

Burnout and Compassion fatigue amongst Carers – the response of the MND Association.

Purpose:

To raise the profile and promote recognition of carers of people with MND.

Background:

Currently 6 million carers in the UK, rising to 9 million over the next 10 years. 1.25 million provide care for somebody for more than 50 hours per week.

Background – MND Association survey of Carers

375 Carer surveys sent out
192 returned.

Key findings.

- $\frac{3}{4}$ of carers are Female
- 70% are concerned for the future
- Only 19% get planned breaks from their caring role
- 60% are over the age of 60
- 40% faced a loss of earnings
- 15% attend an MND Support group.

Key Concerns.

- Carer burnout and fatigue
- Lack of access to respite care
- Loving partner to “Nurse” transition
- Lack of Carer Assessment
- Lack of inclusion in some decision making
- Lack of general support
- Isolation
- Guilt – needing, wanting or taking time for themselves.

MND Association response and action

- Development of a Carers guide to MND – particularly with disease specific information, and signposting to relevant services.
- Raise awareness of the right to a Carers assessment through statutory services
- Development of a MND Association strategy for Carers – carers needs to be filtered in everything that we do and develop
- More formal research into the needs of Carers of those with MND – Edge Hill University project
- On-going support after bereavement – Association Visitors and other forms of support

- Carers Support groups – differentiating between current carers and past carers.
- Care Services Support – Respite care grant
- Education – HSCP's
- Young Carers – new guide to be developed, plus on line interactive web facility and telephone app in 2014.
- A response to “Personalisation” – carers holding their own budgets.