Changing the Language: Integration of *Allow Natural Death* into the National Children’s Hospital in New Zealand

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Overview

- Advanced Care Planning
- Focus on what will be done rather than what will not be done
- Involvement of Maori (indigenous people)
- Tool for communication
- Achieving “buy in” from clinicians
Advance Care Planning

- Possible months or years before the end of life

- Advance care decisions evolve over time through trusted relationships and ethos of shared decision making.
Integrating Culture into Palliative Care

- Open disclosure and honesty
- Autonomy through active participation in decision making
- Maori model
  - Partnership
  - Participation
  - Protection
- Expression of feelings

(Maori Health Strategy, New Zealand, 2002)
Te Whare Tapa Wha

Taha Hinengaro
Mind

Taha Wairua
Spirit

Taha Tinana
Body

Taha Whanau
Family
Allow Natural Death & Advanced Care Planning

- Development
- A.N.D. – focusing on what will be done versus what will not be done (Rev Chuck Meyer, St David’s Medical Centre, Austin, Texas)
- Te Wa Aroha
Allow Natural Death – Te Wa Aroha

- A time of love - a way of communication

- Intent of Plan:

  “to prevent suffering and promote comfort, quality of life and dignity.”

Parental Hopeful Patterns of Thinking, Emotions, and Pediatric Palliative Care Decision Making

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<table>
<thead>
<tr>
<th>Symptom Management</th>
<th>Psychosocial/Social/Spiritual Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment</td>
<td></td>
</tr>
</tbody>
</table>
Acute Deterioration Measures
In the event of an acute deterioration, the care to be provided may include, as appropriate:

<table>
<thead>
<tr>
<th>Response</th>
<th>Yes</th>
<th>Withheld</th>
</tr>
</thead>
<tbody>
<tr>
<td>Call to arrest team (Code Blue)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nasopharyngeal suctioning</td>
<td></td>
<td></td>
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<tr>
<td>Oxygen – passive</td>
<td></td>
<td></td>
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<tr>
<td>Oxygen – bag and mask</td>
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<td></td>
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<tr>
<td>Intubation</td>
<td></td>
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<tr>
<td>Cardiac compression</td>
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<tr>
<td>Electrical cardioversion</td>
<td></td>
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<tr>
<td>Arrest medications</td>
<td></td>
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<tr>
<td>Antibiotics</td>
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<tr>
<td>Other (specify)</td>
<td></td>
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</tbody>
</table>

Is a referral to the Palliative Care Team needed for symptom management and or psychological/social or spiritual support of the child and family? [ ] Yes [ ] No
If yes, has the referral been made? [ ] Yes [ ] No

Have the parents agreed to the acute deterioration measures above or being a standing order? [ ] Yes [ ] No
Parents have agreed that this care plan and the acute deterioration measures will be reviewed in [ ]

This reflects the care options discussed and agreed. It is understood that these decisions can change after discussion at any time.
Senior Medical Officer completing this form
Print Name __________________________ Designation __________________________
Signature __________________________ Date __________________________
Contact Number __________________________

The arrangements for end of life care and allowing a natural death must be reviewed according to the timeframe previously specified, unless the parents have requested a standing order. If the order changes, a new form must be completed and placed in the clinical record.

<table>
<thead>
<tr>
<th>Date of Review</th>
<th>Order remains the same?</th>
<th>Signature of Medical Officer completing review</th>
<th>Print Name and Contact Number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes/No</td>
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</table>

When form is complete fax immediately with the CHD0008 Clinical Alert Notification/Cancellation form to the Clinical Record Department for scanning and place the original into patient's clinical notes. [ ]
Copy of EOL plan sent to GP [ ]
Copy of EOL plan given to family [ ]
Implementation

- Te Wa Aroha/End of Life Care Plan
- Change of language
- Tool for communication for all health professionals
- Technical Support
- Modelling from Paediatric Palliative Care Clinicians
Conclusion

- NFR/DNR replaced with *Te Wa Aroha*
- Tool for communication
- Empowerment of children, families and clinicians
- Increased awareness of Paediatric Palliative Care