



Foundation for PSP | CBD and Related Brain Diseases

*because hope matters*

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# A Family Guide for PSP, CBD & MSA

## Early Stages of Diagnosis

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# Objectives

- Provide a brief overview of PSP, CBD & MSA
- Discuss the process of being diagnosed
- Review the initial adjustment to the diagnosis
- Outline the steps to take to ensure the best overall care
- Develop a frame work to maintain health

# What is PSP?

## **Progressive supranuclear palsy**

- Rare neurodegenerative brain disease  
(5-6 per 100,000)
- Problems with stiffness
- Balance & vision
- Speech & swallowing
- Changes in personality
- Cognitive changes

# What is CBD?

## **Corticobasal degeneration**

- Similar to PSP (balance, vision, speech and swallowing)
- Rare (estimated 2000-3000 in the US)
- Difficulty generating & articulating speech
- Stiffness, jerkiness, slowness, and clumsiness either in the upper or lower extremities
- Asymmetric onset of symptoms
- Memory or behavior problems

# What is MSA?

## **Multiple Systems Atrophy**

- Involuntary functions are affected such as blood pressure, heart rate, actions of the intestines and bladder and breathing activity
- Orthostatic hypotension
- Urinary incontinence & constipation
- Impaired speech & swallowing
- Inability to sweat
- Sleep apnea & sleep disturbance
- Waving hand movements and staggering gait

# The process of being diagnosed

*“If you are facing the right direction, all you need to do is keep walking.”  
Buddhist saying*

# Misconceptions about diagnosis





# Finding out what's really wrong

## Medical response

- Evaluation
- Treating symptoms
- Referrals to other specialists
- New & worsening symptoms
- No diagnosis given
- Some diagnosis given
- Correct diagnosis

## Patient & family reactions

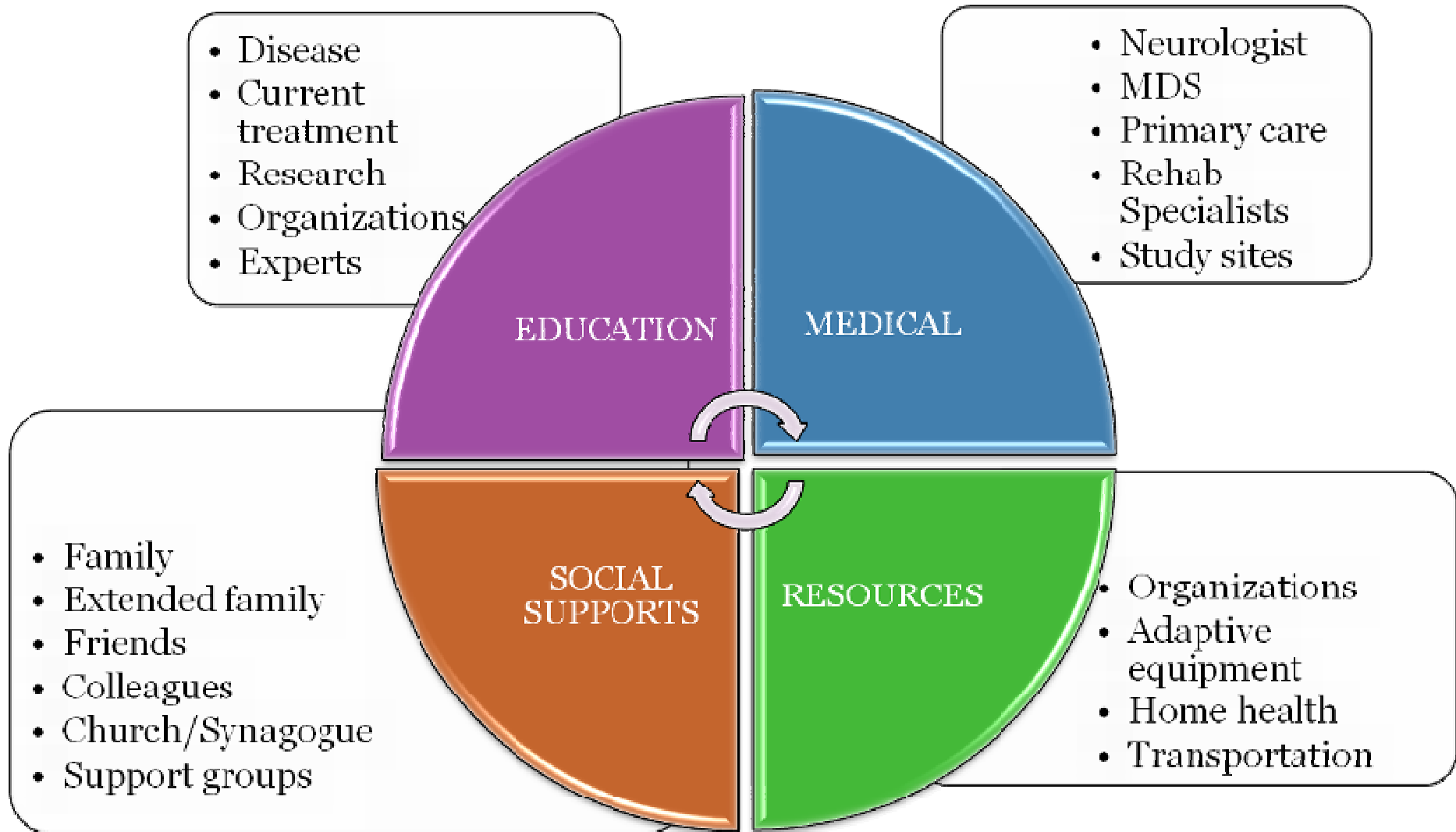
- Hope for answers
- Poor response to treatments
- Frustration
- Fear
- Confusion
- The power of “naming”
- Disbelief / Panic

# Initial adjustments to the diagnosis

- **Intellectual**
  - **Physical**
  - **Psychological**
  - **Emotional**
  - **Social**
  - **Financial**
  - **Life plans**
  - **Spiritual / Religious**
- Patient / Family**
  - Information**
  - Questioning diagnosis**
  - Denial**
  - Anger**
  - Bargaining**
  - Depression**
  - Acceptance**

Five stages of grief / Elizabeth Kubler-Ross

# Taking action



# Creating a framework

Maintaining health for patients and their families

# Continuing to move forward if *you* have the disease

- ❑ Ask for help from medical providers- come prepared to appointments with your questions
- ❑ Acknowledge and accept your own thoughts and feelings
- ❑ Share your concerns and emotions with someone close to you
- ❑ Consider professional counseling / group support
- ❑ Ask for help from your family and friends
- ❑ Stay in touch with people you love and help them understand the disease

- ❑ Remember what helped you cope with other difficult situations in your life and draw from those experiences
- ❑ Maintain daily routines as much as possible
- ❑ Enjoy the simple things
- ❑ Focus on what you can control
- ❑ Find courage and direction in your faith or belief system

*Health is a state of physical, mental and social well-being.*

# If your loved one has the disease

1. Recognize it's normal to feel a variety of emotions
2. Maintain and/or start new routines that promote your physical and mental health
3. Create a Support System
4. Continue to learn as much as you can – connect with others going through the challenges of the disease and share ideas
5. Accept that you are human

# CurePSP can help

- Visit our website
- Request or download our educational materials
- Read our newsletters
- Listen to our ongoing webinars
- Attend our Family Conferences
- Contact us

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