

# Caring, Coping and Planning

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# Adjustment and Caring

- ❖ Adaptation to a disability or a chronic condition is a life-long process of successful coping with the loss of health, transform social standing, environmental restrictions and reduce vocational roles.
- ❖ The process of adjustment is characterized by:
  - Learning the techniques to live with a disability.
  - Making the most of one's residual abilities.
  - Striving to have a productive and satisfying life.
- ❖ Adjustment is evolutionary, changing and highly individualized and determine by psychosocial, sociocultural and environmental interactions.
- ❖ Rehabilitation is the process of defining or re-defining oneself and reveling in the fact that one's spiritual essence is eternal and unchanging.

# Build Your Own Team

► Your team should ideally include:

❖ **Neurologist:** A neurologist is a specialist in disease of the nervous system that will help you explore treatment options and work with you to identify concerns and needs. He/she will provide referrals to therapists to help you find solutions and improve your day to day life.

❖ **Movement Disorders Specialist:** A movement disorders specialist is a neurologist who has received additional training in many types of movement disorders including MSA. They are best equip to tailor a plan of care to meet your specific needs.

❖ **Nurse Specialist:** They are registered nurses who specialize in the area of movement disorders. A nurse specialist can provide you and your care partner with guidance as you navigate the challenges of living with MSA. They are knowledgeable about the symptoms, medications, management strategies, research and resources.

# Build Your Own Team (continue...)

- ❖ **Physical Therapist (PTs):** Provides services to help maintain highest level of functional ability by improving mobility, reducing pain and lowering the risk of falls. This is done through the development of patient specific treatment strategies with a clear purpose and anticipated outcomes.
- ❖ **Occupational Therapist (OT):** Works from a person centered approach to build on the supportive social and environmental context to help you manage the disease as effectively as possible. They will address home safety, community independence, cognition, physical skills and functional vision working closely with PTs to ensure patient safety.
- ❖ **Speech Language Pathologist (SLP):** SLPs treat many types of communication and swallowing problems. These include problems with speech sounds, language, social communication, voice, fluency, cognitive communication, feeding and swallowing.
- ❖ **Social Worker (SW):** A referral to a social worker will provide you and your family with both practical and emotional support as you navigate the journey of living with MSA. A SW takes into consideration all aspects of one's life, including the emotional impact that the disease has on you, your family and your friends, and help address quality of life issues. A SW can offer you information about available community resources and acts as an advocate to assist in accessing these resources.

# Planning Ahead: Advance Care Planning

❖ **Advance Care Planning:** It means making plans for the health care you want during a serious illness. This includes learning about your illness, understanding choices for treatment and care, talking to family and health care providers and completing the written communication of these choices.

## **Advance Directives:**

❖ **Durable Power of Attorney for Health Care or Health Care Proxy:** A proxy directive is a document you use to appoint a person to make healthcare decisions for you in the event you become unable to make them yourself.

❖ **Living Will or Instruction Directive:** An instruction directive is a document you use to tell your physician and family about the kinds of situations you would want or not want to have life sustaining treatment in the event you are unable to make your own healthcare decisions.

❖ Access the Advance Directives Forms from the State of NJ in the following link:

<http://www.state.nj.us/health/advancedirective/ad/forums-faqs/>

# Planning Ahead: Advance Care Planning

- ❖ What is POLTS: <http://www.njha.com/media/84188/njpolstform.pdf>  
POLTS is a healthcare planning tool that empowers individuals to work closely with their medical team to detail their personal goals and medical preferences when facing a serious illness.
- ❖ The POLTS form is designed to be completed jointly by an individual and a physician or advance practice nurse, expressing the individual's goals of care and medical preferences.
- ❖ Unlike other documents like an Advance Directive, a completed POLST form is an actual medical order that becomes a part of the individual's medical record. It also is valid in all healthcare settings.
- ❖ For help in planning and preparation of legal documents, an elder care and disability attorney can provide guidance in this processes.

To locate one in your area visit the Elder Care Locator website at <http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx>

# Coping with Stress

Everyone is susceptible to the effects of stress. However, living with a long-term condition can make you particularly vulnerable. Tips for coping:

- ❖ Understand your condition
- ❖ Self – Management
- ❖ Manage Emotions – increase awareness of negative emotions such as anger and depression
- ❖ Manage Relationships – Make time for those important people in your life
- ❖ Develop Adaptability – Find things to do that give you meaning and purpose
- ❖ Ask for help and accept help and support – Accepting does not make you weak
- ❖ Make stress management a priority



# THANK YOU!!

“Acceptance does not mean resignation; it means understanding that something is what it is and that there’s got to be a way through it.”

Michel J. Fox



# Contact Information

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