

ALS United of Georgia

Sally Panfel In-Home Care and Respite Program

Statement of Purpose:

In March of 2017, ALS United of Georgia, launched The Sally Panfel In-Home Care and Respite Program. The purpose of the program is to provide persons with ALS and their families the opportunity to receive in-home care and respite who currently do not have the financial resources to secure independent of community support. The program is privately funded, and applicants must meet program guidelines for eligibility.

Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's Disease, is a neuro-muscular disease that impacts all voluntary muscle functioning. Ninety percent of Georgia ALS patients currently reside in their own homes. This is by choice as well as necessity due to limited community placements that can meet the medical demands of the disease. As the disease progresses, patients are no longer able to manage their basic daily care needs such as bathing, dressing, feeding and safe transfers. Unfortunately, Medicare, Medicaid and private insurance do not cover this expense within their plans; thus, the need for innovative programming for Georgia patients.

The Sally Panfel In-Home Care and Respite Program has the capacity to provide a person with ALS from 8-18 hours of in home care a week. Hours awarded will be determined by The ALS United of Georgia and not the contracted community provider. Families who benefit from Respite Care as defined by The Center for Medicaid and Medicare can receive between 24-72 hours of specialized care per request. The goal of Respite is to address emergencies, caregiver burnout and education regarding symptom management. The ALS United of Georgia contracts with licensed home and health care agencies to provide the needed custodial care. ***Custodial Care is defined as basic ADL care i.e., bathing, dressing, feeding, toileting, and safe transfers. This program does not cover skilled care which requires a registered nurse, physical, occupational, or respiratory therapist.*** Persons with ALS who need assistance with ventilators, suctioning or tube feeding will be referred to a higher level of care.

The Sally Panfel In-Home Care and Respite Program is not designed to be a permanent solution for needed care. It is designed to provide care while alternative opportunities are investigated and implemented. Once approved for other programs, the person with ALS will transition to programs that have larger capacity for care. The Care Service Coordinators will provide applicants with education and information regarding state opportunities.

Eligibility is determined by information provided in your Application and the Social Worker's Needs Assessment.

Eligibility Requirements:

Candidates for The Sally Panfel In-Home Care Program must:

- Have a diagnosis of ALS and reside in the service area of ALS United of Georgia.
- Need assistance with personal/custodial ADL care and reside in private home.
- Complete all phases of the application process (application, survey, and assessment)
- Be receptive to community based programs and providing agencies.
- Allow minimum of 2 weeks from approval to implementation of services

Candidates for The Respite Care Program must:

- Reside in their private home.
- Need care for a minimum of 24 to 72 hours.
- Address caregiver burnout
- Receive education and support to address continuous care of individuals living with ALS in home.
- Be receptive to respite provided in the home or in a community contracted facility.

You will be considered ***ineligible*** for The Sally Panfel In-Home Care and Respite Program if:

- You are receiving hospice care (depending upon services received from the hospice agency)
- You reside in a Skilled Nursing Facility, Assisted Living Facility or Personal Care Home
- You have a live-in caregiver (not including spouse or child)
- You have a Long-Term Care Insurance Policy that covers care.
- You are currently receiving in home care through another agency or organization under Medicare (Home Health).

Please note: The Sally Panfel In-Home Care and Respite Program is designed to be a temporary solution for a long-term need. Once approved, families are encouraged to work in partnership with their Care Service Coordinator to identify, develop and or implement a program that will address your ongoing caregiving needs. As with all privately funded programs, opportunities are based on availability of funds. We will continue to communicate regarding available opportunities.

**For additional information, contact our Care Services Team at 404-636-9909
or via email at careservices@alsgeorgia.org**



ALS United of Georgia

The Sally Panfel Application - Part I In-Home Respite Program

Name:		Date of Birth:	
Address:		City:	County:
Phone:		Email:	
Insurance(s):			
Contact Person:		Relationship:	Phone:

I am currently receiving help at home from the following agencies:

- | | |
|---|---|
| <input type="checkbox"/> County Office of Aging/Senior Services | <input type="checkbox"/> Insurance Funded RN/PT/OT |
| <input type="checkbox"/> VA (Veterans' Administration) | <input type="checkbox"/> Long Term Care Policy |
| <input type="checkbox"/> Private Caregiver/Agency | <input type="checkbox"/> Palliative Care |
| <input type="checkbox"/> Hospice | <input type="checkbox"/> Medicaid Waiver/Home Care Programs |
| <input type="checkbox"/> None (No Services at this time) | |

Agency: _____ Contact Person and Phone number: _____

This program has limited funds, therefore, in general, The ALS Sally Panfel In-Home Care and Respite Program Funds are not to be used to provide in-home care services where this service is adequately covered through a LTC policy, community agency or hospice. The maximum period services can be provided cannot exceed 6 months.

I am requesting _____ hours per day, _____ days per week. Preferred time of day is _____.
(Hours range from minimum of 8 to 18 hours weekly depending upon circumstances)

Current ADL Needs (check all that apply):

- Bathing Meal Prep Dressing Transfers Range/Motion Exercises

Current physical condition: Weight: _____ Height: _____

Pet in the home? Yes No If yes, what type of pet? _____

Smoking in home? Yes No

Mobility: PWC Walker/Rollator Cane Hoyer Lift? Yes No (check one)

Communication: _____

Nutrition: Feeding Tube? Yes No Food by mouth? Yes No

Respiratory: Currently using any of the following equipment? Check all that apply:

- BiPap Trilogy Tracheotomy (Ventilator) Suction Machine Cough Assist

Lost use of: Check all that apply. Arms Hands Legs Neck

Section must be completed.

- Based on your understanding of the program guidelines and limitations; what is the current plan of care to address patient needs beyond the Panfel opportunity?

By agreement with ALS United of Georgia, I understand that if approved for The Sally Panfel In-Home Care and Respite Program, services will be provided by a preferred provider of ALS United of Georgia. I authorize the In-Home Care Coordinator to release and obtain any information necessary to complete this referral.

I have read The Sally Panfel In-Home Care and Respite Program guidelines and I understand that services will be provided on a limited basis.

By signing below, I also acknowledge ALS United of Georgia is not a provider of medical services and is only arranging for services to be administered by a third-party provider. ALS United of Georgia will not be providing medical services of any kind. As such, by signing below you hereby agree to release ALS United of Georgia from any legal claims you, or any party related to you, may have arising out of the negligence or other actions of the third-party provider.

Person living with ALS or Caregiver Signature: _____ Date: _____

Return Form To:
ALS United of Georgia
ATTN: Care Services Team
Fax: 404-636-9949 or Email: careservices@alsgeorgia.org



ALS United of Georgia

The Sally Panfel In-Home Respite Program Application

Part II - Quality of Life Survey

The completion of this survey is a required part of the Panfel application. Understanding that each family impacted by this disease will experience a unique journey, this information will assist us in continuing its efforts to maximize care opportunities. This information is confidential and will only be used to complete the application request.

PLEASE CHECK ALL THAT APPLY:

Person Living with ALS
 Veteran with ALS
 Caregiver of a Person Living with ALS

How long have you been on this program:
 0-3 months
 3-6 months
 6-9 months
 9 + months

Please check the response that represents your/family's current status:	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A
	1	2	3	4	5	
Support and Community Connections:						
I am receiving support in my community. (SOURCE, CCSP, ICWP)						
I am connected to those that provide care/support for people with ALS navigating ALS.						
I am connected to those that provide care/support for caregivers navigating ALS.						
Education:						
I have an educational awareness regarding care opportunities for ALS within the Palliative Care and Hospice Medicare benefit.						
I have been educated about ALS research in my community.						
ALS United of Georgia has been effective regarding educational awareness in the community.						
Educational information and resources are available and accessible to me.						

Financial and Community Benefits:	Strongly Agree 1	Agree 2	Neutral 3	Disagree 4	Strongly Disagree 5	N/A
I, (We) are currently <i>Not</i> experiencing any financial hardship related to our (my) ALS diagnosis.						
I, (We) are currently able to meet the daily financial needs of our (my) family.						
I am currently engaged in long term financial planning.						
I need immediate financial support.						
Access to Care:						
I am attending an ALS multidisciplinary clinic.						
I am successfully managing other medical needs in addition to ALS.						
I currently utilize community-based support for transportation.						

Quality of Life: Please check the response that would best pertain to your role as a caregiver to a person living with ALS.					
	EXTREMELY HIGH	HIGH	AVERAGE	LOW	NONE
	1	2	3	4	5
How would you rate your stress level?					
On a scale of 1 to 5, identify your current state of emotional well-being as a caregiver.					
Approximately how many times did you participate in self-care (i.e., exercise, reading, family time etc.) in the past 30 days?	1-2 times	2-3 times	4-5 times	5 + times	N/A

Please check the response that would best pertain to your role as a person living with ALS:					
Within the last 30 days have you experienced any falls? If yes, how many falls?	1-2 times	2-3 times	4-5 times	5 + times	N/A
How many <u>hours</u> per day are you at home alone?	1-2 hours	2-3 hours	4-5 hours	5 + hours	N/A
Do you have stairs in your home? If so, how many times do you navigate the stairs per day?	1-2 times	2-3 times	4-5 times	5 + times	N/A

In the section below, read each statement and check the box that best describes your response at the time of this survey.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I have a positive outlook towards life.					
I feel my life has value and worth.					
I often feel alone.					
I am feeling overwhelmed.					
“I have ALS, ALS does not have me!”					
Most days, I am in a good mood.					
ALS United of Georgia is of great assistance to me.					

Thank you for completing our survey.
 ALS United of Georgia
 Email: careservices@alsgeorgia.org
 Telephone 404.636.9909 Fax 404.636.9949

Please provide your name if you expressed concerns and would like us to contact you.

Name: _____ Contact Information: _____