

COMMUNIQUÉ

**From 6th Public Health Palliative Care International Conference
13-16 October 2019**



“Artists, doctors, community workers and everyday folk are telling us what the world whispers back to us from the wild valleys, rock platforms and dense bush of this immense World Heritage National park that surrounds us. That death is natural: a force of nature, a season in life, and not a failure of human striving. Like nature, death presents us with opportunities to connect, to contribute, to grow, to receive.”

Niki Read, 2019

What set this conference apart from any other was the richness in social and cultural diversity of the program, enhanced by its ‘artification’ thanks to the efforts of Dr Peta Murray and Niki Read. People came from Canada, Belgium, Scotland, Ireland, Austria, Holland, England, India, Taipei, New Zealand and across Australia. You can read the [full program here](#).

The conference began by honouring country and Australia’s first nations’ peoples with a smoking ceremony followed by a series of traditional and contemporary dances by the Wagana Aboriginal Dancers. Respect was paid to the Gundungurra and Darug peoples as the traditional custodians of the land upon which the conference was held.

Plenaries

In the opening plenary session we heard from renowned leaders, Prof. Allan Kellehear, Dr Libby Sallnow, Dr Kerrie Noonan and Dr Suresh Kumar as they shared critical reflections on the last 10 years of public health palliative care and what we might expect over the next decade.

Allan Kellehear, recognised as the pioneer of the public health approach to palliative care and development of compassionate cities and communities 13 years ago when he was the director of the Palliative Care Unit at La Trobe University said,

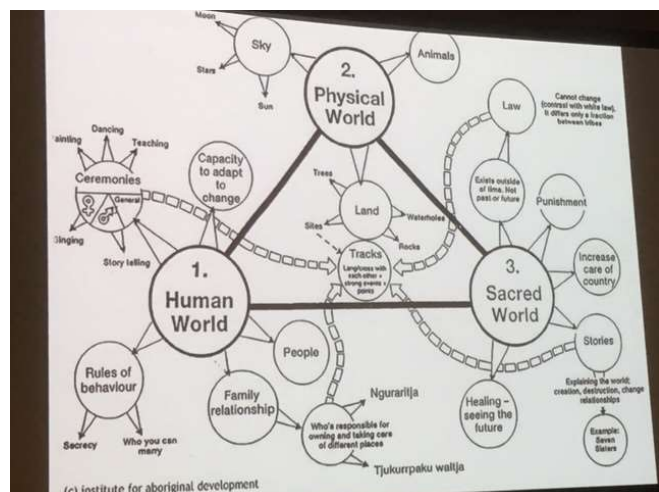
“Public health is not limited to mental health, obesity, sexual health; it also includes end of life care... there has been a mission drift in palliative care; too focussed on symptoms and science and has now moved away from care and compassion. It is not a doctor and nurse’s game... we are trapped in a clinical model of palliative care; we need to view community not as receivers but partners of care... 95% of care at end of life is with the caregiver and community, not healthcare professionals. If you really care, be in the 95%. That’s where the action is. How do we challenge ourselves, our organisations, our colleagues, policymakers and funders to support this work?”

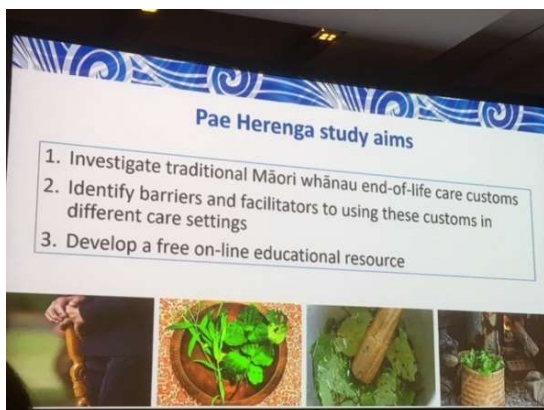


- Most time will be spent with families and friends not with healthcare professionals/services
- More health and social care services does not always result in better care
- Recognizing existing strengths of an individual and their community
- “Caring with” rather than “caring for”



Another plenary provided insights into the beliefs, rituals, customs and death practices of the Australian First Nations’ peoples as we heard from **Susan Moylan-Coombs**, well known as a national television broadcaster and her work in media production for Indigenous programs (ABC and NITV). She directed the Paul Keating Redfern Park Speech in 1992 that launched the United Nations Decade for Indigenous Peoples, and in 2008, was executive producer for the live broadcast from Parliament House in Canberra, of the National Apology to the Stolen Generations, by Prime Minister Kevin Rudd. One of her key messages was that, “if we are made to feel guilty then we have lost the power to change or shift the situation.”





This was followed by a presentation from **Dr Tess Moeke-Maxwell** who shared the power of digital story telling methods to support the reclamation and retention of Indigenous end-of-life care customs in Aotearoa. It must be noted that the NZ contingent was a standout in the way they honoured their first peoples by singing a welcome song before each presentation and a farewell song at the end in Maori language.

Professor Samar Aoun, Professor of Palliative Care La Trobe University, spoke about how one of the modern public health paradoxes is the relative neglect of the experience of bereavement, even though death is universal. The many negative consequences of bereavement, and the disruption of social relationships are primary determinants of both health and mortality. This puts the impact of bereavement squarely into a public health perspective. Adopting and strengthening a compassionate communities approach is necessary, not only for end of life care for dying people but also for providing bereavement support.

Based on reported experiences of the bereaved in a national Australian survey, recruited through funeral providers, the majority of support for the bereaved is provided in informal and other community settings by a range of people already involved in their everyday lives. The data from this survey provided empirical evidence for building a community's capacity to provide the type of social and practical support advocated by the Compassionate Communities approach, which relies on identifying and developing local caring networks around the dying person and their grieving family. This body of work, innovative in content, conceptual model and recruitment approach, has challenged the existing bereavement support structure and provision and has already influenced practice and policy at the national and international levels.



In the last plenary, delegates were treated to a very moving account of the March 15 terrorist attack in Christchurch. A young Maori man, **Tyla Harrison-Hunt**, who married into the Muslim community, recounted the day of the tragedy and the impact on community. Sadly, two of his wife's relatives were among the 50 killed in the attack.



Groundbreakers

There were a number of presentations from the Groundbreaker trial sites supported by GroundSwell showcasing their respective compassionate community projects in action and how they are engaging with community. Of note, The Blue Mountains Compassionate Community hosted a special event in tandem with the conference – *From the Brink* – a fringe festival about ageing, dying, and grieving in their community. **Niki Read** reported that other local activities included an information dinner for GPs to raise awareness about the project. Subsequently, a medical practice has employed a Health Connector, the first in Australia, whose role is to develop the Willing Villagers program and train volunteers to support those people either caring or living with life-limiting conditions in the community.

The Blue Mountains is also the first community in the world to be invited to participate in the Death Literacy Project to measure and understand the level of local death literacy; what assets and knowledge exists when it comes to caring for people at end of life. This will inform ways in which to move forward. The project is a partnership between The Nepean Blue Mountains Primary Health Network, The GroundSwell Project and Western Sydney University.

Equity in Palliative Approaches to Care

The matter of equity informed palliative care was canvassed, raising issues of privilege, structural and social constraints; how settings determine choice. What real options are available? Are the choices genuine, loaded or non-existent? Is it fair to ask disadvantaged citizens about end of life choices?

“We create disadvantage through systems... the more dependent we are on systems, the more we will be let down by them.” If we change the settings, we will change the outcomes. Equity oriented health care directs resources to those most in need.”

Healthy End of Life Program (HELP)

Andrea Grindrod from La Trobe University demonstrated how the Healthy End of Life Program (HELP) being implemented across communities in Victoria aligned with the National Public Health Palliative Care Framework.

HELP Ottawa

The HELP program was taken up by Ottawa earlier this year. The Mach-Gaensslen Foundation committed funding of more than \$640,000 over three years for the implementation of the project which aims to help local communities and neighbourhoods support people to live well, surrounded by family, friends, and social networks, as they approach the end of life. For more information <http://mach-gaensslen.ca/2019/02/10/healthy-end-of-life-project-help-ottawa/>

Let's Talk Advance Care Planning

Kia korero, let's talk advance care planning, is a campaign that encourages people to plan for their future health care in New Zealand. Using the power of digital storytelling, it features the personal stories of six people at different stages of life and wellness.

"My family will have my plan if they need to make hard decisions... Make sure your canoe is ready and your paddle is on board because you need an end to your story."

Keri Kaa (pictured below)



Social Innovation in Partnership

Barbara Binns, The Australian Centre for Social Innovation, and Vicki Barry, Palliative Care WA, co-presented on their partnership to implement the Weavers model of peer support for carers at the Albany Community Hospice launched in February this year.

Their presentation highlighted the value of the lived experience of carers and how their knowledge and skills builds social capital for the benefit of others on their caring journey as well as how to engage with community and leverage existing assets to improve outcomes for end of life care. Importantly, they shared the learnings; the key success factors and 'the trough of reality' where the challenges surfaced and how they have addressed them.



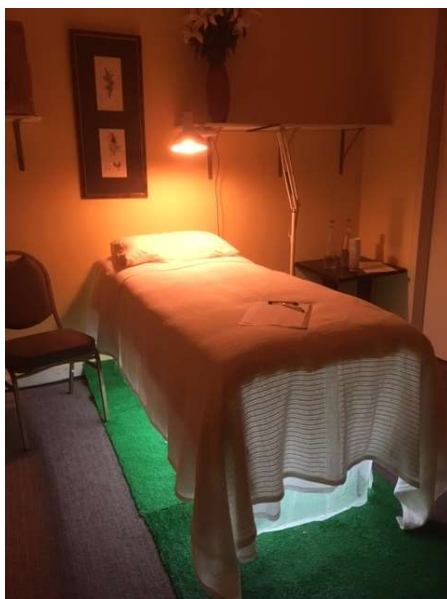
UK Hospice Models of Care

Among the presentations, St Giles Hospice Care, St Nicholas Hospice Care and Strathcarron Hospice each demonstrated how they engage with community, connect to community groups and mobilise volunteers.

The Vigil and The Wake

A two-part art installation designed and delivered by **Dr Peta Murray** caught the attention of many delegates who were invited to *The Vigil* followed by *The Wake* the next day. At *The Vigil*, one was invited into a sensory experience created in a clinical room to sit bedside as if being present to someone at the end of their life. During this time, it was a requirement to respond to a questionnaire – *The Litany of Loss*. It asked questions around recollections of grief and loss in different contexts, the things that matter most in life, any regrets, what your last meal would be and so on.

The following day at *The Wake*, 10 participants joined a nominated session to imbibe in a cup of tea and cake, seated around a long table covered in objects that reflected the things described in response to their respective questionnaires. Peta led the way to open a very personal and intimate sharing of grief and loss.



Other

Many workshops were on offer over the course of the 4 days ranging from tips on how to start a community coffin club to public health palliative care ethics. In addition, posters from many corners of the world were on show.

The 7th Public Health Palliative Care International Conference will be held in Belgium in 2021.