End-of-Life Location

Discussion reflections, prompt and support guide for health professionals

Paediatric Palliative care
NATIONAL ACTION PLAN PROJECT

Palliative Care Australia have developed resources to help you have compassionate discussions with a family about where their child will spend their final days. This is not an exhaustive list, however, it may help you to prepare for these difficult conversations.

We encourage you to also watch the two videos which have been developed – one from the families perspective and one from the health professionals perspective as well as read the two stories from a family whose children had their final days at home and another family whose child spent his final days in a hospice.

Please remember when watching the videos or reading the written stories to take care of yourself and seek out support from your palliative care team colleagues or other health professionals. This checklist should serve as a guideline, allowing flexibility based on the unique needs and dynamics of each family and child receiving palliative care.

How confident are you in having conversations about end-of-life location choices with families?

No matter the choice, the most important thing for you to do is to speak honestly about the considerations for each location. Below are some communication guidelines to help you have compassionate, honest and effective conversations about the end-of-life choices a family makes.

End-of-Life Location Checklist

- ☐ **Establish trust:** Prioritise building a trusting relationship with the family to foster open and honest communication. Ask questions, listen deeply, hold no judgement.
- ☐ **Assess family's understanding:** Gauge the family's comprehension of the child's condition and prognosis before discussing end-of-life options.
- ☐ **Timing:** Choose an appropriate time to discuss end-of-life location options, ensuring the family is emotionally prepared and receptive.
- ☐ **Sensitive approach:** Use compassionate and sensitive language, acknowledging the emotional difficulty of the topic.
- ☐ **Invite questions:** Encourage questions from the family, ensuring they feel comfortable seeking clarification and expressing concerns.
- ☐ **Explain available options:** Clearly explain various end-of-life care settings such as hospital, hospice, home care, or specialised facilities. In particular discuss what services are available in your local area.
- ☐ **Discuss location options:** Outline the advantages and disadvantages of each option, considering the child's comfort, family's emotional needs, and practical aspects. Never assume what a family's chosen location will be.
- ☐ **Consider child's wishes (if applicable):** If the child is able to participate in decisions, consider their preferences regarding the location of care. See Rudi's story.

- **Explore family's preferences:** Understand the family's preferences and values regarding the child's care and their own emotional needs.
- **Address practical considerations:** Discuss logistical aspects including available resources, support services, and medical care available at different locations.
- **Emphasise comfort:** Highlight the importance of the child's care and comfort in the chosen location.
- **Provide emotional support resources:** Offer information about counselling, support groups, or other resources available to help the family cope with emotional challenges.
- **Respect cultural and religious beliefs:** Acknowledge and respect cultural or religious considerations that may influence the family's decision-making. It's ok if you don't know the answer to something the family is asking. But have the kind of compassion and care that allows you to find out, and follow through.
- **Collaborate with the care team:** Co-ordinate discussions with other healthcare professionals involved in the child's care to ensure a unified approach- beware of bias, agenda and judgement.
- **Documentation and legal aspects:** Explain the necessary documentation and any legal aspects involved in choosing an end-of-life care location. Make sure a family knows exactly what to do after a child dies and who to call.
- **Create a care plan:** Collaborate with the family to develop a comprehensive care plan that addresses the child's medical, emotional, and spiritual needs- *note, some families do not want a care plan, and this is a plan in itself.
- **Review and revisit options:** Offer to revisit the discussion or adjust the plan as the child's condition changes or if the family's preferences evolve. Changing your mind is not failure.
- **Ensure family's informed decision:** Confirm that the family comprehends the information provided and feels empowered, safe and supported to make an informed decision. Their decision may differ from what you think is. As long as the family has full understanding of the impact of their decision, your role is to support them through it.
- **Offer continued support:** Assure the family of ongoing support regardless of the location chosen for end-of-life care.
- **Final days and moments:** Have a conversation with the family about what they want to be doing for their child in the final days and moments. Understand that parents and families go through a significant transition of being a 24/7 carer for their child, to slowly starting to turn medical supports off. Many families at this point just want to be a parent for their child and spend time with them. See Jess's story and Maria's story about her daughter Tiarna, where healthcare professionals were able to wrap care and love around these two families so they could just be with their children without the additional burden of medical care.
- **Follow-up:** Schedule follow-up meetings to address any further questions, concerns, or changes in the child's condition and revisit the care plan if necessary and remind the family that the palliative care team is there to support them.

This project received grant funding from the Australian Government