

Bereavement

For each person the bereavement experience is personal and unique. In ALS, there may be a lengthy period of anticipation of the death that may affect the process and outcome of the bereavement. A range of support should be offered according to the individual needs of the bereaved. There is a need for further research to determine whether there are significant differences in responses for people affected by ALS related bereavement (McMurray and Harris 2006).

Some MND associations and palliative care organisations offer individual or group bereavement support for carers.

McMurray and Harris 2006

Individual counselling with a bereavement counsellor or trained listener may be helpful for a person bereaved through ALS.

Numerous studies have shown the significance of religious or spiritual beliefs and experiences at the time of bereavement and in adapting to loss.

ALS may predispose a person to a more difficult experience of bereavement, particularly if protective factors are absent. For someone bereaved by ALS it may be difficult to accept that the illness journey has ended. The following strategies will assist in making real the loss.

- Provide an opportunity to view the body (deceased)
- Allow for the expression of feelings
- Acknowledge the normality of grief
- Review the loss experience
- Provide information and support about the grief process
- Assist with anniversaries and memories
- Consider and acknowledge secondary losses.

The impact of loss on the families and caregivers of people with ALS has not been substantially or adequately researched. This needs to be addressed to directly explore the experience of ALS-bereaved people and the best possible practice outcomes.

Mockford and others 2006

After the death of the patient, only one-fifth of carers report coping well. Protective factors include finding positive meaning in caregiving, problem solving and reorienting, talking to patient and to friends, taking one day at a time, accepting they have no control over it and finding information on the disease. Those who spend more time outside of the home, have broad support networks and do not feel guilty, are the ones who cope best.

On the negative side, those carers who are not able to identify their feelings seem to cope by escaping, avoiding or denying a problem exists which may increase levels of distress. Use of wishful thinking and denial correlates with the greater impact of MND on patients' functioning; those less accepting of the disease anticipate being less likely to cope with future distress and strain than others. Qualitative approaches find that carers may create a 'false' or 'shifting' sense of normality, as a coping strategy but maintaining this may be good for the patient but stressful for the carer.

Evidence suggests that carers of people with MND do not generally talk about the future which could cause distress. Dawson and Kristjanson relate how interviewees face an uncertain future, unable to move forward yet caring for an increasingly dependent person. The authors recommend that empowerment comes through the need to anticipate changes and planning



the future, but carers do not want to acknowledge the death of the patient, which leaves them unprepared.