

RELATIONSHIPS AFTER BRAIN INJURY

PRESENTATION BY
MICHAEL IDELL

PRESIDENT OF BRAIN INJURY
SUPPORT GROUP OF THE
POCONOS

CEO: BRAINWORKS
ASBISG.ORG

HOW BRAIN INJURY AFFECTS RELATIONSHIPS

The emotional, behavioral, physical and cognitive effects of brain injury can often have an impact on existing and future relationships. There are a number of ways in which this can happen and a number of different outcomes. Some relationships may strengthen, whereas others may become strained over time or even completely break down. We will go over details of understanding the struggles and goals we can use to help bridge the gap in understanding the communication barriers that come along with brain injuries.

COUPLES

Couples usually spend a significant amount of time together, and so the brain injury survivor's partner is often aware of the effects of the injury, including 'hidden' effects. Partners also often take on caring roles, which can lead to the boundaries between the roles of the "carer" and partner often becoming blurred.

If the survivor's personality has changed, the partner may feel that they are no longer the person they originally chose to be in a relationship with, resulting in feelings of confusion, longing, sadness and loss. The survivor themselves may no longer feel the same way about the relationship as they did prior to the injury. However, enduring challenging experiences like this can also, with support, strengthen some couple relationships.

STARTING NEW RELATIONSHIPS

- - Being honest and upfront are important factors in any kind of relationship but intimate relationships are usually much more in depth.
- With a brain injury survivor, there are more complex issues for someone outside to understand the aspects of a hidden disability.
- It becomes more important for communication, patience and being open minded for both people to understand. As in any relationship, it also takes teamwork.

PARENTS

The relationship between a parent and their child is one of the strongest bonds that a person can have in their life.

Parents are often deeply affected by hardships faced by their son/daughter, so when a brain injury occurs this can be a devastating and frightening experience for the survivor's parent. On top of this, while it is normal for parents to feel concern for their child's future, a brain injury can cause a parent to feel further fear and apprehension for their son/daughter's abilities and prospects.

CHILDREN

The reaction a child will have to their parent sustaining a brain injury will depend on a number of things such as the child's age, their temperament, the type of relationship that they had with the parent prior to the injury and the way in which the injury has affected the parent.

Relationships between some parents and their children may strengthen. Children can also offer a potential contribution to their parent's recovery, if supported in an appropriate manner. However, it can also be quite common for the child to feel distant and confused about the relationship.

OTHER FAMILY MEMBERS

- It is often family members, such as partners, parents and siblings, who spend the most time with the brain injury survivor in the early stages, for instance when the survivor is in hospital or when they first return home. These are often emotionally intense and difficult times for everyone, and experiences such as this can either strengthen or strain family relationships.
- Family members may take on the role of caring for the survivor. This may lead to feelings of stress as the family member finds that they are less able to spend time with friends or doing activities they enjoy. On the other hand, some families may enjoy being able to spend more time together than they did prior to the injury.

FRIENDS

- Many friends will have little understanding of the nature of brain injury and how this has affected the brain injury survivor. As a result, friends may make fewer allowances of the effects that the survivor experiences, especially if these are 'hidden'. In social situations, friends may initially joke about the survivor's injury, or trivialize the effects of it from a lack of understanding, failing to recognize the impact that this has on the survivor themselves.
- It is unfortunately quite common for brain injury survivors to feel as though friends are drifting away. However, as with family members, some friendships may in fact strengthen, especially if a friend is sympathetic and willing to learn about brain injury.

WORK COLLEAGUE S

The people with whom we work often form an important social network in our lives. Some working relationships with colleagues may even develop into friendships, whereas others stay as professional relationships restricted to the workplace.

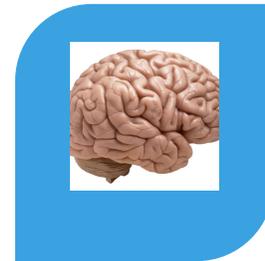
For brain injury survivors who find that they cannot return to work after their injury, relationships with former colleagues may taper off over time. The changed circumstance of not seeing work colleagues on a regular basis can lead to feelings of social isolation and a loss of a familiar social network.

Those brain injury survivors who are able to return to work may have difficulties with maintaining appropriate social contact with colleagues. Colleagues may also struggle to understand and adapt to the survivor's new needs or pace of work. Supervisors and managers may not know how to respond to such challenges, especially if they are not familiar with the effects of brain injury.

THE IMPACT OF CHANGED RELATIONSHIPS FOR ALL INVOLVED



WHEN ANY TYPE OF RELATIONSHIP IS CHANGED, THIS CAN COMMONLY CAUSE FEELINGS OF SADNESS, CONFUSION, HURT AND LONELINESS AMONG EVERYONE INVOLVED. IN TURN, THE BRAIN INJURY SURVIVOR MAY BECOME WITHDRAWN AND SOCIALLY ISOLATED, AND IT MIGHT BECOME MORE DIFFICULT FOR THEM TO SEEK SUPPORT.



SOME BRAIN INJURY SURVIVORS MAY FEEL THAT THEIR LOVED ONES DO NOT UNDERSTAND HOW THEY ARE FEELING, WHICH CAN CAUSE THEM TO BECOME FRUSTRATED AND DISTANT. CONVERSELY, FAMILIES AND FRIENDS OF A BRAIN INJURY SURVIVOR MAY ALSO FEEL FRUSTRATED AND HELPLESS IF THEY ARE UNABLE TO UNDERSTAND HOW THE SURVIVOR IS FEELING AND HOW THEY CAN HELP.



BOTH BRAIN INJURY SURVIVORS AND THEIR PARTNERS, RELATIVES AND FRIENDS CAN BE AFFECTED BY A CHANGE IN THE RELATIONSHIP, AND IT'S IMPORTANT THAT BOTH FEEL ABLE TO ACCESS SUPPORT ACCORDINGLY.

IMPACT OF CHANGED RELATIONSHIPS



If you are friend, family or loved one, you probably have a someone who has sustained a brain injury. Or perhaps you have heard about brain injury and wish to know what to do in the unfortunate event that someone sustains one.



In any case, learning about brain injury is the first step towards helping someone affected by this 'hidden' disability. Indeed, many brain injury survivors feel that their lives would improve if their surroundings had a better understanding about what brain injury is, and their feelings and experiences through this life-changing event.



In both the short and long-term, brain injury can cause changes in the way the individual thinks, feels and behaves, and can also affect their physical ability. Brain injury is often referred to as a 'hidden' disability, as you may or may not be able to visibly see how your friend is affected, but this does not mean they are not experiencing effects that can cause challenges on a regular basis.

**EDUCATION FOR THE
PUBLIC, FAMILIES AND
CAREGIVERS TO
UNDERSTAND.**

THE EARLY STAGES OF AN INJURY

- The early stages of injury can be a frightening and upsetting experience for anyone associated with a brain injury. A survivor may be in for tests or surgery, or they might even have been in an accident. They might be in a coma or a reduced state of consciousness in the early days of their injury, which can be a particularly distressing thing to witness.
- Even if the person is conscious, they might be displaying unusual or uncharacteristic behavior, known as post-traumatic amnesia. Although it can be difficult to see them in this state, be assured that it is a normal part of the recovery process.

THE EARLY STAGES OF AN INJURY

- You will naturally have many questions about conditions, especially if this is the first time someone has been affected by brain injury. However, it can be very difficult to predict the outcome of brain injury, so hospital staff may not be able to give you or your friend's family much information at this stage.
- This can be a frightening, confusing and frustrating time to make sense of and adjust to changed life. Survivors might be unable to drive or return to work or education, and seemingly simple tasks such as grocery shopping or travelling can become major challenges. Rehabilitation might help to regain some of the skills they struggle with over time, but even so, some effects can be ongoing.

SOME OF THE COMMON EFFECTS OF BRAIN INJURY

Some of the common effects of brain injury are listed below.	Physical effects	Fatigue	Mobility issues	Sensory impairment	Hormonal imbalances	Weakness or paralysis on one/both sides
Cognitive effects	Memory problems	Reduced concentration Reduced problem-solving Impaired reasoning	Impaired visual-perceptual skills	Emotional and behavioral effects	Personality changes	Mood swings ('emotional lability')
Difficulties with speech	Epilepsy	Spasticity	Ataxia (irregular or uncontrolled movement)	Visual problems	Problems with motivation	Reduced information processing Repetition or 'perseveration'
Impaired insight and empathy	Language loss (aphasia)	Loss of confidence	Depression and sense of loss	Anxiety	Abusive or obscene language Impulsiveness	Frustration and anger Disinhibition Obsessive behavior

THE COMBINATION OF EFFECTS OF BRAIN INJURY

- The combination of these effects, and the practical impact they can have, can cause many brain injury survivors to feel like a 'new person' after their injury. For many survivors, this change can cause feelings of grief for their old self or the life they had before.
- You may also be grieving if they have changed, and you may deeply miss the person they were. However, rather than walking away from them, try to realize that you are grieving together and that it is possible to move forward supporting one another and creating new memories.
- Remember that while some effects continue for weeks, months or even years after the initial injury, some of them can get better over time. The first few weeks or months may therefore be difficult, but things might gradually improve. Continuing support and care can help them to feel more positive about themselves and their circumstances, which might have a positive impact on their overall recovery and general well-being. Do therefore try to stay in touch and support them, even if this is difficult at first.



DAY TO DAY

- Remember that brain injury effects can fluctuate on a day-to-day basis, so while a survivor may appear to be well and functioning on one day, they might struggle the next day.
- Find coping strategies like breathing exercises, find support services here or research this yourself so that you can provide them with helpful information.
- Don't assume that just because they may appear to be coping or does not take the initiative to contact others, they do not need help. Rather, ask after them and offer to help out where needed. At the same time, respect their independence and do not assume that they cannot do things by themselves, as many survivors learn ways of adapting to their injury over time.

FOR CAREGIVERS

- Fatigue is a very common effect of brain injury and can be a particular issue during or after outings. Try to keep outings short and encourage your friend to rest beforehand and afterwards. Do consider that for many brain injury survivors, even a considerably short outing can cause them to experience fatigue the next day.
- If they struggle in busy, noisy environments, consider going somewhere quieter or visiting one another's house. If they struggle with cooking, offer to bring food over or consider getting a takeaway.
- Alcohol can exacerbate some of the effects of brain injury, particularly behavioral effects. While you can't tell whether or not they can drink, do remind them that alcohol can worsen the effects of their injury. You could even consider going alcohol-free for the outing to encourage them to do the same.
- Ask whether they would like you to explain that they have had a brain injury to others when you are out. This can make social situations easier, as others may be more willing to accommodate for their behavior.



FOR CAREGIVERS

- Try to set a particular day and time for activities you do together on a regular basis, as this can be helpful if they have memory problems or difficulties with organizing and planning. If they have memory problems, send reminders the day before, and an hour before the activity is due to start.
- Try not to take offense if they cancel on a plan at the last minute or does not socialize as much as they did before their injury. They will have their own reasons for this, such as fatigue or anxiety.
- Try to include them in activities that you do. If they are unable to do activities that you both enjoyed before their injury, or are no longer interested in those activities, try to find new or modified things that are safe and enjoyable for both of you. Remember that there are even organizations that offer disability friendly outdoor activities or holidays, so explore these options rather than excluding them from active group outings.

UNDERSTANDING COGNITIVE COMMUNICATION DIFFICULTIES

Communication is a complex process, which involves many aspects of thinking and social skills. If brain injury impairs any of these skills, then it can affect the ability to communicate successfully. 'Cognitive communication difficulties' is the term most often used for the resulting problems.

The frontal lobes are particularly important for cognitive communication skills because of their role in the brain's 'executive functions', including planning, organization, flexible thinking and social behavior. However, many other parts of the brain interact to perform the skills and are also important, such as areas of the temporal and parietal lobes.

WHAT NOT TO SAY

- There are some things that people regularly say to brain injury survivors, which, though said with good intention, can be perceived by the survivor as being unhelpful and sometimes frustrating. The following lines are some examples of this. Do, therefore, try to avoid saying the following:
- “I know what you mean, I’ve got a terrible memory too.”
- An injury to the brain can prevent memories from being stored and/or retrieved. This is very different to the day-to-day forgetfulness that everyone experiences occasionally, and so should not be compared.
- “But you don’t look disabled.”
- The cognitive, emotional and behavioral effects of brain injury can still be present long after any physical injuries have healed. Therefore, just because the effects of the injury are not visible, does not mean that they are not there.



WHAT NOT TO SAY



- “It’s all in your mind.” The effects of brain injury experienced by a brain injury survivor are not purely psychological and should not be treated as such, even if they are not visible.
- “Chin up - there’s always someone worse off.” When trying to adapt to an entirely new life after brain injury, it doesn’t always help to know that others may be dealing with worse, as defined by someone who doesn’t understand what they’re going through.
- “Are you sure you should be doing that?” An essential part of the rehabilitation process is relearning lost skills by pushing oneself to do challenging tasks. Although often said by people wanting to help, having one’s ability judged by someone else can be frustrating.

WHAT NOT TO SAY



- “Move on and stop dwelling on what happened.”
- The effects of a brain injury can be life-changing, and can last for months, years or a lifetime. A person can’t simply decide to ‘get better’ and move on.
- “You should be back to normal by now.”
- No two brain injuries are alike, and no two journeys to recovery should ever be compared.
- “You’re tired? At your age?” Fatigue is a regular and pathological tiredness. It is very different to the tiredness you might feel after a busy day. Tasks that many of us take for granted can become much more difficult when a survivor experiences fatigue.



UNDERSTANDING COGNITIVE COMMUNICATION DIFFICULTIES

- This type of communication difficulty reflects a range of potential cognitive changes, such as:
 - Attention and concentration difficulties
 - Memory problems
 - Literal interpretation
 - Reduced reasoning and problem-solving skills
 - Cognitive fatigue
 - Slowed speed of information processing
 - Impaired social communication skills
 - Reduced insight

SURROUNDINGS AND THE ENVIRONMENT

It is hoped that this information provided helps the public understand what survivors are going through after experiencing a brain injury, and how we all can help in the early days and long-term basis.

Remember that friends and family form an important source of support for anyone going through any sort of difficult time, and continuing support and understanding can have a positive impact on their overall recovery.