Creating a Learning Opportunity Using the Patient/Family Voice

Topic:

Learning Objectives:

Format:
Consider time, setting, learners (what level(s), mixed audience?), live versus video or reading, formal presentation vs discussion based

How will you frame the learning activity?

What might discussion prompts be (if video or written) or guidance for patient families (if live)?

Resources Needed:

Participant Preparation Needed:

Contingency Planning (what could go wrong):

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Sample Video Narratives:

On Diagnosis
There’s a fine line between Hope and Acceptance (2:42)

On the Medical System
Parents feel pressured to be liked by the medical team. (2:43)

On Decision-Making
You have to make a decision and they’re both bad choices (3:34)

On Having Conversations about End-of-Life with Children
Doctors should know that getting past the fear is the biggest step (1:29)

On Preparing for End of Life
It’s helpful to ask questions about End-of-Life. (2:42)

Sample Written Narratives:

On Helping Children Die the Death They Wish

On Parenting a Child with Life Limiting Disease
Emily Rapp: “Notes from a Dragon Mom” New York Times 2011

Sample Grand Rounds Narratives:

Pediatrics Patients’ Tips for Providers
Matthew’s List of Things that Will Help You Help Other Kids (6:10)

Briana’s What Worked Well, What Could have Gone Better (2:16)