

Paediatric Palliative Care Summit 2024

Foundations, Focus and Horizons

Thursday 12 September – Sunday 15 September 2024

Thursday Program

Paediatric Palliative Care Summit	
Date: Thursday 12 September 2024	
Location: Brisbane Convention and Exhibition Centre Sky Room	
8:00am	Registrations open
8:30am	Welcome to Country
8:40am	Plenary by Joan Marston
9:20am	Panel Discussion featuring Dr Helen Irving, Tim Rogers and Michelle Noyes
10:10am	Introduction to Kam Biman Project
10:30am	Morning Tea
11:00am	Interactive Workshop Rotation #1 A series of interactive workshops focusing on themes of the Green Book. <ul style="list-style-type: none">- Pain and Symptom Management: Arbour Room 2- Culturally and Linguistically Diverse Perspectives: Sky Room- Grief and Bereavement: S1 Room- Perinatal Palliative Care: Arbour Room 1
12:30pm	Celebrating 25 years of the Green Book
12:45pm	Lunch sponsored by Palliative Care Australia
1:30pm	Community Choir by Angela Delaney
1:45pm	Interactive Workshop Rotation #2 Rotating to a second interactive workshop focusing on themes of the Green Book. <ul style="list-style-type: none">- Pain and Symptom Management: Arbour Room 2- Aboriginal and Torres Strait Islander Perspectives: Sky Room- Grief and Bereavement: S1 Room- Perinatal Palliative Care: Arbour Room 1
3:15pm	Afternoon Tea
3:45pm	Summary of Workshops from Rachel Callander
4:15pm	Future Thinking <ul style="list-style-type: none">- Policy and Funding by Louise O'Neill- To the Moon and Back by Dr Anthony Herbert- Sustainable Leadership by Kristine Kelly
5:00pm	Wrap up by Rachel Callander
5:30pm	Canapes and networking on the Sky Room Terrace

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Thursday Workshops

Pain and Symptom Management

Presented by Dr Ross Drake and Dr Freya Nicholas, this workshop will be a smorgasbord of symptom management in paediatric palliative care. Topics include feeding, constipation, dyspnoea and pain management, as well as an interactive question and answer session for all those questions that keep you up at night. This workshop is suitable for clinicians, both prescribers and non-prescribers, who are interested to learn more.

Culture and Diversity: Culturally and Linguistically Diverse Perspectives

This workshop is facilitated by Yody Espitia Buritica (Clinical Nurse Facilitator at Hummingbird House) and Taki Langlasse (Family and Community Support Practitioner at Hummingbird House). The facilitators will be speaking from their hearts on how we can all work together to walk alongside CALD families with humility and compassion so that we all can continue to improve the outcomes for all children and families facing life-limiting conditions, death, dying, and grief, regardless of their cultural, religious, educational or socio-economic backgrounds.

This workshop is not about knowing the number of the interpreter and translator services, but rather an opportunity to have honest conversations about our own personal and cultural values and how we meet with families when those values are challenged.

Culture and Diversity: Aboriginal and Torres Strait Islander Perspectives

This Yarning Circle will be hosted by Brooke Kaden and Yasmin Johnson, Aboriginal Health Worker/s and First Nations Project Officers from the Paediatric Palliative Care Service, Children's Health Queensland (QCH), based in Brisbane. Brooke will present on the topic of Culture and Diversity sharing the First Nation's perspectives on what this means for them.

Karen Joy, Clinical Nurse, PPCS (Brisbane) will share some case studies for further discussion and exploration of themes that have emerged from care experiences.

The Yarning circle, support by Yasmin Johnson will explore themes that emerge and together we will discover and understand how the past can affect the present, the diversity that exists within communities and barriers and challenges that exist in delivering culturally appropriate and safe care and how we can bring about improvements.

This workshop is suitable for clinicians, non-clinicians and advocates for the provision of quality care for First Nation's paediatric patients and families.



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Thursday Workshops Continued

Grief and Bereavement

Alyson Gundry, Allied Health Clinical Lead – Paediatric Palliative Care Service and Allied Health Clinical Educator for [Quality of Care Collaborative Australia](#) {QuoCCA} and Dr Leigh Donovan, Peer Mentor Program Manager with [Ladybird Care Foundation](#) and Consultant in Thanatology {[Collaboraide](#)} will be co-facilitating workshops alongside parents who have become *changemakers* as a result of their child's diagnosis with a life limiting condition and/or the death of their child.

Australia is privileged to be able to extend extraordinary care to young people with life limiting conditions and their families through paediatric palliative care and hospice services. However, parents and carers continue to remind us that more can be done.

Six bereaved parents will join us across the Summit's two workshops, as we collectively have conversations about their experiences, delve into what motivated them to become activated, and how they became changemakers to improve future care for parents/ carers. These parents will share what they observed within health and social care professionals that supported their drive to become changemakers.

We envisage this to be an interactive learning circle between parents, health and social care professionals and hold firm that the greatest learning emerges when all can come together for honest and courageous conversations.

Perinatal Palliative Care

Join Deb Gilmour (Neonatologist), Kelly Oldham (Nurse Practitioner, Hummingbird House), Shannon Shorthouse (Midwife, Mater Mothers Hospital) and Holly Foggin (Nurse Educator, Hummingbird House) in a multi-professional workshop focussed on perinatal palliative care. This workshop will utilise small group work and interactive sessions focussed on a clinical case to explore parallel planning, individualised care planning, and ethical issues which arise during pregnancy and newborn care where there is a suspected life-limiting or life-threatening condition. This workshop is suitable for clinicians and advocates from any background, and encompassing the spectrum from those with no experience but a curiosity to know more, through to those with practical or lived experience in perinatal palliative care.



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Speaker Profiles

Rachel Callander

Rachel 's work combines her perspective as an artist, her experience being mum to her late daughter Evie who was born with a rare condition, and hundreds of hours in consultation with both healthcare professionals, educators, and caregivers the world over.

Rachel imparts actionable strategies for effective communication and transformation in the healthcare, education, and disability sectors, for the benefit of all. She believes in human centred-care and that the system should be responsible for the wellbeing of everyone involved.

Rachel is a speaker, trainer, award winning author and artist, and patient advocate.

Joan Marston

Joan has a background in nursing and social science , and has worked in palliative care since 1989 at local, national and international level, specialising in paediatric palliative care. The AIDS pandemic led to her setting up Sunflower Children's Hospice in Bloemfontein in 1998; then leading the development of the South African national children's palliative care programme. These led to her co-establishing and leading the International Children's Palliative Care Network (ICPCN) for the first 12 years.

She remains an ICPCN Global Ambassador. Co-founding PallCHASE- Palliative Care in Humanitarian Aid Situations and Crises in 2016 she is on the executive committee responsible for advocacy and children; and with special interest in Ukraine. As the Vice-President of the Elisabeth Kubler-Ross Foundation Global she co-leads an EKRF Fellowship in South Asia.

Joan remains active in paediatric palliative care education across a number of countries.

Helen Irving

Helen is an Associate Professor, University of Queensland, Pre-Eminent Specialist and the Clinical Lead – Centre Children's Health Ethics and Law at Children's Health Queensland Hospital and Health Services, and Co- Chair of the Queensland Paediatric palliative Care Haematology Oncology sub-Network (QPPHON).

She is recognised nationally and internationally for her contribution to, and development across many aspects of clinical care and research in the areas of oncology, paediatric palliative and supportive care, telemedicine, and medical ethics (Bioethics). Helen was instrumental in the development of the state-wide paediatric palliative care service, initially with a 24 hour on-call telephone support service for patients and families and for clinicians providing care across the Queensland and northern NSW. This vision and recognition of collaborative partnering, and enduring advocacy, has led to the formalised and holistic state-wide paediatric palliative care service.



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Speaker Profiles

Michelle Noyes

Michelle has been a registered nurse for 38 years and for the majority of her nursing career has cared for children with oncology and palliative care conditions. Her knowledge and learnings have come from working in tertiary paediatric and regional hospitals and non-government organisations.

For the past ten years Michelle has worked in nurse coordinator roles at Gold Coast University Hospital and in 2021 completed a Master of Nursing, Nurse Practitioner specialising in paediatric oncology and paediatric palliative care.

Michelle walks alongside families, collaborates with specialist palliative care services, Gold Coast Hospital teams and community agencies to provide child and family centred palliative care, delivered where possible in the child and family's preferred location.

Tim Rogers

Tim Rogers is National Advocacy Manager at Redkite, a national child and adolescent cancer support organisation.

Tim's been a social worker and human services manager since 1985. He's worked in child and adolescent oncology since 1994, including 8 years as Snr Oncology Social Worker and Assistant Director Social Work and at Royal Children's Hospital Brisbane, and 19 years in senior management at Redkite.

Tim has a strong record of developing quality, psychosocial support services in response to unmet needs and led the development of Redkite's community-based support programmes. He's strongly committed to collaborative models of work, both with people with lived experience and between organisations and sectors and to strengths based and narrative practice.

When not working he leads a volunteer charity supporting older people and people with disabilities on the Sunshine Coast and is a husband, father, grandfather (three grandsons), cyclist (far too many bikes), and woodworker.

Aurora Hodges

Aurora was recently promoted to the Principal Learning and Development Manager for the Centre for Palliative Care Research and Education (CPCRE) after working as PEPA Queensland Manager for 12 years.

Aurora is passionate about palliative care being provided for all people regardless of geography or circumstance and this drives her to ensure palliative care education is available to all disciplines throughout the state.

Kam Biman is a project that Aurora and Eliza Munro started together in 2019 and was launched in 2022 at Metro North HHS. Today, we will launch the paediatric version.



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Speaker Profiles

Angela Delaney

Angela Delaney is a Registered Music Therapist in both public health and private practice, dedicated to leveraging music for change. She is currently the clinical lead for music therapy - Qld Paediatric Palliative Care Service and previously the QuoCCa National Allied Health Educator. Angela combines her roles as a music therapist, educator, and researcher, contributing to various research projects. An advocate for music therapy in clinical and community settings, Angela is passionate about advancing awareness and understanding of music therapy's role in health.

Kristine Kelly

Kris Kelly holds a dual role at Children's Health Queensland Hospital & Health Service as the Allied Health Clinical Lead in the statewide "E" Paediatric Palliative Care Service and as the Allied Health Workforce Development & Service Improvement Lead for the HHS. Kris plays a pivotal role in palliative care as Co chair of the Queensland Palliative Care Clinical Network and in collaborating with the Centre for Leadership Excellence within the Workforce Strategy Branch, Clinical Planning and Service Strategy Division of Queensland health on the Palliative Care Capability Uplift Program for Allied Health & Nursing. Her experience spans the development of best practice models of care, robust consumer and community engagement strategies, fostering interprofessional teamwork, and delivering evidence-informed contemporary clinical education across both academic and healthcare landscapes.

Anthony Herbert

A/Prof Anthony Herbert has been Director of the Paediatric Palliative Care Service at the Queensland Children's Hospital, Brisbane for the past 10 years. He has interests in both research and education. He is the project lead for the QuoCCA project (Quality of Care Collaborative Australia) and has research interests supported by the Queensland University of Technology including communication, advance care planning and Symptom management. He is the President of Palliative Care Qld.

Louise O'Neill

Louise O'Neill is the CEO at Palliative Care Queensland, a leading charity and peak body in Australia. She started her career as a Registered Nurse and has over 18 years of experience in the Australian Public Service, holding positions across health, disability and communications portfolios. She moved to the not-for-profit sector in 2020 as CEO of the Aged Care Workforce Industry Council.

Louise has a Communications degree and an Executive Masters in Public Administration.

Louise is dedicated to supporting all palliative care professionals and volunteers to ensure that all Queenslanders have access to quality care at the end of life.



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Friday Program Option 1: Communication Workshop by Rachel Callander

BELOW THE SURFACE: Strategies to forge connection through awareness of language, communication, behaviour and values.

This thought-provoking workshop explores the relationships between our surface words and actions and the deeper drivers of emotion, values and beliefs.

As we understand what drives the behaviours of others, we develop a greater level of compassion for them. Below the Surface advocates for humanity, not hierarchy.

It encourages respect, grace, and an intent towards collaboration, instead of confrontation. This is the space of psychological safety and where shared decisions can be made with trust and clarity. Workshop attendees are left with a sense of hope, validation, and empowerment as they head out into their work, and their lives.

They are better equipped to more effectively communicate, share difficult information, and have more confidence in dealing with confronting emotions and behaviours.

Friday Option 1: Paediatric Palliative Care Summit Communication Workshop

Date: Friday 13 September 2024

Location: Brisbane Convention and Exhibition Centre Sky Room

8:00am	Registrations Open in Sky Room
8:30am	Communication Workshop by Rachel Callander
10:30am	Morning Tea in Sky Room Foyer
11:00am	Communication Workshop Continues
12:30pm	Communication Workshop Concludes

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Friday Program Option 2: EPEC Train the Trainer

The Education in Palliative & End-of-Life Care (EPEC) Pediatrics Train the Train course will teach health professionals to facilitate the international EPEC-Pediatric course within the Australian context with the opportunity to utilise these skills in the weekend EPEC end user course.

Some attendees will have completed the EPEC end user course previously and received a certificate for this, however, attendees who have not completed EPEC previously will need to access the 24 online learning modules prior to the Train the Trainer.

If you have not already received the invitation to the Online Modules, please contact us on PPCSEvents@health.qld.gov.au

Friday Option 2: Education in Palliative & End-of-Life Care (EPEC) Pediatrics Train the Trainer

Date: Friday 13 September 2024

Location: Brisbane Convention and Exhibition Centre Arbour

8:00am	Registrations Open in Arbour
8:15am	Introductions
9:00am	Teaching with EPEC-Pediatrics in the face-to-face Setting
10:00am	Morning Tea
10:30am	Introduction to Palliative Care
12:00pm	Lunch
1:00pm	Communication and Planning
3:00pm	Afternoon Tea
3:30pm	Teaching Pain & Symptom Management
4:30pm	Debrief and Preparation
5:30pm	EPEC-Pediatrics Train the Trainer concludes

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Saturday and Sunday Program

Education in Palliative & End-of-Life Care (EPEC) Pediatrics Day 1

Date: Saturday 14 September 2024

Location: Queensland Children's Hospital, Level 7 Auditorium

7:45am	Registrations
8:00am	Introductions
9:00am	Introduction to Palliative Care
10:00am	Morning Tea
10:30am	Goals of Care & Advance Care Planning
11:15am	Communication and Planning
12:45pm	Lunch
1:45pm	Management of Respiratory Symptoms
2:30pm	Debrief
2:40pm	Multimodal Analgesia
3:25pm	Afternoon Tea
3:45pm	Self-care for Professionals
4:30pm	Summary
5:00pm	EPEC-Pediatrics Day 1 Concludes

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Sunday Program

Education in Palliative & End-of-Life Care (EPEC) Pediatrics Day 2	
Date: Sunday 15 September 2024	
Location: Queensland Children's Hospital, Level 7 Auditorium	
8:00am	Opening
8:00am	Welcome and Reflections of Day 1
8:15am	Spirituality, Grief & Bereavement
9:00am	Ethical & Legal Issues
9:45am	Morning Tea
10:15am	Neuropathic Pain Management & Adjuvant Analgesia
11:15am	Opioid selection & Rotation incl. Methadone
12:00pm	Lunch
1:00pm	Management of Emotional & Behavioural Symptoms
1:45pm	Preparation for Imminent Death
2:30pm	Afternoon Tea
3:00pm	Management of Gastrointestinal Symptoms
3:45pm	Reflections and Evaluation
4:30pm	EPEC-Pediatrics Day 2 Concludes