

Research at Dementia UK



This information leaflet has been written by the Research and Publications Team at Dementia UK along with the Dementia UK Lived Experience Advisory Panel (LEAP): a panel of people with dementia and carers who collaborate, advise and inform on many aspects of our work, including research. It is for people living with dementia and family carers. It aims to tell you about our research and how you can get involved and make a difference.

What is research?

Do you want to learn new things?

Do you want to help discover new knowledge?

If the answer to these questions is yes, then research might just be for you!

Members of LEAP describe research as:

- “Looking for some new knowledge”
- “Thinking outside the box, looking at new ideas”
- “An activity that serves to increase the understanding of a given topic”

At Dementia UK, our research involves trying to find new and effective ways to help people with dementia and their families to live better.

Some members of LEAP prefer the word ‘discovery’ to research, because to some people, ‘research’ might sound daunting.

Research is often misunderstood, so here, we bust some of the myths.



Myth: research is all about testing new drugs.

There are lots of different kinds of research. Some research might be focused on preventing illness or testing drugs, but research can also focus on improving how we care for people or trying to find new ways to solve problems or make things better.

Myth: research only takes place in hospitals.

You do not always have to be in hospital to take part in research. Researchers can often come to people's homes, healthcare settings or community venues, and some research participation can be online.

Myth: you have to be really smart to take part in research.

Research is for anyone who wants to make the world a better place. You do not have to be a genius to take part.



Myth: research does not actually change anything.

Many research studies have led to new ways to treat disease, make medicines safer and improve the quality of care. Sometimes studies are more about exploring and understanding and so do not lead to immediate changes, but they are still important in helping people understand more about a subject or problem.

Myth: taking part in research always takes lots of time.

The amount of time it takes to be part of research depends on the study. Some studies can last years, but others just need five minutes of someone's time. Researchers must tell you up front in the study information sheet what taking part will involve and how long it will take. This means you can pick studies to suit you.

What are the benefits of taking part in research?

Recently there have been some fascinating studies designed and led by people with dementia. These are some of the benefits of getting involved in research, according to LEAP members:

- “It can be something positive to come out of a dementia diagnosis and make you feel valued once more”
- “It is a chance to challenge people’s assumptions about dementia, to convey to others what people with dementia are capable of”
- “I think that we have a duty to take part in research, to make sure that the views of people living with dementia are represented”

Why is taking part in dementia research important?

LEAP members say:

- “It is important that as many people as possible with a diagnosis of dementia take part in research so that OUR views are given proper recognition and weight”
- “We can all learn so much if we are willing to take the time to listen and explore this complex world of dementia”
- “Everyone is going through something different; there is so much to learn from every single person living with or caring for someone with dementia. There is always something new to digest and share”

Historically, people with dementia were not included in research and even now the number who do take part in research is very small.



What research do we do at Dementia UK?

At Dementia UK our focus is on research into dementia care, not its cure or prevention. We research the best ways to support people with dementia and their families after diagnosis. The learnings from this type of research help our Admiral Nurses – who are nurses specialising in dementia – to provide the best care possible.

Our research also helps other health and care professionals learn more about supporting families affected by dementia.

Through our research we aim to show the difference that Admiral Nurses can make so that we can encourage the people and organisations who are responsible for health and social care budgets to employ them. Our goal is that one day, everyone living with a diagnosis of dementia and their families will have access to the support of an Admiral Nurse.

How does Dementia UK support research?

We conduct our own research into Admiral Nursing, focusing on our research priorities. Our research strategy explains what we will focus on for the next three years – you can read this at

► [**dementia-uk-research-strategy.pdf**](#)

We have a Research and Publications Team that leads our research. Dementia UK staff and Admiral Nurses also work with other researchers to help them in their studies. This might include:

- working with them as co-researchers
- providing expert advice on undertaking research with people with dementia and their carers
- helping them find people to take part in their studies
- helping them share important findings

Dementia UK does not fund other people's research.

Why does research matter to Admiral Nurses?

Research is an important part of modern nursing. As specialists in dementia care, it is important that Admiral Nurses have up-to-date evidence about the best ways to care for and support families affected by dementia.

- “Research helps identify best practices in dementia care. It allows Admiral Nurses to stay updated on the latest interventions, therapies and strategies that can enhance the quality of life for individuals with dementia and their families. As such, research is fundamental for Admiral Nursing because it ensures that nurses are providing the highest standard of care, staying up to date with the latest developments in dementia care, and contributing to the overall advancement of the field.”

LEAP member

- “Research is imperative for us as Admiral Nurses. It is only by knowing what works that we can provide the best and most effective care and support for families affected by dementia. Not only that, but research into the value of Admiral Nursing helps us to make the case for increasing our numbers across the country.” **Admiral Nurse**

Admiral Nurses are in a great position to inform people with dementia and their families about research, because they have positive relationships with them and the time to get to know them well.



How can you take part in research?

Dementia UK shares opportunities to take part in research:

- on X (formerly known as Twitter): ➡ **@DementiaUK**
- on the Research and publications page of the Dementia UK website: ➡ **dementiauk.org/research-and-publications**

You can also contact the Research and Publications Team to find out more about research opportunities:

Email: ➡ **researchpublications@dementiauk.org**

Call: 020 8036 5400

Write to us:

Research and Publications Team

Dementia UK

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Join Dementia Research is a national register that connects interested volunteers with research opportunities. You can sign up and the team will match you with suitable studies:

➡ **joindementiaresearch.nihr.ac.uk**

You can also find out about studies on the National Institute of Health Research (NIHR) database: ➡ **peopleinresearch.org**



There are lots of different ways to get involved in research and you can choose what suits you. This could be anything from completing a survey or taking part in an interview to working as part of a team with researchers to design a study.

It is important that when you take part in research, you feel valued and listened to as an expert in your own experience.

Financially you should never be left out of pocket by taking part in research. Any travel and expenses should be reimbursed, and most studies will pay for your time and expertise.

Thank you for taking the time to read about research.

If you want to know more, have any questions, or want to tell us about some research you are involved in, please contact the Dementia UK Research and Publications Team at

➤ researchpublications@dementiauk.org

**To speak to a dementia specialist Admiral Nurse
about any aspect of dementia:**

Contact our Helpline:
0800 888 6678 or helpline@dementiauk.org

Book a virtual appointment:
dementiauk.org/book

**Our charity relies entirely on donations to fund our
life-changing work. If you would like to donate to help us
support more families:**

- Call **0300 365 5500**
- Visit **dementiauk.org/donate**
- Scan the QR code

Thank you.



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