

Parents of adults with multiple sclerosis: what is their role and how does it change over time?

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This presentation outlines the research conducted by Dr Camilla Holden in 2017/18 as part of her clinical psychology doctorate, which explored the role and experiences of parents of adults with multiple sclerosis (MS).

Long term neurological conditions such as MS can impact on all family members; research demonstrates a synchronicity between the emotional well-being of the person with MS and other family members. The extent to which families can adapt to adversity is moderated by their historical view of illness and death, shared meaning about the illness, developmental life cycle of the individual and family, and the family's affective style (Rolland 1994).

While parents of adult individuals with MS are recognised as an important source of practical and emotional support for their children (MS Society, 2014), there is a dearth of research specifically exploring how people with MS's parent generation experience having an adult child with MS. The unknowns include:

- What the parental role involves when an adult son/daughter has been diagnosed with MS.
- How the balance of providing physical and emotional care is, or is not, affected over time.
- The impact on parents.

The aims of this study were to understand what the role of a parent to an adult with MS involves, and how the processes of providing practical and emotional support may change over time. A qualitative research design (Grounded Theory) was adopted to do this.

The research methodology and key findings from the research - including the model that emerged from interviews with parents - will be presented. In addition, recommendations for service delivery and future research in this area will be discussed.

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