

An Overview to Family Meetings and Difficult Conversations

The care of a child with a life-limiting illness involves many potentially difficult conversations. Whilst health professionals cannot take away how these discussions may make the family feel, it is important to ensure the family feel heard, the information has been understood and the family feel cared for and respected.

Family meetings are one way to empower and support the family and offer an opportunity to share and clarify goals of care and other information. Family meetings should take place in a safe environment where people are able to raise their questions and concerns with representatives from their care team. If there is likely to be extensive discussion between health professionals regarding the medical status of the child, this should be done before meeting with the family.

The care of a child with a life-limiting illness can require a number of difficult conversations. Whilst bad news must be given and extraordinary decisions need to be made, this can be a very challenging thing for health professionals to do. Families need honesty, respect and time so it is important to ensure that they feel they have been heard and cared for. Health professionals should approach these conversations with courage, integrity and empathy. For health professionals who are uncertain about how to best approach these conversations, ask for assistance from a senior staff member.

Preparing for the meeting

It is important to be well prepared before the actual meeting, below are some things that may need to be considered before meeting with the family:

- › Take time to read over medical & psycho-social handover
- › Consider preparation around any known cultural & religious backgrounds
- › Identify who informs the family of the potential meeting / catch up
- › Identify who from the care team will convene and organise the meeting. Generally, this is the person who speaks to the family about the meeting
- › Clarity the reason for meeting so as not to cause the family unnecessary stress
 - » They may have experienced difficult or “bad” meetings in the past
 - » Ask the family to think about any concerns they may like to raise and if they would like additional support available so they feel their voice will be heard

- » Ask the family who they think should be there, including whether the child / young person should be present in the meeting
- › Organise interpreter, as required.

The initial family meeting

Family meetings should not just be in response to 'crisis' situations and instead should be considered as part of routine practice. This approach may not only build respect and trust with the family but also assist with health professionals to continue to develop their communication skills and build professional relationships with the family. Below are some points to consider for hosting the initial family meeting:

- › Involve the key care teams, a social worker should be present, if possible. Identify a primary lead for discussion prior to commencing meeting
- › Clarify the family's understanding of the child's current condition with a parent summary
- › The care team should provide an update on the child's current condition with a medical summary in a way the family can understand. This may include a discussion of the child's current prognosis
 - » Allow time for the family to ask questions. Also allow time for pauses and recognise emotions that are expressed during the meeting.
- › Introduce the concept of end-of-life care, if appropriate
- › Explore the child and family's goals and wishes, acknowledging these may change over time
- › Address any fears the family may have, as appropriate
- › Discuss the options available to the child and family based on current condition and the family's goals and wishes
- › 'Pop-up' models of care and telehealth may need to be considered to support community teams
- › There should be clearly documentation about the meeting, this may include: who attended, their relationship, the issues discussed, the outcomes, who is responsible for following up, and any plan for future meeting/s.

It may be helpful to discuss current preferences by using possible scenarios, these may include:

- › Preferred place for end of life. Where would the family like this to be, knowing that they can change their mind? If not a hospital or hospice then consideration will need to be given on what the discharge will look like and who is responsible for the discharge planning
- › Discuss the timing of death (e.g. imminent, hour, day, weeks, or months of survival) and the uncertainty around this
- › Explain the possibility of the child living longer than expected and what this may entail (i.e. parallel planning)
- › Discuss current and anticipated symptoms and clinical management (e.g. a continuous subcutaneous infusion managed in the home by community health care teams).

Follow up post meeting

There are a number of things that will need to be followed up after the meeting, these may include:

- › Identify who is responsible for following up with the family
- › Check in with the family and see how they are feeling after the meeting and if they have any concerns, questions, or points they would like to clarify
- › Confirm the timeframe until the next meeting, as required.

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Subsequent family meetings

Below are some suggestions for consideration for subsequent family meetings:

- › Where possible it is helpful to have subsequent family meetings
 - » This could be on a weekly basis for a child who is having a prolonged hospitalisation, or on a daily basis for a child who is deteriorating rapidly
 - » Family meetings may become a series of meetings, rather than a single event and their content can evolve, and style of communication be tailored to suite the family's needs (e.g. some family's prefer smaller meetings in terms of number of participants)
- › Explore family's goals (e.g. tissue donation, funeral wishes)
- › Clarify family's understanding
- › Discuss concept of end-of-life care
- › Discuss current and anticipated symptoms at end of life and symptom management
- › Address and questions or concerns.

S P I K E S Model

Some health professionals may find it useful to use a model to assist in undertaking a difficult conversation, one example is the SPIKES model,¹ which is outlined below.

S — Set up

The pre-planning of a meeting is just as important as the meeting itself. Identify who is responsible for informing the family of a meeting and make time to:

- › Clarity about reason for meeting so the family don't stress (may have experienced difficult or "bad" meetings)
- › Ask family to think about issues they may like to raise
- › Ask the family who they think should be there. Ensure appropriate supports are available for the family (maybe a friend, relative or trusted staff member)
- › Organise interpreter, if required.
- › Ensure a private and quiet space is available where all can sit down. Offer a cool or warm drink and ensure the room has tissues within reach
- › Minimise interruptions — keep phones outside if possible.

If multiple teams are involved, arrange a time to meet beforehand to ensure consistency in the information to be given and to appoint someone to lead the discussion.

When sitting down, think about who sits where. Ensure the space feels supported and avoid professionals on one side and family on the other.

P — check perception

Find out what the family understands about the situation currently.

I — invitation

Let the family know that some of what you have to say may be difficult for them to hear. Find out if it is okay to discuss such things right now.





'Book Bunker' by Marlie

K — give knowledge/information

Provide information in small chunks. Try to speak in plain language. Stop at regular intervals and check understanding. Be aware that your own anxiety may lead you to speak quickly and in too much detail and that you may revert to the comfort of technical language.

E — respond to emotion

It is hard for parents to process information when they are frightened or very sad. Allow room for the expression and acknowledgement of emotion. Sit with it. If you feel confident, respond to the emotion.

The mnemonic 'NURSE' suggests five possible ways of responding:²

- › **Name:** State the emotion (if you are not sure, you can say, 'I'm wondering if you are feeling x')
- › **Understand:** Empathise with and legitimise the emotion (be careful not to say, 'I understand', because you don't)
- › **Respect:** Praise the parent for their strength or honesty
- › **Support:** Show support
- › **Explore:** Ask the person to tell you more about what they are feeling.

You may be the only person in their circle who can allow them to share how they feel. You don't need to 'fix it'.

S — Summarise

Provide a brief summary and ask the family if they have understood. Make a plan even if it is only to keep talking. Ensure they know there will be opportunities to speak again and to ask questions. Acknowledge their courage.

When talking with parents about their child's illness and trying to get a sense of their values, fears and hopes, Associate Professor Joanne Wolfe from the Boston Children's Hospital uses five 'cardinal questions'.³

- › Who is your child (as a person)?
- › What is your understanding of your child's illness? What does the illness mean to you and your family?
- › In light of your understanding, what is most important regarding your child's care?
- › What are your hopes for your child? What are your fears and concerns regarding your child?
- › Where do you find support and strength?

These questions are gentle and exploratory and the responses are often very illuminating.

For additional information on communication in paediatric palliative care, please visit the Quality of Care Collaborative Australia (QuoCCA) website at caresearch.com.au/caresearch/tabid/4483/Default.aspx

References and Resources

1. Baile WF, Buckman R, Lenzi R, Glober G, et al. SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer. *The Oncologist* 2000; 5: 302-311.
2. Pollak KI, Arnold RM, Jeffreys AS, et al. Oncologist communication about emotion during visits with patients with advanced cancer. *J Clin Oncol* 2007; 25: 5748- 5752.
3. Waldman E, Wolfe J. Palliative care for children with cancer. *Nature Reviews Clin Onc* 2013;10: 100-107.