

Supporting families when a child is at end-of-life



the Grief-Sensitive
Healthcare Project

griefsensitivehealthcare.org

When a child is going to die, their family needs thoughtful care, too

Parents and caregivers of dying children are essential to a child's end-of-life experience. Care received during end-of-life treatment contributes to how caregivers and family members cope when a child dies. Here are some tips to help navigate your work with families when a child is at end-of-life.

Educate

- Caregivers should be informed of what to expect during the dying process and what medical care will be provided.
- Address symptoms. Both caregivers and healthcare providers rate *pain* as the symptom that is most distressing to witness and treat in children.
- Use clear language and avoid euphemisms. For example, use words like *death*, *cancer*, *dying*, *dead*, *stopped working* rather than terms like *lost* or *passed away*.
- Affirm and reassure that parents are doing everything that they can to support their child at end-of-life.
- Revisit information. Stress surrounding diagnosis of a serious medical condition is associated with poor retention of information by patients and families. It's important to check in regularly.

Collaborate

- Caregivers may struggle with the loss of their role as protector. The caregiver-child relationship can be facilitated by active and continuous caregiver involvement in patient care.
- Involve caregivers in decision-making when possible. For example, identify the preferred location of death (e.g., home, hospice) and be considerate of logistics.
- Incorporate caregivers' support network(s) during the end-of-life process since the relationship with the medical team often ends fairly abruptly when a child dies.
- Identify ways to engage caregivers in their child's care. Invite caregivers to help their child create a warm environment when receiving treatment away from home.
- Support spiritual or cultural rituals.

Navigate roadblocks

- Reflect on differences between caregivers' and clinicians' understanding of a child's prognosis: *Might they be confused or uncertain about the treatment plan? Am I communicating clearly?*
- Lack of caregiver readiness to have the discussion: It can be difficult for parents to transition from treatment-to-cure to treatment-to-comfort. Are there additional supporters that can answer questions and aid in this transition?
- Consider whether caregivers are receiving adequate support: It may be helpful to encourage respite for primary caregivers.