Loss and bereavement

MND is a life limiting disease characterised by a series of losses with the accompanying issues of grief and bereavement which affect the patient, the carers and the family from diagnosis (MND Australia 2014).

MND Australia 2014

- coming to terms with reality is constantly challenged by proliferating impairments and increasing severity of symptoms
- establishing links with palliative care at an early stage can provide the primary health care team with a useful source of advice and support
- it is important that people living with MND are clear about the role of palliative care services and the benefits that they can provide.

Mitsumoto and others 2005

Bereavement in ALS has its unique features because both the patient and the family grieve. The patient grieves over lost function. The caregiver grieves over loss of independence and the approaching death of the patient as the disease progresses (anticipatory grief). Although there are many resources on bereavement for other diseases (e.g., cancer), there is limited information about the specific bereavement process in patients with ALS and their caregivers.

Recommendations to the field for development

Offer bereavement support to the patient and caregiver during clinic visits and also to the caregiver after the death of the patient, including a personal acknowledgment and letter of condolence.

Research recommendations

- Determine the scope of bereavement care needed in ALS and identify differences in bereavement care compared to other diseases.
- Develop methods and programs for extending grief support services to patients and families.
- Develop methods and programs for screening for complex grief responses requiring specialized intervention.