

# **Living with Amyotrophic Lateral Sclerosis (ALS)**

A Guide for Patients and Families



## **Introduction**

This guide was created to provide important information for patients who have been diagnosed with amyotrophic lateral sclerosis (ALS), their families and loved ones. The contents of this packet offer an overview of important aspects of living with ALS, including finding support, financial options, leaving a legacy, and more. Keep this information on hand, and refer back to it as needed. If you have any questions or concerns, or would like additional information, please contact a clinic staff member.

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## ALS: A Path Not Chosen

### 1. You are not ALS.

A diagnosis does not define you as a *person*. Take the opportunity to introduce your healthcare team to the person behind the diagnosis. It is important that they know that there is a “whole” person in front of them with dreams, goals, insights, fears, hopes, questions, plans, and loved ones. Connect on a personal level with your healthcare team. You are a person of many dimensions, one of which is now living with ALS.

### 2. A diagnosis of ALS is not a medical emergency, but it is an emotional shock.

It is normal to feel afraid, uncertain, and at a loss of what to do next. It is a crisis which must be addressed, however try to not feel forced into making rushed decisions. There is time to talk and make decisions. You have been experiencing symptoms that up to this point have not been labeled as ALS. You have now “landed on” ALS. As you move forward, remember that this is *your* diagnosis, *your* life, and *your* timeline when it comes to making decisions regarding your care and living the fullness of your life. Take time to experience all your emotions and allow an adjustment period to this diagnosis and its implications. Life is different now.

### 3. Take time to explore what works best for you.

What types of persons and behaviors do you respond to best? Do you prefer direct communication, do you withdraw, are you sensitive? Does too much information overwhelm you, or does too little heighten anxiety? How do you cope best? Being aware of *who* you are and what works best for you will help you as you make healthcare decisions, seek out support, and share your experience with family and friends. If it is too uncomfortable for you to explore these things, that's ok.

### 4. It takes two.

Communication is a two-way street. How do you communicate? We all do it either verbally, through gestures, via body language, through writing, artistic expression or by our actions. What is your listening style? Do you offer your opinion, withdraw, look to others to listen for you, or ask questions? If you feel that your healthcare team is not *hearing* you or you are not able to *hear* them, it may be helpful to share that. In this way, both you and your healthcare team can ensure that you are receiving and giving the information needed to sustain your quality of life.

### **1. You have entered a strange land which has its own language and customs.**

Medicine has its own language. If you don't understand what is being discussed with you, ask for clarification. You are learning a new language. Sometimes healthcare team members will use terms that they are accustomed to, but which you may be hearing for the first time. Ask the clinician to explain your diagnosis, clinical terms, etc. in commonly used language that you can understand. That is ok. This is not a test of your knowledge. The goal is for you to understand as well as possible what is happening to you so that you make informed choices. If you feel the need to do so, seek out a second opinion.

### **2. Ask for what you need when you need it.**

Don't be afraid to ask questions of your healthcare team. Be specific about the resources you need and keep asking for more as your situation changes. Your needs will change along the way and it's important to let others know. You are your best advocate. Involve your family and friends so that they may ask their own questions, for you and for themselves. Let your loved ones know what you need also. They don't always know what is helpful or how to best support a person living with ALS. A hallmark of living with ALS is the persistent and ongoing need to adapt physically, functionally, and emotionally. It is an act of self care, for you and loved ones, when you let others know what you need. Living with a life threatening illness can be isolating. *You are not alone.*

### **3. Spend energy wisely.**

It is a common theme when living with the effects of ALS to focus on *energy conservation*. Listen to your body and pace yourself. If you need to take a break or take a nap then take it. It is important to be aware of and nurture your physical energy, and to also care for your *emotional* energy. You may find you are feeling anxious or fearful. Reach out to whichever professional or personal interventions that work best for you such as supportive counseling, journaling, engaging family or friends, joining a support group, or connecting with your faith community, to name a few.

#### **4. Who am I now?**

You are a *person first*. A person now diagnosed with ALS. You are a husband or wife, daughter or son, father or mother, grandparent, aunt or uncle, a friend, a person with hopes and dreams. The status quo of your life has been radically altered. The way you view yourself and the world has changed. Set both short and long term goals for yourself. Reevaluate them on a regular basis. You may be able to meet some of your goals on your own; others may require some assistance--- recognize the difference and take action. In situations that feel out of control, self-awareness, recognizing your own needs, and self-advocating can help you feel empowered.

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## WHAT TO EXPECT WHEN YOU COME TO THE ALS CLINIC

- A. You will be meeting with potentially 10 disciplines over the course of your morning or afternoon clinic visit which includes the clinic physician, nurse practitioner, nutritionist, respiratory therapist, physical therapist, occupational therapist, social worker, research coordinator, speech pathologist, and wheelchair seating service. An ALSA-MI Chapter representative will also be available.
- B. Please plan to spend the morning or afternoon in clinic. Because we aim to answer as many of your questions as possible, you may spend up to 4-5 hours in clinic.
- C. Please feel free to have family or friends come with you to clinic if you choose. They are welcome to participate.
- D. It is recommended that you bring a lunch or snack as well as a beverage as it can be a long afternoon or morning. There are also vending machines nearby as well as the hospital cafeteria which a family member or friend can access for you.
- E. When you come to clinic there will be paperwork to complete and this will occur for each clinic visit. Please bring a list of your medications.
- F. You will be weighed at every clinic visit by UMHS staff.
- G. After you have been situated in a clinic room that is where you will remain for the duration of your clinic visit. We will come to you.

### NOTES

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## Patient and Family Support

When you, or a loved one, is diagnosed with ALS, the days ahead may feel overwhelming and filled with emotion. What exactly is ALS? What is going to happen to me? How much time do I have left? What should I do now? These questions, and many others, might race through your mind in the days and weeks following your diagnosis.

You might feel sad, and grieve the losses that come along with receiving such a prognosis. Many ALS patients feel alone, never having known another person who has suffered from ALS.

*“Accept the fact that you have this disease, stay positive and surround yourself with positive people.”*

*- Donald, Patient diagnosed with ALS*

### SEEKING SUPPORT

*You are not alone!* Support is available for you and your family. There are several ways to find comfort and encouragement from others who truly understand what you are going through. Online ALS communities and local in-person support groups are available to you and your family.

During this difficult journey, it is important to seek support, and use it often. Below are some resources to get you started.

*“Never give up, do what you love as long as you can, and we hope you have a strong faith as this will carry you through.”*

*- Mark, Patient diagnosed with ALS*

### RESOURCES FOR PATIENTS & FAMILIES

#### Online Resources

ALSA Patient Bill of Rights

<http://www.alsa.org/als-care/patient-bill-of-rights.html>

Patients Like Me

[www.patientslikeme.com](http://www.patientslikeme.com)

“Patients Like Me” is an online community dedicated to helping people learn more about ALS, share their stories and experiences with other people with ALS (pALS), and find support from others who are living with ALS. This chat room was founded by a family affected by ALS. Registration is free.

ALS Chat

[www.alsforums.com](http://www.alsforums.com)

“ALS Chat” by ALS forums is a volunteer resource providing an internet vehicle for information, discussion, and support for anyone affected by ALS. Both pALS and caregivers can register for free.



## Daily Strength

[www.dailystrength.org](http://www.dailystrength.org)

“Daily Strength” offers free, anonymous support for a number of concerns, including ALS. Type “ALS” in the search box on the homepage, and you will find the ALS Support Group page, where you can post your thoughts, respond to others’ notes, or read through experiences shared in the chat room.

## Facebook Support Groups

[www.facebook.com](http://www.facebook.com)

Facebook ALS groups have provided support for a number of families in the ALS Clinic. Type “ALS” in the search box for “groups”, and you will find a number of ALS-related groups where you can post your thoughts, respond to others’ notes, or read through posts shared on the wall. Here are just a few patient recommended groups:

- Living with ALS ~ For PALS ONLY
- Someone I love has ALS
- ALS We are in it together
- Lou Gehrig's Disease (ALS)
- Better Days With ALS
- ALS: Caregiving Spouses support group
- ALS Patients, Family, Friends and Caregivers
- ALS Caregivers -- Finding Time for Ourselves
- KICK ALS!
- Our Lives With ALS
- ALS Sucks
- Familial Amyotrophic Lateral Sclerosis (fALS/MND) Support Group

## The National ALS Registry

[www.cdc.gov/als](http://www.cdc.gov/als)

Enroll now in the national registry! By signing up you will help the ALS community understand how many people have ALS. You can complete surveys to help the ALS community understand who gets ALS and what factors affect the disease by answering questions. PALS can be notified of clinical trials and research studies not only at University of Michigan but all across the country.

In-Person:

ALS Association Local Chapter

[www.alsa.org](http://www.alsa.org)

The ALS Association website provides links to all of the regional chapters' websites, where you can find more information on local support groups and events, and find contact information for local representatives.

ALS of Michigan

[www.alsofmi.org](http://www.alsofmi.org)

ALS of Michigan hosts free, open support groups for PALS and their families, friends and caregivers. To be added to a support group reminder mailing list please call (800) 882-5764.

*"Look to your family and friends for help. Take a day at a time. Look for someone to talk to that knows about ALS...what ALS does or what you're going through or feeling."*

*- Patient diagnosed with ALS*

## **Conserve Your Energy**

University of Michigan Health System Physical Medicine and Rehabilitation  
Occupational Therapy Department & Social Work

- Simplify your tasks and set realistic goals. Don't think you have to do things the same way you have always done them.
- Prioritize. When you have several things to accomplish, make a list and decide what is most important and what can be postponed. Use your energy to perform the most important task first. Then perform the rest of your list as your energy allows. This will allow you to lower your stress level, because you will not waste energy worrying about the things that have not been accomplished.
- Plan your activities ahead of time, and do not schedule too many in one day. There should not be activities planned after a meal. Do the activities that take more energy when you are feeling your best. If needed, rest before and after activities. If you become tired during activity, stop and rest. You may need to finish it another day or when you don't feel as tired.
- Keep all commonly used items (phone, remote control, pens/paper, etc.) in a basket close to your body to avoid reaching.
- Organize your items: try to return items to the same place in order to conserve energy and time instead of needing to search for items.
- Develop a system to organize items in cupboard shelves or cabinets so that every commonly used item has its designated place, easily within reach.
- You can save energy during activities by sitting on a chair. You may even try propping your elbows on the table/counter surface in front of you. Whenever possible, use electric appliances and other energy-saving devices.
- Push or slide items rather than carrying or lifting. Organize your work area, placing supplies near where they will be used. This includes storing objects at shoulder or waist level to avoid bending or reaching.
- When moving anything heavy or awkward in the garage or kitchen, use a utility

cart or wagon to avoid making numerous trips.

- Use long handled items such as a dustpan, broom, mop, reacher or a sponge to prevent bending.
- Ask for help – divide the tasks among family and family.
- Anytime you change your body’s position, it’s a good idea to rest after each movement. This includes even simple chores like standing up and lying down. Be sure to pause at least a second or two in between movements.
- Anything that takes longer than an average of 10 minutes, sit down to perform.
- For every hour of activity, rest for 15 minutes.
- Be sure to get a good night’s rest. Be careful not to nap too much during the day, as you may not be able to sleep at night.
- Allow yourself space to feel your emotions, and find a positive outlet to express what you’re feeling, whether that be a trusted partner, friend, artistic outlet or support group.
- Practice self-care – reserve space to worry and grieve, but conserve your emotional energy by taking deep breaths, using distraction, spending time with loved ones, practicing mindfulness, and other self-care strategies that work best for you.

*“Make plans and modifications early so things are in place when problems arise.”*

*- ALS Patient*

## Caregiver Support

As a family caregiver, you play the most important role in the care of your loved one with ALS. Your experience will surely be physically and emotionally demanding. It will require you to learn new skills and will draw out courage and strength in you that you may not have known you possess.

### **GIVE THE GIFT**

Give the gift of accepting help – often others want nothing more than to help you and your loved one during this difficult time. When others ask what they can do to help, take them up on their offer! Scheduling a time for a friend or family member to provide respite care gives them a chance to help, and provide support to your loved one, while giving you space for self-care.

*“One of the most difficult things for caregivers to do is take care of themselves – but that is the most important thing!”*  
– Shelby, Caregiver of Loved One with ALS

### **USE RESPITE FOR YOURSELF**

When your loved one has respite care, use that time for yourself. The grocery shopping, housework, and other tasks will always be there. Take those precious moments to yourself to relax, recharge and rejuvenate yourself. When you are energized and at your best, you are able to be fully present and available in your caregiver role.

### **SELF-CARE**

During this difficult journey, it is important to make time to take care of yourself. This may seem impossible at times, when you are so busy taking care of your loved one. However, if you are not well, you cannot help your loved one to be well.

It's like being on an airplane when there's an emergency – you are always instructed to secure *your own* oxygen mask *first*, before helping your loved one put theirs on. The same is true in life, especially for caregivers. You must care for yourself before caring for someone else. As difficult as this principle may be to follow at times, there are small, simple things you can do every day to ensure you are at your best.

Here are a few ideas:

- Take 5 deep breaths.
- Go for a 10-minute walk.
- Talk to a friend.
- Listen to relaxing music in the car.
- Exercise.
- Take a nap.
- Eat a healthy meal.
- Laugh!
- Step outdoors for a breath of fresh air.
- Read.
- Write in a journal.
- Pray.
- Take a bath.
- Have a cup of coffee or tea.
- Meditate.

*"Have patience."- Darlene, Caregiver of Loved One with ALS*

*"Find ways to take care of yourself to help manage the fatigue and stress that comes with this diagnosis and care. Find and use as many resources as you can. Stay connected with people. Don't be ashamed to ask for help."*

*- Sharon, Caregiver of Loved One with ALS*

Write your own self-care plan in the space below. You can use the ideas above, or add your own!

**Ways I Feel Nurtured:**

- 1)
- 2)
- 3)
- 4)
- 5)

## SEEKING SUPPORT

During this difficult journey, it is important to seek support, and use it often. Below are some resources to get you started.

*“Find a support group – shared information is priceless from others who know, do it and live it. Don’t be afraid to seek help.”*

*- Jennifer, Caregiver of Spouse with ALS*

## RESOURCES FOR CAREGIVERS

Online Resources:

*“I have come to know others facing ALS & its challenges through Facebook...and have used some of the ALS forums.”*

*- Sharon, Caregiver of Loved One with ALS*

ALSA Caregiver’s Bill of Rights

<http://www.alsa.org/als-care/resources/publications-videos/factsheets/caregivers-bill-of-rights.html>

ALSA Family Caregiving Factsheet

<http://www.alsa.org/als-care/resources/publications-videos/factsheets/fyi-respite.html>

ALS Chat

[www.alsforums.com](http://www.alsforums.com)

“ALS Chat” by ALS forums is a volunteer resource providing an internet vehicle for information, discussion, and support for anyone affected by ALS. Both pALS and caregivers can register for free.

Lots a Helping Hands

<http://lotsahelpinghands.com/>

Creating a support community via an on-line resource.

### Department of Veterans Affairs Caregiver Support

<http://www.caregiver.va.gov/>

This website provides resources for caregivers and Veterans, including resources available to caregivers, and videos and stories of caregivers of Veterans. The website has a zip code look up feature allowing caregivers and Veterans to find the name and contact information of the closest Caregiver Support Coordinator. There is also a toll free number: [1-855-260-3274](tel:1-855-260-3274).

### Information on the Family and Medical Leave Act (FMLA)

<http://www.dol.gov/whd/fmla/>

FMLA entitles eligible employees of covered employers to take unpaid, job-protected leave for specified family and medical reasons

### Caregiving & Medicare

<http://medicare.gov/campaigns/caregiver/caregiver.html>

This website offers resources, stories, and newsletters about caring for someone with Medicare.

### Support a Loved One at the Doctor: Quick Tips

<http://healthfinder.gov/HealthTopics/Population/older-adults/mental-health-and-relationships/support-a-loved-one-at-the-doctor-quick-tips>

A quick checklist of things to consider when taking a loved one to the doctor.

### Caregivers and Exercise – Take Time for Yourself

<https://go4life.nia.nih.gov/tip-sheets/caregivers-and-exercise-take-time-yourself>

### Caregiver Stress Fact Sheet

<http://www.womenshealth.gov/publications/our-publications/fact-sheet/caregiver-stress.html>



## In-Person:

ALS Association Local  
Chapter [www.alsa.org](http://www.alsa.org)

The ALS Association website provides links to all of the regional chapters' websites, where you can find more information on local support groups and events, and find contact information for local representatives.

ALS of Michigan  
[www.alsofmi.org](http://www.alsofmi.org)

ALS of Michigan hosts free, open support groups especially for caregivers of people with ALS. To be added to a support group reminder mailing list please call (800) 882-5764.

## Publications:

- Muscular Dystrophy Association (MDA), *ALS Caregiver's Guide*  
<http://mda.org/publications/mda-als-caregivers-guide>

This guide provides comprehensive instructions for caregivers who care for a loved one with ALS. It helps caregivers understand the progression of the disease, and shares quotes and advice from other caregivers. It can be accessed online, and downloaded as a PDF file.

- ALS Association (ALSA), *For Caregivers*  
<http://www.alsa.org/als-care/caregivers/for-caregivers.html>  
This webpage provides a link to the brochure, *Caregiving... When a Loved One Has ALS*, including a brief list of resources for caregivers of people with ALS. Click the menu options on the left side of the page to access information on respite care, coping with burnout, and caregiving tips and hints.

*"The stress and demands as the caregiver can be overwhelming. Please be cognizant of this and use resources and seek help as needed."*

*- Brian Coltman, Senior Rehab Engineer, ALS Clinic Seating and Mobility Specialist*

## Financial Assistance

Ongoing medical care for individuals diagnosed with ALS can sometimes place a financial burden on the patient and their family that may feel stressful and overwhelming. If financial strain is a concern for you and your family, there are options available to lessen this burden. Governmental assistance benefits exist that you may be entitled to, in addition to services offered by local ALS support organizations. Here are a few commonly used options to get you started.

### SOCIAL SECURITY

Once diagnosed with ALS, you are eligible for Social Security Disability benefits as well as Medicare. It is good to review your current insurance benefits, and compare them to Medicare coverage before applying, to determine what option best fits your needs. With an ALS diagnosis, your application should be expedited, meaning you should receive a decision regarding your application within a couple of weeks, as a part of the Compassionate Allowances program.

In regards to applying for these benefits please be aware of the following points:

- If you are working and your gross monthly income is over \$1,090 the Social Security Administration (SSA) will not accept an application as you will not be considered disabled by earnings criteria. Both earnings and disability diagnosis criteria need to be met to initiate an application.
- While your application should be expedited with a diagnosis for ALS this will not affect the standard 5 month waiting period for benefits to start. Social security disability benefits are not retroactive for this 5 month waiting period though you may qualify for Social Security Income (SSI) for this period if you meet the financial criteria.
- Given a diagnosis for ALS you will begin receiving Medicare coverage the same month you begin receiving social security disability. Typically there is a two year waiting period which is waived with a diagnosis for ALS. You will receive Medicare Part A automatically, but you will need to sign up for Part B. The Part B premium will be deducted from your monthly social security disability benefit check. If you have questions about this it is recommended you contact SSA <http://www.ssa.gov/agency/contact/phone.html> or the Medicare/Medicaid Assistance Program (MMAP) to speak with a MMAP counselor <http://mmapinc.org/>

To learn more about presumptive disability for people with ALS, visit <http://www.alsa.org/als-care/resources/publications-videos/factsheets/new-social-security-rules.html>.

For more information on Social Security and ALS, check out the fact sheet provided by alsa.org ([http://www.alsa.org/als-care/resources/publications- videos/factsheets/professionals-guide-govt-benefits.html](http://www.alsa.org/als-care/resources/publications-videos/factsheets/professionals-guide-govt-benefits.html)).

You can apply for Social Security Disability benefits online at <http://www.socialsecurity.gov/applyfordisability/>.

Disability Planner: Family Benefits

<http://www.ssa.gov/planners/disability/dfamily.html>

This tool from the Social Security Administration will help you come up with a plan for the best way to use your Social Security disability benefits.

## **VETERANS**

Research shows that ALS occurs more frequently in veterans than in the general population. As a veteran, you are eligible for benefits through the Veterans Health Administration. It is recommended that you apply as soon as possible after diagnosis, as benefits are retroactive to the date of application.

The application for benefits consists of filling out the appropriate form and submitting any required documentation. The forms are:

1. Health Care - <https://www.1010ez.med.va.gov/sec/vha/1010ez/>
2. Service Connection - <http://www.vba.va.gov/pubs/forms/VBA-21-526-ARE.pdf>

For assistance with completing the application process, we recommend that you engage the assistance of a service officer through a Veteran Service Organization (VSO), such as Disabled American Veterans (DAV), Paralyzed Veterans of America (PVA), the American Legion, Veterans of Foreign Wars (VFW), or Veteran's Administration (VA).

Here are a few local options:

U.S. Department of Veteran's Affairs Detroit:

<http://www.va.gov>

800-827-1000

Disabled Veterans of America Detroit:

<http://www.dav.org>

313-964-6595

Paralyzed Veterans of America:

<http://www.pva.org>

313-471-3996

A veteran with a diagnosis of ALS may also make use of their local county veterans service officer for assistance in applying for VA benefits. Here is a link to the Michigan Veterans Affairs Agency, <http://www.michiganveterans.com/> and a directory of their county representatives,

<http://www.michiganveterans.com/Home/Benefit-Counselors#CountyContacts>.

Other VA Resources:

Department of Veterans Affairs' Guide to Long Term Services and Supports

<http://www.va.gov/geriatrics/guide/longtermcare/>

This website provides an overview of VA long-term services and supports.

Disabled Veterans exemption for Michigan Property Taxes

[http://www.michigan.gov/documents/taxes/Disabled\\_Veterans\\_Exemption\\_FAQ\\_082614\\_466519\\_7.pdf](http://www.michigan.gov/documents/taxes/Disabled_Veterans_Exemption_FAQ_082614_466519_7.pdf)

## **LOCAL SUPPORT**

Services provided by the following organizations include a loan closet, containing scooters, wheelchairs, communication devices and more, financial assistance for respite care, and support groups.

ALS Association Local Chapter

[www.alsa.org](http://www.alsa.org)

866-927-2873

ALS of Michigan

[www.alsofmi.org](http://www.alsofmi.org)

800-882-5764

## Other Resources:

ALS Guardian Angels

<http://www.alsguardianangels.com/>

Potential financial assistance for people living with ALS

Go Fund Me

[www.gofundme.com/?utm\\_campaign=Emails&utm\\_source=sendgrid.com&utm\\_medium=email](http://www.gofundme.com/?utm_campaign=Emails&utm_source=sendgrid.com&utm_medium=email)

Some have created Go Fund Me accounts as a means of obtaining financial assistance.

*"We are just starting this journey, but I can see it will be the biggest fight of our lives. I would say cherish every moment, say 'I love you' more often, and don't sweat the small stuff."*

*- Amy, Caregiver of Loved One with ALS*

## **Policy Matters for Patients**

### **YOUR VOICE**

When you are diagnosed with ALS, getting involved in public policy initiatives may feel like a distant thought. For some time you and your family may be focused on survival, on understanding ALS and adjusting your lives to this new challenge you are being faced with. However, policy directly impacts your experience, and as a person diagnosed with ALS, caregiver or family member it is your voice that matters most in making change happen at the local, state and federal levels for yourself, and other families facing ALS.

### **POLICY WORKS**

Policy initiatives focus on funding and supporting research to discover new treatments for ALS, removing barriers that may be slowing down the process of finding a cure, and ensuring patient access to important medical benefits, such as speech generating devices, in a timely manner.

Most importantly, speaking out about ALS can raise awareness and inspire lawmakers to take action to help patients with ALS and their families. Reaching out to lawmakers can provide an important opportunity to share your story, make a difference in your own life, and in the lives of those who will be affected by ALS in the future.

### **TAKE ACTION**

There are many ways to fight ALS by taking policy action. The ALS Association is deeply involved in current policy initiatives, and provide a number of resources and ideas for getting involved, including their annual National Advocacy Day and Public Policy Conference in Washington D.C.

Just joining the ALSA advocacy mailing list or writing a letter to your elected official in Congress, telling your story and urging them to take action, makes a difference in joining current advocacy efforts. YOUR voice is needed to take action to fight ALS.

Visit [www.alsa.org/advocacy](http://www.alsa.org/advocacy) to learn more about ways to get involved in policy initiatives.

## Leaving a Legacy

*“The only thing you take with you when you’re gone is what you leave behind.”*

*~ John Allston*

### SHARE YOUR STORY

Life can be a challenging, beautiful, unpredictable, heartbreaking, overwhelming, joyous whirlwind of a journey. Despite the uncertainties that lie ahead, know that *you will be remembered*. We all have an opportunity to determine *how* others will remember us.

Leaving a legacy is an important, purposeful act that allows us to give our loved ones, colleagues and friends a part of us to cherish, even after we’re gone. How will you be remembered?

There are countless meaningful ways to share your life with your loved ones that are unique and personal to you. These are just a few ideas to get you started.

- Create a photo album of your favorite pictures over the years
- Write letters to your loved ones telling them how much they mean to you
- Keep a journal that can be shared with your loved ones in the future
- Fill out a “Remember Book” with important events from your life and family history
- Create a video or audio tape to share with your loved ones
- Share your favorite books or movies with your loved ones
- Teach a skill or hobby you enjoy to your children or grandchildren

*“Help your loved one focus on living with the disease... You don’t have control over the final outcome, but you do have control over how you manage the journey toward that outcome.”*

*- Shelby, Caregiver of a Loved One with ALS*

## BE PREPARED

### Share your wishes for the end of life.

Although it's challenging to think of the end of life to determine our final wishes, it's so important for family members to be aware of your thoughts and beliefs regarding the end of life. We have all experienced the intense impact of grief, and knowing our loved one's wishes makes the decisions required in the days following loss much less stressful, and more meaningful.

#1 Prepare an Advance Directive: An advance directive allows you to designate a patient advocate to make decisions on your behalf in the event that you are unable to make medical decisions yourself. This document also provides space for you to share your wishes regarding life- sustaining medical action and organ donation.

An advance directive is incredibly important for all adults to have, to ensure that a trusted loved one is put in charge of medical decision- making in case of an emergency, and that they are well-informed on how to best advocate for your wishes.

If you would like a UMHS *Advance Directives: Durable Power of Attorney for Health Care* booklet one can be provided to you upon your request by the UMHS ALS Clinic social worker.

In addition, another planning resource that can be helpful is the Five Wishes booklet. Use the following link to review a sample copy:

<https://www.agingwithdignity.org/forms/5wishes.pdf>

#2 Designate a Power of Attorney: The person you designate in a power of attorney (POA) authorization will have the ability to handle your financial and legal matters in the event that you are unable to do so.

#3 Funeral Preplanning: Sharing any preferences or instructions you might have in the event of your death is a loving, selfless act that eases the burden of family members and loved ones who are often left with many decisions to make in a short period of time. Complete this preplanning exercise along with your loved ones – having a conversation about your beliefs and preferences can be important information to share in case of an emergency.



There are a number of planning tools available; however a popular, comprehensive worksheet that is available for free online is the Share Your Wishes.org Preplanning Worksheet (<http://www.shareyourwishes.org/worksheet.pdf>).

#4 Write a Will: Here are some tips for preparing a will –

- Working with an attorney is the best way to ensure that your wishes are clearly stated and abide by state laws.
- If you choose to hire an attorney, ask them up front about fees and expenses.
- There are kits available at your local bookstore and/or library with helpful templates and instructions for drafting a valid will. There are also numerous resources available online – however, be cautious and make sure the source is credible.
- Review the responsibilities given to the executor of your will when choosing an executor.

#5 Life Insurance & 401(k) Benefits: Many adults choose to purchase life insurance as a way to ensure their loved ones are financially secure. If you have a life insurance policy, contact your insurance company to find out if you can receive your life insurance benefits ahead of time, given your diagnosis. The same can be true with 401(k) benefits – find out if you can withdraw from your 401(k) without penalty, if you would like to utilize those funds now.

## Power of Attorney

*A written document in which one person (the principal) appoints another person to act as an agent on his or her behalf, thus conferring authority on the agent to perform certain acts or functions on behalf of the principal.*

Powers of attorney are routinely granted to allow the agent to take care of a variety of transactions for the principal, such as executing a stock power, handling a tax audit, or maintaining a safe-deposit box. Powers of attorney can be written to be either general (full) or limited to special circumstances. A power of attorney generally is terminated when the principal dies or becomes incompetent, but the principal can revoke the power of attorney at any time.

A special type of power of attorney that is used frequently is the “durable” power of attorney. A durable power of attorney differs from a traditional power of attorney in that it continues the agency relationship beyond the incapacity of the principal. The two types of durable power of attorney are immediate and “springing.” The first type takes effect as soon as the durable power of attorney is executed. The second is intended to “spring” into effect when a specific event occurs, such as the disability of the principal. Most often, durable powers of attorney are created to deal with decisions involving either property management or health care.

Durable powers of attorney have become popular because they enable the principal to have her or his affairs handled easily and inexpensively after she or he becomes incapacitated. Before the durable power of attorney was created, the only way to handle the affairs of an incapacitated person was to appoint a guardian, a process that frequently involves complex and costly court proceedings, as well as the often humiliating determination that the principal is wholly incapable and in need of protection.

With a durable power of attorney, on the other hand, a principal can appoint someone to handle her or his affairs after she or he becomes incompetent, and the document can be crafted to confer either general power or power in certain limited circumstances.

Because no judicial proceedings are necessary, the principal saves time and money and avoids the stigma of being declared incompetent.

The concept of the durable power of attorney was created in 1969 when the National Conference of Commissioners on Uniform State Laws promulgated the Uniform Probate Code (U.P.C. § 5-501). Ten years later, the provisions of the code dealing with the durable power of attorney were modified and published as the Uniform Durable Power of Attorney Act (UDPA). All fifty states recognize some version of the durable power of attorney, having adopted either the UDPA or the

Uniform Probate Code, or some variation of them. Versions of the durable power of attorney vary from state to state. Certain powers cannot be delegated, including the powers to make, amend or revoke a will, change insurance beneficiaries, contract a marriage and vote.

A power of attorney should only be issued to someone who is completely trustworthy. Any power of attorney should only be executed after consideration of your particular situation and needs. Serious discussion with an attorney by the individual authorizing the power of attorney is recommended.

Information compiled via the Free Dictionary by Farlex, ALSA-MI, and ALS of MI. You may wish to refer to the Patient Resource Manual – Legal and Financial Section available on the ALS of MI website for further information. (JH 4/1/14)

## Suggested Reading

### BOOKS

Amyotrophic Lateral Sclerosis: A Guide for Patients and Families. By Hiroshi Mitsumoto MD

The Comfort of Home: A Complete Guide for Caregivers. By Maria M. Meyer

Living with the End in Mind; A Practical Checklist for Living Life to the Fullest by Embracing Your Mortality. By Erin Tierney Kramp

Reaching Back: A Workbook for Recording Your Life's Most Meaningful Moments to Share with Future Generations. By Alice Chapin

### AUDIO & APPS

Bruce Kramer: Living with ALS. <http://www.mprnews.org/topic/living-with-als>

Bruce Kramer's Dis Ease Diary Blog. <https://diseasediary.wordpress.com/>

Virtual Hope Box. *Contains tools for coping, relaxation, distraction & positive thinking*

Google Play: <https://play.google.com/store/apps/details?id=com.t2.vhb>

Itunes: <https://itunes.apple.com/us/app/virtual-hope-box/id825099621?mt=8>

### FOR CHILDREN & FAMILIES

When Someone Has a Very Serious Illness: Children Can Learn to Cope with Loss and Change. By Marge Heegaard

ALS Activity Book: Helping Children Understand the Puzzle of Amyotrophic Lateral Sclerosis. By The ALS Association St. Louis Regional Chapter (*available to download at no cost online*) <http://webstl.alsa.org/site/DocServer/ChildrensActivityBook.pdf?docID=72224>

ALS is a Family Matter: A Communications Manual for Patients and Those Who Care for Them. By Joan Krash, Ph.D. ALS Association DC/MD/VA Regional Chapter (*available to download at no cost online*)

[http://webdc.alsa.org/site/DocServer/ALS\\_is\\_a\\_Family\\_Matter.pdf?docID=71906](http://webdc.alsa.org/site/DocServer/ALS_is_a_Family_Matter.pdf?docID=71906)

## Resource List

**University of Michigan ALS Clinic:** <http://www.umich-als.org/>

**Michigan ALS Research Consortium of Hospitals:** <http://www.march-against-als.org/>

**National ALS Association:** <http://www.alsa.org>

(800) 782-4747

**ALSA – MI Chapter:** <http://webmi.alsa.org>

East Michigan – Troy: (248) 680-6540

West Michigan – Grand Rapids: (616) 459-1900

**ALS of Michigan:** <http://www.alsofmi.org>

Southfield: (800) 882-5764

*“Look and pursue every available assistance possible (ALS associations, church, etc.). Get in-depth, in-home counseling to explain EVERYTHING! One-on-one counseling with all family members. Keep connected with people and resources. Don’t say NO to ANYTHING!”*

*- Patient diagnosed with ALS*

**Michigan Area Agencies on Aging:** Provides information regarding available community resources for older adults (60+) and low income adults with disabilities (such as Medicaid Waiver Program). Available to provide information regarding Medicaid and Medicare health care benefits through the Medicare/Medicaid Assistance Program (MMAP). For further information contact your local AAA by phone and ask to speak with a resource specialist or visit their website.

**Detroit Area Agency on Aging Service Area (Region 1a):** *Cities* – Detroit, Hamtramck, Highland Park, Grosse Pointe, Grosse Pointe Park, Grosse Pointe Shores, Grosse Pointe Woods, Grosse Pointe Farms, Harper Woods

1333 Brewery Park  
Blvd. Suite 200  
Detroit, MI 48207  
(313) 446-4444

**Area Agency on Aging 1-B Service Area (Region 1b):** *Counties* – Livingston, Macomb, Monroe, Oakland, St. Clair, Washtenaw

29100 Northwestern Hwy.  
Suite 400  
Southfield, MI 48034  
(248) 357-2255

**The Senior Alliance, Inc. Service Area (Region 1c):** *Counties* – Wayne County except the cities served by 1a

3850 Second Street  
Suite 201  
Wayne, MI 48184  
(734) 722-2830

**Region 2 Area Agency on Aging Service Area (Region 2):** *Counties* – Jackson, Hillsdale, Lenawee

102 N. Main Street  
Brooklyn, MI  
49230  
(517) 592-1974

**Region 3-A Agency on Aging Service Area (Region 3a):** *County – Kalamazoo*

3299 Gull Road  
P.O. Box 42  
Nazareth, MI  
49074 (269) 373-  
5147

**Region 3-B Area Agency on Aging Service Area (Region 3b):** *Counties – Barry, Calhoun*

200 West Michigan Avenue  
Suite 102  
Battle Creek, MI  
49017 (269) 966-2450

**Branch – St. Joseph Area Agency on Aging Service Area (Region 3c):** *Counties – St. Joseph, Branch*

570 Marshall Road  
Coldwater, MI 49036  
(517) 278-2538

**Region IV Area Agency on Aging Service Area (Region 4):** *Counties – Berrien, Cass, Van Buren*

2900 Lakeview  
Avenue St. Joseph, MI  
49085 (269) 983-0177

**Valley Area Agency on Aging Service Area (Region 5):** *Counties* – Genesee, Lapeer, Shiawassee

225 E. Fifth  
Street Suite 200  
Flint, MI 48502  
(810) 239-7671

**Tri-County Office on Aging Service Area (Region 6):** *Counties* – Clinton, Eaton, Ingham

5303 South Cedar Street  
Lansing, MI 48911  
(517) 887-1440

**Region VII Area Agency on Aging Service Area (Region 7):** *Counties* – Bay, Clare, Gladwin, Gratiot, Huron, Isabella, Midland, Saginaw, Sanilac, Tuscola

1615 S. Euclid Ave.  
Bay City, MI 48706  
(989) 893-4506

**Area Agency on Aging of Western Michigan Service Area (Region 8):** *Counties* – Allegan, Ionia, Kent, Lake, Mason, Mecosta, Montcalm, Newaygo, Osceola

3215 Eaglecrest Drive NE  
Grand Rapids, MI 49525  
(616) 456-5664



**Region IX Area Agency on Aging Service Area (Region 9):** *Counties* – Alcona, Arenac, Alpena, Cheboygan, Crawford, Iosco, Montmorency, Ogemaw, Oscoda, Otsego, Presque Isle, Roscommon

2375 Gordon Road  
Alpena, MI 49707  
(989) 356-3474

**Area Agency on Aging of Northwest Michigan Service Area (Region 10):** *Counties*– Antrim, Benzie, Charlevoix, Emmet, Grand Traverse, Kalkaska, Leelanau, Manistee, Missaukee, Wexford

1609 Park Drive  
P.O. Box 5946  
Traverse City, MI  
49686 (231) 947-8920

**Social Security Administration:**

<http://www.socialsecurity.gov>

(800) 772-1213

Office locator: <https://secure.saa.gov/apps6z/FOLO/fo001.jsp>

**Michigan Department of Health and Human Services (MDHHS):**

<http://www.michigan.gov/dhs>

Your local MDHHS office can be located by clicking on *Inside DHS*, then clicking *County Offices*.

**Medicare Hospice Benefits**

[www.medicare.gov/Pubs/pdf/02154.pdf](http://www.medicare.gov/Pubs/pdf/02154.pdf)

**Department of Veterans Affairs:** <http://www.va.gov/health/>

It depends on your specific situation, but in general, military veterans diagnosed with ALS who have served at least 90 continuous days of active duty will be considered service connected for ALS. This is the case regardless of when or where a veteran served in the military and regardless of the length of time between discharge from the military and a diagnosis of ALS. We recommend that if you are a veteran with ALS that you apply for veterans benefits.

ALSA Resources for Military Veterans, Families & Survivors:

<http://www.alsa.org/als-care/veterans/>

We recommend when applying for veterans benefits that you enlist the assistance of a service officer or county veterans counselor to assist in navigating the VA application process. Service officers are affiliated with a variety of veterans organizations such as Paralyzed Veterans of America (PVA), Disabled American Veterans (DAV), the American Legion, or Veterans of Foreign Wars (VFW). We can provide you with service officer contact information. For information on the State of MI Department of Military and Veterans Affairs including a list of Veterans Trust Fund and Veterans Counselor by county please refer to the following website:

<http://www.michiganveterans.com/Home/Benefit-Counselors#CountyContacts>

**Disability Made Easy:** A Michigan-based company committed to residential, barrier free construction

<http://www.dmeasap.com>

(248) 569-1580

**Homemods.org:** Serves as an information clearinghouse on home modification to equip professionals and consumers with a comprehensive inventory of resources such as a National Directory of Home Modification and Repair Resources

<http://www.homemods.org>

**Michigan Assistive Technology Loan Fund:**

[http://ucpmichigan.ucplabs.org/media\\_items/matlf-brochure.original.pdf](http://ucpmichigan.ucplabs.org/media_items/matlf-brochure.original.pdf)

## **Adaptive Clothing Manufacturers:**

Buck & Buck Designs

3111 27<sup>th</sup> Avenue

South Seattle, WA

98144

<http://www.buckandbuck.com>

Clothing, footwear and accessories

Personal Touch Health Care Apparel

P.O. Box 230321

Brooklyn, New York

11223 (888) 626-0200

<http://www.nursinghomeapparel.com>

Good for limited mobility

Silvert's

3280 Steels Avenue West

Suite18

Concord Ontario L4K

2Y2

<http://www.silverts.com>

Variety of men's and women's clothing

Leading Lady Bras

24050 Commerce Park

Beachwood, Ohio 44122

(888) 321-4804

<http://www.leadinglady.com>

Adapted bras

## Patient Reflection

*“Suggestions for ALS patients and their loved ones:*

*Without a doubt, an ALS diagnosis is rotten – but so is any diagnosis of a disease that can/will kill you. Rather than dwelling on the negative, however, I have chosen to focus on the positive and I find that I am experiencing a surprisingly happy period of my life. Let me explain.*

*First, I’ve approached this diagnosis the same way I’ve lived my life: according to the precept that says, ‘There’s nothing either good or bad but thinking makes it so.’ Anything can be seen as good or bad, it’s simply up to you to place a value judgment on it. I decided, for example, to treat myself to a very special trip, something I never would have done without this diagnosis. The trip was wonderful – truly one of the highlights of my life. Thank you, ALS.*

*I think one of the hardest things about getting any type of dreadful disease is the loss of control one feels. I can’t control the ALS, but I can control how I choose to respond to it. And I choose to be positive.*

*Second, I don’t waste my energy searching for other diagnoses or some silver bullet that’s going to magically make things better. ALS is a terminal disease and for the time being that’s all there is to it. Dying sucks, but it’s not like it’s a surprise. We’re all born, we all live, we all die. Why should I expect to be any different? I let go of the ‘it’s not fair’ routine. Life isn’t fair and deep down, we all know it.*

*I choose to use what energy I have on doing things that I enjoy: reading, having lunch with friends, taking short trips (I poop out too quickly now to do anything more than a short jaunt). All my life, I’ve worked very hard and denied myself the chance to do these simple things. Now it’s my time to be good to myself.*

*I truly do now take time to stop and smell the roses. Well, maybe not the roses, but the sunrises I see from my living room window, the birds hopping around my backyard, and the antics of my cat when she finds a bug in the house. Of course, all these things were taking place before my diagnosis, but I never stopped to pay attention – I was too busy. Now, I sometimes just stand in the window for several minutes in the morning, and give thanks that I’m able to witness such beautiful, shifting colors as the sun comes up.*

*Third, I’ve been open and honest with my friends about my diagnosis and I’ve been astonished by the support and love that has come back to me. In part, I’m guessing people are responding so positively because I’m not dwelling on the negative and so it’s not hard (yet) to be around me. The payoff, though, is that everyone is being incredibly nice to me. They take me out to lunch. They tell me how great I am, inspirational, etc...*

*Everyone has to find their own way in life. I can’t advise anyone on what to do, all I can do is say what has worked for me. And for me, I’m finding this stage of the ALS chapter of my life to be a time when I can do what I want and find lots of encouragement from those who care about me. It’s not all bad.*

*Written by Tamara, Patient diagnosed with ALS*

*February 2015*

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