



Progress Report

Funding for Support for Caregivers of People with Amyotrophic Lateral Sclerosis (ALS)

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About the Minnesota Board on Aging

The Minnesota Board on Aging is a 25-member, governor-appointed board that advises on and coordinates government plans around aging to ensure that Older Americans Act requirements are met. MBA administers state and federal funds and also creates public awareness, encourages research on aging issues and provides technical assistance and grants to local aging organizations. administers state and federal aging funds, advises policymakers, and supports local aging services.

Mission:

To ensure older Minnesotans and their families are effectively served by state and local policies and programs so they can age well and live well.

About This Report

This is a legislative-mandated report. As requested by Minnesota Statutes, section 3.197, this report cost approximately \$1,360.49 to prepare.

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Executive Summary

The Senator Tomassoni Caregiver Support Program administered by the ALS Association under contract with the Minnesota Board on Aging (MBA), provides respite care funding and caregiver training to families caring for Minnesotans living with Amyotrophic Lateral Sclerosis (ALS).

Key Takeaways:

- Since the Senator Tomassoni Caregiver Support Program launched in 2023, **\$2,788,981** has been expended to support respite services for family members caring for an individual living with ALS, and training for professionals, families and friends providing care. This represents **230 families** receiving **58,602 hours** of respite.
- Between **November 2024 – November 2025**, **\$1,545,784** was distributed through respite grants to **196 families** statewide.
- In May 2024, the Legislature amended statute to transfer contract authority from Area Agencies on Aging (AAAs) to the MBA. **In 2025, the ALS Association contract was transferred from the Arrowhead Area Agency on Aging (AAAA) to the MBA.**
- MBA continues to collaborate with ALS Association and AAAs to ensure equitable statewide access and strengthen caregiver support capacity.

Pursuant to appropriation requirements, this report is submitted by January 15 to chairs and ranking minority members of legislative committees and divisions with jurisdiction over human services. The report includes:

- (1) Number of applicants receiving grants
- (2) Total funds dispersed through respite grants
- (3) Geographic reach of recipients
- (4) Self-reported outcomes from participating families.

Introduction

In May **2022**, the Minnesota Legislature appropriated **\$5,000,000** from the General Fund to support family caregivers of individuals living with ALS in the community, with funds directed toward promoting caregiver support programs, providing cost-effective services, and offering education and training for respite caregivers (**Minnesota Legislature, 2022**). In **2024**, the legislation was amended to authorize the MBA to directly allocate funds for the program, along with an additional one-time appropriation of **\$2,500,000**. Under the updated statute, caregiver support service funds must be used to reach family caregivers of people with ALS, including those under age 60, and must be used to provide social, community-based services and activities that provide social interaction for participants. The funds may also be used to provide respite care (**Minnesota Legislature, 2024**).

Minnesota Legislature. (2022). *Session Law, Chapter 42: Appropriations for ALS caregiver support*. <https://www.revisor.mn.gov/laws/2022/0/Session+Law/Chapter/42>

Minnesota Legislature. (2024). *Minnesota Statutes § 256.9755: Respite care services*. <https://www.revisor.mn.gov/statutes/2024/cite/256.9755>

Program Administrative Changes (2024-2025)

Key changes

- In **July 2025**, the contract between AAAA and the ALS Association ended.
- A new contract was established directly between **MBA and the ALS Association**.
- A expanded grant agreement to begin January 1, **2026**, incorporates additional funding, updated work plans, and clarifies monitoring requirements.

In 2024, the Legislature revised the statute to remove requirements that ALS caregiver support funds be distributed through the AAAs or follow the National Family Caregiver Support Program rules. Previously, the funding flowed through the AAAA, which contracted with the ALS Association to deliver services. That contract ended in July 2025, and a new contract was established between the MBA and the ALS Association. The new agreement included a planning period to reassess deliverables and strengthen oversight. MBA will execute a new grant agreement for January 1, 2026, that incorporates updated funding from the 2024 legislative changes, along with revised work plans and monitoring requirements.

Respite Grant Amounts

At the start of the Senator Tomassoni Caregiver Support Program, families providing care to an individual with ALS had the opportunity to apply through the ALS Association for a respite grant up to \$25,000 per year. Due to a strong response initially, the maximum was reduced to \$20,000 per year on 2/1/2024. Upon reevaluation of available funding, in early 2025, the maximum respite grant award amounts were increased to \$25,000 per year.

- Original maximum: **\$25,000 per family per year**
- Reduced to **\$20,000** in February 2024 due to demand
- Restored to **\$25,000** in early 2025 following funding review

This report summarizes program activity through **November 2025**, including:

- Number of families served
- Respite services delivered
- Education and training provided
- Reported impacts on caregivers and families

Senator Tomassoni Caregiver Support Program

The ALS Association manages the Senator Tomassoni Caregiver Support Program offering financial assistance to help offset in-home care expenses and provides education for both unpaid family caregivers and paid professional caregivers in Minnesota. Eligible caregivers of individuals living with ALS may apply for funding to support the costs of in-home care.

Eligibility

- The person living with ALS must reside in Minnesota.
- One application per family will be accepted on an annual basis.
- A caregiver evaluation (and re-evaluation) will be required.

Caregiving Supportive Services Reach

Since the launch of respite grants through the ALS Association, 230 families have received funds to hire professional caregivers through a home care agency or an individual of their choice, other than a spouse/partner, parent, or child of the person with ALS. Families choosing self-directed services are referred to a Fiscal Management Service (FMS) for employment and payroll management of the hired individual.

- **November 2024 – November 2025**
 - **Total hours of respite funded: 58,602**

- Provided by Home Care Professionals: 22,378 hours
 - Self-Directed Care: 36,224 hours
- **196 families served**
- **155 applications received**
 - 141 approved and funded
 - 3 ineligible
 - 5 individuals passed away before receiving services
 - 3 withdrew
 - 3 pending

These families reside across Minnesota with the majority living in the seven-county metropolitan area (136). Additional regions include Central Minnesota (32), Southwestern Minnesota (21), Northeastern Minnesota (15), Northwestern Minnesota (13) and Southeastern Minnesota (13). Households receiving support represents 47 of the 87 counties in Minnesota.

Cost of Respite Provided

Since the Senator Tomassoni Caregiver Support Program launched, and the first respite grant was issued in late 2023, **\$2,788,981** has been expended to support direct services for family members caring for an individual living with ALS, and training for professional and family and friend caregivers.

Education and Training: Nov. 2024 – Nov. 2025

The ALS Association delivered:

- Two virtual trainings
- Two in-person learning labs

Participation included:

- 28 families (virtual)
- 9 families (learning labs)
- 27 caregiver consultants

The virtual training includes an overview presentation of ALS, ALS Association’s programs and services and an opportunity to ask questions to a nurse professional.

The learning lab offers families the opportunity to learn about equipment available to support the care of an individual with ALS, observe demonstrations and have hands-on experiences with equipment, communications aids and Smart Home devices.

Caregiver consultants, representing Home and Community-Based Service providers across Minnesota attended ALS focused trainings to better understand the needs of individuals caring for a person living with ALS. Family and friend caregivers attending the trainings are introduced to caregiver consultation during the training, as an additional resource to assist them in their caregiving role. A registry of caregiver consultants who attended trainings will be incorporated into a caregiver consultation referral process under development by ALSA and MBA. These referrals will connect caregivers with professionals in their communities who can assist with access to local resources, support groups, caregiving education and ongoing support.

Impact on Families Served

Families reported that the program:

- Reduced financial stress
- Improved caregiver well-being
- Enabled individuals with ALS to remain safely at home
- Provided peace of mind during a highly challenging time

Selected feedback:

- “The grant eased our worries and allowed us to focus on family.”
- “We could not have afforded the care without this support.”
- “It gave us the help we needed, when we needed it.”
- “The program allowed my daughter to live safely and comfortably.”