



I'll now be tweeting from the first of three concurrent sessions today, sitting in on the first Paediatric [#PalliativeCare](#) session, chaired by Lisa Cuddeford from the WA Paediatric Palliative Care Service [#21OPCC](#)

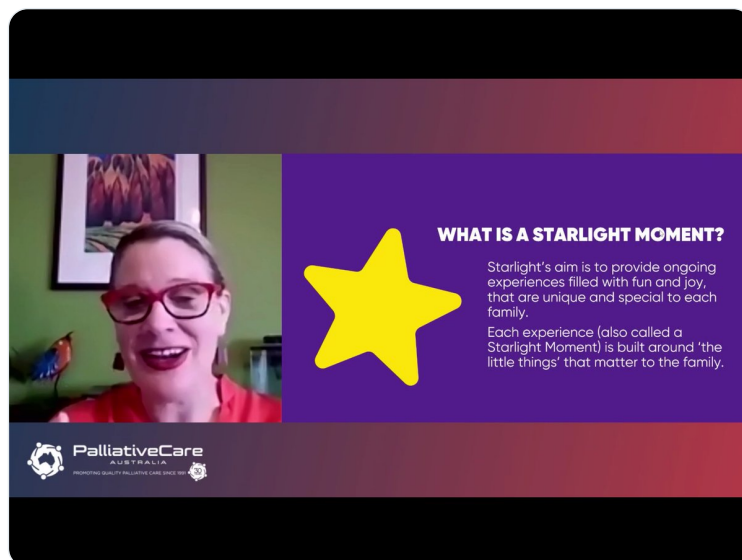
First presenter is Adjunct. Assoc. Prof. Claire Treadgold [@Starlight_star](#) talking about 'Rosie's story'. Rosie is a palliative child with chronic kidney disease who was supported by the Starlight Moments program [#21OPCC](#)

[@Starlight_star](#) Sadly, Rosie died a month ago 😞 Claire says the family are happy to share Rosie's story [#21OPCC](#)

[@Starlight_star](#) Rosie was diagnosed with Bardet Biedl Syndrome, and went on to get chronic kidney disease [#21OPCC](#). Her mum says "she was full of life" and a "great lover of unicorns"

[@Starlight_star](#) And particularly a love of lego - more on this later [#21OPCC](#)

[@Starlight_star](#) Starlight Moments developed after research to explore the needs of families with children who have [#palliativecare](#) needs. Small, positive moments to distract from serious life events [#21OPCC](#)



[@Starlight_star](#) Starlight Moments are small, ongoing moments, tailored to the family [#21OPCC](#)

[@Starlight_star](#) Rosie loved lego - Starlight Moments created a lego treasure hunt for Rosie and family to take part in during [#COVID19](#) [#21OPCC](#)

[@Starlight_star](#) Lego treasure hunt designed with the whole family involved - it's not just about the patient, but whole family [#21OPCC](#)

[@Starlight_star](#) Self-care for parents important - Starlight Moments gives them an opportunity to do activities they may not otherwise [#21OPCC](#)

[@Starlight_star](#) Siblings can often fly under radar - Starlight Moments create special moments for siblings also, and recognise family milestones [#21OPCC](#)

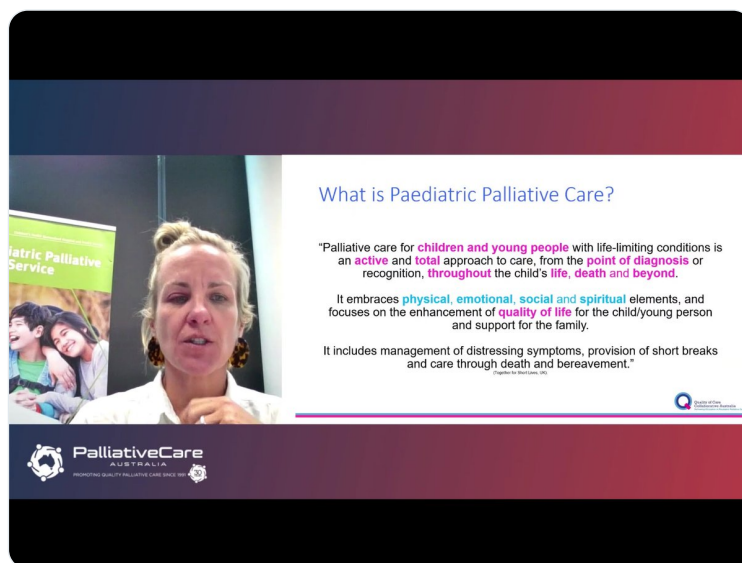
[@Starlight_star](#) The impact of [#COVID19](#) - added an extra layer of isolation for the family, who already were quite isolated [#21OPCC](#). Starlight Moments put together happiness hampers to help get through [#COVID19](#)

[@Starlight_star](#) Starlight Moments program extended to a year post-bereavement to help support the family while grieving [#21OPCC](#)

[@Starlight_star](#) "Ultimately the program is all about making memories" - Claire. [#21OPCC](#)

[@Starlight_star](#) Second presentation in this session is by Angela Delaney & Penelope Slater [@childhealthqld](#) - they are talking about their research exploring the experiences of families who have received paediatric [#palliativecare](#) in Qld [#21OPCC](#)

[@childhealthqld](#) What is Paediatric [#palliativecare](#)? Definition here [#21OPCC](#)



[@childhealthqld](#) One of the challenges delivering paediatric [#palliativecare](#) in Australia is the vast distance to services [#21OPCC](#)

[@childhealthqld](#) Research part of QuoCCA project (Quality Of Care Collaborative Australia (QuoCCA) Home_ [#21OPCC](#)
quocca.com.au

[@childhealthqld](#) They interviewed 11 parents of children with life limiting conditions who received paediatric [#palliativecare](#) [#21OPCC](#)

[@childhealthqld](#) Key findings from interviews incl: integration of child and family within health system inseparable, and informed decision making vital [#21OPCC](#)

[@childhealthqld](#) Two videos were developed based on the findings of the research [#21OPCC](#) - unable to share during presentation due to tech difficulties. I'll share links at the end of the session

[@childhealthqld](#) Third and final presenter in this session, [@StuartEkberg](#) [@QUT](#) is sharing key findings from a rapid review that helped inform a National Paediatric Palliative Care Action Plan for Australia. [#21OPCC](#) [@Pall_Care_Aus](#)

[@childhealthqld](#) [@StuartEkberg](#) [@QUT](#) [@Pall_Care_Aus](#) The plan follows from [@Pall_Care_Aus](#) being awarded funding for a Paediatric [#palliativecare](#) project [#21OPCC](#)

[@childhealthqld](#) [@StuartEkberg](#) [@QUT](#) [@Pall_Care_Aus](#) Paediatric [#palliative](#) care aims to improve the quality of life for families and children with life limiting conditions. Complex care. [#21OPCC](#)

[@StuartEkberg](#) [@QUT](#) [@Pall_Care_Aus](#) Specialist [#palliativecare](#) services needed due to complex needs of children with life limiting conditions. [#21OPCC](#)

[@StuartEkberg](#) [@QUT](#) [@Pall_Care_Aus](#) 369 sources identified in the review (That is a lot of full-texts to read!) [#21OPCC](#)

[@StuartEkberg](#) [@QUT](#) [@Pall_Care_Aus](#) Key findings include: quality of specialist paediatric [#palliativecare](#) needs to be improved. Continuity of care one way care can be improved, and multidisciplinary approach another [#21OPCC](#)

[@StuartEkberg](#) [@QUT](#) [@Pall_Care_Aus](#) Improving advance care planning another key finding, can be done by early integration of specialist paediatric [#palliativecare](#) and patient and family focused interventions [#21OPCC](#)

[@StuartEkberg](#) [@QUT](#) [@Pall_Care_Aus](#) Limitations highlighted in optimal education approaches published in the literature - a focus on clinicians; and little rigorous evidence available [#21OPCC](#)

[@StuartEkberg](#) [@QUT](#) [@Pall_Care_Aus](#) QuoCCA a key resource in Australia, with their aim to deliver education in paediatric [#palliativecare](#) [#21OPCC](#) quocca.com.au

[@StuartEkberg](#) [@QUT](#) [@Pall_Care_Aus](#) Inclusion of wide range of stakeholders important in paediatric [#palliativecare](#), incl families (and siblings) [#21OPCC](#)

[@StuartEkberg](#) [@QUT](#) [@Pall_Care_Aus](#) Major findings from the literature review help inform policy with priority in improving paediatric [#palliativecare](#). [#21OPCC](#)

[@StuartEkberg](#) [@QUT](#) [@Pall_Care_Aus](#) Gaps in knowledge remain, including research about paediatric [#palliativecare](#) in Aboriginal and Torres Strait Islanders [#21OPCC](#)

[@StuartEkberg](#) [@QUT](#) [@Pall_Care_Aus](#) [#21OPCC](#) More info about the Paediatric Palliative Care Project can be viewed online [@Pall_Care_Aus](#)



[@StuartEkberg](#) [@QUT](#) [@Pall_Care_Aus](#) Copy of rapid review can be found here [#21OPCC](#)



[@StuartEkberg](#) [@QUT](#) [@Pall_Care_Aus](#) Q and A [#21OPCC](#) Paediatric [#palliativecare](#) session

Q for [@StuartEkberg](#)- are there plans in place in the Northern Territory?

A - understanding is that it remains the case that families in the NT can access care in SA.

Q for Angela and Penelope - how did the families feel about the interviewing process? (sorry, not verbatim)

A - the families found the interview process therapeutic, valued telling their story [#21OPCC](#) [#qualitativerearch](#)

Q for Claire - is there a dedicated person for each family in Starlight Moments

A - one person starts off process of getting to know family really well, but is a collaborative process. Relationship with initial contact very important [#21OPCC](#)

The two videos developed from the findings of the QuoCCA research [#21OPCC](#)

Both beautiful - recommend viewing.

'Meeting Paediatric Palliative Care'

Meeting Paediatric Palliative Care



Meeting Paediatric Palliative Care

This is "Meeting Paediatric Palliative Care" by #Quocca #Paedpc on Vimeo, the home for high quality videos and the people who love them.

<https://vimeo.com/499870982>

'Life with a child who has a life limiting condition' [#21OPCC](#)

Life with a child who has a life limiting condition



Life with a child who has a life limiting condition

This is "Life with a child who has a life limiting condition" by #Quocca #Paedpc on Vimeo, the home for high quality videos and the people who love them.

<https://vimeo.com/499869110>

plz unroll

[@threadreaderapp](#)

