



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

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 for CALS worldwide. This document is meant for non-professional 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.

CALS have the right to:

- 1) receive support in all areas, including:
 - counselling
 - emotional, social and/or respite care programs
 - time to take care of themselves and to seek help as and when they need it
 - planning for their own future, and
 - palliative care and bereavement advice and services

- 2) have access to all elements and mechanisms that will facilitate and help their efforts as caregivers, including:
 - information and education that will enable them to play an active role in making
 - decisions about care and support
 - regular training and resources to be better able to provide for the person living with
 - ALS/MND at home and
 - timely appointments and treatments for the person living with ALS/MND

- 3) receive any available governmental or other economic remuneration, benefits, and entitlements to assist with the provision of care to the person living with ALS/MND

- 4) 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 living with ALS/MND and themselves.