

## Helpful Tips for Managing Your Child's Brain Injury

### Dealing with Guilt

Many parents feel they could have done something to prevent their child's injury. Some even feel the brain injury is punishment for some previous misdeed. Many times, guilt is linked to the expectation that we as parents should be able to keep our children from harm. But sometimes bad things just happen. They are out of our control.

All parents feel guilty from time to time. It's normal. But excessive guilt can eat away at your self-esteem and even get in the way of being an effective advocate for your child. Acting out of guilt won't make you feel any less guilty. Instead, you can end up feeling resentful, which brings a whole different set of difficulties.

Some people compensate for guilt by trying to do more now to make up for it. They become "human doings" instead of "human beings." Other people deal with guilt by punishing themselves, depriving themselves of things that give them joy. In either case, this can lead to an imbalance between what you think you "should do" and what you are actually doing. To keep from getting bogged down or overwhelmed by guilt, try these strategies that have worked for other parents:

- **Try to eliminate "should" from your vocabulary.** You might try replacing it with "I would like to..." or "I'll try to..." Challenge the idea that a parent "should be able to keep a child free from all harm." Although a parent's role is to protect, no parent's abilities are perfect.
- **Apologize when it is appropriate.** The only time guilt is appropriate is if, in fact, you did something you regret. The best antidote for that kind of guilt is to make amends and apologize. Make sure, however, that you're not apologizing for things that are beyond your control. You are doing the best you can under your current circumstances.
- **Don't let other people push your "guilt button."** All parents feel a normal degree of guilt. Sometimes, children and others close to us can work our weak spots. If you feel guilty about your child's injury, you are particularly vulnerable. Remind yourself that it's healthy to set boundaries. Agreeing to do things you will later regret isn't healthy and it can make you resentful. It's okay to say "no."

- **Look at what you've already accomplished.** Chances are you have already done many things to help your child. The next time you feel guilty, try to give "equal time" to acknowledging all the good things you do. You may be surprised to discover that it's really quite a lot.
- **Face it, trace it, and erase it.** It's important to acknowledge whatever part you may have had in your child's injury. It's equally important to forgive yourself. Acknowledging your role, rather than repressing or denying it, will allow you to move on and support your child better. Carrying guilt around prevents you from being a good advocate. Letting go doesn't mean you don't care. In fact, it's just the opposite. Letting go clears the way for more positive feelings, like joy and serenity, which open the heart for truly genuine expressions of care.
- **Break the "blame habit."** If it is easy for you to feel guilty, you may have a history of frequently taking responsibility or blame for things. In general, taking responsibility is a good thing. But it is possible to take responsibility inappropriately, to assume that you are to blame, even when things happen that are out of your control. This outlook is not healthy for you, for your child, or for other people around you.
- **Talk with a counselor or attend a support group.** Living with a child with a brain injury can be extremely challenging. If you don't talk to anyone else about the situation, you are likely to lose objectivity. It's easy to get caught in your web of emotions. Talking with someone who does not have a history with your child can often help you sort out a more balanced view of your feelings.
- **Develop a new perspective.** Sometimes we feel guilty because we have feelings we wish we didn't have. You may want to feel loving toward your child all the time, but for any number of reasons, you find yourself being irritated or critical instead. Your child may have difficult behaviors and personality changes that are difficult to manage. This can be trying, but finding a new interpretation for your child's actions can help. For example, instead of worrying how you are going to solve your child's problem, it can be more productive to acknowledge that your child needs attention and this is just a way of asking for it. A new perspective on your circumstances can lead you to new, less stressful ways of responding.

## Dealing with Change

### *Changes with a spouse:*

Having a child with a brain injury causes overwhelming stress for parents. Financial difficulties. Changes in roles or jobs. Disrupted family time and social activity. Parents frequently report that having

so many responsibilities creates little or no time for each other. All this can lead to a loss of closeness and intimacy. You may feel like your role as husband or wife is on the back burner.

A few ideas:

- Do things together as a whole family. Find respite care for occasional (or more frequent) dates or nights out.
- Share an interest. Talk about something besides caregiving and stress.
- Arrange time to listen and talk after the kids are in bed.
- When possible, work together on caregiving tasks.
- Seek social support together, such as going to a club or support group.
- Remember that time together is precious for all parents, and even a little alone time, like going for a walk in the neighborhood, is important and meaningful to your relationship.

#### *Changes with siblings:*

Brothers and sisters are affected when a sibling has a brain injury. Younger siblings may suddenly be asked to take on more responsibility, including providing care for their injured sibling. As siblings deal with their sense of loss, their emotions may be compounded by feelings of jealousy, anger, and rivalry for your attention.

When so much of your attention is focused on your child with a brain injury, it's understandable that your other children may feel left out or ignored. How children express their feelings varies widely. Some become fearful and overly cautious. Others become angry and rebellious. All of these feelings are normal reactions to the uncertainty and disruption of brain injury and the changes in a family. Depending on their age, children may be more likely to act out their feelings than to talk about them. Frequently, your child with the brain injury will need much more attention and time than your other children — that is just a fact of your family's situation. However, checking in with your other children and letting them know you are there will help them feel connected and important.

A few ideas:

- Focus on your children's accomplishments and needs. Ask how they did on a quiz that day, or encourage them to talk about their favorite pastime or friends.
- Arrange individual time for them when you can. Even an ordinary thing like grocery shopping can be fun and give special attention to a child.
- Understand their feelings of frustration or jealousy. Let them know that brain injury affects everyone in the family.

- Help them with their guilt about their feelings. It is normal to feel angry at the sibling with a brain injury or at you.
- Work out ways to spend time together as a whole family.

### *Changes with extended family:*

Many people turn to their siblings, parents, and other extended family members for support and caring when times are difficult. However, many parents report that all types of social support gradually slip away as the effects of their child's brain injury continue through the months and years. This lack of support has many causes. Family members may be far away, have hectic schedules, or have difficulty understanding the effects of the brain injury and how your life has changed. You may find it hard to ask for help. When family members say, "I'm just so busy" or "I have problems too," it can be very difficult to ask them for support.

It is often the case that family members simply do not know how they can support you in ways that are manageable for them, or that do not intrude. Understanding their lives and asking for specific help can help keep you connected to a broad base of family support.

A few ideas:

- Family members who are far away can help you with emotional support through emails or phone calls. You can tell them how much you value being able to talk about what's happening, or get a bit of relief by listening to what's happening with them.
- Capitalize on individual talents. For example, if your mother is great at networking and getting information, put her to work. For example, have her investigate community sports opportunities for kids with disabilities.
- Ask for specific help. If it would make a huge difference to you to have dinner cooked for you once a week, ask someone to make an extra casserole for you.
- See if family members would be willing to help with the other kids (e.g., helping with homework, or taking them out when you cannot).
- Admit when you're feeling low or stressed. Your family may not realize how much the situation is affecting you.

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