

End-of-Life Location

Discussion reflections, priorities and question prompt list for families



**Paediatric
Palliative care**
NATIONAL ACTION PLAN PROJECT

Palliative Care Australia have developed resources to help you with having the difficult discussion on where your child will spend their final days. This is not an exhaustive list, however, it may help you to prepare for this conversation.

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. In order to be supported best, a palliative care team will need to know what is important to you as a family.

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 or other health professionals.

Considerations to reflect on when working with a palliative care team

- What most matters to you in end-of-life care?
- What do we need to know about your family?
- Who are the most important people you'd like to be with you?
- Do you have any cultural or religious practices that we need to understand in order to support you best?
- Do you have any emotional needs? How are you feeling?
- Do you have any spiritual needs? How can we best support you in this area of your life?
- What are your physical needs? Is there anything that we can provide you with?
- How can we best support you psychologically?
- Do you feel like you are able to communicate honestly what is going on for you?
- How can we best support your wellbeing?
- What are your social needs?
- Who else needs to be part of your support team?
- What are your biggest fears?

Important things to consider and ask of your team around you

- When is the right time to talk about end-of-life care?
- Who do I talk to?
- What are my options?
- Will I be judged for my choices?
- What do we need to know about each location option?
- Can I change my mind and choose a different location as the final days get closer?

Considerations when choosing the hospital as a location (see Jess's story and a story from an anonymous mum)

- > How well do you know the team – have you developed a good relationship with the team?
- > Have you had frequent visits to the hospital and know the hospital layout?
- > How does my child react/behave when they are in hospital?
- > Can my extended family come and visit? What are the restrictions?
- > What about after death care – how long can we stay with our child?
- > Who will support us?

Considerations when choosing home as a location (see Rudi's story)

- > Do we have support from other family members to care for our child at home?
- > What other support do you have in place, such as carers?
- > Do I need equipment that can't be accommodated at home?
- > How comfortable am I taking on some of the medical roles?
- > Have I understood the emotional impact that providing medications may have on myself and family? (See Maria's story)
- > Do we have local services that can support us?
- > Do we have after hours numbers?
- > Is my child stable to be transferred home or back to the hospital if we need that option?

Considerations when choosing hospice as a location (read Ryan's story)

- > Have we stayed in the hospice for respite care? Is this a familiar environment?
- > Can we visit and check it out?
- > How far away from our social/spiritual support network is the hospice?
- > Do we have a children's hospice in our area? If not does the adult service have an option for children's end of life care?
- > Is there privacy?
- > What are the options for visiting family and friends?
- > What does after death care look like at hospice?