

How can research contribute to promoting autonomy, independence and choice when living with dementia?



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How can research contribute to promoting autonomy, independence and choice when living with dementia?

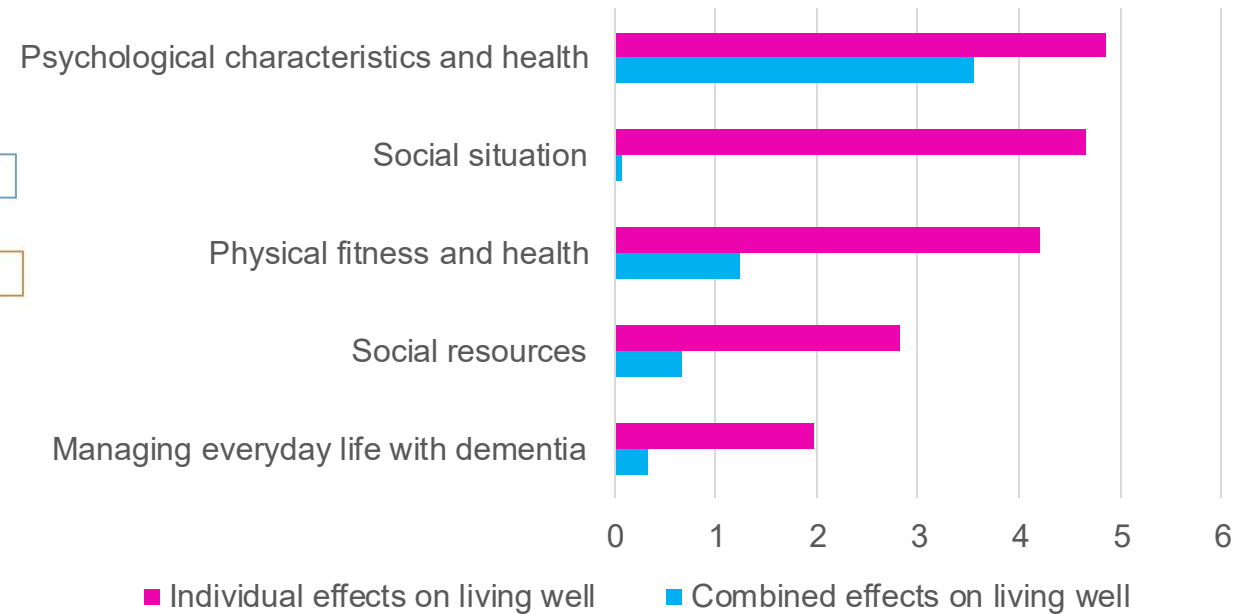
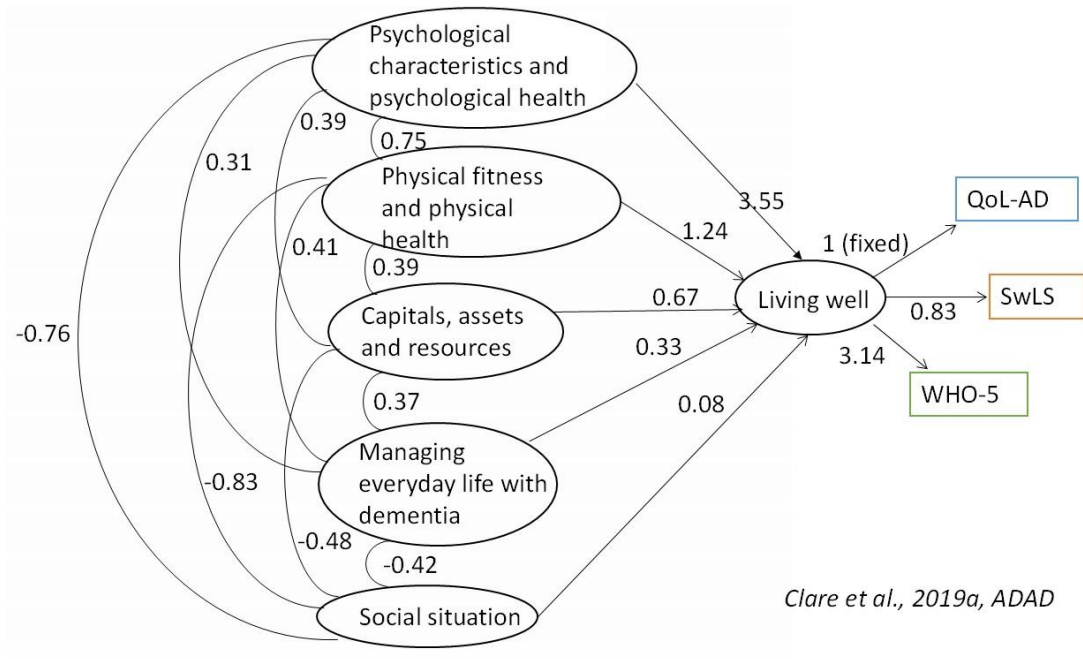
Sharing learning from two research programmes:

- **IDEAL** – improving the experience of dementia and enhancing active life
- **GREAT** – goal-oriented cognitive rehabilitation

The ALWAYSs Group - Action on 'Living Well': Asking You



What supports well-being when living with dementia?



IDEAL Living with Dementia Maps

Living with Dementia Map: People Living with Dementia

For practitioners, professionals and commissioners


Dementia affects many areas of people's lives, and many aspects of life affect the experience of dementia.

What does this map do? It will enable you to:

- Have meaningful conversations about a person's experience of dementia
- Best support the person by considering everything that could affect quality of life and well-being
- Draw on a decade of research evidence to inform your care

Does this person have a carer? Use the Living with Dementia Map: Carers to check in with them.

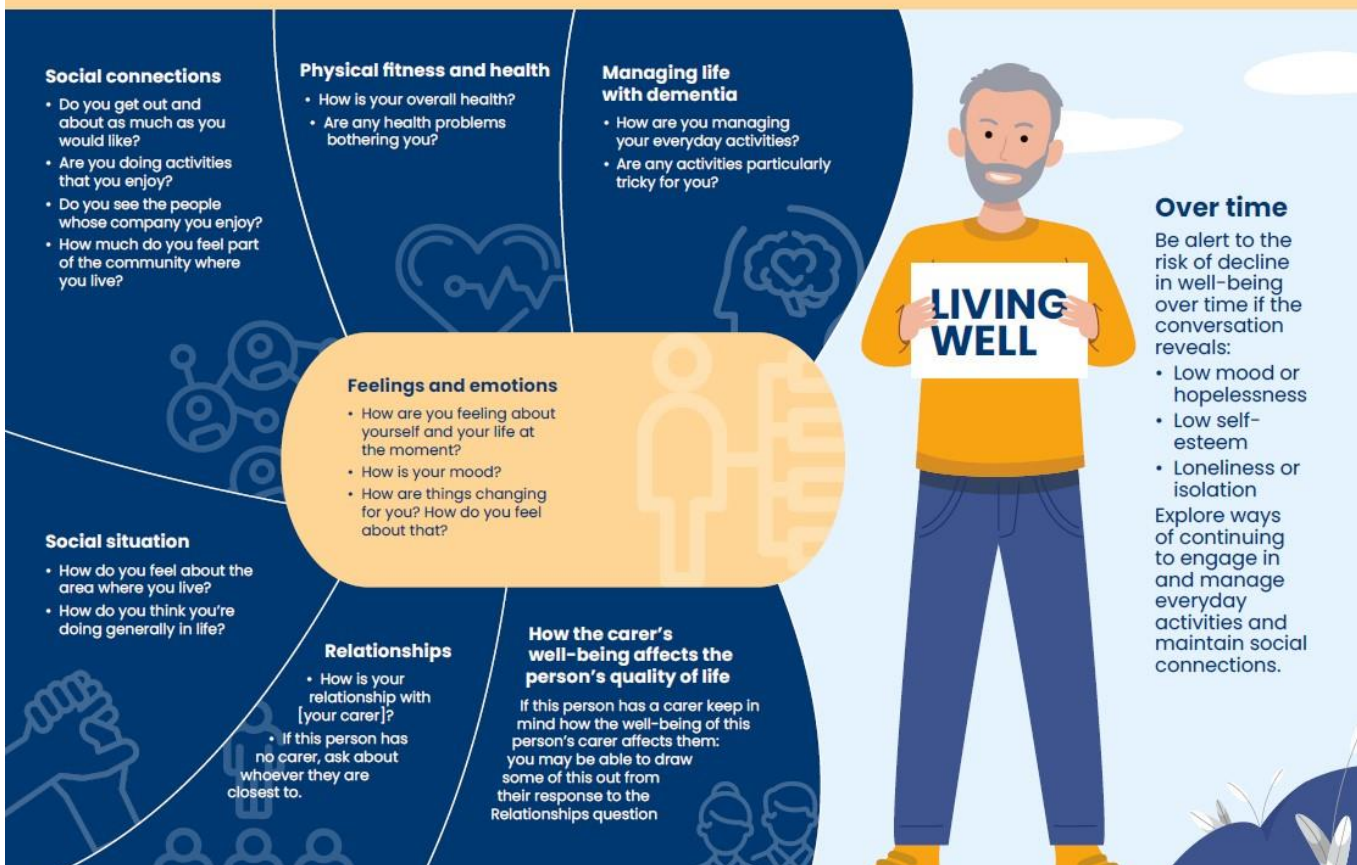
In this map, 'carers' refers to unpaid carers: family members or friends providing support.



IDEAL:
Improving the experience of Dementia & Enhancing Active Life

University of Exeter | NIHR | NIHR | NIHR | NIHR

Examples of topics, beyond dementia symptoms, to cover in your conversations



Social connections

- Do you get out and about as much as you would like?
- Are you doing activities that you enjoy?
- Do you see the people whose company you enjoy?
- How much do you feel part of the community where you live?

Physical fitness and health

- How is your overall health?
- Are any health problems bothering you?

Managing life with dementia

- How are you managing your everyday activities?
- Are any activities particularly tricky for you?

Feelings and emotions

- How are you feeling about yourself and your life at the moment?
- How is your mood?
- How are things changing for you? How do you feel about that?

Social situation

- How do you feel about the area where you live?
- How do you think you're doing generally in life?

Relationships

- How is your relationship with [your carer]?
- If this person has no carer, ask about whoever they are closest to.

How the carer's well-being affects the person's quality of life

If this person has a carer keep in mind how the well-being of this person's carer affects them: you may be able to draw some of this out from their response to the Relationships question

Over time

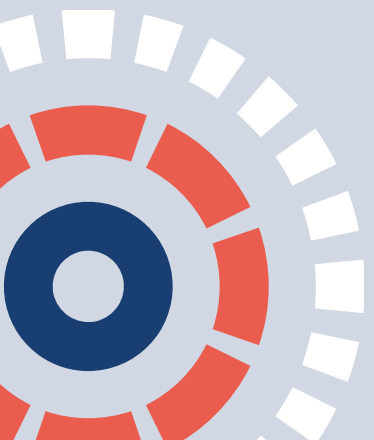
Be alert to the risk of decline in well-being over time if the conversation reveals:

- Low mood or hopelessness
- Low self-esteem
- Loneliness or isolation

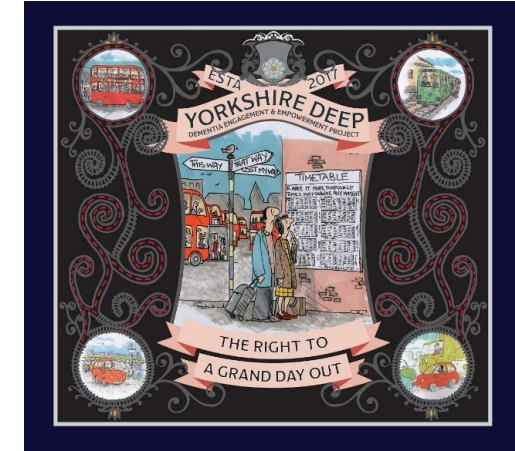
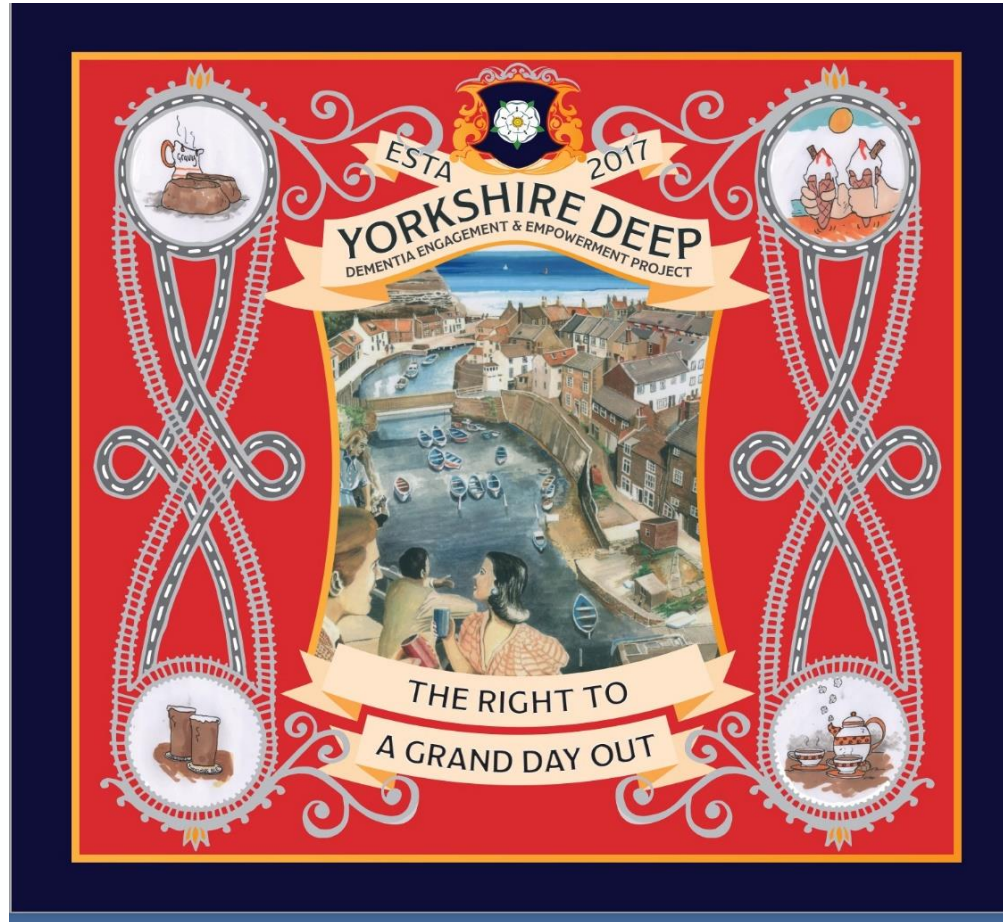
Explore ways of continuing to engage in and manage everyday activities and maintain social connections.

LIVING WELL

Empowerment through having a voice and raising public awareness



Getting out and about



The Unfurlings exhibition



People's History Museum
Manchester, UK, Dec 2019
and then on tour

www.theunfurlings.org.uk

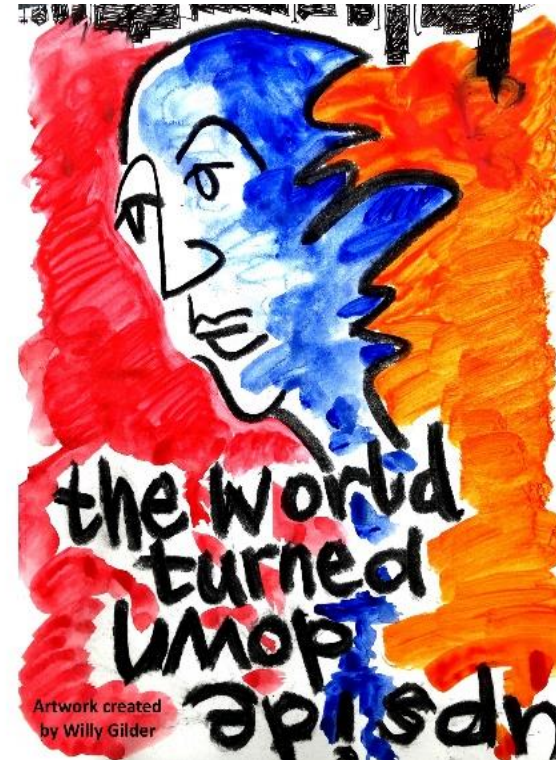


Navigating challenges to autonomy, independence and choice: how communication makes a difference

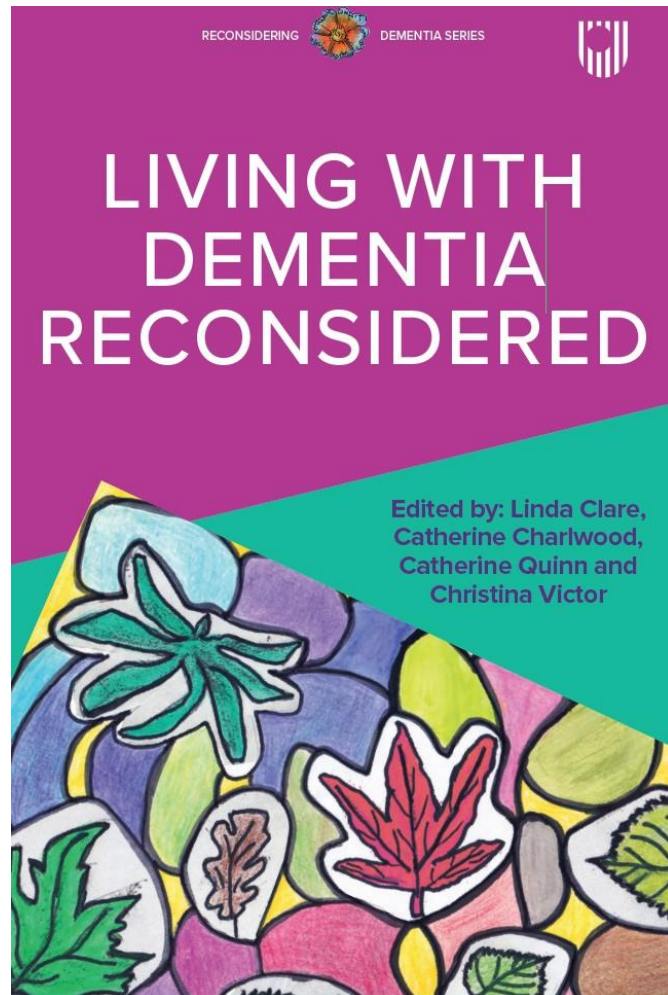
The World Turned Upside Down

An innovative documentary about dementia and communication that encourages us all to think about the role we play in communicating in ways which help rather than hinder.

- Original play using forum theatre approach performed 3 times, including once to sixth-form drama students
- Documentary film has had over 9,000 views on YouTube and 15 public screenings so far
- Scenarios from the film are being used in professional training



Creating a call to action on improving the experience of dementia

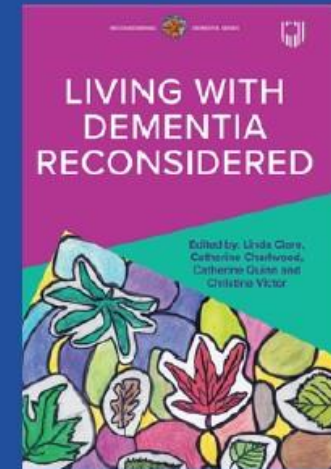


Call to action: a dementia manifesto

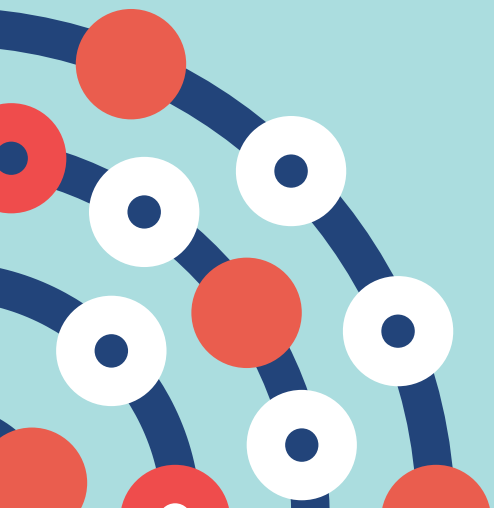
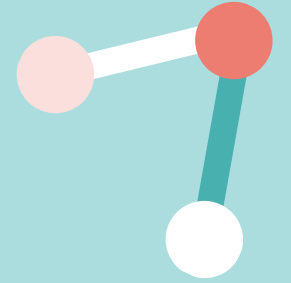
1. We are all different: we want you to find out about us so you can best enable us to live with dementia.
2. We want to live in a way that suits us and be supported to adapt to changes.
3. The well-being of the carer is as important as that of the person living with dementia: we want both to be supported.
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.



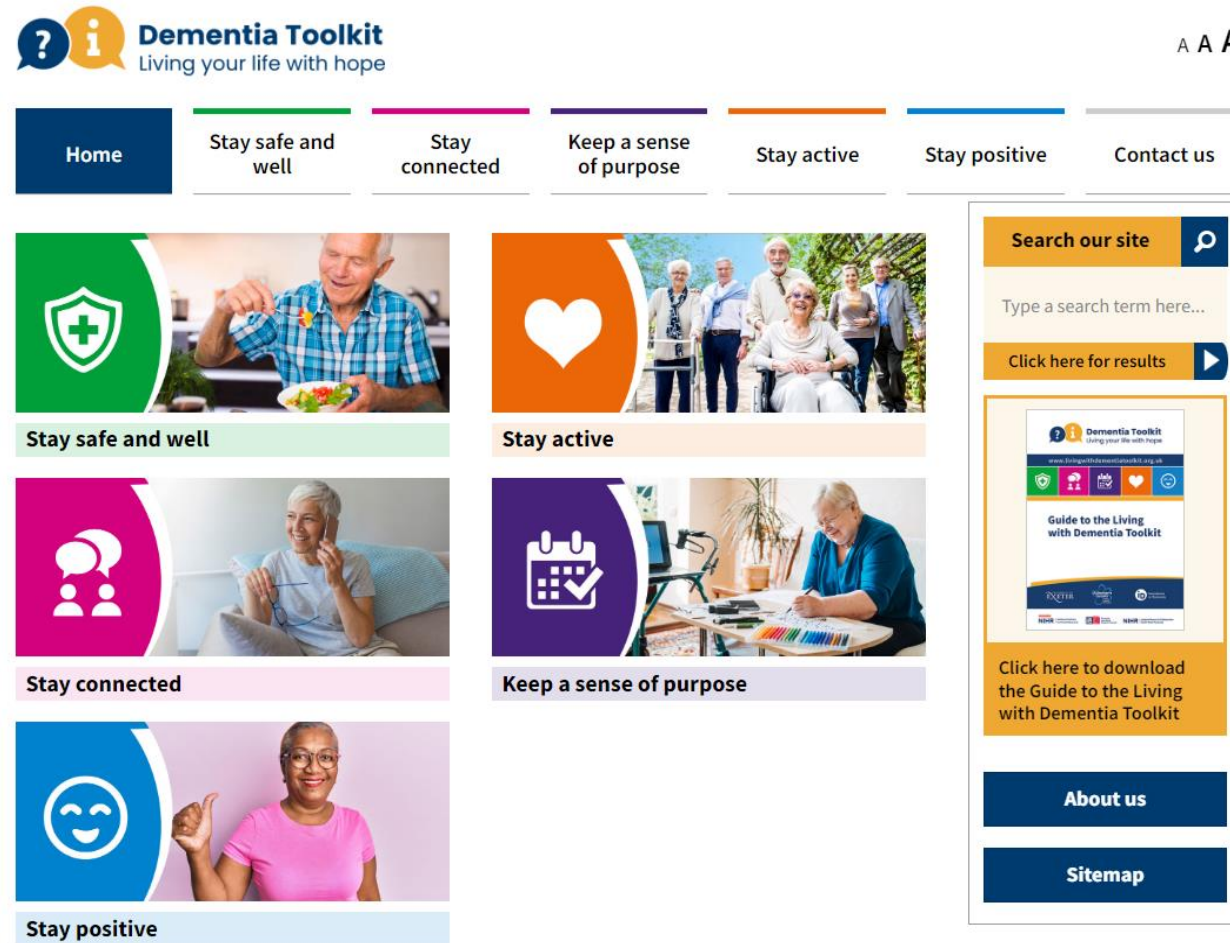
6. We want to be encouraged and enabled to do as much as we can.
7. We want all our health needs to be treated in a way that fits with our requirements, regardless of age.
8. We want our well-being to be supported and to be seen for who we really are.
9. We want to have choices about services and support 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.



Empowerment through promoting
autonomy, independence and choice at
the individual level

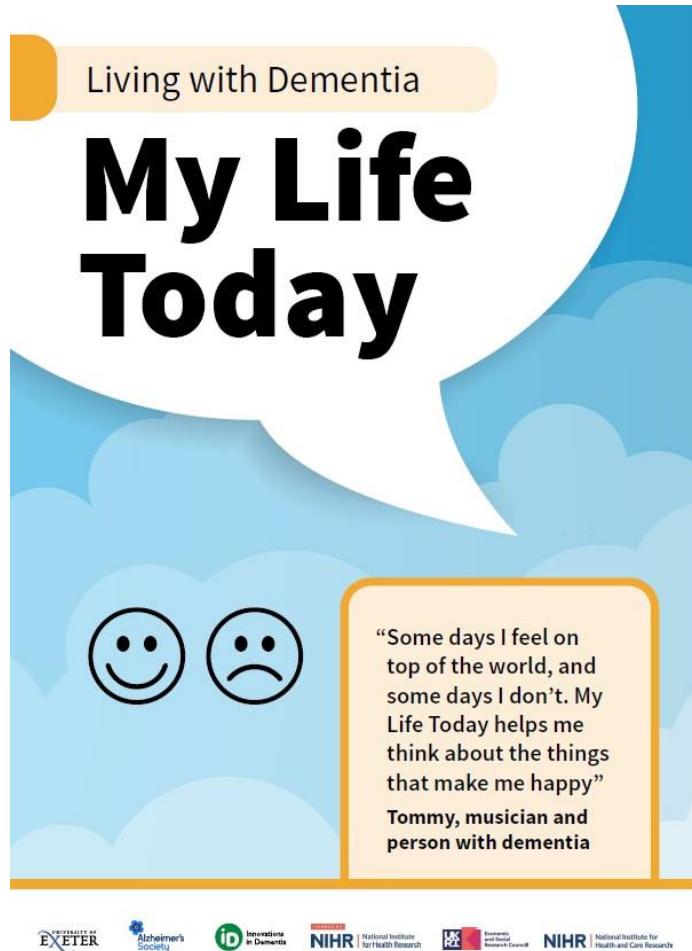


The Living with Dementia Toolkit



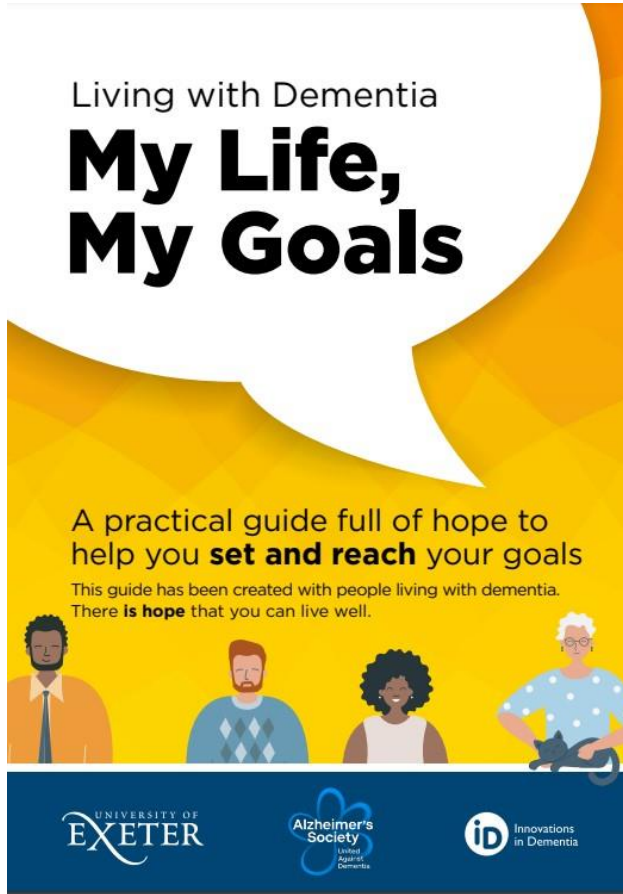
- Accessed by 123,000 users from 130 countries.
- Included in the WHO Global Dementia Observatory Knowledge Exchange Forum.
- Toolkit materials are being used by individuals, by GP services, by memory clinics and older people's mental health teams across 20 ICBs, and by many community and third sector groups.

My Life Today

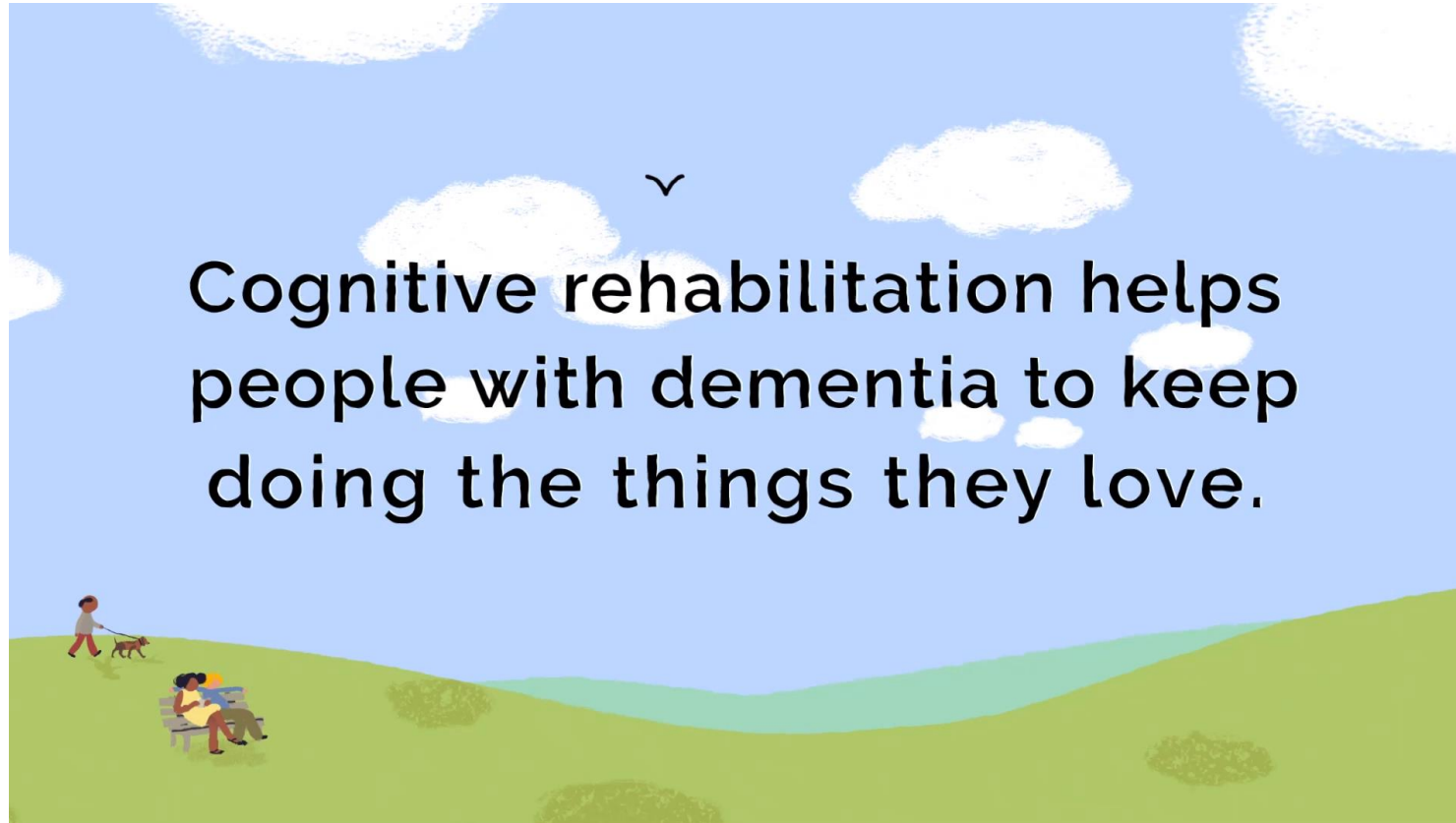


- Co-produced with people with dementia
- Evaluated by people with dementia and people who have supported them to use it
- <https://medicine.exeter.ac.uk/reach/publications/>

My Life, My Goals



What is cognitive rehabilitation?



Rehabilitation promotes autonomy, independence and choice

- **World Health Organization:** Rehabilitation addresses the impact of a health condition on a person's everyday life by optimizing their functioning and reducing their experience of disability. Rehabilitation expands the focus of health beyond preventative and curative care to ensure people with a health condition can remain as independent as possible and participate in education, work and meaningful life roles.
- **NICE Guideline:** Identifying functional goals that are relevant to the person living with dementia and working with them and their family members or carers to achieve these. The emphasis is on improving or maintaining functioning in everyday life, building on the person's strengths and finding ways to compensate for impairments, and supporting independence.

Views from GREAT programme participants



"I have become more independent and will now go out on my own regularly. I have attempted volunteering in a charity shop and will now get shopping on my own."

"More confidence. Boosted my feelings about myself. More secure."



"A big difference - a good outcome by realising there are different strategies to manage the problems we face which do help. It's just finding the right strategies and implementing them."

"Mum has mastered using both the washing machine and her mobile phone and has gained confidence."

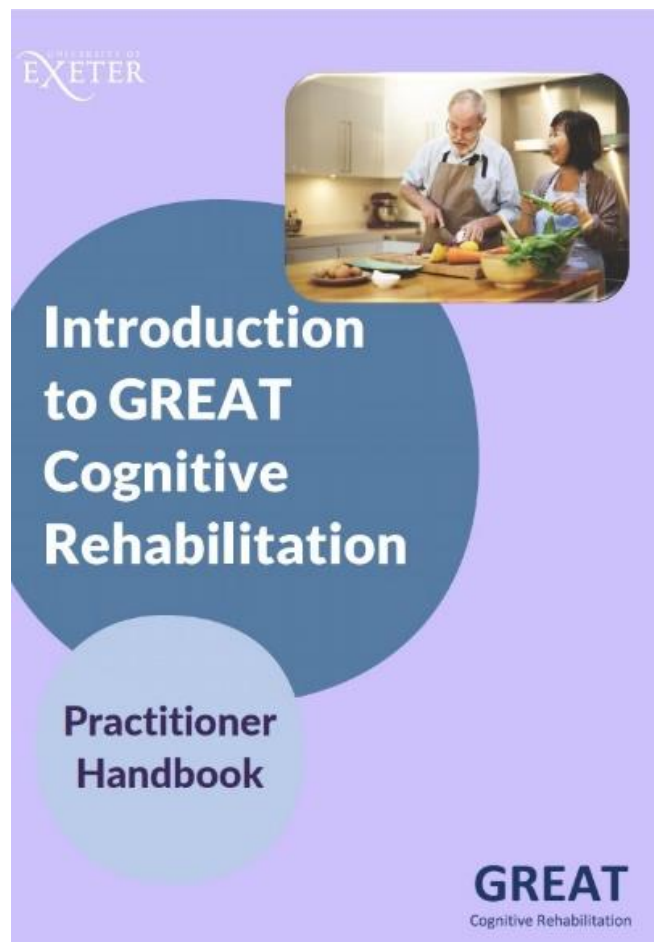


"The person-centred approach means that it can make a big difference to daily life, as the goals are meaningful to the person."




"I do think that [people with dementia], when they understand more about it and are more aware of it, they will be asking for it.... it's a powerful restorative experience for them."

Resources for practitioners



GREAT Cognitive Rehabilitation:
Engaging in activities and personal projects



GOAL: I will go to town on the bus once a week

What are the possible motivations underlying this goal?

- Independence.
- Socialising.
- Purposeful activity.

What difficulties might be interfering with being able to do this activity?

<ul style="list-style-type: none"> • Memory. • Visuospatial difficulties. • Expressive language problems. 	<ul style="list-style-type: none"> • Attention/concentration difficulties. • Anxiety. • Knowledge, for example of the bus timetable or where to get off the bus.
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Could this activity be simplified?

- Think about what the person wants to achieve.
- If going to town is the important thing, it may be better to focus on this first and then introduce the bus journey.
- If using the bus is the important thing, certain steps could be put in place in advance, such as having the bus times and numbers written down, and learning where the bus stops are, so that the focus is on the journey only.

Which strategies would be helpful for addressing this goal?

- Enhanced learning techniques: action-based learning; graded activity; method of loci or mnemonic; effortful processing.
- Compensatory methods: memory aids; assistive technology.
- Other Elements: anxiety management.

How might the practitioner use these strategies?

With the person directly

Planning ahead:

- Identify the bus route, number, timetable and location of the bus stop and write the information down for use on the outward and return journeys.
- Put the date for the bus trip onto the calendar at the beginning of the week.
- Decide on an interesting place to go to, or a person to meet, once the person arrives in town.
- Put a cue card by the front door to remind the person to take his/her bus pass.
- Consider using a mnemonic to remember key details, such as BMW as a reminder to take 'bus pass, mobile, wallet'

(Continued overleaf)

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How might the practitioner use these strategies? (Continued)

With the person directly

The journey itself:

- Use the method of loci or a mnemonic to learn key landmarks on the route to the bus-stop, and/or the bus route.
- Employ expanding rehearsal to help the person learn the sequence of directions to the bus-stop or key timetable facts such as 'bus comes at 10 minutes past the hour'.
- Take photos of the bus stop where the person needs to get off and use this to identify a landmark for him/her to look for as she/he approaches the stop.
- Use applications such as google maps to can track the bus and its stops in real time or a bus company app for details of the timetable and bus stops.
- Enter a speed dial code into the person's phone so she or he can contact a key person if feeling lost.
- As a first step, go to the bus-stop and just watch the bus come and go.
- Go with a friend who also uses a bus pass to watch how she or he uses it when getting on the bus.
- Accompany the person, or suggest someone else accompanies him/her, on initial trips and then gradually withdraw this support overtime.
- Start by walking to town or having a lift in, and then catching the bus home, before moving on to catching the bus each way.

By involving the care partner


- Remind the person to plan the weekly trip.
- Go into town together to begin with to build confidence, then gradually encourage the person to do more alone each time.
- Take photos of the bus stop in town and the key landmarks for the person to look for.
- Support the person with learning things like the timetable, route, and bus number.
- Make a contingency plan about what to do if the bus is late or does not turn up to reduce anxiety.

What associated issues might you need to address to support achieving this goal?

<ul style="list-style-type: none"> • Ability to wear appropriate clothes, for example, taking a coat for the journey. • Any risk of falls due to poor balance or gait. • Ability to manage money. 	<ul style="list-style-type: none"> • Safety aspect of letting someone else know where the person has gone. • Apathy.
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Engaging support from the person's wider network

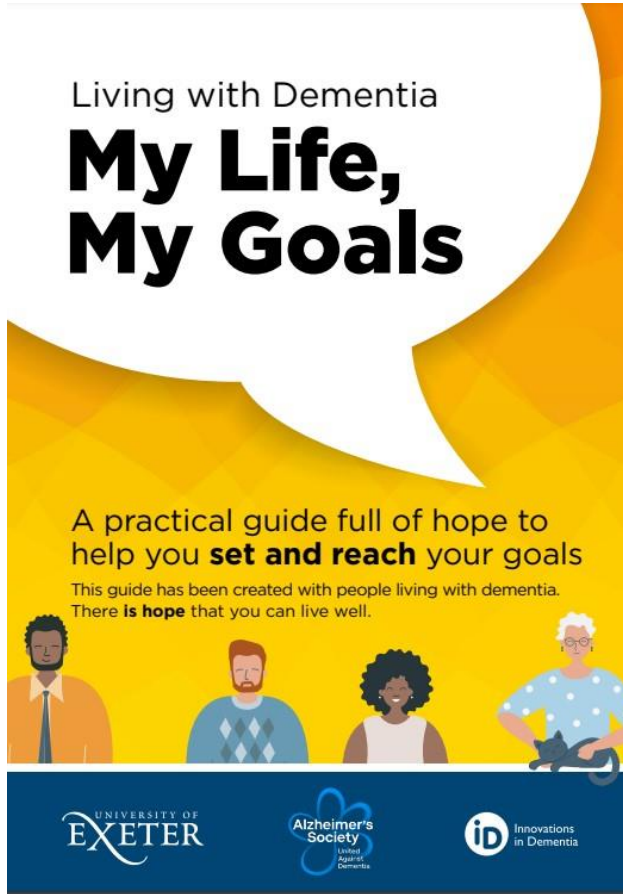
- Make sure all the relevant people, such as other family members or support workers, know about the chosen strategies and can encourage the person to use them.
- Find out if there are friends who might be willing to join the person to go into town together.



Bruce had memory problems and visuospatial difficulties, and had given up his driving licence. He wanted to go into town on the bus with his wife. The CR practitioner worked with him to set up a whiteboard on which he could write the intended date and time of his trips into town. They used the method of loci as an effortful processing method to help him learn the route to the bus-stop. They also identified an activity group he could join. Bruce started attending the Alzheimer's Society 'Games for the Brain' group, run once a week in the city centre, and travelled there by bus.

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My Life, My Goals



Launching 18th September 2025



World Alzheimer Report 2025

Dementia rehabilitation

The upcoming 2025 World Alzheimer Report will explore the important topic of dementia rehabilitation.



Thank you to everyone who contributed to the IDEAL and GREAT research programmes, especially the members of the ALWAYSs group, and to our funders: ESRC, NIHR and Alzheimer's Society.



Further information:

<https://www.idealproject.org.uk/>

<https://sites.google.com/exeter.ac.uk/great-cr/home>

