

**Results** In total 25 babies were referred with Trisomy 18 and 6 with Trisomy 13 from November 2021 to May 2024 (2 years 7 months).

There was a variance in approach to care during pregnancy including whether or not subspecialty reviews were offered. After birth there was a variance in approach to formalising diagnosis if amniocentesis had been declined. At birth different approaches to care were offered including around access to NICU admission, provision of respiratory support and other resuscitation measures. Interventions provided included surgery before and after formalised diagnosis. Prognosis varied, with a large cohort not surviving to delivery (8 trisomy 18; 1 trisomy 13), many having short lives (11 trisomy 18; 4 trisomy 13) a cohort continuing to survive at time of writing (6 trisomy 18; 1 trisomy 13).

**Discussion** Our findings support clinicians having an open mind in their approach to families with a baby diagnosed with or highly likely to have trisomy 18. True parallel planning, a cornerstone of palliative care, should include planning for both the best and worst possible outcomes. Families need to be aware of the possibility of IUD but also extended time at home together to help them navigate choices effectively. Care that supports both pathways should be carefully considered, alongside an understanding of the family's goals and preferences.

#### OP-26 THE ROLE OF CROSS SERVICE SUPPORT IN CARING FOR A PATIENT WITH CHILDHOOD DEMENTIA

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1/2900 babies born have one of the over 100 neurodegenerative genetic disorders associated with developing a Childhood Dementia Syndrome. Patients suffering from Childhood Dementia Syndromes usually have normal development initially, before developing symptoms before the age of 18 years old, which progress over years, or potentially even decades.<sup>1</sup> Around 90 patients die each year in Australia from a Childhood Dementia. Given the progressive, life-limiting nature of the diagnosis, these patients and their families may receive care in Children's or Adolescent and Young Adult Hospices, whether for elective respite, complex symptom management or end of life care as well as from community palliative care teams and hospital palliative care consultation services.

A Childhood Dementia Initiative report of 2024 noted key issues including a severe lack of knowledge and understanding and a chronic absence of expert care. These then lead to increased parental burden, disempowerment of families, risk to children's safety and neglect and inequity of care.<sup>2</sup>

This presentation will highlight the role of cross-service care for patients with a Childhood Dementia Syndrome. This includes Dementia Support Australia, Childhood Dementia Initiative, NDIS, Community Specialist Palliative Care team, outpatient specialist medical consultant teams and the specialist multidisciplinary team at the Adolescent and Young Adult Hospice (including clinical psychologist, psychiatrist, occupational therapist, physiotherapist, art and music therapists, speech pathologist, dietitian and bereavement support worker)

with a case presentation of a 20 year old with a Childhood Dementia Syndrome.

#### REFERENCES

1. Elvidge K, Christodoulou J, Farrar M, Tilden D, Maack M, Valeri M, Ellis M, Smith N J C, Childhood Dementia Working Group. The collective burden of childhood dementia: a scoping review. *Brain* 2023;146:4446–4455
2. Childhood Dementia Initiative 2024. Childhood Dementia: Family experiences of health systems in New South Wales, <https://www.childhooddementia.org/getasset/425L8Q> March 2024 Sydney Australia.

#### OP-27 BEREAVED PARENT EXPERIENCES OF NEONATAL PALLIATIVE CARE IN THE NEONATAL INTENSIVE CARE UNIT (NICU)

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#### Site

Paediatric Palliative Care Service, The Women's and Children's Hospital, Adelaide

**Background** Neonatal palliative care (NPC) is a holistic model of care from the time of diagnosis of a life limiting condition, that focuses on the infant's quality of life and support of the family (Catlin & Carter, 2002; Kain & Chin, 2020). Learning directly from bereaved parents' lived experience has the potential to improve infant care, better support family-centred care and decision making, and address parental distress (Quinn & Gephart, 2016). There is a paucity of interview based qualitative studies of bereaved parent experiences of neonatal palliative care in NICU.

**Study Objectives** To explore bereaved parents' experiences of neonatal palliative care in the Neonatal Intensive Care Unit (NICU), which aims to inform and improve the delivery of family-centred palliative care.

**Method** An exploratory qualitative design was employed using a phenomenology methodology. Parents of an infant who had died in the NICU at the Women's and Children's Hospital (WCH), Adelaide, and were 6–12 months bereaved participated in semi-structured interviews to explore experiences. Interviews via videoconferencing or phone call were audio-recorded and transcribed. Inductive thematic analysis was conducted to generate themes.

**Results** Six parents (four mothers and two fathers) participated in five interviews. Four themes characterised parents' experiences of neonatal palliative care: hope and fragility, decision making role and responsibility, 'taking... in' of their baby, and being together and separate. Parents maintained hope when faced with uncertainty and infant fragility. A high priority was placed on decision making regardless of the scope of options, opportunities for deep infant connection and sharing the infant with family. Families wanted to be together, but many factors contributed to separation.

**Discussion** By elucidating parents' most pertinent experiences of neonatal palliative care the findings from this study can inform family-centred care delivered by staff. Clinicians can recognise hope as a preference and coping strategy for parents to manage uncertainty. Decision making is integral to the parent role and parent autonomy, so clinicians should empower, collaborate and support parents in decision making, regardless of the scope of choices. Given the central importance to parents of 'taking...in' their infant and family visiting, these opportunities should be actively facilitated by staff