

## Palliative care and MS

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### Defining palliative care

Palliative care is defined as the active total care of a person whose disease is not responsive to curative treatment. Management of pain and other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care in MS is to achieve the best quality of life for the person with MS and their families once their symptoms no longer respond effectively to treatment or management.

Palliative care, with its focus on the all-round needs of individuals and their families, and their active involvement in medical decisions, also aims to improve the quality of care and reduce the use of emergency and acute care services.

The five key principles underpinning palliative care which should be practised by all health professionals in primary care, hospital and other settings are:

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1. a focus on quality of life
  2. a whole-person approach, taking into account the person's past life experience and current situation
  3. care encompassing both the person with the life-threatening disease and those individuals who matter to that person
  4. respect for patient autonomy and choice (including preferred place of care and access to specialist palliative care)
  5. emphasis on open and sensitive communication, extending this to the person with the disease, informal carers and professionals.

### **Palliative care in neurological conditions**

The National Service Framework for Long Term Conditions includes the following quality requirement for end of life care: "People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care."

**'It is difficult to anticipate life expectancy in people with MS due to the variability between individuals and the unpredictable nature of the disease. People with advanced MS may need palliative care over decades'**

However, many issues can affect the provision of palliative care in people affected by progressive neurological conditions such as MS. Among these, it is worthwhile mentioning long disease duration, lack of a predictable course, or presence of a fluctuating course; coexisting behavioural and cognitive compromise; complex multidisciplinary care, management of special treatments/devices (for example, a PEG tube for nutrition or a baclofen pump for severe spasticity). Most people with MS die with, but not from, their disease.

One solution to delivering appropriate care to people with such complex needs and unpredictable end-of-life trajectories is to provide input at different times during the disease course, and not to focus only on end-of-life care. Palliative care might offer skills during diagnosis, different options when the progression of the disease exposes people with MS and their families to difficult choices, being a constant help in symptom control and psychosocial care, and being a known resource when a person with MS approaches the end of life. It can also provide bereavement care to family members who had been previously involved in the care of the person with MS.

In practice, palliative care can be integrated alongside neurology and rehabilitation services. The interaction between neurology and palliative care throughout the duration of rapidly progressive conditions is very close, with a relatively smaller role for rehabilitation medicine physicians. However, rehabilitation plays a major role in providing long-term care and support, often over many years, in the more slowly progressive or stable conditions. As a person's MS becomes more advanced, rehabilitation and palliative care approaches often overlap.

### **Lifelong care for people with MS**

It is difficult to anticipate life expectancy in people with MS due to the variability between individuals and the unpredictable nature of the disease. People with advanced MS may need palliative care over decades. Informal carers are an essential source of support for people with MS, and in advanced disease they may take responsibility for meeting most of their loved one's needs. Caring for someone with MS can sometimes lead to a reduced quality of life for the carer, and may adversely affect carer employment and finances if care is needed over a long period. Ageing and other illnesses combined with MS can affect both the person with MS and his or her carer.

Recent studies on adults with advanced MS and their carers and newly-diagnosed people with MS indicate similar areas of concern. These include insufficient time spent with health professionals, lack of information exchange, and discontinuity of care.

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However, unlike those in the early phases of MS, there are no disease-modifying treatments for people with advanced MS. It is therefore all the more important that appropriate recognition and management of symptoms and co-ordination of care is achieved. Including disease-directed treatment and supportive care from the time of the diagnosis of MS should more effectively prevent and treat symptoms, as well as initiate communication regarding goals of care and future planning.

## Conclusion

Palliative care is a complex concept that aims to promote both physical and psychosocial well-being towards the end of a person's life. It is a vital and integral part of all clinical practice, whatever the illness or the stage of the illness progression.

Exploring preferences for future care should be carried out sensitively and at a pace suited to the person with MS and their family.

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To download the full issue of *MS in focus*, go to <http://www.msif.org/living-with-ms/ms-in-focus-magazine/>

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## Useful internet resources

[www.mssociety.org.uk/ms-support/for-professionals/palliative-care](http://www.mssociety.org.uk/ms-support/for-professionals/palliative-care)

[www.nationalmssociety.org/For-Professionals/Clinical-Care/Managing-MS/Continuum-of-Care/Palliative-Care](http://www.nationalmssociety.org/For-Professionals/Clinical-Care/Managing-MS/Continuum-of-Care/Palliative-Care)

## Advance care planning

The challenge for specialist palliative care services is working within cultures and societies where many people are uncomfortable talking about death and dying. Over time, death has become increasingly medicalised and institutionalised. However, the vast majority of people with a life-threatening illness say they would prefer to die at home. Ensuring people with MS, family members and health care professionals are informed and share in decisions about end-of-life and critical care is crucial.

Advance care planning (ACP) is at the core of palliative care. It respects the goals and values of the person with the disease, and promotes a truthful and meaningful exchange between that person, his/her loved ones and the care provider.

Studies have shown that people who engage in ACP with their care providers and surrogates are more likely to have decisions made in accordance with their preferences, and to receive better health care at the end of life. Nevertheless, ACP should be a flexible and continuous process, as an individual's health and circumstances are ever-changing.

In addition, a person's readiness to engage in ACP may vary throughout the course of their illness. A three-step approach for preparing a person for future decision-making has been proposed, which involves choosing an appropriate surrogate, clearly articulating values and preferences, and establishing some leeway in surrogate decision-making given the complexity of a situation.