

PATIENT EDUCATION

How to Help Someone Who Has a Brain Injury

# FEDUCATION EXCELLENCE CARTERSON CARTERSON

BARBARA WOODWARD LIPS PATIENT EDUCATION CENTER

### Talk to Your Loved One\*

- Introduce yourself when you arrive and announce it when you plan to leave.
- Watch the health care providers as they interact with your loved one. Ask questions as needed so you can communicate as well as possible.
- Describe what you are going to do before you do it. This will help avoid startling your loved one. For example, say "I'm going to hold your hand now." Or, "I'm going to take off your arm-splint now."
- Speak slowly and allow time for your loved one to respond. He or she likely is thinking in "slow motion" and needs time to understand what you said.
- Allow your loved one to search for the word he or she wants to say. However, after a minute or so offer clues or guess at the word before your loved one becomes too frustrated.
- Offer correct information gently if your loved one is sharing confused thoughts, then change the subject. It's better for him or her to hear accurate information than it would be for him or her to believe things that aren't true.
- Avoid telling your loved one to "talk right" or "remember." That may lead to your loved one feeling bad that he or she is struggling right now. It's more helpful to encourage and give hope when you see moments of progress.
- Use care when you make promises or comments about your actions. Persons with brain injuries often understand messages very literally. For example, if you say you are going to "be back in a minute," your loved one may expect you back in exactly one minute.
- Give immediate feedback or praise. This will help your loved one connect his or her behavior with feedback.
- Be generous with sincere praise for attempts to communicate and respond.
   For example, say, "Susan, you did a great job answering that question, and I understood what you said."
- Avoid talking *about your loved one* as if he or she were not there.
- Avoid talking *for your loved* one unless it's absolutely necessary. Give your loved one time to answer questions. Jump in after a minute or so if necessary.
- Do not encourage your loved one to respond incorrectly or inappropriately, even if you are teasing or making a joke. This can be very confusing for a person who's trying to learn new information every day.
- Avoid sarcasm and making complicated or abstract jokes. Your loved one probably won't understand these comments and the resulting confusion or frustration may cause him or her to feel bad.

<sup>\*</sup> In the interest of simplifying this material, "loved one" will be used to identify the person recieving care at Mayo Clinic.

### Expect the Unexpected

- Memory can be unreliable after a brain injury. Ask the health care provider what restrictions your loved one has, such as not getting out of bed alone, not leaving the building, not smoking, and watching what he or she eats. If necessary, gently remind your loved one about these limitations during your visits.
- Impulsive thinking and/or behavior are common after brain injury. This occurs when your loved one says or does something without thinking about what might result from it (the consequences). As needed, encourage your loved one to stop and think or to count to three before speaking or acting.
- If your loved one is "stuck" on a topic or thought (known as "perseveration") or becomes upset, distract him or her with a new conversation.
- Occasionally, a person with a brain injury tries to fill in memory gaps by making up information. Known as "confabulation," this behavior is different than lying. *Do not try to argue with, tease or punish your loved one for this.* Point out the truth in a calm, matter-of-fact way, and quickly move on.
- Unusual behaviors, such as swearing, hitting and sexual talk or actions, may happen. This is a result of the brain injury. These behaviors tend to lessen over time. Set limits on very inappropriate behavior.
- Be aware of anything that promotes frustration, agitation or anger for your loved one. Work to reduce or stop anything that may lead to this behavior.

### Present Information in a Simple, Organized and Consistent Manner

- Present one idea or request at a time.
- Add time and location (orientation) cues to your conversations. Examples of these cues are references to where the person is ("the hospital"), what has happened ("car accident"), the day of week ("Tuesday"), and time of day ("morning"). The more your loved one hears accurate information, the more easily he or she may begin to remember the information.
- Use very simple language to briefly explain how the injury happened. For example: "You were in a car accident." "You fell off a ladder." "You were hit by a golf club." Details can be shared later.
- Remember that repeating information is important to do so your loved one will learn and remember.
- Ask questions that require simple "yes" or "no" answers. (These are called "closed-ended" questions.) In the early stages of recovery these are easier to answer than "open-ended" questions, which require longer answers. For example, ask, "Did you sleep well?" instead of "How did you sleep?" And "Do you want me to help you eat? No? Okay. Do you want me to read to you?" instead of "What can I do for you today?"
- Don't give long explanations or get into arguments with your loved one. Simple instructions and conversations are best.

### Review Familiar Information

- Tell the health care team about your loved one's typical daily routines, habits, likes, and dislikes. Help to complete a "Get to Know Me" poster, and add pictures and comments as time goes on.
- Talk to your loved one about familiar names, places, interests, and experiences. Long-term memory usually works better than short-term memory. ("Short-term" refers to anything that happened in the most recent minutes, hours or few days.)
- Bring pictures of family, friends, pets, home, school, and work. Bring in familiar music or recordings of messages from family, co-workers and other friends.
- Sing favorite songs or read from favorite books.
- Explore the possibility of pet visitation if you think that would help.
- Talk to a member of the health care team if you'd like to know more about how to get involved with simple cares, such as brushing teeth or assisting with meals. Your loved one may respond to you better because you are familiar to him or her.

## Simplify Activities and the Environment

- Work with the health care team to develop a consistent daily schedule. Post the schedule in your loved one's room and refer him or her to it often. Predictable daily routines help your loved one know what to expect from day to day.
- Learn the memory notebook system used by the therapists. This system helps to make up for a lack of memory and organization. The more your loved one uses these tools, the more quickly he or she is likely to understand them.
- Remember: Your loved one will likely tire very easily, even without much physical activity. He or she may seem to be not interested or very motivated some days. These are common behaviors. Having predictable routines can help.
- Remove clutter and avoid rearranging items in the room. Most people with brain injuries respond better to simple, familiar environments.
- Present 1 or 2 food or drink items at a time. Even full meal trays may be overwhelming early in the recovery phase.
- Break tasks down into simple steps and offer step-by-step directions. Difficult, complex or multi-step tasks may be more challenging to complete.

### **Avoid Overstimulation**

- Work with the health care team to set up a schedule that promotes a balance between rest and activity. Being overly stimulated may lead your loved one to feel tired, confused and upset (agitated).
- Ask questions of the health care providers if you aren't sure how much stimulation is appropriate. And remember that your loved one's ability to cope with stimulation may change from day to day.
- Limit the number of visitors to 1 or 2 people at a time. Only 1 person should speak at a time.
- Remember that your loved one's tolerance for therapy and other activities is likely to be low. His or her ability to participate in therapy and other activities should improve over time.
- Avoid asking your loved one many questions, such as "Where are you?" "What's your name?" "Who's the president?" Too many questions can be tiring for your loved one.
- Avoid speaking quickly or loudly; use your regular, conversational tone of voice.
- Turn off the radio or TV when you are talking to your loved one.
- Do restful activities, such as playing quiet music, reading softly or using soothing (massage) touch.
- Spend quiet time with your loved one too. Rest is important. A nice visit may include a short conversation and time spent holding his or her hand as he or she nods off to sleep.
- Look for verbal and non-verbal signs of overstimulation and fatigue. Stop the visit or conversation before your loved one becomes overly tired or agitated.

### Attitude is Everything

- Have a sense of "calm acceptance" as much as you can. Your loved one likely will be aware of your acceptance and may feel more comfortable around you.
- Educate first-time visitors about the changes in your loved one. This will help create a more positive visit for everyone involved.
- Do not make comparisons between your loved one's injury/current condition and that of another person with a brain injury. No two brain injuries, treatment plans or outcomes are exactly the same just as no two people are the same. Many people with brain injuries recover in similar patterns. But each person recovers at his or her own speed (pace).
- Remember: Having a brain injury does not mean your loved one now is less intelligent.
- Be as honest and direct as possible with your loved one. However, do not treat him or her differently (younger than his or her age) because behaviors may have changed.
- Expect inconsistency throughout the recovery process. Try not to worry too much if progress isn't consistent. Many people learn to celebrate "the good days" and accept "the bad days."
- Encourage your loved one to participate in all therapy sessions, even if they don't feel like it. *Therapy is very important in helping people recover as fully as possible.*
- Reassure your loved one that everything is being done to provide the care and treatment he or she needs to restore health and well-being.
- Take care of yourself! This is a stressful time. If you are one of the primary caregivers for your loved one, talk to the health care team about resources and ideas for your own self-care. If you want to help your loved one, you need to be as healthy physically, mentally and spiritually as you can be. Your well-being will be noticeable to your loved one too!

### For More Information

If you have questions after reading this information, ask your loved one's health care provider. For more information you may refer to the following websites, which Mayo Clinic does not sponsor or endorse and for which Mayo Clinic does not guarantee the accuracy of the information. These links are provided for general information only and should not be relied upon for personal diagnosis or treatment:

- <u>www.brainline.org</u> A website offering information and resources about preventing, treating and living with traumatic brain injury. The site is hosted by WETA, the public television and radio station in Washington, D.C.
- www.biausa.org A website of the Brain Injury Association of America
- www.medlineplus.gov A service of the U.S. National Library of Medicine and the National Institutes of Health
- <u>www.healthfinder.gov</u> A service of the U.S. Department of Health and Human Services

#### BARBARA WOODWARD LIPS PATIENT EDUCATION CENTER

Mrs. Lips, a resident of San Antonio, Texas, was a loyal patient of Mayo Clinic for more than 40 years. She was a self-made business leader who significantly expanded her family's activities in oil, gas and ranching, even as she assembled a museum-quality collection of antiques and fine art. She was best known by Mayo staff for her patient advocacy and support.

Upon her death in 1995, Mrs. Lips paid the ultimate compliment by leaving her entire estate to Mayo Clinic. Mrs. Lips had a profound appreciation for the care she received at Mayo Clinic. By naming the Barbara Woodward Lips Patient Education Center, Mayo honors her generosity, her love of learning, her belief in patient empowerment and her dedication to high-quality care.



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