

‘We’re happy as we are’: the experience of living with possible undiagnosed dementia.

In this paper we discuss the experiences of people who live with symptoms of dementia, such as memory difficulties, but no diagnosis.

Living with signs and symptoms of dementia but no diagnosis is assumed to be a difficult experience, but we do not know much about what this is like. We can only guess how many people might have dementia but no diagnosis. It is believed that a third of all people with dementia in the UK have no diagnosis. Governments nationally and internationally want to encourage more people to seek a diagnosis if they have symptoms. Not enough is known about what people in this situation might want to do about their symptoms.

We found some people who we thought had possible undiagnosed dementia. This was based on a large study of older people that included a dementia screening test. The study was called CFAS-Wales (Cognitive Function and Ageing Study, Wales). We contacted people if their screening test showed that they might have dementia, but they had no diagnosis on their GP records. This formed part of the IDEAL research programme.

We talked to six people with suspected undiagnosed dementia, and their wives or husbands. Some other people could not meet us. Some were in care homes or otherwise unwell. We talked to another four people who were relatives of some of the people who could not meet us.

There were three common topics that people with suspected undiagnosed dementia and their relatives talked about:

- Physical health is most important. Problems with memory or thinking are less important.
- Having support from family and friends protects us from problems.
- What we expect from health services affects whether we seek outside help.

What this study shows is that one response to possible dementia symptoms is to adapt and make changes to your lifestyle. For people who do not expect help from health services, it is normal to rely on family and friends, and to “manage”. People in this situation might not feel the need to ask for help from health services. They might have tried asking for help, and have been disappointed with the response.



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This means that if there is a push towards encouraging more people to seek a dementia diagnosis, there must also be an increase in the help that is provided for people with dementia. Without this, some people might not see a good reason to seek a diagnosis.

This is a summary of a [research article](#) which appeared in the **Ageing & Society** journal in October 2021.