

Strategies for parenting children with a brain injury

Carolyn Rocchio's natural, easy way of life was scripted with care, right down to preplanned menus and homemade cream pies. Until Nov. 23, 1982. That's the day her son, Tim, turned 22 and suffered a traumatic brain injury in a car crash. "I remember thinking he would survive and be just fine," she says.

She was half right.

Tim survived. But his brain injury left him—and his parents—to navigate Tim's aggression, inner turmoil, memory deficits, depression and confusion. "It took me a while to realize the old Tim was gone," Carolyn says.

Parents of brain-injured children know what she means. Depending on location and severity, a brain injury can trigger violent mood swings, anxiety, aggression or uninhibited sexual behavior. It also can affect the ability to remember, plan and think clearly. Sometimes, changes are so severe that parents must learn to love two different children: the one they had before and the one they have now.

Maybe you're walking that road and you need ideas. Or help. Or hope. Maybe you just need to know you're not alone. Read on to discover coping strategies and resources.

Loving your child twice

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New Roles, New Expectations

Children don't come with a how-to manual. Parenting is a learn-as-you-go job, and one that changes and grows with time. However, parents of brain-injured children must adjust to a rush of new roles and expectations.

"You become a fighter for your child," says Hereford, Texas, mom Jeanette Hawkins, whose 15-year-old son, Christopher, suffered a brain injury three years ago when a car struck his bicycle. "You fight for insurance to pay for therapy. You fight for rights at school. You fight for state government assistance."

Meanwhile, parents may be retraining children in basic hygiene or motor skills. If a child's frontal lobes have been damaged, help with decision-making and problem-solving skills also is required.

James P. Kelly, M.D., professor in the department of neurosurgery at the University of Colorado School of Medicine, likens the frontal lobes to the conductor of an orchestra. "The rest of the orchestra might work just fine, but if the brain is damaged at the conductor level, it's chaos. Parents need to take over that role."

Once-familiar parenting styles also may need to change. A free-flowing, spontaneous style may need to yield to structure and consistency. "Structure is so important. Children with brain injuries often lose their ability to plan. It's not a matter of being unmotivated—they simply can't initiate activity," says Carolyn, who is also founder of the Florida chapter of the Brain Injury Association (BIA) and author of the book, *Ketchup on the Baseboard: Rebuilding Life After Brain Injury*.

Through it all, patience is vital, especially if your child suffers short-term memory loss. "You may tell Johnny what he's going to do today, and 10 minutes later he's asking, 'What are we going to do today?' Instead of saying, 'I already told you'—which will make him feel deficient—you repeat it as if it had never been said," Dr. Kelly says. "Successful parents get this. And it's a thing of beauty to see patience unfold so gracefully."

Eventually, parents may need to adjust their expectations of what their child can accomplish. Some skills may never come back.

Rather than college, career and marriage, your child may now be better suited for a more vocational track while living at home. Or, parents may need to consider long-term care options for children requiring 24/7 care.

"Depending on the severity, the goal that your child would be an independent, self-sufficient adult is not always possible," says Lisa Reed, LMSW, a social worker who helps families adjust to life after brain injury at Our Children's House, an acute rehabilitation center at Baylor University Medical Center in Dallas.



Disciplining Your Child

Whether you previously used spankings, timeouts or groundings, disciplining a child with a brain injury can be a whole new ballgame.

"I can't ground Christopher because he can't go anywhere by himself," Jeanette says. So she has worked with her son's school to develop a system that rewards his good behavior both there and at home.

Reed says disciplining a child with a brain injury is a process of trial and error. "What we encourage parents to do is to continue [disciplining] the same way they have, to see what's effective and not effective," Reed says. "Just because a child is brain-injured doesn't mean discipline and order go out the window."

The trick? Discerning when a child's actions are intentional. "You would never punish a non-brain-injured child for something unintentional. The same rule applies," Dr. Kelly says.

For example, if your brain-injured child blurts out profanity but you know he has no control, you may need to ignore or redirect rather than punish. "It's not the child's fault. As a matter of fact, he probably wishes he could behave more acceptably," Kelly says.

Here are some behavior-management strategies that have worked for other parents:

- Be consistent and repetitive, just as you would with a toddler.
- Redirect your child into a more desirable activity.
- Use positive reinforcement, such as a reward system and/or exaggerated praise.
- Help your child backtrack to the last clear thought. He may just be confused and on the brink of frustration and anger.

7 Tips for Success

When it comes to behavior issues, the Brain Injury Association recommends seven things for families to remember:

- Reinforce behaviors you would like to see increase.
- When safety is not an issue, ignore behaviors you want to see decrease.
- Model behaviors you would like to see.
- Avoid situations that provoke unwanted behaviors.
- Structure the child's environment and use cues for positive behaviors.
- Redirect your child rather than challenging him or her.
- Seek professional help sooner rather than later.

- Make your child toe the line. As much as possible, expect him to follow the same rules everyone else does. “You want your child to have the highest level of self-sufficiency possible. Not disciplining them or holding them accountable for their actions doesn’t enable them to function in any environment,” Reed says.

Helping Siblings Adjust

Helping siblings adjust to a “new” brother or sister can be both heart-wrenching and rewarding.

Carolyn suggests starting early by giving siblings as much information as they can handle, even at a young age. “If they don’t have information, they will either assume the worst or assume that everything is going to be just fine,” she says.

She also encourages parents to respect siblings’ feelings. “They may resent that their brain-injured sibling is different. They may be embarrassed or want to stay away from a sibling who says inappropriate things,” she says.

Additionally, it is important not to neglect siblings—a tall order if a brain-injured child is in a hospital or rehabilitation setting away from home. “Try to treat each child the same way you did before the injury,” Reed says. “Prioritize spending time with them. It’s a balancing act and sometimes you don’t do the best job at it. But try to make sure everyone’s needs are being met.”

Also, resist the urge to overprotect siblings. “I was afraid an injury would happen to the other kids, so I started trying to put them in a bubble,” Jeanette says, realizing in retrospect that she was suffocating them.

Three years down the road, Christopher’s injury-related angry outbursts do embarrass his sisters. Their ability to have friends over is restricted. Yet, Jeanette admires her daughters for their compassion. “They defend Christopher and protect him. They respect other children with disabilities a lot more.”

Nourishing Your Marriage

Through it all, you may not feel like you have much left for your spouse. “Marriage can fall by the wayside,” Reed says, urging parents to create time to nourish their relationship. “It’s like being in a plane when the oxygen falls. You have to put your masks on first before you can take care of your child.”

For starters, you and your spouse need time together, so identify trusted family and friends and train them to care for your brain-injured child. If personal resources are not

available, many state or religious agencies provide in-home respite care. Carolyn suggests calling your local BIA affiliate for a list of state programs and agencies near you.

Exceptional Adult Basic Education (EABE) classes may allow couples time during the day for lunch or a shared activity. Mandatory through public schools in every state, EABE can provide up to 30 hours of day-program skills classes, depending on your child’s level of functioning.

Secondly, don’t forget the things that fueled your marriage before. “The whole focus cannot be on caring for your brain-injured child,” Reed says. “It’s hard, but the things that brought you happiness before need to continue.”

Communication and respect are also essential ingredients, especially when grieving. “Whether you’re grieving the death of your child or the difference of your child, no two parents grieve the same way,” Reed says.

Educating Others

Eventually all parents will have to work with “outsiders.” Usually this begins at school.

When it comes to your child’s teachers and school administrators, learn as much as you can about your child’s injury so you can educate them. Compare notes on behavioral strategies that work. Be in constant communication.

Parents can help their child’s peers understand through a class presentation. Use pictures. Explain the injury in before-and-after terms. This may eliminate some teasing and help your child find friends.

Also, know your rights and be assertive. Make sure your brain-injured child gets the educational services the law allows. The Individuals with Disabilities Education Act, the nation’s special education law, added a provision for brain injury in 1990. Carolyn suggests contacting your nearest BIA chapter to learn your rights.

Outside of school, how you respond to others will be different based on the situation. “If your child commits a social faux pas in the mall in front of a person you might not see again, then it’s OK to blow it off,” Reed suggests.

Try to be alert at all times. Because brain injury can result in a lack of inhibition, your child may say shocking or provoking things. “You have to remain close to them, monitor conversations, and be ready to explain or diffuse a situation if it occurs,” says Pembroke



Where to Turn for Help

For parents, coping with the enormity of change following a child’s injury can be overwhelming. Experts recommend three important first steps.

GET INFORMATION. Contact the Brain Injury Association (BIA) at www.biausa.org for help in understanding brain injury and navigating through the healthcare, insurance and educational systems. The Family Caregiver Alliance (www.caregiver.org) can help with caregiving issues.

SEEK SUPPORT. Your child’s healthcare provider or the BIA can help you locate the nearest brain injury support group, which can be an invaluable aid in venting your emotions and learning coping skills.

ASK QUESTIONS. Be involved with your child’s healthcare team to get a thorough explanation of his or her brain assessment, which is called a neuropsychological evaluation. If it is explained well, you’ll have a better idea of what your child will be able to successfully accomplish.

Pines, Fla., resident Marion Davis, whose 38-year-old son, Andrew, suffered a brain injury in 1995.

Parenting the Adult Child

When your adult child sustains a brain injury, you may have to parent all over again. “My Navy lieutenant son was like a newborn baby. He had to learn to hold his head up, to swallow, to chew. I had to toilet train him. I started from scratch,” Marion says. Today, Andrew lives at home, but could live self-sufficiently.

Marion urges parents to acknowledge their resentment at having to change their lives and dreams. “It’s natural. You think, ‘I already did this once. At this stage in my life, I should be able to relax and enjoy.’” The key, she says, is not to get “stuck” there, and to seek counseling to work through feelings.

Though she was retraining her son in the basics, Marion also learned that it was important to respect him as an adult. “I had to help him reason without being condescending. He is a grown man,” she says.

Sometimes parents need to “plan failures” instead of always saying no. Carolyn offers one example. “When Tim wanted to ride his bike,” she says, “I knew he wouldn’t be able to. But I told him to wear jeans, a flannel shirt, pads and a helmet and we went to a nice, smooth path. It took about three revolutions of the pedals for him to fall. But I let him try.”

When they fail, be there to encourage them. “They need lots of strokes,” Carolyn says.

And, as with little kids, remember that structure is key. “There’s nothing more frightening than being an adult and not knowing what you’re supposed to be doing,” she says. Structure provides a dependable way of life.

It’s a long road, but Marion says every milestone is exhilarating. “If your child doesn’t tie her shoes by age 3, you know she’ll get it by 4 or 5. With a brain-injured adult child, you don’t know if they’ll ever get it. And when they do, the achievement is amazing. You know what they’ve been through.”

No Quick Fixes

Whether you’re parenting a 5-year-old or a 35-year-old with a brain injury, there are no quick fixes or one-size-fits-all solutions. Although parents can find hope in the fact that researchers learn more about the brain every day, the sobering reality is your child may never be “well.”

“It’s hard to tell someone who is feeling overwhelmed that there is no ending point to brain injury. It lasts a lifetime,” Carolyn says. “The good news is, life after a brain injury is worth living.”

Jeanette encourages parents to never give up. “Recovery takes time,” she says. “My son should never have walked, talked and dressed himself. Today, he’s a freshman in high school,” she says. “He is a different kid now than he was then, but he’s a walking miracle.” ■

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