

## **Understanding why behaviours are challenging for dementia family carers**

Dementia is a global health challenge that confronts health and social care systems today. It is characterised by global cognitive impairment. However, it is the disruption to daily living and in particular the non-cognitive, (behavioural and psychological) symptoms, which can be defined as 'behaviours that challenge' others or 'challenging behaviours'. Around 90% of people with dementia exhibit some form of challenging behaviour, including apathy, agitation, psychosis, and mood disorders. Not only do challenging behaviours cause distress for carers but they can also lead to long-term hospitalisation, overuse of some medications, and increased health care costs.

Different strategies including behavioural interventions are recommended to help unpaid (family) carers cope with these behaviours, but they respond to potentially helpful strategies in different ways. This review aimed to find out why unpaid carers have difficulty in coping with challenging behaviours, with a view to improving the quality of support which is offered in the future. After searching scientific databases we found 25 relevant studies, and were able to draw out some high-level explanations from this evidence.

A key finding was the level of unmet need and distress among many family carers who struggled to adjust to their new reality. This included a strong sense of feeling bereft, which was associated with changes in communication, and the impact on the relationship with the person with dementia. For example, reduction of previous behaviour in the relative -described as 'apathy' in the literature, impacted negatively on shared pleasurable activities, and deteriorating verbal communication led to a developing sense of isolation for the family carer. As conversation and shared activities declined there was a detrimental effect on the family carer's relationship with their relative due to their perceived loss of 'companionship'. The sense of loss was particularly potent when the family carer believed that the person with dementia could no longer recognise them, and carers also struggled with the changes in roles and responsibilities between them.

Another key finding was that family carers had difficulty understanding the meaning of their relative's communicated behaviour, particularly when this was believed to be out of character, or within their relatives' control. The way a family carer interpreted their relative's behaviour was also important: for example accusations of stealing when the person couldn't find an important item was interpreted as personally offensive; frustration in the relative was interpreted as aggression. Thus behaviours for some family carers at certain times were described as 'challenging'. Understanding helped some, but for other family carers, their levels of confidence in handling situations effectively, thresholds of tolerance, and socio-cultural expectations affected how they were able to use potentially helpful strategies and cope with their relative's behaviour at a given time. Underlying the experience of challenging behaviour were beliefs that their relative with dementia would inevitably lose their identity to dementia.

The review demonstrates how carers' needs are likely to vary, and are dependent on deeply held beliefs and feelings of loss. To reduce distress in family carers and thus assist them to use relevant behavioural strategies where necessary, they may require tailored counselling to address some of their personal beliefs associated with their relative's behaviour. Another important feature, was the need for skilled support to be offered for family carers in order for them to adapt their understandings and expectations and learn new ways of communicating with their relative. The authors suggest that support programmes for family carers, which often focus on strategies to manage behaviour, should also consider some element of psychosocial support to address some of their hidden needs and thus help them to cope with and manage challenging behaviours in dementia.

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