The MSA Journey

A Guide Book

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This caregiver's manual, including any supplemental pages in the appendix which is published by Defeat MSA Alliance is for informational and support purposes only. The information presented herein should not be used for suggesting any diagnosis or understood as recommending any medicines, tests, or treatments. This manual is only intended to be a summary of how doctors, other caregiver professionals and/or lay caregivers could normally treat the symptoms connected with Multiple System Atrophy. Every reader of this manual should consult with his/her doctor or other health care provider for any health-related questions or before any decision or action is taken or not taken.

Defeat MSA Alliance has used all reasonable care to present accurate information and to provide a careful summary about possible symptoms and known treatments. If you should see anything that you believe is missing, inaccurate or have any further suggestions to include our next edition, please feel free to reach out to Defeat MSA Alliance to help: **info@defeatmsa.org**

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Welcome

Welcome to "The MSA Journey: A Guide Book". This handbook is the result of several months of hard work and passionate dedication by many volunteers from around the world.

Only a few individuals are mentioned as the principal contributors, but our thanks go out to many others, who contributed ideas, tips and suggestions. As the case with any first edition, the primary authors see it as a first step in the presentation of information about caregiving for someone diagnosed with MSA. Some of the content in this manual should be also credited to the members of Defeat MSA Alliance's Facebook Group, "MSA: A Caregivers Journey." We are grateful for their invaluable help too.

This book is not intended to be an exhaustive treatment of all the issues involved in caring for a loved one with MSA. It is only a first step in what could be a long and difficult journey – providing the basic information about MSA, the usual course of various symptoms resulting from the underlying condition, some explanations about treatment options and some ideas on care. At this point in time, we may not be able to slow progression, but at the very least, we can offer tips, encouragement and support for our MSA warriors and caregivers.

> *"Caregiving often calls us to lean into love we didn't know possible."* – Tia Walker, author

Our Collective Mission

Defeat MSA Alliance and MSA United Research Consortium are inclusive US based 501(c)(3) charites which aspire to balance efforts to support patients, educate medical professionals, raise public awareness, nurture promising research and advocate for the MSA community. Staffed entirely by volunteers, Defeat MSA Alliance and MSA United specifically aim to achieve a five-fold mission:

- To build a world that truly supports people with MSA
- To foster better medical education about MSA
- To increase public awareness about living with MSA
- To cultivate promising research into treatments and slowing MSA
- To advance the interests of those affected by MSA

Defeat MSA Alliance, together with its partnering charities in the MSA United Consortium, invite all like-minded individuals, around the world, to join us in this noble fight: to speak for those who cannot, with one mind, one heart and one voice: to defeat MSA forever!

Join our efforts, donate now: ***www.defeatmsa.org/donate***

PART 1: INTRODUCTION TO MSA

What is MSA?

Multiple System Atrophy (MSA) is a rare, rapidly progressing neurodegenerative disorder. The disease impairs the systems that regulate blood pressure, heart rate and the bladder – many of the basic bodily functions that people take for granted every day. People with MSA may suffer from dangerously low blood pressure, speech and swallowing difficulties, sleep disturbances, breathing problems, rigidity, balance, movement, and tremors. The life expectancy for those with MSA is typically 5 to 10 years. There is no remission and almost 80% of patients are disabled within five years of the onset of the motor symptoms. Less than 20% of the cases survive beyond 10 years. The rate of progression, the severity of symptoms and the speed of decline may vary widely from case to case. Patients with advanced MSA often become bed-bound, immobile and unable to speak. At present, there is no cure, no genetic tests to detect it, no therapy to slow it and few treatments to manage its debilitating effects. Currently, diagnosis is clinical in nature with no certainty until an autopsy is performed or a posthumous examination is performed. Although in recent years, there has been some research on biomarkers and tests to distinguish MSA from other similar diseases. The day is getting closer when clinicians will be able to definitively diagnose MSA during a patient's life.

Major symptoms associated with MSA can occur in any combination including ataxia (loss of balance and coordination), severe low blood pressure leading to dizziness or fainting when standing (Orthostatic Hypotension), bladder retention or incontinence, constipation, male impotence, speech and swallowing difficulties, sleep disorders, breathing problems, rigidity, and tremor similar to Parkinson Disease.

Recent consensus guidelines (first, second and third) on the diagnosis of Multiple System Atrophy are based on autonomic symptoms, movement issues and/or urinary dysfunction. There is no known hereditary or genetic cause, but it occurs sporadically. It affects both males and females primarily in middle age. Statistical data gives the average age of onset at 50 and the average course of the disease at about 10 years. With knowledge and vigilant medical care, many troubling symptoms can be managed.

Multiple system atrophy is a rare, progressive, degenerative neurological disorder that affects both the autonomic nervous system, which controls involuntary functions, including blood pressure control, digestion, and breathing, as well as movement. It can present with symptoms like Parkinson's, including slow, rigid movement and poor balance. However, MSA includes more significant problems in the autonomic nervous system which could cause fainting, issues with heart rate, digestion, bladder control and erectile dysfunction. Symptoms associated with motor control may include limited mobility, speech problems, tremor, rigidity and loss of muscle coordination and control.

The disease affects 15,000 to 50,000 people in the US. Although the precise cause of MSA has yet to be determined, many experts associate the accumulation of the alpha-synuclein protein in the brain's glial cells as a key indicator of the disease's origins. Glial cells are responsible for making myelin, which acts as a coating on nerve cells to help them conduct their electrical impulses more quickly. This same protein is found to accumulate in patients with Parkinson's, Lewy Body Dementia (LBD/DLB), but in MSA, the protein is found in glial cells. LBD/DLB is often described as a cousin to MSA. In one post-mortem study, using MSA donated brains, a significant number of patients had LBD/DLB not MSA as originally diagnosed. In LBD/DLB, the presence of hallucinations is sometimes a marker for the disease. However, hallucinations are not typical in MSA.

Today, MSA is understood as a disease which combines three groups of symptoms:

- Sporadic Cerebellar Ataxia
- Atypical Parkinsonism (Parkinson Plus)
- Autonomic Dysfunction (Dysautonomia)

In the past these terms were associated with what was once thought to be three distinct disorders:

- Sporadic Olivopontocerebellar Atrophy (OPCA)
- Striatonigral Degeneration (SND)
- Shy-Drager Syndrome (SDS)

Currently, doctors recognize two types of MSA:

1. MSA-C when cerebellar symptoms are the first prominent symptoms
2. MSA-P when Parkinson symptoms are the first prominent symptoms

Diagnosis of MSA

Diagnosing MSA can be very challenging due to similarity with other related diseases, especially in the early stages of the disease. Many patients with MSA are either misdiagnosed or not diagnosed until the disease advances beyond reasonable doubt.

The first step towards a diagnosis of MSA is for the clinician to conduct a thorough history and physical examination. A number of tests may be ordered, which may include testing of the autonomic nervous system, imaging of the brain and others. Examples of which follow:

- Complete neurologic exam
- Blood pressure
  To check for problems with blood pressure control, it can be checked both sitting up and lying down.

  A tilt table test can also check for this by monitoring heart rate and blood pressure while the patient is lying on a table which is positioned at a 70-degree angle.
- Imaging of the brain can help both diagnose MSA and can help rule out other disorders.

  Both an MRI and a PET scan can show any changes in brain structure and function.

  A DaTscan can find problems with dopamine, a chemical in the brain that helps pass along messages between neurons.
- Tests to check for problems with bladder or bowel function.
- An electrocardiogram to help see if there is a problem with heart rate or rhythm.
- A sleep apnea test

Educating physicians about distinguishing between symptoms, may be the key component of an improved diagnostic journey.

TREATMENT OF MSA

Orthostatic Hypotension

Orthostatic hypotension (OH) is characterized by a drop in blood pressure upon standing, accompanying symptoms which may include dizziness and lightheadedness. Usually, the autonomic nervous system regulates blood pressure (BP) and increases blood vessel constriction upon standing to keep BP constant. In MSA, disturbances in the autonomic nervous system can lead to neurogenic orthostatic hypotension (nOH), defined as a drop in systolic BP ≥ 14 mmHg or in diastolic BP ≥ 6 mmHg. Lying-to-sitting drops in blood pressure can also be used to diagnose nOH in patients if standing is not feasible, with drops in sitting measurements as systolic BP ≥ 14 mmHg or diastolic BP ≥ 6 mmHg indicating the presence of nOH. (Sun 2016) These drops in blood pressure can lead to dizziness, problems maintaining balance, walking and an increased risk of falls. Per statistics, nOH occurs in anywhere from 54%-81% of patients with MSA[1].

1. Non-pharmaceutical treatments for nOH include correcting aggravating factors and implementing other measures to decrease symptoms and risk of fall. But as always one should consult the healthcare provider for any care first. Neurogenic orthostatic hypotension (nOH) has been found to be worse in the morning, in hot weather, after eating large meals (especially carbohydrate-heavy meals) and after lifting heavy objects. Avoiding exposure to these factors can decrease the frequency and severity of nOH instances. Other non-pharmaceutical interventions include:

   a. Expanding blood volume with salt and water supplementation may help minimize symptoms of nOH, though the evidence for this is fairly weak[2]. Patients may be encouraged to consume an additional 1-2 teaspoons of salt per day and increase their water consumption by their doctors[3].

   b. Exercise, when done in a safe environment, can improve symptoms of nOH. Exercise can even be performed in a sitting or recumbent position, either on a recumbent stationary bike or rowing machine, for example. Exercise in a pool could also be a safe option for those who have this possibility available.

   c. Compression stockings have been shown to be an effective treatment for nOH by increasing venous return. In many cases, waist-high stockings have been found to be somewhat effective in preventing nOH[4].

   d. The *Valsalva maneuver* that occurs during bowel movements can be a precipitating factor for nOH, so the straining that occurs during constipation should be avoided. This may be avoided through dietary changes such as increasing fiber in diet and increasing water intake. Fermented milk products with probiotics, such as kefir, have been shown to help prevent constipation in patients with Parkinson's disease and, therefore could be of benefit for patients with MSA[5]. When dietary changes are not enough to avoid constipation; laxatives are sometimes needed.

   e. In some cases, supplementation with coenzyme Q10 has also shown some promise in treating the symptoms of nOH[6].

   f. Raising the head of the bed about 10 cm can also help decrease the symptoms of nOH, especially those that occur in the morning[7].

   g. Postural maneuvers can also be used to combat the drop in blood pressure that defines nOH. Muscle tensing, swaying while standing, bending forward, leg crossing and squatting have been found to have significant effects on blood pressure[8].

2. Pharmaceutical treatments for nOH could be used to either increase plasma volume or to increase peripheral resistance through various mechanisms of action. Drugs used to treat MSA are described in Table 1.

Table 1: Medications to Treat Orthostatic Hypotension in MSA

Drug	How it Works	How it is Used	Side Effects
Fludrocortisone	Synthetic adrenal corticosteroid hormone that increases sodium and water absorption, increases blood volume, sensitivity to adrenaline, and causes contraction of blood vessels and increases in BP.	Commonly used in conjunction with a drug that increases blood vessel constriction, such as midodrine, droxidopa or other agents[3].	Can lead to hypertension and end organ damage, leading to heart and renal failure and has been found to increase risk of hospitalization[9]. Side effects include ankle swelling, hypokalemia or low potassium levels, and headache.
Midodrine	Vasoconstrictive agent that leads to increased BP in laying down, sitting and standing positions	It has been shown to be effective in the treatment of nOH among MSA patients, with an increase in standing systolic BP of nearly 22mg Hg[10].	Found to cause an increase in supine hypertension, or dangerous increases in BP while lying down, and should not be taken close to bedtime.
Droxidopa	Converted to norepinephrine, a hormone that increases BP and has shown significant reductions in BP in several small clinical trials, while results from larger clinical trials have been mixed[11].	Patients with a lower level of norepinephrine while lying down tend to have better success with droxidopa and may be used to predict success[12].	Can have central nervous system side effects including behavioral changes, including memory difficulties, confusion, mania, and irritability. Other side effects include headache, dizziness and nausea
Pyridostigmine	Stops the breakdown of acetylcholine, the main neurotransmitter of the autonomic nervous system, increases the release of adrenalin.	Has been shown to cause an increase of an average of 4mm HG in systolic BP[13].	Side effects can include stomach pain, nausea, vomiting, diarrhea, blurred vision, muscle cramps and twitching.
Epoetin alfa	Recombinant erythropoietin that increases the sensitivity of the blood vessels to the hormone angiotensin, which increases vasoconstriction and consequently BP.	The use of this to treat nOH is not widely recommended as the evidence to support it is weak[2].	UNKNOWN
Non-steroidal anti-inflammatory drugs	Blocks prostaglandin-mediated vasodilation and has been hypothesized as using this mechanism to prevent OH.	Results haven't been validated in large trials.	Possible gastrointestinal irritation
Yohimbine	Leads to increases in the activity of the autonomic nervous system through increases in norepinephrine.	Clinical evidence of effective control of OH is scarce[2].	Side effects can include anxiety, palpitation, tremor and confusion.
Desmopressin (DDAVP)	Helps to contract blood vessels and may combat OH by mimicking the action of the hormone vasopressin.	Helps to prevent nocturnal urination thereby improving BP control in the morning. Limited data on this agent make recommendations for the use of this agent weak[2].	Alterations in blood chemistry, specifically low sodium levels.
Atomoxetine	Short acting norepinephrine transport inhibitor, increases BP in nOH.	Especially effective in patients with high levels of norepinephrine[14].	Side effects can include gastrointestinal and urinary symptoms.

Parkinson-like symptoms

There are symptoms of MSA which mimic Parkinson's disease, including stiffness and rigid muscles, tremors, slow movement, balance issues, trouble walking, and dystonia. These are especially prevalent in MSA-predominant Parkinsonism (MSA-P), which tends to be the more common type of MSA.

1. Non-pharmacologic treatment of Parkinson-like symptoms of MSA include:

a. A regular schedule of physical and occupational therapies can help to control the parkinsonian symptoms of MSA. These can help to maintain balance and flexibility as the disease progresses and can prevent falls and additional injury. Research has shown that inpatient, combined with at-home, physical therapy improves gait disturbances in patients with MSA[15]. Tai-chi has also been shown to have positive effects in patients with Parkinson's disease and may have a similar effect on patients with MSA[16].

b. The Alexander Technique, an educational technique taught to patients to improve balance, posture, and mobility, has demonstrated modest benefits to patients with Parkinson's in small studies, although recommendations are mixed. Extrapolating on PD research, the Alexander Technique may be of benefit for people with MSA.

c. The most common type of speech therapy for Parkinson's patients is the Lee Silverman Voice Treatment (LSVT), in which speech therapists focus patients on speaking loudly (LOUD) as a way to target vocal cords and improve speech fluency. An offshoot of this method (BIG) can be used to improve motor control in Parkinson's patients, with a focus on big, expansive movements to control muscles.

d. Dietary modifications can enhance the effects of certain classes of medication used to treat Parkinson-like symptoms in MSA. In patients taking levodopa, a low-protein diet has been tied to increase effectiveness of the drug and a longer time period where the drug works[18]. Patients on monoamine oxidase inhibitors also have been found to benefit from avoiding foods high in the amino acid tyramine, including fermented foods such as aged cheeses, pickled fish, tofu, soy sauce and sauerkraut. However, excessive tyramine consumption in patients on these drugs may lead to dangerous spikes in blood pressure. As always, consult your doctor.

e. Deep brain stimulation (DBS) has not been recommended for MSA, but there have been anecdotal reports about the possible benefits of this treatment. Recently, however, a review of studies reconfirmed that DBS should not be used for people with MSA[17].

2. Drugs used for Parkinson's disease may provide relief of motor symptoms for some MSA patients, though primarily in the earlier stages of the disease. Parkinson's drugs also can lower blood pressure and may worsen OH symptoms, dizziness, and fainting episodes. Pharmacologic options include:

a. Levodopa is a medication that mimics the effect of dopamine in the brain. It was originally used as a treatment for Parkinson's disease, and a poor response to levodopa therapy is thought to be one of the hallmarks of a diagnosis of MSA. Only about one-third of MSA patients may experience a benefit, and a response is more likely in the MSA-P subtype than in MSA-C[19]. The benefits of levodopa therapy diminish over time and has been shown to be useful for MSA-P individuals for about 2 to 3 years. A side effect of levodopa is an abnormal increase in body movement, called dyskinesia, as well as an increase in the symptoms of orthostatic hypotension (nOH).

b. Other dopamine agonists increase the level of dopamine receptors in the brain, allowing dopamine to have a greater effect. Examples include bromocriptine, pramipexole, apomorphine, and ropinirole. Pramipexole has shown promise with some preliminary improvements in Parkinson-like symptoms. Apomorphine helps to treat muscle stiffness and loss of muscle control. As dopamine agonists can exacerbate orthostatic hypotension, they should not be considered first-line drugs in MSA. Potential side effects of this class of medication includes daytime sleepiness, dizziness, fainting, nausea, difficulty sleeping, hallucinations, behavioral changes, and uncontrolled movements.

c. Monoamine oxidase inhibitors block the enzyme monoamine oxidase, which normally breaks down neurotransmitters like dopamine and norepinephrine. As a result, the levels of these chemicals increase and may alleviate Parkinson-like symptoms. Recently, safinamide has been shown to improve symptoms in MSA patients. This class of medication is typically used in conjunction with other medications.

d. Anticholinergic medications, including trihexyphenidyl and benztropine mesylate, have been used to treat MSA. This class of drugs block the activity of the neurotransmitter acetylcholine, which cause muscles to contract.

e. One glutamate antagonist, amantadine, is used to treat Parkinson-like symptoms in MSA. It works by increasing dopamine release and blocking the reuptake of dopamine, leading to mild symptom improvement. Amantadine, which is also an antiviral medication, helps to alleviate tiredness and stiffness in MSA.

f. Research has indicated that certain selective serotonin reuptake inhibitors (SSRIs) can help to decrease Parkinson-like symptoms. Specifically, paroxetine has shown benefits to MSA patients[20].

Dystonia

Dystonia is a movement disorder causing muscles to contract involuntarily. It can occur anywhere in the body, including the muscles of the arms, legs, trunk, or face, and appears as repetitive, twisting movements and unnatural posture. Nearly half of patients with MSA experience dystonia. Dystonia in MSA predominantly affects the head and neck area in a form called antecollis[21]. It can also affect speech. If dystonia affects the vocal cords, obstructive sleep apnea can result.

1. Non-pharmacologic treatment of dystonia in MSA include:

a. Speech therapy has been shown to be a very effective treatment option in patients with MSA who have more trouble with speech than those with other forms of Atypical Parkinson's Disease[22].

b. Physical and occupational therapy helps to maintain mobility and to reduce the risk of contracture, spasm, and further loss of function. Occupational therapy has been shown to minimize the risk of fall, assisting patients in completing their activities of daily living with the use of assistive devices or modifications around the home[23].

c. *Geste antagoniste* is a sensory 'trick' that involves moving an arm to the face or head to alleviate abnormal posture associated with cervical dystonia. This maneuver could be effective at reducing head deviation in patients with cervical dystonia[24].

d. Electromyographic (EMG) biofeedback has been found to be an effective therapeutic technique for decreasing dystonia in patients with movement disorders[25].

e. Continuous positive airway pressure devices (CPAP, Bi-PAP) can be used when dystonia affects vocal cords and breathing, resulting in sleep apnea.

f. Surgical interventions can either be focused on the brain or peripherally, but the goal for both is to interrupt the communication between nerve and muscle which cause the involuntary contraction seen in dystonia.

2. Pharmacologic treatment of dystonia in MSA include:

a. Botulinum toxin has been found to relieve many types of focal dystonias and is widely used in MSA. Localized injections, especially for facial and cervical dystonias, have proven effective[26].

b. The symptoms of dystonia can also be treated with anticholinergic medications, blocking the muscle-contracting effect of acetylcholine. Drugs in this class include benztropine, biperiden, procyclidine, and scopolamine.

c. Drugs that cause muscle relaxation have also been used in treating dystonia in MSA. These include those that increase levels of the neurotransmitter gamma-aminobutyric acid (GABA) which has the effect of reducing activity of the neurons it binds to, thereby causing muscle relaxing effect (e.g., baclofen, benzodiazepines, and zolpidem) as well as traditional muscle relaxants, such as carisoprodol, cyclobenzaprine, metaxalone and methocarbamol. These medications must be used with caution, as dependency is a side effect of some. Consult with your doctor.

Cerebellar Ataxia

Cerebellar ataxia, seen primarily in patients with subtype MSA-C, arises from problems with the cerebellum, which helps to coordinate and synchronize movements. Patients with cerebellar ataxia have difficulty controlling voluntary movements, including walking, speech, hand movements and other motor functions.

Although no cure exists for cerebellar ataxia, treatment of symptoms can improve quality of life and prevent complications.

1. Non-pharmacologic treatment of cerebellar ataxia relies most on physical and occupational therapy. Occupational therapy has been found to improve ability to perform activities of daily living and decrease disease symptomatology. Aspects of treatment also include speech and swallowing therapy and the use of adaptive equipment.

2. While there are no medications that have proven completely efficacious in the treatment of cerebellar ataxia, there are medications that can help control symptoms. (Table 2)

Table 2: Pharmacologic Treatment of Cerebellar Ataxia Symptoms

Imbalance, Speech symptoms	Tremor	Nystagmus
• amatadine • buspirone • acetazolamide	• propranolol • clonazepam	• gabapentin • baclofen • clonazepam

Neurogenic Bladder

Urinary symptoms are experienced by nearly all MSA patients and can be one of the earliest signs of the disease[27]. Symptoms include trouble voiding, incontinence, increased frequency and urgency and leakage. In MSA, urinary tract problems are thought to occur due to a decline of neuronal control from the cerebellum. These problems can lead to a lack of control of the urinary sphincter and a change in activity of the detrusor muscle found in the wall of the bladder, leading to incontinence and an inability to fully empty the bladder. These problems can lead to repeated urinary tract infections and kidney infections if not properly treated.

1. Non-pharmacologic treatments of neurogenic bladder include:

a. Catheterization can help to control the symptoms of neurogenic bladder. Intermittent catheterization can be used when residual urine volume is >100ml. This can be performed by the patient or caregiver at regular intervals during the day to drain excess urine from the bladder to prevent infection. When urinary symptoms progress, a permanent catheter may need to be placed.

b. Surgery is an option when catheterization does not work or is not feasible. As always consult with your doctor. A permanent suprapubic catheter can be surgically placed to drain urine. In men, surgery may remove the external sphincter to prevent urinary retention. Stents can also be placed into the urethra to maintain a patent pathway for voiding and to prevent urine retention.

c. There are lifestyle modifications that can also help with urinary symptoms of MSA. As always, consult with your doctor before taking any action. Avoidance of diuretics, including caffeine and alcohol, can limit the frequency of urination. Adequate exercise and the use of compression stockings can also decrease edema, which can lead to increased urination, especially at night.

d. A bladder diary is an important way to discern symptoms and the progression of symptoms in MSA patients. A bladder diary can track urinary tract symptoms, fluid intake, urine output, and time to voids.

2. Medications used to control neurogenic bladder include:

a. Anticholinergic agents are used when post-void urine volume is <100ml. These medications block the neurotransmitter acetylcholine and the muscle contraction it causes, and can ameliorate symptoms of urgency, frequency, and incontinence, but increase the risk of urine retention. Drugs in this class include propiverine, which can increase bladder capacity, oxybutynin, which not only increases bladder capacity, but can also decrease the activity of the detrusor muscle. Oxybutynin has the added benefit of being available as an extended-release capsule or a transdermal patch. Tolterodine, solifenacin and darifenacin are other drugs in this class that have been shown to decreases symptoms of neurogenic bladder.

b. Alpha-adrenergic blockers, such as alfuzosine chlorhydrate and tamsulosine chlorhydrate, can be used to reduce post-void urine residuals when there is an impaired urinary sphincter muscle. Given the worsening of orthostatic hypotension that may occur with this class of medication, care must be taken using these[28].

c. Nitrous oxide induces vasodilation and has been shown to relax the muscles of the bladder and increase bladder capacity[29]. Drugs that mimic the mechanism of action of nitrous oxide include sildenafil, tadalafil and vardenafil and have been shown to be effective both for neurogenic bladder and erectile dysfunction.

d. Tamsulosin can be used in conjunction with tadalafil to assist with voiding, decreasing residual urine volume and increases bladder storage capacity.

e. Botulinum injection into either the detrusor muscle or urethral sphincter can be used when medications don’t work. This can decrease overactivity in the detrusor muscle and increase bladder capacity and can be used in the urethral sphincter to assist in bladder emptying.

f. Desmopressin can be used to decrease urine volume and is especially additional benefit of improving orthostatic hypotension, but given its high rate of hyponatremia and cognitive impairment, it is not recommended.

> *“Kindness in words creates confidence. Kindness in thinking creates profoundness. Kindness in giving creates love.”*
>
> *- Lao Tzu, Chinese philosopher*

Sexual Dysfunction

Sexual dysfunction is a frequent and early symptom of MSA and can include erectile dysfunction, decreased libido, vaginal dryness and difficulties achieving orgasm. Erectile dysfunction (ED) is often the first symptom of MSA and is reported by many patients with MSA.

1. Non-pharmacologic treatment of sexual dysfunction include:

a. Cognitive therapy to treat underlying depression and anxiety that is common among MSA patients.

b. Moderation of alcohol and tobacco use, as excess use has been tied to ED.

c. Use of vacuum pumps to increase blood flow to the penis and allow an erection to be attained and maintained.

d. Avoidance of medications known to interfere with sexual function, including beta blockers, SSRIs, and finasteride.

e. Surgical placement of a penile implant can also treat the symptom of ED.

f. Vaginal lubricants can be useful to combat the vaginal dryness often seen in women with MSA.

(As always, cosult with you doctor before seeking teatment)

2. Medications used to treat sexual dysfunction include:

a. PDE-5 inhibitors, including sildenafil, increase blood flow to the penis and have been proven to treat ED in patients with MSA. Drops in blood pressure are an important side effect of this class of medication and in patients with OH, this may not be recommended.

b. Intracavernosal or intraurethral injections of the prostaglandin alprostadil and the vasodilator papaverine are also effective in achieving and maintaining erection.

c. Theoretically, other drugs could be used in the treatment of ED including apomorphine, which can be given either by under the tongue or as an injection into the penis. However, some of these treatments may not be FDA approved and as always, consult with your doctor.

d. Female sexual dysfunction can be treated with hormonal therapy.

REM Behavior Disorder

REM Behavior Disorder (RBD) is a condition that involves agressive movements and nightmares during REM sleep. RBD has been reported in a vast majority of MSA patients, with a prevalence ranging from 69% to 100% of MSA patients[28]. RBD symptoms can often precede other MSA symptoms by years.

1. Non-pharmacologic precautions of REM behavior disorder include:

   a. Ensuring bedroom safety to prevent injury could include lowering the bed, useful in treating excessive nighttime urination, while having the padding bedside furniture and securing any rug to the flooring. Also, it is important to remove any dangerous items from access, especially firearms.

   b. A bed alarm can also alert patients and caregivers when RBD causes patients to get out of bed.

2. Medications used to help with REM behavior disorder include:

   a. Clonazepam, a benzodiazepine, has been shown to reduce frequency and severity and prevent injury in RBD[30]. Residual daytime sleepiness and headache are two side effects of clonazepam therapy, as well as possible worsening of sleep apnea.

   b. Melatonin, a naturally occurring hormone secreted by the pineal gland, has been shown to improve REM sleep and decrease RBD-associated injuries with few side effects.

   c. Zopiclone is a benzodiazepine that decreases sleep disturbances and has been used to treat RBD.

   d. Rivastigmine and donepezil, cholinesterase inhibitors, have been effective among some patients who have not had improvement with either clonazepam or melatonin[31].

   e. Pramipexole, a dopamine agonist, has also been shown to improve RBD symptoms, although some studies have shown mixed results.

As always, every patient should discuss options and decisions with one's healthcare provider.

Psychiatric Issues

Many patients with MSA experience depression, anxiety, panic attacks, and cognitive impairment over the course of their disease. Depression has been found in over half (60%) of MSA patients and anxiety has been found in over 75%. Both are more common in patients with MSA-P and are tied to lower quality of life[32]. Cognitive impairment may also occur in up to 75% of patients.

1. Non-pharmacologic treatment of psychiatric issues include:

   b. Cognitive therapy can not only help manage the mental health symptoms associated with MSA, but it has also been shown to increase memory, help slow down cognitive decline, and decrease fall risk in patients with MSA[33]. Some speech and language pathologists can provide cognitive therapy.

   c. Exercise has been shown to promote positive effects on cognitive function in patients with MSA[34].

   d. Electroconvulsive therapy (ECT) may be an option for patients with depression who have not responded to other treatments. As always, every patient should discuss options and decisions with one's healthcare provider.

d. Repetitive transcranial magnetic stimulation (TMS) has been studied in patients with Parkinson's and has shown a positive effect on depression[35].

2. Medications used to help with psychiatric issues include:

a. Selective serotonin reuptake inhibitors are effective antidepressants and may have a lower risk of orthostatic hypotension than other drugs to treat depression.

b. L-dopa or dopamine agonists may also help mood disorders in MSA.

Breathing Problems

Patients with MSA can develop breathing problems as their disease progresses. These can include obstructive sleep apnea, low oxygenation, breathlessness, and stridor. Stridor, or a high-pitched wheezing sound heard on inspiration, occurs in up to 40% of MSA patients[36]. Stridor occurs because of overactive vocal cord muscles that fail to relax normally during inspiration. It can occur any time of the day, but when it occurs during sleep can result in obstructive sleep apnea, which involves frequent periods during sleep when breathing stops. Breathing problems during sleep have been reported in 15%-37% of MSA patients[37].

1. Non-Pharmaceutical treatment of breathing problems:

a. The primary treatment of sleep apnea is the use of continuous positive airway pressure (CPAP) for patients with mild to moderate stridor and can be useful for symptomatic control, although its impact on survival is unclear[38]. CPAP does not have good adherence by patients as MSA progresses due to discomfort[39].

b. A tracheostomy could be an option for the treatment of persistent and severe stridor or can be used in patients with advanced disease for stridor during wakefulness[36].

2. Medications for the treatment of breathing problems

a. Botulinum toxin injected into the vocal cords has been studied as a treatment of stridor in MSA patients, but there is some disagreement on whether there is enough evidence to recommend this treatment[36].

b. Selective serotonin reuptake inhibitors (SSRIs) have been thought to improve sleep disturbances in MSA, as serotonin induces sleep and throat relaxation during sleep. The combination of ondansetron and fluoxetine has been shown to reduce the severity of sleep apnea, but recent studies have found no difference in survival in MSA patients on an SSRI but was associated with more frequent falls[39].

Pain

Pain is an often-overlooked aspect of MSA, but it is very common. Studies have found that pain is reported anywhere from 50% to 80% in patients with MSA[40]. Pain tended to be more common among MSA-P, as compared to MSA-C subtype. Tracking pain is an important indicator for healthcare providers to evaluate the progression of MSA. We have included a worksheet in the Appendices to this manual to help track pain.

1. Non-pharmacologic treatment for pain may include:

a. Exercise and physical therapy are ways to help deal with the pain associated with MSA[40].

2. Medication for the treatment of pain may include:

a. Dopaminergic medication, including levodopa and pramipexole, have shown promise for pain relief[40].

> *"Love seeks one thing only: the good of the one loved. It leaves all the other secondary effects to take care of themselves. Love, therefore, is its own reward."*
>
> *- Thomas Merton*

PART 2: A BEGINNERS GUIDE TO CAREGIVING FOR MSA

MSA diagnosis…now what

Once your loved one receives a diagnosis of MSA, there is a period of adjustment for both of you. As MSA is a journey, your role will change as the disease progresses. It is important as you start moving on this journey together, to take steps to help you in taking care of your loved one…and yourself.

Being a Caregiver

Taking on the role of caregiver for your loved one with MSA is very important. It is important to learn all you can about MSA, including symptoms and treatments, so that you can be an active partner and contributor in mapping out and guiding your loved one's journey. This knowledge will also help you anticipate how your role and responsibilities may change.

How you help to care for your loved one will change over time. While minimum help might be needed now with walking and bathing, it is important to plan what your future role as a caregiver might look like. Over the course of MSA, you will be taking on a variety of roles and duties for your loved ones. These may include:

Planning doctor's visits and communicate with the healthcare team

- Monitoring and administering medications
- Monitoring the patient's symptoms and disease progression
- Providing transportation
- Helping them with activities of daily living, including cooking, showering, and helping them with the bathroom if needed

Planning and making a short-term and long-term schedule can help you organize daily tasks and keep track of medical appointments and medication needs, making responsibilities of caregiving more manageable.

Building a Healthcare Team

Because MSA is a disease with a wide variety of symptoms and a long disease course, it takes a team to help care for patients. It is important to learn the role that each of the members will play in providing medical care. Members of this team can include:

- Primary care physician-helps coordinate and navigate your loved one's healthcare
- Neurologist- a specialist in diseases of the nervous system.
- Physical therapist-helps maintain function and mobility
- Assisting with physical and occupational therapy and exercises
- Helping with insurance and financial issues
- Occupational therapist-helps manage the changes experienced during the course of MSA, including home safety, independence and physical skills
- Speech pathologist-assists with problems with speech and swallowing
- Dietitian-assists patient maintain proper nutrition as the disease progresses
- Social worker-provides practical and emotional support to patients and families
- Mental health professional-helps patients and caregivers deal with the longterm changes involved in MSA

Members of this team will be added as your loved one's illness progresses. Be sure that providers make time to answer questions and treat your loved one with respect. Use the worksheets in the **Appendices** of this booklet or downloadable at our website to keep track of your healthcare team and their contact information. Find worksheets at **https://www.defeatmsa.org/caregiver_pages** or **https://msa-hub.circle.so/**

Learning How to Advocate for your Loved One

One of the most important duties you will have as a caregiver is becoming an advocate for your loved one, both early in the disease and later, when they may not be able to advocate for themselves. Some steps you can take to help your loved one receive the care they deserve include:

- Asking questions of your healthcare team. Make a list of questions prior to every visit to ensure you don't forget anything during the stress of an appointment. Bring along pen and paper to record answers so you can be clear what information was relayed.
- Organize medical information to be sure to have everything you need at your fingertips, including information around medications, symptoms, test results and medical history. Use the worksheets in the **Appendices** of this booklet or downloadable at our website.

Questions for Healthcare Providers

It is important to attend each doctor's visit as prepared as possible. In order to do this, have a conversation with your loved one prior to the appointment to talk about goals for the visit, questions that you both have for the provider, and any follow up you want. Use the **worksheets** in the Appendices to help you prepare for healthcare visits. Below is a list of sample questions you may want to ask your healthcare provider:

- How might MSA affect home and work life?
- What is the short-term and long-term prognosis for MSA?
- What symptoms should my loved one and I watch for?
- What tests will be involved in managing MSA?
- Do we need a follow-up visit and if so, when?
- What treatments are you recommending?
- Are you prescribing or changing any medications? If yes, why?
- What side effects should we expect from this treatment?
- Should we get a second opinion?
- Are there things we can do at home to help with the treatment?
- Are there other providers you are recommending for us to see?

Managing medication

Managing the medication for a patient with MSA can be very complicated. Not only are multiple symptoms being treated at the same time, but medications can change over the course of the disease. Medication errors in the home are common.

In fact, every 21 seconds someone in the United States calls a poison control hotline (**toll free: 800 222-1222**) because of a medication error. Keeping medication information organized and up-to-date is the best way to ensure that all medications are given correctly. Refer to the Appendices for worksheets to help monitor medications.

Institute of Medicine (IOM), To Err Is Human: Building a Safer Health System, 2000, http:// www.nap.edu/books/0309068371/html/
Nichole L. Hodges, Henry A. Spiller, Marcel J. Casavant, Thiphalak Chounthirath & Gary
A. Smith (2018) Non-health care facility medication errors resulting in serious medical out- comes, Clinical Toxicology, 56:1, 43-50, DOI: 10.1080/15563650.2017.1337908

Nutrition

Dietary changes may be able to provide neuroprotective effects and may hold promise for patients with MSA. There have been connections between dietary patterns and risk of Parkinson's disease, but no large studies have been conducted in relation to MSA. A neuroprotective diet is recommended by some experts for neurodegenerative conditions. As always, consult your doctor before making any diet changes.

Diets rich in foods that fight inflammation may also have a role in MSA treatment. Some people report that curcumin, the main component of turmeric spice has anti-inflammatory effects. Reportedly, other anti-inflammatory focused diets, including diets high in fruits and vegetables, may slow decline in MSA. A Mediterranean diet has been connected to a decreased risk of Parkinson's disease and may also confer protective effects in MSA. Recently, an association between decreased coenzyme Q10 and the severity of motor symptoms in MSA has been found. This may provide further support of a diet rich in antioxidants as a possible way to slow disease progression.

Infection prevention

People who have MSA may be prone to recurring urinary tract infections.

Sometimes even if a catheter is in place, infection incidences may occur. As swallowing difficulties progress, the risk of aspiration pneumonia increases. Due to problems with their autonomic nervous system, people with MSA may not show the normal reaction to or signs of infection that you would expect to see in other cases. This can make it difficult for caregivers to notice the signs of infection in their loved ones. It is important to treat infections in those with MSA early, being tuned into any differences symptoms.

MSA is a progressive disease, so any sudden deterioration could indicate a need to consult with healthcare providers.

Covid-19 has been a global pandemic and may still put those with serious chronic medical conditions at risk for infection and severe disease. In addition many patients with MSA are older and therefore, have an increased risk of pneumonia.

You can learn more about infection control measures at: *https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/index.html*.

> “You have power over your mind – not outside events. Realize this, and you will find strength.”
>
> – Marcus Aurelius

Physical, Occupational, and Speech Therapy

Physical and occupational therapy (PT and OT) assist individuals with MSA to keep moving as long as possible and as safely as possible. The ability to move around is important for most individuals from the initial diagnosis and throughout the course of the disease. In addition to working with the individual diagnosed with MSA, OTs and PTs can provide caregiver training, fall prevention strategies, and environmental modifications within your home environment. They could also provide equipment recommendations and may anticipate patient needs according to certain stages of the disease.

Physical therapy focuses on gait training (walking), generalized strengthening, and determining appropriate assistive devices throughout the stages such as a walker, rollator, or wheelchair. Occupational therapists can assist with strategies for self-feeding, toileting, transfer training (from surface to surface such as: out of bed, into the car/shower/wheelchair), bathing/showering, dressing, positioning, adaptive equipment (such as shower chairs/benches), and generalized home safety/fall prevention. Both OT and PT usually work together and have important roles in assisting with the progression of this disease.

As discussed earlier, orthostatic hypotension (OH) is a major symptom of MSA and thus have a significant impact on a person’s ability to function. A therapist can assist the patient with strategies to manage OH, such as: elevating the head of your bed slowly, wearing compression stockings, taking prolonged rest breaks after positional change, and increasing fluid intake. The therapist will monitor your loved one’s vitals at each position to determine if/when OH is occurring. It is strongly encouraged that OH be monitored in collaboration with your physician.

In addition to OT and PT, speech therapy (SLP) is useful for swallowing and cognition. A speech therapist can provide your loved one with exercises to maintain strength of the muscle that may assist with swallowing. They are also able to provide adaptive strategies for memory and communication through all stages of the disease.

Therapists can assist in a multitude of ways to prevent secondary complications and facilitate an environment that makes both you and your loved one's life easier. You may be wondering how to get started with these therapies. First, you will need to request an order from your doctor. Some options for therapy include home health therapy, outpatient therapy, and inpatient therapy (if hospitalized or in a facility). Once an order has been sent from your doctor, the specific therapy location typically will help work with you on insurance coverage and payment options.

Exercise in MSA can be used to help slow both physical and mental decline. While regular aerobic and strength training can be beneficial, care must be taken to minimize the risk of fall and autonomic symptoms. Exercises that can be safely undertaken include physical therapy in a pool and exercises that can be done while sitting, including exercise bikes, and rowing machines. It is important to talk to your healthcare team prior to your loved one starting an exercise program. To help track exercise, use the worksheets in the **Appendices** of this booklet or downloadable at our website. Find worksheets at **https://www.defeatmsa.org/caregiver_pages** or **https://msa-hub.circle.so/**.

> *"Believe you can and you're halfway there."*
> *- Theodore Roosevelt*

Alternative and Complementary Care

Alternative or complementary therapies can possibly be used along with traditional medicine and may help to alleviate some of the symptoms of MSA. Before trying any of alternative therapies, it is important to check with your healthcare team as some of these therapies have side effects, may cause other issues or may interact with medications. Below is a list of alternative care techniques some of which could be beneficial for people with MSA:

- Yoga
- Meditation
- Stress management
- Massage
- Chiropractic medicine
- Acupuncture
- Reflexology
- Reiki
- Homeopathy
- Cannabis
- Ayurveda
- Chinese medicine
- Chair based Tai Chi

> *"God gave burdens; he also gave shoulders."*
> *- Yiddish proverb*

PART 3: LONGER TERM CAREGIVING FOR MSA

Traveling with MSA

A diagnosis of MSA doesn't mean that you and/or your loved one need be confined to your home all the time. With research and some planning, you may be able to take the show on the road! Below are some tips that could be helpful to make your trips easier:

- Plan to travel early in the disease process and plan carefully;
- Talk to your healthcare team about your plans;
- Make sure you have a plan if you need healthcare on the road, including proper insurance and referral for a doctor at your destination;
- Make sure you have enough medication for the duration of your trip:
  - ○ Always carry medications in the original bottles in your carry-on;
  - ○ If traveling to a different time zone, keep taking your medicines on your regular schedule;
- Medical supplies usually don't count as carry-on bags when you fly;
- Use a gait belt (can be purchased at local medical supply stores or Amazon) when helping the individual in/out of the car. Gait belts go around the waist and give the caregiver a place to put their hands to safely assist someone and prevent falls, especially in/out of the car;
- At the airport, meet-and-assist services can be used to get to the gate and onto the plane;
- Wheelchair transport is appropriate for those who can transfer in/out of their wheelchair but cannot get in/out of a car safely. This transportation can be set up with local wheelchair transportation companies and typically, there may be a cost associated with them;
- Stretcher transportation could be appropriate for your loved one at the advanced stages of MSA when they are bed-bound or unable to sit in their wheelchair for prolonged periods of time;
- Early boarding is allowed for passengers with special needs;

- In the USA, visit TSA.gov to find out all requirements when flying;
- Accessible rooms are available at most hotels, which allow for walk-in showers, grab bars, and lower desks and dressers.

Getting Outside Help

The journey with a loved one with MSA is one with everchanging hallmarks. While providing care may be doable for a while, there will come a time, as the disease advances, that you might need help. This may be a home health aide a few hours a week, elder care service, full-time home or in-patient healthcare facility. Predicting what is needed in the next stage of the disease will help you determine when additional assistance is needed. Refer to the worksheets in the Appendix or on our website.

Since MSA is a rare and progressive disease, you will need to provide detailed and relevant information to all care providers. A good care plan can provide structure and help you lay out expectations to providers.

Managing Difficult Behavior

There are several behaviors that may occur during the course of MSA that can be a challenge to manage. This can include agitation, which can be due to underlying pain, frustration, physical illness or fatigue. If these are new behaviors, connect with your healthcare team as a full assessment may be warranted.

Behavior	Coping Mechanism
Fatigue	Schedule rest times
Pain	Medical evaluation
Depression	Mental health evaluation
Agitation	Create relaxing
Incontinence	Medical evaluation, schedule toileting
Paranoia	Reassure, increase social opportunities

If hallucinations are occuring please reach out to your healthcare provider to discuss this symptom and management options.

Nutrition Solutions in Late Stage MSA

Trying to keep your loved one healthy and strong as their MSA progresses is important, but can be difficult. Decreased appetite due to less exercise, swallowing difficulties, and side effects from medication can make maintaining a healthy diet difficult. Adding to that is MSA-related bloating, decreased appetite, and constipation. Hydration and fiber are ways to combat constipation and the threat of bowel impaction.

Difficulty swallowing is something that almost all people with MSA deal with. Swallowing tough foods or thin liquids can become difficult because of throat muscle weakness or incoordination. This can be a late-stage occurrence and can cause people to have problems with thin liquids and solid food. The swallowing muscles may not work properly and might not form a tight seal that normally happens during swallowing. These problems are best assessed by a trained speech or swallowing pathologist. You can ask your care team for a recommendation.

If swallowing issues progress, aspirated liquids and solids can lead to pneumonia and other health difficulites. A percutaneous endoscopic gastrostomy, or PEG, tube can be placed through the skin into the stomach to help the patient maintain their nutrition. The tube is closed off and can be covered with clothing. PEG feeding can allow patients to maintain their weight and receive nourishment. Food can be pureed at home and fed through the PEG tube. The decision to place a PEG tube is one that should be made in discussion among your loved one, your family and your care team. Sometimes insurance may cover the cost of the PEG food, even organic food might be covered.

Palliative Care

Palliative care provides relief from symptoms including pain, emotional stress and may also involve help for spiritual needs. It may improve the quality of life of patients and families who are facing life-threatening illness. Incorporating palliative care early in the course of MSA has been found to be beneficial. Palliative care involves many services to support the patient and their family. In MSA, symptomatic treatment can be challenging throughout the disease course, and numerous factors may contribute to distress in patients and caregivers. A team approach can be started in early MSA and can continue on later in the disease for management of symptoms and for advanced care planning.

> *"Some days there won't be a song in your heart. Sing anyway." - Emory Austin, motivational speaker*

Advanced Care Planning

End of life discussions and decisions about advance directives can be very difficult for patients and their caregivers. Discussions of this nature must involve the patient and may also include others such as caregiver(s), other individuals in the family, and members of the healthcare team. Also, these discussions may involve talking about possible options given the patient's particular location, available services (i.e. different hospices and palliative care programs) and taking into consideration information offered by healthcare providers. A patient's self-determination, the right and the ability to make one's own decisions about health is an important ethical principle.

Evaluating your loved one's wishes around life-sustaining treatments, spiritual beliefs about death and dying, appointing someone to speak for them, such as the power of attorney (POA) or whomever can make decisions for them if they are unable to do so, and preparing legal documentation for that process and other decisions are all aspects of advanced care planning.

Brain Donation

Brain donations can help researchers find the cause(s), new treatments, and a cure for MSA. The examination of brain tissue is vital in this research process. A brain donation involves a simple procedure and it does not hinder the funeral or any burial plans. For many, a brain donation is the ultimate gift for generations to come, it is a necessary component of most MSA research. If you are a patient and you are considering a brain donation, please contact

Defeat MSA Alliance to help with the process by email: info@defeatmsa.org or by phone: 1 855 542-5672 (855 Kick-MSA). If you are outside the US, Defeat MSA Alliance may still be able to help connect you with its partners to help facilitate a brain donation.

A confirmation of MSA can occur without a brain donation because any post-mortem examination, such as happens in an autopsy, can confirm an MSA diagnosis. However, a brain donation could help further vital MSA research going forward for years to come.

Research and Future Directions

Researchers have determined that the alpha-synuclein protein that clumps abnormally in the brain cells of confirmed MSA cases is the same one that clumps in the brain cells of Parkinson's disease patients. Hence, MSA, PD and other atypical forms of Parkinsons such as Lewy Body Dementia (LBD/DLB) have been all described as 'cousins', related to each other because of this particular protein. Also this means that much of the research that sheds light on the basic cellular abnormality of Parkinson's may also help MSA research. But there is some researches that directly addresses MSA, in particular. Furthermore, the basic problems in many of the neurodegenerative disorders which may turn out to be similar. That means that advances in research on Alzheimer's disease may also help in the fight against Amyotrophic Lateral Sclerosis (or ALS, also sometimes referred to as "Lou Gehrig's disease"), to name two better known examples. When the fine day comes that one neurodegenerative disease is slowed or even reversed, the others such as MSA and PD, may not be far behind.

> "To care for those who once cared for us is one of the highest honors."
>
> - Tia Walker, author

PART 4: CARING FOR YOURSELF

Managing Caregiver Stress

According to the National Alliance for Caregiving, more than in five Americans are providing unpaid care to an adult with health or functional needs. Caregivers report physical, emotional, and financial strain, with 2 in 10 reporting they feel alone (21 percent), and 1 in 4 find it difficult to take care of their own health (23 percent).[1]

Caregivers have an enormous, often underappreciated job. The stress of caregiving can leave caregivers feeling stressed, drained, and unable to cope. The following tips may help you cope with your role as caregiver:

- Take regular breaks. It is important to recharge your batteries as often as you need and to lean on family and friends to get breaks from your role as caregiver
- Be kind to yourself. Caregiving is very difficult, and as much as you want to do the very best for your loved one…no one is perfect
- Join a support group. The benefits of joining a support group include having caregiving in common with the other members, learning how to cope, learning practical tips and tricks from other caregivers, and forming enduring friendships. Please refer to DefeatMSA.org website for a list of online support groups.
- Join the MSA Hub, the world's first independent online community - open to all MSA community members. Connect with others!

  https://msa-hub.circle.so/
- Reduce your stress. Exercise, breathing exercises, meditation, yoga and other mindfulness exercises can help to reduce your stress and improve your health.

> "It is not the load that breaks you down. It's the way you carry it." - Lena Horne, singer

Respite Care

Respite care assists in caregiving by bringing temporary relief from the continuous demands of caring for someone with a chronic disease. Respite care can take place in or out of your home, and can be for a few hours or a couple of weeks. The purpose of respite is to allow the caregiver to rest, recharge, and remember that there is life beyond caregiving. In the USA, you can find more resources and ways to locate services near you, visit ARCH National Respite Network at *archrespite.org.*

- AARP and National Alliance for Caregiving. Caregiving in the United States 2020. Washington, DC: AARP. May 2020. *https://doi.org/10.26419/ ppi.00103.003*

Additional Resources on Diet

Given the possible benefits of making changes to your diet, a nutritionist or dietitian could be someone that you may want to add to your healthcare team. As always consult your doctor.

One such resource to find a specialist in this area is Eat Right: https://www.eatright.org/find-an-expert.

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