CurePSP is the leading nonprofit organization working to improve awareness, education, care, and cure for devastating prime of life neurodegenerative diseases. These include progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), multiple system atrophy (MSA), and others. They often strike when people have careers, family responsibilities, and active lives. Their symptoms are incapacitating, and there are no known causes, treatments, or cures.

Research has shown that there are important links between prime of life diseases and more common neurodegenerative conditions, such as Alzheimer’s disease and Parkinson’s disease. Your support will help advance this research, provide resources for families and caregivers of patients, and better educate the healthcare community. Together, we are unlocking the secrets of brain disease.

CurePSP is a not-for-profit 501(c)(3) organization. Gifts and pledges of support are encouraged, and donations are tax deductible to the extent allowed by law.

Resources for Further Information

CurePSP:
www.curepsp.org

Davis Phinney Foundation:
www.davisphinneyfoundation.org

Smart Patients:
www.SmartPatients.com

The Mighty:
www.TheMighty.com

“How to Support a Friend Who’s Just Been Diagnosed With a Chronic Illness,” by Carolyn L. Todd
www.self.com

National Organization for Rare Disorders:
www.rarediseases.org

Supporting someone diagnosed with PSP/CBD/MSA

Written by Diane Breslow, MSW, LCSW on behalf of CurePSP
Even though each person with a diagnosis will deal with it in their own way, it is safe to assume that most people with these neurodegenerative illnesses want and need support and someone with whom they can talk. Therefore, the intention of this educational pamphlet is to offer guidelines and suggestions to you for acknowledging, discussing, and remaining available to the diagnosed individual.

You are not alone.

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GENERAL GUIDELINES

I. Before talking to someone who has been diagnosed, take time to prepare yourself and to gain comfort not only with the news of a diagnosis but also with the particular diagnosis itself.

II. Reach out; acknowledge the diagnosis. Make yourself available as a visitor and as a support. Let your friend, co-worker, or family member know that they need not traverse their illness alone.

III. Practice “active listening.” Try to stay fully present in the conversation, without judging or giving unsolicited advice.

IV. Choose words, phrases, and concepts that convey support and care.

V. Offer practical or concrete help.

SPECIFICS

I. Take time to prepare yourself:
   • Process and cope with your own feelings before reaching out to your friend. This will enable you to feel more comfortable and composed and to keep the focus on your friend.
   • Think about how you would want to be approached, or what you may have felt like, in a similar situation.
   • Learn the basics of the illness. Use reliable websites. See “Resources” at the end of this pamphlet. In addition, you might consider asking for disease information from the person’s partner or a mutual friend.

II. Stay in touch through conversing and visiting:
   • Involve and communicate with your friend’s care partner as appropriate.
   • Ask your co-worker or friend if they welcome questions or not. Make clear that saying “no” is absolutely fine with you.
   • Ask your friend if they want 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.
   • Treat your friend, relative, or co-worker the same as you did before. If you hugged them, or shook hands, continue to do this. They are the same person they always were.
   • Tell them that you are there for them.
   • Tell them that you know you have a lot to learn about their condition, and that you are willing to do so.
   • Be guided by your friend. Make clear that it is up to the diagnosed person to decide when to talk and how much to share. You can ask if they feel like talking, but always take your cues from them.
   • Allow for sadness or uncomfortable topics or feelings. Also prepare to laugh together, to be humorous or fun, and to talk about subjects other than the illness. Conversing about mutual interests and non-disease-related topics can allow your friend, co-worker, or family member to feel connected to you and to everyday life, to maintain their usual interests, and to take a rest from difficult conversations and feelings.

III. How to practice “active listening:”
   • Focus on the individual and the conversation.
   • Minimize background noise and distractions, such as television, cell phones, etc.
   • Make regular eye contact, even if your friend cannot 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. Remember that your friend may have difficulty or delays in retrieving words, and may even voice an incorrect word. In these cases, allow the person time to respond. This is especially important in a group conversation.
   • If they are not able to come up with a word, gently cue them with words or gestures.
   • Confirm that you understand what your friend has said.
   • If it is your quiet presence that your loved one needs, perhaps you could suggest listening to music or watching a movie together.

IV. Choose words that show your support and care:
   • “I’m sorry this has happened to you.”
   • “I care about you.”
   • “I’m thinking about you.”
   • “I’m here to listen whenever you feel like talking.”
   • “I realize that your illness is chronic. I will be here for you throughout, in whatever ways that I can and that you need.”

V. Rather than saying, “Let me know if I can help,” or “Tell me ways that I can help,” offer your own 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
   • Driving and accompanying your friend, co-worker, or family member to various activities, such as medical appointments, a support group meeting, shopping, hairdresser or barber, etc.
   • Making phone calls to locate resources or supplies
   • Visiting or telephoning on a regular basis
   • Reading a book or magazine with them
   • Being available in case of an unexpected need or emergency
   • You don’t need to verbally offer this, but what about delivering a thoughtful gift—such as music, flowers, magazines? Such a gesture would most certainly be welcome.
   • Remember that staying in touch is always better than staying away.