

RESOURCE GUIDE

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SECTION 8 - Life With ALS

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I HAVE ALS - WHAT DO I DO NEXT?

Receiving the diagnosis of ALS is life-changing. It takes some time to process the information and figure out how to incorporate it into your life. There are some things that are out of your control, like the fact that you have ALS and how it affects your abilities day-to-day. However, there are things that you *can* control. Patients do best when they focus on what they can control as well as paying special attention to aspects of their lives that bring them the most meaning.

Here is some information for you to have as you begin the process:

- **Maintaining your weight** is essential to your wellbeing and the progression rate of your disease. Getting the best nutrition possible is something that you can control. Maintaining your weight will not make you stronger, but losing weight will make you weaker, faster. If you have spent most of your life trying to lose weight, you have entered a new stage where keeping your weight steady is your new goal.
- **Adjusting to your diagnosis** can be challenging. You cannot change the fact that you have ALS, but you can affect how you cope with it. There are resources to help you through the process.
 - To start, the **Emory ALS Center has a social worker** who is here to provide emotional support and resources. If you have not met our social worker already, please make initial contact either through the portal or by calling the clinic. Our social worker assists by providing support, education about community resources, explaining the process of obtaining Social Security Disability & Medicare benefits, provide forms and answers to questions regarding the completion of Advance Directives, etc. Please see section 3 of our resource guide for more information about what our social worker can provide.
 - **The ALS Association Georgia Chapter** has regular support groups that are regionally located (during pandemic via Zoom). Their website has more information about them and more information about ALSA GA is included in section 3 of this resource guide.
 - Consider engaging in **frequent individual counseling** with a therapist that is knowledgeable about the effects of severe illness.
 - **Read Section 3, Patient Resources**, of this guide to begin to learn about resources and aspects you will need to know now and over time.
- **How do you talk with others about ALS?** The ALS Association and Your ALS Guide websites have a thorough review of ALS (see Section 3 of this guide). It can be helpful to refer people to those resources to learn about ALS on their own so that you do not have to be in charge of educating everyone around you.
- **Are you a veteran?** ALS has been identified as a service-related condition and vets have specialized medical care and benefits that can be obtained. Let the staff know that you are a vet and they can help you initiate the process to obtain VA benefits. More information is also in Section 3 of this guide.
- **Where you receive ongoing health care is your choice.** Everyone needs a primary care provider (PCP) in addition to the team that provides specialty care for ALS. A PCP will be needed for routine medical concerns: typical illness like colds/flu, etc. treatments of infections, vaccines, etc. Regarding specialty care for ALS, studies have shown ALS patients who receive care at an ALS center do better than patients who do not. If you live far away from Emory, there may be an ALS center closer to you and we can assist in getting your care transferred. If you want to continue to be seen at Emory, our clinics are located both at Executive Park and the main Emory campus.
- **Contact information for the Emory ALS Center:**
 - Sign up for the Emory patient portal; it is the main means of communication with the Emory ALS Center.
 - The clinic phone number is 404-778-3444.

Living ^{in the} Moment

and Making the Most of Life with ALS

Michelle Hammond-Susten, LCSW, LLC, January 2017

How do people live in the moment and make the most of life when diagnosed with a terminal illness? As the Emory ALS Clinic Social Worker these are issues that I often assist with exploring. Upon initial diagnosis of ALS, families are often overwhelmed by the immediate emotions one might expect; shock, sadness, anxiety and confusion. There is a whirlwind period that follows, trying to grasp the diagnosis and how it will impact their day to day lives and future. Once some time has passed, and the dust settles a bit, there is an opportunity to develop a new normal and embrace the present. Some strategies that may be helpful include:

- **Take time to reevaluate your life.** Acknowledge your accomplishments and things that you would still like to do. Take stock of the things that mean the most in your life and focus on them. Illness has a way of forcing us to shift our perspective. Rarely do I ever hear “I should have spent more time doing housework or more hours at the office.” People most often identify quality of life and meaning with time spent with loved ones, participating in things that they enjoy or things that have brought them a sense of purpose.
- **Think outside of the box.** Continue doing what you enjoy for as long as possible. This can take some creativity. For example, if you love to cook and find yourself losing hand mobility, enlist someone to teach and/or create a family cookbook. If you love to travel, do so with adjustments/accessible resources. If you are no longer able to travel, bring the places to you through pictures, YouTube videos, etc. Explore new interests.
- **Be flexible and expect change.** Your new normal will shift throughout the disease process. Try to be willing to adjust to these changes and continue to be creative.
- **Tackle areas of regret.** If you have relationships that you would like to mend or things that you would like to address with people, don't wait. Find ways to make peace with yourself and others when needed.
- **Honor and acknowledge your feelings- but don't get stuck.** It is to be expected to experience feelings, such as anger and sadness at different times, but if you start to notice having more bad days than good, it is worth considering discussing with your doctor or finding avenues to express your feelings. Taking a daily inventory of how you are feeling emotionally can be helpful.
- **Knowledge is power.** Know your resources and where to find them. Attend ALS Clinic as recommended by your physician. Connect with ALSA and MDA. These organizations offer strategies, skills and services to help you maintain your independence as much as possible throughout the disease process.
- **Don't be afraid to accept help from those who care about you.** That goes for caregivers as well. **It is okay to ask for help.** Not only does it allow time for you to focus your energy on what is important, it also allows others in your life to be an active participant throughout your journey.
- **Let go of the “why?” and instead focus on “what now?”** While it is a perfectly normal response to ask this question, rarely are we afforded the answers and it can keep you from moving forward. When we

begin to reframe the question to what we can do in the present to live a fuller life, it allows for a sense of hope and opportunity.

- **Surround yourself with things you love.** Make your space representative of the things that mean the most to you. Use your senses as your guide, some ideas include: visual (pictures, art, memorabilia, etc.), olfactory (candles, oils, etc.), and auditory (music, books on tape, sounds of nature, etc.) senses.
- **Connect with a deeper sense of something greater than self.** If religion or spirituality is important to you or if you find yourself questioning your faith, reach out to a spiritual leader in your religious community or someone who can help you explore or reconnect with your beliefs. Feeling a part of something bigger than yourself, or leaving a legacy can feel like an important way to find meaning/purpose. Get involved in the ALS community, volunteer to mentor another ALS family, use your family's story as a way to inspire or provide hope for others.
- **Find relaxation and coping strategies that help you stay in the present.** There are many relaxation tools that you can put into place that can assist with staying focused on the present. Breathing exercises, guided imagery, meditation and mindfulness exercises are a few tools that can be easy to incorporate and can be found on apps for smart phones and assistive technology devices. Practice, practice, practice and find what works for you.

It is possible with a terminal illness to continue to live a life full of purpose and meaning. This has certainly been the case with our ALS families, who have been some of the most resilient, creative and hopeful group of people I have had the pleasure to work with. Continue to consider ways that you can live in the moment in your own lives and keep sharing your experiences and successes with each other.

Thank you to Michelle for the above letter. Michelle was the Emory ALS Social Worker for many years and provided wonderful support for our patients and families. I feel fortunate to follow her footsteps and serve as the the Emory ALS Center social worker. You can contact me by sending a MyChart message to your doctor or call 404-778-3444 and ask for the ALS Social Worker. –Sarah Penna, LCSW