

Living with Dementia Map: Carers

For practitioners, professionals and commissioners

Caring for a person with dementia affects many areas of life, and many aspects of life affect the experience of being a carer.

'Carers' refers to unpaid carers: family members or friends providing support.

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

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

What about the person with dementia? Use the **Living with Dementia Map: People Living with Dementia** to guide a meaningful conversation about quality of life.



IDEAL:

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Examples of topics to cover in your conversations with the carer

Social situation

- How do you think you're doing generally in life, relative to others?

Social connections

- Do you get to do activities that you enjoy?
- Do you get to see the people whose company you enjoy?

Physical fitness and health

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

Experiencing caring

- How are you finding being a carer for [the person with dementia]?

Feelings and emotions

- How do you feel about yourself? And about the future?
- How is your mood?
- Do you tend to be a worrier?
- Do you feel lonely?

Relationships

- How is your relationship with [the person with dementia]?

Managing life with dementia

- Are there everyday challenges in supporting [the person with dementia] that you find difficult?
- Does [the person with dementia] have any other symptoms that you find particularly troubling?

How the person with dementia affects quality of life for the carer

- How do you feel [the person with dementia] is doing?
- Do you find [the person with dementia] is depressed or experiencing low mood?



LIVING WELL

Over time

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

- The carer is experiencing low mood
- The carer is experiencing high stress levels
- The carer describes increased severity of dementia or more troubling symptoms in the person with dementia
- The carer is spending more time than before providing care and support to the person with dementia

Aspects of carers' experiences that affect quality of life

Social situation

- + Feeling positive about one's position in the community and in society

Social connections

- + Having enough social contact
- + Having people to call on for help when needed
- + Doing social activities outside the home
- + Participating in the community
- Being socially isolated
- Feeling unsupported and insecure in the local area

Physical fitness and health

- Rating one's own health as poor
- Poor eyesight
- Smoking

Experiencing caring

- + Making sense of dementia in a way that is personally helpful
- Feeling trapped by the demands of caring
- Being less able to do things and see people due to the demands of caring
- Feeling stressed

Psychological characteristics and health

- + Optimism
- + Self-esteem
- + Feeling younger than one's age
- Being a worrier
- Feeling lonely
- Experiencing low mood

Relationships

- + Good relationship with the person with dementia

Managing life with dementia

- Feeling distressed about troubling symptoms in the person with dementia

How the person with dementia affects quality of life for the carer

- The person with dementia has more difficulties
- The person with dementia is experiencing low mood



LIVING WELL

Over time

These things may signal a risk of declining quality of life and managing them may help to prevent this:

- Low mood
- High stress levels
- The carer is spending more time than before providing care and support to the person with dementia
- Feeling the severity of dementia has increased or symptoms are more troubling

Key

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

Further information

The **Living with Dementia Maps** – one for people living with dementia, one for carers – can be accessed at 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.

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 carer, 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 carers. This is a reminder that we always need to ask about what matters most to the individual.

Key references

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Find out more...

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