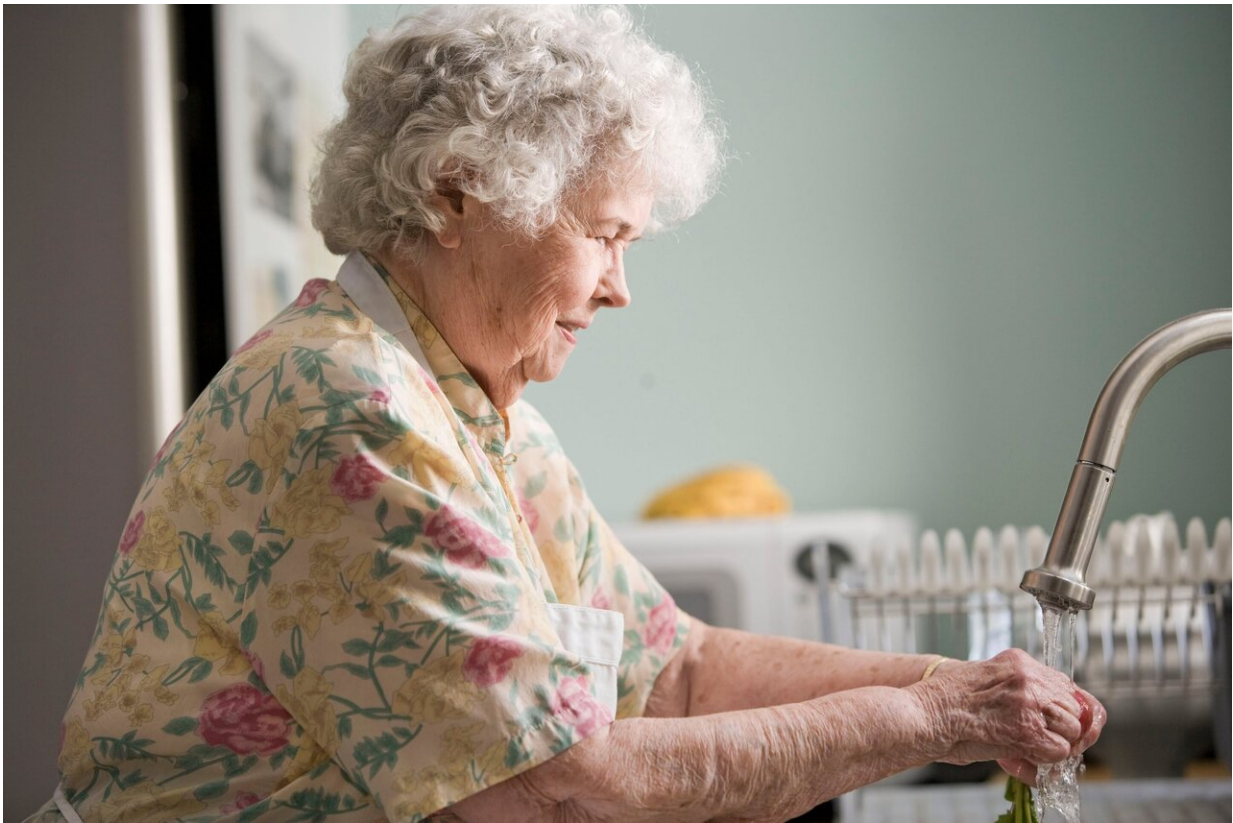


# **New resource launched to help people live as well as possible with dementia**

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The experience of thousands of people affected by dementia has fed into a new resource which aims to be a comprehensive guide to supporting people to live as well as possible with the condition.

A wide range of advice, resources, and accounts of people's own experiences are included in the Living with Dementia Toolkit, which will launch today (November 27) as part of the [ESRC Festival of Social Science](#).

The University of Exeter-led program Improving the Experience of Dementia and Enhancing Active Life (IDEAL) has received funding from Alzheimer's Society, the Economic and Social Research Council (ESRC) and the National Institute for Health Research. The project, recognized as an Alzheimer's Society Centre of Excellence, seeks to understand, and find ways to improve the experience of living with [dementia](#). The study recruited 1,547 people diagnosed with mild to moderate dementia and 1,283 carers and is following as many as possible over seven years.

The Living with Dementia Toolkit amalgamates the findings from the IDEAL project, drawing on the experience of thousands of people affected by the condition. The [toolkit](#) is linked to the INCLUDE project, part of IDEAL, which is also funded by the Economic and Social Research Council, as part of UK Research and Innovation's rapid response to COVID-19. INCLUDE seeks to understand and support people affected by dementia during the COVID-19 pandemic. The new toolkit draws on that learning to incorporate a wide range of advice, resources and accounts of people's own experiences.

Professor Linda Clare, of the University of Exeter, who leads the IDEAL program, said: "This project is the culmination of the most in-depth exploration to date of what can really make a difference and help people live as well as possible with dementia. Through our extensive research program and through ensuring people with dementia and carers are at the core of all our activities, we have developed a comprehensive toolkit to enrich every aspect of life. The COVID-19 pandemic was a particularly difficult time for people affected by dementia, but we

learned so much, not just about how best to support people through such a crisis, but about how we can help with managing the challenges of everyday life."

The new toolkit is organized into five themes: Stay safe and well; Stay connected; Keep a sense of purpose; Stay active; and Stay positive. It includes content proposed by the involvement group of four people with dementia and four carers, including the challenges of dealing with risk. Carers are motivated to keep people with dementia safe from harm, yet the individual they are trying to protect may be more worried about losing autonomy and independence. The new resource includes materials to help facilitate discussions and improve communications.

The involvement group met fortnightly with facilitator Rachael Litherland, of Innovations in Dementia. As David, a carer, notes, "This group of questioning and sharing individuals has, I think, added a very particular character to the end result." The information is diverse and includes practical advice and activities designed to inspire people to stay connected and active, as well as videos, top tips, animations and poetry. It includes the voices of people with dementia and carers, as well as researchers and leading dementia professionals.

Program manager Dr. Claire Pentecost of the University of Exeter said: "We know that everyone with dementia is different. They each have different priorities and challenges, and activities they want to stay engaged with. Our resource provides a huge breadth of variety and choice—we believe it will enhance people's lives, provide answers, assurances, information and a range of different perspectives to help people live as well as possible."

Keith, who lives with dementia, was part of the involvement group. He said: "The challenges are great, and we have been realistic in discussing them, but what we've come up with is a range of potential solutions

based on pragmatism and the sharing of lived experiences."

Being realistic while offering hope has been a guiding principle for the group, as has remembering that everyone is different. Involvement group member and former family carer Julia hopes that people will "choose and use what they find suitable for their individual needs" from the toolkit.

Many reflected on their own experiences of diagnosis. For Allison, who lives with dementia, "Yes, the situation is difficult and the initial feeling is "This is the end," but if someone can pick up this toolkit and get a little bit of hope that they can live... to be involved in that has been brilliant."

Professor Alistair Burns, National Clinical Director for Dementia and Older People's Mental Health at NHS England, said: "The Living with Dementia toolkit is a major resource developed through the extensive person centered research project that learns how to optimize quality of life for people with dementia through the experiences of people living with the condition. It will be a very valuable resource for anyone involved in dementia diagnosis and care and will be of benefit to people living with the condition, their families and carers."

Katherine Gray, Research Communications Manager at Alzheimer's Society said: "Improving quality of life for people diagnosed with dementia now is just as important as research looking for treatments for the future. After receiving a dementia diagnosis, people may feel like they have to give up the activities they love doing, like singing in a choir, going to a book club or volunteering in their community.

"We're excited to be funding the IDEAL study—this toolkit, built in collaboration with people affected by dementia, will inspire hope and ideas on how to live well with the condition, empowering people to

continue doing the things that matter most to them."

**More information:** The toolkit is available online:  
[livingwithdementiatoolkit.org.uk/](http://livingwithdementiatoolkit.org.uk/)

Provided by University of Exeter

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