

ALS Focus Survey 1 Key Findings Show High Financial Burden in the ALS Community

People with ALS and their caregivers face a substantial burden accessing and understanding insurance coverage and paying for medical treatments and services, causing high stress, added work burden and debt for the ALS community. These barriers to accessing insurance lead to financial burdens that demand attention in our community.

The findings come from the first ever ALS Focus survey, which The ALS Association and its partners conducted earlier this year, focusing on “understanding the insurance needs and financial burden” of people with ALS.

- The costs for medical treatments and services topped the list of stressors for respondents with ALS.
- Almost half of respondents living with ALS stated that understanding medical insurance coverage and dealing with medical paperwork impacted their stress level substantially.
- One in four respondents say that they experienced debt or had to borrow money due to ALS treatment or caregiving.
- Almost a quarter of respondents said that they had worked longer than they had planned to after their ALS diagnosis or the diagnosis of the person they care(d) for, and of those, nearly half said it was because they needed to keep their health insurance.
- One in 10 respondents said they lost their health insurance coverage after their ALS diagnosis.

ALS FOCUS

Key findings from the Spring 2020 Focus survey, “UNDERSTANDING INSURANCE NEEDS AND FINANCIAL BURDENS”

1 out of 4

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Almost 1/4 of
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1/4

ALS Focus brings
the perspectives of
people with ALS and their
caregivers to the forefront of
research, care, and advocacy.

1 in 10

respondents
said they **lost
their health
insurance** coverage after an
ALS diagnosis.



Of those respondents, **nearly
1/2 worked longer than
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**keep their health
insurance.**



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To learn more about ALS Focus and to sign up for the next survey,
visit www.als.org/als-focus.



The ALS Association Core Values: COMPASSION. INTEGRITY. URGENCY

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The challenges of paying for health care could be even more pronounced than the data indicates: most of the people who participated in the survey were in a mid- to high socioeconomic bracket. The ALS Focus team is committed to finding better ways to reach those

in U.S. in remote areas and with the greatest need to better understand their burdens to improve their quality of life.

Over a period of 10 weeks, 530 people filled out demographic information and 444 people from all over the U.S. completed the insurance and financial burden survey.

The ALS Association is committed to taking these results and working with our partners in the pharmaceutical and insurance industries to turn them into action and inform crucial changes in our system. All information collected is open and free to researchers, clinicians, and anyone who wants to learn more. In addition, all data is de-identified and protected using a unique code called a global unique identifier (GUID), which is also used to combine data with other rich data sets that broadens the impact of participation.

On August 14th, we are launching survey 2 around “what matters most” to people with ALS and caregivers. This three-minute survey delves into how ALS symptoms and daily functions impact their lives. Participating will help the Association and ALS community find ways to improve quality of life. Look-out for that announcement soon!

ALS Focus is a patient- and caregiver-led survey program that asks people impacted by ALS about their needs and burdens. A committee of 18 people with ALS and caregivers inform survey topics and every step of the survey development process. The goal is to learn about individual experiences throughout the disease journey so that the entire ALS community can benefit. Your opinions matter to help strengthen the care, accelerate therapy development, improve clinical trials, influence insurance coverage decisions, and more.

Learn more and how to participate here: www.als.org/als-focus/