

The ALS Journey:
A Caregiver's
Perspective

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Challenges of Caregiving

ALS changes the lives of the PALS and the primary caregiver.

ALS is nothing less than a battle, and while the battle is being waged, the caregiver's responsibilities grow exponentially.

These responsibilities include...

- *researching and finding solutions;*
- *long term planning;*
- *advocacy;*
- *and many day-to-day responsibilities.*

There are also important considerations for caregivers regarding diagnosis and ensuring their own health and well-being.

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Researching & Finding Solutions

- Researching ALS: what the illness is, progression, PALS' needs & treatment.
 - *Understanding the trajectory of ALS to arrange for essential equipment (e.g., power wheelchair, Hoyer lift, hospital bed).*
 - *Researching major purchases (e.g., van, accessible home).*
 - *Staying informed on current trends, new medications/treatments, best practices, and new products.*
- Seeking out medical professionals to work with PALS.
- Searching for resources, including financial assistance.
- Being a problem-solver/creative thinker. As ALS progresses, PALS' needs will change and adaptations will need to be made.
- A great deal of information can be gained by
 - *talking to clinic staff,*
 - *attending ALS support groups,*
 - *requesting information from your local ALS Association, and*
 - *joining ALS Caregiver Facebook sites.*

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Advocacy

- Serving as an Advocate for the PALS with medical professionals, to ensure his/her needs are met.
- Advocating for the VA & other government organizations to provide additional resources (be the squeaky wheel!);
 - *Knowing when/how to get government officials (e.g., your representatives) involved*
- Advocating for PALS regarding insurance coverage, filings, and claims.

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Long-Term Planning

- Long-term financial planning:
 - *Making sure the spouse has access to all accounts;*
 - *Ensuring all accounts are in the spouse's name or list both spouses jointly;*
 - *Verifying that all accounts have the correct beneficiary;*
 - *Knowing current financial situation and planning for future financial needs;*
 - *Working to evaluate major purchases and budgeting for them currently or in the future.*
- Encouraging the PALS to make important legal decisions regarding as POAs, Wills, Advanced Directives, Financial POAs, etc.
- Facilitating discussions on PALS desires for his/her final arrangements, and making arrangements with the funeral home, etc.

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Day-to-Day Responsibilities

- Coordinating all medical and ALS clinic appointments, transportation, medications, therapies, supplies and equipment needs, and maintaining supply inventory.
- Oversight of medical insurance correspondence and claims.
- Managing all aspects of personnel management when caregivers are hired.
- Providing physical, emotional, and cognitive support for your loved one.
- Being the hands, arms, hands, legs, feet and voice for your PALS as the illness progresses.
- Planning for activities to prevent isolation and loneliness for your PALS and yourself.
- Assisting/Handling ADLs: feeding, grooming, showering, dressing, toileting, etc.

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Day-to-Day Responsibilities

- Taking 100% responsibility for managing all aspects of the illness, maintaining the home/vehicles, as well as handling finances, childcare, and your own care.
- Collaborating with the ALS team and updating them on progression & PALS needs.
- Serving as a “dietician” for meeting nutrition/hydration needs.
- PT/OT: assisting PALS with range of motion exercises.
- Managing medical needs day to day:
 - *Administering medications/pain management*
 - *maintaining medical records, taking/recording vital signs*
 - *handling issues of infections, skin breakdown, pressure sores, and incontinence*

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Issues that Impact Caregivers at Diagnosis

- ALS is difficult to diagnose; numerous appointments with various doctors.
- Can take months or even years to get an ALS diagnosis.
- By the time of diagnosis, the PALS often already has advanced symptoms/losses.
- Initial costs for equipment may have to come out of pocket.
- At diagnosis, the PALS and Caregiver are often in shock, and may have difficulty absorbing the information provided or knowing what questions to ask.
- This means that the vast majority will leave the appointment without answers and will need to research on their own at home.

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Caregivers: Health & Wellness

Caregivers often...

- Become overwhelmed and anxious because of the many responsibilities that now are solely handled by the caregiver.
- Are fearful of what is to come: the progression of the illness and the impact on their PALS, financial worries, end of life issues, and their future without the PALS.
- Suffer from undiagnosed depression.
- Experience feelings of guilt or anger.
- Face social limitations because they cannot leave the PALS without a caregiver.
- Are isolated because the impact of ALS is painful for family and friends to see.
- Have difficulty finding and paying for caregivers.

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Caregivers: Health & Wellness

Caregivers need ...

- Physical support. Caring for a PALS requires strength and agility.
- Mental health support.
- Adequate sleep to remain healthy and effective.
- Training to meet the multi-faceted needs of PALS.
- Respite to prevent exhaustion and burnout, especially if they are the only caregiver.
- Visitors and people to talk to--they are a lifeline for caregivers.
- Help with everyday activities (meal prep, cleaning, etc).

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Resources

ALS Association

www.als.org info@ALSAlabama.org 800-664-122
Extensive resources for Caregivers and families, guides, information about government services, support groups, resources, equipment loan program, & more.

ALS Pathways

www.alspathways.com/caregiver-support 833-788-1396
Caregiver support, education, and resources.

ALS Support Services

www.youralsguide.com
Extensive and downloadable list of resources with contact information.

Family Caregiver Alliance

www.Caregiver.org. 800-445-8106

I AM ALS

www.lamals.org. 866-942-6257
Emotional support and logistical guidance for families and caregivers affected by ALS.

Team Gleason

TeamGleason.org
Provides technology, equipment, and care services.

ALS Association (Alabama Chapter)

Phone: 205-637-7833 email: info@ALSAlabama.org

Alabama Aging Network

- Central Alabama Aging Consortium Phone: 334-240-4680
- Middle Alabama Aging Consortium Phone: 205-670-5770
- Southern Alabama Regional Council on Aging Phone: 334-793-6843
- United Way Area Agency on Aging of Jefferson County Phone 205-458-3330

The above agencies are part of a statewide aging network, offering educational conferences, monthly mailed resources, supplies, and paid caregiver hours for respite for people over 55, including those with disabilities and ALS and certain other illnesses.

Alabama Department of Senior Services Phone: 800-AGELINE (Disabled or over 50)

Services include resources and referrals for seniors. An Aging and Disability Resource Center is also available

AL Department of Rehabilitation Services SAIL Program

Phone: 334-293-7500

Assists individuals with significant disabilities to have a higher quality of life. Some of their services include counseling, home care attendants/aides, and supplies.

Facebook Pages

- ALS Caregiver Support
- ALS-Patient and Caregiver tips for every day living
- ALS Equipment Exchange
- ALS Equipment Donations
- Better Days with ALS
- ALS We are in it together
- Team Gleason House
- Veterans with ALS and Caregivers Network

Through these groups, I learned a lot about how to care for my PALS, where and what to purchase to meet his needs, caregiver tips, and more.