

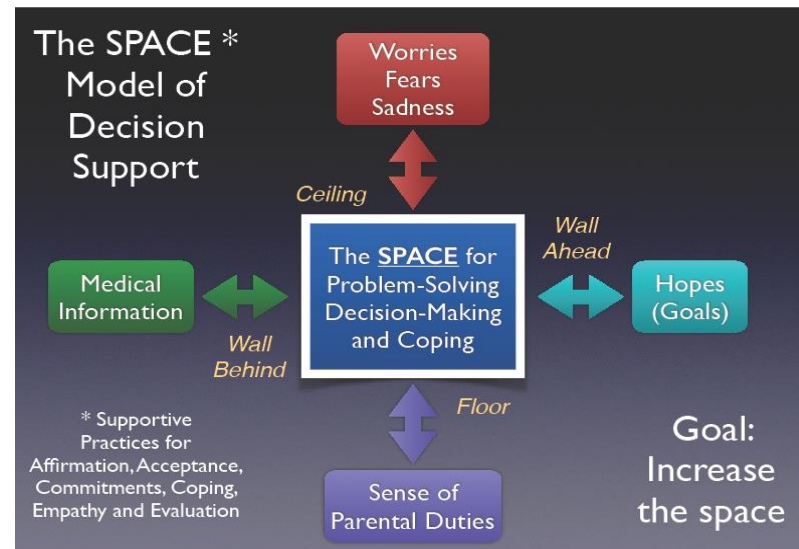
Values-Guided Decision Support

This is not a script. These are suggestions of phrases to weave into a conversation.

1. Tell me about _____. Tell me about your understanding of what she is up against. What have been hardest things for her during these recent days/weeks months? For you and your family?
How does she let you know how she is feeling? How does she respond to your voice, your touch?
2. What are you hoping for? We are as well. If that hope does not occur, what are your other hopes? What else is important?
3. What are you most worried about? What are other people in the family worried about?
4. In this difficult situation, how can you see how to be the best parent for her?
5. Based on what you've told me about your hopes and your worries, and what we know about the situation...
 - a. ...can I make a recommendation? or
 - b.it sounds like what we should plan to do is..... or
 - c.it seems that the best decision to be made is
6. **Most important: A period of silence to listen for agreement or further questions.**

Resources for High Stakes Decision Support:

- October TW, Fisher KR, Feudtner C, Hinds PS **The Parent Perspective: “Being a Good Parent When Making Critical Decisions in the PICU** Pediatric Critical Care Medicine 2014 May; 15(4): 291-298
- Tucker Edmonds B, Torke AM, Helft P, Wocial LD. **Doctor, what would you do? An ANSWER for patients requesting advice about value-laden decisions.** Pediatrics. 2015 Oct;136(4):740-5.
- Feudtner C. **Collaborative communication in pediatric palliative care: a foundation for problem-solving and decision-making.** Pediatric Clin North Am. 2007 Oct;54(5):583-607.
- Wyatt KD, List B, Brinkman WB, Prutsky Lopez G, Asi N, Erwin P, Wang Z, et al. **Shared decision making in Pediatrics A systematic review and meta-analysis.** Acad Pediatr. 2015 Nov-Dec;15(6):573-83.
- deVos MA, Bos AP, Plotz FB, et al. **Talking with parents about end-of-life decisions for their children.** Pediatrics. 2015 Feb;135(2):e465-76.



SPACE Model, courtesy of C. Feudtner