



## **SUPPORTING A CHILD WHEN SOMEONE THEY LOVE HAS A SERIOUS ILLNESS**

### **Anticipatory Grief Encompasses:**

Anticipatory grief is all of the thoughts, feelings, changes, and reactions a patient and their family may feel when expecting a death. Anticipatory grief is individualized, which means it is different for each person, and in some cases does not occur at all. Children can experience anticipatory grief, and like adult family members, it may be different for each child.

### **Examples of children's experience of anticipatory grief may include:**

- Feelings: fear, sadness, anger, confusion, shock, anxiety, guilt, etc.
- Difficulty falling asleep or staying asleep, or sleeping more than usual
- Clinging to caregivers
- Physical complaints: headaches, stomachaches, sore throat, etc
- Difficulty concentrating
- Behavior changes at home or school
- May play one minute, then become withdrawn the next
- Regressive behaviors (e.g. bed wetting, sucking thumb)
- Any other thoughts, feelings, or physical expression

### **Children and Change:**

When someone has a serious illness there are often many changes that affect those around them. Although not always evident through words or behaviors, children are very sensitive to changes around them.

### **Examples of possible changes may include:**

- Family roles and responsibilities
- Eating and sleeping times or routines
- Transportation routines
- Extra curricular activities
- Holiday traditions
- Caregiver routines
- Family time
- Moods
- Finances
- Family rules

Children find a sense of security in routines. When these daily routines are shifted, stress and tension may occur. Preparing your children for change can help alleviate some of the stress.

**When changes are necessary, try to prepare children in these ways:**

- Explain the change, if possible before it happens.
- Check to see if your child has concerns with the new changes. Talking about these concerns can help reduce fear and anxiety.
- Be honest about why the change is occurring, using language they can understand.
- If possible have them involved in small decision-making. This may help give your child a sense of control (e.g. "Since I won't be here when you go to bed which teddy bear would you like me to make sure you have each night?").
- Be mindful of the details that may be important to your child (e.g. if someone different is going to be putting your child to bed, and you know your child likes a glass of water on their night stand, be sure to note this detail).
- Don't be afraid to share your feelings about the change with your child. Often parents/caregivers try to hide their feelings from children in hopes of protecting them. Children are stronger than we sometimes realize. Sharing your feelings is an opportunity to model good grief expression, and it lets children know adults are human too.

**Acknowledging the Small Goodbyes:**

Some of the changes that result from their loved one's illness may feel like losses to your child. We call these "small goodbyes." Small goodbyes may be different for each child depending on their previous relationship and interactions with the loved one who has become ill. Different small goodbyes may occur as your loved one's illness progresses. Try to acknowledge them as they occur. Grieving the small goodbyes is part of anticipatory grief.

**Examples of "small goodbyes" include:**

- Not being able to do the things they once did with their love one who is ill
- Not being able to see them as much
- Not having them come to special events like school plays, sporting events, etc.
- Not being able to sit on their lap
- Changes in how the person is active in a child's daily routines
- Having a hospital bed or other medical equipment brought into the home
- When their loved one becomes unresponsive

**Finding the Words- Ways to Communicate with Your Child:**

Deciding how to talk to your child about your loved one's illness may feel overwhelming. It's okay to ask for support from those around you and remember, as grown ups we don't have to have all the answers (and it's okay to let kids know this).

### **Helpful guidelines for talking to your child include:**

- Be honest.
- Explain diseases in simple and compassionate language. Reassure your child that their loved one's illness is a different kind of sick than when they get a cold or the flu. This will help prevent misunderstandings.
- Avoid euphemisms (e.g. "God is calling grandma home to heaven. Grandma is going to live with the angels.") This can confuse children. Instead, use simple and clear language using words like sick and dying.
- Too much information can be overwhelming or bore a child.
- Be aware of your child's developmental stage (e.g. a five year old may not clearly understand the concept of death, so you may have to explain it in language they can understand).
- Be prepared to answer the same questions repeatedly. It can take children time to make sense of things.
- Try not to wait too long to tell them what is happening to their loved one. Children, like adults, need time to make sense of what is going on and say their goodbyes.
- It's okay if you don't know what to say. If you are talking to your child and you become overwhelmed, it's okay to take a break. Let them know how you are feeling and assure them you will get back to them (e.g. "Right now I'm having a lot of feelings that make it hard to talk, so I need a little break, but we can talk about it some more later.") Be sure you do follow through and get back to them, as difficult as it may be. This is a chance to model healthy communication.
- Don't expect all responses from children to be immediate. Children live in the present and may take time to process new information. They may hear what you have explained now, but not respond until a later time.
- Be prepared to revisit conversations. Children process things in pieces. A child may be listening or talking then suddenly shift their interest to something else. This is their cue to you that they have had enough for the moment. Follow their lead. At a later time, they may pick up the conversation where you left off, or you can try to revisit it.
- Find ways to allow you and your child to communicate in addition to using words (e.g. drawings, books, games, stories, poetry, songs, etc.).

### **What Children Want to Know:**

It is important to remember that children have "magical thinking," or a belief that what he/she wants, wishes or expects can affect what really happens (e.g. "I wished for my brother to go away, so I caused him to get sick" or "If I wish really hard, grandma will get better.") In very young children egocentric thinking is normal. This means they see everything that happens as it relates to him/ her and cannot understand different points

of view. For instance, if a child sees grandma is sick, he/she may give her their favorite teddy bear thinking it will make her better.

**Common concerns of children whose loved one is dying include:**

- What is happening to my loved one?
- How will my life be affected?
- Will I be taken care of?
- Did I cause this?
- Can I catch this? Will this happen to me or other family/friends?

**Ways to Support a Child When Their Loved One is Dying:**

It is important to reassure your child that their physical, mental, emotional and spiritual needs will be met.

**These needs may include:**

- A safe, open, and compassionate environment for them to express their anticipatory grief.
- Someone to listen.
- Someone to explain things and/or answer their questions honestly.
- Adequate sleep, plenty of water and nutritious foods.
- For parents/caregivers to care of themselves.
- Affection and security. Find brief moments. For example, a little extra time tucking them in at night or playing a game they enjoy can foster a sense of closeness and normalcy that can be comforting. Let them know they are loved.
- Encourage your child to participate in activities they enjoy, if they wish to.
- Have them be a part of the family's new roles in caring for the family member who has become ill, if they want to be. This helps them feel important, needed and included.
- Look for red flag behaviors including: prolonged changes in eating/sleeping patterns, behaviors that are physically harmful to self or others, prolonged withdrawal from others, or ongoing lack of interest in play or things of previous interest. This could indicate your child may need additional support from a professional.

**Ways to ensure your child is supported at school:**

- Let your child's teachers know what is going in their life. This will help them attend to your child's need if changes occur in your child's moods, schoolwork, ability to concentrate, etc. Keep them abreast of changes at home.
- Help your child come up with a plan, identifying an adult they trust, in case they feel like they need to talk to someone during the school day.

- Help your child manage their schoolwork, especially if there are many changes in home routines. Communicate to teachers early and honestly if your child is having problems keeping up.

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