

# 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**



# 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.

# Aspects of people's experiences which affect quality of life, beyond the impact of dementia itself and any troubling dementia symptoms

## Social connections

- + Being involved with people and the community
- + Having a good social network
- + Doing social activities outside the home
- + Doing interesting and enjoyable activities
- + Being happy with one's living situation
- Being socially isolated
- Feeling unsupported and insecure in the local area

## Physical fitness and health

- Rating one's own health as poor
- Poor sleep
- Poor appetite
- Smoking
- Sensory limitations such as poor eyesight, hearing, or sense of smell
- Having other health conditions in addition to dementia

## Managing life with dementia

- + Being better able to carry out everyday tasks
- Being more dependent on others

## Psychological characteristics and health

- + Optimism
- + Self-esteem
- + Feeling able to manage challenges
- + Approaching getting older with a positive attitude
- + Making sense of dementia in a way that is personally helpful
- Being a worrier
- Feeling lonely
- Experiencing persistent low mood
- Feeling 'not the same person'

## Social situation

- + Feeling positive about one's situation in life
- Living in an area with fewer resources or advantages

## Relationships

- + Having a better relationship with the carer if there is a carer involved

## Carer effects on quality of life for the person with dementia (if relevant)

- + The carer feels s/he is doing a good job
- The carer is experiencing low mood
- The carer feels stressed
- The carer finds that the demands of caring makes it difficult or impossible to do other things



## Over time

Although quality of life for people with dementia does not necessarily change much over time, these things may signal a risk of declining well-being and managing them may help to prevent this:

- Low mood
- Low self-esteem
- Limited optimism or hope
- Loneliness
- Isolation
- Difficulty managing everyday tasks and activities

## Key

- + Linked to better quality of life
- Linked to poorer quality of life

## Further information

The IDEAL **Living with Dementia Maps** – one for people living with dementia, one for carers – can be accessed at [www.idealproject.org.uk/projects/maps](http://www.idealproject.org.uk/projects/maps). The website contains a wealth of other information and links to additional co-produced resources such as the Living with Dementia Toolkit: [www.livingwithdementiatoolkit.org.uk](http://www.livingwithdementiatoolkit.org.uk).

The maps are based on evidence derived from statistical analyses of information provided by people with dementia and carers participating in the IDEAL cohort study. The evidence from IDEAL has been published in over 80 scientific papers, all available on the website with an accessible summary in each case.

The maps give an overview of the aspects that came out as most important for quality of life overall, but for each individual, some will be more relevant than others. Some things that were linked with living well in our analyses are not included here because they would only be relevant for a few people. This is a reminder that we always need to ask about what matters most to the individual.

## Key references

Clare, L., Wu, Y.-T., Jones, I.R., Victor, C.R., Nelis, S.M., Martyr, A., Quinn, C., Litherland, R., Pickett, J.A., Hindle, J.V., Jones, R.W., Knapp, M., Kopelman, M.D., Morris, R.G., Rusted, J.M., Thom, J.M., Lamont, R.A., Henderson, C., Rippon, I., Hillman, A., & Matthews, F.E. on behalf of the IDEAL study team. (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., Sabatini, S., Nelis, S.M., Quinn, C., Pentecost, C., Victor, C., Jones, R.W., Jones, I.R., Knapp, M., Litherland, R., Morris, R.G., Rusted, J.M., Thom, J.M., Collins, R., Henderson, C., & Matthews, F.E., on behalf of the IDEAL study team. (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)

**Thank you to everyone who helped us develop this, including Kim Grosvenor (IDEAL Advisory Group), Reinhard Guss (Oxleas NHS Foundation Trust), David Sealey (NHS Somerset), Steve Shelley-King (Gloucestershire Health and Care NHS Foundation Trust), and Melanie Williamson (Essex County Council).**

**Our sincere gratitude to the hundreds of people with dementia and carers who were involved in the IDEAL programme: we could not have made this without your input.**

## Find out more...

**Web:** [www.idealproject.org.uk/projects/maps](http://www.idealproject.org.uk/projects/maps)

**Email:** [IDEAL@exeter.ac.uk](mailto:IDEAL@exeter.ac.uk)

