Initiating end of life discussions

Discussions about prognosis and end-of-life issues can be conceptualised as a process of ongoing conversation over time, rather than a single discussion (Clayton and others 2007).

Ideally consultation by a palliative care team or physician should be initiated early in the course of the disease with subsequent periodic review. Palliative care involvement potentially assists the multidisciplinary team with the initiation and timing of end of life discussions.

Mitsumoto and others 2005

The Workgroup agreed that palliative care begins at the time of diagnosis for patients with ALS. However, initiating end-of-life discussion is difficult for many physicians and health care providers (in the following text, 'physicians' may be extended to include other health care providers) depending on their own experience and philosophy. The timing of when to introduce end-of-life discussions with patients and their families also is uncertain.

The Workgroup developed six triggers for identifying when end-of-life discussions should be introduced (Table I). These triggers were created with a consensus from the Workgroup, and based on their years of clinical experience in caring for patients with ALS and their family members. Important factors that determine when the patient and family are ready to discuss end-of-life issues include coping skills, depression and anxiety, cultural issues, use of functional assistive devices, and physiologic status, among others.

TABLE I. Six triggers for initiating discussion about end-of-life issues

1. The patient or family asks – or 'opens the door' – for end-of-life information and/or interventions (elicited or spontaneous, verbal or non-verbal)

2. Severe psychological and/or social or spiritual distress or suffering

3. Pain requiring high dosages of analgesic medications

4. Dysphagia requiring feeding tube

5. Dyspnea or symptoms of hypoventilation, a forced vital capacity of 50% or less

6. Loss of function in two body regions (regions include bulbar, arms, and legs)