

# The Senator Tomassoni Caregiver Support Program FAQs

## What does this program offer?

This Program will offer **caregivers** of persons with ALS living in Minnesota an annual award to help cover the costs associated with in-home support.

## What is in-home support?

A paid caregiver to assist with activities of daily living such as dressing, bathing, toileting and feeding. They may also assist with instrumental activities of daily living such as shopping, meal preparation, light housekeeping, as well as managing finances/transportation/medication. (See tables below for information about ADLs and IADLs.) You could also hire your paid caregiver for skilled cares such as medication administration or assistance with a feeding tube.

IADL	ADL
Managing finance	Walking
Managing transportation	Feeding
Shopping and meal preparation	Toileting
House cleaning and home maintenance	Transferring
Managing communication	Bathing
Managing medications	Dressing

## Who is this program for?

This program is for persons caregiving for someone with ALS in MN. The person (age 18 or older) who *provides the most caregiving* is encouraged to apply. **Only one caregiver per family may apply.**

## Do I need to live in MN to apply for caregiving funds?

You, the caregiver, do not need to live in MN, but the person with ALS does need to live in MN.

## The person I care for with ALS lives in an assisted living facility. Can I apply for this program?

Yes. Caregivers may qualify if the person with ALS resides anywhere other than a long-term care facility, such as a nursing home, skilled nursing facility, or hospice facility. It is up to the assisted living facility to determine whether or not they are able to bill the ALS Association or allow you to hire an outside agency for in-home assistance.

## How long will this program last?

Through June 2026 or until the funds are expended.

### **What happens when the program ends in June 2026?**

The ALS Association is working closely with MN State legislators to secure continued funding for the Senator Tomassoni Caregiver Support program. If the state legislature does not approve additional funding, the ALS Association will continue to offer caregiver support in MN; however, the level of funding may change.

### **How long can I use these funds?**

New awards may be applied for once every 12 months. The program is currently set to end June 2026. The award does not roll over.

### **How much of an award can I get?**

Award amounts are based on availability of funds, how much caregiving is needed and whether families have additional support to provide this type of service.

### **How can I apply for funding?**

Click this [link](#) to complete the application. Once submitted, please allow up to two weeks for a care services staff member to be in touch.

### **What if I use all of my award before I'm eligible to apply again?**

You will be responsible for covering any costs associated with home care support; the invoices will be billed directly to you.

### **What are the ways these funds can be spent?**

The funds are for the caregiver to use to hire for in-home personal care and home management assistance that makes your job as caregiver easier.

- You can hire a **MN licensed home care agency** or **home management agency registered with the MN Department of Human Services**.  
Or
- You can hire an individual of your choice. The ALS Association will provide a referral to a Fiscal Management Service (FMS) for employment and payroll management of the individual. Immediate family members (spouse/partner, parent and child) of a person with ALS are not eligible to be paid caregivers.

### **How does hiring a home care agency work?**

- **What agency can I use?** You can use any Minnesota home care agency you prefer. We recommend using an agency **licensed in the State of Minnesota**. The ALS Association can provide you with names of licensed providers in your area.
- **Who pays the bills?** The ALS Association will cover the monthly invoices using your award amount. You will be responsible for covering any and all additional fees beyond your award amount.
- **Will I get a bill?** You will receive a copy of the bill from the home care agency for review. It is advised that you review your expenditures each month and track how much is remaining in your award. The ALS Association will pay the invoice each month, as long as it does not exceed your award amount.

**How does hiring an individual work?**

Caregivers who choose to hire an individual of their choice (other than a spouse/partner, parent or child of the person with ALS) will be referred to a fiscal management service (FMS) provider. The FMS will hire the individual and manage the employment and payroll responsibilities. Fees for this will be paid from your award.

**Can the person I hire be a family member?**

The person you hire may be a family member as long as they are not a spouse/partner, parent, or child of the person with ALS.

**How much does home care cost?**

Home care costs vary, depending on the agency. The average hourly cost of home care services is between \$40 and \$50 per hour. Also keep in mind that there may be fees for other services such as nursing assessment and supervision.

**What if I become dissatisfied with home care agency I've hired?**

You may discontinue service with one company and hire a new company.

**Can I hire more than one company?**

Yes, as long as you are able to coordinate your schedule and manage the amount you are spending.

**Can home care services continue even if the person with ALS is on hospice?**

Yes. If a person with ALS is residing in their home and not in a skilled nursing or hospice facility.

**Can caregivers of veterans access the program?**

Caregivers of veterans who are not eligible for service-connected Veteran's Benefits are welcome to apply.

**Will we always have the same caregiver coming to our home?**

When utilizing a home care agency, consistency with caregivers is always the goal. That said, home care agencies cannot guarantee certain paid caregivers every time. Changes in schedules, staff turnover, and vacation/sick days all play a part in the options an agency has for staff at any given time. The best way a family can maximize the likelihood of consistency with paid caregivers is to be consistent with using the service. If family caregivers choose the same day and time each week to utilize home care services, there is a higher likelihood of seeing the same paid caregivers.

*\*If contracting with an individual through a Fiscal Management Service company, the consistency will be dependent on that individual's availability.*

**Why do I need to complete an application to use The Senator Tomassoni Caregiver Support program?**

The Tomassoni caregiver program application provides information that staff will use to help identify provider options and other potential resources. In addition, it provides a baseline measure for the stress a family caregiver has. Our goal with this program is to reduce the stress a primary/family caregiver has by offering home care support and educational programs.

## How can I access the Senator Tomassoni Caregiver Support Program?

Several steps including:

- Application: Caregiver completes the application form along with the caregiver self-assessment.
- Intake: Family will meet with intake staff to determine needs and discuss options for home care support (contract with agency or hire an individual through an FMS).
- If a family elects to receive services from a home care agency, the ALS Association staff can assist in providing options for the family. The family will be responsible for establishing the relationship with the home care agency.
- If a family chooses to work with an individual, the family will contract with a Financial Management Service (FMS) provider who will provide a background check and hire the individual. The FMS will take care of all applicable taxes for that individual.
- Each month invoices will be sent to the family as a copy and to the ALS Association as a bill. The ALS Association will pay the monthly fees and this amount will be deducted from the annual grant amount approved for each family.

## What will make my Senator Tomassoni Caregiver Support Program experience the most successful?

- The more **flexible** you are, the more options the agency will have to staff your in-home support.
- **Realistic expectations** are important! Understand that home care support is **not an on-demand or on-call service** and is **not for emergencies**.
- The more closely you track and pace your spending, the more you will be able to count on making it last through the year.