

## **Parkinson's, Dementia and Special Communication Challenges** *Tips for Caregivers, Family and Friends*

Communicating with anyone suffering from dementia can be difficult but it can be even more challenging if the person with dementia also has Parkinson's disease (PD). In the late stages of PD, the combination of cognitive changes together with physical symptoms, such as lack of facial expression, diminished voice quality and limited body language, can make it especially difficult to connect and have a conversation with the person you care about.

The purpose of this help sheet is to provide a general overview of cognitive changes may occur with PD and provide you, the care partner, friend or family member, with some tips for enhancing communication.

While about 50% of people with PD will experience some cognitive decline as the disease advances, only approximately 30% of those with cognitive decline will go on to develop dementia in the later stages.

**As with all symptoms, of PD, everyone is different.**

The following are some of the symptoms of advanced cognitive decline and/or dementia that can get in the way of interactions and communication with the person you care about:

- Difficulty concentrating
- Difficulty with planning and sequencing tasks
- Changes in perception
- Altered judgment
- 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)

The skill that is 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.

Another skill that may be impaired early on is the ability to understand complex sentences and concepts. A person's contributions to conversations are often 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. As PD advances, these communication skills may begin to worsen.

**So, how do you enhance your communication with a person with PD dementia?**

Sometimes the best thing you can do is to just listen and show that you care.

### **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 and 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.

### **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**

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.

### **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.

## **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 seems to have lost their train of thought, clarify what was being discussed e.g. “we were talking about going out this evening. Would you still like to go out?”

## **Encourage Exchange**

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

## **Take Time**

PD 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 PD 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 PD enough time to process the conversation and plan their contribution.

## **Pay Close Attention**

Facial expression and body language can be impaired by PD. 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.

## **Choose the Best Time to Communicate**

“Off” periods (when medication is not managing symptoms effectively), 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 by, for example, finding a secluded corner to have an intimate conversation. Avoid large groups when possible and encourage conversations with one or two people at a time.

## **Keep to a Regular Routine**

Maintaining a regular routine can help reduce confusion and stress for the person with dementia.

Keeping to a consistent schedule for meals, visits and surroundings can provide more opportunities for a comfortable conversation.

## **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 and appropriate physical contact may be reassuring.

## **Hearing or Vision Problems**

Make sure that you and the person you care about have had vision and hearing tests and are wearing the appropriate hearing aid or glasses if required.

## **View Communication as a Partnership**

Avoid over-correcting errors made by the person with PD. 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 you care about.

Remember, the person you care about has the same feelings and needs as they had before developing dementia.

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