



hello

From PICU to a Children's Hospice

Who, Why, When and How?

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For families from across the East Midlands whose children (babies, children or young adults) require hospice care

- End of life care
- Palliative care
- Symptom management
- Short breaks
- Family support
- Sibling support
- Bereavement support
- Play and therapies



What?

**So what can a Children's Hospice
offer a family whose child is on
PICU?**



Why?

Although proportion of children dying in hospital is decreasing there remains a large proportion of children dying after discharge from PICU continue to die in hospital.

‘the involvement of palliative care at the point of discharge from PICU has the potential to offer choice around place of care and death for these children and families.’

Fraser et al 2018



Compassionate extubation outside
an acute environment – a new
concept?

NO





Valuing short lives

A Care Pathway to Support Extubation within a Children's Palliative Care Framework

First edition 2011



ACT for children **ACT** for families **ACT** together **ACT** now!



Who?

Those children where extubation/withdrawal of treatment is being considered with no plan to re-escalate treatment



Why?

- Choice
- Environment
- Additional services
- Shift of focus
- Initial bereavement support
- Ongoing support of family
- Extended family



When?

Not just Friday afternoon!



How?

Not as complicated as one may think

COMMUNICATION IS KEY



Potential challenges:

- Subcutaneous rather than IV access
- No piped oxygen
- Transport
- Timing



Parallel Planning

Up to 1/3 of children transferred to a children's hospice for end of life care survive to go home

ACT 2011



Case Study

- 6 week old baby, diagnosed with a complex disability
- Initially anticipated that extubation would be successful
- After failed attempts and an ongoing deterioration, decision made with family to withdraw ventilation
- Plan identified between PICU and hospice teams
- Large extended family
- Once arrive, time for cuddles and photos
- Baby died within a few minutes
- Remained at hospice
- Initial support including funeral planning
- Ongoing bereavement support



“It is so difficult to find the right words to express our thanks to everyone at Rainbows for the great care, understanding, thoughtfulness and support shown”



What else?

- Earlier support for long term patients on unit who meet criteria – to include complementary therapy, music therapy, family support, sibling support
- Involvement/support at point of discussions and decisions
- Support withdrawal at the hospital
- Transfer to hospice following extubation



“The way people die lives on in
the memories of those left
behind”

Cicely Saunders - (Palliative Care Pioneer and founder of the modern hospice movement)





thank you

for helping us brighten short lives

rainbows.co.uk