

Advanced Care Planning

Knowledge for the Future

According to the National Institute of Neurological Disorders and Stroke, corticobasal degeneration (CBS/CBD) typically progresses over the course of 6 to 8 years and progressive supranuclear palsy (PSP) progresses over the course of 5 to 7 years from symptom onset

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CURES BRAIN DISEASES™

(NINDS, n.d.). Complications resulting from PSP and CBD may lead to death. Due to the variation of PSP and CBD progression, advanced planning is important soon after diagnosis. Make your decisions known to family and health care professionals involved. This will ensure your wishes are honored. The future may appear daunting and unpredictable, however planning for it does not have to be.

Arrangements

Thinking about making arrangements for the future after receiving a rare diagnosis is extremely tough.

Prioritizing what is most important can help. We have outlined a few topics to consider when arranging finances for future expenses. This can ensure your wishes are fulfilled and can assist your family with planning for the future.

- Will and Testament
- Life insurance arrangements
- A Medical Power of Attorney
- Full Power of Attorney
- Arrangement for your celebration of life expenses

Accessibility

Is your home handicap accessible? If not, it is ideal to consider what you may need to make it accessible. Contact your local occupational therapist and physical therapist for recommendations.

Long-term Care

As CBD and PSP progresses overtime, an individual will need assistance with activities of daily living. Early planning for long-term care needs will help ease the stress and prevent last minute decisions. The preference of being cared for in a long term care facility versus in your home with a care attendant may be considered with many other factors.

Consider if you would want to be assisted with care in your home, with a paid care provider. Contact your local social service office to inquire if you qualify for any elderly and/or disabled assistance. It is important to reach out to your local community services to ensure you are receiving all the benefits you are entitled to. Contact us should you need assistance finding your local services: info@pspcbdfoundation.org

Would you prefer to live in a long-term care or assisted living facility? Taking a tour of multiple facilities may help you make this decision. Many places provide **virtual** tours online! Check out this great checklist of questions to consider when speaking with the facility prior to decision, provided by *A Place for Mom*: [Checklist of questions for a long-term care facility](#)

Medical Considerations

Participation in clinical trials: Would you like to participate in clinical trials to further knowledge, treatment, and a cure for PSP and/or CBD? www.ClinicalTrials.gov

Pain management: What type of pain management are you willing to receive?

Feeding Tube: Would you want to receive a feeding tube to provide nutrition if you were no longer able to eat/drink by mouth?

Resuscitation: Would you prefer to be resuscitated by artificial means if you experienced respiratory failure (loss of lung function)?

Organ Donation: Would you prefer to gift any of your organs after passing over. Contacts for brain donation information can be found on our resource page at www.pspcbdfoundation.org

We hope this short handout provides you with direction on topics to consider when planning for the future. We are always here to support you throughout your journey with PSP and/or CBD. Please contact us should you need any assistance. We provide support group meetings for individuals with PSP and CBD, caregivers, and family members to connect across the world. Check out our resources for PSP and CBD at www.pspcbdfoundation.org

References:

National Institute of Neurological Disorders and Stroke. (n.d.) Retrieved from:
<https://www.ninds.nih.gov/>