

“Will Lumpy Junk Make Me Die?”

Advance Care Planning Conversations with Children

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Goals of ACP Conversations

- Who is this child? What do they enjoy? What do they find hard? How do they experience their illness and treatment?
- Timely discussions with parents and the child (if possible) may help to improve understanding of the child's prognosis and prepare for future situations
- Respect the child and family's values, wishes and goals
- Non-medical goals e.g., holiday, graduating from school, birthdays
- General Medical and Supportive Cares e.g., antibiotics, blood products, preferred location of care, resuscitation planning
- Organ and Tissue Donation
- It can be hard to know when to introduce the concept of ACP to a family and to know if they are ready

A Bubble Bath Provided an Opportunity

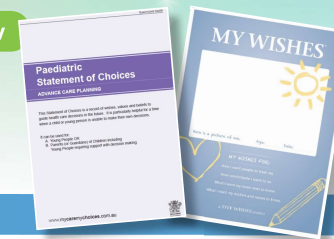
Emily started the ACP conversation with her family, whilst enjoying one of her favourite things – a bubble bath! She asked her Mum “Is lumpy junk going to make me die” Emily's Mum in that moment wanted to protect her but chose to be honest. Said “yes” whilst providing reassurance “not right now” and making her feel safe and supported. Emily's family continued to include Emily in ACP conversations and therefore:

- Gave her a sense of control
- Provided Emily with opportunities to observe, reflect, think and talk



Some ACP Tools Used by Emily and her Family

- Tools to help the family have ongoing conversations
- Tools to include Emily
- Tools to document goals and wishes
- Paediatric Statement of Choices, My Wishes and a PARP (Paediatric Acute Resuscitation Plan)



How Emily Would Like to be Cared for

Communication

“If possible try not to spring these things on me,”

“Please don't rush me when I am talking”

“Please don't finish my sentences for me!”



Emily likes to know what's happening to her and why and have some time to prepare.

Supporting Emily and Her Family with ACP Conversations

- Dynamic and ongoing process
- Time and patience
- Relationship building and trust



Being Brave
Giving The
Child a Voice
Often the child
leads us



Meet Emily

- A delightful 4-year-old girl
- Diagnosed in December 2021 with a DIPG brain tumour
- Emily called her tumour 'lumpy junk'

I Love: Cuddles, Paw Patrol, tickles, bubbly baths, music, telling jokes, swimming

My Favourite Things: Frankie the Flamingo. It is important these stay with me especially when I am feeling sick, in hospital.

Sometimes I Feel Scared of: Being lonely, giants and people touching or harming Frankie the Flamingo – Emily can be overstimulated by noise and/or lots of people

Goals of Care

- A priority is for Emily not to be in pain or to suffer.
- Emily's parents would like to only have interventions that sustain Emily's independence and quality of life.

Locations of Care

- Emily has expressed the wish to die in hospital as she has positive memories there and she feels safe.
- Emily would like photos of family and friends in her room if she is in hospital but they should be pulling silly faces!

Religious/Cultural Preferences

- Emily and her family do not have any specific religious or cultural preferences or goals

End of Life Care

- Emily has a PARP which documents her parents' wishes for appropriate treatment when she deteriorates and/or is at end of life.

Tumour and Tissue Donation

- Emily's parents would like to donate Emily's tumour to research after she has died. They would also like to consider corneal donation.



Thank you to Emily and her family for showing us how to be brave to have these important conversations and to hear the voice of the child or young person no matter their age.