this is proving a really good way for people to keep up to date. I don’t necessarily go into the nitty gritty but I signal when there are changes or developments and that keeps them connected.

At one stage, I got them all to send photos of themselves with Julie, or just themselves, and another friend gave her one of those digital frames, so people she loves are constantly passing through in the frame. Sometimes I do very practical things, like shopping, or, as Julie does public things, part of my role is in supporting her to get there. (As well as her conference presentation, Julie has also been interviewed a number of times about her opposition to voluntary euthanasia.)

Marie McInerney: What makes for a good carer and good care?

Julie Morgan: It’s not what the carers do, it’s how they do it. It’s not always the practical things that are important to me, but the symbolic things that they will remember when I am gone. Confidence and trust I think are the important things. If they’re accompanying you to the doctor, you know that they’re advocating on your behalf. You’re confident that they know what you like, know when it’s time to change the sheets, and trustworthy about financial matters.

In terms of what I learnt as a carer and what I learnt in being cared for, sometimes I think it’s harder to be the carer, to know where the boundaries are, what you can do to help and where your helping starts to interfere with the autonomy of another person.

Robyn Horner: People at work know that I’m caring for Julie, and I have the luxury of their confidence that if I need to be here (with Julie), I can be here. That happened the other day. I spoke to Julie in the morning as I was on the freeway going to work and she wasn’t very well. So I turned right instead of left and came here. It meant that a whole lot of things that were unravelling in terms of her medication were dealt with as a result of an intuitive sense of where things were. But I couldn’t have done that or be in this role if I wasn’t in a job or with an organisation that allowed me flexibility.

Marie McInerney: You talked about the risk of the “host becoming the hostage” for people who rely on care: what do you mean?

Robyn Horner: The trope of the “host becoming the hostage”, words which have etymological links, comes from French philosopher Jacques Derrida’s reading of the idea of “radical hospitality” of Emmanuel Levinas, a French philosopher of Lithuanian Jewish ancestry who was a prisoner of war in World War Two. I was actually at Derrida’s lecture in Paris in 1996, part of a series of lectures on hospitality, where he spoke about this.

Derrida picked up this idea of radical hospitality, to ask: but what happens when someone comes to your house and you say ‘make yourself at home’ and they do? They stay for weeks or months, and in the end they take over, they’re running your house.
It became a very relevant reference for us. Julie is very well educated; she has had a great career, taking on high-level roles around the world (including as Regional Director of Franciscans International in the Asia Pacific and Deputy National Director of Caritas Australia). Yet here she is, feeling as though much of that is taken from her, the cancer doesn’t allow her to do that anymore, and other people are here in her house telling her what to do.

**Julie Morgan:** It comes across in different ways. I made the joke at the conference about how it prompts ‘competing pumpkin soups’ between friends. For example, when Cath was sick, people would ask what food could they bring to help. When she was going through radiation, her esophagus was badly burnt and she was vomiting most of every day so she could only eat certain things. A friend offered to cook something for Cath. I suggested a fairly bland soup because Cath had such difficulty eating. In spite of this, she insisted on making a lemon tart; once again, hosts became hostages.

Recently I had a visit from a palliative care nurse and we were having a really lovely conversation about politics. Then she suddenly switched and asked every nurse’s most important question: ‘Have your bowels opened yet today?’ I got suddenly thrown back into ‘you are just a patient’. They can forget that you’ve actually been a person all your life, not just a patient.

---

**Marie McInerney:** Given the difficulty of not wanting to reject good intentions while relying on carers, what’s your advice to carers on how not to become hostage-takers?

**Julie Morgan:** I think the critical skill of the carer is the capacity to listen, to deeply listen, and to allow the person to be themselves. Even when they’re sick, they’re still themselves, they don’t stop being themselves. For example, I don’t stop being a carer too. Even when I’m sick I still need to care, so let me care for other people in the way that I need to care for them.

---

**Marie McInerney:** You talked about often health practitioners see patterns, not patients – how does that manifest?

**Julie Morgan:** So many times I’ve reported symptoms to doctors and they have said ‘no, that doesn’t actually happen with your illness’, but I am still experiencing the symptoms! They want you to believe that all patients are different, and every hospital talks about patient-centred care, but really what they’re looking for are patterns of the disease, and not the person, so with every best intention, they can still very easily dismiss what you’re saying to them.

**Robyn Horner:** We are two people who are highly educated and have the confidence to engage with doctors, as professionals. I obviously have a lot of respect for what doctors know, and you’re in their hands, but our life experiences mean we can ask questions and raise issues. We often wonder, when we go into the Peter Mac, about what it’s like for others there, can they ask the same questions we do? If the doctor says a symptom can’t happen, do they just have to accept that?

I felt I was being a bit demanding this week when I rang the hospital about Julie’s medication, saying this isn’t right, this isn’t working, can you reassess? We ended up being treated very well. But if I hadn’t had the confidence to ask, what might have happened?
Marie McInerney: Around 70 per cent of Australians say they want to die at home (although less than 15 per cent do). But Julie, you’ve said you don’t want to. What’s your preferred place and why?

Julie Morgan: I don’t want to die at home because I don’t want to put pressure on family and friends to look after me when the professionals can do that. If I can stay at home for as long as I can, that would be great – it means I can keep my little dog Timmy beside me, and that’s really important. But I’m quite happy to die in a palliative care facility. I know there’s a push for us to die at home and I can see that would work for some people, but it’s not something I would choose for myself or my family and friends. I would rather my family and friends had energy to focus on loving me, talking with me and stroking my arm, rather than toileting and bathing me.

Cath wanted to die at home and we made as many arrangements as we could for that to happen. In the end that didn’t work out. We would often sit up at night because she found it hard to breathe lying down and one morning, after a very long night, she lost consciousness. When the ambulance came, the choice was made to send her to the local palliative care facility. My hope was that it was just to get things recalibrated and she’d be able to come home but in fact, three days later, she died there.

I think in the end it was probably the best decision, because she was from a large family…. Just managing (her care) with a house full of people would have been very hard. The palliative care facility was very good: they cleared a big room for us, her sister was able to stay over at night, and I think in the end it was a beautiful death. It wasn’t where she wanted it to be but it was probably how she wanted it to be: in the sense that all her family were there.

We were all there, able to stroke her arm, able to make jokes even though she couldn’t respond. I’d tell her who was phoning and texting … she was surrounded by as much love as she could have been. A couple of us kept talking to her. I think hearing is one of the last things to go and I wanted her to keep hearing she was not alone, that she was not in the dark, that she was deeply loved.

After Cath died, no one rushed us out of the room; we were able to sit with her for a long time. The Pastoral Care people came around with a drinks trolley, and we all shared Cath’s favourite drink, which was a gin and tonic. I’d like to think my family and friends could have a gin and tonic with me as I go.
Wrapping some “life-changing conversations” from palliative care conference. Plus #17APCC selfies

Aged care doctors may soon be making house calls in Australia via hologram – at least that was a suggestion at the Australian Palliative Care Conference.

But for all the technical advances that may help us deal with end of life matters, the conference also revealed significant gaps in the basics – including how we talk about death and dying, and important misunderstandings about palliative care.

This final post in Croakey Conference News Service coverage of the conference wraps reports on more presentations and discussions, including radical new understanding about pain and feedback from delegates.
Marie McInerney writes:

It looks like we soon may be able to beam in doctors for hologram house calls to help elderly people to stay longer in their homes.

Western Australia’s Silver Chain Group did not want to say more about its hologram health plan than the brief mention by its CEO Chris McGowan at the conference’s final session on ‘Building innovative ways of caring in our communities’.

Its media person would only say the Western Australian community health provider is “a couple of weeks away from doing a major reveal”. This United States story about a “virtual care clinic” may offer a glimpse, however.

The same session featured a new Uber-style disruption. Ubercare general manager Renae Sullivan said the South Australian business was transforming home care by providing “carers on demand” to the elderly or sick.

It’s not connected to the global rideshare and food delivery business, but has some of its features – including being able to “rate” carers, and is batting back international interest until they bed down the local service, she said.
Death-denying

We know from gory and gruesome shows like Game of Thrones that death is “a best-seller in the box office,” author and doctor Leah Kaminski told the conference.

“But real death happens offstage a lot of the time,” she told a panel session that looked at ways to improve “death literacy” in the community.

They included growing interest in **natural burial grounds** (being buried in a natural environment with a marker such as a native tree or just a location identified on a map) and the **Groundswell Project** which hosts #DyingToKnow days and is the Australian base for the global **Compassionate Communities** movement.

The author of **We’re All Going to Die**, Kaminski is also a big champion of getting “the D word” out of the closet. She remembered that, as a medical student, she rarely saw dead bodies and questioned why there remains such stigma around miscarriage that prospective parents often don’t reveal a pregnancy for 12 weeks in case they lose the baby.

Ironically, she said, we are happy to say we are “dying for a pee” but when it comes to someone dying, we opt for the euphemisms: “he passed... he went to a better place” and, a new one for many at the conference, someone had “taken a dirt nap”.

“We are a death-denying society,” she said.

Watch the community panel discussion [here](#).

Not just a place to wait for death

Most of us also don’t fully understand what palliative care is, according to a study led by Anna Collins from the Victorian Comprehensive Cancer Centre’s Palliative Medicine Research Group.

Collins told the conference the study was set up to explore initial perceptions of palliative care with patients with advanced cancer and their families, to uncover some of reasons behind variable engagement with palliative care in Australia and often late first engagement (with the median time to death currently 25 days).

Most previous studies, she said, had surveyed palliative care and other health practitioners on what they saw as the barriers for patients and families, not the patients and families themselves.
Collins expected that the results would reveal gaps in knowledge and understanding, but she was a little surprised at how narrowly and negatively most regarded palliative care before they experienced it.

Their perceptions fell within three themes:

- **Diminished care:** seeing it as non-medically focused, exclusively nursing care, a “lesser” treatment alternative, only about basic pain relief.

- **Diminished possibility:** seeing it as “a place to wait for death, “the end of the line”, a time of dependency.

- **Diminished choice:** seeing it as “institutionalised” dying, a time of limited choice for care, and sometimes confused or seen in opposition with voluntary euthanasia.

Collins said:

*It was basically seen as hospitalised dying – the care received in hospital while dying, which they understood to be the final days really.*

*It was not seen (as palliative care is) as a treatment option, not seen as care than can be provided in the community, not seen as care provided by a team with a medical specialty behind it."

What’s not surprising though, Collins said, is how they might get those views.

She showed a slide of the first 20 images that came up when she Googled palliative care.

It’s understandable then, she said, that people have impressions of dependency, slow death, nursing care, death in hospital, imminent death and “just” comfort care.

Collins challenged palliative care services to make sure that they way they present their own work “is in line with the evidence for what we do and the full scope of the services we offer”.

Better images would be taken outside of hospitals, and of a person doing things they might like to do, “the result of a medical team which focuses on your quality of life as well as your medical treatment.”
“It’s not about hospital and it’s not about a bed in the final days and it’s not about “just” holding hands!” she said.

In response, she is developing short stories about palliative care told from different perspectives – by doctors, carers and patients, exploring both evidence and experiences, to find out what elements and characters of stories resonate more.

A full paper of her study findings is expected to be published in the October edition of *Palliative Medicine*.

---

**Bust the taboos**

Sue Pieters-Hawke told the conference about the “amazing experience” that she had been privileged to have with the death of her mother, Hazel Hawke, who lived her last days in an aged care facility which, “unusually”, had strong integrated palliative care.

For nine days, the conference heard, the family was able to sit with Hazel. They enjoyed takeaway meals together and a bottle of wine in her room every night, and were able to sleep over in the room with her, while knowing that a dementia specialist nurse and palliative care specialist doctor were on hand if needed.

“We knew medical expertise was there in the background but our experience was of personally being with Mum at the end of her life,” said Pieters-Hawke, who is now an ambassador for Alzheimer’s Australia, informed by her mother’s experience of dementia.

“It was a precious, precious experience.”

What she took out of that, she told the conference, was that “death might be sad but doesn’t necessarily have to be bad”.

Pieters-Hawke said one of the reasons the family chose the aged care facility that it did was because management and staff were very open to talking about death, they didn’t use euphemisms.
The family was also driven by wanting to reduce unnecessary suffering that comes from ignorance or being unprepared, of having to make decisions under pressure.

“There are a lot of conversations to be had in families, in the medical profession, about getting ‘The D word’ out of the closet,” she said.

“Taking the taboo out of it, so we can be emotionally present, available and supportive for the person who is dying, but also for ourselves and each other.”

“There’s a sense of joy about how it happened that has left me sad that she’s gone but so grateful to all who contributed in so many ways to that being so sad but a meaningful and precious experience,” she said.

Her experience, however, is not routine. A recent Productivity Inquiry into end of life care found that the aged care sector is “ill equipped” for end of life care.

In a plenary panel session on the need for palliative care to be “core business” for aged care, Pat Sparrow, National CEO of Aged and Community Services Australia talked about the changing profile of people who go into aged care, to which the sector is still learning to respond.

Sparrow said:

- *They used to be built with car parks because residents would drive in and out, but that’s just not the case anymore.*

- *Residents are much older now when they go in, with more complex health conditions.*
  *They also stay for much shorter periods, some for just 24 hours, often because of death but also for recuperation, after which they can go back home.*

Palliative care physician Dr Roger Hunt said they have become “slow stream hospices”, with more cancer deaths now occurring in aged care in South Australia than in hospices and at home combined.

That raises big funding and workforce issues for the sector, which one panelist said operates on maximum funding of $212 a day – “not an enormous amount of money to provide extremely complex care”, Helping Hand Aged Care director Susan Emerson said.

That’s particularly so, the panelists agreed, when good arrangements with specialist community palliative care services and GPs are “patchy” across Australia.

A new funding model is also on the agenda, questioning whether the current dollar amount per day based on certain resident characteristics is the right way.

Training and workforce skills are also a big issue, likely not assisted by Emerson’s revelation that the Certificate III in Aged Care no longer deems palliative care to be a core subject.

Ilsa Hampton, CEO of Meaningful Ageing Australia said strengthening the workforce is a major priority that has been raised with Aged Care Minister Ken Wyatt.

“It’s not just a skills base, where you learn to move a trolley from here to there, or to feed someone in a certain way,” she said.
“It’s a vocational thing, it actually has to involve your whole person in order to do really well. If you have that happening, people are more able to more flexible, not so rules based or task based so when you meet complexities in families or cultural situations, you’re better prepared to respond.”

Watch the conference panel discussion on aged care here.

---

It's a vocational thing, it actually has to involve your whole person in order to do really well. If you have that happening, people are more able to more flexible, not so rules based or task based so when you meet complexities in families or cultural situations, you're better prepared to respond.
Unraveling the mysteries of pain

Delegates were also wowed by radical new thinking about the link between pain and the brain’s immune system that suggests “talk-based” therapies – like cognitive behavioural therapy – can actually change the cellular processes associated with pain.

Nuroscientist Professor Mark Hutchinson, Director of the ARC Centre of Excellence for Nanoscale BioPhotonics in Adelaide, outlined the theory based on the connection between chronic pain and glia – immune cells that support the brain’s nervous system.

It’s an approach that could open up treatment of debilitating chronic pain.

Read more about his work here and here.

Also watch the conference panel discussion on pain management, which included Professor Hutchinson.
You can track Croakey’s coverage of the conference here.

Wrapping some “life-changing conversations” from palliative care conference. Plus #17APCC selfies

Tweet reports

Liz Callaghan @PCACEO · Sep 7
Natasha Michael says we need to challenge PHI funds to fund privately funded community based palliative care #17APCC

Mike Kennedy @MikeKennedy1906 · Sep 7
Setting up under-resourced palliative care services can do more harm than good - Michael #17APCC - applies equally in public & private services

Liz Callaghan @PCACEO · Sep 7
Consult etiquette in the private sector differs to public sectorsays Natasha Michael. Surely this should be the same in public sector?? #17APCC

Australian Palliative Care Conference
Consult Etiquette in the Private Sector
- Referring doctor is your primary stakeholder
- Consider a shared care model with clearly defined boundaries
- Clear communication – dictated letters, discharge summaries
- Availability and responsiveness
- Continuity of care
- Do what are asked to do – no more and no less
- Patient and family etiquette

Anthony Herbert @AnthonyHerbert9 · Sep 7
Sue Kearney and Rachel Ficinis speaking on multi-disciplinary care in a children’s hospice. #pedpc #17apcc

Way Special Kids
- Founded in 1983 by two families who supported each other through the death of their children from leukaemia
- Not for profit organisation
- Based in Melbourne, Victoria, co-located with Yarra Valley Health
- 50 full-time and part-time staff, 800 volunteers
You can track Croakey’s coverage of the conference here.

Wrapping some “life-changing conversations” from palliative care conference. Plus #17APCC selfies

Hearing from delegates

Croakey thanks the following delegates for providing their feedback on highlights, take-home messages, and what the conference has put on their agendas:

Danielle Bowden, Registered Nurse, working across community, acute and aged care settings on Kangaroo Island, coordinating in home palliative care within the community.

Christopher Martin: Clinical Psychologist who works in a specialist palliative care service, providing assessment and therapeutic support to patients and their families/carers who are experiencing emotional/psychological distress.

Q1. What is your main takeaway/reflection from the conference?

Danielle: My main reflection from the conference is around frailty and working with the community and work colleagues to begin the conversation about the ethics of futile treatment.

Christopher: Palliative care espouses for our community to increase their acceptance that death is a part of life, however we negate including the word ‘death’ in our field’s definition; instead emphasising improving an individual’s quality of life. Our definition needs to be altered to demonstrate us “walking the walk”.

Q2. What were the standout presentations and why?

Danielle: Liese Groot-Alberts’ session was the most inspiring, while the keynote talk by Dr Beth Russell (on palliative care triage) was the most exciting as issues surrounding the assessment of need occur so often.
Christopher: Dr Alex Jadad – helped us to step back and consider the underlying motives of our field during his keynote. Professor Mark Hutchinson – highlighted recent advances in chronic pain understanding and emphasised the dual benefit from medication & ‘talk therapy’.

Q3. What change/challenge will most occupy your work in palliative care over the next 12 months?

Danielle: Integrating PCOC (Palliative Care Outcomes Collaboration) tools within the inpatient setting and starting a conversation around recognising frailty and what is futile treatment will be my palliative care areas of focus for the next year.

Christopher: There has been limited research in ‘talk therapy’ within palliative care, so I’m hoping to commence a PhD that explores the potential beneficial role of Acceptance and Commitment Therapy for palliative care patients and their families/carers. I imagine this will take up some time!
You can track Croakey's coverage of the conference here.

Wrapping some “life-changing conversations” from palliative care conference. Plus #17APCC selfies

Read about the award winners here.
Wrapping some “life-changing conversations” from palliative care conference. Plus #17APCC selfies.
Wrapping some "life-changing conversations" from palliative care conference. Plus #17APCC selfies

You can track Croakey's coverage of the conference here.
You can track Croakey's coverage of the conference here.

Wrapping some “life-changing conversations” from palliative care conference. Plus #17APCC selfies.

#17APCC

“Conference News Service”
You can track Croakey’s coverage of the conference [here](#).

Wrapping some “life-changing conversations” from palliative care conference. Plus #17APCC selfies.

Warm thanks to all who helped to share the #17APCC news via Twitter and social media.

---

**Lillian Krikshel** @lliterate · Sep 7
Final day of #17apcc Conference MO @LaTrioli has done a stellar job. @amahaath and I had to sneak a photo!

---

**Liz Callaghan** @PCACEO · Sep 7
Thankx @DecisionAssist for yr support for @Pali_Care_Aus #17APCC ! Nearlly finished 😊

---

**WeEOLC** @WeEOLC · Sep 7
Really really useful tweets coming out of #17APCC for all those interested in ACP #eolc #hospice #palliativecare

---

**Palliverse** @palliverse · Sep 7
@PCACEO doesn’t have a Facebook page but loves a Tweet. We love her tweets too #17apcc
The #17APCC Twitter transcript can be read [here](#) and the analytics are [here](#) (and below), showing more than 30 million Twitter impressions and 950 participants.

### The #17APCC Influencers

<table>
<thead>
<tr>
<th>Top 10 by Mentions</th>
<th>Top 10 by Tweets</th>
<th>Top 10 by Impressions</th>
</tr>
</thead>
<tbody>
<tr>
<td>@pall_care_aus 872</td>
<td>@croakeyblog 672</td>
<td>@croakeyblog 12.9M</td>
</tr>
<tr>
<td>@palliverse 764</td>
<td>@palliverse 588</td>
<td>@wepublichealth 6.6M</td>
</tr>
<tr>
<td>@wepublichealth 703</td>
<td>@anthonyherbert9 570</td>
<td>@pall_care_aus 1.8M</td>
</tr>
<tr>
<td>@elissa_campbell 417</td>
<td>@wepublichealth 451</td>
<td>@pall_care_aus 1.5M</td>
</tr>
<tr>
<td>@alonjewad 364</td>
<td>@elissa_campbell 334</td>
<td>@anthonyherbert9 1.0M</td>
</tr>
<tr>
<td>@sonialf 268</td>
<td>@pall_care_aus 214</td>
<td>@elissa_campbell 972.9K</td>
</tr>
<tr>
<td>@mariencinerney 267</td>
<td>@pcaccoo 191</td>
<td>@helenfindlay 471.8K</td>
</tr>
<tr>
<td>@pcaccoo 251</td>
<td>@alleencoller15 141</td>
<td>@latrio8 415.0K</td>
</tr>
<tr>
<td>@alleencoller15 174</td>
<td>@kim_dever 138</td>
<td>@hospicedoctor 358.3K</td>
</tr>
<tr>
<td>@meera_agar 157</td>
<td>@sonialf 133</td>
<td>@groundswellau 350.2K</td>
</tr>
</tbody>
</table>

### The Numbers

- 30.434M Impressions
- 7,371 Tweets
- 950 Participants
- 14 Retweets/Hashtag
- 8 Retweets/Me


---

**Croakey Conference News Service**

- Reporting by Marie McInerney
- Editing by Melissa Sweet
- Layout and design by Mitchell Ward