What can I tell my children?

Supporting children and parents when a parent has a life limiting illness.

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Welcome

Thanks for Being Here!

This is by no means an exhaustive resource for supporting adults with a terminal illness who are parenting minor children. It is meant to be a beginning to a discussion and a beginning resource for social workers to dig deeper into this topic.

No research was conducted at Virginia Hospital Center. I have cited sources where applicable. Please feel free to reach out with questions or concerns.
Once upon a time there existed a land where death was never talked about. In this land children were always happy and resilient and bounced back from any loss or trauma they might experience. In fact, children in particular were thought to be incapable of feeling depressed or truly understanding or experiencing loss. Children in this land held their heads high and were “strong little troopers” when faced with issues like death, divorce, or other life transitions. In this land, parents and other adults decided that it would be better not to talk about traumatic events with their children so as not to “confuse” them or make them feel upset.

* The Land of Myth and Make Believe
The less said the better. In fact, the parents and other adults around these children decided that they should also hide their own feelings so as not to upset the children. The adults were very surprised then when the children began to behave differently, act sad or angry, or engage in risky behaviors after they experienced a traumatic event or life change. “How could this be,” the parents thought, “when we have tried our best to insulate our children from pain?” “Could we have been wrong all along?” “Do children grieve?” (Fiorini & Mullen, 2006, p. 10)
* About 2.5 million (3.5%) children in the United States will experience the death of a parent before they reach the age of 18 (Sheehan et al., 2014)

* Approximately 35% of women diagnosed with breast cancer each year are under the age of 55 and are likely to have at least one child living at home (Howell et al, 2016,152)

* 24% of US adults with cancer are parents with dependent children.(Park et al, 232)
“…Children experience the highest levels of anxiety and depression during the period of advanced illness.” (Christ, G.)

With more available treatments, “families are increasingly living with the longer-term consequences of the illness, its treatment and the threat of recurrence.” (Osborn, T.)

(Think about the impact of family systems theory and attachment theory)
* John’s mother was admitted to inpatient hospice last week. John (5 years old) has been told by his aunt that his mother is “at a business meeting.”

* Casey’s father is in the hospital and receiving comfort care. Casey (7 years old) has been told that her father “has a bad cold.”

* Christy’s mother is receiving hospice services at home. Christy’s father has not told Christy (age 3) about her mother’s illness. Christy has been acting out, throwing tantrums at home.

* When good intentions make things harder.
Parents want to protect their children
Four themes of concern for Parents:

* Impact of their illness and death on their children.
* Maintaining parental responsibilities despite life-limiting illness.
* Parental identity influencing decision making about treatments.
* “Missing out”—losses of parental roles and responsibilities.

Parents are under stress
*Discussions of a child’s fears do not heighten anxiety but reduce alienation and assuage the belief that the illness is too terrible to discuss. (Beale et al, )

*Children can cope with change and loss when provided with the right tools and supports.

*“Too young to understand” – Even very young children have an awareness of changes. “Children as young as three have a limited understanding that something is wrong.” (Christ and Christ, 2006)

*What we Know
1. Be honest
2. It's okay to share your feelings.
3. Use the right language
4. Respect a child’s desire to not talk
5. Children can react in different ways at different times.
6. Understand that children grieve differently than adults and they grieve in ways that are individualized.
7. Make sure children know that they will always be cared for.

Basic Strategies
* There is the physical loss and then there are the intangible losses associated with the death of a parent.
- Loss of security, control, stability, routines.
- Anxiety regarding what may happen to the parent.
- Heightened concern regarding the well being of the other parent.
* Concern about what may happen to them in the aftermath of parent’s death.

*Themes for kids*
* Drawing
* Games
* Books
* Special toys
* Art (memory box, scrapbook)
* Memorial (ornament)
* Writing or drawing narratives.
* Making/playing with puppets

*Interventions for kids*
1. Timing of when to disclose information.
2. Asking for help
3. It doesn’t need to be a “one time discussion”
4. Avoid euphemisms.
5. Caregiver attributes contribute to a child’s adaptation. (Christ and Christ, 2006)
6. Family dynamics preceding the death have an impact on the grieving process.

*Interventions for adults
**Skirted telling: Beating around the bush (generally positive)**

Talking about death in generalities; Hinting, but not stating directly; Providing unclear information open to interpretation; Providing limited information; Talking about death only as a possibility; Waiting for the child to bring up the illness.

**Measured Telling: Being kept in the loop (positive)**

Taking time to absorb information before sharing it with the child; Preparing for disclosures; Making reasoned choices about what information to tell; Embracing the adolescents “right” to know; Giving information to the adolescents gradually.
**Matter-of-fact telling:** Having a conversation (neutral)
Laying out the realities of the parent’s illness; Discussing future practical implications; Presenting decisions that needed to be made

**Inconsistent telling:** Not knowing what is going on (Negative)
Giving mixed-messages; Telling adolescents that information is not available; Giving conflicting information from that provided by other family members; Sometimes not telling any information or telling dire information “straight-out”

*Types of Disclosure*
* “If you have any questions about cancer, you can ask me. Sometimes you hear scary things about cancer, but there are lots of different kinds of cancer. I will tell you what we know about my cancer.”

* “Being sick makes me feel sad. You are helping me. It’s all right for you to feel sad or angry or worried. Our feelings change but Mommy/Daddy and I will always love you.”

* “I am receiving medication right now to try to make the tumor smaller. The doctors think it may help, but it may make me tired or sick.”

* Examples
At this age, children may see death as reversible. Children are present oriented at this age. Their assumptive world is small (focused on family)

* Interventions:
Provide brief explanations and repeat when necessary.
Assure children that they are not the cause of an illness.
Use books or toys to help discuss illness.
Provide simple explanations when schedules change.
Encourage children to have fun and play.

* 3-5 Years Old
Children at this age may still see death as reversible. They may blame themselves; “Magical Thinking.” They may have trouble managing emotions.  

*Interventions*  
Observe for their feelings (may not be expressed verbally.)  
Use books and toys to explain illness.  
Use activities to help manage emotions and feeling.  
Reassure them that you will tell them what is happening.  
Discuss illness and dying.  
Give them tasks to help around the house.  
Reassure them that it is okay to have fun.  
Provide structured environment.

*6-8 year olds*
Beginning to understand that death is permanent (concrete operational thinking).
They need more detailed explanations to feel in control.
They are better able to control strong emotions and “compartmentalize.”

*Interventions:
Provide children with the opportunity to talk about their feelings
Provide outlets for strong emotions (sports, music)
Provide incremental information so as not to be overwhelmed.
Reassure them that they will be cared for.

*9-12 year olds
Want to be treated like adults, are trying to establish their identity.

Advancing abstract thinking

Peer relationships are important

* Interventions
Give the opportunity for involvement, but do not give them excessive responsibilities.

Provide privacy
Encourage them to talk about their feelings and let them know you are available.

Provide opportunities for counseling

Set limits
Provide resources for learning about illness
Encourage family time when illness is not a topic.
* Death and rituals around it
* Child’s relationship with the deceased.
* The functioning of the surviving parent.
* Family influences
* Characteristics of the child
* Support from peers and friends.
* Socioeconomic status / Resources

* Mediators and moderators
Role reversal - when the parent becomes the child.
- Stressful and overwhelming for the child.
- Has an impact on the functioning of the entire family.
- Underlying mental health concerns (parent or child)
- Loss of structure surrounding daily life.
- Self-destructive behavior and/or serious difficulties with every day activities.

Complications
Involvement and inclusion.
Their fears and concerns to be addressed
Modeling of grief behaviors
Help with modulating big feelings
To be listened to
To know they are not to blame
Consistency and routine.
Validation of feelings and concerns.
when given the opportunity to communicate, children can conquer their fears as well as express their love in the terminal phase of a parent’s illness and that honesty is indeed the best policy with children of all ages.

*Concluding thoughts*
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Questions
Books
* When Someone Very Special Dies by Marge Heegaard
* Helping Children Grieve and Grow by Donna O’Toole and Jerre Cory.
* The Invisible String by Patrice Karst
* I Miss You: A first look at death by Pat Thomas
* Great Answers to Difficult Questions about Death: What Children Need to Know by Linda Goldman.
* Cancer in The Family: Helping Children With a Parent’s Illness. By Sue Heiney
* Helping Your Children Cope with Your Cancer by Peter Van Dernoot.
* Raising an Emotionally Healthy Child When a Parent is Sick by Paula Rauch

Websites
https://www.sesamestreet.org/toolkits/grief
https://www.dougy.org
https://drjaychildrensgriefcentre.ca


