

Staying Connected through Communication Parkinson's Disease Changes Communication

Staying connected requires working together. Let your loved ones know how to help.

Communicating with others when you have noticed changes in your own speech, memory, or thinking:

1. Give yourself some grace.

Try to not be critical of yourself when you cannot do things the same way you used to do them. You are doing the best you can for what your body will allow you to do right now.

2. Help your family and friends.

Let people know what is difficult for you regarding communication. Ask for help with communication. Many people have told us that when they share with their family and friends what they are having difficulty with, family and friends can be more understanding. Try this sentence: "It helps me when you _____ when we talk."

3. Explore new conversations and activities together.

Old friends often want to stay in touch, but they don't know what to say or how to talk to you. Let them know what you enjoy talking about or doing now. Invite them to do something that you enjoy together that does not depend on a lot of conversation such as watching a TV show or movie together, or doing an activity together.

4. Certain times of the day are easier than other times for conversations.

Speech, memory, and thinking can fluctuate depending on time of the day, your energy level, and medication. If you are tired or having more difficulty than usual, let the other person know. Schedule a time to talk later. Plan to have important conversations or appointments at a time you are most rested.

5. Reduce distractions during conversations; have conversations face to face.

Turn off the TV, radios, or other distractions. Try to have conversations in quiet places where you can be face to face. Avoid having conversations with someone who is in a different room or far away from you.

6. Take notes of what you need to remember.

If there is information you need to remember, such as an appointment or something you need to do, write it down or ask someone to note it down for you. You can also put a reminder in your phone or on your calendar.

7. Connect with people with similar experiences.

As much as your family and friends care about you, they may not fully understand what you are experiencing. Connect with professionals and other people who have expertise in the area or have experienced the same thing. Here are some examples:

- a. **Talk to your doctor** about your difficulties with communication.
- b. **Ask your doctor to refer you to a speech-language pathologist.** Speech-language pathologists often work with people with speech, thinking, and memory changes to help them manage their day to day activities and to communicate with other people.
- c. **Connect with groups in-person.** Look for Parkinson's disease groups that may be meeting near you for support and camaraderie. Your doctor or other healthcare provider may know of some groups.
- d. **Connect with safe online groups.** Online groups allow you to connect with people with similar experiences but do not live near you. Consider groups backed by a reputable organization, or with strong moderators who keep content safe.

Communicating with a family member or friend with speech, memory, and thinking changes:

1. Give yourself some grace.

This is difficult. While you want to be present for your loved one, this impacts you too, and it is ok to acknowledge that.

2. Do not expect your loved one to be the way they used to be.

Do not be critical of your loved one when they are not able to do the same things they used to do. They are doing their best for what their body will allow them to do now.

3. Talk to them as the adult that they are.

Do not 'talk down' to them in childish manner. Even if they need you to repeat something or simplify what you are saying, keep your mannerisms when you interact with them appropriate for the adult they are.

4. Do not pretend to understand them if you do not. While you may not want to hurt their feelings, pretending to understand can lead to bigger miscommunications. Try some of the other strategies on this page to improve your understanding.

5. Plan extra time for conversations.

If you need to tell them something or have important conversations, intentionally set time aside for them. Take extra time to explain one thing at a time, and give them extra time to respond to you.

6. Do not shout at them.

If they have hearing problems, help them see an audiologist to get their hearing tested. Shouting does not help.

7. Say it another way.

If they do not understand you after you have repeated something to them, try rephrasing it, or add gestures.

8. Ask them what helps them to communicate.

Ask your loved one what might help to make your conversations more successful. What works for one person might be different than what might work for another person. Be willing to explore new ways for communicating.

9. Communication may be easier at certain times of day than others.

Just because your loved one could do something fairly easily at one time does not mean they will be able to do it as easily a few hours later. If a conversation is difficult, ask your loved one if you can postpone it until a time when they feel more rested. Plan to have important conversations at a time when you and your loved one are well rested.

10. Reduce distractions where you are having conversations.

Turn off the TV, radio, or other distractions. Have conversations in quiet places.

11. Help them 'back-up' information they need

If there is something they need to do or remember, help them write it down, enter it as a reminder in their phone, or create some other way to 'back up' the information instead of relying on their memory.

12. Help other friends and family connect with your loved one.

Let others know how to best communicate with your loved one. If speech becomes frustrating, suggest activities that do not involve a lot of conversation such as watching a show together or doing another activity together.