

# Cognitive-Communication Guidelines Recommended by Persons with Lived Experience of Brain Injury

3 February 2022      Authors: ABISS & Sheila MacDonald

**Purpose of the Guidelines:** The purpose of these guidelines is to guide speech-language pathology services for adults who experience cognitive and communication difficulties after brain injury. They are intended to capture the experiences and preferences of individuals with brain injuries and their families. They were created based on the input of the members of Acquired Brain Injury Survivor Solutions (ABISS, [www.abiss.ca](http://www.abiss.ca)). ABISS members chose to consult and to offer their time to assist others with brain injuries. The guidelines were drafted by Sheila MacDonald, speech-language pathologist to incorporate and synthesize the ABISS consultations. ABISS members then reviewed and finalized these guidelines and consented to their distribution in this format.

## Terms

*Speech-language pathology* – is also called “speech therapy” or “communication therapy”.

*Cognitive-communication Impairments* – are a type of communication difficulty that arise because of cognitive problems (e.g., difficulty paying attention, remembering etc.).

*PWLE* – Persons with Lived Experience of Brain Injury- PWLE is a short form to refer to individuals who have themselves had a brain injury or their family members or close others who have learned a lot about living with the effects of a brain injury.

## Outline of the Guidelines

1. Overall Approach & Communication Support Strategies
2. Access to Cognitive-Communication Services
3. Education & Counseling
4. Assessment
5. Treatment
6. Lifelong Participation

Anyone may use these guidelines as a reference when writing new guidelines, care pathways, or education and resource materials. Cite these guidelines as:

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## 1. Overall Approach

1. **Cognitive and Communication Supports**– Most individuals with brain injuries will have difficulties with cognitive (attention, memory) and communication skills (listening, speaking, reading, writing, social interaction). These are called cognitive-communication deficits. Therefore, all communication partners, including family, friends, and health professionals, should adapt their communications (plain language, one thing at a time, quiet environment, repetition, visual supports) and provide supports (allow close other to attend appointments and take notes, key word writing, handouts, or checklists) for ALL communications (screening, interviews, assessments, education, counseling).
2. **Communication is Central and Communication Supports are Essential**

Communication skills are required each time a person with a brain injury interacts with a healthcare professional, insurer, disability insurer, workplace representative (human resources, union representative), school (teacher, guidance counselor, accessibility counselor, thesis advisor etc. After brain injury, each time a person engages in updates, education, access to resources, funding, or planning for return to life roles, communication skills are required. All persons who interact with the person with a brain injury need to recognize that they will experience communication challenges in these critical communications whether they are in person, on the phone, online, or by written communications (email, text). All persons interacting with a person with brain injury should be required to assist the person with their communication by providing the following types of communication supports:

<b>Plain Language</b>	Use plain language. Avoid or minimize the use of medical terms and acronyms or explain them.
<b>Self-Advocacy</b>	Encourage self advocacy. “Let me know if there are things, I can do to support you”.
<b>What Helps?</b>	Ask the person if there are any communication supports that they find helpful.
<b>Look</b>	Look directly at the person with a brain injury as you speak.
<b>Quiet Calm Environment</b>	Reduce or eliminate, if possible, any background noise or visual distractions (e.g., quick movements within sight or intermittent lights, etc.)
<b>Support Person</b>	Allow them to have a support person there to take notes or clarify etc.
<b>Speak to Them</b>	Speak directly to the person with the brain injury and do not let the support person take over the conversation.
<b>Paper &amp; Pen</b>	Have a piece of paper and pen available.
<b>Key Word Writing</b>	Write key words or summaries as you discuss to help them process as you speak.
<b>Notes</b>	Ask if it’s easier if you write or if they do.
<b>Slow</b>	Slow down, pause regularly

<b>Repeat</b>	Add redundancy. Use “Respectful Repetition” by saying the main points in different ways.
<b>Questions</b>	Encourage the person to bring a list of questions to ask.
<b>Summarize</b>	Summarize the “bottom line” and “next steps”
<b>Verify</b>	Ask if you understood them correctly. Verify what you heard.

## Access to Cognitive-Communication Services

1. **Self Referral.** An individual with a brain injury or their family members or close others should be able to self-refer or refer for cognitive-communication services.
2. **Blanket Referral** In hospital settings where physician referral is required, physicians should adopt a “blanket referral” or “team referral” system should be adopted to expedite access to multidisciplinary rehabilitation professionals. This would mobilize the team of multidisciplinary professionals with brain injury expertise who can then screen and prioritize based on patient needs.
3. **Case management and patient navigation systems** are **critical** to assist individuals with brain injuries and their families in navigating through the multiple services and professionals that they may require.
4. **Professional Roles.** Education should be provided to healthcare professionals, people affected by brain injury (individuals and families) and funding sources about the role of each professional. That education should be written and provided by the professionals who have done the training.
5. **Cognitive-communication & SLP** Speech-language pathologists should recognize the limitations of the name of the profession and provide public education to convey that they assist with communication and cognitive factors that affect communication.
6. **Ongoing Access and Education.** There may be multiple entry points to the system and many with brain injuries may not access cognitive-communication services until long after they have left the hospital. Therefore, there should be an approved website where people with brain injuries and their family members can go to match their needs or concerns to the professional role descriptions listed. These role descriptions should be written in plain language and approved by the professional associations for each healthcare or rehabilitation profession.
7. **Objective Diagnosis and Referral.** The decision about service needs and referrals should be made by objective health professionals who have specific expertise in brain injury and rehabilitation and not by funding sources or those in their direct employment.

## Education and Counseling

8. **Education Materials:** Education and counseling materials should be provided to all persons with ABI and their families in written form, in plain language with visual accommodations, and with methods to personalize the materials (language, amount of info, specific to their difficulties) to the individual involved. Persons with lived experience of brain injury recommend a workbook that can be personalized and added to on an ongoing basis.

## Assessment

9. **Assessment Conduct: Respect & Understanding.** The consequences of brain injury are frequently invisible (i.e. not apparent on scans) and subtle (i.e. not apparent until challenged in complex, daily activity) but debilitating in that they disrupt return to work, school, and full life participation. Accordingly, diagnosis of brain injury is often delayed or disputed leaving individuals with subtle but significant deficits to feel discounted or dismissed at a time when they are most vulnerable. Symptoms may have both brain injury and non-brain injury (e.g. emotional, stress) origins. Regardless, of the origin of the symptoms, assessors must recognize that to the individual, their life has been significantly altered by those symptoms and that assessments can add further stress, inconvenience, fatigue, and emotional repercussions. Therefore, assessors should conduct themselves in a professional and empathetic manner. Assessors should be aware that the assessment itself can be a helpful part of the therapeutic process which informs, validates, reframes, identifies hope for improvement, or highlights strengths. Conversely, an assessment when poorly conducted can hinder progress to the extent that it focuses on deficits, discounts concerns, or is led in an adversarial or dismissive nature. Professional regulatory bodies should demand that assessors adopt therapeutic rather than adversarial conduct.
10. **Minimize Repeated or Duplicate Assessments** – Individuals with brain injuries and their families find that repeated and duplicate assessments are exhausting, inconvenient, frightening (in the case of travel and passenger or driving phobias), and can set them back into a negative focus on loss and disability rather than a resilience focus on improvement or re-activation. Healthcare professionals should therefore seek to streamline assessments and avoid duplicate history taking and testing across professions.
11. **Cognitive-communication** – All assessors need to recognize that brain injuries result in cognitive and communication deficits. They should prioritize these knowing that cognitive-communication deficits will affect return to life participation, refer for cognitive-communication assessment, and adapt their communications and provide cognitive supports accordingly.
12. **Assessment of Real-World Functioning** – Assessors and funding sources need to be aware that tests and assessments in clinics cannot effectively evaluate how individuals with brain injuries function in their complex daily lives. The clinic environment is quiet and controlled. Real life is complex with multiple inputs. SLP assessors need to examine factors such as speed, stamina, and symptoms in the contexts of family communications, community interactions with stores and services, social communications, and school and work pursuits. Therefore, all involved in the funding and administration of assessment protocols need to consider real world evaluations to be more important than clinical testing. This includes such evaluation tools as clinician observations in the real world, evaluations from the individual and family (e.g., questionnaires, rating scales), patient reported outcome measures. These are likely more sensitive than test scores.

## Treatment

13. **Selecting & Prioritizing Services.** Individuals with brain injuries and their families should be provided with support in selecting health professionals' services to match their needs as well as help in prioritizing needs and services, particularly if they have limited funding, time, or stamina for multiple services. Helpful strategies include case management, team meetings, plain language descriptions of difficulties, plain language descriptions of professional services, website resources of local professionals with ABI expertise, personalized workbooks of needs and services, and discussions to match service options to needs, short- and long-term priorities, and funding constraints.
14. **Cognitive-Communication Services** – Communication is part of every aspect of life and health professionals should recognize the importance of helping the individual to address cognitive and communication difficulties. Referral for speech-language pathology services to provide cognitive-communication supports, strategies, and recommendations should be considered an essential part of care and not an afterthought.
15. **Family and Close Other Involvement-** SLP's should involve family members and close others in cognitive-communication intervention as much as possible and with consent. This is a collaboration whereby the family member or close other collaborates in providing observations in the real world, goal setting, implementation of strategies at home and in the community, and provision of encouragement and feedback.
16. **Social Relationships.** The SLP will consider the critical importance of social relationships and will provide education, supports, training, practice, and opportunities to maintain/strengthen social connection and prevent social isolation as per the individual's needs and life context”.

## Lifelong Participation

17. **Brain injury is lifelong-** Therapists need to recognize that in most cases a brain injury doesn't “resolve”, “recover” or go away entirely. A brain injury has lifelong implications with lifelong needs for adjustment, support and strategies, and this need for support will increase at all life transitions (i.e., independent living, new job, marriage, loss of a loved one, moving etc.). Also, decline in functioning may occur during aging and cause need for further cognitive and communication supports. The goal of treatment is to maximize recovery, adaptation, participation in life roles, and quality of life. Treatment needs to be provided along the continuum, especially into the community and attempts to return to work or school. Community based intervention should be provided to assist with these lifelong transitions.
18. **Long Term Improvements and Neuroplasticity-** It is not helpful, accurate, or constructive to tell a person with a brain injury that their changes will stop at 2 years. Although the rate of change slows and becomes more subtle after the 2-year mark, long term changes have been seen by those who follow people with brain injuries into the long term many years post injury. Persons with lived experience of brain injury emphasize that they see functional changes every year, that it is not helpful to deny them the hope of change. As one person with lived experience of a brain injury said, “Therapists need to be taught that neuroplasticity is a thing!”. Therefore, therapists need to be mindful of balancing realistic predictions with the hope for ongoing development in daily life.