Fundamental Rights for People Living with ALS/MND

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

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

Upon diagnosis — or likely diagnosis — people living with ALS/MND have the right to:

1. Access the highest-quality treatments available.
2. Access approved drugs.
3. Access clinical trials.
4. Receive the highest standard of care.
5. Receive accurate information, tailored resources, ongoing education, and training that promote health literacy and informed decision-making about ALS/MND.
6. Make informed choices with respect to:
    - health and support professionals;
    - the setting in which care is received; and
    - the types of treatment or support they receive.
7. Make end-of-life choices, including the right to accept, decline, or stop treatment within the legal framework of their own country.

8. Contribute to the design, delivery, and evaluation of healthcare and support systems, including policy, care practices, and research.
9. The freedom to have the highest possible quality of life, according to their own values and preferences.
10. Live free from any form of discrimination.
11. Confidentiality and privacy regarding their personal information, and the ability to provide consent for others to communicate on their behalf.
12. Receive any available governmental or other financial support, benefits, and entitlements.
13. Have access to:
    - up-to-date education about clinical genetics in ALS/MND;
    - genetic counselling;
    - genetic testing; and
    - safeguards against genetic discrimination.

Note on genetic rights: Where appropriate, and with education and counselling, blood relatives of people living with ALS/MND should also be offered access to genetic counselling and testing.