Parent Knowledge Network Session summary: Palliative care

This session of the Parent Knowledge Network featured **Amy, whose son Louis was diagnosed with Krabbe disease** and **Rose, whose son Thomas was diagnosed with Sanfilippo syndrome** discussing the topic of 'Palliative care'. Amy and Rose shared reflections on the experience of palliative care in each of their families. From the first mention of the 'P' word, and the difficult associations that it triggered initially, to discovering additional layers of care, respite and support they had not known were possible, as well as reflections on things they wish they had known sooner. While both parents' experiences were unique - we have summarised key themes and insights that Amy and Rose shared with the Parent Knowledge Network for this session.

Preexisting ideas of palliative care can be a barrier, at first.

Although both parents remember consideration and care from the clinicians who first introduced the concept, they also described feeling very confronted initially - because the very idea of palliative care meant the end and giving up. Amy's family was introduced to the palliative care team at Louis's formal diagnosis meeting, when he was 11 months old. With only adult experiences of end of life care to compare it to - Amy recalled not being able to look the team members in the eye at that meeting because they represented a sense of giving up. Although Rose was asked by her son's pediatrician whether she had considered palliative care several years before Thomas needed end-of-life care (at age 23), she remembers shutting that first conversation down due to similar pre-existing negative associations with the word palliative.

A type of care, not an ending

Although their circumstances of care were different, both parents came to similar understandings of the potential benefits of palliative care over time. For Amy's family, the palliative care team provided individualised specialist care to Louis over many months through both 24/7 phone support, and home visits. Amy reflected that palliative care could do with a rebrand, and that rather than being a point at which care stops, it can work

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as a quality of life enhancer. Rose reflected that for children with childhood dementia, these days she sees palliative care as a type of care, rather than a (chronological) stage that signals you are 'at the end'.

Remembering the first stay at a Children's Hospice

A few weeks after Amy met Louis' palliative care team, they spoke about the possibility of accessing Bear Cottage (a children's hospice in Sydney) for additional support and respite stays. After agreeing to a first stay - which included a tearful and overwhelming first night - Amy shared a key turning point happened the very next day - when she ventured out of their family room to discover the gentle and warm welcome from hospice staff, offers of shared meals with other children and families 'like ours', in a kitchen that felt more like a home than a hospital. The warmth of the welcome they received really shifted how the family felt about accessing the hospice, which they would go on to do many times in the coming months.

Meeting the team early

Amy offered gentle guidance for families who have not yet met a palliative care team: 'engage as early as you can, so the team knows you and knows your child'. Amy had contrasting recollections when comparing visits to their local hospital, where they encountered staff who were either shocked by Louis' condition, or who didn't know how to care for him- alongside memories of visiting a children's hospice, where nothing the staff encountered while caring for Louis seemed to surprise or phase them. The nurses at Bear Cottage also taught the Louis' family practical skills, such as how to use a suction machine and gave them support to practice their new skills during stays - this extra layer of care for them as parents was another highlight of their time engaging with hospice and palliative care.

Supporting the life you want for your child

By facing the challenge of 'allowing other staff to learn how to hold and care for her son, visits to the hospice shifted from hesitant to what became known as 'Louis' tune-ups. Amy shared 'we would arrive with a problem, and they would support us by reviewing medications, offering care and Louis would always leave better than he arrived'. Amy had found comfort in the idea of building their life around the goal of

focusing on 'what (our) children can do, rather than what they cannot'. Over the months the family planned many experiences and

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outings together - the palliative care and hospice teams were a great support - from packing feeds and helping adjust dosages of medication ahead of time, so that Louis wasn't sedated during their special time together. Through the holistic support from the teams, Amy's memory of leaving a Bear Cottage stay just before Louis' second birthday and seeing him smile for the first time in many weeks was a unique memory that the family still carry with them.

Deciding what you want ahead of time

Both families made a decision about where they wanted their child to be for end of life care. Amy's family decided early that Louis would be at Bear Cottage and they were able to plan this care at their own pace. Rose shared that Thomas being cared for at home was a key priority for everyone in their family. Highlighting that although conversations about the death of your child can be very confronting - the value in having the conversation with your partner and family before you need it is that it offers you more time and space to think about who is most important to be present during that time.. Both Amy and Rose shared that although they initially put off conversations around end-of-life care planning, as they reflect back on the benefits these conversations brought - they encouraged families to consider exploring these conversions earlier than they may think they 'need to'.

Choice at the end of life and afterwards

Thomas died at home at the age of 23. Rose's palliative care nurse told her that Thomas could stay at home for a time afterwards, which Rose had not known was possible. Thomas's carers, many of whom are from Papua New Guinea, held a vigil with him for 48 hours, singing, praying and sitting with him, and the family had time to be with him as well. A smoking ceremony was held as he was taken from the house, and a traditional dance was performed at his funeral. Amy's family arranged Louis's funeral through a not-for-profit that finds venues outside the usual settings, and built it around the space theme that ran through his life. Both parents said families have more choice here than they expect, and that it is worth asking.

Support that continues alongside your family

Amy offered reassurance for future families who might be worried that all professional services just fall away after your child dies. Support from palliative care teams continues on into bereavement - and these are

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relationships that Amy's family have really valued . As an example, she shared how Bear Cottage runs events for bereaved families as well as its regular events, and the family still attends and she is still able to speak to the hospice team if she feels she wants to.

The value of family voices

Members of the session acknowledged how the death of a child is still often considered a 'taboo subject' - how hearing from parents who have lived through it is valuable, and may relieve some of the pre-existing fears (non-bereaved) families have. Both Amy and Rose also offered to speak further with any other families in the Parent Knowledge Network who may want to.

Finally, we are especially grateful to both Amy and Rose for sharing some of their experiences of palliative care with the network. In particular we appreciate how the legacy of Louis' and Thomas' lives continue to bring care and support to other families in turn.

Helpful resources discussed in the session

- Understanding Paediatric Palliative Care: A guide for parents of children with childhood dementia conditions: A resource guide from Childhood Dementia Initiative, co-designed with parents
- What is Paediatric Palliative Care?: A 3 minute introductory video, produced by Palliative Care Australia and the Quality of Care Collaborative Australia (QuOCCA)
- What do you know now that you wish you had known before?: A 4 minute video of reflections

from multiple families who have accessed paediatric palliative care.

- A Guide to Children's Palliative Care: A detailed guide produced by Together for Short Lives in the United Kingdom
- Specialist Pediatric Palliative Care Services : Australian State Directory: A webpage with contact details for hospital and hospice palliative care teams - along with a general overview of some of the typical roles you might find on a palliative care team.

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If reading or listening back to this session has raised questions for your family that you would like to discuss , we encourage you to reach out to us at services@childhooddementia.org

To view the recording from this session, please register to become a member of the Parent Knowledge Network. Presentation recordings will be shared with members during the monthly reminder emails. Here is a reminder of the Parent Knowledge Network Community Guidelines.

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