



SIBLINGS AND PEERS: UNDERSTANDING TBI IN THEIR OWN WAY

JOEL'S DIARY

June 2: My Dad told me I should keep a diary to help me. Ever since my brother got injured it has been awful. My parents are at the hospital all the time. I have to stay at Joey's house. School is a bunch of crap. And I don't know anything that is going on. I just hope my brother lives.

June 7: Dad said my brother is not in a coma anymore. But he still can't move or talk. They said I could see him on Saturday. I'm pretty scared. Dad said they had to shave his head and he has lots of tubes and things in him.

June 10: I finally saw my brother and I almost threw up. He looks so bad. I tried to cry but nothing would come out. Dad told me to speak to him normally so I told him about school stuff and his friends. He didn't move or anything. I don't know if he heard me. I feel so sick.

June 14: I'm not doing well in school. I flunked my math test today. I know my teacher is going to call my parents. Mom and Dad are arguing a lot lately. I try to sleep but I hear them fighting. Dad is sleeping in my brother's room.

June 17: I'm going to go see my brother again. I hope he's looking better. I hope he still knows who I am. I hope he doesn't die.

June 18: Dad told me tonight that my Mom is going to live with Grandma for a while. Mom is really stressed Dad said. Ever since this accident happened everything has been awful. Now my Mom is leaving. I hate school. I hate everything.

The excerpts from the diary above are from a 9 year old boy whose 15 year old brother was injured and sustained a severe traumatic brain injury. Siblings also find it extremely difficult to deal with an injury to their brother or sister and often cannot understand the "injury" itself and how devastating a TBI is to the entire family constellation. Siblings are shuttled to school, to a friend's or relative's home, sometimes to the hospital, and end up an emotional roller coaster that makes no sense to them. Much of the information they receive is second-hand

or overheard from adults. While they may understand the need for their parent(s) to be with their brother or sister, they still have their own needs.

A number of questions surface in their minds: will my brother or sister live? If they do live, will they be the same as before? What does it mean to have a “traumatic brain injury”? How long is all this going to go on? Why are my parents so stressed or why are they arguing so much? Who will help me with my school work? How will I get to my baseball game this weekend? How come nobody tells me anything?????

Friends as well need support and understanding. Too often the injury is left “out-of-sight, out-of-mind.” Their friend’s accident and injury is not discussed with them and they only receive information that is overheard from phone calls and adult conversations. They begin to question: Will my friend come back to school? Will they be retarded? Will they be able to walk?

Siblings and peers need to be part of the information loop concerning their brother/sister/friend. The ideas that follow will help parents, relatives, friends, and teachers enable the sibling or peers understand TBI and the injury itself and provide continuity as their brother/sister/friend recovers and returns home.

At the time of the accident and during the hospital/rehabilitation stay:

1. Explain exactly what happened to the sibling/peer in language and ideas they can understand. “Your brother/sister/friend was in an accident. They were hurt and taken to the hospital so the doctors and nurses could help them.” Oftentimes it is upsetting for siblings/peers to see their loved one in the hospital, but it may help to drive by the hospital so that they know exactly where their sibling/peer is. When children ask whether their sibling/peer will live, answer them directly. Tell them it is still too soon to know in cases of severe head injury, but assure them that the doctors are doing all they can and when you know you will tell them. Continually let them know that their sibling/peer is in good care.
2. Explain words like “coma” and “traumatic brain injury.” Medical terms are frightening to children and often do not make any sense. Tell them that “coma” is when you are unconsciousness because your brain has been hurt. Just like when you twist an ankle and it swells up and gets black and blue, your brain swells and bleeds and that can make you unconsciousness. The doctors are trying to stop the swelling and bleeding, but people just don’t wake up from coma like we wake up from sleep. Explain to them how people wake up very slowly from coma over days and weeks. In addition, tell them that your brain helps you to do 3 things: think, move about, and feel (behave). When you have a head injury, you may have problems with your thinking (memory, language, etc.), your ability to move around, and the way you act or feel. Our brain is the most important and most complicated organ in our body. When the brain is injured it takes a long time to heal and while some problems get better, some may stay with us forever. But there are ways to help people work around their difficulties.
3. Allow the sibling/peer the opportunity to communicate. Some children need to talk, some need to keep diaries, some need to ask 100 questions a day over and over. The more opportunities we create to help children express their feelings, fears, and needs, the better they will understand and feel a part of what is going on. Trying to “protect” children by isolating them or not answering their questions only increases anxiety and misunderstanding. Children fear what they don’t know and are wonderfully resilient to the things that they can understand at their level. Schools can generally provide many kinds of support services to help the sibling/peer. However, some children may require additional professional counselling supports to help them cope with the injury to their sibling or peer.

At discharge to home, school and community:

1. When a child returns home from a long stay in the hospital or rehabilitation center, his/her siblings and peers think that their loved one is “all better,” that they have been “fixed” and “cured.” For many children with TBI, their return home is the real beginning of recovery. Returning to home, school, and community presents its own challenges and siblings and peers play a vital and integral part of this period of recovery. But siblings and peers need to know ahead of time that the return to home and school does not mean that everything is OK and will return to normal. They need to know that we are all still working on ways to help their sibling or friend continue to get better. By using words like “better,” rather than words like “rehabilitated, cured, recovered, etc.,” it will help children understand that “getting better” is something that happens over time. Every one of us is always trying to do “better.”
2. Siblings and peers are often the first to recognize that their friend is “not the same as before.” Even subtle personality and cognitive changes rarely escape their recognition. However, siblings and peers are also the most accepting of these changes when they know how they can help. Unfortunately, for children who are severely disabled, the effects on their siblings and peers can be devastating. Younger brothers and sisters with an older sibling with TBI may find suddenly themselves as the “older child” in the family and that new roles and responsibilities will fall on their shoulders. Again, counselling, especially for the entire family, may be needed to help the family as a whole and as individuals accept, adjust, modify, and redevelop their relationships with each other.
3. Siblings and peers will be a tremendous support for their friend in the school and community. But, along with that support comes tremendous responsibility and guilt if the sibling/friend does not feel they can be the “same” brother/ sister or friend as they were before. The high school years, in particular, can be hard for all adolescents, but life for an adolescent with a TBI can seem like a never ending series of challenges and losses. Siblings and peers who truly understand that their loved one’s needs are really the same as their own need (i.e., a supporting family, a good place to live, school/work, and friends who care about them) will realize that while life changes, it is in change that growth occurs. While one does not want to burden children and adolescents with having to “care for” their sibling/friend with a disability, part of life is learning how to best handle situations with maturity and understanding.

These guidelines will hopefully help siblings and peers better understand that while life for their brother/sister/friend may change, their own lives change as well. The more the siblings and peers are given opportunities to learn about traumatic brain injury, express their needs and feelings, and have their questions and concerns answered honestly, the better they will understand their brother/sister/friend...in their own way.

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