



Fundamental Rights for Caregivers of People Living with ALS/MND

The International Alliance of ALS/MND Associations supports the following fundamental rights for caregivers of people living with ALS/MND (CALs).

These fundamental rights represent the ideal standard for caregivers worldwide. This document is intended for non-professional caregivers. Although the Alliance and its member organizations recognize that some of these rights may not be immediately attainable in all countries, this document represents the set of rights all member organizations should adopt and promote as conditions, systems, and resources allow.

Caregivers have the right to:

1. Be treated with dignity and respect, and be recognized as knowledgeable and experienced in the care of their person with ALS/MND.
2. Receive comprehensive support and services for their own well-being, including:
 - counselling;
 - emotional support programs;
 - mental health services;
 - social programs;
 - respite care programs; and
 - the ability to seek help as and when they need it.
3. Receive palliative care advice and services.
4. Receive bereavement advice and services.

5. Receive any available financial support, benefits, or entitlements — whether governmental or private — to assist in providing care to their person with ALS/MND.
6. Access all tools, services, and systems that support their caregiving role, including:
 - education, training, and resources that promote ALS/MND health literacy;
 - the ability to remain with their person with ALS/MND during hospital or clinic admissions;
 - timely access to medical appointments and treatments;
 - the ability to request professional support in daily care and living arrangements; and
 - the ability to communicate directly with the healthcare team, with prior consent from their person with ALS/MND.
7. Contribute meaningfully to the development, implementation, and evaluation of healthcare and support systems — including policymaking, care practices, and medical research — that affect both themselves and their person with ALS/MND.