

Understanding the Needs of People Affected by ALS

On November 5, 2019, I AM ALS launched a survey designed to understand the challenges experienced by ALS patients, caregivers, loved ones and surviving caregivers as a result of an ALS diagnosis. The survey was anonymous and received 841 complete responses.

30%
Patients

26%
Caregivers

21%
Loved Ones

32%
Lost Someone
to ALS

The below represent the top five challenges respondents experienced.



46% had difficulties with modifying their home



44% had difficulties finding in-home caregivers



44% had difficulties finding information about research and clinical trials



43% had difficulties finding information about treatment options



42% had difficulties with finances

81% asked for help with their challenges from a neurologist (61%), friends or family (45%) or a non-profit (44%)



65% who asked for help reported that they still experienced one or more challenges



30% disagreed that it is easy to find trustworthy information about ALS online

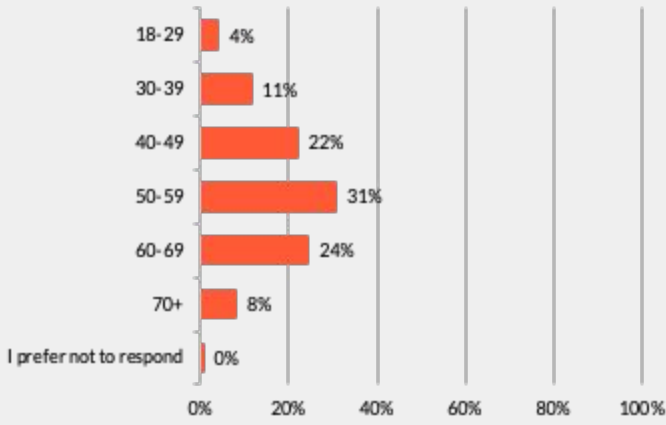


The top five things that would help respondents navigate ALS:

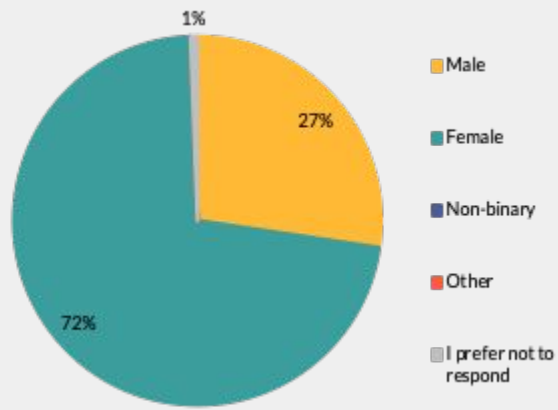
- ❖ More options for professional home health care
- ❖ Access to emotional assistance and support groups
- ❖ Compassionate health care professionals
- ❖ Assistance with financial planning and navigating federal benefits
- ❖ Support with navigating the health system

About Our Respondents

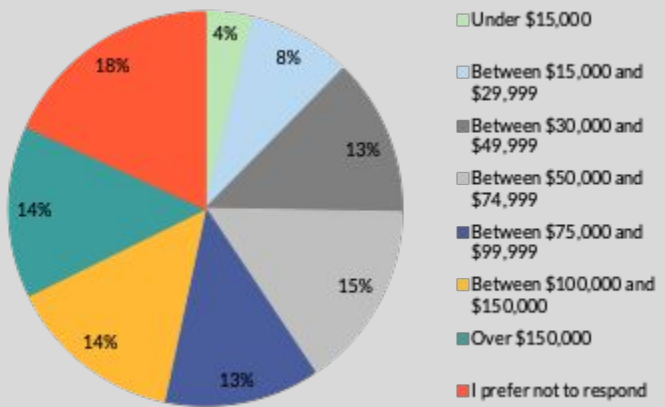
Age



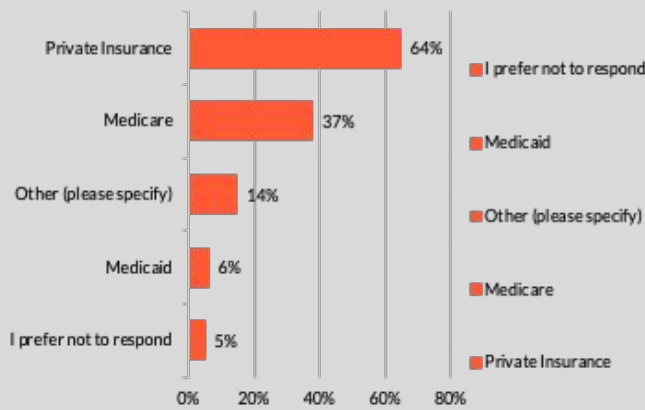
Gender



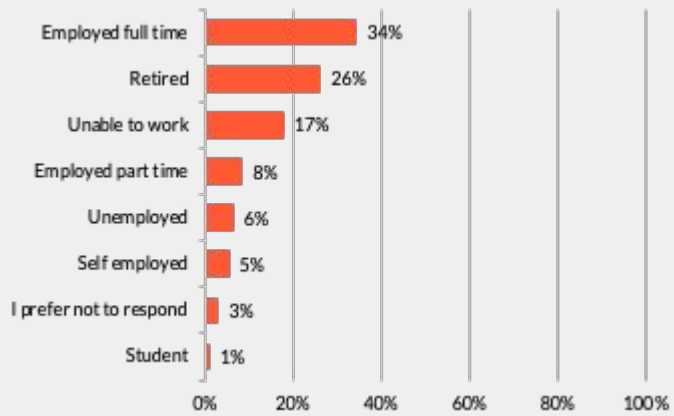
Annual Household Income



Insurance Status



Employment Status



Level of Education

