

# Supporting children at end-of-life



the Grief-Sensitive  
Healthcare Project

[griefsensitivehealthcare.org](http://griefsensitivehealthcare.org)

## Pediatric end-of-life care is inherently challenging.

When a child is dying, it's normal to have a range of emotions. It may feel as though the "natural order of things" has been disrupted, or it may feel as though we have not achieved our original treatment goals. It's no wonder that it can be difficult to communicate during pediatric end-of-life care. Importantly, though, research and clinical experience with families indicate that candid, compassionate communication is important to end-of-life care, especially in pediatrics. Here are some tips for working with children during end-of-life care.

### Involve the child

When developmentally appropriate, children benefit from being informed and involved during the end-of-life process and early in treatment when possible. However, it is always important to respect caregiver values around the level of child involvement.

### Identify key support providers early

When giving a difficult diagnosis or prognosis, it can be helpful to have someone present who has good rapport with the child and family, and who has been involved regularly in their care. Consider collaborating with palliative care early in a child's treatment.

### Engage the child in advanced care planning

Resources such as *My Wishes* (children) or *Voicing My Choices* (teens and young adults) can be useful tools to engage in advanced care planning with pediatric patients. Involvement in decision-making can be empowering when age appropriate.

### Consider the child's viewpoint

Examples of what a child might be thinking or feeling:

- *Fear, Anxiety, Sadness*
- *What is going to happen to me?*
- *Can I cope?*
- *Can my family cope?*
- *What is the dying process like?*
- *Will it hurt?*

### Legacy planning

*Creating legacy projects can be meaningful for some children and their families during end-of-life care. Children may be comforted by making things that their loved ones can see and hold after they have died.*