

Carer wellbeing and support

Caring can be a highly rewarding experience when appropriate support is available. However, without such support, the responsibility of caring can have an adverse effect on a carer's physical, mental and emotional health as well as an impact on their short and long-term financial security. The demands of caring can make it harder to have a job, go to school or to simply take some time to relax. It is important to remember that whatever affects carers also affects their whole family (Carers Australia 2010).

MND Australia 2008

The feelings of people with MND are often mirrored by their carers although not always at the same time. Additionally, responses may vary depending on cultural background.

Physical exhaustion from the caring role is coupled with powerlessness to prevent suffering.

Gallagher and Monroe 2006

Carers require:

- adequate nursing support
- confident, committed family doctors
- good symptom control for the patient
- coordinated care that is individual and flexibly delivered
- access to specialist care
- practical help: household tasks, personal care, equipment
- respite care as an inpatient or a home sitting service
- knowledge about the illness and training in skills to enhance patient comfort
- financial support
- advice and information on services available and help to secure them
- emotional support directed specifically at the carer.

Mockford and others 2006

There appear to be six main challenges faced by carers emerging from the literature on service provision:

- dealing with a vast array of health professionals which can seem confusing and business-like to carers;
- needing a named coordinator as a first contact to assist carers and facilitate services;
- needing adequate support with the new nursing skills some carers have to learn;
- having enough consideration and information at time of diagnosis and as it is needed thereafter, particularly on how this will affect them;
- needing confidence in, and access to, resources and service provision such as respite care;
- needing emotional support when a carer requires it during the course of the disease and after the death of the patient.

