

Conversation Starters

A worksheet to accompany the video 'Walking Alongside: a guide for health professionals caring for a dying child.'

About this worksheet

This worksheet is designed for health professionals who do not regularly encounter paediatric patients with life-limiting illnesses and/or paediatric deaths. It accompanies the 'Walking Alongside' video, which presents the insights of a group of professionals that regularly cares for patients in these situations (e.g. specialist palliative care and paediatric oncology teams).

The group was interviewed about issues that arise while engaging in this kind of care, and optimal ways to frame thoughts and adjust one's own behaviour in emotionally challenging situations. Key themes that emerged from the discussion include trust, safety, vulnerability, hope, uncertainty and connectedness.

The following questions are based around these themes. They're designed to help you and your colleagues begin a conversation with each other. We hope they'll prompt reflection and help you consider how you might shape your own interactions with families, for emotionally healthier outcomes for you and for them. As everyone's experiences will be uniquely their own, there are no right or wrong responses.

Themes for discussion

TRUST

***"Trust builds from Day One.
You just need to keep building it, re-visiting it and checking in."***

Consider your experience of walking alongside families. What mechanisms do you use to build trust between yourself, patients, their family and friends?

"You develop different relationships with different people. Some are looking to you to be very professional at all times and collaborate at maintaining a professional distance. Then there are those families who you connect with more deeply and need you to be more involved."

What do you feel would be the opportunities and challenges for health professionals in working with families in each of these situations?

SAFETY

***“It’s about helping families feel safe in a world that’s suddenly unsafe.
No matter what the prognosis is.”***

In this quote the concept of emotional safety is raised. What does the concept of emotional safety mean to you? How can health professionals maintain emotional safety for themselves when engaging in difficult experiences and conversations with families?

***“I’m always asking, ‘How can we make them feel as safe as we can?’
Compassion is the key. Quiet spaces, little practical things, the language
we use – this is all important.”***

Consider the environment you work in. How might you create a sense of safety and security for families and health professionals in your work setting?

***“How do you address what people are thinking about but not saying?
What’s left unsaid can follow on and linger.”***

Broaching the topic of poor prognosis and preparation for end of life can be difficult for health professionals as well as the family. How could you introduce these topics with a family while maintaining safety within the relationship?

HOPE

“For parents, there’s that idea of being hopeful for the best outcome, and also preparing for the worst possible scenario.”

How can you as a health professional hold the tension between the reality of a child’s prognosis and a family’s need to maintain hope?

“When the future is not looking good, some people need to prepare and some prefer to keep riding the rollercoaster.”

Hope can present differently between families and individual family members. What are some of the different ways you have observed families maintaining hope during difficult times?

VULNERABILITY

“In a way, you have to be confident about feeling vulnerable. It’s okay to be a frail human being.”

What does vulnerability mean to you? How do you think expressing your vulnerability as a health professional can enhance the relationship between a patient, family members and health professionals?

“We have access to counselling through the workplace. But you need to be able to recognise the stress as it creeps up on you.”

Feeling some vulnerability in the context of a dying child is expected. What steps would you take to ensure a balance between feeling emotionally vulnerable and maintaining professional boundaries? What role does self-care play here?

UNCERTAINTY

“It’s about knowing the right questions to ask, but not having all the answers.”

What situations have you found yourself in where you simply couldn’t provide a clear answer for a patient or family member? How was this experience for you?

“It’s good to have awareness of your uncertainty. Don’t fall into the trap of trying to find certainty and dictate ‘how things should be’. Uncertainty is a resource.”

How can health professionals convey uncertainty in a way that does not detract from building a trusted relationship with a patient or their family members?

CONNECTEDNESS

“You never forget any of the children who’ve died. You remember every one.”
“We try to honour the child by taking what’s happened, what we learned, and transferring it to the next child and family – it’s cumulative.”

What is your experience of working through the death of a patient? What was the professional and personal impact of this for you?

“The longer you’re a staff member in the same place, the more families you establish connections with – the more overwhelming it can feel to provide those families with what they need.”

What unmet needs do you feel families have in bereavement? What steps can you and your team take to meet the needs of bereaved families? How might you and/or your team honour a child after they have died and their family?

“I got feedback from a past client of the hospital and she emphasised the importance of me having known her daughter while she was alive.”

What are some ways you could show families that you still remember them and their child?

“We can’t stop what’s going to be a difficult time for them. Grief does hurt, it is going to be a struggle, it’s going to be difficult ... Medication can’t take that away.”

What meaning do you derive from working as a health professional?

“It’s a privilege to be with parents as they walk through their grief.... It means so much to see them regain function, joy and purpose beyond their child’s death.”

How do you feel having a sense of meaning can support health professionals working with a dying child and their family and bereaved families?

Background

Conversations with parents about their child's dying are never going to be easy.

Many health professionals haven't been trained in this kind of care and can find it confronting. If you don't experience paediatric deaths very often in your work, the best way to gain an understanding of that experience is to listen to other professionals who have been there before.

This kind of communication with parents shouldn't be limited to families whose child's illness has been pronounced incurable. Research tells us that the interactions parents have with health professionals in the community and in hospital - from the point of diagnosis onwards - has a considerable impact on their experience of bereavement.

There is a perception that specific professions are responsible for family members' wellbeing around end-of-life and bereavement: social workers, palliative care and bereavement specialists. In reality, whichever stage you meet a family during their child's illness, if the child dies the memory of your interactions and relationship as a health professional may become part of the family's experience of bereavement. Compassionate care is everyone's business.

The Compass study: research into resources

The 'Walking Alongside' video emerged from the University of New South Wales (UNSW) 'Compass' study led by Dr Leigh Donovan from 2012 to 2016. Proudly supported by the Kids Cancer Centre, Sydney Children's Hospital, Cancer Council NSW and UNSW, the mixed-methods study explored the experiences of parents whose child had died from cancer in Australia. Over 100 parents generously shared the story of their child's cancer experience, end of life and their family's journey into bereavement.

The study found that parents whose child dies from cancer experience complex layers of loss: loss of their child, of pre-existing formal and informal relationships in their community, and the loss of what some term, the 'hospital family'.

Through a partnership with Redkite, the voices of those parents were brought to life through the publication of the book 'By My Side', and an accompanying animation. Both support resources are designed to help bereaved parents feel less isolated and to provide guidance and insight for family and friends. These resources are freely available at www.redkite.org.au/bereavement



Walking Alongside Video
- for health professionals



By My Side Book
- for bereaved parents



By My Side Video
- for bereaved parents

The Compass study findings also highlighted the important role of the health care team. Participants in the Compass study spoke about the trusted relationships they built with health professionals who 'became like family' throughout their child's cancer care trajectory. Parents also noted times when these relationships were lacking and the long term impact this had for them when their child died.

The 'Walking Alongside' component of the project is designed to support health professionals to reflect on their role in families' lives following a diagnosis of childhood cancer. With Redkite's support a focus group was convened, comprising diverse health professionals with extensive experience caring for children and families from diagnosis through treatment, palliation and bereavement. The group discussed the Compass study findings and responded to questions about how they engaged with these families. Their insights were thematically analysed and translated into the 'Walking Alongside' video.

You can access the above resources at www.redkite.org.au/bereavement

Further resources

We hope this exercise has been helpful for you.

If you or your health care team would like more information about walking alongside a dying child and their family, you may like to continue this conversation with the following organisations.



The Paediatric Palliative Care Team in your state - contact details and additional resources can be found at:
www.palliativecare.org.au/children



Quality of Care Collaborative Australia project - delivering education in paediatric palliative care to health professionals in urban, rural, regional and remote areas
www.caresearch.com.au/quocca



Caresearch - palliative care knowledge network
www.caresearch.com.au



PCC4U - palliative care curriculum for undergraduates
www.pcc4u.org



The Australian Centre for Grief and Bereavement - provider of grief and bereavement education
www.grief.org.au

Redkite's experienced social work team provides free, confidential support for health professionals working in the field of paediatric and AYA cancer. This includes support around a patient's death and a family's bereavement.

www.redkite.org.au | support@redkite.org.au | 1800 REDKITE (1800 733 548)

