Compassionate Communities events: Presenter bios and abstracts

(in chronological order)

Monday 12 October

Tuesday 13 October

Wednesday 14 October

Thursday 15 October

Monday 12 October

Professor Allan Kellehear, PhD, FAcSS

Reorienting the health system

Allan is a British-Australian end of life care academic who has held chairs in Australia, Britain and Japan. He founded the 'new' public health movement in palliative care – variously known as 'health promoting palliative care', or 'public health approach' to palliative care, or the 'compassionate communities' movement. He is past president of Public Health Palliative Care International (PHPCI).

Allan is currently Emeritus Professor at the University of Bradford, Associate Director of the UK charity Compassionate Communities UK, and honorary professor at McMaster University Medical School and Durham University's Department of Theology and Religion.

Among his 25 books, he is best known for: *Compassionate Cities: public health and end of life care* (Routledge 2005), *A Social History of Dying* (Cambridge University Press 2007), and *The Inner Life of the Dying Person* (Columbia University Press 2014). His most recent book is *Visitors at the End of Life: Finding meaning and purpose in near-death phenomena* (Columbia University Press 2020).

Abstract

This talk discusses the WHO health promotion advice (Ottawa Charter) to 'Reorient health services'. What does this advice actually mean, and how might you go about it? Who might do what in the task of moving clinical services toward a wider brief in community partnership, engagement and health promotion? This discussion will occur in the context of a public health approach to end-of-life care.

Waratah-Wynyard and Circular Head Consultative Committee

Handy hints: Starting the conversation on palliative care in small communities.

A short presentation highlighting Compassionate Communities, the sharing of Mary's journey, and a positive way of talking with people about palliative care.

Dr Kerry Howells

Accessing gratitude in times of grief

Dr Kerry Howells is a thought-leader, author, award-winning educator and experienced researcher, who has spent over 25 years researching, teaching and practising gratitude. School leaders and teachers at all levels of education, as well as whole school communities have reported flourishing relationships and improved resilience through their gratitude practices. Some of these case studies can be read in her book, *Gratitude in Education: A Radical View,* which has been used globally to guide educational programs, pedagogy and many professional book clubs. Kerry has a particular interest in cross-cultural lenses of gratitude and their implications for communication and has studied this in Australian indigenous and African indigenous cultures.

Abstract

Research has shown that gratitude plays an important role in our physical, emotional and social wellbeing. However, even if we have experienced the benefits of gratitude or consider ourselves to be a grateful person, it is often very difficult to access gratitude when we are grieving. In fact, it can seem disrespectful or inappropriate to even think that gratitude and grief can be experienced at the same time. This seminar will give participants opportunities to consider this dilemma as well as a deeper meaning of gratitude where gratitude and grief can actually co-exist side by side. We will explore gratitude practices that are both relevant and accessible for those who are grieving and those who are caring for others in their times of grief.

Jackie Tarabay

The Forgotten Grievers

Jackie Tarabay is a Specialist Bereavement Counsellor, Clinical Supervisor, Trainer and Groups Coordinator at the Australian Centre for Grief and Bereavement (ACGB). Jackie provides individual counselling to children, adolescents and adults and has years of experience coordinating various support groups, including the facilitation of the Kids Grieve Too (KG2) program. Jackie also creates and delivers workshops, programs and customised training.

Jackie's therapeutic philosophy toward grief and loss is based on a client lead approach where every person is seen as unique, grieving in their own way and their own time. Jackie focuses on the core qualities of genuineness, empathy and unconditional positive regard in supporting the bereaved. Jackie advocates creating a safe, compassionate and non-judgmental environment to help integrate loss in a way that is both effective and personal.

Jackie has presented talks at the ACGB National Conference, Australasian Cemetery and Crematorium Association (ACCA), and Good Life Good Death Expo and was a member of the focus group for Palliative Care Australia (PCA). Jackie's educational background includes a Bachelor of Counselling, a Master Practitioner Certificate in Neuro Linguistic Programing (NLP), a Diploma of Shamanic Studies, Clinical Supervision and a Cert IV in Training and Assessment. Jackie also has studied in a host of other areas including psychotherapy, grief and loss, drama and personal development.

Abstract

Let's start with the unavoidable fact: Death is part of life that will come to us all. It is one of the *givens* of our existence that brings us together in our shared humanity. Frequently, we veil our displays of grief and mourning from our children believing we are protecting them. But rather than protect, we often leave our grieving children feeling alone to make sense of the loss of someone that they love.

Adverse childhood experiences, in particular when a loss is unaddressed, can often have lifelong negative consequences. Learning to recognise, understand and respond to the various needs of our grieving children is a crucial component in helping them adapt and integrate their losses.

This presentation caters for parents, counsellors, and allied health workers striving to broaden their knowledge on grief theories, models and best practice for grieving children. The content incorporates children and adolescent developmental stages and tasks, and the impact on a child's grief experience. A range of practical, appropriate and simple tools will also be provided that assist children in sharing and managing their grief and loss effectively.

Dr Kerrie Noonan

Death literacy for health professionals

Dr Kerrie Noonan is a clinical psychologist and social researcher.

Over the past 25 years Kerrie has been working to create a more death literate society, one where people and communities have the practical know-how needed to plan well and respond to dying death and grief.

Kerrie has a long-standing interest in community capacity building approaches to death, dying and bereavement, palliative care and how people can build their death literacy. She was the founding executive director of The GroundSwell Project and national initiatives Dying to Know Day, FilmLife Project and ComComHub. She is active in the Compassionate Communities movement internationally.

Kerrie is a member of the Caring at End of Life Research team at Western Sydney University, and is an Investigator on the Death Literacy Index project. This pioneering research has investigated the role of family, friends and neighbours play when someone is dying at home and coined the term 'death literacy' and on the team that developed the Death Literacy Index.

Kerrie was awarded her PhD in 2018 by Western Sydney University for her study titled Renegade Stories: A study of deathworkers using social approaches to dying, death and loss in Australia. Kerrie has a Masters degree in Clinical Psychology, a BA (Psychology), and a Grad. Dip. in Systemic Therapy (Family

Therapy) and a fellow of the Sydney School for Social Entrepreneurs. She is on the council of Public Health Palliative Care International.

Abstract

As a health professional working with people and families at end of life, how is your death literacy? How are you integrating this knowledge and experience in your practice?

Death literacy is the knowledge and skills that people need to make it possible to gain access to, understand, and make informed choices about end of life and death care options. People, and communities, with high levels of death literacy, have context-specific knowledge about the death system and the ability to put that knowledge into practice.

This 1-hour workshop provides an overview of four components of death literacy - skills, experience, action, and knowledge and how you can utilise each of these factors in your clinical practice. In particular, we will focus on developing your own death literacy and using a death literacy approach to advance care planning conversations. It will invite you to consider the question of how you provide enabling and strengths-based support to your clients, families, and the communities.

Back to top

On to Tuesday

Tuesday 13 October

Last Hurrah Funerals

Dying Queer

This is a recording of an online event organised by Last Hurrah Funerals that brings together queer experts from the death space, legal arena, queer support and health areas, plus advocates and activists who have been fighting the good fight for decades. The aim is to address some of the issues faced by the queer and gender diverse community (which is diverse, so necessarily the issues will also be broad), and how we as a culture and industry can address and improve things for queer people.

Waratah-Wynyard and Circular Head Consultative Committee

Memory Quilt Community Arts Project Live @ Waratah

This project invites members of the public up until 9 October 2020 to make a square to honour the memory of a loved one or a time in their life that brought them great joy. The Waratah group will assemble the squares into a quilt which will be displayed initially at the St James Church Art Gallery and History Centre in Waratah, then possibly tour Tasmania.

The focus of the Zoom session will be dependent on the stage the quilt is at.

Margarita White-McColl, Information Hub Project Officer – Southern Tasmania, COTA Tasmania

Information and tips to help you navigate the Australian Government's subsidised aged care system

In two short videos, Margarita White-McColl from COTA Tasmania provides information about the Australian Government's subsidised aged care system including tips on how to get started. The second video covers what happens at a face-to-face assessment and what you might do to prepare for it.

Margarita will be with us in the Zoom Room to share some FAQ and answer any questions at the end of each video.

Dr Heather Bridgman and Dr Suzanne Mallick, University of Tasmania

Understanding Bereavement Experiences of Migrants and Refugees in Tasmania

Dr Heather Bridgman is a Clinical and Health Psychologist and Lecturer in Rural Mental Health at the Centre for Rural Health. She has a strong community engagement focus and has previously worked in rural Tasmania as a Clinical Health Psychologist specialising in comorbid chronic disease and mental health. She was involved in the establishment of the Tasmanian Bereavement Care Network (www.bcntasmania.org.au) which is currently being evaluated, evaluated the Palliative Care After Hours Phone Support Service Tasmania and is currently working on a research project to Understanding Bereavement Experiences of Migrants and Refugees in Tasmania.

Dr Suzanne Mallick has research interests in social inequality, migration, refugees, international development and forced marriage and has worked in senior policy roles for the Tasmania Government. She did her Honours study on women's experiences of poverty in Tasmania, her Masters in International Development and her Doctorate study on patterns of social inequality in new technology use. Suzanne is currently a Lecturer with the Centre for Rural Health working on barriers for new graduate employability, healthy eating for migrants with cancer and impacts of conservation activities for refugees learning English at TasTAFE.

Abstract

Australia is one of the most culturally and linguistically diverse countries in the world. In 2016, 37% of people aged 65 and over were born overseas, with 67% of these people born in Europe and 16% in Asia. Tasmania hosts more than 61 200 people (12% of the total population) that are born overseas and accepts an average of 1200 new migrants every year with significant diversity. Providing quality death, dying and bereavement care for migrants and refugees requires understanding of their cultural background and cultural considerations. This presentation will explore the current literature on cultural considerations in the end of life care context for migrants and refugees settling in other countries and how compassionate communities can best support the bereavement care needs of this population. We will also present an update on our study investigating the bereavement experiences and needs of migrants and refugees in Tasmania.

Advance Care Planning Australia

Resources for Advance Care Planning

Join Catherine and Gloria, Advance Care Planning Australia Ambassadors, as they share with you some of the comprehensive resources available via Advance Care Planning Australia’s website.

Professor David W. Kissane, AC, MD, BS, MPM, FRANZCP, FAChPM, FACLP

Demoralisation

Chair of Palliative Care Research, The University of Notre Dame Australia and The Cunningham Centre at St Vincent’s Hospital in Sydney, Australia; Emeritus Professor of Psychiatry, Monash University and Weill

Medical College of Cornell University, in conjunction with Memorial Sloan-Kettering Cancer Center, New York, NY, USA.

David W. Kissane, MD is an academic psychiatrist, palliative care physician and researcher in the fields of psycho-oncology and palliative care. He currently holds the Chair of Palliative Care Research with the University of Notre Dame Australia and the Cunningham Centre at St Vincent's Hospital, Sydney (2019-present). He has previously been Head of the Department of Psychiatry for Monash University in Australia (2012-2019), Chairman of the Department of Psychiatry and Behavioral Sciences at Memorial Sloan-Kettering Cancer Center in New York (2003-2012) and, before that, the Foundation Chair of Palliative Medicine at the University of Melbourne (1996-2003).

Professor Kissane's academic interests include studies of existential distress, group, couples and family psychotherapy trials, communication skills training, and the ethics of end-of-life care. He is best known for his work on demoralization syndrome as a specifier for adjustment disorder and major depression in the medically ill, a form of low morale and poor coping that has preceded interventions to promote meaning-based coping. His model of family therapy delivered to 'at risk' families during palliative care has prevented forms of complicated grief and prolonged grief disorder in bereavement. He has developed the Demoralization Scale, and the Shame and Stigma Scale in Head & Neck Cancer. He is the author of over 350 publications, including books exemplified by Oxford Textbook of Communication in Oncology and Palliative Care, Management of Clinical Depression and Anxiety, Psychotherapy in Cancer Care, and Bereavement Care for Families.

Prof Kissane has been recognised by the International Psycho-Oncology Society with its Sutherland Award for lifetime achievement, by Cornell University with its Klerman Award for psychotherapy research, by King's College with its Dame Cecily Saunders lecture, and in 2018, he was made a Companion in the Order of Australia for his contribution to the development of the disciplines of Psycho-oncology and Palliative Care.

Abstract

Demoralization is a clinical state of low morale and poor coping, characterized by hopelessness, pointlessness, entrapment, and the potential desire to suicide. Systematic reviews have suggested a prevalence of 15% among palliative care patients. The risk of suicide points to its clinical importance. Screening with a psycho-existential symptom assessment tool improves its recognition. Clinicians need strategies to enhance a person's sense of the value of their life, promote hope, and increase the person's sense of control over whatever life remains. Demoralization can be managed with cognitively-oriented, supportive and meaning-centered therapies, while also treating co-morbid anxiety and depression, and optimizing physical symptom control.

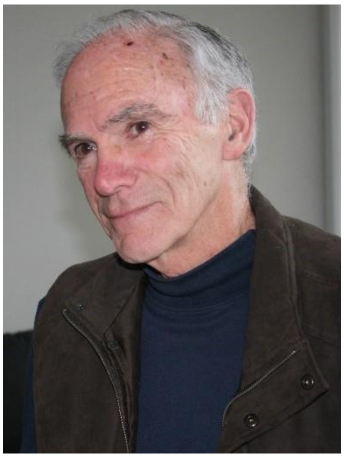
Back to top

On to Wednesday

Wednesday 14 October

Michael Barbato

The Mystery of Unconsciousness. A time of suffering or a time of peace?



Michael is a retired palliative care physician with a long-standing interest in the care of the dying and unusual events that commonly precede death. He has recently completed research into the patient's experience of unconsciousness and the use of medication at the end of life. He has spoken at national and international palliative care conferences and is the author of three books on death and dying. For the past eight years he and his wife Ann have co-ordinated a Midwifing Death Course for carers.

Abstract

In the majority of palliative care patients, death is heralded by a period of unconsciousness that lasts hours to days. Our understanding of the dying patient's experience of unconsciousness is limited and treatment administered during this time is based solely on the attending doctor's clinical experience and expertise. With good palliative care most unconscious patients are thought to be relatively comfortable and unaware of their situation. Anecdotal reports of unconscious patients waking up prior to death has, however, led many to question what is going on in the mind of those who are dying and whether they are aware of what is happening to them or around them. In this webinar we will

- Explain the difference between unconsciousness and unresponsiveness and why this distinction is important.
- Outline factors that contribute to unresponsiveness
- Attempt to answer commonly asked questions such as
    - Do unresponsive patients experience pain?
    - Can they hear?
    - Are they aware?
    - Do they know if we (family) are present or not?
- Talk about palliative sedation and ask whether it shortens the life of an unresponsive patient.
- Give examples of lightening up
- Reflect on what it is like for family and friends at the bedside, their perceptions and how they can best relate to their unconscious loved one.

Dr Faizal Ibrahim

Dignity and caring for cognitive impairment

DIGNITY IN CARE
in the heart, mind and actions

Dr Faizal Ibrahim FRCP Edin FRACP Au CCT MRCP UK MBBCh BAO LRCPSI Ireland

Consultant Geriatrician Aged and Extended Care Services, TQEH Acute and Urgent Care Program Central Adelaide Local Health Network and Port Lincoln Geriatric Clinic Services

Clinical Associate – SBRT and DSA Dementia Behaviour Management Advisory Services, HammondCare

Clinical Associate – Nightingale Services, Dementia Australia

Dr Faizal Ibrahim came to South Australia in 2010 after years of service for NHS at the University Hospitals Birmingham (UHB). He currently works as a Consultant in Geriatric Medicine with an interest in Dementia and Delirium at the Queen Elizabeth Hospital, Central Adelaide Local Health Network (CALHN), and provides clinical support for Port Lincoln Geriatric services. He also works as the Clinical Associate for the Severe Behaviour Response Team National Services and Clinical Associate for the SA Dementia Behaviour Management Advisory Services (DBMAS) HammondCare. He is also the Clinical Advisor to Nightingale Nurses Services Dementia Australia SA.

Until recently Dr Ibrahim was the lead clinician for National Dementia Care in Hospitals Pilot Program South Australia and the co–lead champion for AHSQHC Caring for Cognitive Impairment campaign for CALHN. His previous roles include working as the Clinical Director of Dementia Behaviour Management Advisory Services (DBMAS) Alzheimer's Australia SA and was the Chair of Alzheimer's Consumer Alliance SA. Dignity in Care is very important to Dr Ibrahim. He proudly champions the Dignity in Care campaign in Australia with Ms Maggie Beer as the Patron. The campaign aims to change the culture of Australian health services by reinforcing the importance of treating people with dignity and respect.

When he is not working, Dr Ibrahim is usually busy with his family, pets and his garden. Before he goes to work he spends quality time in the morning feeding his many hundreds of pet parrots and parakeets. He also enjoys travelling and hope to complete his long list of places to see before he dies.

His parting message is a quote from Hippocrates: “Cure sometimes, treat often and comfort always.” Dr Ibrahim's ways of working are as follows:

The 10 Principles of Dignity in Care:

1. Zero tolerance of all forms of abuse.
2. Support people with the same respect you would want for yourself or a member of your family.
3. Treat each person as an individual by offering personalised service.
4. Enable people to maintain the maximum possible level of independence, choice and control.

5. Listen and support people to express their needs and wants.
6. Respect people's privacy.
7. Ensure people feel able to complain without fear of retribution.
8. Engage with family members and carers as care partners.
9. Assist people to maintain confidence and a positive self-esteem.
10. Act to alleviate people's loneliness

Abstract

Dignity in Care in the Heart, Mind and Actions. Dignity and caring for cognitive impairment - Zero tolerance to all form of abuse - Improving the journey of consumers and their care givers in the acute and community care setting.

The presentation will explain the evolution, successes and lessons learnt in championing Dignity in Care in Australia, with the aims of improving the quality of life of people with cognitive impairment and end of life in the acute and community care setting. To achieve this all health care professionals must have an up to date knowledge and need to work collaboratively with consumers, carers, service providers, policy makers and advocacy bodies to promote the use of the 10 principles of Dignity in Care as the basic standard of care.

This presentation will also discuss:

- How to update knowledge including national guideline and principles of care in relation to management of people with dementia, delirium and BPSD.
- Understand the impact of the environment and environmental design on the management of people with Cognitive Impairment
- The role of community care team in managing the behavioural and psychological symptoms of dementia in people at the end of their lives.

Dignity is concerned with how people feel, think and behave in relation to the value of themselves and others. To treat someone with dignity is to treat them in a way that is respectful of them and as valued individuals. In a care situation, dignity may be promoted or lessened by physical environment, organisation cultures, attitudes and behaviour of the staff or others. When dignity is present, people feel in control, valued, confident, comfortable and able to make decisions for themselves.

Paper garments for the grave: Six Years On

A film by Natasha Foster, followed by live reflections with several of the artists.

Ten Tasmanian paper artists designed and made paper garments following six months of conversations, exploring community, death, dying loss and grief. Their creations toured Tasmania, along with works by Dr Pia Interlandi, fashion designer and funeral celebrant, who has a particular interest in textile manipulation and garment transformation. The fascinating exhibition invited people to share in the journey and join them in conversation.

Where are the artists now? Following a screening of the film, several artists reflect on their journey since participating in the Paper Garments for the Grave process.

This filmed was funded by the Better Access to Palliative Care funding in 2013.

Pat Baines, Program Officer Tasmania, Dementia-Friendly Communities, Dementia Australia

Living with dementia: The right to be included

Join Pat for a chat plus an opportunity to hear from people living with dementia on their thoughts and experiences of being included from the outset and how Dementia Friendly Communities can facilitate those with lived experience of dementia to be included.

The Groundswell Project

Gather My Crew: Interview and ‘how to’ guide

Asking for and offering help in times of crisis. How can we make it easier? Dr Susan Palmer, CEO and founder of online tool Gather My Crew joins Groundswell to talk about what led her to starting Gather My Crew and the impact it is having around the country followed by a ‘how to do it’.

Professor Allan Kellehear, PhD, FAcSS

Reorienting the health system

See above

Back to top

On to Thursday

Thursday 15 October

Zenith Virago

DIY, after-death care options and considerations

Zenith is EO and founding member of the Natural Death Care Centre charity for over 25 years.

A maverick and respected pioneer, teaching both nationally and Internationally, her work is best described as assisting people to die well, and for families and friends to have a healthier bereavement, especially involving sudden death or trauma.

With a legal and welfare background Zenith is a community resource, assisting people to know and reclaim their legal rights, and co-create their own social rites of passage. She is committed to cultural change, informing, educating and empowering individuals and communities.

Co-author of *The Intimacy of Death and Dying*, subject of *Zen and the Art of Dying*, and patron of the Good Funeral Guide, UK.

Abstract

Empowering ourselves and others by knowing our legal, physical, personal and community options, considering them for each particular person, and then making informed decisions can make our participation in the whole experience more beneficial and much more satisfying. Looking at DIY after-death care, ceremony and disposal and all that it includes and needs.

Glamorgan Spring Bay Consultative Committee

Live @ The Living Room from Swansea

You are invited to join us at The Living Room for a short presentation including a video of a community's member experience of The Living Room, followed by an opportunity for conversation on all things death and dying.

Emily Adams, Social Ventures Australia

The Funeral Saver Plan (soon to be launched)

Emily Adams is Principal in the consulting team, specialising in aged care, end-of-life, and supporting start-up ventures.

Abstract

The premise of the Saver Plan is this – that it provides a viable and attractive alternative to using funeral insurance or funeral benefit products. The Funeral Saver Plan achieves this by encouraging the consumer to save what they might otherwise have made in monthly insurance payments. In this way, they can cease making payments after the savings period rather than being stuck with a lifetime of payments. The incentive to save (and peace of mind) comes from a ‘top-up’ payment. All Saver Plan accounts will pay out the customer’s entire savings plus interest in the event of death, but - crucially - if a ‘regular saver’ dies before reaching $4,000 in savings, their family is eligible for a payment on top of what has been saved. In these cases, it will mean there is at least $4,000 to go towards funeral costs. The Funeral Saver Plan will be distributed by one national Friendly Society at the outset, with the possibility of other distributors over time.

From little things big things grow

Dianne Baldock, Circular Head Aboriginal Corporation

Di Baldock is a Tasmanian Aboriginal woman who resides on the north west coast of Tasmania.

Di is passionate about the health and wellbeing of the Aboriginal community of Circular Head. Di has extensive knowledge of the cultural and social impacts that affect Aboriginal people within the community and throughout the country. Di has worked in many programs at the Circular Head Aboriginal Corporation (CHAC), commencing in 2002 where she was employed as a family support worker. Her roles within the corporation over many years have been very broad – youth justice, cultural educator, counsellor – and she continued on to be the Chief Executive Officer. In 2019 Di resigned her position at CHAC and became the Chairperson for the organisation.

Di represents her community as a Tasmanian representative on several government committees and roundtables addressing Aboriginal and Torres Strait Islander issues. They include the Australian Bureau of Statistics, Tasmanian Aboriginal Health Reference Group (TAHRG), Tasmanian Regional Aboriginal Communities Alliance (TRACA), and National Aboriginal and Torres Strait Islander Legal Service (NATSILS).

Di is an active director on the Tasmanian Aboriginal Legal Service, which is a new legal entity for Tasmania. She recently submitted the seven names proposed for dual naming for the north west/west coast areas of cultural significance. Di has recently submitted a large submission for a language program to be developed and initiated for the Circular Head region.

Abstract

Dianne will give an insight into how the programs at CHAC work and what their primary objectives are.

What does it feel like to be on country, see country and speak country as an Aboriginal person?

Waratah-Wynyard and Circular Head and Glamorgan Spring Bay

Trial sites project slideshow and discussion

A reflective slideshow of the project from inception followed by an opportunity for discussion, learnings and questions with the two trial sites. All welcome.

Back to top

This program of events celebrates the work of the Waratah-Wynyard, Circular Head and Glamorgan Spring Bay communities under the Greater Choice for At Home Palliative Care measure – an Australian Government initiative supported locally by Primary Health Tasmania.

Some of these webinars are made possible through funding provided by the Tasmanian Department of Health under the Better Access to Palliative Care program.