



The International Alliance of ALS/MND Associations supports the following fundamental rights for caregivers of people with ALS/MND (“CALS”):

These fundamental rights represent the ideal for caregivers worldwide. This document is meant for nonprofessional caregivers.

Although the International 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 organisations should adopt and promote as conditions, systems and resources allow.

Caregivers have the right to:

- 1) be treated by all with respect and regarded as experienced in managing the care of their person with ALS/MND.
- 2) receive support in all areas, including:
 - counseling
 - emotional, social and/or respite care programs
 - time to take care of themselves and to seek help as and when they need it
 - palliative care and bereavement advice and services
- 3) receive any available governmental or other economic remuneration, benefits, and entitlements to assist with the provision of care to the person with ALS/MND.
- 4) have access to all elements and mechanisms that will facilitate and help their efforts as caregivers, including:
 - participate in information, resources, education and training that lead to health literacy about ALS/MND
 - to stay with the person with ALS/MND when admitted to medical facilities

- timely appointments and treatments for the person with ALS/MND
 - to ask for a professional support person in all living and care activities
 - having direct communication with the medical team on behalf of their person with ALS/MND with prior consent from the person with ALS/MND
- 5) provide input on the healthcare and support systems, including policymaking, care delivery and the implementation of medical research procedures and protocols that affect both the person with ALS/MND and themselves.

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