

The precariousness of living with, and caring for people with, dementia: Insights from the IDEAL programme

How do feelings of uncertainty affect people living with dementia?

Many people face insecurity and uncertainty in their lives due to circumstances they cannot control. This could make it harder to cope when living with dementia or caring for someone with dementia.

We spoke with 20 people with dementia and their family carers about their experiences. They were all part of the larger IDEAL study. We purposely spoke to people who were different from each other. Some felt positive about life, some negative. Some lived in a rural area, some in an urban area. We also had a range of ages, socio-economic backgrounds and a good gender balance.

Researchers sometimes call feelings of insecurity and uncertainty 'precarity' and study how precarity affects different people. We wanted to explore how feelings of insecurity and uncertainty affect people living with dementia and carers. We wanted to understand which uncertainties arose from dementia. We also thought there might be things about people's situations before dementia entered their lives which could make them feel more insecure or uncertain.

Some people experienced a lot of insecurity and uncertainty. They felt vulnerable. We found four themes:

1. Feeling unsure about how the symptoms of dementia would progress
2. Worrying whether they would be able to access the care and support they needed in the future
3. Trying to stay independent even if that was getting harder
4. Lots of different worries building up together

These things made it harder for them to manage.

Some uncertainties were due to dementia, like worrying about symptoms. Others were about systems beyond people's control, such as benefits and finances. Some worries were to do with beliefs, like remaining independent.

Lots of different things affect the experience of living with dementia. We need



University
of Exeter



Economic
and Social
Research Council

NIHR | National Institute for
Health and Care Research

to remember that caring is difficult and that our needs change. People would manage better if they felt more confident that they would get the support they need.

This is a summary of a [research article](#) which was published in the **Social Science & Medicine** journal in July 2023.