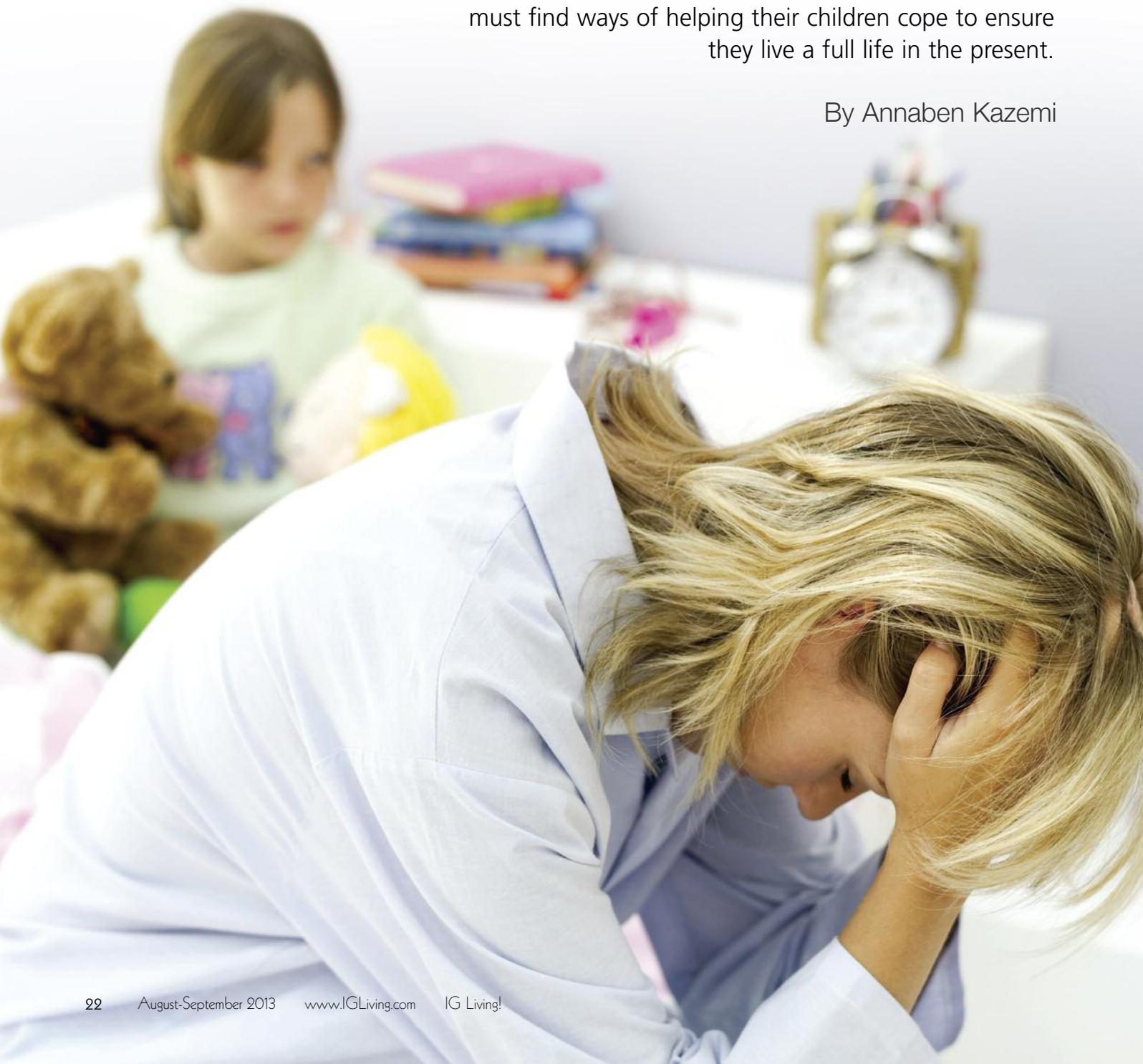


CHRONICALLY ILL PARENTS: *Helping Children Cope*

When parents are diagnosed with a chronic illness, they must find ways of helping their children cope to ensure they live a full life in the present.

By Annaben Kazemi



Under the best circumstances, parenting is a demanding job. But, parents with a chronic illness face additional challenges. Besides having their own pain to deal with, they must help their children adjust to the illness. Common questions are: “Is my mom/dad going to be OK?” “Who will take care of me?” and “Can I catch this disease?”¹

Although the situation is life-altering for a family, it is possible to turn it into an opportunity to strengthen family bonds and create resiliency. The ways parents can help their children deal with the uncertainty of illness and to help their children become secure and well-adjusted include being honest, revising expectations, keeping a positive attitude and teaching them to cope.

Be Honest About What’s Going On

One of the most difficult things for parents to do after one is diagnosed with a chronic illness is to tell others, especially their own children. Yet, experts agree that parents shouldn’t try to shield their children by hiding the illness, because it is impossible to keep such a secret over time. Children are highly perceptive and notice the smallest nonverbal cue or change in routine. Very young kids tend to sense when something is going on. And, older children may overhear conversations, find medications or notice symptoms, and jump to the wrong conclusions.

While some parents worry that talking with their children may cause fear, honest communication is a key factor in creating security because it builds trust.¹ Most children want to handle crisis in a positive way, and they have the potential to cope and grow through difficult times. But, careful planning is needed. The information must be communicated to them on their developmental level; otherwise, children won’t be able to make sense of it, and they will be alone in their worry.

Having an open and honest conversation about the parent’s illness is a good place to start. Children should be told the name and symptoms of the disease. They should be asked what they already know or what they have heard, and any wrong information they may have should be corrected.

Younger children need reassurance that their parent’s illness is not a punishment for their bad behavior, it is not a monster that comes to get them, and it is not contagious. Most important, they need to know that they will still be loved and taken care of. Older children may want to be included in what the ill parent is going through. Kathleen McCue, MA, child life specialist at the Cleveland Clinic Foundation, recommends taking the

children along to watch the parent’s routine medical treatment. This will help to give them a realistic view of the illness, and it will make them feel involved in the parent’s care in a nonthreatening way.²

Revising Expectations of Family Life

When parents share the diagnosis of a chronic illness, family life doesn’t cease. Parenting continues, but some adjustments have to be made. The family may no longer look the way their children imagined it would, which is a loss that can hurt a lot. Therefore, children need to be able to express their negative feelings of anger or sadness, and parents need to acknowledge those feelings.

Even if children don’t admit to having negative feelings, they should be assured that they are not to blame. And, while the illness doesn’t mean they will be alone, parents must be honest in telling them things may have to change. Kids should also be told that the illness doesn’t mean they are loved any less and that it is not contagious, so they cannot catch it by spending time with the sick parent or by hugging or kissing that parent. Instead, it should be emphasized that the parent really wants to be as much a part of their life as possible.

Postponing or missing events and activities will be inevitable because of the unpredictability of their illness. Yet, while parents can’t protect their children from the disappointment, it is possible to ease their feelings of being let down. Parents can let them know how proud they are of their accomplishments and find creative ways to share in them. For example, if parents have to miss a spring recital, another adult can videotape the performance, and then the parents and children can watch the tape together and allow the children to narrate the experience.

“To help a child grow from this experience, it’s not necessary for an ill parent to be strong as a rock,” explains Elliot Rosen, EdD, medical family therapist at the Family Institute of Westchester in Mount Vernon, N.Y. “It’s important for kids to know that their parents are human. And, a parent who readily admits that she can’t do it all — and reaches out for help from others in her community — sets a great example for her child.”³

Attitude Matters

One of the most difficult parts of coping with chronic illness is for parents to take care of themselves so that they can continue to actively parent, especially when that means saying no — to the baseball game, holiday pageant or family gathering — when the heart wants to say yes.

Developmental Stages of Coping

The way children react to a parent's illness is largely dependent on their developmental stage. Meeting children's needs in an age-appropriate way eases stress within the family and increases the parent's ability to focus on treatment and well-being.

Babies

When babies' parents are diagnosed with a chronic illness, they may experience significant changes in their routine, which may cause them to become agitated or even have difficulty eating and sleeping. They may be more susceptible to colds or indigestion. How the parent can help:

- Provide a lot of physical contact and reassuring attention to the baby.
- Maintain a baby's routine for physical needs as best as possible (i.e., feedings, sleep schedules, walks, playtime).

Young Children

Very young children can grasp the gravity and frustration when someone they love is diagnosed with an illness, even though they may not understand what the illness means. How the parent can help:

- Use simple, truthful words about the illness.
- Allow the child to ask questions over and over (when the answer isn't known, say "I don't know").
- Allow the child to make choices about being exposed to the medical parts of treatment.
- Maintain structure and routine.
- Allow the child to have free and joyful fun away from the illness.

School-Aged Children

The family is the basis of security for school-aged children. Home is the major environment within which they learn how to express their feelings. How the parent can help:

- Continue to answer the child's questions honestly and as many times as asked.
- Offer to include the child in seeing some of the medical aspects of the illness (always ask a child

Smith, I. *A Tiny Boat at Sea*, 2000.

And, children can learn a valuable lesson from parents who are able to explain their limits yet still function with pride and confidence. They will realize that having an illness doesn't affect a person's worth. "The single most important factor is the parent's attitude," emphasizes Manuel D. Reich, DO, director of the Center for Pediatric Psychiatry and Medicine at the University of Pittsburgh Medical Center. "If the parent is depressed, complains a lot and acts needy, the child is at risk for having more problems — or may even develop his own disability, such as headaches, stomachaches or a breathing difficulty. But if the parent is taking care of herself and leading as normal a life as possible, the child will be secure in the fact that Mom is doing the best she can do to accommodate his needs. In fact, many of these children become responsible and well-organized early on. They may have a somewhat less idyllic sense of childhood, but the trade-off is that they may also be more mature. Many go to work in one of the helping professions, such as medicine or advocacy law."³

Coping with Hospital Stays

When a parent has to stay at the hospital, fear of separation is a crucial issue for children; even the

youngest infants are sensitive to their parent's absence. They want to know who will care for them while the parent is away, what will happen while the parent is gone and when the parent can return home. Older children may question why the hospital stay is needed and how long it will take. Therefore, it's important to help reassure children and to answer their questions honestly and directly.

Many of the worries that parents and children have about hospitalizations can be alleviated with preparation. Developing a plan is crucial. Keeping a routine and setting expectations make the daily routine predictable and safe. For example, Grandma will pick the children up from school each day, and homework will get done in the hospital lounge while everyone takes turns visiting the ill parent. Or a neighbor will walk the children to school, and Mom will Skype after school to hear about the day. The key is to help the children stay informed and connected.

Unless there are extreme logistical obstacles or health-related reasons to postpone visits, families should support children of all ages coming to the hospital. Any apprehension the children may be feeling can be eased by explaining to

- whether he/she wants to be involved and how).
- Clarify any confusing thoughts or misperceptions.
- Read out loud books that have stories about the illness of a family member.
- Offer lots of hugs and holding.
- Find peer support groups for the child and for the parent.

Tweens

Tweens alternate between their family and peer relationships for support. Their emotions are heightened by the onset of puberty. Yet, their emotions are often perceived as a threat that the pre-adolescents are struggling to overcome. How the parent can help:

- Expect a child of this age to be in battle with emotions (be respectful of the child's efforts to control or conceal their vulnerability; let them know the parent is there for them).
- Understand that the tween's emotions may manifest in feeling physically ill (i.e., headaches, stomachaches, colds).
- Look for peer support groups, and encourage peer relationships and involvement.

- Answer questions honestly and thoroughly (be as detailed and scientific as possible).

Young Adults

The primary support for teenagers is their peer group. While the family remains a significant resource, it is not uncommon for teenagers to act ambivalent about depending on their family. Having a parent diagnosed with a chronic illness can present a conflict for teens between their need to focus on the critical matters at home and their need to assert independence. How the parent can help:

- Make time for the teen, even if he/she is not taken up on it (occasionally remind the teen of the parent's availability).
- Expect to hear a teen discuss the illness amid larger issues such as the meaning of living, the unfairness in the world, etc.
- Expect that a teen may exaggerate the importance of certain aspects of this experience (strong feelings may seem out of proportion, but they must be allowed for and accepted).
- Encourage peer support.

them what it will be like at the hospital: the building, the hallway, the room, how Mom or Dad will look, etc. Also, it should be planned how long the children will stay, but the time should be flexible, and there should be alternatives if the children want to step out of the room.

Some children may say that they don't want to visit their parent in the hospital. In this case, patience is required. Younger children may be frightened of what might happen there, while older children may not want to see their parent looking very ill. Or, they may just be uncomfortable in a hospital environment. Talking through some of these worries can help.

Sometimes, a visit is just not possible. Phone calls are good alternatives, but technology can allow for video chat, texting, email and photo communication. Even being able to send a drawing, note or small token and then receiving feedback about how much the hospitalized parent appreciated it often feels gratifying to children.

Striving for a Full Life

Growing up in a household where a parent has a chronic illness can place added stress on children. They are impacted by the diagnosis of a parent's serious illness in many ways.

Frequently, their emotional needs and concerns can go unaddressed. Therefore, it's important for parents to find ways of caring for their children's needs while also caring for themselves. And, if parents are able to demonstrate a positive attitude, their children will mirror it.

Ultimately, parents need to explain to their children that they will need to learn to move on and to embrace a new family dynamic, which means they will have to let go of what may have been. They can't cling to: "What would my life have been like if my mom/dad wasn't sick?" Otherwise, they will miss the opportunity to live a full life in the present. ■

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