A guiding document for the International Alliance of ALS/MND Associations is the Fundamental Rights of People Living with ALS/MND (PALS), which states the aspirational rights of the global community. Originally conceived in the late 1990s as the "Baseline of Services for People Living with ALS/MND", these rights represent the ideal for individuals living with ALS/MND and caregivers worldwide. They are updated each year by the Alliance’s PALS and Caregivers of People Living with ALS/MND (CALS) Advisory Council. In 2021, the previously melded PALS and CALS rights became separate documents, and the Fundamental Rights of CALS was launched.

Although the Alliance and its representatives understand that some of these conditions might not be immediately attainable, this document represents the set of rights all Alliance member organizations should adopt and promote as conditions, systems, and resources allow. In April 2021, the Alliance created a survey to ascertain the level of agreement that these rights were being respected for CALS. In May 2023, the second survey of its kind was launched to benchmark against the data captured in its first version.

Respect of the Fundamental Rights of Caregivers (CALS) is universally low and inconsistent, lacking support in all areas including access to remuneration, emotional support programs, palliative care, bereavement advice and services, and social support and respite.

Overall, the figures are low with an average of 39.5% (up from 33.8% in 2021) of Fundamental Rights being respected for caregivers, which is significantly lower than the PALS Survey which had an average of 52%. Caregivers are mostly female (75%) and feel an overall lack of support in all areas. Some specific findings that merit discussion are:

- Only 36% of caregivers report being able to have time to take care of themselves. Only 1 in 3 caregivers agree about receiving social or respite support.
- Rates of support for caregivers in the Global South (34%) were higher than in the Global North (21%).
- The economic impact of ALS/MND is significant: 4 in 5 respondents’ economic situation is affected, 1 in 5 caregivers leave employment, 1 in 5 caregivers make adaptations to their job.
- Support to plan for their future is higher in the Global South.
- Overall data indicates that advocacy remains low. Caregivers are unable to provide input about their experiences or feedback.

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The survey was done by Bramm Research, an independent third party and it was launched both through our member organizations and on social media in May 2023. It was in the field for 60 days. We received close to 2000 responses from 54 countries; 53% of the respondents are CALS. The survey was available in 16 different languages; 75% of CALS respondents are female (81%) (MID).

This could also be represented in a pie chart. Female 75%, male 24%, non-binary/other 1%.

We would like to thank the 1900+ people who responded to the survey, particularly the people living with ALS/MND and their Caregivers. We would also like to thank the PALS and CALS Advisory Council of the International Alliance of ALS/MND Associations who provided feedback and guidance on each iteration of this survey as it was developed.

For more information on this project and others please contact us at alliance@als-mnd.org or visit us at als-mnd.org.