



International Alliance of ALS/MND Associations

Patients Rights

The International Alliance of ALS/MND Associations supports the following as fundamental rights for its members:

1. Equitable access to reasonable and acceptable standards of healthcare.
2. Access to information which will enable the individual ALS/MND patient to play an active role in personal healthcare.
3. Choice with respect to: 1) health workers who are providing treatment or advice, 2) the place where care takes place and, 3) the type of treatment 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. The individual ability to participate in the healthcare system, through consumer representation, in planning and evaluating the system of health services, the types and quality of services, and the conditions under which they are delivered.
5. Preservation of personal dignity and access to humane care, meaning that every patient, whether well or ill, has the right to be treated with care, consideration, and respect, without discrimination.
6. Assurance of confidentiality, wherein privacy is secured until the patient authorizes its release or unless there are compelling medical or legal reasons to divulge the information.

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