



Toolbox Kit

SELF MANAGEMENT AND PREVENTION

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Strategies 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. Most times, they are affiliated with major universities or teaching hospitals and possess cutting edge knowledge and treatment of movement disorders. They are best equipped to tailor a plan of care to meet your specific needs.

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Build Your Own Team (continued)

❖ **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.

❖ **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.

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Build Your Own Team (continued)

❖ **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.

❖ **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.

Strategies (continued)

Planning Ahead / Know Your Resources

Social Security and Compassionate Allowances

- ❖ **Compassionate Allowance:** The compassionate allowance initiative is a program that allows the SSA to process certain diseases and diagnoses faster based on the extensive medical proof that they are extremely disabling. Multiple System Atrophy has been listed as a Compassionate Allowance condition since December 2011.
- ❖ **Applying for SSD with a Multiple System Atrophy Diagnosis:**
 - ▶ Prior to beginning the application process, it is extremely important that you collect through medical evidence to document your illness and symptoms.
 - ▶ Find a neurologist who has experience diagnosing Parkinson's Disease and its variants. Documentation must show the presence of the autonomic dysfunctions which occur only in MSA. Brain scans are useful in diagnosis as they often show characteristic activity in the affected areas of the brain.

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Planing Ahead/Know Your Resources (continued)

- ▶ Other medical documentation should include records of your diagnosis, lab test results, treatment history, response to treatment, hospital visits, and even personal statements from your doctors.
- ▶ Collecting these records prior to the application process will prevent delays from occurring.
- ▶ The other qualifications for SSDI or SSI must be met such as “work credits” and financial eligibility respectively.
- ▶ For a complete description of required information and documentation, please visit the social security website and access the “starter kit” in the link below:
<https://www.ssa.gov/disability/Documents/SSA-1170-KIT.pdf>
- ❖ **How to Apply for Social Security Disability Benefits**
 - Once ready to begin, you can apply online at the SSA's website or in person at your local Social Security office. The link below will take you to the application page:
<https://www.ssa.gov/applyfordisability/>
 - You can also call **1-800-772-1213** and request an appointment in your local social security office.
 - Once the application is filed, under a compassionate allowance condition, in some cases you may expect to receive Social Security Disability benefits in as little as several weeks.

Planning Ahead/Know Your Resources: The New Jersey Family Leave Act

- ❖ **NJFLA:** The New Jersey Family Leave Act grant eligible employees time off from work in connection with the birth or adoption of a child or the serious illness of a parent, child or spouse.
- ❖ The NJFLA provides for up to twelve weeks of leave in a 24-month period. The 24-month period begins on the first day of the employee's first NJFLA leave.
- ❖ All employers with 50 or more employees anywhere worldwide must comply with the NJFLA for their New Jersey employees.
- ❖ To be eligible for family leave under the NJFLA, an employee must be employed in New Jersey by a covered employer. The employee also must have been employed for at least twelve (12) months for the employer, and must have worked 1,000 base hours in the preceding twelve (12) months.
- ❖ For detail information on FMLA please visit the State of NJ Division of Civil Rights:
<http://www.nj.gov/oag/dcr/law.html#1>

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Planning Ahead/Know Your Resources: Medicaid

- ❖ **What is Medicaid:** Medicaid provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults and people with disabilities. Medicaid is administered by states, according to federal requirements. The program is funded jointly by states and the federal government.
- ❖ **Services Covered:** This program pays for hospital services, doctor visits, prescriptions, nursing home care and other healthcare needs, depending on what program a person is eligible for.
- ❖ **How to Apply:** 1- Fill out an application through the Health Insurance Market Place (Slide 9)
2- Contact you County Welfare Agency
<http://www.state.nj.us/humanservices/dfd/programs/njsnap/cwa/>
- ❖ **Eligibility Requirements:** NJ resident, US Citizen or Legal Alien with 5 years of legal residence in the US and meet the require standards of financial income and resources.
- ❖ **Special Programs:** The Division of Disability Services in the Department of Human Services administers the **Home and Community Based Services for people with** disabilities. These programs were implemented to provide support services to an individual in the community to: prevent placement in an institutional setting (e.g. nursing home or hospital) or provide support to individuals who are re-entering a community setting after a period of institutionalization.

Planning Ahead/Know Your Resources: Durable Medical Equipment (DME)

- ❖ **Durable Medical Equipment (DME)** is any **equipment** that provides therapeutic benefits to a patient in need because of certain **medical** conditions and/or illnesses. **Durable Medical Equipment (DME)** consists of items which are primarily and customarily used to serve a **medical** purpose.
- ❖ Durable Medical Equipment (DME) is covered under **Medicare part B**. Medicare covers 80% and you pay 20% of the Medicare authorized amount. Private health insurances also cover DME. Policies differ therefore inquire about your coverage with your health insurance company.
- ❖ Only your Medical Doctor can prescribe your medical equipment and the need must be documented and justified.
- ❖ Medicare will only cover your DME if your doctors and DME suppliers are enrolled in Medicare. Doctors and suppliers have to meet strict standards to enroll and stay enrolled in Medicare. If your doctors or suppliers aren't enrolled, Medicare won't pay the claims submitted by them.
- ❖ For a complete list of DME that Medicare covers, visit the following link:
<https://www.medicare.gov/coverage/durable-medical-equipment-coverage.html>
- ❖ For a complete guide on how to pay for home and durable medical equipment please visit the following link:
<https://www.payingforseniorcare.com/durable-medical-equipment/how-to-pay-home.html>

Planning Ahead/Know Your Resources

Assistive Technology

- ❖ **What is the difference between durable medical equipment (DME) and assistive technology (AT)?**
- ▶ According to the Assistive Technology Act of 2004, AT is an item, piece of equipment or product system whether acquired commercially, modified or customized, that is used to increase, maintain or improve functional capabilities of individuals with disabilities. A DME is considered a subset of AT.
- ▶ Knowing whether your AT is a DME is important as it has implications on coverage. Congress reference DME as a classification of products covered by Medicare. Most private insurance providers use Medicare's DME classification system as the basis for their own payment systems.
- ❖ What are your options to pay for assistive devices?
 - Medicare/Medicaid, Private Insurance Office of Vocational Rehabilitation in your county, Aging and Disability Resource Centers (ADRC), Major non for profits and Crown funding. Open the link below for a complete guide:
https://abledata.acl.gov/sites/default/files/What%20are%20Your%20Options%20to%20Pay%20for%20Assistive%20Devices_PDF.pdf
- ▶ **Electronic Assistive Devices for Speech and Language:** All sorts of new portable devices are available to help you manage everyday tasks and communicate with caregivers. Your Occupational Therapist can help you choose the right combination of electronic assistive devices for your situation.

Planning Ahead/Know Your Resources

Assistive Technology

- ❖ **Speech and Language Resources:** www.asha.org/public/speech/disorders/AAC/
- ▶ Proloquo2Go: www.assistiveware.com/product/proloquo2go
- ▶ Speak it!: www.itunes.apple.com/us/app/speak-it!-text-to-speech/id308629295?mt=8

- ❖ **Personal Voice Amplifiers**
- ▶ Chattervox: 847-816-8580 www.chattervox.com
- ▶ Spokeman: 800-255-3408 www.luminaud.com/spokeman.htm
- ▶ Speech Enhancer: 314-467-0772 www.speechenhancer.com

- ❖ **Oral Hygiene Products:**
- ▶ Biotene oral care products contain moisturizers: 800-922-5856
- ▶ Plak-Vac & Plak-Vac/Res-Q-Vac oral suction toothbrush system: 800-325-9044
www.trademarkmedical.com/personal/personal-oral.html

Planning Ahead/Know Your Resources

Assistive Technology

❖ Adaptive Devices and Utensils for Eating and Drinking:

- ▶ Flexi-cut Cup & Provale Cup: 800-225-2610 www.alimed.com
- ▶ Independence Spillproof Flo Tumbler: 888-843-5287 www.kcup.com
- ▶ Wedge Cup: 985-722-8269 www.wedgecup.net
- ▶ Provale Cup: 434-265-3574 www.meyerpt.com/provable-cup
- ▶ Maroon Spoons: 800-225-2610 www.alimed.com/maroon-spoons.html
- ▶ Scooper Plate w/nonskid Base: 913-390-0247 www.southpaw.com/non-skid-scooper-bowls-and-plates.html
- ▶ Skidtrol Non-Skid Bowl: 973-628-7600 www.maddak.com/skidtrol-nonskid-bowl-p-27963.html
- ▶ Bruce Medical Supply: 800-225-8446 www.brucemedical.com

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/>

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Plan Ahead/Advance Care Planning (continued)

- ❖ **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>

Planning Ahead: Advance Care Planning (Continued)

❖ Palliative Care

- ▶ Palliative care is specialized medical care for people facing serious illnesses like MSA. The goal is to improve quality of life for both you and your family. You can have palliative care at any age and at any stage of your illness. You can also have it together with curative treatment.
- ▶ Palliative care teams work in partnership with you, your neurologist and other physicians to manage your symptoms and oversee the coordination of your care. These teams are expert in managing the symptoms and stress of your illness. They are also well-versed in navigating the complex health care system. Visit [GetPalliativeCare.org/providers](https://www.getpalliativecare.org/providers) for a state-by-state list.

❖ Hospice Care

- ▶ Hospice care can be provided to patients with a life expectancy of six months or less. Rather than seeking a cure, hospice care aims to make their remaining time with us as comfortable and as meaningful as possible. This may mean pain relief and nursing care, but also includes emotional support and help with everyday tasks.

❖ Payment Methods

- ▶ Hospice care is paid for in full by the Medicare Hospice Benefit and by Medicaid Hospice Benefit. Most insurances and the Veteran's Administration also cover hospice services in full or with minimal co-pays. **Center for Hospice Care** is committed to providing hospice and palliative care to anyone in the community who needs it and meets the qualifications, even if they are un-insured, under-insured or unable to pay.
- ▶ Palliative care is paid for by Medicare, Medicaid and most private insurances if the patient meets criteria.

Methods and Skills Communication

“The single biggest problem in communication is the illusion that it has occurred.” – George Bernard Shaw

❖ Steps for Effective Communication:

▶ **Be Aware:**

Become mindful of your own communication errors.

▶ **Choose Your Words and Actions Wisely:**

Think of whom you are sending your message to and how that person, at that specific time would better receive and understand the message you are trying to send. So deliver it that way.

▶ **Check In:**

When you are receiving a message make sure you have the right understanding. Ask the sender if you are hearing correctly instead of trusting your interpretation completely.

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Communication (Continues)

Two Types of Communication Skills

- ❖ **Assertive Communication:** helps to be open, honest and direct without hurting feelings. Getting what you need.
 - ▶ It is NOT aggression.
 - ▶ It is honest and open communication.
 - ▶ Shares feelings and thoughts.
 - ▶ Statements are clear and direct.
 - ▶ Does not blame or accuse.
 - ▶ Uses “I” messages.
- ❖ **Steps towards assertive communication:**
 - **Describe** the situation.
 - ▶ **Express** the feeling.
 - ▶ **Specify** what needs to be done.
 - ▶ **Consequences** are spelled out

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Communication (Continues)

Two Types of Communication Skills

- ❖ **Aikido communication:** Finding common ground.
 - ▶ uses principles from the Aikido School of Marital Arts.
 - ▶ The concept is based on moving or aligning yourself with the other person's energy and NOT arguing.
 - ▶ It is design to help people break out of habitual reactions to threatening, emotional, or stressful interaction and instead **blend** with the other's energy in a way that reduces the conflict and does no harm to you or the other.
- ❖ **Steps towards aikido type communication:**
 - ▶ **Align:** Put yourself in the other person's shoes by practicing careful listening and asking for clarification if necessary.
 - ▶ **Agree:** Find areas you can agree on. Find goals, needs, and feelings that are similar with the person so you are able to find common ground.
 - ▶ **Redirect:** Once you identify areas of shared concern, team up and work together to find a way to resolution.
 - ▶ **Resolve:** Using "I" messages, try to resolve whatever issue you agreed upon and compromise or agree to disagree about it

Methods and Skills Managing Cognitive Changes

- ❖ **Identifying Needs:** Ask your love one what is more bothersome, rank the need and develop a plan through problem solving or finding positive and effective ways to cope. Below are some suggestions:
- **Cognitive Changes:**
 - Stay physically, mentally and socially active.
 - Establish a **routine** and **keep** a daily routine.
 - Use a daily planner **religiously**.
- **Neuropsychological Changes:**
 - Develop tolerance, choose battles wisely, acknowledge and redirect, refrain from arguing, support group involvement, work closely with local psychologist, explore with your MDs some medications that help with apathy.

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Managing Cognitive Changes (Continue)

❖ **Motor Changes:**

- Physical and Occupational Therapy
- Assistive Therapy

❖ **Speech and Swallowing**

- Speech therapy
- Begin discussion on PEG tube sooner, rather than later.

❖ **Sleep:**

- Sleep study.
- Sleep is a quality of life issue and should be dealt with.

These information was obtained from Cure PSP Guidebook. For an electronic copy, please open this link: https://www.psp.org/wp-content/uploads/2018/01/2018-GUIDEBOOK_web.pdf

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Quotes

- ▶ My advice to other **disabled** people would be, concentrate on things your **disability** doesn't prevent you doing well, and don't regret the things it interferes with. Don't be **disabled** in spirit, as well as physically.”
- ▶ “**Intelligence is the ability adapt to change**”

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