

NOTES TO PARENTS OF A HEAD INJURED CHILD

Things that should be considered after the accident:

1. Parents must inform the school as soon as possible about the accident.
2. A member of the school staff to take responsibility for liaison with the family.
3. Efficient and effective two way flow of information needs to be established.
4. Identify a child's current strengths and needs.
5. Ongoing rehabilitation and provision of therapy.
6. Physical access to buildings if necessary.
7. Social, emotional and behaviour support.
8. Should have staff expertise in a range of special educational needs e.g. communication or sensory difficulties.
9. Plans for a phased re-entry to school e.g. the length of school day.
10. Arrangements for rest periods.
11. Management of unstructured time.
12. Transport or travel arrangements to and from school.

PARENT'S COMMON FEELINGS

Much has been written about adaption to death and loss. A unique aspect of adapting to traumatic brain injury, though, is that family members must simultaneously come to terms with their losses while meeting their injured loved one's new needs. Adaption is further complicated by the ongoing nature of the recovery process (often over years) and the uncertainty of outcome. Your child's needs change with time and no one can tell you for sure when or if the problems will resolve.

Shock, Numbness, Disbelief

In the acute phase, your initial reactions to your child's injury are likely to be shock, numbness and disbelief. The information being forced upon you simply does not compute. You may not hear what is said to you, in the sense that you are not processing what is said. Things don't "sink in" and you forget what you've been told.

Loss of control

Loss of control is another typical feeling early on. The sense of order or predictability in life vanishes. A parent can easily feel overwhelmed. It seems that most matters are out of your hands – you did not prevent the injury, professionals are in charge of your child's life, most of the variables in the situation are beyond your influence, with only fragments of a daily routine remaining. Even your own emotional responses – tears of sorrow or joy, anger, laughter – can be difficult to predict and modulate.

Anxiety and fear

Anxiety and fear usually quickly flood through a parent's being and can be pervasive in the early days of the crisis. Uncertainty, more questions than answers, and an unfamiliar new reality trigger feelings of panic, hyper-vigilance, agitation and emotional discomfort. It can be hard to concentrate and to eat or sleep.

Remorse, Guilt, Blame

Embedded in this mix of feelings, parents often find remorse or guilt, sometimes blame. These feelings surface as it becomes clear that your child is badly hurt, is suffering and will have difficulties to face for some time to come. Remorse, deep sadness over the turn events took, can well up. Thoughts like “if only we had not taken that ride in the car” or, “I wish I had said ‘no’ instead of ‘yes’ that night” hover in your consciousness.

You can feel guilty when there is no conceivable way you could have prevented the injury. As a parent, a basic task is to protect your child from harm. The feeling of failure can be immense, even if it does not match the objective reality.

Sometimes parents do regret certain decisions, actions taken or not taken, or mistakes made. There can be terrible pain. It can be all-consuming. You can feel overpowering blame toward yourself or others. Somehow you must put this aside.

Parents have found that if they try to focus on the present circumstances and keep in mind how much their child needs them now – no matter what their own pain or regret – they can go on in spite of negative feelings. They have found, too, that they may need to go outside of themselves or their usual circle of family and friends for help in struggling with remorse, guilt and blame.

A member of the clergy, the clinical social worker or psychologist at the hospital, a psychotherapist in the community can provide support and direction. If you are able to find it in your heart to forgive, your child’s recovery and your family’s well-being will be enhanced.

WAYS OF COPING

When your child is hurt, you are suddenly whisked to an alien planet, assigned to a journey you did not choose to take and pointed toward an unknown destination. You are in foreign territory.

The ability of individuals and families to respond to difficult, almost unbearable challenges sometimes defies comprehension. Family members of a child with a brain injury often bring impressive strengths and develop new skills as they adapt. At times you feel the world will end. At times you discover and tap astonishing resilience.

The following are just ideas that may help you cope. Some strategies are uniquely applicable to the time period soon after your child’s injury. Some techniques will continue to make sense over the long haul. Choose the techniques that you think will maximise your family’s chances for future well-being.

1. Get Information

There is a lot to learn. Ask questions. Ask again if you forget an answer. Be honest when you do not understand. Write down what you are told. Write down names and numbers of people with whom you talk. Talk with other families in the hospital. Always remember that your child, your child’s injury, and your family’s circumstances are unique. No information you are given will definitely apply to you, but it will help you get your bearings on your journey.

2. Start a Journal

It is important to organise and safeguard the information you gather. Many parents find an ongoing log of information, events, observations, thoughts and feelings to be an indispensable tool. Be sure to date and label each entry and each volume of the journal as it expands. This can help you keep track of current happenings. This journal also gives a message to staff treating your child: you are organised, tuned in, documenting your observations. Often your journal tracks information that helps the professionals helping you.

3. Find Listening Ears

Your child's trauma is yours too. You must identify a few family members, friends and/or professionals who can listen to you, no matter what you need to express. The emotional turmoil of a child's near death and uncertain recovery evokes strong emotions. The very process of being heard, of sharing feelings with a listener who is empathic and nonjudgmental, is healing. Often you do not seek advice; you just need to have someone present for you in the midst of your anguish. A concerned friend who can be calm under pressure or an extended family member who wants to be helpful and is slightly less immersed in the situation is a good choice.

4. Do Talk with Loved Ones

Your "listening ear" may be someone who is not emotionally close to you. Sometimes it is painful to pour out your heartfelt sorrow or bitter anger to the spouse or partner or family member suffering beside you. You may also find it hard to listen to your companion's grief. Sometimes it feels like your hurt is magnified when the process of sharing it further pains the listener. Nevertheless, it is crucial to keep communication, and if possible, emotional support, flowing between your partner and you.

Following a child's brain injury, there are many forces pulling parents in separate directions. Survival often dictates specialisation: one parent stays at the bedside while the other tries to work so a pay check is coming in; one parent pays the bills while the other calls relatives to provide updates. In the new split routine, the two of you can lose contact and closeness.

This is a life-changing time when important decisions are made and new patterns are established. In a two-parent household, parents need to be available to each other somehow. You may want to plan supper together in the hospital cafeteria; spend weekends together partly at home, partly at the hospital; set up planned, routine phone appointments; strive for at least one overnight home together each week.

By sharing the crisis with aunts, uncles, grandparents or parent figures that have been active participants in your family's life before the injury, new bonds are forged and emotional links strengthened. These ties are needed so you can shoulder future burdens and celebrate future triumphs together.

5. Include Sisters and Brothers

Siblings are full of questions and concerns and are often the forgotten victims. The adults in the family must reach out to provide them honest information, opportunities to visit their injured brother or sister, and time to spend alone with parents. Adult relatives, teachers, and close family friends can be asked to supplement parents' efforts.

It helps if they reach out, express concern and provide extra support and supervision, because the primary concern and attention is directed at the injured child, siblings easily can be overlooked. The turmoil at home inevitably affects siblings. Young siblings mistakenly may believe they are responsible for the injury since young children's magical thinking often confuses cause and effect. Siblings may have witnessed the injury and have recurrent nightmares, fears, or trouble sleeping. Siblings may be jealous of the attention focused on the injured child and angry at disruptions in the family's routine. They may also feel embarrassed about changes in their sibling's behaviour, particularly in public places. Older siblings may have additional responsibilities of caring for others and managing the household while parents are at the hospital.

These stresses may become evident at school as the grades of siblings drop, as attention wanders, or as behaviours change. Families may fail to inform the teachers of siblings about the family crisis. Consequently, it is important to inform the teachers of siblings when schools are advised of a child's injury. School staff can then be alert to changes in siblings' behaviour and grades and provide additional attention, support and counselling.

If you routinely provide your non-injured children information and support, it can minimise their hidden suffering. It can also decrease problem behaviours and emotional difficulties over time.

6. Respond to Inquisitive Well-Wishers

Social support is a mixed blessing. Your child is injured and the whole family is hurting and vulnerable. We need help for practical and emotional reasons. If relatives and friends come forth, you have the challenge of figuring out how and when to respond to their questions and offers of help.

It can help if you as parents, or you as a single parent, decide who needs to know what and how they will find out. In the very beginning, identify a family spokesperson who will be the primary contact person for hospital staff and the conduit for key information back and forth. Also decide which family members or friends you want to provide with detailed information.

If your child is in school, you may want someone to be a liaison with classmates and teachers. Consider ahead of time how much information you want to share.

Use technology creatively. Instead of worrying about not returning concerned friends' calls, try leaving a message on your answer phone with information about injured child's condition. You can change this message weekly or whenever you feel a need to update the information. Sending updates by email is an easy way for recipients to respond to you.

Another way to manage concerned or curious questioners is to rehearse what you might want to say to them. A face to face encounter can be easier if you practice your answers ahead of time. Expressions of concern by others may trigger your own emotions, sometimes tears. Though this can be embarrassing, there is no need to apologise. Just try saying that you appreciate their concern and that it means a lot to your family.

7. Accept Help

Accepting help is tricky business, but you will have to learn to do so when your child has a brain injury. You simply cannot manage alone and your child deserves every possible resource.

The private trauma of a family is somehow a public event because news travels fast and a child is part of a community. Those who wonder how your child is doing may ask what they can do to help. This may startle or embarrass or anger you. The best answer is simply to thank them and tell them that you can't think of anything right now. Often those who offer help need to give it. They have their own fears, grief and helplessness and want to do something tangible. Your acceptance can help their adaptation and yours.

Sometimes professional help is offered. You need not always say "yes" to their offers of help, but try to rule out the automatic "no" that might restrict certain opportunities for your child or family. You are in a serious situation and unusual measures may be warranted.

8. **Eat and Sleep**

When your child is acutely injured he becomes the centre of your universe and his needs are like a strong magnet pulling you. Your immediate reaction is to put your own needs aside and to focus wholly on his fragile life. Neglecting your own needs will soon translate into decreased ability to respond effectively on your child's behalf. Meeting your needs is not always incompatible with meeting your child's needs. Meeting your own needs can actually help you meet his needs. Taking care of yourself helps you care for your child.

Source: Schoenbrodt, L. (2001) *Children with Traumatic Brain Injury – A Parent's Guide* (pp. 80-89).
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