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HANDOUT-ABLE: For Families/Caregivers of a Person with a Traumatic Brain Injury (TBI)

This handout-able is available for loved ones and caregivers of patients who have experienced any type of Traumatic Brain Injury. Considerations to keep in mind as this new diagnosis presents itself are recommended by Nice Speech Lady.



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The shocking and heartbreaking news of a TBI has occurred. There may be a lot of information to process, and there may still may be a lot of unanswered questions. The purpose of this handout is to provide helpful details to families/caregivers on effects of TBIs, and provide guidance on how to now proceed.

Speech Pathology Recommendations:

- **Understand that effects in speech pathology areas can vary in symptoms/severity with persons with TBIs.**

Location of the injury, severity of the damage, the individual with TBI's pre- injury personality and pre-injury abilities all play a role in the symptoms that present themselves for a person with a TBI. It is difficult to compare different TBI patients because the differences in deficits can vary in symptoms and severity. It is helpful, however, to know that the brain damage effects are generally the greatest immediately following the injury.

- **Understand that recovery takes considerable time.**

The spontaneous recovery period is a window of time after the TBI where the brain is attempting to recover, and the brain works to repair the bruised neurons. This is why therapy, such as speech, physical therapy and occupational therapy are so vital once the patient is medically stable — rehabilitation helps stimulate the brain to retrain other neurons to act in the place of neurons that are no longer functioning. The spontaneous recovery period can last from six months to a year, but improvements can sometimes still be seen after 12 months. As a general rule, most of the healing that will spontaneously occur happens in that first 6 months to a year-long period. The complexity of brain's recovery, and its ability to continue recovery over time is individual to your loved one. There may be some skills that do not return despite quality therapies.

- **Seek out support**

There are a lot of information sources available on TBIs in books and other resources, and there are in-person and online brain injury support groups to pursue. Hiring personal care workers for assistance can be helpful. In addition, seeking out assistance from family, friends and members of your community groups can be beneficial. Some family members may desire to seek counseling in order to receive the support needed to problem solve how to proceed in different situations. Suggestions for this new chapter in life:

- ⇒ Remain honest with family members, providers and the person who experienced a TBI;
- ⇒ Understand your limits and when to seek additional support;
- ⇒ Be diligent and seek answers to areas of difficulty that interfere with your loved one's functioning; and,
- ⇒ Take care to perform daily self-care so to allow you the strength to face what is coming ahead.



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• **Understand future medical risks**

Educate yourself on the facts that a TBI can cause risk of other medical issues, such as seizures or a greater risk of a stroke. It is important to know these risk factors and speak to your provider about what can be done to mitigate the risk. It is important also to understand the impact of aging on TBI patients as well, for down the line.

• **Ask questions of your speech pathologist and other providers**

Examples of questions that might be helpful to ask include:

- ⇒ "What is the prognosis, in general?"
- ⇒ "What are strengths that you see to help achieve goals?"
- ⇒ "What do you project will be the biggest challenges?"
- ⇒ "What can I do to help my patient?"
- ⇒ "The location of the injury impacts what functions of the brain?"
- ⇒ "What materials are needed that I can provide?"
- ⇒ "Would it be helpful if I participate in sessions, or am present?"
- ⇒ "Would you like biographical background information on my patient to use in therapy?"

• **Consider legal resources**

Legal affairs, such as Power of Attorney (POA) or guardianship measures may be indicated. Speaking to a social worker or lawyer about your needs and options may be beneficial.

• **Become as educated as possible on the effects of TBIs. Then, proceed with steps to address these areas as best as possible.**

From a speech pathology perspective, a TBI can result in:

1. *Articulation deficits*

Articulation is the movement of the lips, tongue, jaw, teeth and soft palate for making speech sounds for the purpose of communication. It requires breath support from the lungs and the vocal cords for the shaping of air in the mouth into sounds that make up words. Your loved one may have dysarthria, which involves an articulation difficulty that results in slurred speech. Your loved one may have apraxia, which is a motor planning articulation difficulty, where the coordination of sounds are a challenge. A speech pathologist can assess articulation skills and provide more information on the particular difficulty that is presenting. Notes from SLP on articulation skills: _____

2. *Difficulties with judgment, problem solving and safety*

Patient's with a TBI may have difficulties with navigating how to proceed in different real-life scenarios, or problem solving. Having an internal ability to decide if an action is safe or not, or prudent or not, may be



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impacted. Or, the ability to consider all aspects of a problem-solving scenario may be a challenge. It is important to consider the environment of your loved one to ensure safety, and carefully consider potential situations where the judgment from a caregiver may be needed, and plan ahead for these.

Notes from SLP on judgment/problem solving/safety: _____

3. Visual, hearing hyper-sensitivities

Often, patients who experience a TBI may require a low-stimulation environment where light and sound are muted — so to prevent over-stimulation, or having difficulty tolerating visual and hearing content. This may mean educating all caregivers who come into contact with the patient about what measures are being taken. Notes from SLP on the potential need for environmental changes: _____

4. Memory problems

Having difficulties with recall or memory may be present for your loved one with TBI. Knowing the type of memory difficulties the patient demonstrates can be helpful. Asking an assessing speech pathologist about the specific type of memory involvements can be helpful in planning for cueing for the future to increase independence.

There are different types of memory skills. They include:

-- Working Memory = the cognitive framework of processes that are used for the temporary storage and manipulation of information. Short-term memory is one component to working memory.

-- Explicit/Declarative Long-Term Memory = conscious memory of facts and events; the "knowing what" memories (one type is Episodic (long-term) Memory = biographical memories that are remembered in a be connected to emotions. Another type is Semantic (long-term) Memory = factual knowledge that is independent of personal experiences).

-- Implicit/Procedural Long-Term Memory = unconscious memory of skills and how to do things, especially involvement movements of the body, such as riding a bike or tying a shoelace. These are also called "body memories" and are considered recall tasks for "knowing how."

-- Retrospective vs. Prospective Memories

- Retrospective memory = where the information to be remembered is from the past (includes semantic, episodic, declarative member and can be explicit/declarative or implicit/procedural).
- Prospective memory = where the content to be remembered is in the future, such as a planned doctor's appointment. It is important to take whatever measures are needed for safety if your loved one exhibits memory involvements. If possible, you may want to consider using signs, visual aides, lists, or other environmental supports. Notes from SLP on memory skills: _____



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5. Expressive communication problems

Some patients who experience TBIs lose the ability to speak expressively, and become non-verbal in communication. Some patients may lose only part of the ability to speak. It is important to try to anticipate the needs of your patient as much as possible. Asking questions that would involve your patient answering with a "yes" or a "no" with a head nod or shake can be helpful in this process. Asking the patient to "show you" (if possible) what they are communicating about can be helpful. Word-finding or vocabulary difficulties may exist for your loved one with a TBI. There are strategies available in order to treat word-finding difficulties. Traditional approaches to trying to regain verbal abilities tend to be focused upon first in speech treatment sessions. If it is apparent that there will not be a natural re-gaining of speaking skills after all attempts are pursued, Augmentative/Assistive Communication (A/AC) options may be considered by the speech pathologist, which involves technology in order to allow for a computer to speak for the patient when fingers indicate a message through touching an app on a tablet. Notes from SLP on expressive communication skills: _____

6. Receptive/understanding communication problems

Some patients with TBIs may have difficulty understanding what speakers say to them, such as not being able to follow directions or in answering yes/no questions. Questions may need to be asked in a simpler fashion, or at a slower rate of delivery. Visual aids, just as "yes/ no" visual boards may be needed to assist in communication. It may take time before your patient has the ability to fully understand what is being said to them, or they may always have difficulty. It is important to follow the directions of the speech pathologist in how to proceed with communicating. Notes from SLP on understanding communication skills: _____

7. Attention/focus deficits

Your loved one may have difficulties attending to tasks, have poor levels of alertness, or may have difficulties focusing on activities. It is important to identify any tasks you can find or scenarios that can be discovered that result in increased functional attention or focus. Notes from SLP on attention and focus skills: _____

8. Difficulties in understanding abstract concepts

Persons who experience a TBI may have deficits in non-concrete language or concepts. If this is the case for your loved one, choosing words that are concrete in nature would be of benefit, at least for a time. For example, stating "it is raining cats and dogs" might be too figurative of a phrase to utilize. Instead, stating "it is raining very hard outside." Notes from SLP on abstract concept abilities: _____



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9. Impulsivity

Depending upon where the injury occurred on the brain, patients who experience a TBI may have difficulties with self-control, and may demonstrate impulsivity. Difficulties may manifest in physical actions without properly thinking ahead about safety, or what outcome could come of it. Measures should be taken in order ensure safety by caregivers and family members. A person who is unsafe to walk because of a TBI at a certain point in his recovery, for example, may need constant assistance to avoid impulsively getting up to try to walk Notes from SLP on self-control skills: _____

10. Social skills challenges

Social appropriateness vs. inappropriateness may be a challenge for your loved one who has a diagnosis of a TBI. Not being able to pick-up on social cues from others, topic maintenance to turn-taking appropriateness may be areas of difficulty. If your loved one demonstrates deficits in social skills, it is important that all caregivers understand this prior to interacting with the patient with a TBI. Notes from SLP on social skills: _____

11. Difficulties with reading and writing

Written language may be an area of involvement for your loved one who experienced a TBI. Understanding and producing written language are considered higher-level skills as compared to verbal understanding and expression in terms of communication. It is important to know if your loved one has difficulty with reading or producing written language, as this will impact what types of supports or visual aides that would be utilized. For example, pictures may need to be utilized rather than words if reading words isn't possible right now. It is possible, however, for persons with verbal communication problems to retain the ability to read and write, depending upon the area of injury. Notes from SLP on reading/writing: _____

12. Difficulties with new learning

Acquiring new skills, and learning how to perform new tasks might be challenges for a person with a TBI. It may take more repetitions in hearing how to perform new tasks, or visual aides may be needed. Care would need to be taken to determine what aides would be needed in order to assist with a better ability to acquire new skills. Notes from SLP on new learning: _____



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13. Physical difficulties

There will likely be a need for physical and occupational therapy in order to assist with presenting physical difficulties, such as movement disorders or paralysis. Another type of physical difficulty which may occur includes sleep difficulties. It is important to communicate with all members of the team to hear how to best cue the patient for the most functional ability to perform physical tasks. Notes from SLP on physical difficulties: _____

14. Behavioral problems or personality changes

Aggression, mood swings, difficulties with change or difficulties empathizing may be behavioral or personality changes which may present themselves. Depression can also be a condition that presents itself within the context of a TBI. It is important to inform the patient's provider of any unsafe or undesired behaviors which are concerning or interfering with function. Notes from SLP on behavior or personality changes: _____

15. Swallowing problems (dysphagia)

Patients who experience TBIs may experience swallowing problems. The problems may be focused on the oral (mouth) phase of swallowing, or the laryngeal (throat) phase of swallowing. Refer to your speech pathologists' recommendations regarding swallowing modifications and compensatory strategies for swallowing safety. Notes from SLP on swallowing: _____

16. Visual, hearing or other sensation changes Visual field cuts, visual acuity difficulties or hearing changes may occur in patients who experienced a TBI. It is important to have visual or hearing skills evaluated by specialists in order to determine if there are any steps you can take as a caregiver to address these changes in senses. Notes from SLP on vision or hearing: _____

• In conclusion

Take a deep breath and know that helping a loved one recover from a TBI can be an incredible undertaking.

Hopefully, some of the data on this handout provide you with guidance on good starting-points.