

Helping Brothers and Sisters

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Introduction

A brain injury affects everyone in the family, including brothers and sisters. Siblings often feel abandoned or forgotten as parents spend long hours, days, weeks and even months at the hospital or rehabilitation program. As they are shuttled to school, stay with friends or relatives and overhear conversations, things often just don't make much sense. Common questions are: Will my brother live? What does it mean to have a brain injury? Will he be different now? How long will it take for him to get better? The unspoken question is "What about me?"

The following essay by Katie Beck is a poignant reminder to parents and clinicians that children of all ages need comfort, time, attention, information and support not only during the initial crisis of injury but over time as well. When Katie, now 13 years old and entering eighth grade, recently was given a school assignment to write about conflict, even her parents were surprised to learn how deeply she had been affected by her brother's brain injury eight years ago.

The Accident

by Katie Beck

A long time ago, when I was four years old, my brother got hit by a car. It happened on Kensington Road when he and my sister were on their way back to school after going home for lunch. I remember that day well. It's not something that could be easily forgotten.

That day my brother's pet bird had died and he didn't even want to go to school but my mom made him as she thought it would be good for him. Well, he went to school, complaining all the way and when he and my sister Maria came home for lunch, everything was back to normal. I even remember what we had for lunch (Spaghettio's). My brother was still sad about his bird but school helped take his mind off it.

When it was time for them to go back to school we walked with Lewie and Maria for a block and said goodbye. We went back home and after a couple minutes decided to catch up with them on bike, so we got my mom's bike and some helmets and rode to school.

When we got to Kensington Road we saw a crowd of people around two people that had been hit by a car. As soon as my mom saw it was my brother and sister she screamed louder than I have ever heard anyone scream.

The weird part is I know I saw my brother before he was taken to the hospital but I had so much counseling I don't remember what he looked like. My sister was hit too but didn't get injured permanently. She drifted in and out of consciousness. They were both rushed to the hospital while I was taken from house to house not knowing most of the people that helped out my mom by watching me. It scared me a lot.

Even though I didn't know exactly what was happening, I knew it was really bad. Hours later my dad picked me up and took me to my aunt's where I stayed for the night. The next day I was taken to the hospital to see my parents but I was not allowed anywhere near Maria or Lewie. I was taken to a lot of social workers who talked to me about what happened and what was probably going to happen. They said my brother would probably die but I didn't understand that either.

About four days after the accident, Lewie was finally cleaned up enough for me to see him. When I went into his room, he was surrounded by tubes, machines and blinking lights. I went up to his bed, sat down and began to talk to him though I didn't know why he wasn't talking to me and I was kind of hurt.

My sister was fine and got to go home about two weeks after she was hit and I was very jealous of her. [Mom's note: actually, she was released one day after the accident.] She got tons of attention, presents, visitors and she got to ride in an ambulance with the lights flashing even though she wasn't that hurt.

It was all very depressing for me. My parents hardly paid attention to me and when they did they were tired and exhausted and got mad at me for no reason. It really hurt!

My brother got out of his coma a month after the accident but he still couldn't talk. He got lots of visitors and many prayed for him. Windsor School made a thousand cranes and strung them together because it is said that a thousand cranes makes a dream come true.

Lewie's first words were "Ay, carumba" because he was wearing a Bart Simpson shirt and a nurse asked what it said on it. My mom screamed almost as loud as before and ran to tell the doctors.

When Lewie went home, Windsor had a huge homecoming and party for him. His homecoming was on TV and everyone made a big deal about it. I felt left out and hurt even though I was happy my brother was home.

When Lewie got home everything changed. My parents had no time for my sister and me. Lewie had to go to the hospital for treatments and we had no time to do anything fun. All this created a strain on my family's relationship and I found out that my whole family had

changed after the accident. My sister was depressed, my mom was sad and tired all the time, my brother was not loud and hyper all the time and my dad didn't talk as much. I didn't like it at all.

Then things got better. My aunts and grandma either helped out my parents or did fun stuff with my sister and me. My bother's speech improved and my parents were under less strain.

Now things are much better. My brother goes to a regular school, I don't want my parents' attention and Lewie can do things on his own so my parents are under less stress. I know Lewie wishes the accident never happened but I think if it didn't he would get himself in a lot of trouble because before the accident Lewie got into lots of trouble and showed no signs of slowing down any time soon.

Helpful tips for siblings

Brothers and sisters need information to understand what has happened and what it means to have a brain injury. You can help by doing the following:

- Explain exactly what happened in understandable language
- Explain medical terms, tests and procedures
- Answer questions directly, but simply
- Admit what you don't know
- Give information as soon as you can
- Reassure them that the injured child is getting good care

Siblings need to be prepared for hospital visits, especially the first time.

- Let them choose when to visit and for how long
- Tell them it's okay to feel nervous or scared
- Before the visit, describe how their brother or sister looks and behaves
- Describe equipment such as monitors, ventilators, IV lines and catheters

Help siblings, even young children, feel included by:

- Introducing them to people caring for your child
- Showing them what to do or how to help with care or therapy
- Drawing pictures for hospital rooms
- Making cassette tapes
- Sending cards, pictures or letters
- Starting a diary or journal

Coming Home

Brothers or sisters may think that coming home from the hospital or rehabilitation program means that the brain injury has been "fixed" or "cured." Discharge from the hospital doesn't mean that life is "back to normal." The future still is uncertain.

Siblings have many feelings to sort out as life at home changes. Parents may argue more, or be quiet, moody or tearful. They may be exhausted by the end of the day. This leaves less time and attention for siblings even though the family is together again.

Siblings can feel resentful and angry if life at home still revolves around the injured child. Siblings may even wish the child had died or that parents would divorce. These are not "bad" thoughts that deserve punishment. They are normal reactions to loss. They are signs that siblings need emotional support and information to adjust to changes in their family.

Some siblings cope by being "extra good," while others rebel, act out and create even more stress for already exhausted parents. Signs that siblings are troubled and need help are nightmares, unusually quiet behavior, changes in eating, increased quarrels or fights, tearfulness, moodiness or difficulty at school.

Counseling with a psychologist or social worker experienced in brain injury can help siblings sort out complicated feelings. Some trauma centers and rehabilitation programs have support groups or special meetings for siblings.

The following checklist can be used by parents, relatives and professionals to help siblings:

- Prepare them before visiting the hospital or rehabilitation program
- Give them verbal and written information about brain injury
- Encourage them to talk about their feelings
- Include them in the child's care if they want to help
- Take some special time to be with them
- Include siblings in discharge planning
- Include them in rehabilitation team meetings
- Ask about groups or special programs for siblings
- Have school guidance staff watch for signs of change
- Consider counseling to help adjustment
- Discuss the future

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