

EFFECTIVE COMMUNICATION WITH A PERSON WITH PARKINSON'S EXPERIENCING COGNITIVE CHANGES

Parkinson's disease is a disorder of the brain. It is a complex condition associated with mood and cognitive changes as well as motor symptoms. Approximately 50% of people with Parkinson's will experience some form of cognitive impairment.¹

The purpose of this help sheet is to provide a general overview of cognitive changes in Parkinson's and provide you, the care partner, with some tips.

Changes in cognitive function can include any of the following:

- Difficulty concentrating
- Difficulty with planning and sequencing tasks
- Changes in perception
- Altered judgement
- Slowness of thought and in expressing thoughts
- Problems with word-finding
- Difficulty following conversations in large groups
- Difficulty understanding the emotional meaning of a conversation
- Difficulty changing topics quickly, or losing 'train of thought' when talking
- Visuospatial difficulties (such as conceptualizing things in 3D)
- Forgetfulness and difficulty with retrieval of learned information
- Behavioural changes (such as aggression)
- Language deficits (including finding words, articulation, volume and tone)

A skill often impaired first is the ability to think of the right word. People may struggle to put thoughts together and require more time to organize and communicate their thoughts. The ability to understand complex sentences and concepts may be impaired early as well.

A person's contributions to conversations are often largely affected. In the early stages, the person may not try to explain original thoughts or insights and their breadth of topics for conversation may be narrower. They may speak less than they used to and conversation may be reduced. In advanced Parkinson's, the person may not be able to stay on topic and may become vague. They may speak more but make less sense and repeat messages.

Given the many cognitive changes that can be associated with Parkinson's it is important that care partners learn different ways of conveying their message in order to stay connected with the person they care for.

Consider some of these strategies to enhance communication with a person with Parkinson's experiencing cognitive changes:

¹ Mind, Mood and Memory, National Parkinson Foundation, Chapter 3, *Cognitive Changes in Parkinson's Disease*, p. 19.

Choose the Best Time to Communicate

Symptoms of Parkinson's can create communication challenges. "Off" periods (see note), excessive day-time sleepiness, and periods of anxiety and depression may not allow for effective communication. You may have to choose your time.

Set the Stage

It can be difficult to communicate if there are distractions. Turn off the TV or radio and avoid multi-tasking so you can focus on communicating. Also, simplify the environment; for example, find a secluded corner to have an intimate conversation. Avoid large groups when possible and encourage conversations with one or two people at a time.

Get the Person's Attention

Some ways of getting the person's attention include slowly approaching and facing the person, gently touching a hand or arm then waiting until he or she seems ready to listen. Making eye contact is very important. Sit or stand facing the person and maintain eye contact (unless this is culturally inappropriate).

Speak Slowly, Clearly and Carefully

Speak to the person as an adult but make a conscious effort to speak slowly and clearly. Use simple words and short sentences. Also, say exactly what you mean. Minimize implied messages to make a point. For example, rather than saying 'it's raining again!' Say: 'It's raining so we can't go out for a walk'. Use real names instead of pronouns, to remind the person who you are speaking about. Also be careful with teasing or sarcasm which can be easily misunderstood. Make sure the person you are talking to understands the intent of your humour.

Ask Closed Questions

Closed questions which elicit a "yes", "no", "maybe" or "I don't know" answer may be more effective than open questions. For example, "Are you ok?" may be more effective than "How are you doing?"

Be Aware of Non-Verbal Communication

How we say things communicates as much, if not more, than what we say. Be aware of your tone of voice and other forms of non-verbal communication such as your facial expression and body language. Do not however, rely on non-verbal communication to clarify the meaning of your message as the person you are speaking with may not intuitively understand what your tone of voice, body language or facial expression means. Always verbalize how you are feeling and what you are thinking.

Pay Attention to the Person with Parkinson's

Facial expression and body language can be impaired by Parkinson's. Watch closely in order to be able to respond to moods and emotions particularly if what the person is saying does not make sense. If you are unclear, ask the person what emotion they are feeling.

Show and Talk

Use actions and gestures as well as words. For example, if you are going out for a walk, motion towards the door or bring the person's coat to illustrate what you mean. Also, regularity in the physical environment can be very important to someone with moderate to severe cognitive challenges. If you are moving things, explain what you are doing as you do it and where you are moving the object to.

Repeat Important Information

If you are uncertain that your message was understood, repeat it using different words. Also try summarizing segments of your conversation. If the person with Parkinson's appears to have lost their train of thought, provide a cue e.g., "shall I go over that again?" Clarify what was being discussed e.g., "we were talking about going out this evening. Would you still like to go out tonight?"

Take Time

Parkinson's may have slowed the person's ability to respond or react. Be positive and reassuring and give ample time for the person to respond. For social situations, come up with and agree upon some cues that you can give the person with Parkinson's so that they can participate in conversation. Examples include 'fillers' e.g., "John and I were talking about this the other day and he had the most interesting point, John ...". Using fillers and other cues allows the person with Parkinson's enough time to process the conversation and plan their contribution.

Encourage exchange

Make conversations a two-way process that engages the person. Avoid interrupting or answering questions directed at the person with Parkinson's, which may discourage them from communicating. Assist with finding the right word if they seem to be struggling.

Don't forget to consider hearing or vision problems!

Make sure the person is wearing a working hearing aid and/or correct glasses, if needed.

View Communication as a Partnership

Avoid over-correcting errors made by the person with Parkinson's. Be mindful that you both have a role in making communication successful. Also, be aware that learning to recognize disease-related changes and to communicate differently takes time. Be patient with yourself and with the person with Parkinson's.

A smile is a great communication skill and can go a long way!

Note: When Parkinson's medications are not working and symptoms return, the person is in an "off" state. Taking medication on time can help the person stay in an "on" state.

Sources:

Communication and Cognition Challenges in Parkinson's, Angela South, Speech-Language Pathologist, London Health Sciences Centre, The Parkinson's Update, Parkinson Society Southwestern Ontario, Winter/Spring 2010, Issue 51.

Communication Tips for Caregivers, Day to Day Series, Communications: Alzheimer Society Canada, www.alzheimer.ca.

Dementia and Parkinson's Information Sheet, Parkinson's UK
Interacting with People with Dementia, Communication Tele-workshop handout, Alzheimer Society of British Columbia

Based on a fact sheet developed by Parkinson Society BC: reprinted with permission.