

Society

Dementia

In 2015 Alzheimer's Society reported that there are over 850,000 people living with dementia in the UK. It is thought that this number will grow to over 1 million by 2025. As more and more people are diagnosed with the disease social scientists have been researching how those living with dementia can keep a good quality of life.

Dementia is a term used to describe a range of diseases that affect the brain. There are different types of dementia, the most common form is Alzheimer's disease. In 2015 529,655 deaths were registered in the UK and just over 11% of these were due to dementia.

There are four main areas of dementia research, which the Alzheimer's Society describes as:

- Cause
- Cure
- Care
- Prevention.

Most of the funding for research goes to cause and cure, and yet there are 50 million people living with dementia around the world who need high-quality care and support. Over the last 25 years a lot of attention has been given to 'person-centred' care, which focuses on the person with dementia, rather than the illness itself.

Within dementia research, it is becoming more common for members of the public who have dementia or those who care for someone that has dementia to work alongside the researchers, sharing their experiences, thoughts and opinions. For example, people with dementia can lead on a research project in partnership with researchers or act as advisers on a research project. Researchers understand that those with dementia and those that care for them bring with them a unique viewpoint and experience to the research - that is something researchers wouldn't necessarily have themselves.

Dementia progresses through stages, which are often called mild, moderate and advanced. If you were to meet someone in the mild stage of dementia, you might not even know that they had dementia. Someone in the more advanced stages of the disease would need full-time care. These very different pictures of how someone lives with dementia need different responses to how to 'live well' with it.

The importance for people with dementia and those who care for them to 'live well' was also highlighted in the 2009 government report 'Living Well with Dementia'.

"The right support, at the right time and in the right place, is especially important for people with dementia, to give them choice and control over the decisions that affect them." - The 'Living Well with Dementia' report.

But what does it mean to 'live well' with dementia? What might make that harder for someone who is living with the disease? How can social science enable us to make sense of these questions?

The 'Improving the experience of Dementia and Enhancing Active Life' (IDEAL) project is a project led by Professor Linda Clare and the Research in Ageing and Cognitive Health (REACH) group based at the University of Exeter.

Dementia

IDEAL is the first research project to collect data that looks at living with dementia over a long period of time - what's known as a 'longitudinal' study. The IDEAL project studies a group of 1500 people who are either living with dementia or who care for someone that has the condition. They are studied over a six-year period, completing questionnaires that ask them about their quality of life, mood, their living situation and surrounding neighbourhood, social contacts and activities. A smaller group of the same 1500 people are then interviewed in much more detail in an extended conversation, which is written down and analysed to draw out key themes and issues.

The team's research questions focus on:

- What factors influence how people with dementia and carers are able to live well?
- How do changes over time affect people's ability to live well?
- What do people with memory, thinking or behaviour problems, and their carers, believe helps or hinders the ability of living well?
- How can we predict whether a person is at risk of a declining ability to live well?



Disappearing - depicting how a dementia sufferer may appear vague or foggy by Stella Wharmby.

The project identifies what changes could be made by individuals, families and communities to enable people to live well with dementia. At the end of the study the researchers will produce recommendations and an action plan

for organisations that care for those living with dementia, as well as guidance for politicians who decide on government rules and policies in this area. The research team will also create guides for people living with dementia and those who care for them.

Whilst getting a diagnosis of the disease is important as it helps a person find the right support and care, some people would also prefer to have information about how to live with the disease, as Professor Clare explains: "Some people do want their difficulties acknowledged with a diagnosis, but our research shows that many others understand what is happening to them as part of a normal process of ageing...we may be better targeting support and information based on their symptoms or the type of everyday difficulties they are having, rather than focusing on giving a diagnostic label."

We move towards a future where by 2025 there will be over 1 million people with dementia. With this in mind, we must be able to understand not only its effect on our bodies through medical research, but also on our identity, quality of life and wider society. This is where social science plays a central part in helping us understand these big questions.

Key facts and figures

- **There are approximately 850,000 people living with dementia in the UK.**
- **By 2025 it's estimated that over 1 million people will be living with dementia.**
- **Dementia costs the UK economy £26.3 billion a year.**
- **Other health challenges receive more priority: For every one dementia researcher there are five cancer researchers.**