

WHAT IS APHASIA?

An information booklet for adults with aphasia,
their families and their caregivers.



Acknowledgements

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An interactive resource for adults with aphasia, their families and their caregivers

Purpose

We have prepared this resource called “What is Aphasia?”. In it, we hope to provide basic information about aphasia, directed at people who **themselves** are living with aphasia. We have used a format that is easier for people with aphasia to understand. It relies less on reading but, rather, is assisted by pictures to give a basic overview of what has happened to them.

When to read this booklet

From our experience, we have come to realize the importance of timing in giving information. As one deals with the initial shock and the unravelling of diagnosis, treatment and prognosis, there are specific stages where some pieces of information are more useful than others. We would recommend that you keep this resource handy so you can refer to it on an ongoing basis.

How this booklet can help the person with aphasia

You may have been able to benefit from reading some of the available material on aphasia. You may also know that people with aphasia are **not** able to pick up this material and **read** the explanations of the condition with which they are now faced. They may be present when medical staff provide explanations, treatment plans and prognosis... **but**, as you may realize, they may not be able to **understand** what is said. What of the many questions and concerns they may have? People with aphasia are often unable to **say** or **write** something to express their thoughts or feelings. This resource may help answer their questions.

What is Aphasia?

Masked competence – knowing more than you can say.

Aphasia is a language problem that masks a person’s inherent competence, and most dramatically affects conversational interactions (talking and understanding), as well as the ability to read and write.

Aphasia is usually the lasting result of a stroke or brain injury, but may also be caused by other neurological conditions such as dementia or brain tumours. Aphasia may be classified as an invisible disability, though it’s not well known or understood in the community.

Many adults with aphasia know exactly what is going on, have opinions on issues, have the desire to socialize, and are capable of participating in decisions that pertain to them. Aphasia affects a person’s ability to communicate feelings, thoughts and emotions, and their ability to understand what others say.

Impacts every part of life

Conversation is central to the ability to participate in virtually every realm of adult life.

Without the ability to participate in conversation, every relationship, life role and almost every life activity is at risk. With additional reading and writing difficulties, the impact is devastating. The results are not only barriers to accessing services and information in stroke/health care, but also results in an inevitable loss of self-esteem and a profound sense of social isolation.

There are over 100,000 Canadians living with aphasia today. One in three stroke survivors are diagnosed with aphasia. The number of people with this devastating disorder is expected to increase significantly.

Therefore, this resource has been designed for the person with aphasia. We hope that the adaptations we have made will make the information more accessible. People with aphasia will likely feel more secure with explanations, and with knowing that their communication problem is **not** unknown or rare.

How to use this booklet

In summary, we have endeavoured to provide the information in an “Aphasia-Friendly” way (with simplified language and pictured adaptations). We know that with your help we can empower people with aphasia to be informed and feel like competent adults.

We suggest that you **first become familiar with the material yourself**, and **then go through the booklet together** with the person with aphasia. It may be particularly helpful to become familiar with pages 14-21, to understand your conversation partner’s aphasia and what is relevant to them. As you read through the following pages, use the notes at the bottom of each page as a guide to help the person with aphasia more easily understand the material presented.

We suggest that, as you read the main text with the person with aphasia, you draw his/her attention to the bolded words and the pictures by pointing to them as you say them. Use the yes/no/question/wrong track page located on page 39 as you read through the pages.



As you proceed, take your time and be supportive. The material is presented in a way that will help the person with aphasia indicate questions or concerns. Encourage this sharing. It is essential that feelings are acknowledged, even in his/her silence. It is also important to address concerns around progress and improvement, as this will impact on his/her mood and motivation.

It may be helpful to go through the material more than once, and to keep the booklet nearby so that you both can refer back to it at a later date.

General Instructions

What is Supported Conversation for Adults with Aphasia (SCA™)?

SCA™ is designed to ensure that people who “know more than they can say” feel as though their competence is acknowledged. SCA™ also ensures accurate exchange of information, opinions and feelings. The techniques include spoken and written keywords, gesture and body language, hand drawings, and sophisticated pictographs designed to support conversation on complex topics.

At the centre of SCA™ is a well-trained conversation partner committed to enabling conversation with those who have communication barriers like aphasia.

Through SCA™, people with aphasia and their conversation partners – be they doctors, nurses, spouses or old friends – are once again able to communicate.

Acknowledging competence and revealing competence are at the heart of SCA™.

Acknowledging Competence

Acknowledging competence refers to techniques that show people with aphasia that you know they are inherently competent.

To acknowledge competence *indirectly*:

- Let the person with aphasia know that you know they have retained more cognitive and social skills than are immediately apparent
- Use a natural tone of voice that is not patronizing
- Choose adult or complex topics

To acknowledge competence *directly or explicitly*:

- Use a phrase such as, “I know that you know” at appropriate times
- Acknowledge the frustration you will both share when – despite your efforts – communication breaks down. This act allows for a break in tension that often facilitates repair of miscommunications

Revealing Competence

Revealing competence refers to techniques that facilitate the exchange of information, opinions and feelings between you and the person with aphasia. There are three main categories of strategies to help reveal competence - **IN**, **OUT**, and **VERIFY**.

IN: Since people with aphasia may have difficulty understanding what others say, techniques to help get our information or message ‘IN’ to the person with aphasia are beneficial. When a person with aphasia does not understand, it is not necessarily the concepts that cannot be understood; maybe our delivery is at fault. We need to modify how we communicate, so that the person with aphasia understands us. We call this getting your message ‘IN’. An example of an ‘IN’ technique would be to combine your talk with meaningful gestures to help the person with aphasia to understand what you are saying. (Caution: even people with mild aphasia can experience difficulty in understanding and may need help to get the conversation back on track.)

OUT: People with aphasia may also have difficulty expressing themselves or 'getting their message 'OUT'. There are techniques you can use to help the person to communicate his or her thoughts to you. An example of an 'OUT' technique would be to give written choices so the person with aphasia can answer by pointing to the picture of his/her choice.

VERIFY: Finally, by making sure you 'VERIFY' the message, you are checking to make sure that you have understood the person with aphasia's message correctly. By stating what you believe the person with aphasia has told you, and checking to see if they agree, you can avoid potential miscommunications and consequently communicate in a more time efficient manner.

Materials needed to use SCA™ techniques

- Thick black marker
- Blank white paper
- Pencil

Tips to improve communication:

- Write key words
- Reduce visual distractions
- Use pictographic resources
- Incorporate gesture and facial expression where natural into the conversation
- Prompt the person with aphasia when you know key information has been omitted
- Write choices to get information about new topics

How does facial expression impact the success of the conversation?

Combine facial expression with the words and gestures. Any visual information you can give will increase the chance for the person with aphasia to understand.

What is the best way to incorporate the use of gesture into a conversation?

The use of gestures can help the person with aphasia to understand content. For example, miming driving for transportation or holding a telephone for talking on the telephone.

TIP: Remember to always combine the gesture with the words you are saying.

How do I reduce visual distractions?

The amount of visual material presented on a single page of the resource may be overwhelming for some people with severe aphasia or visual field deficits. We suggest that you present only one or two pictured items at a time. **TIP:** Use a blank sheet of paper, self adhesive notes, or your hand to cover some of the page and/or material that is not currently being discussed.

What are key words?

Key words are the words in a conversation that establish the topic and carry meaning (e.g. nouns and verbs). Incorporate writing and drawing as you talk. We recommend that you use a thick, black marker when writing for the person with aphasia. This results in larger and bolder writing. In contrast, most people with aphasia seem to write best with a pencil. Some may write or draw if a sheet of paper and a pencil are placed directly in front of them.

What are pictographic resources and how do I use them?

The Aphasia Institute has developed many pictographic resources that illustrate complex concepts that may arise in conversation. You will enhance the success of your interactions if you use the pictographic resources together with other techniques of SCA™. When you are using a page with more than one pictographic illustration to represent one concept (e.g. transportation), use a sweeping gesture to show you are referring to all areas in this topic.

How do I get information about new topics?

One way to get information about new topics is by asking open-ended questions (e.g. questions starting with what, when, who, why and how) and then giving choices in the form of written key words.

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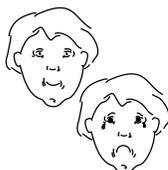
Table of Contents



Left Side of the Brain 1–3



Aphasia - Relationships and Activities 4–9



Aphasia - Emotions 10–13



Aphasia - Types and Speech Disorders 14–23



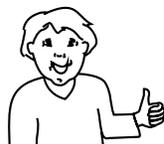
Aphasia - Future 24–28



Communication 29–36



Life is Larger 37

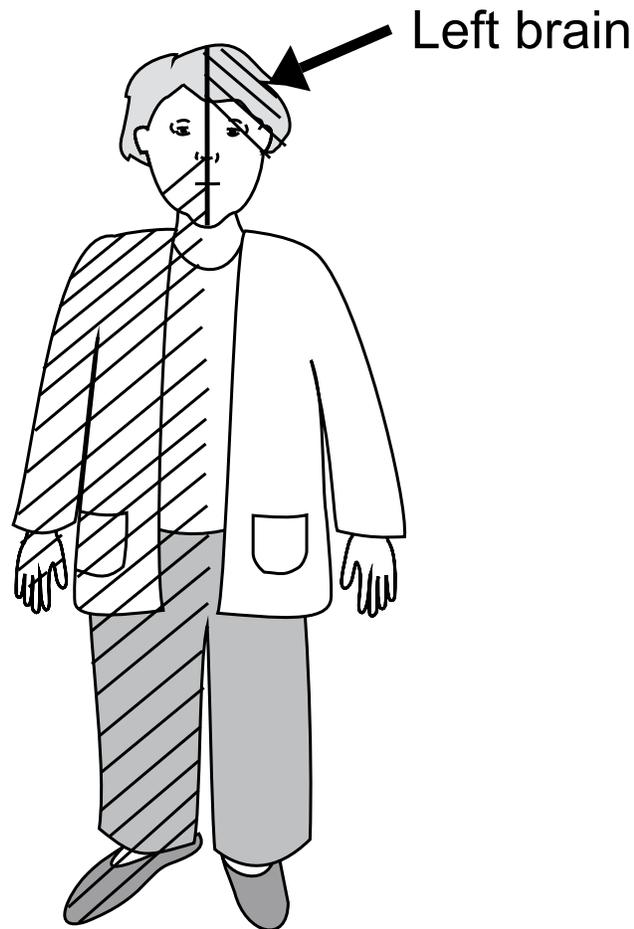


Good News 38



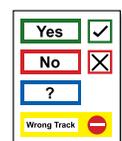
Yes/No/Question/Wrong Track 39

Stroke, injury or other illness affecting the left side of the brain

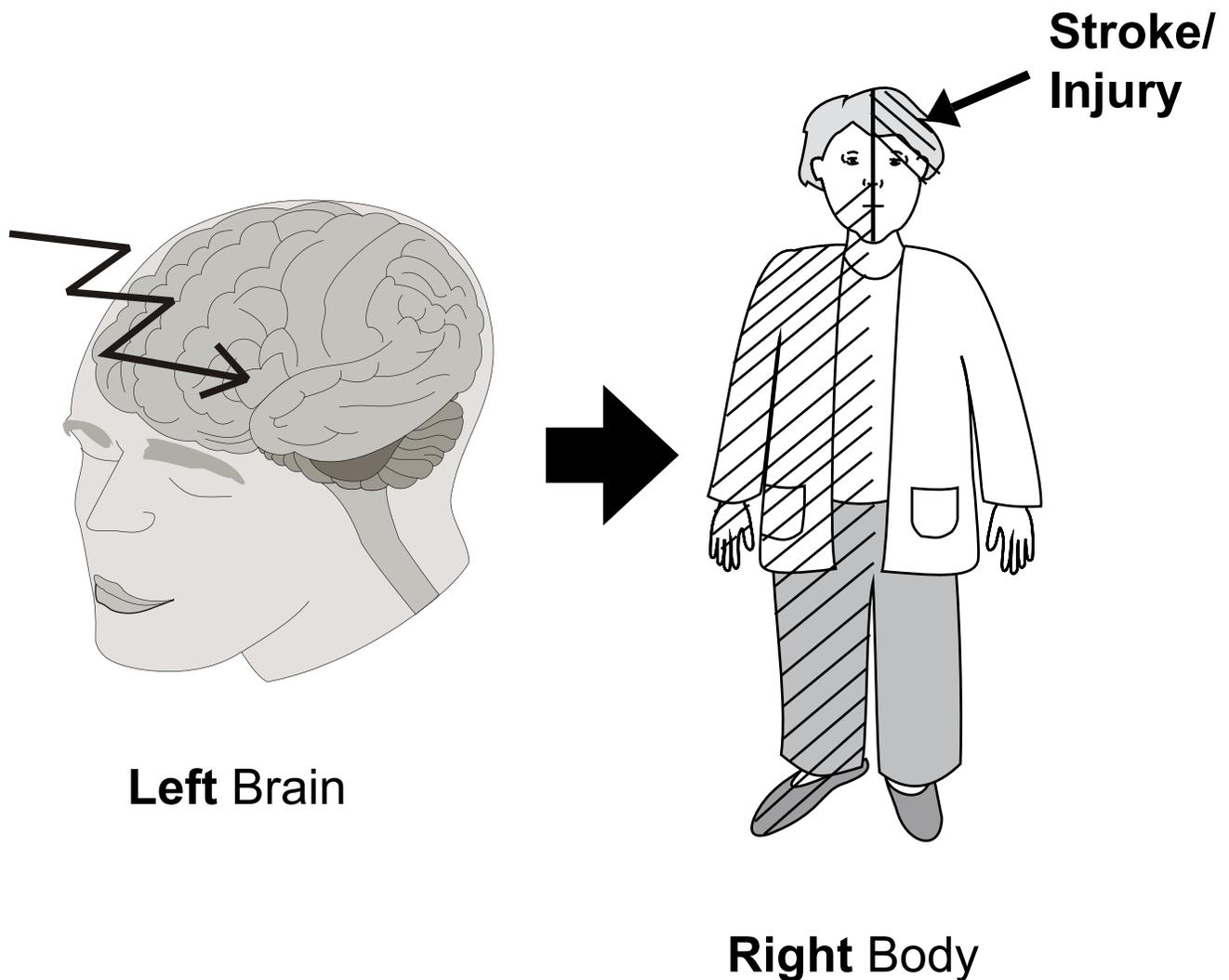


Read the text out loud.

1. Try to point to parts of the pictures that are **the focus** e.g. left side of the brain- point to the left side of **your head**.
2. Point to or emphasize the **bolded** key words e.g. **left side**.
3. If you can, gesture any part e.g. Move your right arm when discussing that the brain controls movements.
4. Use **blank pieces of paper** and a **black marker** to add **single important words** that will help eg. Dates, family names, your name, etc.
5. **Reduce visual distractions** when necessary by using a blank piece of paper to cover up any parts of the page that are not currently being discussed.
6. Use the **yes/no/question/wrong track page** at the end of the resource (pg 39) to verify information and to allow your partner with aphasia to initiate questions.



Left side of the brain controls movement and feeling on the right side of the body



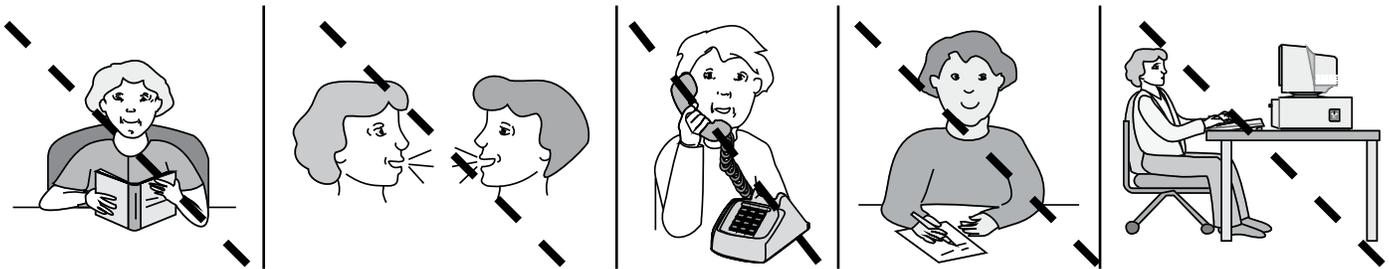
Read the text out loud. Try to point, gesture, use your marker and yes/no/question/ wrong track page at the end of the resource (pg 39) as needed.

Yes	<input checked="" type="checkbox"/>
No	<input checked="" type="checkbox"/>
?	<input type="checkbox"/>
Wrong Track	<input type="checkbox"/>

Left Side of the Brain



The **left** side of the **brain** controls **communication**.



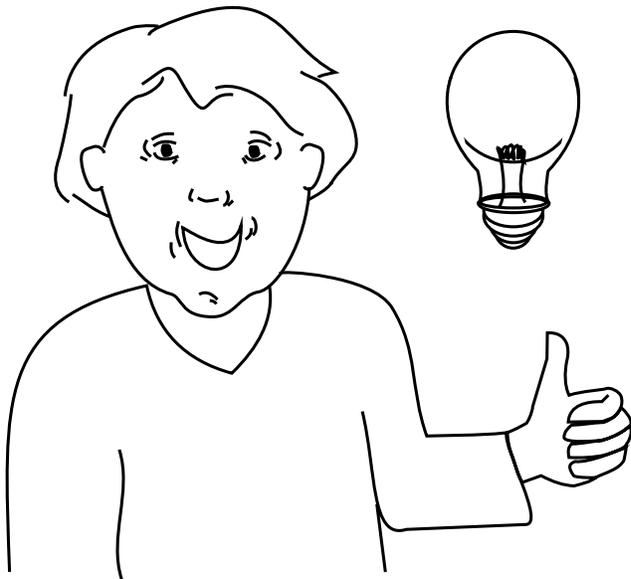
Left brain injury causes communication problems.

Communication problems = “Aphasia”

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



All People with Aphasia:



- ✓ Are still **intelligent**
- ✓ **Know** what they **want**
- ✓ Are **competent** adults
- ✓ Can make their own **decisions**

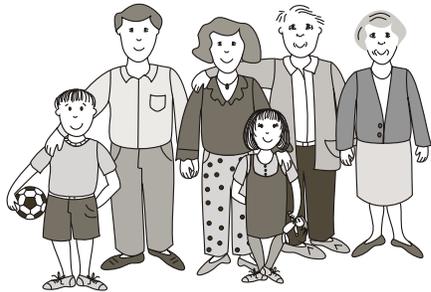
Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



This page is very **important**. It reminds the person with aphasia that there are **many things** that remain **very positive**.

Aphasia can affect relationships

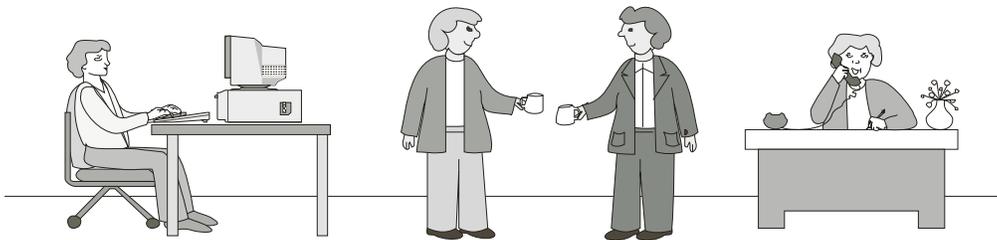
Communication may be difficult with



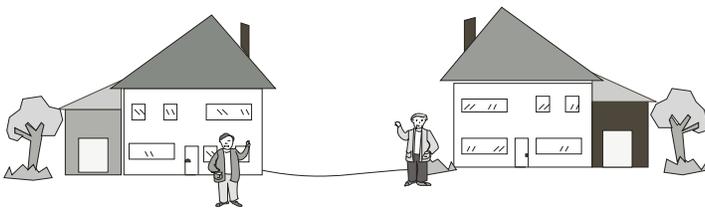
Your Family



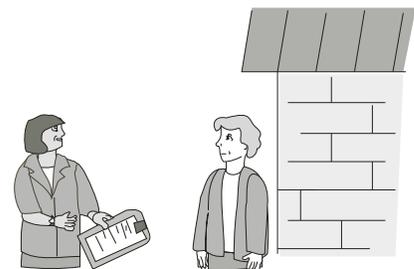
Your doctor



Your colleagues from work



Your neighbours



Strangers

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



Aphasia can affect activities



Computer



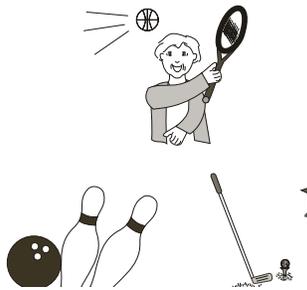
Chat on telephone



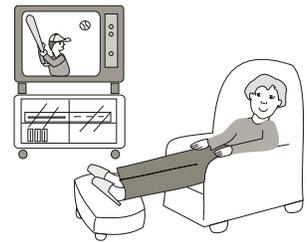
Exercising



Walking



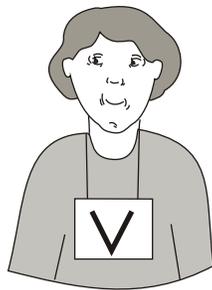
Sports



Watching T.V.



Hobbies



Volunteering



Other

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



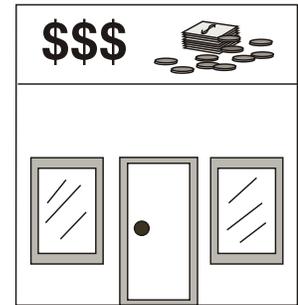
Aphasia can affect activities



Working



Making appointments



Banking



Cooking



Cleaning



Driving



Supermarket



Reading/Writing



Other

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



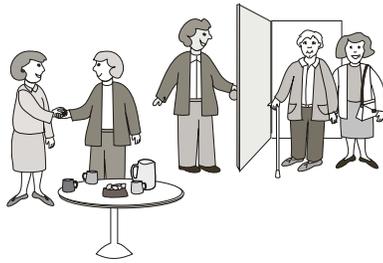
Aphasia can affect activities



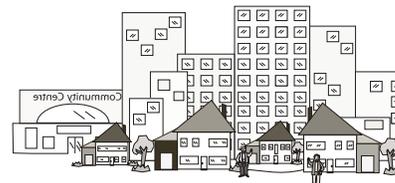
Friends



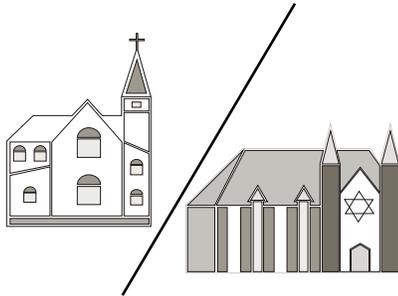
Family



Have guests over



Downtown, museum,
theatre...



Church, Mosque,
Synagogue, other

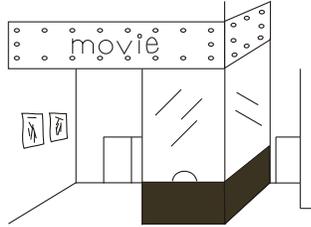


Other

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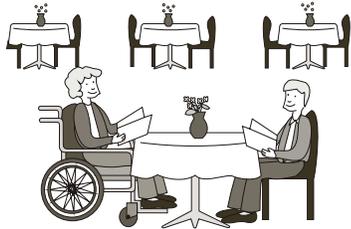
Aphasia can affect the places you go



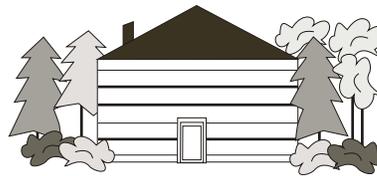
Movie Theatre



Club/Meetings



Restaurant



Cottage



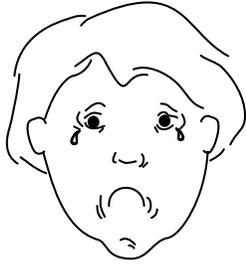
Other

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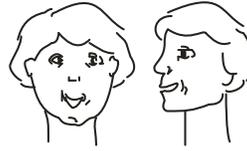


Aphasia can affect how you feel.

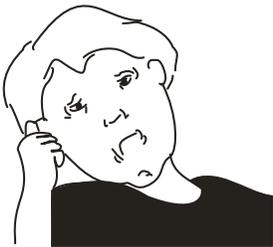
You may feel



Sad



Lonely



Depressed



Frustrated



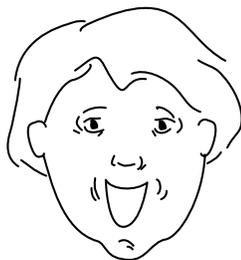
Worried



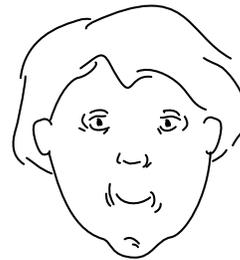
Bored



Angry



Happy



O.K.



Not in control of my affairs

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



Don't be alarmed by an emotional reaction. Tears (or anger) may come easily and unexpectedly. It is important to acknowledge any emotion and leave time to let the emotion subside. Remember to look up at your partner to see their facial expressions. Add other concerns if appropriate. Write them in the book or on a separate piece of paper.

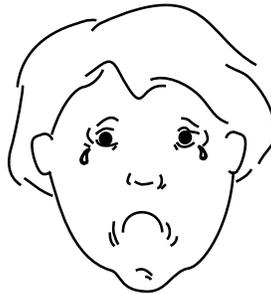
Emotions

Many people with aphasia feel frustrated

Frustration may make you



Angry



Sad



Scared

Some people may feel



Depressed



Anxious



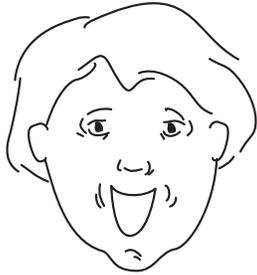
Normal

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.

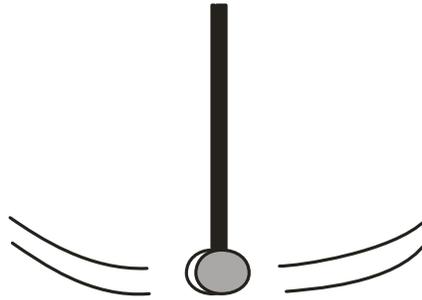


Aphasia can affect how you feel.

You may feel



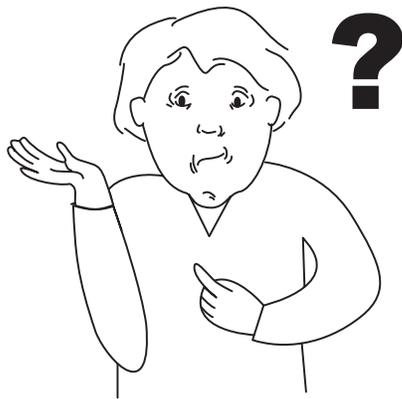
Happy



Mood swings



Sad



Why me?



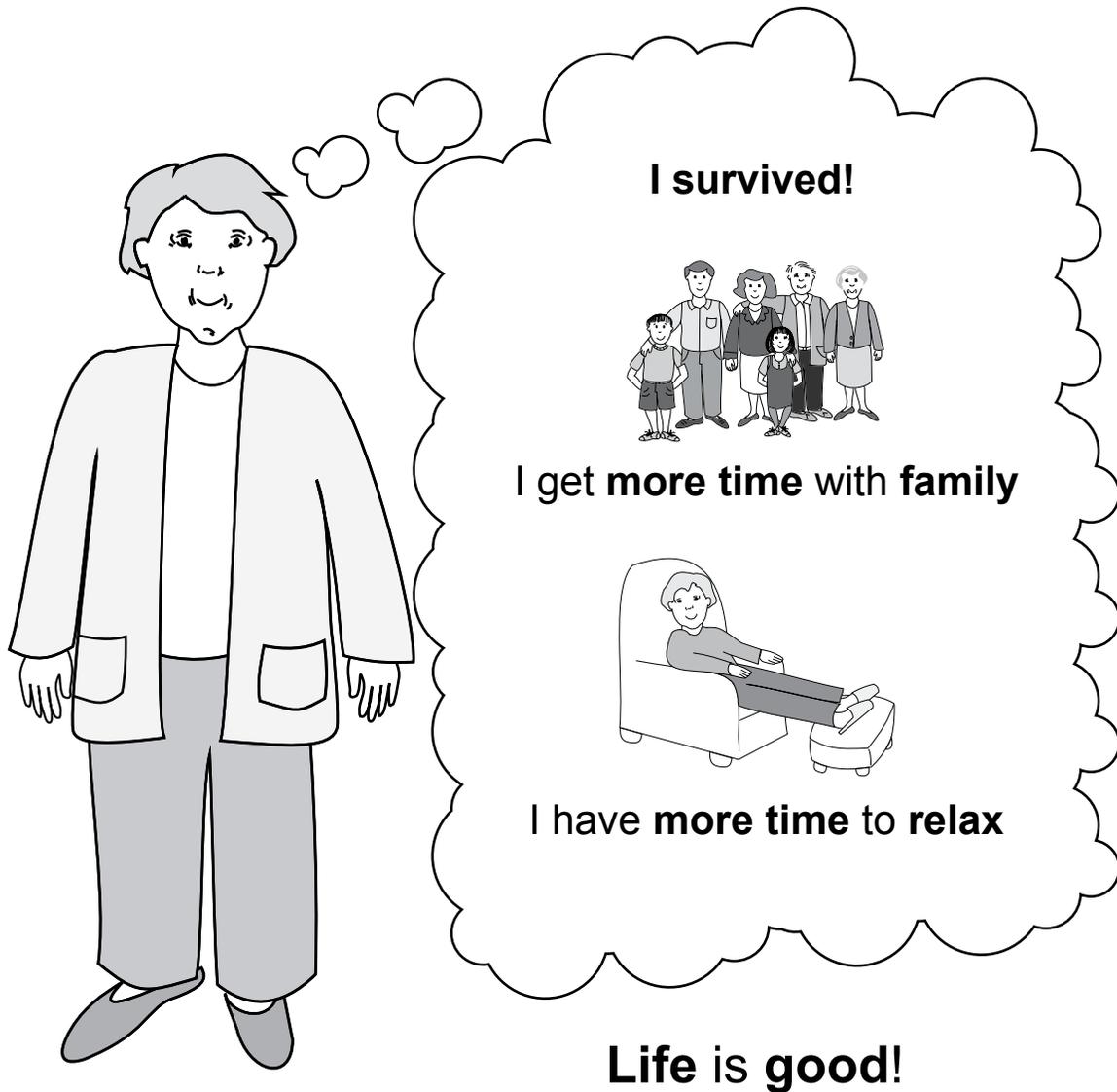
Other

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



Emotions

Some people with aphasia feel happy



Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.

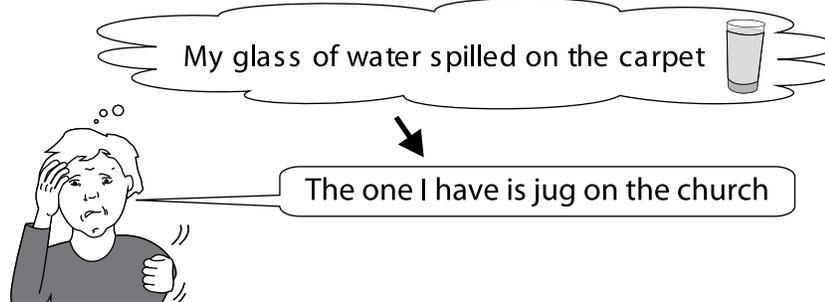
Use this page if your partner with aphasia is ready to think about this topic.



Different Kinds of Aphasia



1. Non fluent, **Broca's**



2. Fluent, **Wernicke's**



3. **Global**

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



It may be helpful to read this section ahead of time to understand your partner's aphasia and what is relevant to them. It is important to know that there are **different** types of aphasia. You may want to help your partner **pick** the **aphasia type** that is **theirs**. You can then go through the other pages if you or your partner want more details about other kinds of aphasia. You don't have to go through these pages all at one time.

1. Broca's, Non-Fluent Aphasia

Difficult to find words



Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



1. Broca's, Non-Fluent Aphasia

Messages out



Hard to talk and get your thoughts out

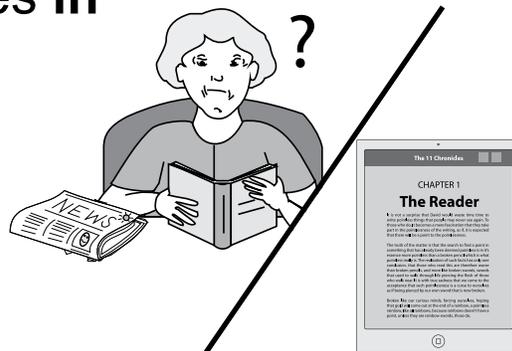


Hard to write or text

Messages in



Hard to understand when others talk



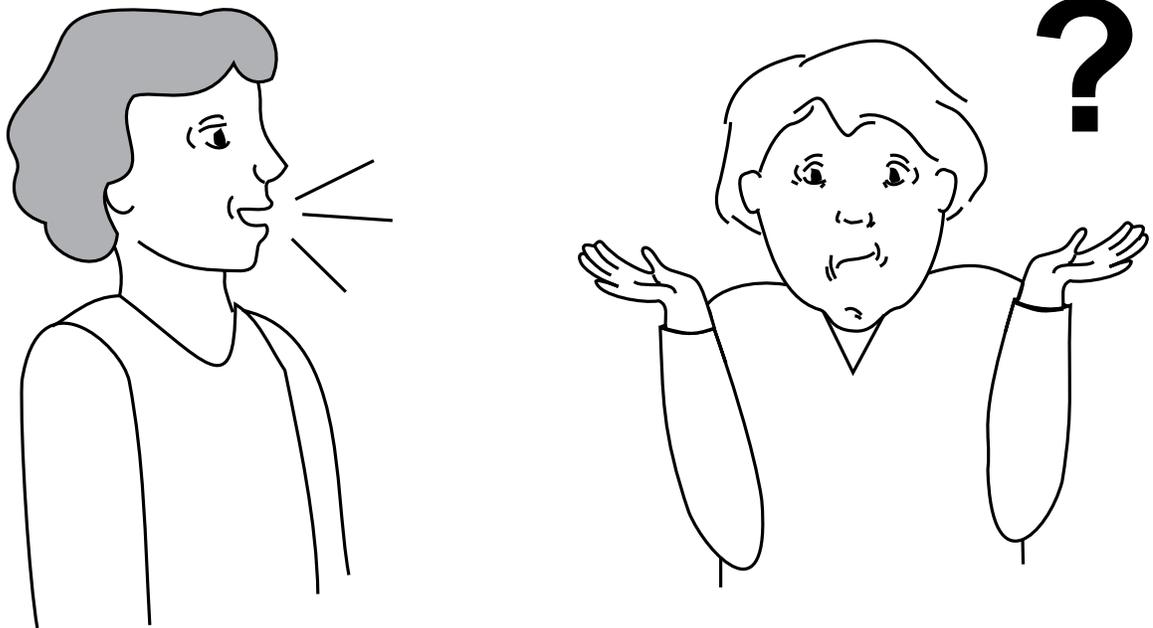
Hard to understand when you read

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



2. Wernicke's, Fluent Aphasia

Understanding language is difficult
May not use the right words

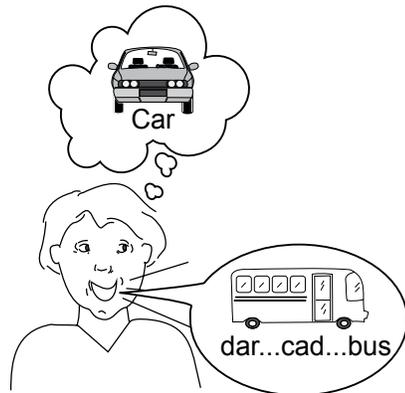


Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.

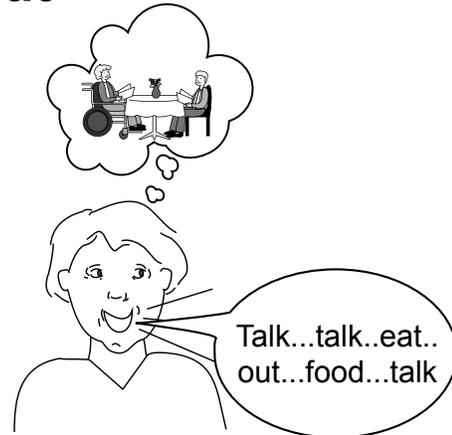


2. Wernicke's, Fluent Aphasia

Messages out



Choosing **wrong** words

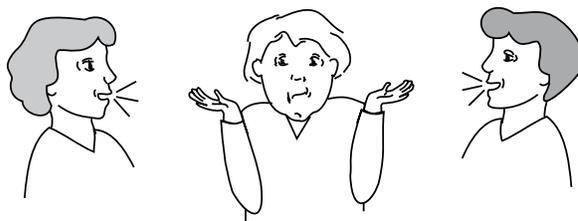


Telling **too much**

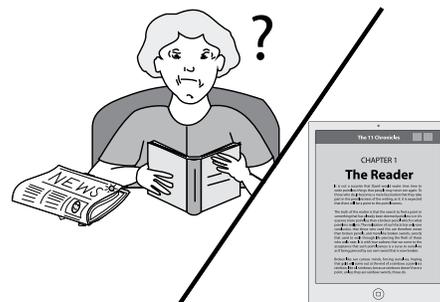


Hard to write or text

Messages in



Hard to understand
when others **talk**



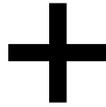
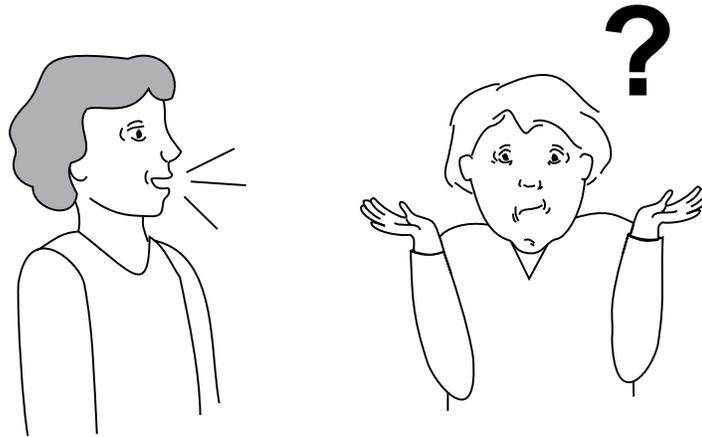
Hard to understand
when **you read**

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



3. Global Aphasia

Understanding and finding words are difficult



Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



3. Global Aphasia

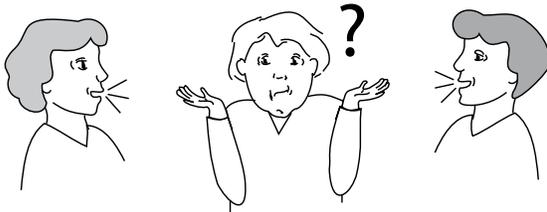
It may be hard to get messages
in and out



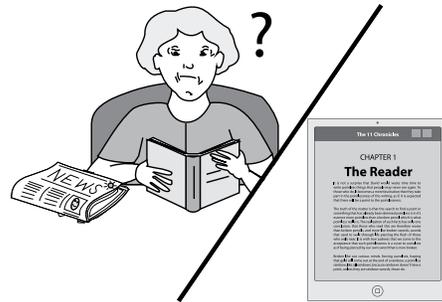
Hard to talk



**Hard to write
or text**



**Hard to understand
when others talk**



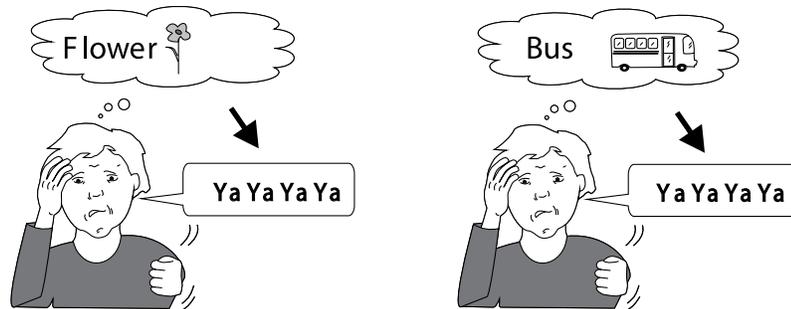
**Hard to understand
when you read**

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.

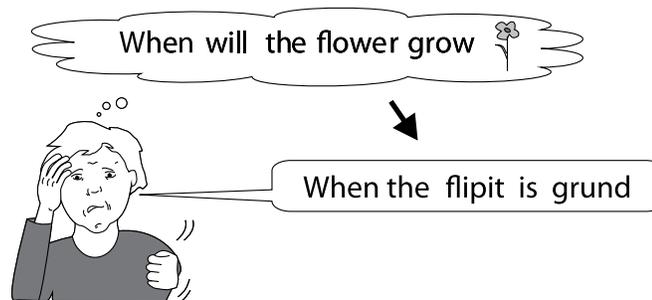


Aphasia and Speaking Patterns

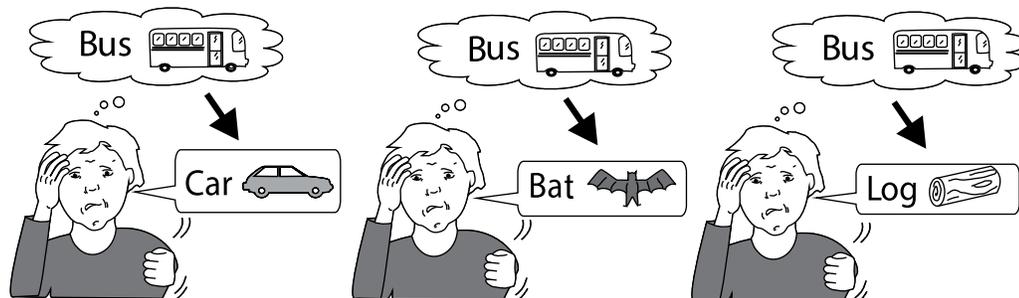
Stereotypes



Jargon



Paraphasias

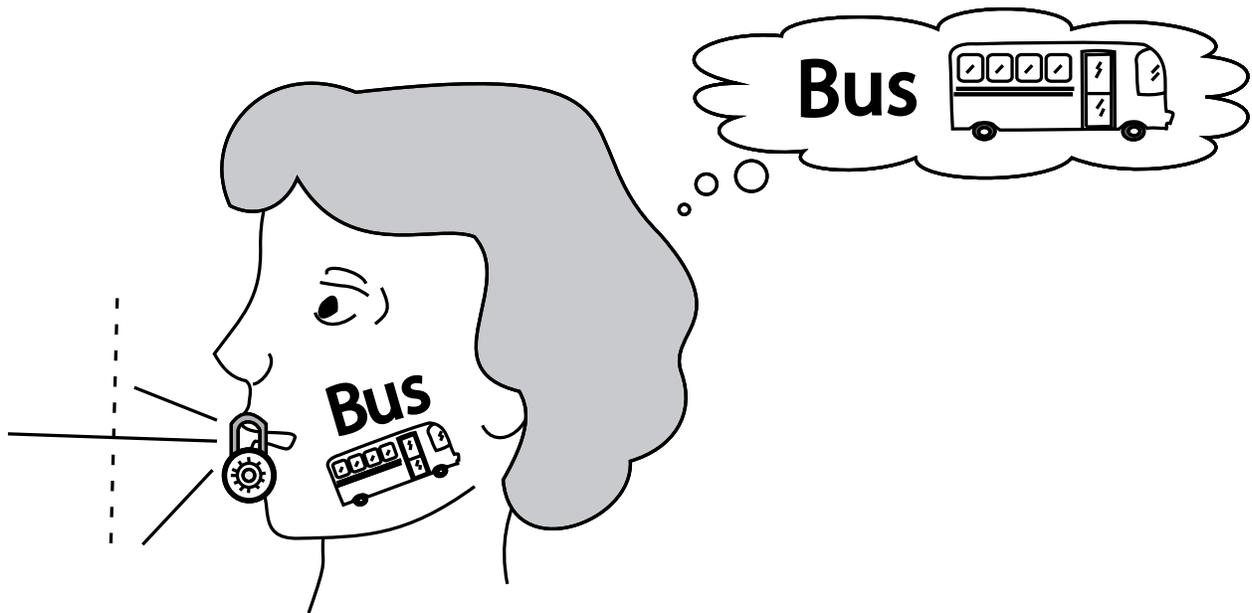


Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



Speech Disorder Involving Muscle Movements

Apraxia often accompanies aphasia.



Hard to coordinate movement of speech muscles.
Hard to get your messages out

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



Speech Disorder Involving Muscle Movements

Dysarthria often accompanies aphasia.



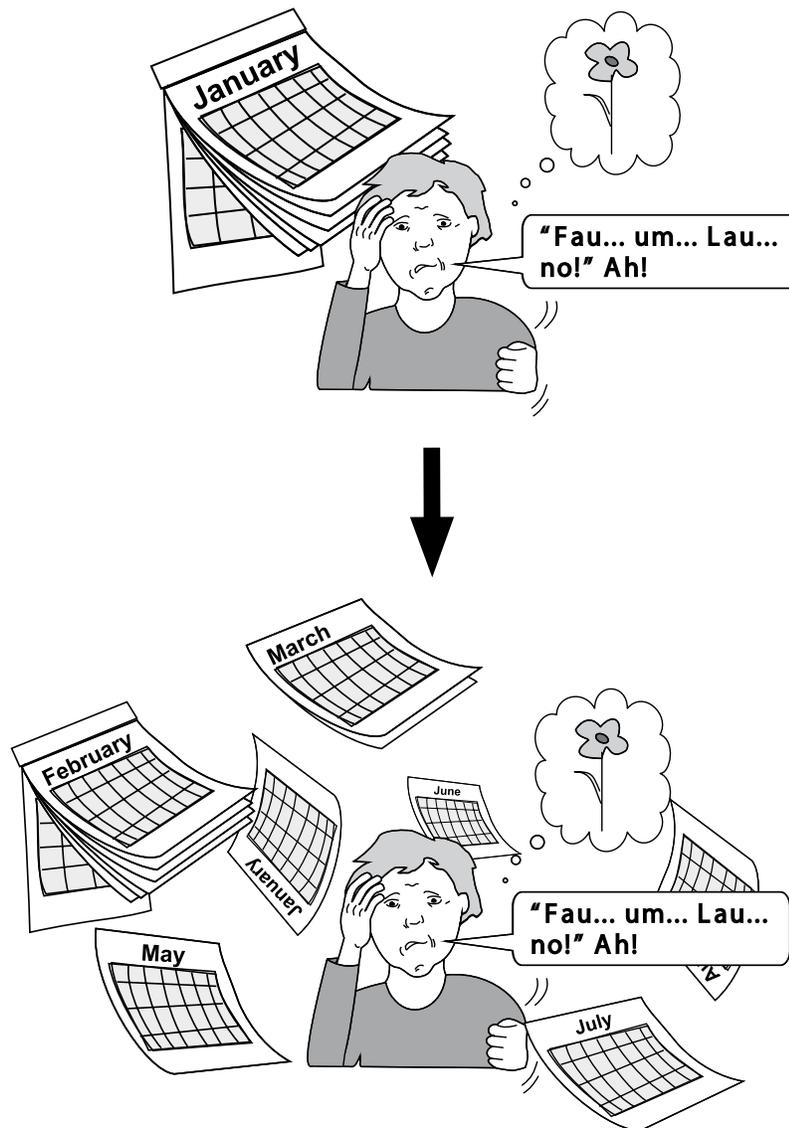
Speech **muscles** are **weak**.
Hard to get your **messages out**

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



Aphasia and the Future

Aphasia does **not** go away for most people

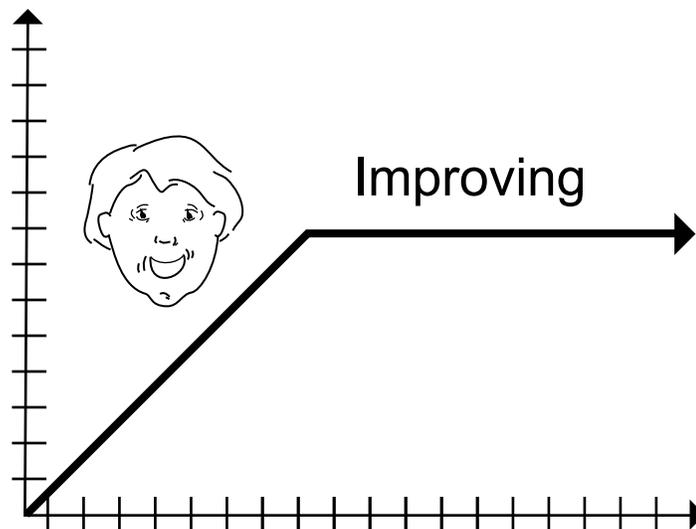


Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.

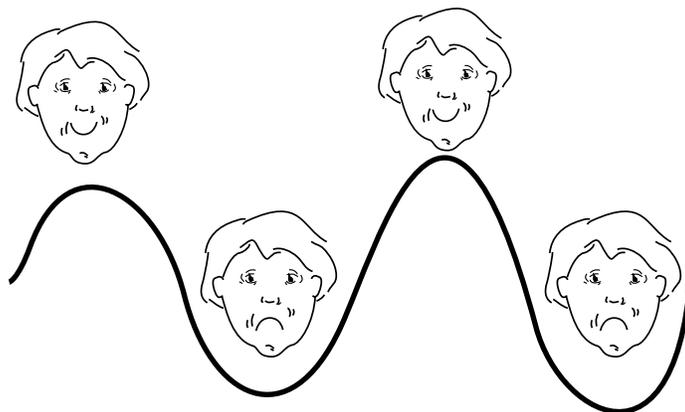


Aphasia and the Future

Improvement and Hope



Aphasia can improve



Good days, bad days

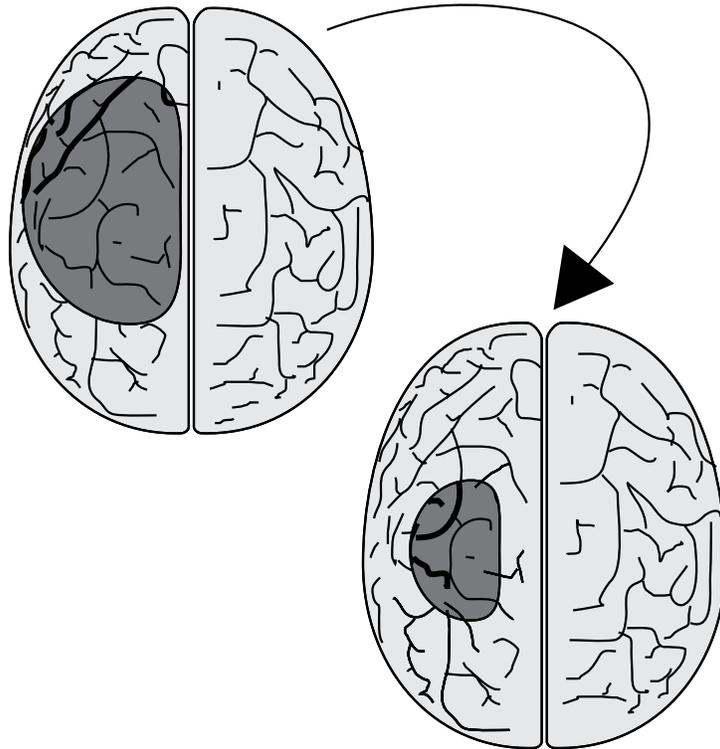
Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.

While you talk, **point** to the directional **arrows** and **waves**.



Aphasia and the Future

The Brain



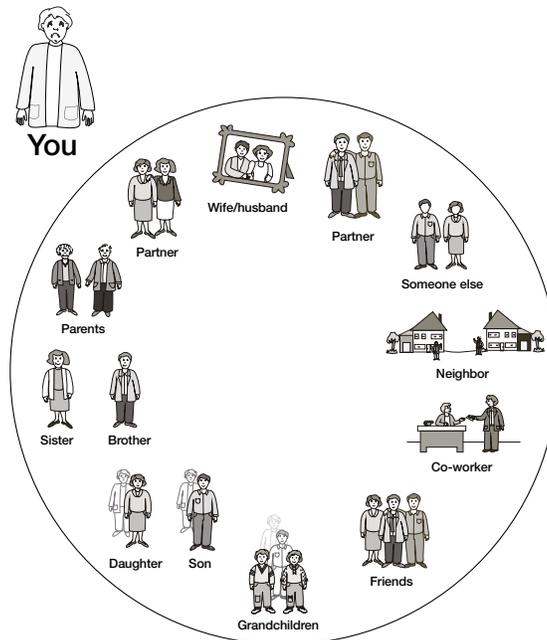
Some **healing** may occur

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.

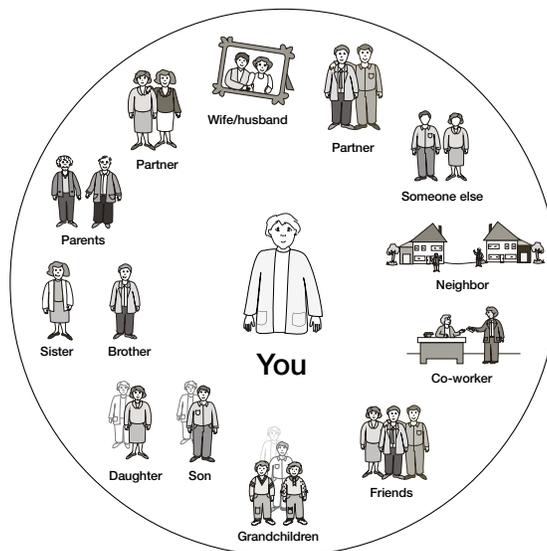


Aphasia and the Future

Improving Conversations

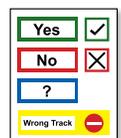


Now Conversations = frustration



Future = better conversations

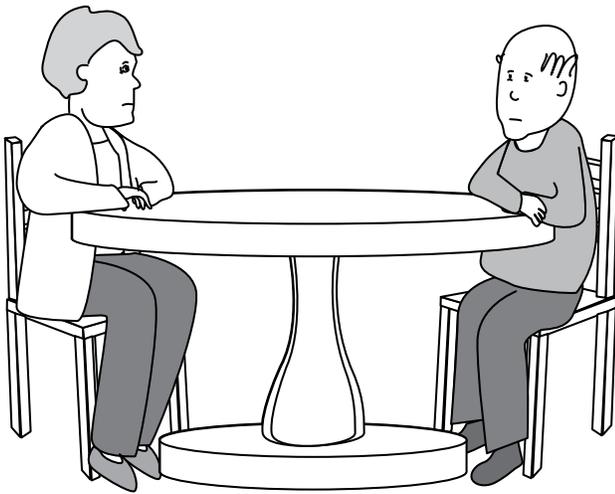
Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



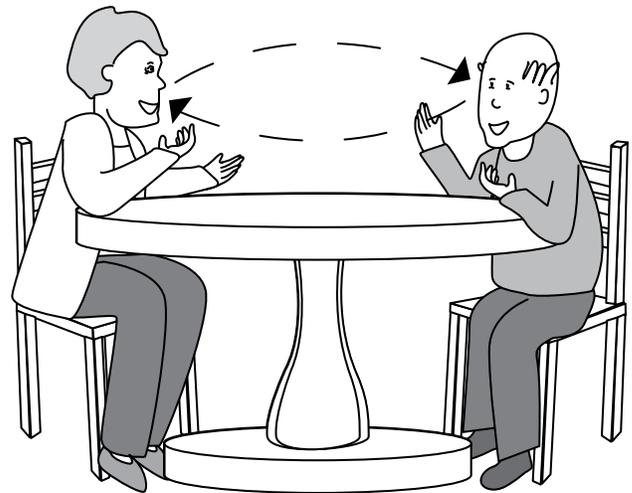
Aphasia and the Future

Improving Conversations

Conversation



Now conversations are frustrating



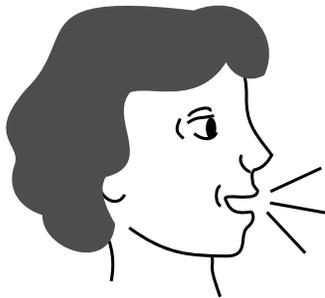
In the **future**, conversations will be better

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.

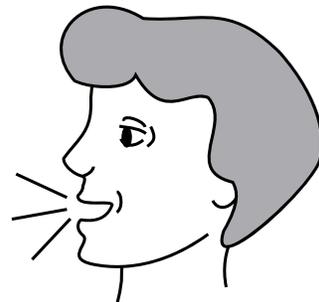


Communication

It takes two people



You



Partner

**Aphasia makes communication
difficult for both of you**

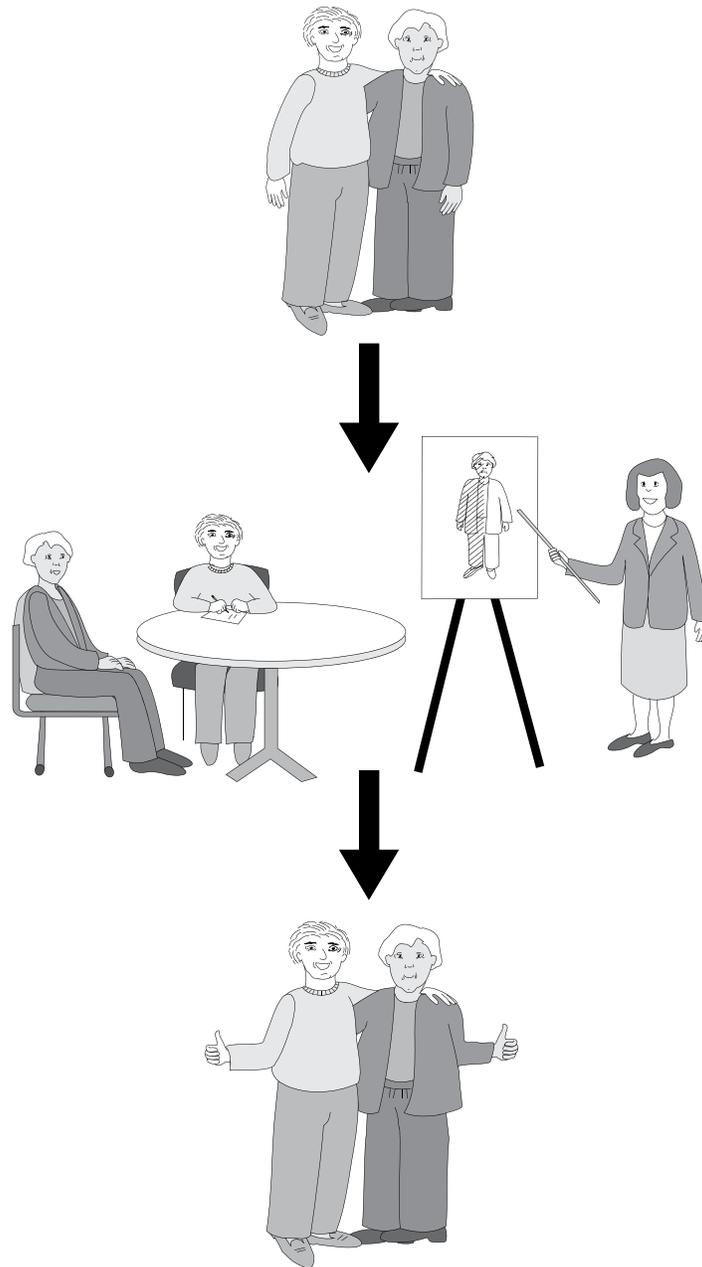
Work together

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/
wrong track page at the end of the resource (pg 39) as needed.



Aphasia and the Good News

People who are **important** to you can be **taught** to **communicate better** with partner **training**



Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



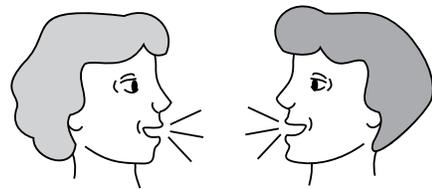
Remember to **personalize** the **information** e.g. This is about _____ (client/name and your name).

Improve Communication

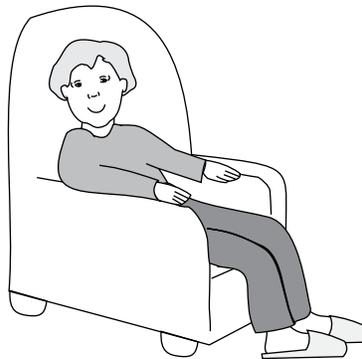
How



Speech therapy



Improve your communication with people around you



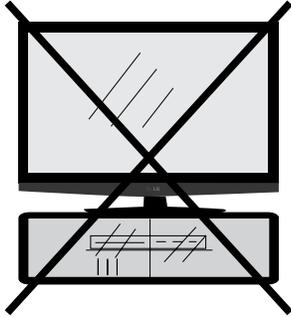
Control your environment

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.

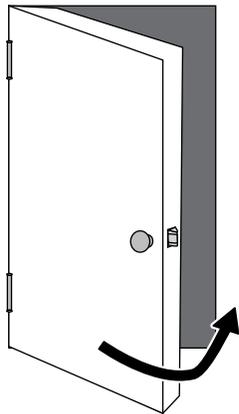


Improve Communication

Control your environment.



Control noise
e.g. Turn **off** the T.V.



Avoid distractions
e.g. Close the door



Wear your glasses
and **hearing aids**

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.

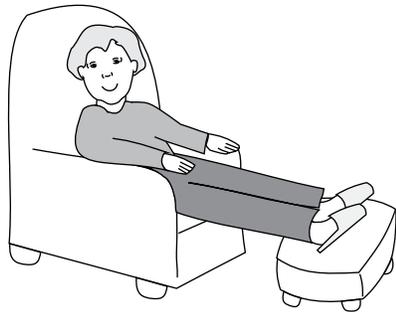


Over the next few pages you will discuss different ways to **improve communication**.

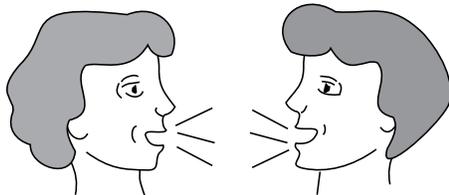
Improve Communication



Be comfortable
Focus



Relax
Stress makes
aphasia worse



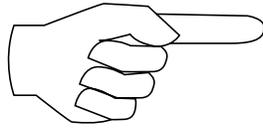
Look at your partner's face
Watch for confusion

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.

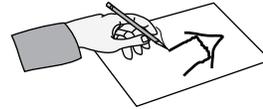


Improve Communication

What do you do?



Point



Drawing



Use pictures



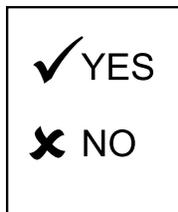
Use gestures



Writing



Use resources



Yes/No



Other

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.

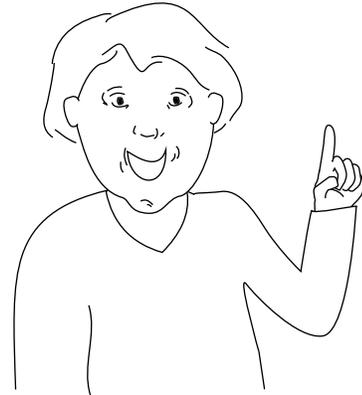


Improve Communication

What does your partner do?



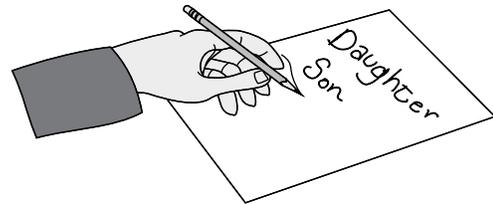
Be patient



One piece of information



Write the **topic** down



Write **key words**

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.

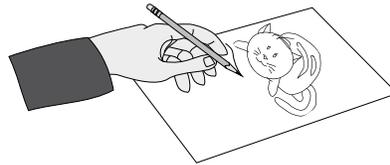


Improve Communication

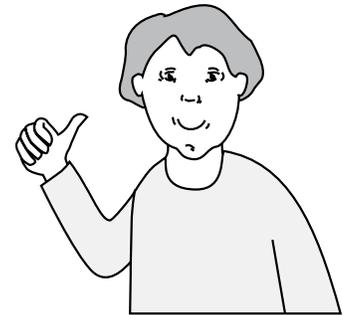
What does your partner do?



Repeat



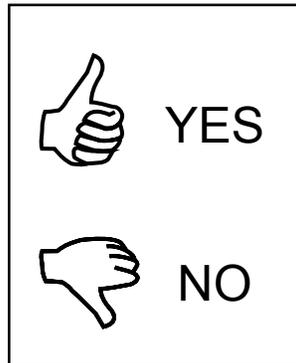
Draw



Use gestures



Keep it simple



Check you are understanding

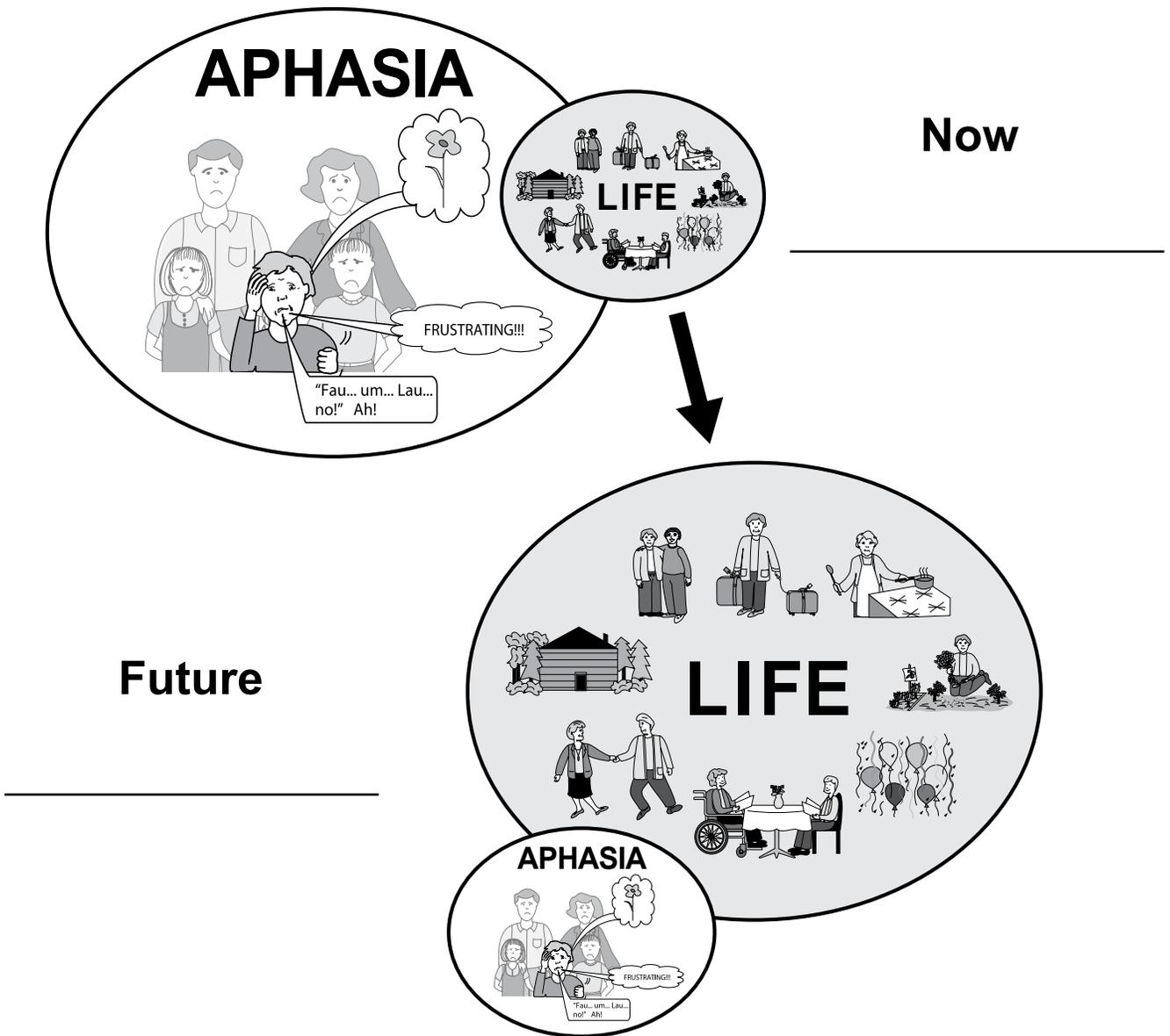


Other

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



Life is Larger than Aphasia



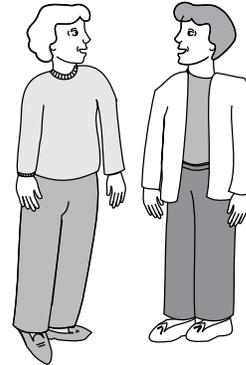
Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.



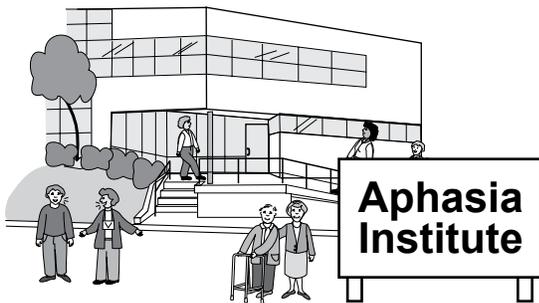
Aphasia and the Good News



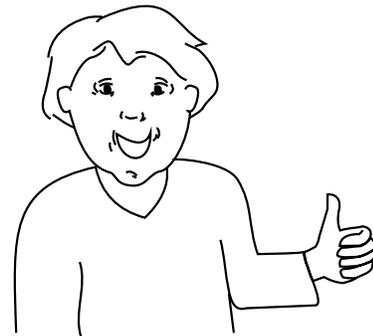
You are **not alone**
You can **meet** many people
with **aphasia**



You can **participate**
in **conversations**



There are **places** for
people with **aphasia**



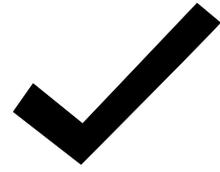
You can make **progress**
and **achieve** your **goals**

Read the text out loud. Try to point, gesture, use your marker and yes/no/question/wrong track page at the end of the resource (pg 39) as needed.

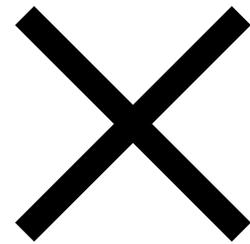


Let your partner with aphasia know that **years later**, people with aphasia still notice **improvements**.

Yes

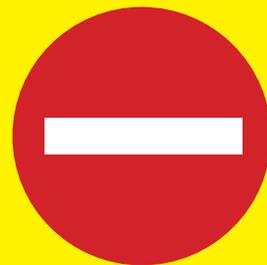


No



?

Wrong Track





For more information on training and resources, contact the Aphasia Institute at 416-226-3636. Or talk to your Speech Language Pathologist.

www.aphasia.ca