

Brain Injury: Impact on Family and Care Givers. Strategies for supporting your loved ones.

Donald L. Mickey, Ph.D.
Counseling Resources/Neuropsychological Associates, LLC
4781 Hayes Rd.
Madison, WI 53704
(608) 242-7160

Mistakes Start early in Process. Communication Lapses

- **From the Hospital:** He has a mild brain injury.
- **What is heard:** He will be fine. He has a MILD brain injury.
- **What is actual:** He has an insult to the brain and may have impairment in many areas of functioning for the rest of his life.

Mistakes Start early in Process. Communication Lapses

- **From the Hospital:** Things look very good. He is coming along fine.
- **What is heard:** He is fine.
- **What is actual:** The hematoma was evacuated, the dura matter was sewn up, and the scarring looks like it will be minimal. The physical repair is done and I have little or no idea regarding long term cognitive functioning or sequelae.

Mistakes Start early in Process. Communication Lapses

- **From the Family:** Questions are asked about prognosis, recovery, treatment methods, outcome, peculiarities of treatment, etc.
- **What is heard:** Family feels that hospital personnel are saying "We are the experts, we know what we are doing, so don't interfere, let us do our job."
- **What is actual:** Family and professionals are not communicating, thus the family feels left out and confused.

Mistakes Start early in Process. Communication Lapses

- **From the hospital:** One individual says your family member is doing fine, one says they're not doing well, one says they are not sure.
- **What is heard:** Family feels that the people taking care of their family member do not know what they are doing.
- **What is actual:** One may know what is happening, one may not, one may want to "protect" the family from dealing with the real situation. All may be unsure, but are unwilling to let the family know that they are uncertain.

Mistakes Start early in Process. Communication Lapses

- **From the sub-acute program:** Reports are that your loved one is making excellent progress in post acute recovery.
- **What is heard:** Excellent progress, good recovery.
- **What is actual:** In their clinical enthusiasm to report progress the clinical individual fails to realize that progress, although good, is substantially different than where this person was prior to the injury (25%/100%). The family often only hears the enthusiasm, not the whole message.

Mistakes Start early in Process. Communication Lapses

- **From the hospital:** You are in denial.
- **What is heard:** I am denying that my family member has problems, some of which I may see, some I do not. My biggest problem is that I do not understand much because nobody has told me much.
- **What is actual:** Full information has not been conveyed to the family. They are not fully informed as to the actual injury limitations and outcomes

Mistakes Start early in Process. Communication Lapses

- **From a family member 8/11/05:** From the Neurosurgeon (date of injury 8/16/2004) relating to the question, "Will he have any memory problems?"
- **Response:** "That part of the brain was not injured."
- **What is actual:** Presently (9/2005), severe memory impairment.

Problems

- Basic communication problems set family up for differing expectations from the start. Meanwhile, they still struggle with personal grief while trying to guess the outcome for their loved one.
- Insurance problems mean short hospital stays and a fast return to home or the community. May have little to do with "recovery."
- Not aware of difficulty of transition.
- Information as to actual depth of impairments not available. Return to past life "fit."
- Impairments block understanding of impairment information.

Difficulty With Family and Community Reintegration

- How the family becomes the default case manager for their loved one.
- Questions:
 - Do you know what questions to ask while you are trying to figure out what has happened to your family?
 - Who is responsible for the family?
 - They are not the one injured.
 - But will they eventually be put into a caretaker and individual management role for a loved one?
 - Where should they look for help and support?
 - Role of Brain Injury Associations

Manifestation of Injury

- Large variety of deficits, which may include impaired memory, language problems, agitation and irritability, problem solving difficulty, anger control problems, initiation issues, fatigue, impaired adaptive behavior, etc.
- Catastrophic reaction and reactive depression.
- Exacerbation of pre-injury mental health issues or decrease of pre-injury mental health issues.

Becoming a Case Manager

- Fun learning new terms:

- | | | |
|--------|----------------------------|---------------------|
| - SSDI | - CBRF | - Psychiatrist |
| - SSI | - DVR | - Psychiatrist |
| - COP | - Guardian | - Neuropsychologist |
| - CIP | - Community support agency | - Etc. |

Family Issues - Individual

- Accepting change (individual)
 - What changes?
 - Success becomes more dependent on individual than on others.
 - Accomplishments become less clear and more abstract. (Pragmatics)
 - Recovery focus often switches from physical to cognitive realms.
 - The pace changes.
 - Support has to come from the real world vs. the hospital world.
- Individuals often experience failure when trying to get back on the treadmill.
- Yet learning comes from failure. I need to occasionally run into the wall; like touching wet paint, you must experience it yourself; you just can't take someone's word for it.
- Then who should be in charge of risk taking?

Family Issues - Individual

- Can I just wait this out and eventually get better?
- What is a "realistic outcome." Based on what?
- Who will tell you the truth?
- Will you believe it??
- Shifting roles. Spouse/child (adult child).
 - Are you willing to accept role changes?
 - Will he/she be willing?
 - Should a spouse be put "in charge" of the injured other?
 - Should an adult child return to "home"?
- Alignment of Expectations >Is everybody on the same path?
 - Can I have my old role back at some point?
 - Who defines risk taking?
 - Are roles clearly defined?
 - Do we know the roles?
 - How do you as a family member deal with the positive statements that don't equal what you see daily?
 - "He looks and sounds great."

Family Issues

- How does one with many kinds of problems "adapt" to new roles and changes in the family?
- Are you willing to accept poor proposed outcomes?
 - What were the decisions based on?
 - Is the decision sound?
- Where does the grieving process enter in for the individual and the family?
- Can you figure out how to be a family and have fun when you are so wrapped up with the task of fixing everything?
- You must look for ways and outlets to manage stress!!!
- One individual should not carry the burden of responsibility for the success and failure of another.

Inconsistencies-Individual

- Everyone says you look good and are doing well.
- Mirror says I look good.
- No retrograde amnesia so I can remember all the things I have done and can do.
- The hospital said I would continue to improve.
- Higher functioning individuals who use cognitive processes are more aware of even small shortcomings. Which in turn magnify the impairments.
- Major memory impairment and adequate intellectual capacity often has impairment as focus of treatment versus use of preserved skills.
- Minor memory impairments often are ignored as not important.
- The affect of fatigue compounds the effects of the injury.
- "Can't walk and chew gum"! Multi-tasking.
- Frontal lobe problems - Too many choices and decisions.
- Simple definition: No auto pilot now, must always be alert.

Community Issues

- Care givers; either family or community support systems or both, are not prepared or ready for the individual.
- Lack of understanding of the functional deficits, or too much understanding of the "deficits" blocks community success.
- "Normal" verbal abilities and/or normal "IQ" often has support people downplaying the impairments or ignoring the impairments as not important.
- What does brain injury mean to you? Individual's often select one or two cases as their idea of brain injury; may not represent current case.

Community Issues

- Supports not available in community due to funding or lack of existence, family becomes default care provider.
- Underlying or pre-existing mental health and/or life style issues ignored or become focus.
- Unawareness of how to treat the brain injured individual; i.e. Can I set limits, what should I say when...happens, we don't want him to get upset, etc.

Needs

- Awareness of injury deficits in a functional sense. How does "a right frontal lobe injury affect me in the environment"? This has to be an ongoing educational process with supports available following failures to process what happened.
- Functional and verifiable knowledge of strengths.
- Functional and verifiable knowledge of weaknesses.
- Energy Output
 - How much?
 - How Long?
 - Crashes/recovery.
- Risk taking to develop new skills or verify existing skills.
- Planned failure in the community setting to assist the learning process.

Why?

- How can you expect one to change if the individual does not know what's wrong?
- When individual knows, it is easier to take responsibility for themselves versus listening to others tell them what and why they need to change.
- Planned failure and community challenges, how we grew to understand prior to the injury.

Ongoing Needs

- Neuropsychological examination results---updates, how often?
- Community supports-education.
- "Family" supports-education.
- Functional information for all service providers so they know how to assist the individual.

Behaviors

- Why does the individual not want to do what we believe is right.
- Can you separate out organic (injury based) problems from others?
- You usually don't end up with more than what you started with; i.e. were the behaviors pre-existing?

Questions and Ideas

- Importance for survival in the community.
- Psychological impact of accepting change.
- Need to adapt everything to a "real world" environment. Importance for care providers. Life in the community and at a job is a continuation of rehabilitation.
- Remembering the person was a whole person prior to the injury and did have another life.

Life After Brain Injury

- Need for support and education for individual to understand changes in self.
- Need for support and education for the family to understand changes.

Life After Brain Injury

- Families and Brain Injury Associations must continue to work at change from the local level to the national level.
- BIAW, N35W2110 Capital Dr., Suite 5 Pewaukee, WI. 53072
(262)790-9660
BIAW.org
- Be aware of the changing research climate in TBI which came about due to efforts at the NIH National TBI Consensus Conference:
 - Recognition that the medical model has failed with this population.
 - Recognition that this is not a quick fix, that the injuries last a life time and care and support may be needed for a life time.

Life After Brain Injury

- **COMMUNICATE!! YOU ARE NOT IN THIS ALONE.**
 - Talk to other families and survivors.
 - Ask questions of your Dr.
 - Communicate with your insurer.
 - Ask questions of your care provider.
 - Ask questions of the case manger and request to be part of the "treatment team."