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.
GENERAL SUGGESTIONS
Before tackling the question of what you want to say, when, and to whom, first consider some possible approaches and attitudes.

1. You can enlist the help of an objective outsider or third party. For example:
   • You could include a trusted friend, or perhaps a counselor, in a planned, family discussion.
   • You can suggest to certain people that they read specific websites or disease-education articles and then get back to you for a conversation.
   • Consider asking a close friend, co-worker, or therapist to role-play with you the scenario in which you reveal your diagnosis to another person.
   • You may choose to speak with a clergy person or religious leader for faith-based guidance.

2. Think of the first conversation as “laying the groundwork” for conversations down the road.
   • What information do you want to share at first? Two suggestions are: general disease education and a little about how you are handling the diagnosis.
   • Suggest that people who are close to you seek out reliable information about your diagnosis. See “Resources” at the end of this pamphlet.

3. Before sharing with others, take time to prepare yourself mentally and emotionally.
   • Anticipate questions that someone might ask you.
   • Practice certain responses that feel right to you. For example: “I really can’t talk about that now.” Or, “I’m trying not to look too far ahead.”
   • Be prepared for comments such as, “I wondered if something was going on,” or “You have seemed different, but I wasn’t sure what to say to you about it.”

4. Consider writing a letter or an email to your loved ones.
   • Educate them about your illness.
   • Describe some of the changes you personally are experiencing.
   • Share how you are feeling about this unanticipated change in your life.
   • Let them know specific support that would be especially meaningful and helpful to you.
   • Let them know about the support you are currently receiving from healthcare providers or family.

5. Accept that not everyone will be able to handle the change in your life.
   • Some people may never accept this development and may even emotionally distance themselves from you.
   • Your diagnosis may trigger others’ fears or memories of illness and their own mortality.
   • Do not expect of yourself that you can change the way another person thinks or acts.
   • Surround yourself with those people who embrace you just the way you are. Remember, you are still the same person.

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. Individuals may feel uncomfortable reopening the subject with you. Perhaps they are waiting for a cue or overt invitation from you. Or they may simply not know what to say or do.

If you have the desire and emotional energy to reach out to others, you might want to:
   • Share what your life is like now.
   • Describe what you are still able to do and are interested in doing.
   • Invite friends or family members to attend a support group, educational symposium, doctor visit, or physical therapy session with you. In these ways, people in your support system will learn more about your disease.
   • In specific terms, inform people about the kinds of concrete help and emotional support you need and would appreciate.

TALKING WITH CHILDREN
Choose a time that is calm and not emotional, and when nothing else is on the schedule. Don’t blindside children.
   • Speak in a calm and clear manner.
   • Address the subject on a level that the particular child(ren) can understand.
   • 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.
   • Especially with children up to the age of 10 or 11, keep conversations simple and short. Wait for the child to ask questions before diving into more and more information. Remain aware of cues as to when the child has heard enough.
   • Tailor your explanation to the child’s level of maturity and understanding.
   • Clearly state that your illness is not the child’s fault, not contagious, and not genetic.
   • With older children, particularly adult children, invite them to express their feelings and concerns.
   • Give your children time to think about your diagnosis and the information you have shared.
   • Encourage future conversations.

TAKEAWAYS
It is your decision as to whom you tell, what you say, and when you say it.
   • Set your own pace.
   • Your goal is to maintain and strengthen your relationships with those people you care about and who care about you.
   • If someone reacts negatively when you share your diagnosis, it is not your fault. Refocus your physical and mental energies on the relationships that respect, protect, and enhance your well-being.