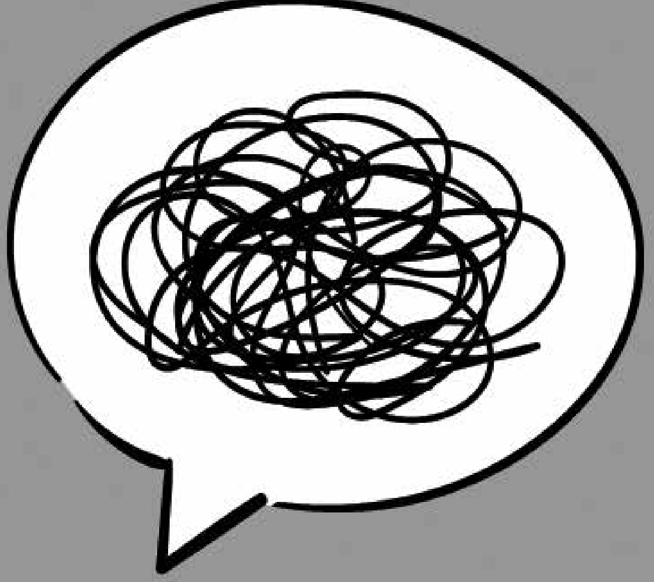
When words fail you

Aphasia, a disorder that affects how you communicate, and can impact your speech as well as the way you write and understand both spoken and written language, is four times more common than Parkinson's Disease, yet is not widely known. Here's help.

BY CAROL LEGG



There are over 7,000 languages in the world, and 35 in South Africa alone. Each has its own sounds or signs, grammar, writing systems, and lexicon; our mental dictionary. The diversity of human language is astounding, but so are its universal features.

First, we all learn and process language in similar ways, regardless of which languages we speak. Second, language for all of us is a tool for collaboration and connection. An expression of our shared humanity. Third, language is resilient. Once learned, it becomes part of our inner voice and thought, used with automaticity. Finally, save for a small percentage of people, language is stored in the same part of the brain, the left cerebral hemisphere. With close connections to our auditory and visual systems and to the motor centres that control our lips, tongue, and hands, the language centre of the human brain is as built into our anatomy as our organs and bones.

When this area is damaged – by stroke, trauma, or disease – access to language is disrupted. This is called aphasia. Though not widely known, aphasia is four times more common than Parkinson's Disease. About a quarter of people who suffer a stroke or brain injury will have aphasia. In South Africa, we lack a national database, but we know the incidence is high due to the high prevalence of stroke and traumatic brain injury here.

Understanding the universal features of language helps us understand aphasia. Language consists of sounds (or symbols), grammar, and meaning in both spoken and written forms. Aphasia can affect any or all of these. For people who are multilingual, aphasia will affect all their languages but not always in the same way. Some people with aphasia may struggle to understand language. They can speak fluently but without meaning. For example, Zubaida's first sign of stroke was when watching TV and it was for her as if the channel switched to a foreign language. Her family said her words made no sense either. Others may understand language but struggle to find words, like the tip-of-the-tongue phenomenon, but constant. Or use words incorrectly – like *ewe* for *hayi*, which can be so frustrating for people. Some, like George, will lose access to grammar, and communicate using keywords like a telegram: "Today good, family, you?" For some, the sounds of their language are disrupted. Scissors become a *skizzle, swizzers* or a *skisler*. In severe cases, people may only speak a single sound and lose the ability to read or write. Some retain only automatic words. John, for instance, expressed a whole lot with bugger!

For all, no matter the different forms of aphasia, there are losses beyond language skills. Aphasia affects identity, independence, and well-being. Language connects us to culture, relationships, and everyday life. Without it, people face barriers in work, transport, finances, shopping, social media, legal services, and healthcare – leading to isolation and vulnerability. In addition, many report that societal attitudes and lack of awareness worsen their experience, as one patient reported, "No speech, no notice".

SO HOW CAN WE SHIFT THIS?

First, is recognising aphasia and recognising that people with aphasia know more than they can say. Aphasia has been documented since ancient Egypt and Greece; Hippocrates wrote about it in 400 BC yet it remains widely unrecognised. As a result, people with aphasia are often excluded from conversations, spoken to like children, or ignored. Few recognise that people with aphasia retain intelligence, and decision-making capacity. As one of my patients expressed: "Position is lost: job, home and family. Job hard but home and family worst. I'm a child, they all test me and teach me as a child. I'm in charge – no". Respecting people's competence – regardless of their ability to communicate – is the first step. "I know you know" are powerful words.

Second, remember language is resilient. It has remarkable staying power. With slight adaptations to your communication you can help people access their language. Speak clearly with pauses, use gestures, write keywords, give time, offer choices and double check that you understood correctly. By adapting your communication, you act as a communication ramp – just as people with physical disability who use wheelchairs need ramps to enter buildings, people with aphasia need communication ramps. This is vital not only for family members but also for service providers – drivers, hospitality staff, law enforcement, retail workers, and most especially healthcare professionals. Research shows people with aphasia face higher risks in hospital, including misdiagnosis, increased sedation due to communication barriers, and have very poor experiences of healthcare. Training is available – reach out to a speech therapist who can provide this. Communication access is a right.

Third, if you, a family member or friend has aphasia, find new ways to connect and build a support team. As a speech therapist, a common question I'm asked is what pill can I take for aphasia? Unfortunately, there is no miracle cure, or any ritual or remedy that will take it away. But there are ways to live well with aphasia. This includes having communication partners who act as ramps, and engaging in activities that maintain connection but don't rely on language, such as adopting a pet, volunteering at a pet shelter, walking groups, listening to music together, and watching sport. Support groups, especially with others with aphasia, make a difference. If there's no group near you, ask your clinic or community organisation to start one, or start your own. As one young man with aphasia after a cycling accident told me, "In my group, I don't have aphasia".

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RESOURCES

- Aphasia access video training and advocacy tools: www.aphasiaaccess.org
- Free video training for communication partners and healthcare professionals: www.aphasia.ca/communicative-access-sca/ www.aphasia.ca/communityhub/
- Constantiaberg Stroke Support Group (monthly, free): 0825777164
- Helderberg Stroke Support Group (therapeutic and advocacy groups for stroke survivors in Strand, Grabouw, Lwandle and Somerset West): (021) 852 8233/079 612 8903
- A national network for post-discharge support for stroke survivors and families though an online communication portal: www.strokesurvivorsfoundation.org