RESOURCE GUIDE

SECTION 3 - Patient Resources

Resources for Patients, Families & Care Partners

When you or a loved one is diagnosed with ALS, your first reaction is typically shock and fear. You may be overwhelmed, experience many emotions, and have many questions, all of which is completely normal. You might not have ever known anyone with ALS and feel alone – *but you are not alone!* There is support available and it is important to engage early and seek support. Below are resources available to help you during your journey with ALS.

Table of Contents

Information and Resources on the Internet

www.als.emory.edu
Emory ALS Center website. You can learn about Emory's ALS Center here as well as access resources and information about ALS.

www.alsa.org
The national ALS Association (ALSA) focuses on information, research, care, and support for patients with ALS. This organization partners with the Emory ALS Center to support our clinic and our research program. You will find accurate information at this site. ALSA provides a thorough explanation of what ALS is and what symptoms might be expected. This can be a useful website to share with family and friends who are trying to understand ALS. 1-888-636-9940.

www.alsgeorgia.org
ALS United of Georgia focuses on information, research, care, and support for patients with ALS. This local, Georgia-based organization partners with the Emory ALS Center to support our clinic and our research program. You will find accurate information here and learn about what programs might be available to help. You can contact them at 404-636-9909 or info@alsaga.org.

www.alsuntangled.org
ALSUntangled reviews alternative and off label treatments with the goal of helping people with ALS make informed decisions about them. The reviewers are all ALS clinician scientists.

www.cdc.gov/als
National ALS Registry
The National ALS Registry may be the single largest ALS research project ever created and is designed to identify ALS cases from throughout the entire United States. Registering and taking the surveys can help make a difference in the lives of those living with ALS today and for generations to come. Enroll at: www.cdc.gov/als

www.clinicaltrials.gov
This is a federally mandated website where all clinical trials must be posted. This is the most reliable resource for information about ALS research (or research into any medical condition). We suggest searching using the term "amyotrophic" since searching ALS will give you any medical condition where those letters are next to each other.

www.mda.org/disease/amyotrophic-lateral-sclerosis
The Muscular Dystrophy Association (MDA) has been a supporter for care and research in ALS along with other neuromuscular diseases. You will find accurate information here and learn about what programs might be available to help. MDA covers ALS as one of the 43 types of muscle debilitating conditions they cover. MDA has a National Resource Center where trained professionals can help provide information and respond to questions associated with ALS. They will help you identify local and national resources as well.

www.neals.org
The Northeast ALS Consortium (NEALS) is committed to translating scientific advances into new treatments for people with ALS. They are committed to the principles of open scientific communication, peer review, full and open disclosure of potential conflicts of interest and democratic governance of the organization. NEALS started in 1995 with nine academic centers in New England and has grown to over 100 research centers in North America. This website is a reliable and accurate source of information.

www.theaftd.org
The Association for Frontotemporal Degeneration (FTD) strives to improve the quality of life of people affected by FTD and drive research to a cure. FTD is sometimes experienced by people with ALS (pALS).

www.youralsguide.com
Your ALS Guide is developed by patients, families, and friends who want to provide a clear, practical guide for anyone facing ALS. They specifically have a guide for newly diagnosed patients: www.youralsguide.com/newly-diagnosed

Programs for Financial and Tangible Assistance

ALS United of Georgia
www.alsgeorgia.org
The ALS United of Georgia has Patient Services staff members who are available to ALS patients and their families from the time of diagnosis. They will assess a patient's needs and help families plan for the future. They have multiple programs and services for resources and support. To gain access to their support and services, you must complete a registration form with them. If you need help with this, let us know.

227 Sandy Springs Place, Suite D, #304, Sandy Springs, GA 30325. Phone number is 404-636-9909.
********See the separate page below that is dedicated to information about ALS United of Georgia programs.***

Georgia's Aging and Disability Resource Connection (ADRC)
Contact information: 1-866-552-4464 or https://www.georgiaadrc.com/ Georgia's ADRCs serve older individuals, individuals of all ages with disabilities, families, care partners and professionals. The ADRC is locally based by county, currently serving all of the 159 counties across the state. The services vary from county to county, so it is important to reach out to them directly and ask for an **intake specialist** who can walk you through all available resources and their cost. The ADRC is not a place or a program. Rather, it is a coordinated system of partnering organizations that are dedicated to:

1. Providing accurate information about publicly and privately financed long-term supports and services.
2. Offering a consumer-oriented approach to learning about the availability of services in the home and community.
3. Alleviating the need for multiple calls and/or visits to receive services.
4. Supporting individuals and family members who are aging or living with a disability.
5. Providing an avenue to report neglect or abuse in a facility.
6. Answering questions regarding available local assisted living facilities, long term care facilities, personal care homes, and nursing home facilities.
7. Provide respite care options.
8. Provide care partner support groups.
9. Discuss programs in Georgia that do allow family members to receive payments for providing care. These programs include Structured Family Caregiving through Medicaid waiver programs and Support Options.
10. Discuss assessable housing options.
11. Resources for home delivered meals
12. Provide in-home free vaccines
13. Provide utility assistance plans
14. Provide SNAP and food stamps information
15. Offer Georgia Elderly Legal Assistance Program (ELAP) services include: legal information, legal counseling, case representation, and legal education sessions. Additionally, the Georgia Senior Legal Hotline (1-866-552-4464, Option 7) provides brief legal advice by phone.
16. Tools for Life, Georgia's Assistive Technology (AT) Act Program, provides access to and acquisition of assistive technology devices and services to individuals of all ages and all disabilities living in GA. Tools for Life is a statewide program focused on all areas of life including: living, learning, working, and playing. Core activities include AT demonstration, AT assessments, funding education, access to AT lending libraries, AT & durable medical equipment reuse, and training for individuals and groups. Additionally, each Georgia Area Agency on Aging and Center for Independent Living has an Assistive Technology lab where local residents can see and test assistive technology devices.

Families and Communities Together (FACT) Relief
FACT Relief's goal is to help ease the burden and worry associated with concerns for the financial stability of a family when dealing with a health crisis like ALS. They do this by offering targeted support for medical expenses that are not covered by insurance, as well as necessary day-to-day living expenses related to the disease. They also offer planning and guidance for tax-exempt fundraising for the benefit of those families with a demonstrated need.

In March 2022, FACT Relief launched a new program called the Brian Parker Enhanced Quality of Life (EQOL) Program, which provides up to $3000 per year to assist with 24/7 aide care at home. FACT Relief has worked closely with many Georgia families dealing with ALS and can provide support specific to those needs. They also work closely with local home care agencies to find creative ways to support home care needs, including paying supplemental care to nurses for more hourly pay.

FACT Relief truly understands the needs of PALS and their families, providing compassionate and informed support. 678-447-8083 www.factrelief.org

FindHelp and United Way
www.findhelp.org and www.unitedway.org (for United Way, you can also dial 211 from any phone)
Search and connect to support for financial assistance, food pantries, medical care, utility assistance, rent and mortgage assistance, and other free or reduced-cost help.

Friends of Disabled Adults and Children (FODAC)
With a strong network of volunteers and partners, FODAC provides refurbished equipment and services for adults and children with disabilities to improve their overall quality of life. Over the years, their model to assist individuals with disabilities has remained the same: to provide free or low-cost wheelchairs and other home medical equipment (HME), vehicle and home adaptations and more. Above all, their staff is like a family that works together to make every day a little easier, and a little more affordable, for people in need. 770-491-9014. www.fodac.org

Goode Foundation Travel Assistance Program
The mission of the Goode Foundation is to support, assist, and empower ALS patients and families, and inspire the pursuit of improved treatment and research toward a cure. Sometimes clinic appointments require an overnight stay for patients who live far away from Atlanta. As ALS progresses, extra time to get the pALS up and dressed, into the car or van for travel, and into the ALS clinic building can turn that appointment into a 12+ hour day that is exhausting for the patient and care partner.

The Goode Foundation Travel Assistance Program is for those Emory ALS Center patients who live outside the metro Atlanta area who would benefit from an overnight stay prior to a clinic appointment. The Goode Foundation has partnered with the Emory Conference Center Hotel to pay for the overnight stay prior to your appointment at the Emory ALS Clinic or Emory Brain Health Center. ***There are two pages below with the application and information for this program.*** 877-354-6633. www.goodefoundation.org

Healthwell Foundation
Healthwell Foundation's mission is to reduce financial barriers to care for underinsured patients with chronic or life-altering diseases. They are a leading non-profit dedicated to improving access to care for America's underinsured. When health insurance is not enough, we will be the gap by assisting with copays, premiums, deductibles and out-of-pocket expenses. They have a fund specifically for patients with ALS. www.healthwellfoundation.org/fund/amyotrophic-lateral-sclerosis

Hope Loves Company for Children and Young Adults
Hope Loves Company (HLC) is the only non-profit in the U.S. with the mission of providing educational and emotional support **to children and young adults who have or had a loved one** with Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's disease.
www.hopelovescompany.org

Live Like Lou
The Live Like Lou Foundation is a nonprofit dedicated to *leaving ALS better than we found it*. The mission is to create and connect communities to stimulate emerging ALS research and uniquely support families affected by Lou Gehrig's disease. We provide ALS families with hands-on volunteer service, financial grants for home improvements, and scholarships for dependents to pursue higher education.
www.lifelikelou.org

Military Veterans with ALS: Benefits and Resources
www.als.org/navigating-als/military-veterans

Momento Foundation
Momento Foundation helps people heal in grief. One of the ways we do this is by photographing people facing a terminal diagnosis to preserve memories and the love shared with loved ones. Photographs create a physical way to be present in the moment, share a legacy, and continue a genuine connection. Because of the sensitive nature of these sessions, we request that the person or primary care partner of the person facing the terminal diagnosis be the one to apply for the session. Photography sessions and images are provided at no cost to families.
https://www.momentofoundation.org/get-involved

Patient Advocate Foundation – Case Management Services
The Patient Advocate Foundation is a non-profit organization dedicated to providing services to eliminate obstacles in access to quality health care. They **provide case management services** to assist with access to care, paying for treatment, paying for living expenses, navigating employment issues and understanding laws like the ADA as well as your health insurance and leave benefits, and assistance with applying for disability.
Case Management Services: 800-532-5274 www.patientadvocate.org

Project Main Street
Providing direct financial assistance to people living with ALS. 1-800-965-6246
www.projectmainst.org

ALS Ride for Life
Has a few grant programs, including Care for Life (for help with respite care costs) and Plan for Life (legal costs, i.e. power of attorney, wills, etc.). 631-444-6317
www.aslrideforlife.org

Student Loan Forgiveness
If you are totally and permanently disabled, you may qualify for a total and permanent disability (TPD) discharge of your federal student loans or TEACH Grant service obligation. If you receive a TPD discharge, you will no longer be required to repay your loans or complete your TEACH Grant service obligation. If the federal student loan is in your name but for your child or someone else, you and that loan might also be eligible. 1-888-303-7818
https://www.disabilitydischarge.com/

Team Gleason

Team Gleason's mission is the improve life for people living with ALS by delivering innovative technology and equipment, as well as providing and empowering an improved live experience. They offer help with assistive technology and care partner respite.
www.teamgleason.org

Winning with ALS

Winning with ALS is a non-profit providing support for families with children living with a parent diagnosed with ALS through grants, education and resource access. Grants seek to support the special needs of children to encourage a sense of normalcy and make a difference in the lives of those with a parent living with ALS.
www.winningwithals.org
https://www.winningwithals.org/caregiver-forum - grant application information

Prescription Drug Resources

(Note that some of the below programs assist with more than prescriptions)

Help When Uninsured:

$4 Generic Medications

- Some generic medicines are available for $4/month at many pharmacies, like Walgreens, Kroger, Wal-Mart, Target, etc.
- In addition, some of these companies (i.e. Publix) offer a few free medications like amlodipine (blood pressure), Lisinopril (blood pressure), metformin (diabetes), and a few antibiotics.

Mark Cuban Cost Plus Drugs
"We offer hundreds of common (and often life-saving) medications at the lowest possible prices...We're different than your normal pharmacy. We think that you should know how much your medications cost and why. We cut out the middlemen and pass the savings on to you…Every product we sell is priced exactly the same way: our cost plus 15%, plus the pharmacy fee, if any…When you get your medicine from Cost Plus Drug Co., you'll always know exactly how we arrived at the price you pay. And as we grow and our costs go down, we will always pass those savings on to you!"
https://costplusdrugs.com/

Needy Meds
To find pharmaceutical programs that may help cover part or all of the cost of medications, please visit:
www.needymeds.com

GoodRX
To compare prices of prescription drugs at various pharmacies and obtain coupons.
www.goodrx.com

Blink
Reduced cost medications that can be sent to your local pharmacy or mailed to your home.
www.blinkhealth.com

Help with Insurance Prescription Copayments:

If the co-payment for your medication is more than you can afford or if you have reached your maximum benefit, we suggest you take the following steps to explore assistance options.

- Call your insurance company. Tell them your situation to determine if there are any options. Using the mail order program of your insurance company may save money.

- If you are in the low-to-moderate income level, you may qualify for assistance from an organization listed below.

- Whether an organization can assist you is based on your diagnosis and treatment. You may need to call all of them before you find a plan that might help. **If you need to utilize the help of a caseworker rather**

than making an application yourself, you may want to utilize the Patient Advocate Foundation (listed below).

Patient Advocate Foundation and their Co-Pay Relief Program

The Patient Advocate Foundation is a non-profit organization dedicated to providing services to eliminate obstacles in access to quality health care. When a patient contacts the **Co-Pay Relief Program**, the call counselor works directly with him/her, as well as with the provider of care to obtain necessary medical, insurance and income certification in an expeditious manner. They also **provide case management services** to assist with access to care, paying for treatment, paying for living expenses, navigating employment issues and understanding laws like the ADA as well as your health insurance and leave benefits, and assistance with applying for disability.

Co-Pay Relief: 866-512-3861 www.copays.org
Case Management Services: 800-532-5274 www.patientadvocate.org

Healthwell Foundation

The Healthwell Foundation provides copayment and premium payment assistance to eligible individuals. So, if you've been prescribed a medication, but are unable to afford the copayment required by your insurer, they may be able to help by paying some or all of your copayment. Also, if you are eligible for health insurance, but cannot afford the insurance premium, they may be able to help by paying some or all of your insurance premium.

Telephone: 800-675-8416 Website: www.healthwellfoundation.org

Patient Services Incorporated

Developed in 1989, Patient Services Incorporated (PSI) is a non-profit charitable organization, primarily dedicated to subsidizing the high cost of health insurance premiums and pharmacy co-payments for persons with specific chronic illnesses and rare disorders. Families requiring assistance in maintaining the high cost of their health insurance premiums or co-payments are offered assistance based upon the severity of medical and financial need.

Telephone: 800-366-7741 Website: www.patientservciesinc.org

Partnership for Prescription Assistance

The Partnership for Prescription Assistance offers a single point of access to more than 475 public and private patient assistance programs, including more than 150 programs offered by pharmaceutical companies. Patients can be screened for eligibility and begin enrollment applications for medication assistance programs by calling the phone number or visiting the website.

Telephone: (888) 477-2669 Website: www.medicineassistancetool.org

Additional Resource Information Available through the Emory ALS Center Social Worker

Our ALS Center Social Worker has additional resources about the below topics. Please reach out to our social worker if you would like more information on the below topics. You can contact the social worker through MyChart by sending a message to your doctor or by calling 404-778-3444 and asking a message to be sent to the ALS Social Worker.

- Advance Care Planning Consultation, including Advance Directives (sometimes referred to as healthcare power of attorney)
- Assisted Living Facility and Personal Care Homes Guidance
- Care Partner Support
- Community Resource Referrals
- Counseling and Emotional Support for patients and care partners
- Child and Teen Resources and Guidance for Discussing ALS
- Disability Benefits Guidance (workplace and Social Security Disability)
- Geriatric Case Management Resources (can be for someone of any age)
- Health Insurance Guidance
- Home Aides – additional information and list of agencies
- Home Renovation Resource with Certified Aging in Place Specialists (CAPS)
- Legacy Work (sharing your story with loved ones)
- Legal Resources for power of attorney and other needs (i.e. Elder Care Law Services, Atlanta Legal Aid)
- Medicaid Waiver, SOURCE, & EDWP (FORMERLY CCSP) – programs to assist with cost of home aides
- Medical decision-making education and resources covering information about:
    - Palliative care
    - Feeding tube (PEG tube)
    - Ventilation and tracheostomy
    - Hospice care
- Patient and Care Partner/Family Education

Thoughts for Care Partners

Being a primary care partner for your loved one will bring many emotions and challenges. We recommend that you develop **a support system of your own consisting of family, friends, and professional support**. We suggest that you establish a relationship with a **counselor/therapist** who has experience supporting individuals and families during a life-altering illness.

The Emory ALS Center is also here to help. Our social worker and nurse navigator are two of our staff members with whom you can connect for support, resources, and questions about caregiving. Please do talk with your loved one about how they feel about you asking questions during appointments or talking with the social worker or nurse navigator on your own at a separate time. Your questions, concerns, worries, and fears are valid and important. Admittedly, the health care system does not make it easy for a medical team to dedicate time solely with a care partner. As such, we strive to do the best we can to support you while also recommending that you develop a support system outside of the ALS Center that can support you both now and well into the future.

Below are some resources specifically meant for care partners that you can consider reviewing for information and support.

ALS United of Georgia Care Partner Support Groups. See the page in this guide dedicated to ALS United of Georgia for more information. www.alsgeorgia.org

Videos that demonstrate caregiving techniques for caring for someone who is in bed, assist with transfers, medication administration, personal hygiene, etc. from Virtual Canadian Hospice. Main Page: https://www.virtualhospice.ca/ then click on "Support" then "The Video Gallery" and "Caregiving Demonstrations."
Direct Link:
https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Support/The+Video+Gallery.aspx?type=cat&cid=110f65fd-0447-4e6e-b860-7646e02b997b#video_content_index

Zen Caregiving Project. A four-part on-line course, run by experienced instructors, will provide the foundations of an approach to caregiving that reduces stress and burnout and allows you to provide quality care and connection to those you care for.
https://zencaregiving.org/events/event/foundations-of-mindful-caregiving-online/?gclid=EAIaIQobChMIsqXw0cjA9QIV9ciUCR0x8wXMEAAYAiAAEgIwpfD_BwE

The Care Partner Space. A non-profit dedicated to providing a supportive online space where care partners can share their stories, tap into resources and learn from the real experts: other care partners. They can tap into their community to get comfort, share stories, and find solutions at any hour of the day or night. www.thecaregiverspace.org

Rosalynn Carter Institute for Caregivers. The Rosalynn Carter Institute for Caregivers (RCI) promotes the health, strength, and resilience of all caregivers at every stage of their journey. https://www.rosalynncarter.org/

Caregivers Library. "One of the most extensive libraries for caregivers that exist today." This is a website that has various support articles, resources, etc. for caregivers. www.caregiverslibrary.org

CaringBridge. An online space where one can connect, share news, and receive support. It's a health social network, coming together on a personalized website. They offer personalized CaringBridge sites as well as a SupportPlanner that coordinates assistance from friends and family. www.caringbridge.org

MealTrain. An online site to help coordinate volunteers to bring meals. www.mealtrain.com

Today's Caregiver. This website offers caregiver resources as well as a search tool for caregiver support groups. Click on Local Resources, click on your state, and then select your county for a list of support groups. http://www.caregiver.com/index.htm

State of Georgia's ADA (American Disabilities Act) Coordinator's Office. Website with resources and connections on caregiving in Georgia. http://ada.georgia.gov/resources-caregivers

Jewish Family and Career Services. Offers support groups, resources, voucher program for caregiver respite services, and one-time financial and case management crisis support. https://yourtoolsforliving.org/services/older-adults/caregiver-support

Caring Across Generations. Seven in ten Americans will need home care at some point due to disability or the simple process of getting older. Caring Across Generations is building a national movement of the "caring majority" by addressing four major program areas: culture change work; local, state and federal policy advocacy; online campaigning; and field activities and civic engagement. https://caringacross.org

Family Caregiver Alliance. The FCA was the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care for loved ones at home. It strives to illuminate the caregivers' daily challenges to better the lives of caregivers nationally, provide them the assistance they need and deserve, and champion their cause through education, services, research and advocacy. www.caregiver.org

Respect a Caregiver's Time (ReACT). ReACT is an employer-focused coalition seeking to create a supportive business environment where the challenges faced by caregivers juggling the demands of both work and caregiving for an adult with a chronic age-related disease are understood and recognized by employers so that employees can better meet their personal and professional responsibilities. https://respectcaregivers.org

National Alliance for Caregiving. A non-profit coalition of national organizations focused on improving the lives of family caregivers, the Alliance was created to foster research, conduct policy analysis, develop national programs, and increase public awareness of family caregiving issues. It is dedicated to improving quality of life for families and their care recipients through research, innovation, and advocacy. https://www.caregiving.org

Resources for Parents and Adults to Talk with and Support Children

Websites

ALS Association

Families and ALS: A Guide for Talking with and Supporting Children and Youths
https://www.als.org/sites/default/files/2021-03/Families%20and%20ALS%20Guide-%20Manual.pdf

Real Kids Talk About ALS: Feeling Normal, Sad, and Different
https://www.als.org/sites/default/files/2020-04/youth-guide1.pdf

Book for Teens
https://www.als.org/sites/default/files/2020-04/youth-guide2.pdf

Multiple age resources
https://www.als.org/navigating-als/resources/Youth-Education

I AM ALS
List of resources to support children
https://iamals.org/get-help/resources-for-kids-and-teens/

Kids Grief
“What do I tell the kids? How do I support them? KidsGrief.ca is a free online resource that helps parents support their children when someone in their life is dying or has died. It equips parents with the words and confidence needed to help children grief life’s losses in healthy ways.”
They also have a workbook for children to help explore what’s happening.
https://www.kidsgrief.ca/
https://www.kidsgrief.ca/local/staticpage/pdf/My-Life-Their-Illness-EN.pdf

Books

Giving Hope: Conversations with Children About Illness, Death, and Loss
By Elena Lister, MD, Michael Schwartzman, PhD, Lindsey Tate

Helping Children & Teens Cope
By Vickie Leff, MSW, LCSW, APHSW-C and Anne Kelemen, MSW, LICSW, APHSW-C
www.helpingchildrencope.org

I Have a Question about Death
By Arlen Grad Gaines, MSW, LCSW-C, ACHP-SW and Meredity Polsky, MSW, LCSW, MS
They have multiple books and they have a focus on making the material accessible for those on the autism spectrum as well as other special needs.

*Ask your social worker if you would like a list of books for children to read.

ALS
UNITED
GEORGIA

The mission of the ALS United of Georgia (ALSU) is to find the cause of the disease and discover a cure through global, cutting-edge research. ALSU empowers people with Lou Gehrig's disease and their families to live fuller lives by providing compassionate care and support.

The ALS United of Georgia

Since its founding in 1988, the ALS United of Georgia has worked with ALS patients and their families to ensure the highest quality of life possible. The progression of ALS varies significantly from one patient to another. No matter a patient's situation, the ALS United of Georgia is available to provide vital services and reliable information.

Through the Care Services Program, the ALS United of Georgia employs Care Services staff members who are available to ALS patients and their families from the time of diagnosis. The Care Services staff assesses a patient's needs, recommends equipment, and helps families plan for the future.

The ALS United of Georgia programs and services include:

> **ALS 101** is held monthly with small groups for patients and care partners to obtain information about ALS, caregiving, resources, and connect with others.
>
> **Kostiuk Care Grant** to assist with ALS associated costs that are not covered by health insurance.
>
> **Medical Equipment Loan Program** that provides mobility equipment and augmentative communication devices when insurance and other programs cannot fund needed items.
>
> **Support Groups** for patients, family members, care partners, and friends.
>
> **ALS Care Grant Program** that has some guidelines and requires an application.
>
> **Sally Panfel In-Home Care & Respite Program** to provide in-home care to pALS and respite relief for their care partners. There is a questionnaire and application process.
>
> **Paul B. Williams ALS Transportation Program** to address the need of accessible van rentals, non-emergency transportation, van adaptations, and van vouchers.

All of the above program applications and additional information can be found on ALS United. You must register with ALS United of Georgia to engage with any of their programs. Let us know if you need help registering with them. www.alsgeorgia.org. The ALS United of Georgia is located at 227 Sandy Springs Place, Suite D, #304, Sandy Springs, GA 30325. Phone number 404-636-9909.

GOODE GF FOUNDATION

TRAVEL ASSISTANCE PROGRAM

The mission of the Goode Foundation is to support, assist, and empower ALS patients and families, and inspire the pursuit of improved treatment and research toward a cure. Sometimes clinic appointments require an overnight stay for patients who live far away from Atlanta. As ALS progresses, extra time to get the pALS up and dressed, into the car or van for travel, and into the ALS clinic building can turn that appointment into a 12+ hour day that is exhausting for the patient and care partner.

The Goode Foundation Travel Assistance Program is for those Emory ALS Center patients who live outside the metro Atlanta area who would benefit from an overnight stay prior to a clinic appointment. The Goode Foundation has partnered with the Emory Conference Center Hotel to pay for the overnight stay prior to your appointment at the Emory ALS Clinic.

Please complete the form on the next page as soon as your appointment is scheduled to make sure that a handicapped room is available.

Contact goodestrong@gmail.com or 877-354-6633

GOODE FOUNDATION

Travel Assistance Program

Name: ____

Address: ____

Email: ______________________________________ Phone: ________________

Purpose of Travel:

_____ Clinic Appointment _____ Doctor Appointment _____ Research Appointment

Date/Time of Appointment ___________________________

Emory Clinic _____ Emory Brain Health Center _____

How far away do you live from the Emory ALS Center?_______________________

Please tell us about your mobility (walking with assistance? Wheelchair? Rollator?)

____

What assistance/caregiving do you need to get dressed, hygiene, etc.?

____

Do you need transportation?_____Yes _____No

Preferred method of contact from the Goode Foundation:

Email _____ _____ Phone

PLEASE SEND COMPLETED FORM TO goodestong@gmail.com

Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), Medicare & Medicaid Benefits

Please note this is a general overview and available benefits are always evaluated on a case-by-case basis for each applicant.

Medicare and Medicaid are health insurance programs administered by the federal and/or state governments. SSDI and SSI are financial benefits. Medicaid is not the same as Medicare. SSI and SSDI are not the same, either.

Social Security Disability Insurance (SSDI) & Supplemental Security Income (SSI)

With a diagnosis of ALS am I eligible for Social Security Disability Insurance (SSDI)?
Yes, as long as you ALSO meet the work history requirements (qualified worker: typically available to any person who has paid into the Social Security system for at least ten years). A diagnosis of ALS is considered a presumptive disability. The applicant must meet specific criteria, but most pALS (patients with ALS) meet these. You must stop working to apply for Social Security disability benefits, but you can be using short- or long-term disability benefits through your employer or other private plans you might have. For more information, visit www.ssa.gov 1-800-772-1213

Supplemental Security Income (SSI, associated with Medicaid-qualified PALS) is funded by general tax revenues, not by taxes taken from individual workers' paychecks. SSI has very strict financial requirements. These benefits typically are retroactive to the date you are deemed disabled but check with your disability contact person in the Social Security Administration for details. ***SSI beneficiaries typically also receive Medicaid.***

pALS should also have **expedited approvals** for disability claims. This is called a **TERI** case and should always be mentioned while you are applying. Emory ALS Center can provide you with a TERI letter to go with your application.

Note: Typically, dependent children of recipients of SSI and SSDI are eligible for some benefits also.

To apply for disability benefits, call the Social Security Administration at (800) 772-1213, online at www.ssa.gov, or visit your local Social Security office. **Ensure that you provide them with the ALS Center DIRECT FAX NUMBER: 404-778-3495.** Otherwise, we might never receive the request. Always have them **send all faxes to 404-778-3495.**

Medicare & Medicaid: Health Insurance

Medicaid is a federal program administered by each state. Therefore, Medicaid is different in each state. Eligibility is based on income. The income threshold is quite low; see Georgia Medicaid guidelines for information. https://medicaid.georgia.gov 1-877-423-4746

Note: If you are eligible for both Medicare and Medicaid, you can have both and they will provide you with well-rounded health coverage.

Medicare is a federal program. Traditional Medicare (Medicare A/B) is the same in every state. It provides health coverage (1) when someone turns 65 or (2) at any age if you qualify for SSDI (and have waited the qualifying period). **IMPORTANT: there is NO waiting period for Medicare for pALS. pALS are eligible for Medicare as soon as they are eligible for SSDI.** You must also be a qualified worker. Typically, this means you have paid into the Medicare/Social Security system for at least ten years. You can learn about Medicare at www.medicare.gov 1-800-MEDICARE

Medicare-eligible pALS, there are different parts you need to be aware of:
Very briefly:

- A= hospital insurance (free)
- B= medical/outpatient insurance (requires monthly insurance premium)
- D= pharmacy/medication insurance (requires monthly insurance premium)
- C= Medicare Replacement Policy, also known as Medicare Advantage Plans. Medicare Replacement policies are administered by private insurance companies *in place of* traditional Medicare (Parts A & B). These are NOT supplemental plans but replace traditional/regular Medicare. We often refer to these as Medicare Replacement plans as it makes clearer what is occurring if you select one of these plans. The private insurance companies take charge and have their own individual policies about benefits coverage. They also maintain a network of providers, so be sure that your health care providers are in network when choosing a plan. To see if your Emory team is in network, you can go here. https://www.emoryhealthcare.org/medicare-advantage/index.html We also encourage you to speak directly with your insurance company to confirm your in-network providers.
- Medigap/Supplement plan: Medigap is Medicare Supplement Insurance that helps fill "gaps" in traditional Medicare and is sold by private companies. Traditional Medicare pays for much (usually 80%), but not all, of the cost for covered health care services and supplies. A Medicare Supplement Insurance (Medigap) policy can help pay some or all of the remaining health care costs, like copayments, coinsurance and deductibles. You pay the private insurance company a monthly premium for your Medigap policy. You pay this monthly premium in addition to the monthly Part B and Part D premiums that you pay to Medicare. Unfortunately, if you are under the age of 65, the costs of Medigap can be quite high due to Georgia's rules. You can read about that here: https://www.healthinsurance.org/medicare/georgia/#Medigap

Luckily there is free help navigating Medicare!
The website www.gacares.org provides resources including the state SHIP program (state health insurance assistance program). They can be reached at 866-552-4464 option 4.

SHIP offers free one-on-one counseling and will explain all of your options regarding Medicare and many other issues. SHIP services support people with limited incomes, Medicare beneficiaries under the age of 65 with disabilities, and individuals who are dually eligible for Medicare and Medicaid. Ms. Shirley Thomas, Certified Medicare Counselor, GA SHIP Program, GA Legal Services, sthomas@glsp.org, 470-552-3162, specifically helps patients with ALS.

Medicare Advocacy Center
In the event you have an experience with Medicare/Medicare Advantage that does not hold to the standard of expectations, you can consider contacting an advocacy center like the Medicare Rights Center at 1-800-333-4114, www.medicarerights.org.

A note from Emory ALS Center. From our team's observation as well as comments we hear from our patients, most patients are pleased with the coverage they receive with their traditional Medicare A/B and a supplement. We do hear and observe that Medicare Replacement/Medicare Advantage plans can sometimes provide challenges in approving equipment (i.e. power wheelchairs) and other recommendations (i.e. home health) given by Emory ALS Center doctors. In Georgia, supplement plans are often too expensive for people 64-years-old and younger, thus necessitating the use of Medicare Advantage/Replacement plans. No matter your insurance, The Emory ALS Center will do all it can to advocate with your insurance company so that you can obtain what your doctor recommends.

Serious Illnesses and Insurance Case Managers

Utilize Your Insurance Case Management System (Medicare and Medicaid do not offer these services)
Seeking the assistance of an insurance Case Manager (CM) will gain you an advocate who can help you understand the benefits and resources provided by your insurance plan.

Most private insurance organizations have a Case Management department. Calling the insurance company and requesting case management is the first step in the process; asking for a Case Manager with knowledge of ALS is the next. A CM, typically a nurse, will work with the physician to provide the care that is needed and may be able to uncover more care options.

Educating Your Case Manager
ALS patients and families find that they are frequently educating others about ALS. Living with ALS 24 hours a day imparts rapid knowledge. Physical progression changes from day to day and what works today may be different tomorrow. For the CM to truly understand the progressive status of ALS, the concept of planning and "staying ahead of the curve" on symptom management needs to be emphasized. Depending on the CM's experience, you may need to educate them. If the CM is local, ask them to do a home visit to assess the situation. List all of the types of care you require and take pictures if appropriate to forward to them. Make the CM feel like a part of the team. If you don't feel the CM is proactive enough, you have the right to request a different CM.

Skilled and Unskilled Home Care – Coverage for People with ALS?
The skilled care designation indicates that treatment is provided by licensed nursing personnel (RN), physical therapist, occupational therapist, and/or speech pathologist versus a home health aide or other unlicensed healthcare worker. The usual criteria considerations for skilled home care include that the services need to be ordered by a physician as part of a treatment plan for a covered medical condition. As the disease progresses, and if the person with ALS has chosen certain treatment options, there may be a point where the necessary hands-on care fulfills criteria for skilled care. In certain circumstances a CM can be asked to approve some additional unskilled and skilled coverage. Navigating the insurance system requires fact gathering, knowledge about care options, and negotiation of your insurance benefits by a cooperative CM.

Get Educated on Case Management
Since some policies and guidelines vary by company, request your specific Evidence of Coverage or Insurance Contract.

Think Outside the Insurance Coverage Box
Case Managers are solution seekers. The CM has flexibility that allows them to exchange one benefit for another. This is done when the care that is needed costs less than the alternative. If they don't offer solutions like this, then you need to ask some specific questions.

Ask if the plan allows for a substitution of benefits. One example might be converting the home health or SNF benefit into skilled in-home nursing hours. The insurance company generally is not going to provide a service for which there is no contractual benefit, however they may be willing to convert or substitute one benefit for a similar service. If this alternative way fits within the physician's treatment plan, this argument can then be made. The terminology or language of the insurance company's guidelines needs to be used to make the case for coverage.

Highlighting the critical issue of airway protection, as seen when a patient is on Non-Invasive Ventilation (NIV) or has a tracheostomy, can be an important argument in having assurance of 24-hour airway maintenance and having appropriate care coverage.

Let the CM know all the other care and support being provided by family and other organizations so you are aligned as partners in the case. Showing cooperation in this care partnership can be mutually beneficial.

Remind them that:

1. In-home care is less expensive than an acute hospital or nursing home admission.
2. The goal is to avoid an inpatient hospitalization, emergency room visit or an expensive or serious complication.

By having the appropriate home health coverage engaged, the care cost may be less.

What is the Case Management Goal?

It is encouraged and worthwhile for the person with ALS to engage in a relationship with their insurance Case Manager. It can then be assessed if the CM can assist in meeting the treatment plan goals by being flexible with the existing benefits. These alternatives may provide helpful options for home care.

Benefits for Veterans

(Source: Youralsguide.com)

Am I eligible for service-connected benefits?
If you have been diagnosed with ALS, served in the U.S. military for 90 or more consecutive days of active duty, and have been honorably discharged, you will likely be eligible for special service-connected benefits.

What are service-connected benefits?
If you qualify, you can receive numerous benefits through the VA, including:

- **VA ALS clinics** – visits with ALS specialists at your nearest VA medical center
- **Durable medical equipment** – devices for your respiratory, mobility, communication, daily living, and other needs
- **Disability compensation** – a monthly tax-free payment that you can use as you wish
- **Specially-adapted housing grant (SAH)** – money to help build, buy, or remodel a home that meets your disability requirements
- **Automobile grant** – a one-time payment of up to $20,000 to buy a disability-accessible vehicle
- **Aid and attendance allowance** – additional money to help pay for care at home

The ALS Association goes into greater detail on their website.

Multidisciplinary ALS Clinic at the Atlanta VA Medical Center
Veterans who receive ALS care at the Atlanta VA Medical Center will have access to services from a multidisciplinary team during VA neurology appointments. The ALS clinic meets on the first, third, and fifth Monday of each month. Patients will continue to see Dr. Fournier, but now in addition, will also be able to see a physical therapist, occupational therapist, speech therapist, social worker, and research coordinator in the same location without having to schedule additional appointments. ALS clinic visits with the full team typically take at least 90 minutes but should streamline ALS care and reduce the number of future in person visits that are needed to see different specialists.

How do I apply for benefits?
If you have been diagnosed with ALS and have 90 days of consecutive active duty, you should be eligible for service-connected benefits. But you cannot make an appointment with ALS clinics at the VA until you have been approved for service-connected benefits and enrolled in the VA system.

- To apply for your service-connected benefits, we strongly recommend reaching out to a veteran's service organization like the Paralyzed Veterans of America (PVA) at pva.org. Navigating the VA system on your own can be a confusing and frustrating process. PVA or DAV will become your advocate—they will explain your benefits, answer questions, give you tips, help you with paperwork, and expedite your application, which may take 90 days or so to get approved.
- While waiting for your benefits, you should get connected with either your local ALS Association and/or Muscular Dystrophy Association chapter. Make an appointment at the Emory ALS Clinic, and begin attending the clinic. Follow the team's recommendations and do not stop attending until you fully transition to the VA.
- When the VA accepts your application and approves your service-connected benefits, you will automatically get an appointment within 30 days. You will also be assigned a social worker/case manager and primary doctor.

What if I need a power wheelchair?
Custom tilt-and-recline power wheelchairs are one of the most helpful—and expensive—pieces of medical equipment for ALS patients. If you are a service-connected veteran, the VA should cover all of the costs associated with your wheelchair, including the additional power-elevating seat feature.

If you become concerned that a walker, scooter, or standard power wheelchair will no longer meet your mobility needs, schedule an appointment with your primary care physician at the VA to discuss getting evaluated for a tilt-and-recline power wheelchair.

Your physician will likely refer you to an occupational or physical therapist for an evaluation, which will be submitted for approval. Once approved, your wheelchair should arrive within 4-12 weeks. Your physical or occupational therapist will schedule a follow-up appointment to make adjustments—with you in the chair—before training you how to use it. Procedures between VA facilities will vary.

Note: When you are approved for your power wheelchair, you will also become eligible for an automobile grant of $21,000 that you can apply toward the purchase of a handicap-accessible van.

Can I receive VA benefits and Medicare benefits?
Yes. As a veteran, you can also get Medicare benefits—if you are eligible. With an ALS diagnosis, you do not have to be 65 years old or retired to qualify for Medicare. If you have worked in the last ten years and have paid taxes into Medicare for a total of 40 quarters (ten years) or more, you should qualify.
If you do not qualify for Medicare, the VA health care system will cover you fully.

Can I receive VA benefits and Medicaid benefits?
No. Once you begin receiving disability compensation from the VA, you cannot also receive benefits through Medicaid. Your VA health care or Medicare will become your primary insurance.

What can I do?

1. Let the Emory ALS Center know that you are a veteran. We can then assist you with the required paperwork and steps for a referral to the VA.
2. Contact ALS United of Georgia. www.alsgeorgia.org You can receive support from the VA and The ALS United of Georgia at the same time.
3. Contact your Paralyzed Veterans of American (PVA) Chapter. The PVA has chapters across the country. Locate your nearest chapter to find out what services they offer. You may also want to ask your ALS Association Georgia Chapter representative if there is another organization in your area, such as The American Legion, to help with your application.
4. Get organized and plan ahead. Remember that there are waiting periods between applying for your benefits and receiving them. If you are not working, you will need to cover your finances until you begin receiving disability income. There is a 90-day waiting period between applying for your VA benefits and receiving them. We suggest organizing your paperwork, contacting The ALS Association and PVA, and applying as soon as you can.

Home Equipment, Home Health & Home Aides

A Few Words about Health Insurance

Health insurance companies and programs (including Medicare and Medicaid) are known as “payor sources.” Most private insurance companies (such as Blue Cross, Aetna, Cigna, etc.) loosely follow Medicare guidelines for coverage.

If you have private insurance, ask for a case manager. We have a separate section above that describes how to use private insurance case management to your advantage.

The Emory ALS Center will send referrals on your behalf to agencies that can provide equipment and home health services. Unfortunately, (1) it has become difficult to find agencies that have the clinical staff to provide the requested services (i.e. nurses, physical, occupational, and speech therapists) due to national/local health care staffing shortages and (2) private insurance companies, including Medicare Advantage/Replacement plans, maintain networks with certain agencies that limits options. **These factors can sometimes result in a situation where there are no agencies that can provide the home health care that we recommend and order.** This is frustrating and unfortunate. In the event that there are no home services available, we can write prescriptions for outpatient therapies. If you find that this is happening to you and you have a Medicare Advantage/Replacement plan, you might want to consider whether reverting back to traditional Medicare could help. However, reverting back to traditional Medicare when you are under 65 can be especially challenging as obtaining a supplement/Medigap plan is quite costly due to Georgia rules. https://www.healthinsurance.org/medicare/georgia/#Medigap

In order to obtain home durable medical equipment (DME) and/or skilled home health services, some minimum requirements must be met:

- The DME or service company must be Medicare certified and/or in network and serve the area where you live.
- You must have seen the ordering MD/NP/PA within the past 90 days.
- The need for the DME or services must be justified in the medical provider’s note from your visit
- For home health services you must be considered “home bound”

Where can people with Medicare get answers to billing questions?

Questions about billing should first be directed to the health care providers who delivered the care or services. These providers file the claims with and are reimbursed by your insurance company and will know if the requested DME or services will be covered.

If the question isn’t resolved, call 1-800-MEDICARE (1-800-633-4227) to speak to a government representative or your insurance company.

Durable Medical Equipment (DME)

With a doctor’s order, the following equipment generally is covered at 80% (Medicare pays 80%, but Medicaid and other payors may cover 100%)

- Walkers, bedside commodes, hydraulic Hoyer lifts with sling, semi-electric hospital beds and gel mattress overlays, wheelchairs (either power or manual but not both)
- Respiratory equipment and tube feeding formula and supplies (if medically necessary)
- Some communication devices, if medically necessary
- Some external catheters
- Chair lift-- Medicare typically covers the cost of the motor only, not the cost of the entire piece of equipment
- Orthotics, such as wrist and ankle splints, neck collars, etc.

- Medicaid will cover a tub transfer bench
- *Rollator walkers: insurance does cover these, however, they typically cover them at the same cost as a rolling walker. This means that they likely will give you the cheapest rollator walker they can find. You might want to consider purchasing your own rollator to have better quality and have the insurance provide the typical rolling walker. (Rollator has four wheels and a seat. Rolling walker has two wheels, no seat.)

Note – In general, the payor will pay for a *single* initial or replacement item in each category once every five years. Therefore, it is important to ensure the piece of equipment ordered is the best possible fit for you.

Examples of equipment Medicare will NOT cover, even if our clinic writes a specific order for you. Most private insurance companies follow Medicare guidelines, but you can call your insurance and ask.

- Canes
- Shower chairs (they substitute a bedside commode), bathroom or shower equipment other than a standard bedside commode
- Fully electric hospital beds (includes the power up/down), specialty beds, and low air loss or specialty mattresses
- Electric lifts, sit to stand lifts
- Stair lifts (installed in home)
- Wheelchair accessible vans, wheelchair lifts/racks for vehicles
- Incontinence supplies, gloves
- Personal electronics (tablets) for use in communication via text-to-speech applications

Some equipment companies will allow pALS to pay the difference for upgraded equipment such as fully-electric operation for beds and hoyer lifts, and walkers with seats and brakes. Some companies will not - you will need to speak with the equipment provider directly.

Some equipment that is not covered by insurance can be purchased without sales tax with a letter of medical necessity from your doctor. Ask the vendor from whom you are obtaining/purchasing the equipment.

Home Health Care and Home Aide Care:

Home Aide Care and **Home Health Care** are different.
*The last page of this guide is a log. Please use it to record the agencies that you encounter for home health, equipment, etc. It will become important to have their names and phone numbers.

Home Health Care involves medical services requiring a nurse, physical therapist, occupational therapist, respiratory therapist, speech therapist, or social worker. Home Health Care may be authorized for coverage through health insurance if someone is "home-bound," meaning the only reason they may be able to physically leave the home is for doctors' appointments. Home Health Care requires a doctor's order. These services are typically paid by insurance for a short period of time, but once the goals have been met, the services must end. Not all services are available in all areas.

If the pALS has new needs as their disease progresses, home health services can be renewed since there are new goals to be attained. Examples: training on using new equipment in the home, new onset of difficulty swallowing, the development of wounds or other nursing needs.

Home Aide Care involves non-medical care. Home aide care can also be referred to as private duty care, companion care, paid caregivers, custodial care, etc. This may include respite care, companionship, medication reminders, bathing, dressing, assistance with activities of daily living (ADLs), light house cleaning, running errands, and other non-medical in-home care by caregivers. Home aide care does not require a doctor's order.

Most home aide agencies are staffed by Certified Nursing Assistants (CNAs) or Licensed Practical Nurses (LPNs). They cannot, due to licensure and state regulations, administer medications nor take care of skilled nursing needs, like caring for a tracheostomy, ventilator or feeding tube. There are a few agencies that have Registered Nurses (RNs) for hire that can provide that level of care. RNs will cost more per hour than CNAs or LPNs. (There are individual people/aides that can be hired that are not subject to the licensing and regulations and could, therefore, assist with the breathing machines, tube feeds, medications, etc. One must be cognizant of what comes with hiring an individual outside of an agency structure. See below.)

Home aide services are not traditionally covered through health insurance. Home aides may be paid privately (out-of-pocket), through a long-term care policy, or through **Medicaid waivers (Independent Care Waiver Program ICWP)** and programs, such as **EDWP (formerly CCSP) and SOURCE**. For ICWP, SOURCE, and EDWP, one must meet eligibility requirements including financial criteria and physical need. There is more information on these programs in another resource guide. More information is available at https://dch.georgia.gov/programs/hcbs and www.mygeorgiacares.com. There are **case management agencies that can help with applying** for ICWP, SOURCE, and EDWP. Please contact the ALS Center Social Worker for more information on these agencies.

If a patient has Medicaid, the **Structured Family Caregiving** program **pays a related (biologically or by marriage) family member to provide care to a patient at home**. The reason for this is to try to keep patients at home instead of needing to be placed in a nursing home. ***A spouse is not eligible as a paid care partner.*** Here are links to learn more. You can also ask your ICWP, SOURCE or EDWP case managers for more information.

- https://www.nashp.org/chart-comparison-of-medicaid-covered-structured-family-caregiving-in-three-states/
- file:///H:/ALS%20Guides%20to%20Share/Home%20Aides/Structured%20Family%20Caregiving/Medicaid-Structured-Family-Caregiving-by-Neva-Kaye-1.pdf
- https://www.mmis.georgia.gov/portal/Portals/0/StaticContent/Public/ALL/HANDBOOKS/EDWP-%20CCSP%20and%20SOURCE%20Personal%20Support%20Services%20October%202022%2020220913142406.pdf

***Companion care** might be helpful if one does not need help with bathing, tube feeds, etc. www.careyaya.org is a nonprofit organization focused on connecting top healthcare students who provide companion care with people who need the support. The students can provide companionship and assistance in daily activities (mobility, grooming, meals, technology, light housekeeping, pet care, etc.)

Obtaining Home Aide Care

Finding home aide care is similar to finding any other service agency/company. You might want to interview several before picking one agency and ask about their experience with ALS. If you have Medicaid, ask them if they accept payment through the ICWP and/or are an approved agency with EDWP and/or SOURCE. You might also want to consider contacting your local Area Agency on Aging (Atlanta area 404-463-3100) for their thoughts on home aides and whether they have any programs.

Most agencies provide home aide care on an hourly basis. Arrangements can typically be made for two to four-hour blocks of time, eight-hour shifts or round-the-clock care depending on your needs. Fees vary by agency and need to be negotiated privately. We suggest that you contact several agencies to compare services and costs.

Two approaches to securing this type of care include using an agency or a private individual(s).

- The advantage to using an agency is that they should be licensed and bonded. The agency should be managing taxes and withholdings. Agencies also screen their workers (ask exactly how they do this, i.e. background check, etc.). If the worker is unavailable at the last minute, it is usually the agency's responsibility to try to find a replacement.
- The advantage to finding independent aides is it usually costs less, but you will need to consider and plan for how taxes, etc. are paid. Seek information from a tax consultant about this. You might also find an independent aide that is willing/able to provide more skilled care, such as being trained to manage a tracheostomy and oversee ventilator care.

Transportation

When one is not physically able to get in and out of a family car/van, transportation can become a challenge. It can be even more challenging with a power wheelchair. Most power wheelchairs cannot be easily moved into nor fit in a typical van. Unfortunately, health insurance does not typically cover non-emergent medical transportation, even to and from doctors' appointments. One option is to purchase a handicapped accessible wheelchair van. However, these specialty vehicles are expensive and it is not an option for everyone. Below is some information we hope will help as you navigate your transportation needs. Ask the social worker if you want a longer list of public and private resources for-hire.

FREE Transportation Options

ALS Association FREE Van Loaner Program
The ALS Association has a program where you can borrow a wheelchair van for doctor's appointments or other outings as long as you plan with them at least two weeks in advance. For more information, call ALSA GA at 404-636-9909.

NORD ALS Travel & Lodging Assistance Program
The ALS Travel & Lodging Assistance Program provides individuals diagnosed with amyotrophic lateral sclerosis financial assistance for travel and lodging to ALS medical consults, care and treatment appointments. There is a financial eligibility criteria; contact them for details.
Call 203-794-6992, fax 203-702-4215, email ALS@rarediseases.org, or bit.ly/patient-assist.

Medicaid Transportation
If you have Medicaid, call the number listed on your Medicaid identification card to inquire about transportation services to and from medical appointments. Typically, if you schedule at least three days in advance, you can receive free transportation to and from medical appointments.

Transportation Companies for Hire

Below is a list of private companies you can contact directly to arrange transportation.

Aces Express Services
404-875-8444
Power wheelchair: $150 per day and $5.50/mile
They accept patients with ventilators
They cover all over Georgia

Advantage
770-274-9846
Atm-ga.com
advantagemedtrain@aol.com

Destiny Transport
770-560-2432
Wheelchair van: $65 each way. First 10 miles free, then $2.00/mile.
They will transport patients with ventilators.

Mobility Works Van Rentals
1-877-275-4915
www.mobilityworks.com
They have a discount for patients with ALS. It is $85 per 24-hour period. This includes unlimited miles with a maximum of seven days.

Providence Transportation
1-800-560-0253
https://www.providencetrans.com/
Providence504transportation@gmail.com
Wheelchair van is $75 each way for 10 miles, then $4.00/mile for miles 11-50, then $0.50 after 50 miles. They can staff with nurses or EMTs and provide care with power wheelchairs and ventilators. They work frequently with patients in power wheelchairs, with dementia, and medically fragile.

Patient Name: ___________________________

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ALS CENTER *Celebrate Life... Imagine a Cure*

Services and Adaptive Equipment Log

Equipment	Date ordered	Vendor	Phone Number
Home Health Agency			
Home Aide Agency			
Trilogy or BIPAP			
Cough Assist			
Suction Machine			
Hoyer Lift			
Hospital Bed			
Bedside Commode			
Walker			
Power Wheelchair			
Manual Wheelchair			
Tube Feedings			
Neck			
Braces			
Communication Device			
Other			

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