A guiding document for the Alliance is the Fundamental Rights of People Living with ALS/MND that states the aspiration rights of the global community. Originally conceived in the late 1990s as the "Baseline of Services for People Living with ALS/MND" these rights are updated each year by the Alliance’s PALS and CALS Advisory Council. In February of 2021, it was identified that the previously mailed CALS and PALS rights needed to be in separate documents as the pandemic had exacerbated the Caregiver burden to the point where it was important to consider these rights separately. Therefore in 2021 the Fundamental Rights of People Living with ALS/MND was launched.

In addition, it was recognized that there needed to be a right added around Genetic Counseling and Testing which we now recognize is an important element to be considered at or near diagnosis.

These fundamental rights represent the ideal for individuals living with ALS/MND. Although the International Alliance and its representatives understand that these conditions might not be immediately attainable, this document represents the set of rights all Alliance member organizations should adopt and promote as conditions, systems and resources allow. Therefore in 2021 the Fundamental Rights of Caregivers of ALS/MND (PALS) and Caregivers (CALS) worldwide.

These fundamental rights represent the set of rights all Alliance member organisations should adopt and promote as conditions, systems and resources allow.

The International Alliance of ALS/MND Associations supports the following fundamental rights for people living with ALS/MND:

1. The right to confidentiality and privacy.
2. The right to access healthcare.
3. The right to genetic counseling.
4. The right to genetic testing.
5. The right to the highest quality of healthcare and treatment.
6. The right to information and education.
7. The right to health insurance.
8. The right to receive care.
9. The right to supplement care.
10. The right of remuneration.
11. The right to support.
12. The right to have care in the individual’s own home.
13. The right to support from qualified professionals.
14. The right to receive care from qualified professionals.
15. The right to counseling and training.
16. The right to advocate for oneself.
17. The right to the right to a living wage.
18. The right to a disability pension.
19. The right to re-employment.
20. The right to support from organizations.
21. The right to the right to remuneration.
22. The right to a legal remedy.
23. The right to social benefit.
24. The right to protective measures.
25. The right to a legal aid.
26. The right to substantial living.
27. The right to personal and family life.
28. The right to personal freedom.
29. The right to personal privacy.
30. The right to personal integrity.
31. The right to personal security.
32. The right to personal autonomy.
33. The right to economic independence.
34. The right to access to all forms of care.
35. The right to freedom of movement.
36. The right to a sense of belonging.
37. The right to a voice in decisions.
38. The right to personal expression.
39. The right to expression of opinion.
40. The right to hear and be heard.
41. The right to have a fortified list of rights.
42. The right to access to the highest quality of healthcare and treatment.
43. The right to information and education.
44. The right to health insurance.
45. The right to receive care.
46. The right to supplement care.
47. The right of remuneration.
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