

REHABILITATION RESEARCH AND TRAINING CENTER ON COMMUNITY INTEGRATION OF PERSONS WITH TRAUMATIC BRAIN INJURY

Family Members As Paraprofessionals

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Traumatic brain injury (TBI) often results in negative changes for the person with injury. These changes occur in many areas, including physical abilities, thinking abilities (such as attention and memory), and emotions (such as depression and irritability). As a result of these changes, persons with injury are often unable to go back to their former activities, including work, school, and social activities. They may become inactive and bored, which can lead to greater problems. Family members often wonder what they can do to help the person with injury. If possible, getting your family member into a rehabilitation facility could be beneficial. The rehabilitation staff can help to identify what problems he or she is experiencing and the ways that these problems can affect activities. The staff can also help you and the person with injury to develop strategies or techniques to get around problems. For example, if your family member with injury is having difficulty remembering things, the rehabilitation staff can teach you memory strategies. Successful use of strategies to get around problems can make a difference in whether persons with injury are able to go back to activities they enjoy.

Unfortunately, many people do not have access to rehabilitation services after injury. Some people do not have insurance and do not have the money to pay for these services. Other people may live in areas that do not have rehabilitation services. They may not have the transportation to travel to the hospitals or centers that offer services. Our Rehabilitation Research and Training Center (RRTC) is focused on bringing rehabilitation services to people who may not otherwise receive them. One way to do this is to train family members as paraprofessionals. A paraprofessional is a lay person, such as a family member, friend, or other person in the community, who does not have professional training in rehabilitation, but who has been trained by a professional to deliver certain services. Since family members often spend the most time with the person with injury, they are in a position to deliver services. Training family members as paraprofessionals is one way to get needed services to persons with injury who do not have access to traditional rehabilitation.

One of our RRTC projects offers training to family members by way of video-conferencing. Video-conferencing is similar to using a telephone, but it also allows you to see the person that you are talking to. By using video-conferencing, rehabilitation professionals in another town can interact with persons with injury and their family members. This study is being conducted at West

Texas A&M University in Canyon, Texas and Northwest Texas Hospital in Amarillo, Texas. These are rural areas where there is little access to rehabilitation services. Persons with TBI and their family members are offered participation in this project when they are discharged from Northwest Texas Hospital. Those who are interested receive a visit in their homes from a research staff member who conducts an assessment to determine the needs of the



person with injury. Based on their needs, the staff member recommends that family members attend certain video-

conferencing training sessions. These sessions are conducted using video-conferencing equipment at West Texas A&M University. Family members and/or the person with injury go to West Texas A&M University, where they are trained by a neuropsychologist in Houston, Texas. There are 6 training sessions offered:

Family members and/or the person with injury may

1. General education about TBI and its consequences
2. Strategies for improving awareness of problems
3. Strategies for improving memory and attention
4. Strategies for improving language and social communication
5. Strategies for improving initiation and organization
6. Strategies for coping with emotional and behavioral changes

participate in one or all of these sessions. They are also provided with written education materials. They have access to the professionals by telephone and e-mail if they should have questions when they return home. So far, 9 families have received training through this project and have expressed much satisfaction. In the next year and a half, we expect to have 40 families receiving training. We are collecting data on the impact of this training on the abilities of the person with injury and on whether they go back to work and other independent activities. We are also collecting data on whether the training leads to reduced stress for family members. We will have our results on the web site by Spring 2008! In the rest of this newsletter, we have included some excerpts from our training sessions that we hope you will find helpful.

WHAT ARE SOME COMMON MEMORY PROBLEMS AND WHAT CAN I DO ABOUT THEM?

Memory problems are common after TBI. Most people with TBI remember information from their past, but they may have trouble learning new information. They also may have difficulty recalling what happens to them from day to day. Memory for events that happen irregularly (like medical appointments) may be worse than memory for routine things (like when a T.V. show comes on). Typical memory problems include:

- ◆ Forgetting appointments
- ◆ Forgetting peoples' names
- ◆ Forgetting to take medications or forgetting that they were taken
- ◆ Losing or misplacing things
- ◆ Repeating the same story over and over
- ◆ Needing to have information repeated

Following are some strategies that can be used at home to get around some of these problems.

- Help your family member make a memory book. This can be a notebook divided into sections or an organizer that you can buy from Office Depot and other office supply stores. Divide the notebook into sec-

tions, such as a daily calendar, to-do-lists, and an address book. Help them add important dates, appointments, and lists of things to be accomplished each day. It is important that you remind them to carry the notebook with them everywhere and to check it to find out what they need to do. Your family member may have difficulty remembering to use the book at first, but with practice, it can become a habit.

- Organize things at home so that your family member will have an easier time remembering. For example, keep household items (like keys) in specific places. Make sure that everyone in the household returns items to their special places. You can also label drawers and cabinets as to their contents.
- Use a pill box to help them take their medications correctly. These boxes have separate compartments that you can label for each dosage of medication. You can buy these boxes at drug stores.



<http://www.tbicommunity.org>

General Tips for Family Members:

- ⇒ It is easy to get into the pattern of only correcting the person with injury when he or she does something incorrectly. Remember to also praise them for small daily accomplishments.
- ⇒ Encourage them to try different strategies for improving. Everyone is unique, and not every strategy works for everyone. Encourage them to practice a strategy several times before giving up. If one strategy doesn't work, help them choose another one.
- ⇒ When giving them information on things they need to correct, start off with emphasizing what they are doing well, followed by what they still need to work on. Then end with a re-focus on what they are doing well. For example: "You are doing a great job at telling that story and it's really interesting. You got off track for a moment and I'm having difficulty following you. Can you go back to telling me about ___ because I'm really interested."
- ⇒ Try to avoid taking difficulties personally. The injury is a direct cause of changes in thinking and behavior. Most of the time, the person with injury is not in control of the changes.
- ⇒ Avoid reacting with frustration to problems. It is normal to feel frustrated, but when you feel this way, it is best to take a short break. You can return to talking with your injured family member when you feel calmer.

Depression After TBI and What To Do About It:

Many persons with TBI experience depression at some point after injury. Feeling sad is a normal part of dealing with the injury and the changes that it has caused. Often, people with injury become more depressed as time goes on and they become more aware of their limitations. While it is normal to feel sad over losses, depression can become a problem if it interferes with the person's ability to improve and to get back to activities. Some common symptoms of depression are:

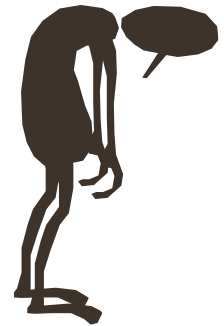
- o Sad or irritable mood
- o Loss of interest in things they used to enjoy
- o Difficulty sleeping or sleeping too much
- o Having little or no energy
- o Increased or decreased appetite
- o Decreased self-esteem or feelings of self-worth
- o Saying things like, "I would have been better off if I had died in the accident."

Most people have some, but not all of these symptoms. They also may have a different combination of symptoms over time. Following are some strategies that you can use to help your family member deal with depression.

- ◆ Talk to them about their feelings. Let them know

that you support them and realize how hard it is to have so many things in life changed. Let them know that it is normal and O.K. to feel sad. Encourage them to talk to others when they are feeling down.

- ◆ Talk to their doctor about whether counseling or medication would help.
- ◆ Get your family member involved in activities that might take their mind off their sadness. Some possibilities are engaging in hobbies (like gardening or crafts), participating in church or neighborhood groups, and joining activities at the local Y.M.C.A.
- ◆ Encourage your family member to exercise daily. Exercise contributed to improved mood. Be sure to discuss your exercise plan with your doctor or therapist to make sure that it fits with your family member's abilities.



You can find more strategies for different types of problems in our family education manual titled "Picking Up the Pieces After TBI: A Guide for Family Members." You can download a copy from our web site by following these instructions:

- Go to www.tbicommunity.org
- Click on button that says Research Projects.
- Click on Project R3: Family members as paraprofessionals.
- Click on Upcoming products.
- Click on the link to the family education manual.

You can also request that a copy of the manual be mailed to you by calling
713-383-5655.

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