



## Association Internationale Aphasie (AIA)

### ***What is aphasia?***

*You may or may not have ever heard of the word 'APHASIA' before.*

*When you do hear the word for the first time, several questions may come to your mind, such as: What is aphasia? What causes it? and Which difficulties can accompany aphasia?*

### ***What is aphasia?***

Every human being uses language. Talking, finding the right words, understanding, reading, writing, and making gestures are part of our everyday language use. However, if as a result of brain damage one or several aspects of language use stop functioning properly, this is called aphasia.

Aphasia - A (=non) phasia (=speaking), therefore, means that someone can no longer say what he or she wants in the way he/she did before the incident. Aphasia is a language disorder. The person with aphasia (PWA) cannot use language 'normally' anymore.

In addition to the language disorder, a PWA can also be paralyzed on one side and/or he/she can have problems with regard to voluntary actions, observing the surroundings, concentrating, taking the initiative, and also memory problems.

A PWA may not be able to do two things at the same time anymore. PWAs can become frustrated during their holiday abroad for not being able to clearly state what they mean, or for not properly understanding what other people say to them. Even in countries for which a PWA mastered the language well, he/she can experience this for example when visiting a doctor. In countries for which a PWA masters the language less well, communication capacities with the local population can become more limited, and the PWA may not even be able to order the food he/she would really like to eat. People who suffer from aphasia experience these problems on a daily basis.

There are not two people who suffer from aphasia who have the same exact difficulties: Aphasia is different for every person with aphasia. The severity and scope of the aphasia depend, among other things, on the location and the severity of the brain damage, the person's earlier linguistic competence, and his/her personality. Some people with aphasia can understand language well, but have trouble finding the right words or constructing sentences. On the other hand others speak a lot, but what they say is not understandable or it is difficult to understand for their conversation partner. These persons often have great difficulty understanding language. The linguistic competence of most people with aphasia is somewhere between these two extremes.

It must be stressed that aphasia is a language disorder which does not affect intellectual capacities!

Almost always there is some spontaneous recovery of the language abilities in the first six or so months following the incident. However, the recovery is seldom or never complete. Still, with intensive practice, effort and perseverance, improvement can be made.

### **Causes of aphasia**

Aphasia is the result of brain damage. The origin of such brain damage is mostly a blood circulation disorder. Such a disorder is also called a stroke, cerebral haemorrhage, cerebral infarction or apoplexy. In medical terms it is called a CVA short for Cerebral (= brain) – Vascular (=blood vessel) – Accident. Other causes of aphasia are for example a trauma (an injury to the brain as a result of for example a (car) accident or a brain tumor).

Our brains need oxygen and glucose in order to function properly. If as a result of a CVA or one of the other causes the blood circulation in the brain is disrupted in an area of the brain, the brain cells can die in that specific location. In the brain, there are areas with different, specific functions. For most people the areas for the use of language are located in the left half of the brain. In the case of injury in these language areas aphasia may be the result.

Which additional symptoms or problems can a PWA have?

It is seldom the case that someone only suffers from aphasia. Often other areas of the brain are affected as well. Examples of additional problems are: **hemiplegia** (hemi=half, plegic=paralysis). For people suffering from aphasia this is often the right side of the body. The muscles on one side of the body can also be affected, or as a result of the brain damage, the muscles may not collaborate well anymore. Another deficit is loss of half of the eyesight (**hemianopsia**, hemi=half, opsia=to see). Most people do see everything that is located on the healthy side of their body half, but not the things that are located on their affected side.

It can also be the case that certain actions cannot be performed (**apraxia**, a=not, praxia=perform). Simple actions such as getting dressed, eating, and drinking can suddenly be affected and the person may not be able to perform these activities, in particular when requested to do so. Someone who suffers from apraxia does, for example, not know how to blow out a candle, if he or she is asked to do so (conscious action), whereas he/she can automatically blow out the match he/she is holding, if he/she is in danger of burning his/her fingers.

A PWA may also have problems with eating, drinking, and swallowing (**dysphagia**, -dys=not well, phagia=swallowing). Because of the brain damage the digastric and swallow muscles can become paralyzed, very sensitive, or even insensitive. This makes eating and drinking a difficult task. Because of the paralysis and loss of feeling in a part of the cheek, saliva can drip from the corner of the person's mouth unnoticed.

**Memory** problems are another symptom. When remembering information language plays an important role. Because of the language problems the person's memory seems to function less well. Therefore, he/she should write down a couple of key Words. This makes it easier for someone suffering from aphasia to

remember things.

**Reacting differently:** Sometimes a PWA may react completely differently to events after having suffered a stroke, than he/she did before. Controlling one's emotions may become more difficult. It is possible that someone laughs and cries more often and cannot stop laughing. It is also possible that it costs him/her more effort to stop reacting in a certain manner.

**Epilepsy:** When the brains recover from an injury scar tissue is created in the affected area. Sometimes this scar tissue can cause a short circuit, so to speak, inside the brain. As a result of that the body convulses and the person often has trouble breathing, and he/ she may lose consciousness. Such an epileptic fit may last only a minutes or so, but it often comes unexpectedly and the fright for the person who suffers from it – as well as for the family member(s) – is often great. The above list of accompanying symptoms and difficulties is by no means complete.

The aphasia symptoms and the additional difficulties are different for every human being. The abovementioned problems can occur in combination with aphasia, but do not have to be present.

## Treatment for aphasia

Many people who suffer from aphasia have been hospitalized for some time. That hospital stay often took place after the brain damage occurred. After being dismissed from the hospital many PWAs still need further treatment. It is not always clear who they can turn to for help. Please consult with the doctor who treats you on the possibilities in your area. The treatment for aphasia is almost always given by speech therapists. In principle anyone suffering from aphasia is eligible for speech therapy. The duration of the treatment is, among other things, connected with the recovery from the aphasia, and with the possibilities and regulations in the country you live in.

## Guidelines for communication

Because of aphasia the way in which someone understands something or expresses himself/herself changes. By making the best possible use of the remaining communication options people can still communicate with a PWA. Someone with severe aphasia often only understands the most important words from a sentence. He or she understands the 'key words'. To understand things by means of key words can cause misunderstandings, since the selected combination of key words may remain ambiguous and the persons may not share the same general knowledge of things. The result is that the message can be misunderstood. Sometimes the communication partners – the PWA and someone else think they have understood each other well. However, a later reaction reveals that this was not the case.

If you would like to really talk to a PWA you must 'take time' and 'give time' for the conversation. Sit down and relax and make yourselves comfortable and make eye contact.

If you are not willing to have a lengthy conversation with a PWA, then tell something simple about yourself and subsequently ask questions to which you yourself already know the answer.

Speak slowly and in short sentences, and stress the most important words in the sentence.

Write down the most important words. Repeat the message and show the PWA what you wrote down, if he/she can read. The PWA can use it as a reminder or as a means of communication.

Provide assistance to a PWA after giving him/her time to find the words on his/her own. Immediately jumping in and 'helping' a person by speaking for him/her is not helpful. It can be demotivating for the PWA. If the PWA asks or gestures that he/she needs help, then provide the information to him/her.

When expressing himself or herself, pointing, gesturing, drawing, or writing may all be used to facilitate the conversation

Ask whether he/she can point out, gesture, draw, or write something down. You may also search together in a pocket dictionary or in a conversation book.

If a PWA wants to tell you something the following tips may help: First it has to be clear who is concerned, what happens or has happened, and possibly where or when the event takes place or took place. It is very important that you ask the right questions, are inventive, and proceed as systematically as possible. Always try to ask simple questions and you can provide a short list of the possible answers from which the PWA may choose from.

**Communication aids:** In many countries there are special picture-pointing books or apps for tablets with words and drawings. By pointing to words or drawings one can get one's message across and make clear what one means. Consult your doctor or a speech therapist on which aids are available in your country. If that is not the case, you can make a communication book yourself. In it you can include pictures or images and words that are important for communication with the PWA. In this way a discussion about events can take place and feelings can be expressed.

When communicating with a PWA by means of such a picture-pointing book you can try and look together for concepts that are important for the discussion. See to it that you have a pen and paper at hand. You can then write down the most important words from the conversation below each other, so that it becomes easier to follow and remember the contents of the conversation.

**Patience conquers all!** Having a discussion with PWA requires a lot of time and patience. Despite the aforementioned tips it can happen that you still do not really understand each other. In that case, you should take a short break and then try again later to express yourselves. You will probably be more successful! More information is available on the website of the Association Internationale Aphasie (AIA). There you can find more information on aphasia in various languages:

[www.aphasia-international.com](http://www.aphasia-international.com).

Here you will also find links to national aphasia associations with information provided in the various languages.

The objective of this website is to bring aphasia to the attention of people around the world and to stimulate the foundation of contact groups for fellow PWAs, and thus to enable them to participate more fully in everyday life and in the society and to prevent PWAs from becoming isolated.