The Impact of ALS: Current Perspectives from the ALS Community and American Public

At a Glance

In 2024, I AM ALS conducted two surveys to capture needs and gaps among 1) those directly impacted by or living with ALS as well as 2) current awareness of ALS among the general public. 947 individuals completed the survey assessing the needs of people living with and impacted by ALS, and 10,000 people responded to the survey assessing awareness of ALS. For the purposes of this paper, we have analyzed 10,000 general public respondents and 657 respondents who identify as people living with ALS and primary caregivers to assess their challenges, needs, pain points, and gaps in care.

Major themes that emerged from the surveys were:

- **Low public awareness of ALS**: Although 20% of respondents noted that they personally knew someone diagnosed with ALS, 70% had never heard of or knew little to nothing about ALS, and 90% could not name an organization that supports people living with ALS.
- **Impact of the overall financial burden related to ALS**: ALS is a costly disease, and 74% of caregivers and 68% of people living with ALS said this was their top challenge. They also highlighted high expenses related to home health, devices/equipment, and/or home modifications.
- **Strain on social and emotional wellbeing**: People living with ALS reported a wide range of challenges, including loss of independence, increased emotional strain, inability to engage in enjoyable activities, and feelings of social isolation. 67% of caregivers and 55% of people living with ALS noted feelings of isolation from family and friends. Caregivers also reported increased emotional strain, physical exhaustion, and decreased time for self-care.

Findings from these surveys highlighted several key opportunities to address:

- **Expand collaboration and coalition-building** across the ALS community and neurodegenerative disease advocates to improve care, accelerate cures, and drive other common advocacy efforts.
- **Engage the public to increase urgency for and awareness of ALS** and other neuro diseases to move collective priorities forward.
- **Improve social, emotional and advocacy systems** for people living with ALS and their loved ones, including community-based services, advisory councils, and resource sharing.
- **Address financial hardship** of people living with ALS and their caregivers through systems and policy changes.

Background

Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, is a neurodegenerative disease that slowly kills motor neurons, losing the ability to move, speak, eat, and breathe. Unfortunately it is 100% fatal, with life expectancy averaging only 2 to 4 years after diagnosis.

According to the National ALS Registry, there were nearly 33,000 people in the United States living with ALS in 2022. This number is projected to increase more than 10% by 2030.[1] Globally, this number is projected to increase by 70% by 2040.[2] Because ALS is not a notifiable disease, identifying cases presents a challenge; these numbers are likely higher. Further, there are specific populations that see higher rates than others. In the U.S., the estimated demographic makeup of people living with ALS in 2018 were male (60%), female (40%), White (71%), Black (6%), Other races (5%), less than 50 years old (10%), 51-65 years old (26%), and 66 and older (48%).[3]

Like other rare diseases and similar neurodegenerative diseases (NDs), ALS is an emerging area of research, with more needed to collect more robust surveillance data, to recognize signs and symptoms, to develop more effective treatments and therapies, and to understand the needs of people living with ALS and their caregivers.

To better understand and respond to the current landscape, I AM ALS led two surveys in 2024 to collect current data on ALS awareness, needs, and gaps through the lens of both the general public and also those directly impacted by or living with ALS. This paper presents and discusses key findings from the ALS patient and caregiver survey, as well as themes from the general public survey.

Survey Methods

ALS Patient and Caregiver Survey

I AM ALS worked with Inspire Inc. to develop, recruit, and disseminate a survey to the ALS Community. Participants were recruited through existing I AM ALS channels including social media, e-mail, and outreach from I AM ALS Board members to their networks. I AM ALS also promoted the survey through partner organizations. The survey was open from September 16-November 21, 2024. 947 people completed the survey. Respondents were people living with ALS, primary caregivers of a person living with ALS, individuals who have a loved one living with ALS, and individuals who have lost someone to ALS. Most survey respondents (69%) were either a person living with ALS (n=356) or a primary caregiver (n=301). Data was analyzed using Stata 18. Basic frequencies of all questions were generated, with additional crosstabulations and stratified frequencies by person living with ALS or primary caregiver, race/ethnicity, income, and insurance. Where applicable, row percentages, column percentages, and chi 2 statistics were also included.

Public Awareness Survey

I AM ALS worked with Inspire Inc. to develop, recruit, and disseminate a survey to two panels representative of the U.S. population. Panels were recruited and completed the survey from September 11- 20, 2024 and October 5-9, 2024. The two panels combined resulted in 10,000 people completing the survey. Data was analyzed using Excel.

---

[1]https://www.tandfonline.com/doi/full/10.1080/21678421.2024.2447919#abstract
[2]https://www.nature.com/articles/ncomms12408#Abs1
[3]https://www.tandfonline.com/doi/full/10.1080/21678421.2023.2245858#d1e400

Findings

People Living with ALS and Primary Caregivers

For people living with ALS, survey respondents were split between men (52%) and women (47%). Most individuals (64%) were between the ages of 50-69, but notably 11% of people living with ALS were between the ages of 18-39. 79% of people living with ALS were White and 13% were Hispanic. Many people living with ALS were insured through Medicare (63%) and close to half are retired. Nearly one third (29%) of people living with ALS reported not being able to work.

Primary caregiver survey respondents were mostly women (70%), followed by men (30%). Slightly over half (51%) were between the ages of 50-69, while only 13% of caregivers were between the ages of 18-39. Caregivers were also predominantly White (81%) followed by Hispanic (14%). More than half of caregivers were insured through Medicare (56%). Compared to people living with ALS, more caregivers reported being employed full time (38%) or part time (10%) or retired (31%). *For more information on the sociodemographic makeup of respondents, see Table 1 in the Appendix.*

Impact of an ALS Diagnosis

People living with ALS and primary caregivers reported numerous challenges including the overall financial burden ALS, access to health care services, navigating health insurance, management of symptoms between clinic visits, and social isolation. Yet, both people living with ALS and primary caregivers reported the same top three challenges:

- Overall financial burden related to ALS
- Expenses related to home health, devices/equipment and/or modifications
- Isolation from family and/or friends

Overall Financial Burden

In the survey, 74% of caregivers and 68% of patients cite the overall financial burden of ALS as a top challenge. Studies estimate the annual cost of health care for people living with ALS is in the tens of thousands of dollars. This number increases as the disease progresses: one study estimated that people with early-stage ALS spent an average of $31,000 annually while people with late-stage ALS spent $122,000 annually.[4] The biggest cost drivers include in-home care, ventilation, and inpatient hospital care.[5] One study estimated the annual cost of healthcare for people with ALS in the U.S. to be $1 billion.[6] While the overall financial burden is significant for all people impacted by ALS, it is important to note that in the survey, Hispanic, Black, and Asian people living with ALS or people living with ALS who are uninsured reported an increased financial burden compared to their insured counterparts.

Cost and Access to Care

Other major challenges faced by patients include navigating insurance, accessing treatments, and affording medication co-pays. Caregivers similarly report challenges navigating insurance as well as accessing reliable and knowledgeable home health care and ancillary health professionals such as physical, speech, and occupational therapists, and finding emotional support like counseling and other support groups.

Further, people living with ALS are often unable to work or have to retire early due to their diagnosis. 46% of people living with ALS noted undesirable changes to employment status as a result of their disease. Black people living with ALS (64%) or Asian people living with ALS (100%) reported higher rates of undesired changes to employment compared to White people

[4] https://www.jmcp.org/doi/10.18553/jmcp.2024.30.11.1239
[5] https://pubmed.ncbi.nlm.nih.gov/25245119/
[6] https://www.tandfonline.com/doi/full/10.1080/21678421.2023.2165947#abstract

living with ALS (47%). Additionally, people living with ALS whose income was less than $50,000 a year reported higher undesired changes to employment compared to people living with ALS in other income groups.

Similarly, caregivers may not be able to work or must work part time to be a full-time caregiver, resulting in lost income and potentially lost health insurance. In the survey, 35% of caregivers noted undesired changes to employment status and 14% indicated a loss of health insurance due to employment changes. Further, Black caregivers reported higher levels of undesired employment and loss of health insurance compared to other caregivers. Also, caregivers whose income is less than $50,000 a year also reported higher undesired changes to employment status compared to caregivers in other income groups.

Home Health Care

A persistent theme in responses to questions of challenges, impacts, and pain points for caregivers and patients was the need for reliable, affordable in-home care. 72% of caregivers and 63% of patients cited the expenses of in-home healthcare and 65% of caregivers and half of patients cited simply accessing reliable and affordable home healthcare as challenges. More than half of caregivers (65%) and people living with ALS (53%) indicated that access to affordable in-home care would improve the quality of medical care. As with the overall financial burden, Black or Hispanic people living with ALS and caregivers, people living with ALS and caregivers who are uninsured, or had an income of less than $50,000 a year had increased challenges related to home health care. Caregivers (54%) and people living with ALS (48%) also noted insurance coverage of in-home care would improve quality of life.

Long term in-home care is often not covered by private insurance. Notably, Medicare does not cover full-time in-home care or most long-term care services. Medicaid and VA insurance covers some care options, while private insurers may cover some as well. People living with ALS and their caregivers must navigate multiple coverage options or pay out of pocket for these services. Additionally, not only are in-home care services in high demand and costly, there are concerns over trust, safety, and efficacy.[7]

Social, Emotional, and Physical Impact of ALS

67% of caregivers and 55% of people living with ALS noted the challenges of isolation from family and friends. However, social isolation is not the only impact people living with ALS and caregivers experience. People living with ALS report a wide range of impacts, including loss of independence (77%), increased emotional strain (65%), inability to engage in enjoyable activities (65%), feelings of social isolation (49%), new mental health challenges (45%), and strained relationship dynamics (41%). Notably, 45% of patients experienced challenges in finding meaning or purpose after an ALS diagnosis.

Clinical Trials

Half of people living with ALS and 42% of caregivers were interested in access to clinical trials or experimental treatments, but over half of people with ALS (58%) had not participated in a

[7] https://www.ihi.org/sites/default/files/2023-10/PatientSafetyInTheHome_2017.pdf

Caregivers consistently indicated an ALS diagnosis increased their emotional strain (75%), physical exhaustion (75%), decreased time for self-care (70%), increased financial burden and worry (68%), and social isolation (62%). More than half of caregivers (53%) noted they were the sole primary caregiver for their loved one with ALS and additional family members, which can increase overall caregiver burden and strain. *For more information on significant pain points experienced by primary caregivers see Table 2 in the Appendix.*

clinical trial. Of those respondents, about a third did not meet the criteria for a clinical trial and about a quarter were not aware of any trials. There is an opportunity for providers and care teams to better connect people living with ALS with clinical trials and expanded access programs.

Sources for Help

Most people living with ALS (79%) and primary caregivers (87%) asked for help to address challenges faced. People living with ALS (67%) and caregivers (69%) predominantly turned to neurologists for help with their challenges. Friends and family were also a common source who people living with ALS and primary caregivers turned to for help. Underutilized sources to help address challenges included nurses, social workers, and non-profit organizations.

Services to Improve Medical Care and Quality of Life

People living with ALS have complex and expensive care needs, including medications and other treatments, durable medical equipment, mobility and communications devices, accessibility accommodations, multiple doctors and other ancillary health professionals like speech and occupational therapists, and other support personnel like nurse and patient navigators.[8]

When asked what services could improve the quality of medical care, 65% of caregivers and over half of people living with ALS stated affordable in-home care, and 54% of caregivers and 48% of patients noted insurance coverage for in-home care, further emphasizing the need for home health services. Nearly half of caregivers expressed interest in respite care (49%) and support with preparing for end of life (45%). Notably, less than a third of people living with ALS indicated interest in support for end-of-life and respite care. Respite care was a distinct priority for caregivers, following similar trends in responses to pain points and other challenges.

Further, 42% of people living with ALS were interested in information about potential symptoms and how to best manage them, while 40% sought support resources like counseling or financial assistance. People living with ALS noted that more awareness of community resources and how to access them (36%) and financial assistance for other ALS-related needs (34%) would improve their quality of life. Caregivers were interested in information about symptoms and management (54%), but notably also sought resources on the emotional and mental health impacts of ALS (52%) and training for caregivers (49%). *For more information on services needed to improve medical care and quality of life of people living with ALS and primary caregivers see Table 3 and 4 in the Appendix.*

Public Awareness of ALS

In the 2024 survey, 20% of the public awareness respondents knew someone who had ALS. Given respondents were a representative sample of the U.S. population, this suggests approximately 68 million people in the U.S. know someone with ALS. While ALS is considered a

[8] https://pubmed.ncbi.nlm.nih.gov/37248728/

rare disease[9], this potential finding underscores the pervasiveness of the disease, and paired with results from the patient and caregiver survey, highlights the significant social, emotional, and financial impact ALS causes in communities across the U.S.

However, there is still an urgent need to raise awareness about ALS, its impact, and available resources to support communities. 90% of respondents, whether they knew someone with ALS or not, did not know of any organizations that support people with ALS and their loved ones. In fact, 70% of respondents had either never heard of ALS or knew little to nothing about it. When asked about other neurodegenerative diseases, many respondents had either never heard of or knew little to nothing about Alzheimer's disease (31%), Parkinson's disease (31%), and Dementia (40%). These results demonstrate that there is more work needed to raise awareness for ALS specifically, but collective efforts could bring substantial benefits for all neurodegenerative diseases.

The Ice Bucket Challenge has been the most prominent annual event for the past 10 years by the ALS community to help raise awareness about and funds for ALS research. However, less than half of survey respondents (46%) connected the Ice Bucket Challenge as a fundraiser for ALS. In addition, respondents were asked if their knowledge or awareness about ALS had changed over the past 10 years and 38% indicated no changes. Finally, in comparison to responses from previous I AM ALS public awareness surveys[10], there appears to be a decline in awareness of the Ice Bucket Challenge over time. The percentage of respondents who were aware in 2024 was 46%, down from 49% in 2018, indicating an overall decline in awareness of the Ice Bucket Challenge and raising a need for more work in this area.

Calls to Action

These surveys underscore and highlight critical calls to action that must be addressed to continue to improve care and move research forward, which are:

- **Expand collaboration and coalition-building** across the ALS community and neurodegenerative disease advocates to improve care, accelerate cures, and drive other common advocacy efforts
- **Engage the public to increase awareness of ALS** to help move collective priorities forward
- **Improve social and emotional support systems** for people living with ALS and their loved ones, including community-based services, advisory councils, and resource sharing
- **Address financial hardship** of people living with ALS and their caregivers through systems and policy changes

Expanded Access Programs

EAPs are a potential pathway to help patients with serious diseases or conditions get access to medication when there are no other available treatment options. However, close to half of people living with ALS (44%) and primary caregivers (49%) did not know about EAPs, and only 14% of people living with ALS reported being enrolled in an EAP. Given the current treatment landscape for ALS, it is important to raise awareness about EAPs and continue to grow this option.

[9] https://rarediseases.info.nih.gov/diseases/5786/amyotrophic-lateral-sclerosis
[10] https://www.iamals.org/wp-content/uploads/2024/04/IAMALS_Ipsos_ALSStudyTopline-1.pdf

Expand Collaboration and Coalition-building

While ALS is a rare disease and an emerging advocacy area, organizations focused on neurodegenerative diseases have an opportunity to learn from advocates in other health areas, such as cancer or maternal and child health, who have successfully advocated for significant changes to health care delivery and research over time. For neurodegenerative disease advocacy groups there is an opportunity to build on efforts and potentially cross-collaborate with other health groups to address issues, such as:

- resources for caregivers
- financial support for home health or long-term care
- support for expanded access programs
- funding for basic and clinical research.

Further, neurodegenerative disease groups could collaborate to establish centers of excellence for neurodegenerative diseases to both raise the standard of care, recognize excellence in clinical care, and share successful models of multidisciplinary care which engages the full range of care professionals, including patient navigators, social workers, occupational and physical therapists, speech therapists, and more.

In addition, since ALS lacks a definitive standard of care, collaboration and coalition-building could increase awareness among multidisciplinary health care providers through education and training. These opportunities can directly impact the quality of care that people living with ALS receive. Providers will be better equipped to recognize the early signs and symptoms of ALS or identify people who are at higher risk for ALS because of genetics and other factors. Also, with an informed network of multidisciplinary providers, they could quickly connect people living with ALS to clinical trials or EAPs, and implement navigation support services to address financial hardship, access to accessibility tools and devices, and other care services.

In 2024, I AM ALS launched the Cures Collective, an ALS and neurodegenerative disease coalition to identify gaps, reduce duplication, increase effectiveness, and unlock critical breakthroughs by uniting advocates and organizations that are committed to ending NDs. The goal of the Cures Collective is to unify the neurodegenerative disease field, accelerate finding treatments and cures, and increase and improve access to care through intentional collaboration, and sustained public awareness and mobilization. This coalition can serve as an example or a launch pad to even broader efforts across neurodegenerative diseases.

Engage the Public

The 2024 survey demonstrated a clear need for increased awareness of ALS and other neurodegenerative diseases. It is worth noting that while ALS is a rare disease, it shares commonalities with other neurodegenerative diseases like Parkinson's, Alzheimer's, and related dementias. There is a distinct benefit to engaging the public, so they too can advocate for collective ALS and neurodegenerative disease priorities among policymakers, private sector leaders, and scientific researchers.

Support for People Living with ALS and Caregivers

It is imperative to center the ALS community and listen to their needs first. The 2024 survey demonstrated significant gaps in support for social and emotional needs, especially feelings of isolation from family, friends, and loved ones. Caregivers of people living with ALS could greatly

benefit from resources to support their specific needs, such as respite care or help navigating end of life. Opportunities to address these needs include but are not limited to:

- Health care systems and scientific researchers forming patient advocacy councils to address priorities
- Health care providers/systems collaborating with existing ALS patient advocacy organizations to connect people living with ALS and their caregivers with education, resources, support, and a community of peers

Address Financial Hardship

Financial hardship was another clear theme in the 2024 survey. Both people living with ALS and their caregivers noted significant impacts and challenges with the overall financial burden of ALS, but the cost of home health care was a standout challenge. This is not unique to ALS; most neurodegenerative diseases and other serious or chronic conditions that require home health care are extremely costly, particularly in the U.S. Insurance coverage for long term and home health care could go a very long way to improving the lives of people living with ALS and their loved ones. A specific need for this community is medical devices and equipment or other accessibility tools, particularly as the disease progresses and motor neuron functions decline. People living with ALS need mobility devices like power wheelchairs, speech and communication tools, and equipment for basic functions like breathing and eating. They may also require adjustments to their living spaces or have limited transportation access. These are serious challenges for this community and will require creative and collaborative solutions to solve.

Conclusion

The 2024 I AM ALS surveys reveal a portrait of the lived experience of ALS and the widespread lack of public awareness about the disease. While people living with ALS and their caregivers face immense challenges—financial strain, inadequate home health support, and deep emotional and social isolation—the general public remains largely unaware of ALS and its profound impacts, despite 20% of people personally knowing a person with ALS. This gap in understanding underscores the urgent need for coordinated action across advocacy, healthcare, and policy systems. Addressing these challenges will require expanding coalition-building efforts, strengthening support systems, and confronting the financial burdens tied to care, as well as the urgency to access emerging therapies. Ultimately, by centering the voices of those most affected and uniting stakeholders around shared goals, we can advance meaningful progress toward a future where people living with ALS receive the care, dignity, and hope they deserve.

Acknowledgements

I AM ALS would like to share its deepest gratitude to the ALS community, especially people living with ALS and caregivers of those living with ALS for their time, effort, and partnership. Thank you to all survey participants for sharing their experiences, and our sincere gratitude to our partners who distributed the survey including ALS United Arizona, ALS United Connecticut, ALS United Greater Chicago, ALS United Mid-Atlantic, ALS Network, ALS United New York, ALS United North Carolina, Bridging Voice, MAC Angels Foundation, Matt's Place Foundation, and the ALS Association. I AM ALS would also like to thank our board members and Inspire Inc.

for their support with designing and executing the surveys, and Rhizome, LLC for analysis support.

Appendix

Table 1. Sociodemographic Characteristics of Respondents

	Person Living with ALS		Primary Caregiver	
Characteristic	*Percent*	*Number*	*Percent*	*Number*
Gender				
Man	52%	185	30%	88
Woman	47%	169	70%	212
Non-binary	0.3%	1	0%	0
Age				
18-29	7%	25	3%	9
30-39	4%	14	10%	30
40-49	11%	40	20%	59
50-59	25%	88	25%	75
60-69	39%	139	26%	78
70-79	13%	45	15%	47
80 or older	1%	4	1%	3
Race/Ethnicity				
Hispanic	13%	45	14%	41
White	79%	283	81%	245
Black or African American	4%	14	3%	8
Asian	2%	7	1%	4
Other Race	2%	6	0.3%	1
Multiple Races	0.3%	1	0.7%	2
Insurance Status*				
Private	41%	146	39%	118
Medicare	63%	225	56%	168
Medicaid	9%	33	17%	50
Veterans Affairs	10%	37	12%	35
Tricare	8%	27	5%	16
No health insurance	2%	6	3%	8
Other	10%	36	11%	33
Income				
Under $50,000	24%	74	25%	62
$50,000-$99,999	35%	105	36%	89
$100,000+	41%	125	40%	99
Employment Status				
Full time	13%	45	38%	112
Part time	7%	25	10%	28
Unemployed	7%	24	7%	20
Unable to work	29%	102	5%	15
Retired	42%	147	31%	92
Self Employed	2%	6	6%	19
Student	0%	0	0.7%	2

*Survey respondents could select all that apply

Table 2. Significant Pain Points Experienced as Primary Caregiver

	Primary Caregiver	
Pain Point*	*Percent*	*Number*
Coordinating and managing care for my loved one	54%	162
Being the sole primary caregiver for my loved one living with ALS and additional family members	53%	159
Supporting children with processing the impact of ALS on a parent/loved one	26%	79
Lack of time for self-care activities	60%	182
Undesired changes to employment status including early retirement, extended leave, etc.	28%	84
Reduction in household income	44%	131
Loss of health insurance related to employment changes	11%	34
Finding and paying for in-home caregivers with expertise in ALS	45%	135
Accessing trusted respite care	35%	104
Feeling emotionally and mentally overwhelmed	77%	231
Financial strain and worry	56%	169
Finding affordable and reliable accessible transportation	22%	65
Physical demands	64%	193
Lack of information/resources	32%	95

*Survey respondents could select all that apply

Table 3. Services that Could Improve Quality of Medical Care

	Person Living with ALS		Primary Caregiver	
Service*	*Percent*	*Number*	*Percent*	*Number*
Virtual visits to address new symptoms and needs	25%	89	35%	104
Virtual and/or in-person visits to check on caregivers' health	29%	102	41%	123
Virtual and/or in-person visits to provide training to caregivers	34%	122	49%	148
Information about potential symptoms to anticipate and how to manage them	42%	150	54%	164
Information about the impact of ALS on cognitive health	30%	106	41%	123
Education and resources for the impact of ALS on emotional and mental health for the person living with ALS and caregivers	37%	130	52%	157
Access to clinical trials and experimental treatments	50%	179	42%	127
Access to assistive devices and equipment	40%	141	37%	112
Access to affordable in-home care	53%	190	65%	195
Access to support resources, i.e. counseling, financial assistance, etc.	40%	143	44%	132

*Survey respondents could select all that apply

Table 4: Services that Could Improve Quality of Life

	Person Living with ALS		Primary Caregiver	
Service*	*Percent*	*Number*	*Percent*	*Number*
Insurance coverage of in-home care	48%	172	54%	163
Insurance coverage for medical equipment	17%	59	17%	51
Financial assistance for other ALS-related needs	34%	120	30%	90
Guidance with helping children process the impact of ALS on a parent/loved one	16%	58	24%	73
Connecting with or receiving support from another person impacted by ALS with similar experiences	28%	101	40%	119
Awareness of available community resources and how to access them	36%	129	43%	130
Support groups	21%	75	27%	82
Guidance in how to ask for help and/or build a support system	21%	75	40%	120
Support with preparing for end of life	32%	114	45%	134
Counseling	24%	84	31%	94
Respite care for ALS	28%	100	49%	147
Legal advice	27%	96	33%	100

*Survey respondents could select all that apply

References

Arthur, K., Calvo, A., Price, T, Geiger, T., Chió, A., Trayner, B. (2016). Projected increase in amyotrophic lateral sclerosis from 2015 to 2040. *Nature Communications*, 7. https://doi.org/10.1038/ncomms12408

Berry, J. D., Blanchard, M., Bonar, K., Drane, E., Murton, M., Ploug, U., … Heiman-Patterson, T. (2023). Epidemiology and economic burden of amyotrophic lateral sclerosis in the United States: a literature review. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, *24*(5–6), 436–448. https://doi.org/10.1080/21678421.2023.2165947

Institute for Healthcare Improvement. (2017). *Patient Safety in the Home Assessment of Issues, Challenges, and Opportunities*. Cambridge, MA. https://www.ihi.org/sites/default/files/2023-10/PatientSafetyInTheHome_2017.pdf

Ipsos. (2018). *ALS Survey: Awareness, Knowledge, Fundraising.* Chicago, IL. https://www.iamals.org/wp-content/uploads/2024/04/IAMALS_Ipsos_ALSStudyTopline-1.pdf

Mehta, P., Raymond, J., Nair, T., Han, M., Berry, J., Punjani, R., … Horton, D. K. (2025). Amyotrophic lateral sclerosis estimated prevalence cases from 2022 to 2030, data from the national ALS

Registry. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 1–6. https://doi.org/10.1080/21678421.2024.2447919

Mehta, P., Raymond, J., Zhang, Y., Punjani, R., Han, M., Larson, T., … Horton, D. K. (2023). Prevalence of amyotrophic lateral sclerosis in the United States, 2018. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, *24*(7–8), 702–708. https://doi.org/10.1080/21678421.2023.2245858

National Academies of Sciences, Engineering, and Medicine. (2023). *Amyotrophic Lateral Sclerosis: Accelerating Treatments and Improving Quality of Life: Proceedings of a Workshop–in Brief*. Washington, DC: The National Academies Press. https://doi.org/10.17226/27395.

National Center for Advancing Translational Sciences: Genetic and Rare Diseases Information Center. (2025). *Amyotrophic lateral sclerosis*. https://rarediseases.info.nih.gov/diseases/5786/amyotrophic-lateral-sclerosis

National Institute of Neurological Disorders and Stroke. (2023). *Priorities of the NIH Amyotrophic Lateral Sclerosis Strategic Planning Working Group*. Bethesda, MD. https://www.ninds.nih.gov/sites/default/files/documents/ALS%20Strategic%20Plan_11_20_23_508C.pdf

Obermann, M., & Lyon, M. (2015). Financial cost of amyotrophic lateral sclerosis: a case study. *Amyotrophic lateral sclerosis & frontotemporal degeneration*, *16*(1-2), 54–57. https://doi.org/10.3109/21678421.2014.951946

Stenson, K., Chew, S., Dong, S., Heithoff, K., Wang, M., Rosenfeld, J. (2024). Health care resource utilization and costs across stages of amyotrophic lateral sclerosis in the United States. *Journal of Managed Care & Specialty Pharmacy, 30*(11). https://doi.org/10.18553/jmcp.2024.30.11.1239

Young, H. M., Kilaberia, T. R., Whitney, R., Link, B. M., Bell, J. F., Tonkikh, O., Famula, J., & Oskarsson, B. (2023). Needs of persons living with ALS at home and their family caregivers: A scoping review. *Muscle & nerve*, *68*(3), 240–249. https://doi.org/10.1002/mus.27849