

IDEAL: IMPROVING THE EXPERIENCE OF DEMENTIA AND ENHANCING ACTIVE LIFE

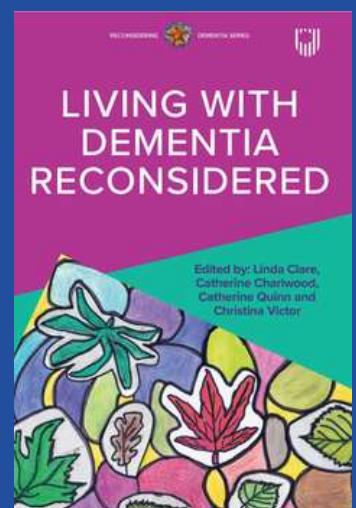
Key Messages

- ‘Living well’ is reflected in a sense of well-being and a good quality of life.
- IDEAL research shows that ‘living well’ is not just a matter of prescribing medication and managing symptoms. Many things must come together to create a sense of well-being and enable people with dementia and carers to experience and sustain a good quality of life (see Key Findings, page 2).
- There is potential to change some of the things that make it difficult to live well with dementia. For example, we can support social connections to reduce isolation and loneliness, offer rehabilitation to help manage daily challenges, and tackle the inequalities that give rise to social disadvantage.
- To make this possible we need the right policies, structures, services and support in place.
- IDEAL evidence is documented in over 80 scientific papers each accompanied by an accessible summary, available on the IDEAL website. It has been translated into a range of co-produced resources that are freely available online (see page 3).
- Learning from IDEAL has been distilled into a uniquely co-produced book, Living with Dementia Reconsidered, published in May 2025. It presents a 10-point manifesto for change created by people with dementia and carers that summarises the policy and practice changes indicated by IDEAL:

The 2009 National Dementia Strategy emphasised ‘living well’; the 10-year IDEAL research programme examined what helps people to live well, what makes it harder, and what needs to change. The research focused on people with any type of dementia living in the community and their family carers.

Call to action: a dementia manifesto

1. We are all different: we want you to find out about us so you can best enable us to live with dementia.
2. We want to live in a way that suits us and be supported to adapt to changes.
3. The well-being of the carer is as important as that of the person living with dementia: we want both to be supported.
4. We want to be included as active members of our communities and wider society, with opportunities to grow and maintain meaningful social connections.
5. Relationships matter: we want to be supported to build and maintain our relationships.
6. We want to be encouraged and enabled to do as much as we can.
7. We want all our health needs to be treated in a way that fits with our requirements, regardless of age.
8. We want our well-being to be supported and to be seen for who we really are.
9. We want to have choices about services and support and to know about the options which are available to us.
10. We urge you: do something, change something, because every action makes a difference.



Key Findings

Over 80 scientific papers can be found on the IDEAL website with accessible summaries

People living with dementia

Physical fitness and health

Social connections

Social situation

Managing life with dementia

Relationships

How the carer affects the well-being of the person with dementia (if relevant)

What affects well-being?

Psychological well-being

Carers

Physical fitness and health

Social connections

Social situation

Managing life with dementia

Relationships

Experiencing caring

How the person with dementia affects the well-being of the carer (if relevant)



Over time

To help maintain well-being, focus on providing support when the person experiences

- difficulty managing everyday tasks;
- low mood, hopelessness or poor self-esteem;
- loneliness or isolation.

Over time

To help maintain well-being:

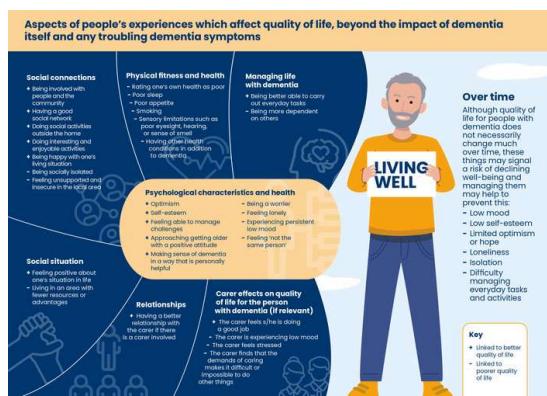
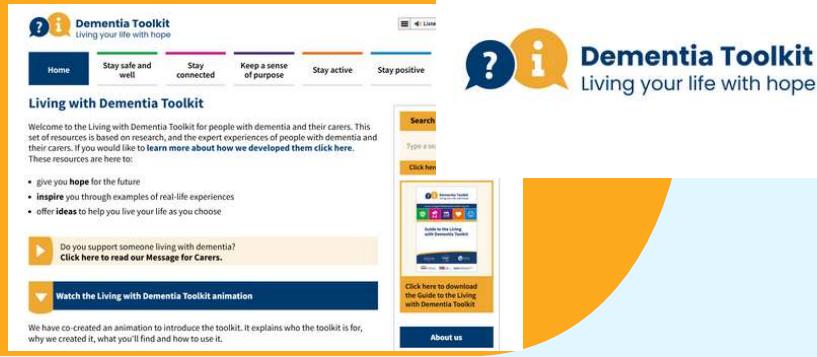
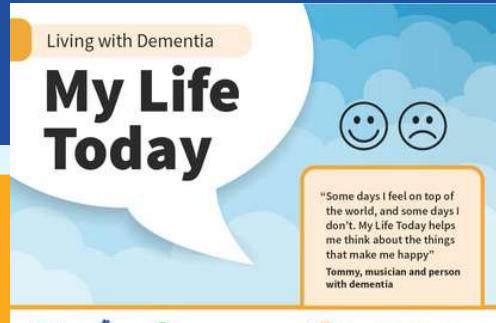
- focus on addressing low mood and reducing stress levels;
- provide more support when the severity of dementia increases or symptoms become more troubling.

IDEAL resources

These resources are available at www.idealproject.org.uk and www.livingwithdementiatoolkit.org.uk

Resources for people living with dementia and carers

- [The Living with Dementia Toolkit](http://www.livingwithdementiatoolkit.org.uk): a comprehensive collection of information and examples combining research evidence with lived experience to provide hope and inspiration, covering five themes: Stay safe and well, Stay connected, Keep a sense of purpose, Stay active and Stay positive.
- [My Life Today](http://www.livingwithdementiatoolkit.org.uk): a personal record to help people keep an eye on what supports their well-being day-to-day: the things that make life good, and the things that could be changed.



Resources for commissioners and practitioners

- [The Living with Dementia Maps](http://www.livingwithdementiatoolkit.org.uk): one focusing on people living with dementia and the other on carers. These distil evidence from IDEAL into a practical resource to inform service planning and support practitioners in holding effective conversations that promote well-being.
- [My Life Questionnaire](http://www.livingwithdementiatoolkit.org.uk): a scientifically-validated, co-produced measure covering key aspects of 'living well' to help identify strengths and needs.

Resources to promote awareness and understanding

- ['The World Turned Upside Down'](http://www.worldturnedupside-down.com): a documentary film based on an original theatre production which explores how to navigate challenges in communicating about difficult issues.
- ['Y Bont/The Bridge'](http://www.ybontthebridge.com): a one-act opera conveying the experience of adjusting to a dementia diagnosis.
- ['The Unfurlings: Banners for Hope and Change'](http://www.unfurlings.org): groups of people with dementia worked with artists to create campaign banners to raise awareness of everyday challenges such as accessing public transport or finding opportunities for friendship and social connection.
- ['Brave New World'](http://www.bravenewworldsong.com): an inspiring song written and performed by two musicians with dementia.



About IDEAL

- IDEAL is a programme of research spanning a decade, centred on a large longitudinal cohort study exploring the experiences of people with dementia and carers and how these change over time. Additional workstreams explored individual stories and diverse experiences, considered the effects of the COVID-19 pandemic, and created resources using arts-based methods.
- Over 1,700 people living with mild-to-moderate dementia in the community and over 1,400 unpaid carers shared information about their experiences with the IDEAL research team.
- The programme has shown what it means to 'live well' with dementia and set out what can be done to enable people with dementia and their family carers to live as well as possible with the condition.



Key research papers:

Clare, L., Wu, Y.-T., Jones, I.R., et al. (2019). A comprehensive model of factors associated with subjective perceptions of "living well" with dementia: findings from the IDEAL study. *Alzheimer Disease and Associated Disorders*, 33, 36–41. doi: 10.1097/WAD.0000000000000286 (open access)

Clare, L., Gamble, L.D., Martyr, A., et al. (2022). Longitudinal trajectories of quality of life among people with mild-to-moderate dementia: a latent growth model approach with IDEAL cohort study data. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 77, 1037–1050. doi: 10.1093/geronb/gbac022 (open access)

Clare, L., Wu, Y.-T., Quinn, C., Jones, I.R., et al. (2019). A comprehensive model of factors associated with capability to "live well" for family caregivers of people living with mild-to-moderate dementia: findings from the IDEAL study. *Alzheimer Disease and Associated Disorders*, 33, 29–35. doi: 10.1097/WAD.0000000000000285 (open access)

Clare, L., Gamble, L.D., Martyr, A., et al. (2022). 'Living well' trajectories among family caregivers of people with mild-to-moderate dementia in the IDEAL cohort. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 77(10), 1852–1863. doi: 10.1093/geronb/gbac090 (open access)

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Further information:

Please see www.idealproject.org.uk and www.livingwithdementiatoolkit.org.uk or contact Professor Linda Clare L.Clare@exeter.ac.uk

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