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.

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

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

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

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

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