



THE INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS STATEMENT OF GOOD PRACTICE FOR THE MANAGEMENT OF ALS/ MND

Support and care management for people living with ALS/MND is underpinned by five basic principles:

- Management of the disease determined by the needs and wishes of the person living with ALS/MND, treating the person with ALS/MND with care, respect and dignity
- Timely response to identified needs
- Access to a coordinated and integrated care plan
- Regular monitoring and review of the person's condition, and appropriateness of the care plan
- Information about the person's medical condition held in confidence

The International Alliance of ALS/MND Associations recommends the following good practice that will result in effective management of the diagnosis and care of people living with ALS/MND.

Before Diagnosis...

Early recognition of symptoms and access to a physician competent to diagnose complex neurological diseases

At Diagnosis...

Diagnosis given by a physician who is informed about ALS/MND, in a sensitive way appropriate to the person with ALS/MND and, in an appropriate setting with family and/or friend(s) present

Information provided in verbal and written forms about the disease, including its impact, sources of help and support, and referral to the ALS/MND Association as appropriate to the needs of the individual

Information sent to the patient's principal health practitioner about the disease, management implications, and the ALS/MND Association

The opportunity to return to the diagnosing physician for further information, care and follow up

After Diagnosis...

Access to:

- information and support services
- planning and coordination of support and care

These include:

- advice about personal care and equipment, clinical interventions, treatments and therapies, palliative care
- support for caregivers and families eg: respite care, bereavement support
- health and financial benefits
- research and clinical trials
- access to support from the ALS/MND Association

In summary, it is essential that people living with ALS/MND are enabled to make informed decisions about living with ALS/MND so as to achieve quality of life, and dignity in living and dying. Adopting a proactive approach to disease management and respecting the needs and wishes of the individual and their caregivers is imperative.