

PHILOSOPHY OF CARE



The key is being non-judgmental, non-directive, consistent and flexible.

- Talk families through their decisions so they understand options. Assure them that they are protecting their child's comfort and the wellbeing of their family, and doing the best job as parents possible. Ensure that they have no regrets.
- Help families understand that goals and philosophy of care may change over time. Explore this in the hypothetical: "If we knew for certain that no matter what choices we made, this disease will run its course in xx months, what would make the most sense to focus on?"
- Affirm that parents can trust their own ability to know what their child is telling them.
- Introduce palliative care/hospice as services that can complement a family's philosophy of care without implying that they are giving up on their child.
- Some families caring for children affected by incurable neurological disorders decide against technological interventions designed to extend a child's life. Often parents hear, "he needs a G-tube." Strive to instead use language that offers families choices without bias or judgment.
- Families may not be able to voice their unspoken questions about end of life and may need to be offered information. Explore a family's biggest hopes and fears around the end of life for their child to allow them and their caregivers the chance to address them.

The total care of these children has many dimensions. Remember, when there is no good option, there is no wrong answer.

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