



# Rights and responsibilities of people living with motor neurone disease (MND)

## POSITION STATEMENT

### Background

MND Australia is the national peak advocate for motor neurone disease (MND). Together with the state MND associations and our research arm, the MND Research Institute of Australia (MNDRIA) we advance, promote and influence MND care and research with a vision to achieving a world without MND. The six state MND associations provide direct support to people living with MND in all states and territories.

We work collaboratively to promote access to the right care, in the right place and at the right time to ensure choice, control and the best quality of life possible for all Australians living with MND, their families and carers.

### MND Australia believes:

*People living with MND have the right to take charge of planning their care and managing their condition. People living with MND should have access to evidence-based and best-practice information to facilitate discussions with family, friends and health professionals and enable them to make informed decisions about their care.*

**MND Australia supports a person's rights in all things that are lawful.**

### People living with MND have the right to:

- 1. Health and care services based on clinical and support needs including:**
  - access to highest quality care and treatment available regardless of age, cultural background or geographic location
  - access to care that is coordinated by your healthcare team to minimise the burden on the person with MND and their family
  - access to timely, equitable and quality, evidence-based palliative and end-of-life care
  - access to health professionals and providers who are motivated to achieve best practice in understanding MND and in the management of people with MND
  - treatment and support given with care, compassion, respect and dignity at all times
  - individual choice with respect to:
    - health and support workers who are providing treatment or advice
    - the place where care takes place
    - the type of treatment that is provided

2. **Accept, refuse, or discontinue treatment or intervention within the legal framework of the person's state or territory to ensure:**
  - Choice, control and the best quality of life possible, including access to preservation of personal dignity and to humane care, without discrimination.
3. **Be informed and involved through:**
  - access to information to enable the person with MND to play an active role in decision making including:
    - advance care planning
    - information about managing symptoms of MND and treatment options
    - information about relevant organisations and government services
  - participation in the health and support system including:
    - evaluating the types and quality of services received
    - contributing to policy making
    - opportunities to participate in research

State based MND Associations and MND Australia can assist in this process by advocating for the needs of individuals living with MND and consumer representation for the common needs of all those diagnosed with MND and their families.

4. **Confidentiality**
  - People living with MND should be assured of personal privacy and the confidentiality of their medical details
  - This right to privacy should be secure until permission is given to release appropriate medical details unless there are compelling medical or legal reasons to divulge the information.
5. **Timely, appropriate, adequate and high quality support for their carer including:**
  - Counseling and bereavement services
  - Flexible respite care
  - Relevant government benefits and entitlements.

## **People living with MND have a responsibility to:**

1. **Communicate openly and honestly**
  - provide relevant information to their care team
  - raise any concerns in a timely manner
2. **Be actively involved in treatment and care decisions**
  - ask questions and seek information from the team providing care
  - make decisions based on reliable and accurate information

### **3. Respect the needs of those involved in your care**

Remember that MND is a challenge not only to the person living with this disease but to all those involved in providing health and supportive care. It is therefore important that people with MND:

- allow family members to take time away from the caring role to rest and re-energise. This includes giving family carers permission to access respite care
- show consideration and respect for all members of the health and supportive care team who are involved in providing their care

## **Acknowledgements**

These rights and responsibilities encompass the fundamental rights of people living with ALS/MND outlined in the [\*International Alliance of ALS/MND Associations Rights of People living with ALS/MND\*](#) April 2016, endorsed by more than 25 member countries.

[Palliative Care Australia Euthanasia and Physician Assisted Suicide Position Statement August 2016](#)

**Reviewed by Executive Management Group**

**Endorsed by the MND Australia board on 25 May 2017**

**Signed**

**David Ali (President)      Review date:**