

Supporting Children . . .

When a Loved One is Seriously Ill

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“What should we tell the children? We don’t want to frighten them.”

I’ve heard this concern voiced numerous times over the years in my work with families who are dealing with a loved one’s serious illness.

The simple answer is: the truth.

With a serious illness, the truth can also be the most difficult answer.

Not only because we want to protect our children from imagining the worst-case scenario, but because we adults (doctors included) don’t always know how the illness is going to play out. When children ask big questions there often isn’t a concrete “yes” or “no” response. If you really don’t know, say so. Add your hope and plans to the answer. It could sound something like this:

(In this case child is around six and Mom is recently diagnosed with advanced cancer)

Parent: “I went to the doctors this week and found out I have a sickness called cancer. It’s when something that doesn’t belong in my body is growing inside.”

Child: “Will it go away?”

Parent: “I’m don’t know. The doctors are going to give me medicine to help me try to make it leave or at least keep it from hurting me.”

Child: “Will you die?”

Parent: “I don’t know if I will die from this illness. Usually people live to be old and that is what I’m hoping to do.”

Child: “What if you don’t. Who will take care of me?”

Parent: “If I died, your Mom would take care of you. Uncle Charles and Aunt Karen would help her.”

Believe it or not, this conversation would probably end here if the child is younger. There may be emotions (older children), behavior (younger children) and similar questions (both) to follow as the child digests the news. The important point is the child has begun adjusting to what is actually happening (and not what they’ve imagined for better or worse) and the parent has established trust through honest communication and reassurance from the beginning. This will serve their relationship no matter where the illness ends.

Contrary to this type of conversation, and what seems to be our first instinct, is to protect and reassure our children through vague white lies. We might want to tell them (and we might really believe it ourselves) everything is going to be “fine.” Or we may not tell them anything, thinking we’re sparing them difficult feelings. The problem here is that children pick up all sorts of cues from us. Their ears are much bigger than they look and their imaginations ten-fold. Usually, they already know something is wrong and have already worried about the parent becoming disabled, not being able to care for them and dying. Not talking about it gives them nowhere to go.



Talk, reassure and then listen.

Once the “elephant in the room” is identified, give the child/teen some time to adjust, ask questions and share feelings/concerns. Younger children will often bounce off to play and we may wrongly assume they don’t understand. Though they may not comprehend the implications of illness and the finality of death, they do understand something has changed. Their emotional adjustment often shows up unrelated to hearing the news. For instance, a toddler may cling to a parent and be more anxious upon separation. A school-aged child may return to bed-wetting or may have melt downs over seemingly insignificant issues. This age group is prone to “magical thinking” meaning they did something to cause the illness.

Older children and teens tend to have feelings in direct response to the news, which could include numbness, disbelief, anger, sadness and guilt. For teens, regression can show up as grades dropping, difficulty paying attention, weight loss/gain, difficulty sleeping and/or loss of interest in activities. Teens are already dealing with a myriad of feelings and changes rushing through them simply by nature of their developmental stage. Having a seriously ill loved one in the house can feel overwhelming and they may cope by focusing on their peer group, seeming not to care.

Ways to support kids and teens beyond the initial conversation:

- Listen, reassure and answer questions honestly.
- Keep routine as much as possible & discuss changes.
- Invite their help with caring for person who’s sick.
- Allow child’s lead on contact/visiting with person who is sick.
- Create support network that includes support for kids.*
- Encourage outlets for sharing and expression.
- Let school, church, coach (etc.) know what’s happening.
- Get support for yourself, so you can best support your kids.

Routine

There are many changes that can happen very quickly when one is diagnosed with a serious illness. Hospital stays, medical treatments, leaving work, needing care—all of these wreak havoc with a family schedule, not to mention the emotional state of those adjusting to the news and implications of the illness. Keeping routine is an ultimate challenge here and it isn’t always possible.

Tell your kids how important being flexible is when someone is sick. Let them know you will do your best to keep some routine (ie. getting them to school, keeping them in an activity and having someone else bring them.) Prepare them for changes you can anticipate. Get help (*see setting up a support network) so others can help pick up the slack created by the new roles of patient and caregiver. Listen when your kids are upset about changes and answer with simple reflections like: “I’m sorry. It must feel unfair that you can’t go on a vacation this year because Dad is sick.”

Invite their help

Younger kids, especially, like to feel important and part of things. Older kids may feel put-upon or scared of the person who is sick. Never force contact, but invite them to be part of the care in a way that fits for them. It could be bringing fresh water to the bedside, making posters for hospital room, clipping nails, preparing food, reading aloud or picking out videos at the library and delivering them. Make a list of tasks divided by appropriateness for age of children and let them pick from it.

Allow child's lead

If a child/teen is scared of the ill person, listen to what about it scares them. Prepare them for what to expect (ie. if ill person will lose hair from treatment, hallucinate due to medication/dying process, be in a wheelchair, etc.) Normalize the situation by integrating the changes into your new circumstances (ie. Treatment Tuesday means Dad will be very tired and irritable. Make this the new library evening.) Encourage contact, without forcing it.

Support Network

A support network is made up of people from all circles of your life. They are brought together (can be done via email) and asked to fill out forms that are used to organize the way they may want to help and their time availability. One person is the “coordinator” who matches helpers your needs. Brainstorm the kinds of help you need and include your kid's needs. Kinds of help can be driving patient to appointments, making meals, picking kids up from sports—even house cleaning and researching treatment options! People often find it satisfying to help on their own terms. Good book: *Share the Care: How to Organize a Group to Care for Someone Who is Seriously Ill* by Cappy Capossela and Sheila Warnock (2004) *Click on Setting up Support Networks under Resources for more.

Encourage Sharing & Expression

Part of keeping routine and sharing can be your kids maintaining their social relationships. Play-dates for younger children may need to slow down and go one-way for a while. However, if the people involved are comfortable with it, encourage your (especially older) kids to have friends over when it works. This helps them adjust to changes and share with others. Avoid making the illness or even dying a “taboo” subject.

Feelings are another part of sharing. It's okay to cry—even adults in front of kids! Sometimes kids will take on the parent's feelings and become anxious if they aren't accustomed to this kind of expression. If the parent is able to reassure them that all feelings are okay and need (safe) expression, showing them s/he can still function (ie. make dinner after a good cry)—the child/teen can learn to do the same. Younger children are inherently receptive to using art and play to express their feelings and respond well to picture books about like situations, while older kids and teens may be more direct with their feelings and find art, writing, exercise and reading and discussing books on like situation helpful vehicles of expression. (Click on Books for Children & Teens)

Let people know

When you let those around you know what's happening, it helps them help you. For children it may mean getting extra support at school via counseling groups or homework help instead of visits to the principal's office. Kids can act out as a response to the changes and their anticipatory grief. It doesn't mean there aren't consequences to actions (ie. discipline), but some may be prevented if support is in place or heard as a cry for help if it isn't.

Get support

Setting up a support network is a big step for both the patient and caregiver. Beyond this—time with friends, support groups (often available at hospitals free of charge), therapy, exercise, books (see lists), supportive websites, internet support groups, downtime, sleep and good nutrition are some other modes of support. Remember, if you don't get it, you can't give it. This is key if you are a caregiver and/or a parent.