



## 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.

People living with ALS/MND have the right to:

- 1) the highest quality care available within their healthcare system
- 2) the highest quality treatment available within their healthcare system
- 3) information and education that will enable them to play an active role in making decisions
- 4) choice with respect to:
  - health and support workers who are providing treatment or advice
  - the location where care takes place, and
  - the type of treatment or support that is provided
- 5) end of life choices which include the right to accept, refuse, or discontinue treatment or intervention within the legal framework of one's own country
- 6) provide input on the healthcare and support systems, including policy-making, care delivery and the implementation of medical research procedures and protocols
- 7) the best quality of life possible
- 8) live without discrimination
- 9) confidentiality and privacy regarding their personal information
- 10) receive any available governmental or other economic remuneration, benefits, and entitlements
- 11) have access, upon diagnosis, to:
  - up-to-date education about clinical genetics in ALS/MND
  - genetic counselling
  - genetic testing
  - safeguards against genetic discrimination
  - subject to education and counselling, blood relatives should also be given the same access, where relevant.