



## **Motor Neurone Disease Australia**

### **Rights and Responsibilities of people with MND**

#### **The Rights of people with motor neurone disease (MND)**

MND Australia supports the following statement as outlining the rights of people with MND:

*As a person receiving supportive care for Motor Neurone Disease you have the right to be a partner in planning your care and managing your illness. It is important for you to be well informed, to participate in treatment decisions and to communicate openly with your doctor and other professionals involved in your care.*

This statement and the following rights and responsibilities encompass the fundamental rights of members outlined in the International Alliance of ALS/MND Associations, Patients Rights, March 2008.

**As a person living with MND you have the right to:**

#### **1. Access health and care services based on your clinical and support needs including:**

- the expectation of equitable access to reasonable and acceptable standards of healthcare regardless of age, cultural background or geographic location
- access to care that is coordinated by your healthcare team to minimise the burden on you and your family
- access to health professionals who are motivated to achieve best practice in understanding MND and in the management of clients with MND
- treatment and support given with care, compassion, respect and dignity at all times
- individual choice with respect to:
  - health workers who are providing treatment or advice
  - the place where care takes place
  - the type of treatment that is provided.
  - the right to accept, refuse, or discontinue treatment or intervention within the legal framework of each state or territory

#### **2. Be informed and involved**

- access information to enable you to play an active role in personal healthcare including
  - information about managing symptoms of MND and treatment options
  - information about relevant organisations and government services that may be beneficial



- participate in the healthcare system including:
  - planning and evaluating the system of health services
  - evaluating the types and quality of services,
  - offering feedback about the conditions under which services are delivered.

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

### **3. Confidentiality**

- You should be assured of personal privacy and the confidentiality of your medical details
- This right to privacy should be secure until you give permission to release appropriate medical details unless there are compelling medical or legal reasons to divulge the information.

## **The Responsibilities of people with MND**

As a person receiving supportive care for MND your responsibilities are to:

### **1. Communicate openly and honestly**

- provide relevant information to your care team
- raise any concerns that you may have in a timely manner

### **2. Be actively involved in treatment and care decisions**

- ask questions and seek information from the team providing your 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 reenergise. 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 your care

#### **Acknowledgements**

*The International Alliance of ALS/MND – Patient's Rights, March 2008*

*Standards for providing Quality Palliative Care for all Australians (2005) – Patient's Rights & Responsibilities, Palliative Care Australia*