



FAMILY  
OF ALS/MND  
CHARTERS

## The five rights listed below extend to all people with ALS/MND, worldwide.

These rights will ensure that people living with ALS/MND have the power to make informed decisions about their own care and needs. All people living with ALS/MND are entitled to these basic rights so that they can achieve quality of life and dignity in living and dying.

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### 1. People with ALS/MND have the right to an early diagnosis and information.

This includes:

- early access to a physician who is informed about ALS/MND
- an accurate and early diagnosis, delivered sensitively
- timely and appropriate access to information at all stages of their condition

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### 2. People with ALS/MND have the right to access quality care and treatments.

This includes:

- access to support and care services managed by a professional who has experience with ALS/MND
- educated advice about personal care and equipment, clinical interventions, treatments, and therapies
- access to the drug riluzole wherever possible

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### 3. People with ALS/MND have the right to be treated as individuals and with dignity and respect. This includes:

- being offered a personal care plan to specify what care and support they need
- access to appropriate end-of-life planning tools and support in meeting their personal wishes
- being offered support to help them make informed medical choices to meet their personal needs
- access to appropriate communication support and aids
- opportunities to be involved in research if they so wish

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### 4. People with ALS/MND have the right to maximise their quality of life.

This includes:

- timely and appropriate access to equipment, home adaptations, wheelchairs, and suitable housing
- timely and appropriate access to disability benefits

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### 5. Carers of people with ALS/MND have the right to be valued, respected, listened to and well supported. This includes:

- access to support and counselling, such as respite care and bereavement support
  - having their needs assessed as carers and as individuals, ensuring that their personal emotional well-being is recognised and supported
  - access to appropriate benefits and entitlements wherever possible
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