

Supporting Someone Diagnosed with PSP, CBD or MSA



You may have a family member, friend or co-worker who has been diagnosed with progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) or multiple system atrophy (MSA). It can be hard to know exactly how to support them. You may be feeling unsure about how to relate, be helpful or offer empathy. You are not alone.

Even though each person with a diagnosis of PSP, CBD or MSA copes with it in their own way, it is safe to assume that most people with these neurodegenerative illnesses want and need support through the journey. Many of them fear burdening people they care about, and unfortunately, it is common for people with health conditions to share that they have experienced people in their life who shied away after they told them about their diagnosis. The fact that you are reading this resource is a sign you want to show up for this person in your life, even if you are still figuring out what that could look like or may still be processing your own emotions about their diagnosis.

The intention of this resource is to offer guidance and a starting place for acknowledging, discussing and remaining available to the diagnosed person in your life. When reading these suggestions, consider how you might adapt these ideas to your unique situation and relationship.

Take time to prepare yourself.

- Process and cope with your own feelings before reaching out. Doing so will enable you to feel more comfortable and composed and to keep the focus on the person you care about with PSP, CBD or MSA.
- Think about how you would want to be approached or what you may have felt like in a similar situation.
- Learn the basics of their diagnosis by using reliable websites and resources. Consider asking for disease information from the person's partner or a mutual friend. CurePSP offers educational information on PSP, CBD and MSA at www.psp.org/iwanttolearn

Make yourself emotionally available.

- Treat them the same as you did before. If you hugged them or shook hands, continue to do so. They are the same dynamic person they always were, and they do not want to be treated only as a person with an illness. Talk to them as you did before and with respect.
- At the same time, you do not have to pretend that everything is how it always has been and that they are not living with this diagnosis or experiencing new challenges. This behavior can make them feel isolated or as if there is an elephant in the room.
- Ask if they would like to discuss their diagnosis and if they are open to questions from you. Make it clear that saying no is absolutely fine. You can ask if they feel like talking and how much they want to share, but always take your cues from them. Tell them you know you have a lot to learn about their condition and that you are willing to do so.
- Allow for sadness, anxiety or uncomfortable topics or feelings that may arise (from them and from you). It is important to normalize and validate these emotions as part of the experience.
- Also prepare to laugh together, to have fun and to talk about subjects other than the illness. Conversing about mutual interests and non-disease-related topics and finding moments of humor can offer a rest from difficult conversations and feelings, especially as people with PSP, CBD or MSA can sometimes feel their energy and time revolve around their diagnosis and care.
- Tell them you are here for them.

Be present and practice active listening.

- Focus on the individual and the conversation in the moment.
- Minimize background noise and distractions, such as television or cell phones.
- Make regular eye contact, even if they are not able to reciprocate.
- Listen without judgment and without providing unsolicited advice.
- Be attuned to, and comfortable with, the person's possible need for slowness in conversations—or even silence. Because of their symptoms, they may have difficulty or delays with organizing thoughts and expressing words and may even voice an incorrect word. Speech may be soft, slurred or more difficult to understand. Allowing the person time to respond is especially important in group settings when conversations can be quicker and more complex.
- Educate and advocate for others to practice patience in their communication with them as well.
- If they are not able to come up with a word or thoughts, gently cue them with words or gestures. Do not assume what they were going to say or finish sentences for them. Confirm that you understand what they said.
- You do not need to talk to fill silent space, unless that is what the person wants. If your quiet presence is what they need, perhaps you could suggest listening to music or watching a movie together.

Reach out and offer tangible support.

- Stay in touch with the person and their care partner. Ask them what their preferred method of communication is. Check in.
- Ask if they would like a visit. If a visit is planned, follow through. However, be flexible; your friend may not feel up to a visit on the scheduled day.
- Consider surprising them with a special gift, such as flowers, magazines, comfy slippers or yummy food you know they like. Your surprise is one way of letting the person know they are loved and thought about.
- “Let me know if I can help” or “Tell me how I can help you” can sometimes leave someone stressed that they must think of a way for you to help or fearful they are going to be a burden. Instead, offer practical, concrete suggestions of activities you can and are willing to perform. For example:
 - Shopping for groceries or picking up prescriptions
 - Helping with household chores
 - Cooking a meal
 - Reading with or to them
 - Driving and accompanying them to various activities, such as medical appointments, a support group meeting, shopping, hairdresser or barber, etc.
 - Making phone calls to locate resources or supplies
 - Being available in case of an unexpected need or emergency
 - Staying with the person for a short period of time so that their care partner can have respite

Choose words that show your support and care.

- “I hate this for you.”
- “I care about you, and I am thinking about you.”
- “I’m here to listen whenever you feel like talking.”
- You do not need to try to relate. Instead, you can just say: “I recognize I don’t know what you are going through. No matter what, I will be here for you throughout your journey with this diagnosis, in whatever ways I can and that you need.”

Remember that staying in touch is always better than staying away.

