

Living with Amyotrophic Lateral Sclerosis (ALS)

A Guide for Patients and Caregivers

Pranger ALS Clinic

www.umich-als.org



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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. We encourage you to 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.

"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

Pranger ALS Clinic

The Multidisciplinary ALS Clinic at Michigan Medicine is an ALS Association Certified Center of Excellence providing comprehensive and compassionate care to persons with ALS and their loved ones. You will be evaluated in the Department of Neurology every 3-6 months. Here are some reminders for your visit:

- You will be meeting with up to 10 specialists over the course of your half-day session with us, including a neurologist (physician), nurse, physical medicine & rehabilitation physician, physical therapist, occupational therapist, dietitian, social worker and research coordinator. Additionally, some people may be evaluated by a pulmonologist, respiratory therapist, speech pathologist, and/or mobility engineer. You will stay in the same room for all of these evaluations.
- Please plan to spend the morning or afternoon in our clinic. It is not unusual for one to be at clinic for 4-5 hours.
- We encourage you to have family or friends accompany you to your clinic visit.
- It is recommended that you bring a lunch, snack, or beverage in the event you are hungry/thirsty during the visit.
- Please bring a list of your medications to each appointment.
- You will be weighed at every clinic visit. This is an important part of your care.

Contacting Us

The next page includes a list of frequently contacted numbers. Please keep this list available to refer to when contacting us. In addition to the numbers listed the Patient Portal (www.myuofmhealth.org) offers the advantage of contacting your physician by sending a portal message, viewing your appointments, requesting refills and viewing a review of your clinic appointments with us in the ALS Clinic.

Health Care Contact Information

Neurology – Pranger ALS Clinic

(734) 936-9010 Triage Phone Line (734) 936-9006 Scheduling

Physician: _____ Nurse: _____

Pulmonology Adult Ventilation Clinic (respiratory & respiratory equipment needs)

(734) 232-3795

Physician/NP: _____ Nurse: _____ RT: _____

Speech Language Pathology

(734) 936-7080

Speech Language Pathologist: _____

Interventional Radiology (feeding tube needs)

(734) 936-4536

ALS Research

(734) 936-8776 or (734) 936-8775

Research Coordinator: _____

Physical Medicine and Rehabilitation (Wheelchair Clinic)

(734) 936-7175

Patient Registration (insurance, address, contact changes)

(734)-936-4990 or (866) 452-9896

Guest Assistance Program

(734)-936-6893 or (800) 888-9825

Medical Records

(734)-936-5490

ALS: A Path Not Chosen

1. You are not ALS.

A diagnosis does not define you as a *person*. You are a person first. A person now diagnosed with ALS. The reality of your life has been radically altered. When meeting your healthcare team take the opportunity to introduce yourself. Help them understand that there is a “whole” person with dreams, goals, insight, hope and fears. 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. 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.

5. Communicating with your healthcare Team

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.

- Medicine has its own language - If you don't understand what is being discussed ask for clarification
- Don't be embarrassed to ask for language that you can understand
- The goal is for you and your family to understand what is happening so you can make informed choices
- Self-determination - You will receive many recommendations from your healthcare team but remember you are the expert in your own life. Voice your feelings and determine what is best for you. Your healthcare team will respect the decisions you make
- Ask your healthcare team for resources
- Involve your family and friends
- 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

"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

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.

Resources for Patients & Caregivers

Pranger ALS Clinic <http://www.umich-als.org>

The National ALS Registry 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.

ALS Association www.alsa.org

The ALS Association website has a wealth of information. It 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. The ALS Association Michigan Chapter phone number is (616) 459-1900.

ALS of Michigan www.alsofmichigan.org

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

Online Caregiving Community

"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

Family members of persons with ALS may benefit from using an internet based calendar to schedule visits from family, friends, caregivers, or other volunteers. A Google calendar is one option.

Other web services include:

Lots a Helping Hands (<http://lotsahelpinghands.com/>)

Care Calendar (www.carecalendar.org).

Family & 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

Michigan Area Agencies on Aging (AAA): <http://www.mi-seniors.net>

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 (MMAAP). For further information, contact your local AAA by phone and ask to speak with a resource specialist or visit their website.

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*.

“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

Caregiver Support

As a 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.

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. 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.

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.

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 Administration

<http://www.socialsecurity.gov>

(800) 772-1213

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. 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.

When applying for these benefits **please be aware of the following points:**

- If you are working and your gross monthly income is over \$1,220.00, before taxes, 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.
- With an ALS diagnosis you will begin receiving Medicare coverage the same month you begin receiving social security disability. Typically, there is a 2 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 contact the Social Security Administrative Office <http://www.ssa.gov/agency/contact/phone.html> or the Medicare/Medicaid Assistance Program (MMAP) to speak with a MMAP counselor <http://mmapinc.org/>

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Additional resources:

- Fact Sheet for Social Security Disability - ALS Association:
<https://tinyurl.com/ycc2q48x>
- Apply for Social Security Disability Benefits Online:
<http://www.socialsecurity.gov/applyfordisability/>
- Disability Planner: Family Benefits:
<http://www.ssa.gov/planners/disability/dfamily.html>
- Checklist for Adult Social Security Disability:
<https://tinyurl.com/yc9keoa7>
- Veterans-Department of Veterans Affairs:
<http://www.va.gov/health/>

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. Apply as soon as possible after diagnosis, as benefits are retroactive to the date of application. 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 veteran's benefits.

For assistance with completing the application process, seek the assistance of a service officer through a Veteran Service Organization (VSO). We work closely with Paralyzed Veterans of America. Our team will collaborate with the VSO to complete and update forms so that you can receive the benefits you are eligible for. If you would like additional VSO's please inquire. Once you are connected with the VA you can inquire about any additional resources or services that they can provide.

Paralyzed Veterans of America:

Stephanie Strickland-Sr. National Service Officer <http://www.pva.org>, (313) 471-3996

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 important for family members to be aware of your thoughts and beliefs regarding end of life. We have all experienced the intense impact of grief. 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. If you would like an Advance Directives booklet one can be provided to you upon your request by the ALS Clinic social worker. You can also access online at the web address below:
 - Start the Conversation: Making your health care wishes known: Advance Directives and Durable Power of Attorney for Health Care BOOKLET and FORMS: <http://michmed.org/3912Y>
- 2. Designate a Power of Attorney:** The person you designate in a power of attorney (POA) authorization, for finances, 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.
- 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 confirm your benefits. Some policies offer money before a death to allow for caregiving financial assistance. 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.

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

- HeadSpace – App that assists with meditation and mindfulness

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): <https://tinyurl.com/yc9awthj>
- *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): <https://tinyurl.com/ycxcmcnf>

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*

Caregiving Support Contact Information

Name _____ Phone _____
Email _____ Relationship _____
Days Available _____ Times Available _____

Name _____ Phone _____
Email _____ Relationship _____
Days Available _____ Times Available _____

Name _____ Phone _____
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