

My Child's Brain Injury: Family Matters

A child's brain injury is felt by the whole family. It changes the way a family works and challenges even the strongest relationships. Below are some common problems — and solutions — that some families use to help them feel supported and strong.

Changes with 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.

The good news is, statistics show that parents of a child with a brain injury are no more likely than other couples to break up. In fact, many couples use creative ways to manage the stress and find ways to connect.

Some suggestions:

- 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. For example, plan a garden or follow a sport or television show.
- 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.

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's just a fact of your family's situation. But checking in with your other children and letting them know you're 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's normal to feel angry at the sibling with a brain injury or at you, for example.
- Work out ways to spend time together as a whole family.

Extended family: feeling connected and supported

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. It can be particularly difficult if you feel unsupported by or disconnected from your extended family members. 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 yourself frustrated by the need to justify your stress and explain the impact of the brain injury over and over again. 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 don't know how they can support you in ways that are manageable for them, or that don't intrude on you. How many times do people say to themselves, "I would have called but I didn't want to bother them" or "I'm not sure what they need?" Understanding their lives and asking for specific help can help keep you connected to a broad base of family support.

Some 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 can't).
- Encourage family members to participate in school activities or even IEP meetings if that would help them better understand the effects of the brain injury.
- Admit when you're feeling low or stressed. Your family may not realize how much the situation is affecting you.

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