Isolation and social support

Issues of intimacy and sexuality are about much more than intercourse. They concern fundamental need to communicate and receive love, to feel at ease with their bodies and physical closeness (Gallagher and Monroe 2006).

Although most professional cannot be expected to become specialist psychosexual counsellors, all have a responsibility to become comfortable with offering and responding to cues about sexuality, offering first line help and referring for specialist support (Stausmire 2004, in Gallagher and Monroe 2006).

McLeod and Clarke 2007

Social support and social disability
Lazarus and Folkman assert that there is a reciprocal relationship between social support and depression. The stress-buffering model explains that stress, such as that associated with a chronic or terminal illness can be significantly moderated by good social support. Sadly, the lives of many MND patients are significantly limited in social interaction. Remarkably, some patients describe their most stable form of social interaction as being their visit to the doctor or clinic. Patients may even lose the companionship of their spouse whose roles change from lover and confidant to full-time physical carer. Patients “experience ever increasing isolation from family, friends, events of the world and nature.” (p.5). This has been described as the ‘social disability’, accentuated sometimes by rejection and desertion by loved ones.

Social support is of course protective against depression, with depression being associated with low social support, social withdrawal, and feeling housebound and searching for social integration. Social support is also strongly associated with QoL and inversely to a wish to hasten death. The loss of or difficulty in communication and mobility are examples of the limitations to socialisation that MND imposes.

Mockford and others 2006

Informal support
Future strain and distress is alleviated by the greater the number of friends and relatives seen at least once a month, and the less the patient's illness is affecting other areas of their lives. However, friends, in particular, may stop calling once the patient is diagnosed: “…people don’t know how to react or what to say..” . The less satisfied carers are with social support the higher they perceive their levels of stress.