

Talking About Your Diagnosis



Receiving the diagnosis of a neurological condition, including progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) or multiple system atrophy (MSA), can be a very emotional experience. The same is also often the case for those close to you, including your partner, children, extended family, friends and professional associates. These emotions are on top of the physical changes you have noticed and had to make accommodations around as well as the questions, care considerations and decisions that have arisen as a result of the diagnosis. Disclosing your diagnosis to others in your circle is part of this experience. The decision to tell others about your diagnosis is yours alone, and there is no right or wrong way to go about it. For many with PSP, CBD or MSA, it can take a while to process diagnosis to the point where you feel more prepared to share it with others. Inevitably, a time will come when you will want to, or even need to, disclose and discuss your condition with others.

There are many factors that can influence the decision to share this news:

- Your understanding of your diagnosis
- If you have the information and the support from your healthcare team that you need
- How you typically communicate important information and emotions
- If you are feeling emotionally ready
- How obvious your symptoms are, and particularly if others are starting to notice
- Whether or not you are working
- The makeup of your support system
- Your individual relationship dynamics with people in your life

It is natural to experience some hesitation and anxiety around having such a conversation. You may be asking yourself: “What should I say?” “How will people react?” “Will I be able to handle others’ feelings when I am already dealing with so much uncertainty and so many emotions?” “What if someone reacts with pity?” “What if people ask questions I cannot answer?”

The purpose of this document is to help you think through and decide how, when and what you might want to share with others about your diagnosis.

Preparing To Disclose Your Diagnosis

Reflect on possible approaches, considerations and steps:

1. You can enlist the support of others as you prepare to share the news.

- You could include your partner, trusted friend, spiritual leader or a professional (such as a therapist or a member of your healthcare team) in a planned family discussion.
- If you attend a support group, ask the other members how they have shared the news with others and what advice they have for you.

- Consider asking someone to role-play with you the scenario(s) in which you reveal your diagnosis to another person.
- 2. Consider what information about your diagnosis you would like someone to know.**
- How you tailor the conversation will largely depend on the nature of your relationship, such as your child compared to a close friend or a coworker.
 - Educate them about your illness as you understand it and with the specific information you would like them to be aware of.
 - Invite friends or family members to attend a support group, educational symposium or doctor visit with you. In these ways, people in your support system will learn more about the disease.
 - Describe some of the changes you are experiencing.
 - Share how you are feeling about this unanticipated change in your life.
 - Let them know about the support you are currently receiving from family, healthcare professionals and others in your support system and what support you are needing at this time.
 - Think of the first conversation as laying the groundwork for conversations down the road.
 - Direct someone to printed or online resources to learn about your diagnosis or to seek additional support in their role in your care. Support groups and educational materials can be found at www.psp.org/ineedsupport
- 3. Recognize that each person will have varying perspectives, questions and emotional responses.**
- Reflect on the (often many) emotions you experienced when you were first diagnosed with PSP, CBD or MSA and those you have experienced in the time you have had to process the diagnosis since. Perhaps you have felt shock, grief, fear, sadness, anger or numbness. Sometimes people may also feel relief or appreciation for finally arriving at a diagnosis and having some answers. It can be an emotional rollercoaster and feel overwhelming at times. These emotions will likely also be experienced by others when they learn the news of your diagnosis.
 - Anticipate questions that someone might ask you regarding your symptoms, diagnosis and preparations for the future.
 - Be prepared for comments such as:
 - “I wondered if something was going on. You have seemed different, but I wasn’t sure what to say to you about it.”
 - “But you look so good!”
 - “Are they sure that is the diagnosis you have? Have you pursued a second opinion?”
 - “I just read an article the other day about [fill-in-the-blank medication, supplement, exercise or other treatment approach]. Have you tried that to see if it would work?”
 - Sometimes people will offer information and advice. This may be helpful for you, but if it is not what you are looking for in that moment, you can share that with them.
 - Someone may react with too much positivity or not enough, depending on what you are needing from them.
 - Unfortunately, not everyone will be able to handle this change in your life. This inability could be for a variety of personal reasons, including that they do not know how to cope with the sadness of seeing you change, or perhaps your diagnosis triggers other memories of illness for them or fears of their own mortality. Sometimes this situation leads to the person having a very intense emotional reaction that is not helpful for you, leaving you feeling like you need to support them. It is possible that some people will distance themselves from you. If someone reacts negatively, please remember that it is not your fault.

- Surround yourself with people who embrace you just the way you are. Remember, at your core, you are still the same person, and it is important to have people in your support system who will show up for you and uplift you through your journey with PSP, CBD or MSA.
- 4. Remind yourself that you are your own best advocate.**
- You can suggest that someone read about the diagnosis and then get back to you for a conversation where they feel more prepared.
 - Practice certain responses that feel right to you. For example: “That is not something I am able to answer yet.” Or, “I do not really feel like talking about that right now.”
 - Let them know what specific support they could provide that would be especially meaningful and helpful to you now and as you journey through your diagnosis.
- 5. Take time to prepare yourself mentally.**
- Telling other people about your diagnosis can feel scary or heavy. Be aware that each experience of disclosing your diagnosis can be a reminder of the reality of your situation.
 - Recognize that having these conversations may bring up emotions for you. Try not to judge these emotions or reactions. Normalize and validate the emotional journey of living with PSP, CBD or MSA.
 - Notice and hold onto the positive emotions and gifts brought about by conversing about your diagnosis—such as gratitude for those in your life, a sense that a weight has been lifted off you once certain people know about your diagnosis or a sense of empowerment that you advocated for yourself and educated others.

Talking With Children

How you share your diagnosis with children in your life, such as grandchildren, young adult children or even older adult children, is often approached differently than conversations with others in your support system. How and when you share your diagnosis with a child can depend on a number of factors like their age, their learning style and communication patterns, and your relationship with them. Young and older adult children alike are often very observant and may have noticed changes in you before you tell them. Young children may be more blunt in their questions and observations. Also, some younger adults and children may not always have the capacity or experience yet to process the full implications of your situation or their own emotions.

Prepare yourself to talk with children in your life about your diagnosis.

- Choose a time that is calm and not emotional, and when nothing else is on the schedule. Don't blindside children.
- Cut down on distractions during the conversation so that you can really focus and listen to one another.
- Speak in a calm and clear manner.
- Tailor the information you provide to the child's level of maturity and understanding.
- Especially with children younger than 10 or 11 years old, keep conversations simple and short. Wait for them to ask questions before diving into additional information. Remain aware of cues as to when the child has heard enough.
- Be prepared for questions as to how your disease will affect the child. Adult children may be concerned about who will care for you and how.
- Clearly state that your illness is not the child's fault, not contagious and not genetic.
- Invite them to express their feelings, concerns and questions.

- Give the child time to think about your diagnosis and the information you have shared.
- Encourage future conversations.

As Time Goes On

Even after an initial conversation or two, your extended family members, friends or colleagues may not understand your condition or its symptoms as things change over time. Individuals may feel uncomfortable reopening the subject with you. Perhaps they are waiting for a cue or invitation from you. Or they may simply not know what to say or do.

If you have the desire and emotional and physical energy to reach out to others, you might want to:

- Share what your life is like now and what has changed since the last time you spoke.
- Describe what you are still able to do and are interested in doing.
- Ask them to talk about your diagnosis more, if you feel like it is not discussed enough. Or, ask to talk about it less, if you are feeling that conversations and life are revolving around it too much.
- In specific terms, inform people about the kinds of concrete help and emotional support you need and would appreciate at that time.

Takeaways

Ultimately, it is your decision as to whom you tell about your diagnosis, what you say and when you share it.

- Set your own pace.
- Advocate for your needs.
- Your goal is to maintain and strengthen your relationships with those people you care about and who care about you.
- Focus your physical and mental energies on the relationships that respect, protect and enhance your well-being in this journey.
- Remember that you are not alone. CurePSP, those in your personal support system and the PSP, CBD and MSA community are here for you.



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