

Dementia

Out of the shadows

Executive summary

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Executive summary

This report describes a research project that explored the experiences of people with dementia and their carers (usually members of their family) of finding out they had dementia, the assessment and diagnostic process and how they, together with their families and friends, have adjusted and coped since being diagnosed. Investigating the possible benefits of being diagnosed early was an area of particular interest to the researchers.

The research took place in 2008, a time when dementia has an increasingly high profile for a number of reasons. These include an ageing population and increasing numbers of people believed to have dementia but still, worryingly, low rates of diagnosis, concerns about the quality of care and treatment for people with dementia and the imminent publication by the government of England's first national dementia strategy.

The research was undertaken by the Mental Health Foundation and commissioned by Alzheimer's Society. It involved a literature review, seven focus groups in different locations around England, and eight one-to-one interviews. A total of 61 people participated in the research, 32 of whom had dementia. The primary focus of the research was on the experience of people with dementia and it was undertaken in a way that aimed to facilitate their participation as much as possible. However it was recognised that at times people may have difficulties recalling their experiences and therefore the contribution of carers was also important.

Findings

The research covered four main areas. Firstly it investigated the different dementias that participants had and the length of time they had had them. All the most common forms of dementia were represented by participants. Most of the participants had been diagnosed for two or three years and had received the diagnosis at a relatively early stage.

Secondly, it looked at people's experience of finding out that something was not right and the experience of going to see their doctor. People reported noticing a number of dementia-related symptoms. Some people became concerned because of physical illnesses or symptoms. For some the process of getting a diagnosis was quite quick but for many participants it was a long, protracted and at times distressing experience. This was for a number of reasons but particularly because of dismissive, unhelpful or

uninformed responses from GPs and doctors working in specialist services. Even when dementia was diagnosed people were often left with little or no support, information or advice about what to do or where else they could seek assistance.

Thirdly, the research looked into people's lives after receiving a dementia diagnosis and the ways in which their lives had changed. Family and friends were particularly important in providing support to people, as was Alzheimer's Society, though help from health and social care services was mentioned much less. People described a range of practical and psychological coping mechanisms that they had developed themselves to cope with having dementia. Many of the practical coping mechanisms involved stimulating the mind. In terms of psychological adjustment, the emphasis on 'acceptance' was of particular note. This was not at the expense of other coping strategies such as retaining control, or 'getting on with it', but did seem to be particularly important in enabling people to come to terms and adjust to having dementia. However, while there were commonalities, coping mechanisms and strategies were also often very specific and customised to the individual. Many were also of great help to carers.

Finally, the research asked people's views on the key ingredients for a 'good' diagnostic process and experience, and the issue of stigma. A number of features were identified of a 'good' diagnostic process, some of which were quite generic such as good communication and being listened to. Others were more specific to the experience of people with dementia, such as doctors knowing when to refer on for more specialist assessments and taking into account the views of carers. While there were mixed views about how dementia was reported by the media and there was a belief that coverage was improving, there was a general concern that the wider public were still getting a skewed picture. The experience of people such as those participating in the research was not felt to be adequately portrayed, adding to ignorance of the condition and the stigma that surrounds it.

Themes

Four main themes emerged from the research.

- Early diagnosis was important and enabled people with dementia and their carers to understand what was wrong, begin to adjust to it and find ways of coping with it. However the variation in people's experience was of real concern and the negative experiences that people described were perhaps indicative of why so much dementia goes undetected. Given that the majority of people with dementia are not diagnosed, and the distress and difficulties this causes, the response of health services needs to improve significantly.

- A number of key features of a ‘good’ diagnostic process for dementia were identified by participants. These features may be helpful to reinforce or improve clinical practice, but might also provide guidance for people who are concerned that they might have dementia or who are being referred for specialist assessments, giving them helpful tips for what they can expect, look for, or ask for as part of a ‘good’ diagnostic process.
- An important array of both practical and psychological coping mechanisms and strategies that participants had found to be very helpful emerged, but when and how these were used seemed very dependent upon the individual and their circumstances. These coping mechanisms and strategies, alongside an acknowledgement of individuals’ styles and preferences, potentially offer professionals and carers a wide range of ‘tools’ that can be used to support people with dementia as well as their carers.
- The stigma of dementia was very pervasive. Media representation of dementia often did not help but the research indicated that the reaction of people close to them, as well as the responses of professionals, had a more detrimental impact on people with dementia and their carers.

Recommendations

Five major recommendations arose from this research. These are listed below and spelled out in full on pages 56–58.

1. Improve public understanding of dementia.
2. Improve GPs’ understanding of dementia.
3. Develop better specialist diagnostic assessment services for dementia.
4. Provide information which is timely and accessible.
5. Develop stronger peer support networks to help people cope.

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