# Creating paediatric end-of-life capacity in a regional hospital setting

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# Background

- 9 year old child receiving palliative care at home had a parallel plan for hospital-based end-of-life care as requested by the family
- The regional hospital team was familiar with the child through regular outpatient visits for infusions, etc.
- This child was being supported by the local Primary Care Community Health Palliative Care Team alongside the Children's Hospital Westmead Palliative Outreach Support Team who took overall responsibility for managing the child's care.
- End-of-life care within the local hospital paediatric ward is outside of usual clinical practice.  Fostering and enhancing the confidence and capability of the paediatric nurses and midwives in delivering high quality EOLC within the hospital environment was essential.

# Identifying staff educational needs

- Discussions were held with staff working on the Womens and Childrens ward to determine their concerns and educational needs.

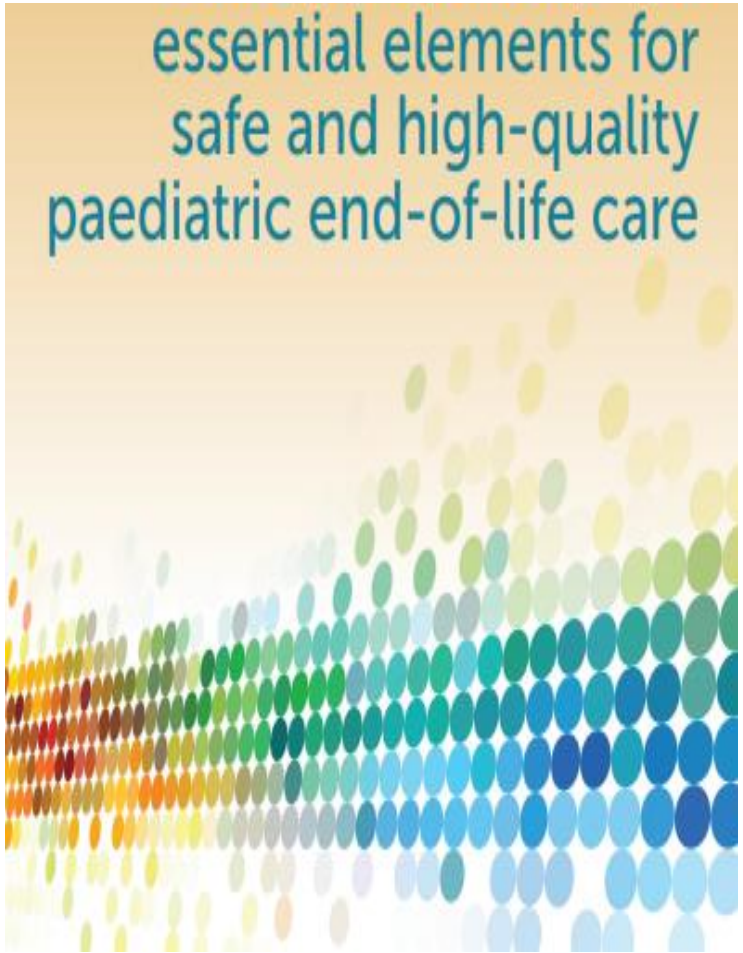
- Team meetings were held to update the staff of the childs progress at home.  Staff were able to raise any new concerns that they had at these meetings.

- The regional hospital team, with executive support, collaborated with Childrens Hospital Westmead Palliative Outreach Support Team, the local Primary Care and Community Health palliative care team, and the district Palliative Care Nurse Practitioner to develop and deliver tailored education and support following the Essential Elements for Safe and High-Quality Paediatric End Of Life Care Framework.

# Initiatives included:

- Pre-briefing sessions involving MDT
- Staff training on CVAD access
- Staff training on subcutaneous infusions with NIKI T34 pump
- Introduction to some important documents to guide practice in this space
- Education on care of the deceased child
- Creation of a care cart
- Access to psychosocial support to promote emotional resilience
- Streamlined hospital admission including direct admission pathway
- Coordinated care planning including access to on-call palliative care consultant
- Close collaboration with PCCH and CHWPOST
- Post death debriefing

# Staff were introduced to some important documents




The Sydney children's Hospitals Network
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# LAST DAYS OF LIFE TOOLKIT

## PRACTICE GUIDELINE *

## DOCUMENT SUMMARY/KEY POINTS

- The Last Days of Life Toolkit: Paediatric & Neonatal (LDOL: P&N) provides best practice guidance to clinicians who may or are caring for a dying child or neonate in the last days of their life
- The guideline may not encompass all the complexities relevant to end of life in the neonatal or paediatric intensive care setting in SCHN. Variation from the guideline for individual practice may be considered by Admitting Medical Officer in neonatal or paediatric intensive care.
- The Toolkit promotes a standardised, equitable, and safe approach to end of life care. This standardised approach enables care to be individualised to the needs of the child so that a high level of care regardless of the clinician's experience, the patient's location, ethnicity, religion, or social status.
- The LDOL: P&N is specific to care of the dying child/neonate and their family when cared for in an acute care setting (hospital or hospice).
- Documents developed for the *Toolkit* include:
  - *LDOL: P&N Compass*
  - *Initiating the LDOL P&N*
  - *Anticipatory Prescribing Guide*
  - *Pain Medication Guidance Document* ,
  - *Breathlessness Medication Guidance Document*
  - *Nausea and Vomiting Medication Guidance Document*
  - *LDOL: P&N Guidance document*
  - Thirteen *Additional resources* are available to support communication.
- SCHN staff should consider completing the *LDOL: P&N* HETI Module prior to using the Toolkit



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| **Approved by:** | SCHN Policy, Procedure and Guideline Committee | | |
| **Date Effective:** | 1st January 2026 | **Review Period:** 3 years | |
| **Team Leader:** | Clinical Nurse Consultant | **Area/Dept:** Paediatric Palliative Care | |

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# Hands on education sessions


Hands on education sessions

| Draw 1 | Draw 2 | Draw 3 | Draw 4 | Draw 5 |
|---|---|---|---|---|
| Tea | Essential oils | Water Colour | Instant Camera | Books |
| Mugs | Bubbles | Liquid Jewellery | USB Stick | |
| Lip Balm | Squeeze Balls | Metallic Colouring | Sound Machine | |
| Lotions | Inkless Ink Pad | Gel Pens | Key Rings | |
| Creams | Sketch Book | Paint Brushes | Small Portable Fan | |
| Body Wash Packs | | Origami Paper | Journal | |
| Nail Polish | | Busy Nipper Booklets | Organza Bags for Keep Sakes | |
| | | Scissors | | |


# Comfort Cart

Drawer One


# Comfort Cart

Drawer 2


# Comfort cart

Drawer 3


# Comfort Cart

Drawer 4


The Invisible String WORKBOOK
Creative Activities to Comfort, Calm, and Connect
PATRICE KARST
The Invisible Web
An INVISIBLE STRING Story Celebrating Love and Universal Connection
THE NEXT PLACE
Memory Box
A Book About Grief
By Joanna Rowland
The Memory Book
A Grief Journal for Children and Families
By Joanna Rowland
Illustrated by Thea Baker
ON THE NIGHT YOU WERE BORN
Nancy Tillman
Comfort Cart
Drawer 5

# Some comments from staff:

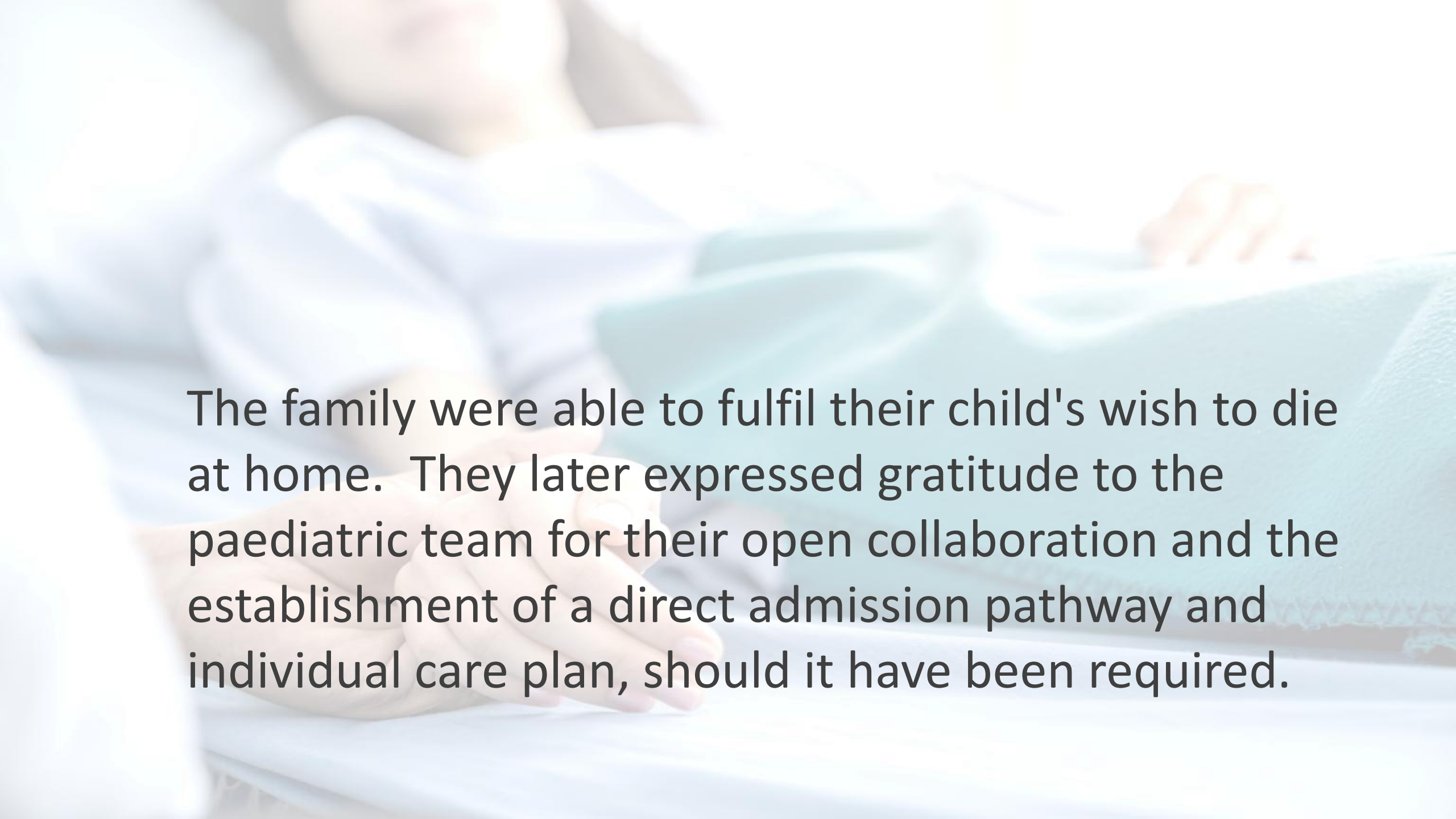
The training provided allowed me to view the case from a clinical perspective as well as to understand my personal response to the situation.

NUM reported enhanced team cohesion and emotional well-being.

I feel more prepared and supported to care for a dying child now

I was able to realise that this was not my tragedy, this was the childs and the families tragedy. This enabled me to be prepared to provide good clinical care.

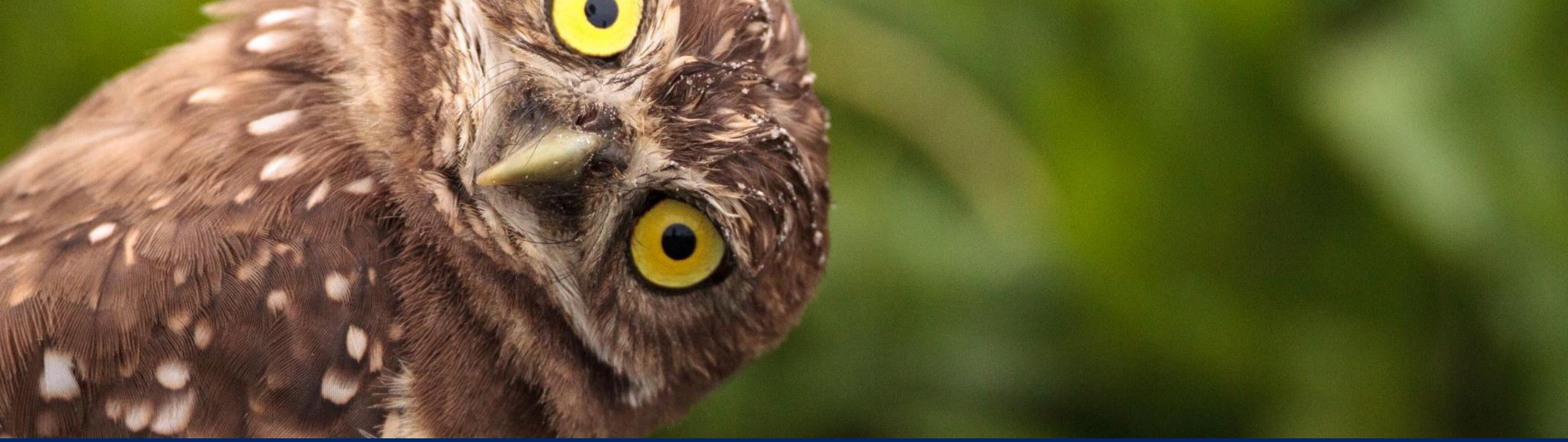
The training in the use of the NIKI pump and subcutaneous infusions has put my mind at ease about this child coming onto our ward.



The family were able to fulfil their child's wish to die at home.  They later expressed gratitude to the paediatric team for their open collaboration and the establishment of a direct admission pathway and individual care plan, should it have been required.

# Post-death debriefing session

- The meeting was held shortly after child had died and was chaired by the Children's Hospital Westmead Palliative Outreach Support Team
- All members of the health care team were invited
- Meeting was held via Teams and in person, and was very well attended
- All staff members were given the opportunity to contribute and were encouraged to share their feelings/personal responses as well as to discuss clinical concerns
- Staff were offered further support if needed



# Key Learning Message

- Understand the needs of the teams that you are trying to support.
- Understand the needs of the family that you are supporting.
- Collaboration is essential. Keep in contact with the treating team and other essential services involved in the individual patient’s care.
- Follow up on all skill enhancement training provided to staff.

# References


1. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality paediatric end-of-life care. Sydney: ACSQHC, 2016.
2. Last Days of Life Toolkit. Guideline No: 2022-129 v2.0; The Sydney Children's Hospital Network; K:\CHW P&P\ePolicy\2025\Last Days of Life Toolkit v2.0.docx

# Questions