

Information for patients from JNNP

How do dementia carers cope with abusive behaviour?

More than one third of people caring for relatives with dementia regularly experience some form of abusive behaviour, such as being shouted at or insulted, a new study has found. Although aggressive behaviour is a relatively common symptom of dementia, this is the first study to look at carers' experiences of abuse.

What do we know already?

One of the most distressing parts of caring for someone with dementia is that their personality may change because of changes to their brain, and they may act in an aggressive or upsetting manner. A gentle, quiet person might start shouting or using bad language, completely out of character. It can be hard to see this as part of the illness, and not a personal, intentional attack on you. A big study of people with dementia in the US found that about a quarter were sometimes either aggressive or agitated, and a UK study found about 1 in 5 people with Alzheimer's disease were sometimes aggressive. So it's a common symptom of the condition. People caring for relatives with dementia quite often say they've been the subject of upsetting or abusive behaviour, but this hasn't been studied properly before.

This new study interviewed 220 people who cared for a family member with dementia for at least 4 hours a week. Researchers asked about specific types of behaviour, and also about how the carers coped. They also measured how much satisfaction people had from their relationship with the person they were caring for, and how good the relationship had been before the dementia began. The researchers use the phrase 'abusive behaviour', although they recognise that the person with dementia did not intend to be abusive.

What does the new study say?

More than one third (37 percent) of people said they'd experienced some form of abusive behaviour at least sometimes, over the previous three months. The most common reports were of verbal abuse, where the person with dementia had used a harsh tone of voice, insulted or sworn at the carer, or screamed or shouted at them. In total, 36 percent said they'd experienced some form of psychological abuse. But others had been hit or slapped, or made to fear they would be hurt. Almost 6 percent said they'd experienced physically abusive behaviour.

Unsurprisingly, people receiving more abuse were less likely to be happy with their relationship, and more likely to report a deterioration in their relationship since the dementia started.

The researchers looked at aspects that might be associated with abuse. They found that carers who experienced more abuse had a less happy past and present relationship with their family member, and were more likely to be using what the researchers describe as 'dysfunctional' coping strategies. These strategies included denial, venting their emotions, and using drugs or alcohol to cope. More helpful coping strategies included seeking emotional and practical help, accepting the situation and planning for the future. The researchers suggest that future research might look at teaching carers about helpful coping strategies. But they say their research can't show whether helpful coping strategies reduced the amount of abuse that carers received. It could be that people's coping strategies were a result of the amount of abuse they were receiving.

How reliable are the findings?

It's always hard to know whether people answer questions honestly when they're asked about sensitive issues like this. Some people not want to acknowledge that behaviour they're experiencing from a loved family member is abusive. But overall, the results are likely to be reliable.

Quite a lot of people (31 percent) who were asked to take part in the study could not be contacted, or decided not to take part. That might affect the figures, if people decided not to take part because they were being abused by their family member and they didn't want to talk about it.

Where does the study come from?

The study was done by researchers at University College London in London, UK, who interviewed carers of people referred to the community mental health teams in London and Essex.

What does this mean for me?

If you are caring for someone with dementia, and you're experiencing upsetting behaviour such as shouting or swearing, you're not alone. And it's not personal but a symptom of the illness. However, it's tough to deal with alone, and you certainly shouldn't be expected to cope with physical violence.

What should I do now?

Talk to your doctor about the types of help available. This could include help in the home, respite care, or changes to the treatment of the person you're caring for. You may also find it helpful to talk to other carers, for example through the Alzheimer's Society. Their website (<http://www.alzheimers.org.uk>) has a useful section for carers, which includes advice on coping with aggressive behaviour.

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C Cooper, A Selwood, M Blanchard, et al. Abusive behaviour experienced by family carers from people with dementia: the CARD (caring for relatives with dementia) study. *Journal of Neurology, Neurosurgery, and Psychiatry*. 2010; **81**: 592-596.

<http://jnnp.bmj.com/content/81/6/592.full>

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