

Traumatic Brain Injury

in Children and Teens
A National Guide for Families



Developed by

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Special Note

Families have many different members and living arrangements. Not all children live at home or with both parents. The words “family” and “parents” are used as general terms. They are intended to include all parents whether married, single, widowed or divorced. Family may also include step-parents, grandparents, adoptive parents, foster parents, aunts, uncles, cousins, and even very close friends. Please interpret the words “family” and “parents” to fit your situation.

The word “child” is used in this manual to include son or daughter, step-child or adoptive child. It includes children of all ages, including adolescents.

The Intensive Care Unit

Your child may be cared for in a special part of the hospital called the Intensive Care Unit or ICU. There is some basic information that you will need to know about the ICU. This includes knowing:

- who is caring for your child
- what each person does
- how to contact them

A child with a brain injury is often moved to the ICU from the Emergency Department or after surgery. The ICU is designed to give very special care with close monitoring of your child’s condition by specially trained nursing and medical staff. ICUs often include children with other conditions besides brain injury. A child with a brain injury may be in the ICU for:

- close observation
- swelling, bleeding, or other damage to the brain
- coma or lowered alertness
- other injuries
- treatment for complications or infections
- special care after surgery

Hospitals may have different types of ICUs specializing in the care of patients by age or type of medical illness or injury. Special ICUs include:

Suggestions for communicating with ICU staff:

- know who is in charge of your child's medical care
- keep a list of all the medical staff and their specialty
- find out which nurses are in charge of your child's care
- keep a list of therapists and their specialty areas
- let staff know
 - phone number(s) to call you
 - where you are staying if you are away from home
- who to contact in your family for decisions and/or information
- who not to contact in your family
- set up a daily time and person to contact for a report on your child

Gather the following information about each person you want to talk with:

- name and specialty
- telephone number(s)
- best times of day or week to talk or meet with you
- best ways to contact them (by phone, appointment, in office, at child's room)
- who to ask for if they are not available at the hospital or in their office
- most reliable way to leave messages
- when they expect to get information from special tests

See worksheets at the end of this chapter for organizing information about hospital staff.

Helping Your Child in the ICU

Your child may not be very aware of what is going on during this stage of recovery. Many children lose consciousness after a brain injury and are in a coma. This may be caused by the brain injury. Medications may also affect your child's alertness. Other injuries may require casts, surgery, and special care. Things from home may help orient your child but the number of things you can bring may be limited. The nurses can give you suggestions. Possible things include:

- picture of your child and family
- favorite toy, doll or stuffed animal
- favorite stories to read to your child
- familiar videos

Taking Care of Yourself While Your Child is in the ICU

During the first days of your child's hospital care, nothing may seem more important than being close to her and getting information about her care and condition. There are probably many things at home or at work that you had planned or need your attention. Try to set priorities by asking yourself:

Reading Resources for Families

For Children:

For Kids Only: A Guide to Brain Injury

Published by Department of Physical Medicine and Rehabilitation, MCV, Box 434, Richmond, Virginia 23298-0434. Call (804) 828-0231 to order.
Reading level is third grade or less.

The Don't-Give-Up-Kid (and Learning Differences)

Published by Verbal Images Press, 19 Fox Hill Drive, Fairport, New York 14450. Call (716) 377-3807 to order.
Reading level is third grade or less.

Eagle Eyes (A Guide to Paying Attention)

Published by Verbal Images Press, 19 Fox Hill Drive, Fairport, New York 14450. Call (716) 377-3807 to order.
Reading level is third grade or less.

Kidnapping Kevin Kowalski

by Mary Jane Auch (1990)
Published by Apple Paperbacks (Scholastic) 0-590-44335-6.
Reading level is at a middle school to high school level.

For Parents:

When Your Child is Technology-Assisted: A Home Care Guide for Families

by Paul Kahn, Med. (1997)
Published by Research and Training Center in Rehabilitation and Childhood Trauma, New England Medical Center, 750 Washington Street, #75K-R, Boston, MA 02111
Call (617) 636-5031 to order.

Resource Guide: Children and Adolescents with Brain Injuries

by Marilyn Lash, M.S.W. (1998)
Published by Lash and Associates, 22 Keewaydin Road, Wolfeboro, NH 03894
Call (603) 569-3826 to order.