Compassionate Extubation in the Community

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Consultant in Paediatric Intensive Care and Retrieval Medicine
350 – 400 admissions per year

95% Survival to PICU discharge
16-23 deaths per year in PICU

27 – 34% of deaths were in children with chronic life limiting conditions

Since 2015, 53% of families offered, received end of life care outside of the PICU

Home
Local hospital
NICU
Laura Lynn Hospice
Withdrawal of care in the PICU

Reasons not to go home
• Acceptance of end of life situation
• Not wanting to ‘give up’
• Fear
• Memories tied to home/hospice

Reasons to stay in PICU
• Support system in hospital
• Controlled environment
• Less stress / organisation
‘I wouldn’t have it any other way. If I couldn’t have him, at least I got one thing that I wanted for us and that’s to bring him home.’

‘It gave me a sense of closure…. I don’t know how I would have felt if I hadn’t been able to get him home. It was better to be here. And he seemed much more relaxed and ready and accepting himself.’

‘If he had never come home, we would have come back to …. A never used nursery. I think that would have been hard.’

‘Bring him home well, but since that didn’t happen, just to have him come Home if only to pass’
End of Life Hospice Care

- Home away from home
- Guaranteed clinical support
- Prioritising family time
- Support for the whole family
Barriers to WLST outside of PICU

• Lack of health care provider experience
• Access to a paediatric critical care transport team
• Access to hospice bed
• Access to the home

• Patient instability
• Risk of death before arrival home
• Impact on ICU/Transport resources
<table>
<thead>
<tr>
<th>Country (year)</th>
<th>Study population</th>
<th>Mechanical ventilation</th>
<th>Haemodynamic support</th>
<th>Transfer destination</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK, 1994 Hawdon et al</td>
<td>3 Neonates – NICU</td>
<td>100%</td>
<td>0%</td>
<td>Home</td>
<td>2/3 died following extubation</td>
</tr>
<tr>
<td>US, 2006 Zwerdling et al</td>
<td>1 infant – PICU</td>
<td>100%</td>
<td>0%</td>
<td>Home</td>
<td>Died shortly after extubation</td>
</tr>
<tr>
<td>UK, 2007 Longden et al</td>
<td>4 children – PICU</td>
<td>100%</td>
<td>50%</td>
<td>Home (2) Hospice (1) Adult hospital (1)</td>
<td>All died shortly after extubation</td>
</tr>
<tr>
<td>US, 2010 Needle</td>
<td>1 infant – PICU</td>
<td>100%</td>
<td>0%</td>
<td>Home</td>
<td>Died shortly after extubation</td>
</tr>
<tr>
<td>UK, 2012 Gupta et al</td>
<td>12 children – PICU</td>
<td>100%</td>
<td>0%</td>
<td>Hospice (12)</td>
<td>8 children died soon after extubation 4 survived beyond two weeks</td>
</tr>
<tr>
<td>UK, 2014 Laddie et al</td>
<td>15 children – 4 NICU / 11 PICU</td>
<td>100%</td>
<td>Some</td>
<td>Home (5) Hospice (8) Other (2)</td>
<td>All died within 5 days of extubation</td>
</tr>
<tr>
<td>US, 2015 Nelson et al</td>
<td>10 children – PICU</td>
<td>50%</td>
<td>U/K</td>
<td>Home (9) Hospice (1)</td>
<td>60% died shortly after 40% survived for 4-40d</td>
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<tr>
<td>US, 2017 Noje et al</td>
<td>3 children – PICU = 49 children over 23 years</td>
<td>100%</td>
<td>33%</td>
<td>Home</td>
<td>All died shortly after extubation</td>
</tr>
<tr>
<td>Ireland – CUHTS 2015-present</td>
<td>6 children - PICU</td>
<td>100%</td>
<td>0%</td>
<td>Home (3) Hospice (1) Other hospital (2)</td>
<td>3 died shortly after withdrawal of mechanical ventilation 2 within 2 weeks 1 survived</td>
</tr>
</tbody>
</table>
### The Temple Street PICU Experience – 2015-2017

<table>
<thead>
<tr>
<th>Age</th>
<th>PELLC</th>
<th>PICU LOS</th>
<th>Resp support</th>
<th>CVS support</th>
<th>Destination</th>
<th>Survival post D/C</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;10yr</td>
<td>Yes</td>
<td>24 dys</td>
<td>No</td>
<td>No</td>
<td>Home</td>
<td>2 days</td>
</tr>
<tr>
<td>&lt;10yr</td>
<td>Yes</td>
<td>12 dys</td>
<td>I&amp;V</td>
<td>No</td>
<td>Home</td>
<td>&lt;12hrs</td>
</tr>
<tr>
<td>&lt;1yr</td>
<td>Yes</td>
<td>18 dys</td>
<td>NIV</td>
<td>No</td>
<td>Home</td>
<td>4 days</td>
</tr>
<tr>
<td>&lt;10yr</td>
<td>Yes</td>
<td>24 dys</td>
<td>NPA/HFNC</td>
<td>No</td>
<td>Home</td>
<td>&lt;12hrs</td>
</tr>
<tr>
<td>&lt;1yr</td>
<td>Yes</td>
<td>21 dys</td>
<td>No</td>
<td>No</td>
<td>Home</td>
<td>&gt;2 weeks</td>
</tr>
<tr>
<td>&gt;10yr</td>
<td>Yes</td>
<td>2 dys</td>
<td>No</td>
<td>No</td>
<td>Home</td>
<td>&gt;1 week</td>
</tr>
<tr>
<td>&gt;10yr</td>
<td>No</td>
<td>21 dys</td>
<td>I&amp;V</td>
<td>No</td>
<td>Hospice</td>
<td>2 weeks</td>
</tr>
<tr>
<td>&lt;10yr</td>
<td>Yes</td>
<td>26 dys</td>
<td>NIV</td>
<td>No</td>
<td>L. Hospital</td>
<td>survived</td>
</tr>
<tr>
<td>&lt;10yr</td>
<td>Yes</td>
<td>0 – ED</td>
<td>NIV</td>
<td>No</td>
<td>L. Hospital</td>
<td>&lt;4 hours</td>
</tr>
<tr>
<td>&gt;10yr</td>
<td>Yes</td>
<td>19 dys</td>
<td>HFNCC</td>
<td>No</td>
<td>L. Hospital</td>
<td>u/k</td>
</tr>
<tr>
<td>&lt;1yr</td>
<td>Yes</td>
<td>8 dys</td>
<td>I&amp;V</td>
<td>Yes</td>
<td>NICU</td>
<td>N/A</td>
</tr>
<tr>
<td>&lt;1yr</td>
<td>Yes</td>
<td>2 dys</td>
<td>I&amp;V</td>
<td>Yes</td>
<td>NICU</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Stage 1
Towards a decision to withdraw life-sustaining therapies

Stage 2
Practicalities of withdrawing life-sustaining ventilation

Stage 3
Care at the time of death

Sharing significant news
An agreed plan of care
An end of life plan
Planning the extubation process
Enabling end of life wishes
Continuing bereavement support
An agreed plan of care

- Consensus
  - ICU team

PARALLEL PLANNING

- Early liaison with appropriate teams/services
An end of life plan

• Develop and consolidate a resuscitation plan

• Discuss organ donation and post mortem examination with the family

• Discuss symptom management and survival expectations

• Ongoing liaison with
  • Palliative care (local and paediatric)
  • Local consultant paediatrician
  • Public health nurse
  • GP
  • Hospice (local/paediatric)
  • Pharmacy
Planning the Extubation process

Ensure all possible scenarios have been discussed with family and medical teams

• Immediate death
• Survival for hours – days
• Long term survival
• Discuss desired level of sedation for the child at the time of extubation
• Discuss removal of breathing tube/additional LSTs and monitoring with family
• Discuss ‘change of heart options’

Clear parallel plan regarding:

• Feeds/fluids
• Location of ongoing care in the event of prolonged survival post extubation
• Risk of accidental extubation/death
• Appropriate sedation/pain relief regime in place

Clear plan with transport team

• Day & time of arrival
• Suitability of location
• Clear timeline for how long the transport team can remain with the child
Planning the Extubation process

Local services:
- Clear on-call arrangements – palliative care/gen paeds team
- Ability to admit child if required
- ?availability to visit at home (GP)

Clarity:
- Who will prescribe/provide medication
- How long nursing can be provided
- Who will certify death

Supplies:
- Regular medications
- Symptom management medication
- Oxygen/monitoring/suction
- Feeding supplies
- Catheters/pads/nappies
- Syringe drivers
Future Goals

• Families of all children in PICU stable enough to be transferred are offered a choice for place of extubation/WLST
  • Regardless of acuity/background
  • Regardless of length of stay
  • Regardless of geography

• To be able to offer safe home/hospice extubation in time sensitive cases when necessary

• Development of robust 360° algorithmized approach to discharge planning with terminal and parallel plans for each child formally agreed upon

• Development of a national working group to start this process

• Early end of life planning and consideration of destination preferences
And Finally......