End of Life Essentials Paediatric Palliative Care Module: an important resource for hospital staff working with dying children and families

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End of Life Essentials

‘End of Life Essentials’ (EOLE) provides online learning opportunities and practice resources for health professionals to improve the quality and safety of end-of-life care in hospitals [1]

- EOLE is funded by the Department of Health.

https://www.endoflifeessentials.com.au/

‘Paediatric End-of-life Care’ is one of these modules, launched in Dec 2018 highlighting the importance of this work and its place in palliative care nationally

[Commissioned by Palliative Care Australia]

[Paediatric Palliative Care Australia and New Zealand (PaPCANZ) provided national consultancy group membership for this module]

EOLE Paediatric module

- Causes of expected deaths
- Empowerment – enabling yourself
- Empowerment – enabling the family
- How comfortable are you with EOL care?
- Decision making
- Discussing with parents what to tell a child
- Basic human conversations
- Are you brave enough to use the words that need to be used?
- When a child with a life-limiting illness is admitted to hospital
- Symptom management
- Don’t be afraid – be brave
- Referring to palliative care
- Moral Distress and staff support
- Self awareness and mindfulness
- Aboriginal and Torres Strait Islander Inclusive and culturally respectful care
- Loss, grief and bereavement
- Think about your professional compassion
- Showing compassion

Excerpts from the EOLE paediatric module: Communicating prognostication and End-of-Life care

Strengthen your tolerance of

- ○ clinical ambiguity
- ○ strong emotions
- ○ complexity

end-of-life ESSENTIALS education for acute hospitals

Chochinov H, 2012

Excerpts from the module: Prognostic uncertainty

Childhood life-limiting conditions are most commonly non-cancer illnesses with an uncertain trajectory.

Often parents will learn of their baby’s serious illness during pregnancy or soon after birth.

Unsurprisingly, many parents will ask if their baby will be born alive or, once born, how long their child has to live.

Prognostic uncertainty/ambiguity: *“We know Gemma is seriously ill, what lies ahead is uncertain, however we can and will support you into the future.”*

Strong emotions: *“I can see you are both distraught, I can't imagine what you are going through, what's been happening for all of you recently?"*

Complexity and discussing difficult topics: *“Would Daniel wish to discuss Gemma's condition and future? If so how can we assist with this communication?”*

Excerpts from the module: Preparing for challenging conversations

Certainly, clinicians can be prepared for these challenging end-of-life care conversations by incorporating these essential factors into their communication: [7]

Emotions: *"I can see you are going through so many feelings."*

Regret: *"I'm sorry it is so hard for all of you right now."*

Hope: *"We are here with you, we'll keep doing our best for Gemma here and now."*

Quality of life: *"We'll do the best we can to keep Gemma comfortable and ensure you have as much time with her as possible."*

Resilience: *"You have all been through a lot and you have supported each other."*

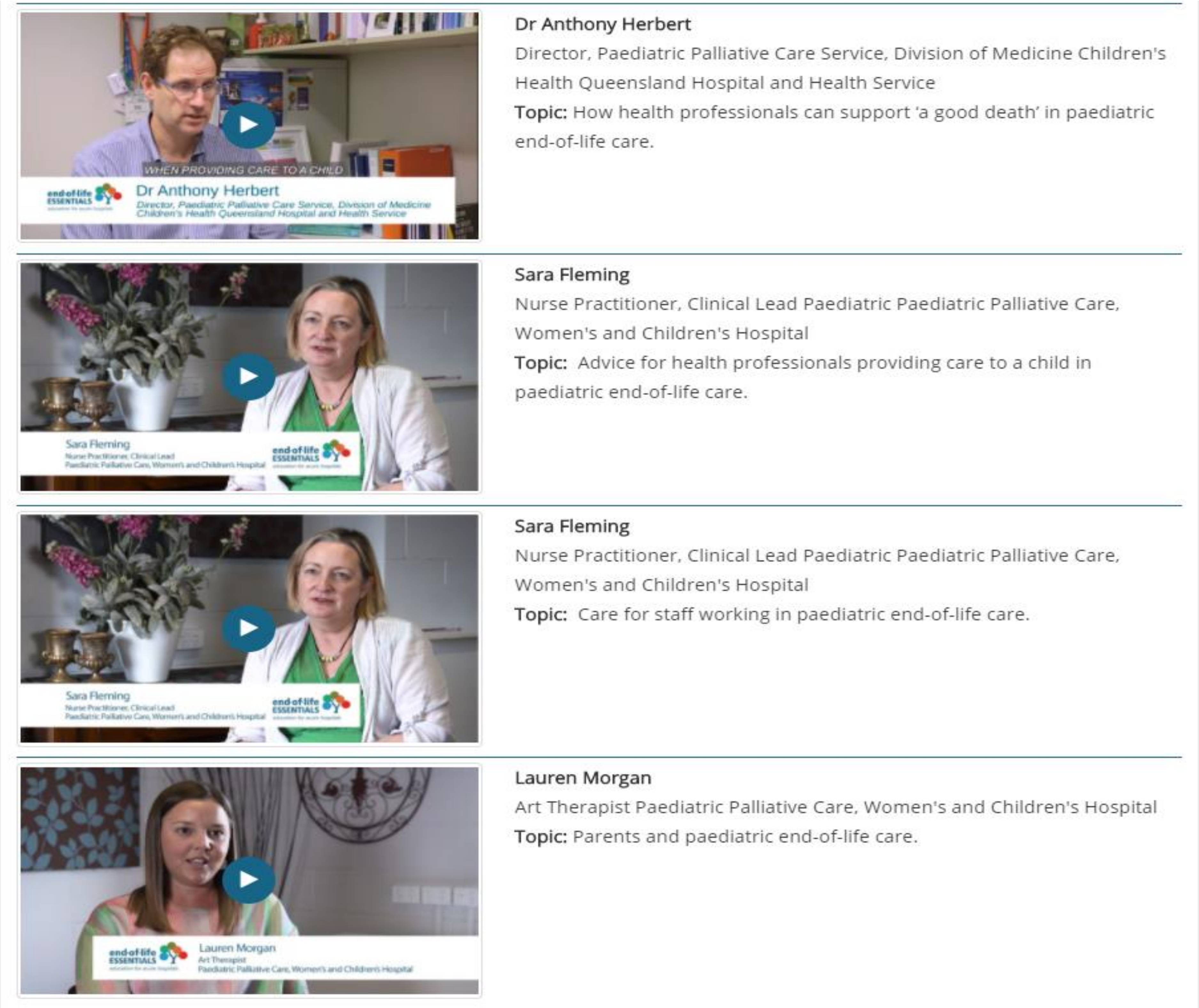
Relationships: *"You have all worked so well together to keep caring for Gemma."*

Over and above all else, your role is to support parents. Whether to disclose a prognosis to a child can be an enormously difficult decision for parents.

There is no one right way – some parents will want to discuss with their child that she is dying and others will not. You can support parents with their individual approach in discussing or not.

In your clinical practice, this may mean you putting aside you own preference and supporting parents, even if their decision opposes your own.

Video resources

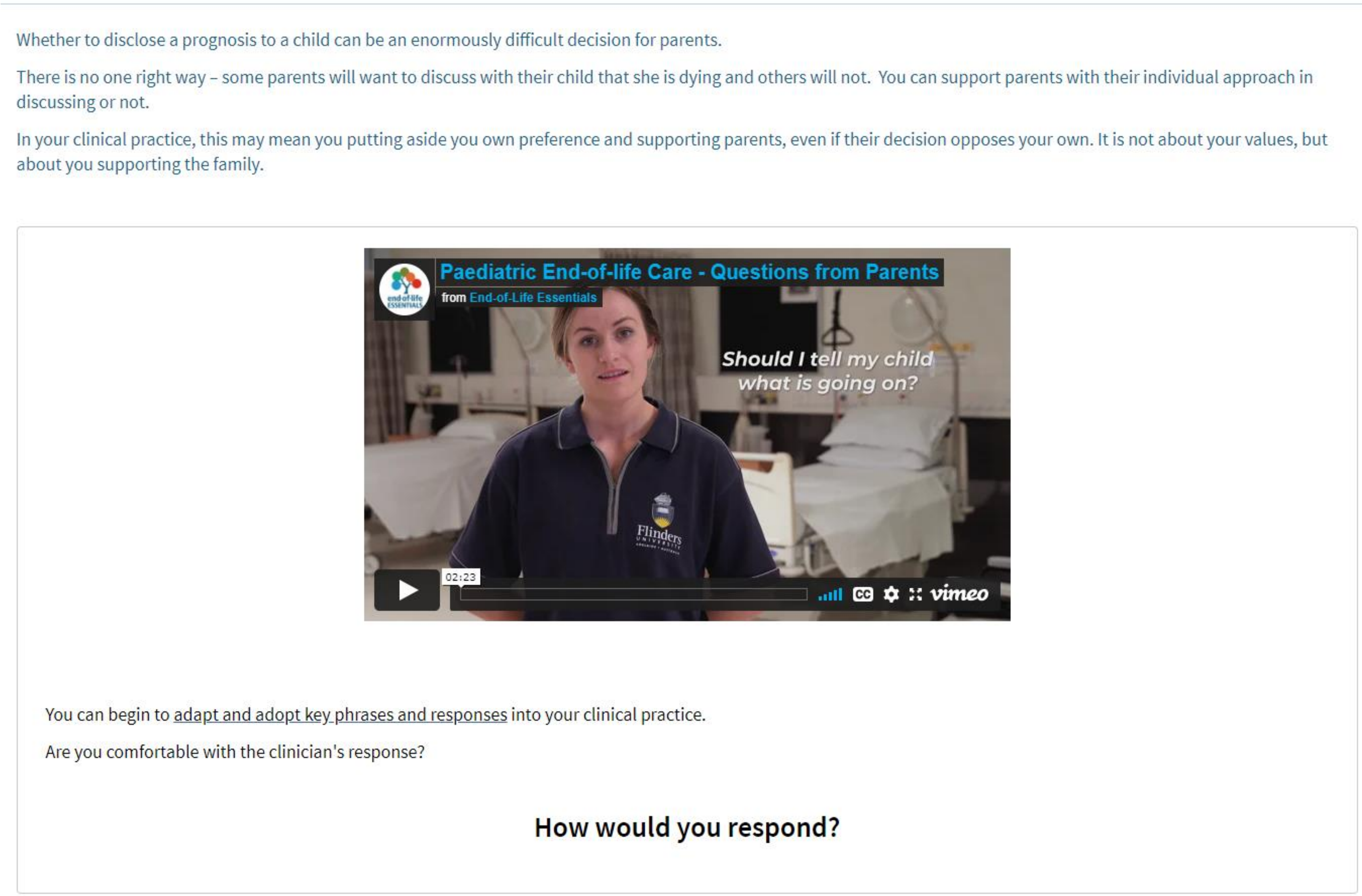


Dr Anthony Herbert
Director, Paediatric Palliative Care Service, Division of Medicine Children's Health Queensland Hospital and Health Service
Topic: How health professionals can support 'a good death' in paediatric end-of-life care.

Sara Fleming
Nurse Practitioner, Clinical Lead Paediatric Paediatric Palliative Care, Women's and Children's Hospital
Topic: Advice for health professionals providing care to a child in paediatric end-of-life care.

Sara Fleming
Nurse Practitioner, Clinical Lead Paediatric Paediatric Palliative Care, Women's and Children's Hospital
Topic: Care for staff working in paediatric end-of-life care.

Lauren Morgan
Art Therapist Paediatric Palliative Care, Women's and Children's Hospital
Topic: Parents and paediatric end-of-life care.



Whether to disclose a prognosis to a child can be an enormously difficult decision for parents.

There is no one right way – some parents will want to discuss with their child that she is dying and others will not. You can support parents with their individual approach in discussing or not.

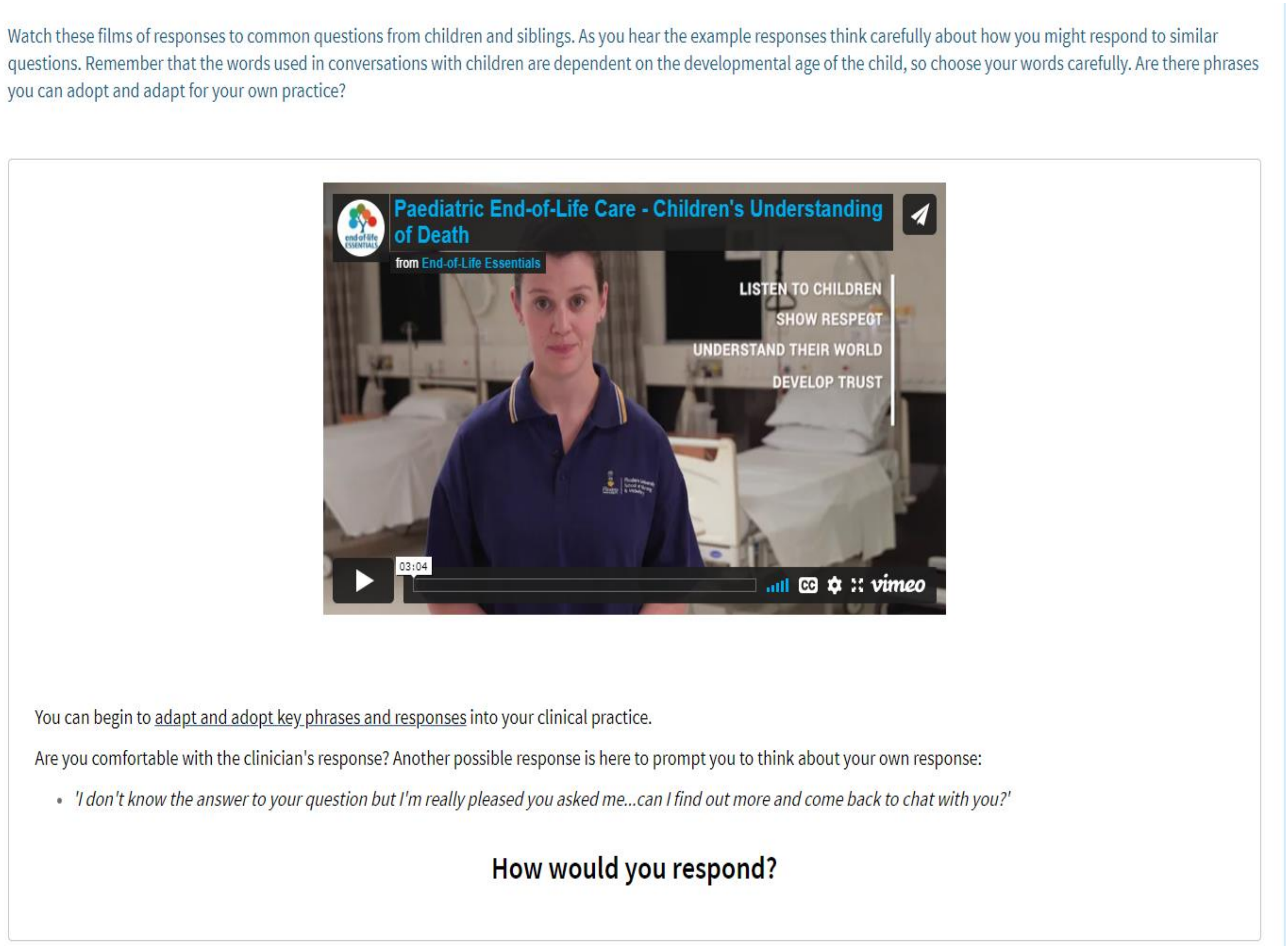
In your clinical practice, this may mean you putting aside you own preference and supporting parents, even if their decision opposes your own. It is not about your values, but about you supporting the family.

You can begin to adapt and adopt key phrases and responses into your clinical practice.

Are you comfortable with the clinician's response?

How would you respond?

Deb Rawlings



Watch these films of responses to common questions from children and siblings. As you hear the example responses think carefully about how you might respond to similar questions. Remember that the words used in conversations with children are dependent on the developmental age of the child, so choose your words carefully. Are there phrases you can adopt and adapt for your own practice?

You can begin to adapt and adopt key phrases and responses into your clinical practice.

Are you comfortable with the clinician's response? Another possible response is here to prompt you to think about your own response:

- *'I don't know the answer to your question but I'm really pleased you asked me...can I find out more and come back to chat with you?'*

How would you respond?

Methods

Mixed methods approach [2]

Evaluation research with questions derived from the education modules [3]

Pre- test/post- test data (knowledge, skills, attitudes, confidence) are collected routinely for each module (not presented here)

A question '*What is your biggest challenge when engaging with a dying child and supporting families and friends?*' is also asked at the end of this module

Ethical approval was obtained from the Flinders University Research Ethics Committee (Project 7012).

Qualitative thematic analysis

- Open-ended question: ***'What is your biggest challenge when engaging with a dying child and supporting families and friends?'***
- n=395 participants statements analysed in Nvivo
- Main categories and themes summarised
- Two overarching categories were 'Dealing with emotions' and 'Communicating effectively'

Dealing with emotions (n=254; 64.3% of participants)

Managing own emotions

e.g. becoming overwhelmed, emotional involvement, own feelings of sadness.

“trying to be professional while holding back my own emotions”

“Biggest challenge is keeping own emotions in check”

Providing adequate emotional support and comfort

e.g. comforting the family, showing empathy, providing the support that they need.

“Supporting the family in a meaningful and genuine way.”

“wanting to provide space to allow for grieving, though also wanting to assure my presence and if there are any needs or requests they can be fulfilled.”

Dealing with emotions (n=254; 64.3% of participants)

Witnessing the emotions and grief of families

e.g. heightened emotions, pain, loss, and grief of parents.

“Dealing with the immense emotions associated form direct and indirect family is huge”

“Seeing the devastating fear in parents’ eyes”

Unfairness/unnaturalness of the death of a child

e.g. death is far too soon, parents should not outlive their children.

“The loss of a future for that child.”

“My biggest challenge is the simple fact that it is a child and on many moral levels, parents are not to bury their children.”

Dealing with emotions (n=254; 64.3% of participants)

Being a parent

e.g. thinking about own children.

“I can't help but think about what it would be like for one of my children to die.”

“Since having children I find it difficult not to put myself in the parent's situation.”

Feeling helpless or inadequate

e.g. cannot change the outcome or fix the situation.

“I feel as though nothing I can say or do will help to lessen their hurt and anger with the situation.”

“I feel so inadequate because I cannot change the outcome.”

Communicating effectively (n=140; 35.4% of participants)

Answering questions, knowing what to say

e.g. knowing the right words to say, responding to questions from family.

“Knowing how to respond to on-the-spot difficult questions from family members correctly”

“Knowing what to say, and when to say it.”

Being honest about the child’s prognosis

e.g. talking about dying, discussing the child’s condition with the child and family.

“Communicating about death with that child”

“Having to provide honest answers which involve sharing the reality of the child’s condition.”

Communicating effectively (n=140; 35.4% of participants)

Discuss goals of care, respect and incorporate family's needs and wishes

e.g. involve family in care discussions, respect parents' decisions.

"Having a clear understanding of their wishes, worries, what's important to them as a family unit. Respecting their wishes and not putting your own beliefs ahead of theirs."

"setting goals of care. Family to be involved. Encourage siblings to voice their concerns."

Discussion

All health care professionals require support in the care of children who are dying, with care taking place in many settings, not just in specialized palliative care units [4]

Caring for dying children can be stressful / challenging [5,6]

Principles of family centred care underpin paediatrics [7] and intrafamily communication is important [8]

Managing emotional responses can be a balance (empathy, own distress) [9]

Conclusion

Providing quality care for children dying in hospital is challenging.

Health professionals working with dying children can benefit from targeted resources addressing knowledge gaps.

The paediatric EOLE module is an important resource for hospital staff working with dying children and families. Findings identify areas that if addressed may improve the quality of end of life care for children in hospitals.

End of Life Essentials would like to thank the many people who contribute their time and expertise to the project, including members of the National Advisory Group and numerous peer reviewers.
www.endoflifeessentials.com.au

Quality of Care Collaboration Australia (QuoCCA)

https://www.caresearch.com.au/quocca/tabid/4509/Default.aspx

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