



International Alliance of ALS/MND Associations

Statement of Palliative Care in ALS/MND

The intent of the statement is to increase understanding that palliative care occurs throughout the continuum of care and is a quality of life concept rather than an end-of-life concept; to increase understanding that palliative care can occur alongside care that may be curative in approach (i.e., they are not mutually exclusive); and to promote universal best practice in the delivery of and access to palliative care.

1. Palliative Care should be viewed as a quality of life service integral throughout the continuum of care not only at end-of-life.
2. People living with ALS/MND should be eligible to access any service or device available* that improves their quality of life at any time during the course of the disease from the time of diagnosis to last days of life.
3. People with ALS/MND should be informed about and eligible to access available services that help them to remain as functional as possible in their accommodation of choice throughout the continuum of care.
4. The provision of Palliative Care can occur simultaneously with interventions aimed at slowing down, halting, or reversing the underlying disease process.
5. Palliative Care providers should recognize that the needs of persons with ALS/MND are different than other life-threatening illness and should develop programs to address these needs.
6. Access to a support system to help family members cope during the course of ALS and after death should be included in Palliative Care service plans.

*Availability of certain devices and services may differ from one jurisdiction of care to another.

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