
MOTOR NEURONE DISEASE

FACT SHEET No 15

Palliative Care in Motor Neurone Disease For Patients and Carers

WHAT IS PALLIATIVE CARE?

Palliative care is defined by the WHO as *'an approach that improves the quality of life of patients and their families facing the problem associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual'*.

In the past, palliative care has been seen as terminal care (care of a person in the last few days or weeks before death). It is now recognised that palliative care is an approach to managing the whole of a condition like MND, right from the time it is diagnosed. It involves looking not just at symptoms but at the whole person and their family and all the issues that concern them.

A palliative care approach respects the person's right to have access to all of the treatment options and to make their own decisions about how they want to live their life. It involves giving information, managing symptoms, communicating openly and working for the best quality of life possible for the person with MND and their family.

Who provides palliative care?

Specialist MND clinics and Palliative Care Services are both able to provide expert care from the time a person is diagnosed. They can provide a full range of services using a team of health professionals who have expertise in managing MND.

There are a lot of different people involved in the care of someone with MND (it has been estimated that over 60 new people will enter the home of someone with MND). It is therefore ideal to have a key person who is an expert in MND and can act as a link and coordinator. This worker is a resource person

to the MND family and acts as a link between them and the services in the community and is available for advice when needed.

In South Australia there is a Specialist Clinic at the Repatriation General Hospital and the MND Association has an Outreach Worker who work together to coordinate care for people with MND.

There are a number of health professionals and services available for people with MND. These include:

- The neurologist who makes the diagnosis and who may offer regular check ups.
- The local doctor who is responsible for the medical management.
- The MND association provides counseling, information and support.
- Private health professionals provide occupational therapy, speech therapy and physiotherapy.
- Options Coordination provides a case management service to those under 65.
- Domiciliary Care provides services to those over 65.
- Palliative Care Services

In South Australia, palliative care services are developing considerable experience and expertise in MND and are now regularly involved in management right from the early stages. Palliative care teams provide specialised palliative services including symptom management, support, volunteer services, complementary therapies, community follow-up and inpatient services.

Regardless of who coordinates care, it is important that they are easily accessible and the people providing the services are experienced in the care of people with MND.

PALLIATIVE SERVICES

Information. It is important that people with MND and their families have access to information at each stage of the disease to enable them to make informed choices. Good palliative care involves providing accurate and honest information as it is requested and needed.

Symptom management. Many people with MND feel that because MND cannot be cured, nothing can be done to help them. This is not the case, and problems such as immobility, pain, swallowing, speech, and breathing can all be helped.

Quality of life. Anxiety and tension can add to the burden of MND and part of good palliative care is being sensitive to the issues facing those with MND and their families. It is important that everyone involved is committed to making the quality of life for those involved as good as possible.

What is a hospice/palliative care unit?

A hospice/palliative care unit is a place designed to provide care for people who have life-limiting illness and who want the focus of their care to be comfort and quality of life.

For people with MND, admission to a hospice/palliative care unit may be suggested at some stage. This may be for a short period while the management of their symptoms is assessed and treatment is modified, for respite care to give the family a break or in the final stages of the disease for end-of-life care.

What is an anticipatory directive?

In South Australia, legislation provides for people to give instructions about what type of treatment is acceptable to them. It allows people to decide what they consider to be “life-sustaining measures” and the circumstances under which they would consent to or refuse such measures. They are also able to appoint a Medical Power of Attorney to make decisions on their behalf, if the time comes where they are no longer able to communicate their wishes.

It is important with MND that if a person signs a directive, it should be discussed with palliative care professionals and updated during the course of MND. This can then be used as a checklist for care plans. Specific areas that should be covered are ventilation, resuscitation, antibiotics, nutrition and emergency action.

References

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