Sedona Montelongo, MAPS, BCC

- Hospital Hospice and Palliative Care
- Children’s National Medical Center
- Fairfax Hospital
- Virginia Hospital Center
- Sophie’s Place www.sophiesplace.com
Be gentle with yourself

- This is a difficult subject
- Be gentle with yourself
- Walk away if necessary
- Read at another time
Objectives

- Address common concerns about discussing terminal illness
  - Should we talk?
  - Could talking be harmful?
  - When should we talk?
  - How should we talk?

- Age appropriate conversations and concerns
Should we talk?

YES!
Could talking be harmful?

- No
- Belief that children will become depressed
- Don’t want to burden them
- Does not take away hope
When should we talk?

- The earlier the better
- Elephant in room
- Children need to prepare
How should we talk?

- Tell them the truth
- Do not assume
- Ask children what they know and what they want to know
- Clarify
- Ask children what they worry about
- Go slow
- Be prepared to repeat yourself
The 6 E’s of communication

- Establish - an agreement concerning open communication
- Engage - the child at an opportune time
- Explore - what the child knows
- Explain - medical information according to her needs
- Empathize - with his emotional needs
- Encourage - reassure him you will support him and always be there to answer questions

Beale E, et al. JCO 2005
Age appropriate conversations

- Infants or very young children
  - Still need conversation
  - Need structure and routine
  - Need continuity of care
  - Same caregivers
  - Lots of cuddling
Children age 5-12

- Magical thinking
- The Year of Magical Thinking-Joan Didion
- No one’s fault
- Punishment
- Can’t catch it
- Use correct terminology
- Avoid Platitudes
Adolescence

- Already facing difficult transitions
- Can make conversations challenging
- Give detailed information
- Peer relationships most important
- Be a good listener
- Respect
- Protect parents
Be prepared for tough questions

- Are you going to die?
- Who will take care of me?
- What will happen to me?
- How will I...
- Mom/caregiver or Dad/breadwinner
- Both parents
Effective responses

- Exploratory responses
  - What are you hoping for now?
  - I want to listen to you, tell me more
  - What concerns you most right now?
  - Can you tell me what has been most difficult for you so far?
  - What do you worry about happening next?
  - You mentioned (name emotion), tell me more about that.

Baile et al
Empathetic responses

- Sitting silently with Child
- I can tell you were not expecting this.
- I am sad too.
- I see this is upsetting you.
- I find this to be very hard too.

Baile el al
Validating responses

- I believe I would have a similar feeling (thought) too.
- Yes, what you said makes sense.
- Your understanding of what I said is good.
- Many patients and families coping with ALS feel the same way.
- I hear you.

Baile et al
Spiritual Beliefs

- Religion and Spirituality
- Magical thinking/set up for anger
- Avoid Platitudes
God is all loving?

- Why did God do this?
- Why would God allow this?
- Why does God want to take my Mommy?
- God already has enough angels.
- I hate God!
- Did Daddy do something to make God angry?
- Did I do something to make God angry?
The Four Things that Matter Most

- Please forgive me
- I forgive you
- Thank you
- I love you
Things to remember

- Be emotionally prepared
- Be honest and tell the truth
- Be prepared to have ongoing conversations
- Be patient
- Be available
- Remember children are resilient
- Get outside support if necessary
Resources

- Talking About Death: A Dialogue Between Parent & Child - Earl Grollman
- Tear Soup - Pat Schweibert
- Children Also Grieve: Talking About Death & Healing - Linda Goldman Preschool-Grade 1
- Help Me Say Goodbye: Activities for Helping Kids Cope When a Special Person Dies - Janis Silverman Ages 4-8
- Water Bugs & Dragonflies: Explaining Death to Young Children - Doris Stickney
- The Next Place - Warren Hanson
- The Tale of Freddie the Leaf - Leo Buscaglia, PHD
- Healing Your Grieving Heart for Teens: 100 Practical Ideas - Alan D. Wolfelt
- You Are Not Alone: Teens Talk About Life After Loss Of a Parent - Lynne Huges
- When Will I Stop Hurting? Teens Loss and Grief - Edward Myers
- The Four Things That Matter Most: A Book About Living - Ira Byock, M.D.