

RIGHTS OF PEOPLE WITH ALS/MND

THE INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS SUPPORTS THE FOLLOWING FUNDAMENTAL RIGHTS FOR PEOPLE LIVING WITH ALS/MND:

These fundamental rights represent the ideal for individuals living with ALS/MND worldwide.

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.

1. People living with ALS/MND have access to highest quality care and treatment available within their healthcare system.
2. People living with ALS/MND have access to information and education that will enable them and their caregivers to play an active role in making decisions about care and support.
3. People living with ALS/MND have choice with respect to:
 1. health and support workers who are providing treatment or advice
 2. the place where care takes place and
 3. the type of treatment or support that is provided. This includes the right to accept, refuse, or discontinue treatment or intervention within the legal framework of one's own country.
4. People living with ALS/MND have the ability to provide input on the healthcare and support system, including policy-making, care delivery and the implementation of medical research procedures and protocols.
5. People living with ALS/MND have the best quality of life possible, including access to preservation of personal dignity and to humane care, without discrimination.

6. People living with ALS/MND have assurance of confidentiality and privacy regarding their medical records and information.
7. Carers of people living with ALS/MND have access to the highest quality support available, including counseling and bereavement services, respite care and any available government benefits and entitlements.

Resource: International Alliance of ALS / MND Associations ,<http://www.alsmndalliance.org/>