

The Big List

There are so many times when you need to share information about your child's injury. Whether you're meeting with a new teacher or a medical specialist, it can be hard to know just how much information you should share.

Many parents find it helpful to complete a "big list" of all relevant information about their child and the effects of the brain injury. Then, the "big list" can be broken down to what information is necessary for a particular situation.

This process is like taking a snapshot of your child. The snapshot captures your child's abilities and strengths, difficulties and needs, and changes since the injury. Professionals have many formal tests to gather information. They are the experts in their field. But, your experience with your child is just as important as any formal evaluation by an expert. **You** are the expert on your child. You know your child better than anyone.

Describe your child

Overtime, family members become very knowledgeable about brain injury. By sharing this information, you can help others understand your child. Families need to constantly educate others about what it means to have a brain injury and how it has affected your child. The difficult part is organizing what you know into a quick summary for others less familiar with your child and less experienced with the consequences of brain injury.

Organize your knowledge and experience with the following checklist. Each survivor of a brain injury is different. Each will be affected differently.

The Big List

Use the following form to compile information about your child.

About the injury:
<i>How was your child injured?</i>
<i>How was your child hurt?</i>
<i>How serious was the injury? (mild, moderate or severe)</i>
<i>Was your child in a coma? (if yes, how long?)</i>
<i>Does your child have other injuries?</i>
<i>How long was the hospital stay?</i>
<i>Was your child in a rehabilitation program?</i>
<i>Did your child receive physical therapy, occupational therapy and/or counseling?</i>

Describe your child now, including changes resulting from the brain injury:

Physical abilities:

Energy and fatigue:

Speech and language:

Vision:

Personality:

Hearing:

Appearance:

Behavior:

Judgment:

Describe how the injury has affected the way your child thinks and learns:

Attention:

Concentration:

Memory:

Organization:

Planning:

Reasoning

Problem-solving:

Describe how the injury has affected your child emotionally:

Confidence:

Temper and irritability:
Awareness of others:
Social skills:
Alcohol or drug use:

Describe how the injury has affected your child's ability to get along with others:
Friendships:
Personal relationships:
Employer relationships:
Family relationships:

Describe how you help your child:

Remember/Use memory aids:

Organize/Plan:

Arrange:

Change behavior:

Listen

Problem solve:

Make:

Develop:

Write and communicate verbally:

Describe how the injury has affected your child's ability to:
<i>Attend social activities (e.g. birthday parties, school events, etc.)</i>
<i>Participate in sports:</i>
<i>Participate in music, drama, or art:</i>
<i>Participate in other recreational/leisure activities:</i>
<i>Travel in the community (e.g. use public transportation):</i>
<i>Function independently:</i>
<i>Work or earn spending money:</i>

What is Critical?

You have just created the BIG LIST. This list includes everything. It is important because it contains all the details that you will need to access frequently. When you talk to someone (a professional, a friend, an acquaintance), you don't need to share the BIG LIST. Instead, you need a brief summary that gives the most important information that person needs at that time.

Think of this as painting a verbal picture or snapshot of your child. Try asking yourself, what are the three most important things that I want this person to know? Reducing this to a two-minute description forces you to prioritize what is most important. The ability to quickly and clearly describe your child is a valuable skill that you can use in meetings, interviews, and discussions. The content will change, but the skill remains the same.

Putting the skill into action

In conversations with professionals, you can use this skill to describe your child and identify your concerns. Consider the following example.

To a teacher at the beginning of the school year:

Parent - This is what happened and how it has affected my son.

Patrick had a brain injury last year when he hit a tree while skiing. At first we thought he would be paralyzed because he injured his spinal cord as well as his brain. Now it seems ironic that what first worried us the most was his physical injuries and whether he would be able to walk again. He got back the use of his arms and upper body, but his legs are very weak and he has a lot of spasticity. He uses a wheelchair, although inside the classroom he uses a cane for short distances.

His unpredictable behavior and mood swings are really difficult to handle. When he's frustrated or overwhelmed by too much noise or activity, he blows up. He hasn't hurt anyone, but he can be very loud and intimidating. We've learned that he does better if we reduce his frustration by keeping his routine as structured and consistent as possible. Any major change is really difficult for him – and for those around him.

Mentally, he has changed too. His memory isn't bad, but learning new things can be frustrating for him. He needs lots of practice. We also found that he learns best in the morning, before he gets tired.

Concise Description

This example shows how a brief but accurate description can help the listener not only understand who your child is, but start to figure out what help is needed.

A concise description will be most effective if you tailor it to the person and the situation. Make sure you give all the important details for THIS situation, but leave out extra information that this person doesn't really need. If you remember to include only what the person needs to know at this time, you can give most of the important information in very little time.

The benefits of this approach are 1) the person quickly understands your situation and your needs, 2) less time is wasted, and 3) your child may get needed help.

To practice this skill, see Paring Down the Big List in the Brain Injury Partners Program