

Living with Dementia or Memory Loss (suspected dementia) in Cornwall:

Carer experience of services and support

Healthwatch Cornwall and Cornwall Memory Cafe Network would like to hear about carer experience of dementia and memory loss services and support in Cornwall. We are working with local system partners to develop and improve services and support for people living with dementia and memory loss, and for their carers. Healthwatch Cornwall is an independent, publicly-funded organisation. We are here to make sure health and social care services in Cornwall are the best they can be for people, now and in the future.

We would like to understand your experiences as a carer/as someone who has recently been a carer of a person with either memory loss (suspected dementia), or a diagnosis of dementia. By carer we mean someone who helps another person, usually a relative or friend, in their day-to-day life.

Our survey takes 10 to 15 minutes to complete and asks you about:

- Diagnosis
- Services you have accessed – what's worked well and what you would like to see improved
- What we can learn from how services changed during the pandemic

Please return your completed survey to Healthwatch Cornwall in the Freepost envelope provided by **Sunday 29th May 2022**: FREEPOST RTUL-UBEJ-ERCA, Healthwatch Cornwall, 6 Walsingham Place, Truro, TR1 2RP.

You can also complete the survey online or over the phone:

- Online: bit.ly/dementia-survey
- Telephone Healthwatch Cornwall: 0800 0381 281.

We are working with PFA Research Ltd. to administer the survey.

To complete the survey, please agree to Healthwatch Cornwall and PFA Research Ltd. processing your information in line with General Data Protection Regulations. All your answers will be anonymised. This means that anything that might identify you in any comments you make will be removed before sharing with Cornwall Memory Cafe Network and other service providers, and before publishing in reports. For more information, please see Healthwatch Cornwall's [privacy policy](#) on their website.

- Yes, I agree to Healthwatch Cornwall and PFA Research Ltd. processing my information in line with General Data Protection Regulations.

About you and the person you care for:

These questions help us to understand how carer experience differs depending on people's circumstances. If you look after or support more than one person living with dementia or memory loss, please provide details about the person **you currently provide the most support to or want to tell us about**. If you want to tell us about the experience of more than one person you care for, you can fill in more than one survey.

1. What is your age?

- Under 15
- 16 to 17
- 18 to 24
- 25 to 49
- 50 to 64
- 65 to 79
- 80+
- Prefer not to say

2. How old is the person you care for?

- Under 65
- 65 to 74
- Over 75
- Prefer not to say

3. Your gender?

- Male
- Female
- Non binary
- Other:
- Prefer not to say

4. Your postcode?

5. Who do you care for?

- Spouse/partner
- Parent/Parent-in-law
- Grandparent
- Other relative
- Friend or neighbour
- Other
- Prefer not to say

Diagnosis:

Dementia is an umbrella term used to describe a range of progressive neurological disorders, that is, conditions affecting the brain. The term is used to describe common symptoms such as memory loss, confusion, and problems with speech and understanding – that get worse over time.

6. Has the person you care for been diagnosed with dementia by a healthcare professional?

Tick all that apply:

- Yes, by a GP
- Yes, at a memory clinic or other specialist service for dementia
- Yes, at another healthcare setting (e.g. during a hospital stay)
- No, we have been referred for an assessment for dementia and are waiting for an appointment
- No, we are waiting for diagnosis following tests/assessments
- No, we haven't yet talked to a GP or healthcare professional about our concerns *(if you selected this response, please now answer Q6b)**
- Don't know
- Prefer not to say

If you selected 'Yes'

6a. How long did it take from first discussing this with a health care professional to receiving a diagnosis?

- Less than 3 months
- 3 to 6 months
- 6 months to one year
- More than 1 year
- Don't know

If you selected 'No, we haven't yet talked to a GP or healthcare professional about our concerns', please answer 6b.

For all other responses, please go straight to Q7.

6b. Can you tell us why you or the person you care for have not yet seen a GP or healthcare professional about their memory loss symptoms?

Tick all that apply:

- The person I care for is not concerned
- The person I care for does not want medical advice
- Our concerns are not urgent
- I/they are concerned about what a diagnosis might mean for them (i.e. fear of losing independence, ability to drive etc)
- I/they do not want to burden NHS
- It is difficult to get an appointment to see a GP/healthcare professional
- I cannot discuss the person I care for with their GP or healthcare professional due to patient confidentiality
- Other:

Your experiences of services and accessing support:

Please note: At the end of this survey, you will have space to tell us anything else you may wish to share about your experiences of services and support.

There is a wide range of health, social care and voluntary sector services which support carers and people living with dementia and memory loss in Cornwall. This may include your GP, memory services, specialist nurses, physiotherapy, occupational therapy, carer services and assessments, memory cafes, charities, and local support groups etc. You may have accessed them through your GP surgery, social care services, a hospital, in your own home or community, online or over the phone.

7. What has been **helpful** or **working well** for you and for the person you care for?

Tick all that apply:

- I have a phone number I can call for help and advice when I need it
- I am able to access the GP when I need to
- It has been easy to get help or advice when I need it
- I am able to see health care staff face-to-face when I need to
- I have a fast response when I ask for help or advice
- I am given the opportunity to take a break from my caring role
- The person that I care for has access to meaningful activities they enjoy
- I am able to go out with the person I care for to do the things we enjoy together
- Healthcare staff listen to me and understand our situation
- I get on well with key staff who support the person I care for
- I can help myself by looking up information and advice online
- I am able to meet with other carers and share experiences
- I have a supportive employer
- Other:

8. Which **three** things would you **most** like to see improved in relation to services and support you have accessed?

Please pick your **top three** responses:

- To have a phone number I can call for help and advice when I need it
- Easier access to an appointment with a GP
- Support to access online GP consultations or online information services
- Easier access to help or advice when I need it
- To be able to see health and care staff face-to-face
- A faster response when I ask for help or advice
- More opportunities to take a break from my caring role
- For the person I care for to have more opportunities to access meaningful activities they enjoy
- More opportunities to go out with the person I care for to do things we enjoy together
- For health care staff to listen to me and understand our situation
- More continuity in health and care staff who visit the person I care for
- To be more involved in important decisions about the person I care for
- For my employer to be more accommodating / supportive of my caring role
- Other:

9. Is there any additional information and advice that would help you in your caring role?

Tick all that apply:

I would like **more** information and advice on:

- The type of dementia the person I care for has and the changes to expect as the condition progresses
- Advice to support the person I am caring for to live well and keep them safe
- Advice on how to communicate with the person I care for
- How to recognise and what to do if the person I am caring for has unsettled behaviour
- Local services and support groups available
- Dementia friendly activities we can engage in
- Financial affairs, such as lasting power of attorney
- Advance care planning and planning for end of life
- Medical matters, such as medication and other physical health needs
- Dealing with incontinence
- Supporting mobility issues
- How to access funded care and eligibility for financial support
- Finding a care home
- Other:

10. What **additional** support or **new** service would help you and the person you care for live well with dementia or memory loss?

11. Do health and social services know about your caring responsibilities and identify you as a carer?

Tick all that apply:

- Yes, I have had a formal carers assessment by my local council or carers service **over the phone**
- Yes, I have had a formal carers assessment by my local council or carers service **in person**
- Yes, I am recognised by my GP as a carer
- Yes, I am on the carers register (i.e. registered as a carer on my medical records)
- Yes, I was identified as a priority to receive the COVID vaccination due to my caring role
- No
- Don't know
- Other: (e.g. I am not the main carer)

12. When accessing services and support, have you been given the opportunity to discuss what matters most to you and the person you care for, in managing their health and wellbeing?
- Always
 - More often than not
 - To some extent
 - Not at all
 - Not relevant / another person who helps care for the person was involved
13. Were you involved as much as you wanted to be in decisions being made about the person you care for and in planning the care and support you/they may need?
- Always
 - More often than not
 - To some extent
 - Not at all
 - Not relevant / another person who helps care for the person was involved

Your experience of changes to services during the pandemic:

We know there has been a significant, ongoing impact of social restrictions and staffing pressures on health and care services because of the pandemic, which has directly affected people living with dementia and memory loss, and their carers.

We are interested to know if there have been any **positive changes** to service provision, that we can build on for the future. For example, there have been changes to the way health care and support is delivered, such as online and telephone consultations; increased use of video technology for social groups; and local community innovations.

14. What **positive** changes to services and support during the pandemic have helped you and the person you care for, that you would like to see continue?
- Telephone consultations
 - Video consultations
 - Online social group
 - Online information and advice
 - New local community organisations
 - New services
 - Other:

Please provide details:

15. Please use **three words** to describe your overall experience of dementia and memory loss services and support in Cornwall.

16. Please use this space to tell us anything else you wish to share about your experiences of dementia or memory loss services and support in Cornwall.

(Please continue on a separate sheet if you need more space.)

Can we contact you again?

We are interviewing a small number of carers to ask about their experiences in more detail. We may also hold some group discussions with other carers to discuss people's views and improvements to services:

- Are you happy to talk with us in more detail about your experiences? This could be over the phone, in person, or by video link.

Tick all that you are interested in taking part in:

- No, thanks
- Yes, an interview over the phone, in person or by video link
- Yes, a group discussion online via video link
- Yes, a group discussion in person

Please provide your contact details if you are happy to be contacted about this (you can change your mind at any time):

Name: _____

Phone number: _____

Email address if possible (we would always arrange a suitable time to talk with you):

Thank you so much for completing the main body of the survey.

The last few questions are about you. They help us to understand how people's experiences differ depending on their circumstances and characteristics. They are optional.

17. How would you describe your ethnicity?

- White: British / English / Northern Irish / Scottish / Welsh
- White: Cornish
- White: Irish
- White: Gypsy, Traveller or Irish Traveller
- White: Roma
- Any other White
- Arab
- Asian / Asian British: Bangladeshi
- Asian / Asian British: Chinese
- Asian / Asian British: Indian
- Asian / Asian British: Pakistani
- Any other Asian / Asian British
- Black / Black British: African
- Black / Black British: Caribbean
- Any other Black / Black British
- Mixed / Multiple ethnic groups: Asian and White
- Mixed / Multiple ethnic groups: Black African and White
- Mixed / Multiple ethnic groups: Black Caribbean and White
- Any other Mixed / multiple ethnic groups
- Any other ethnic group
- Prefer not to say

18. How would you describe your Sexual Orientation?

- Heterosexual/Straight
- Gay man
- Lesbian/Gay woman
- Bisexual
- Pansexual
- Asexual
- Other
- Prefer not to say

19. Do you have other caring responsibilities?

Tick all that apply:

- No
- Yes, I have children
- Yes, I care for other relatives / friends
- Yes, I care for people in my work
- Other (please specify):

20. Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months (include any problems related to old age)?

- No
- Yes, limited a little
- Yes, limited a lot
- Prefer not to say

If Yes, please indicate your disability:

- Vision (e.g. due to blindness or partial sight)
- Hearing (e.g. due to deafness or partial hearing)
- Mobility, such as difficulty walking short distances, climbing stairs, lifting and carrying objects
- Learning or concentrating or remembering
- Mental Health
- Stamina or breathing difficulty
- Social, behavioural or communication (e.g. due to neuro diverse conditions such as Autism, Attention Deficit Disorder or Asperger's Syndrome)
- Other impairment (specify)
- Prefer not to say

21. Which of these statements describe your work situation?

- I am in full-time paid work
- I am in part-time paid work (working 30 hours or less)
- I look after the home full-time
- I am fully retired from paid work
- I have a long-term illness or disability that prevents me from having paid work
- I am unable to work due to caring responsibilities
- I am currently unemployed
- I am in full-time education
- I am in part-time education
- Other
- Prefer not to say

22. Which of the following best describes your current financial situation?

Pick the option that best describes your financial status:

- I have **more than** enough for basic necessities, and a **lot** spare that I can save or spend on extras or leisure
- I have **more than** enough for basic necessities, and a **little** spare that I can save or spend on extras or leisure
- I have **just enough** for basic necessities and little else
- I **don't have enough** for basic necessities and sometimes or often run out of money
- Don't know/prefer not to say

23. How would you describe your environment (the area that you live in)?

- Rural
- Semi-urban
- Urban
- Prefer not to say

Thank you for completing this survey, your feedback is greatly appreciated.

Please return it to: FREEPOST RTUL-UBEJ-ERCA, Healthwatch Cornwall, 6 Walsingham Place, Truro, TR1 2RP.

The answers you have given will not be reviewed in real time, so if you have disclosed anything about your life which you may need support with, please contact any of the organisations below:

- www.cornwallcarers.org.uk Phone 01736 756655
Adult carers in Cornwall are supported to self-manage via an Adviceline run by disability Cornwall, where there is enhanced support when you need it. There is a dedicated Team available to answer Carer calls and queries, text-to-chat options, support to access a Carers Emergency Card, Carers Passport, Carers Register and Carers Newsletter.
- www.ageuk.org.uk/cornwall Phone 01872 266383
Age UK CIOs have Carer's Coaches and Community Support available to help carers to connect with their communities and to improve their wellbeing.
- www.alzheimers.org.uk Phone 0333 150 3456
- Dementia UK (staffed by Admiral Nurses): Phone 0800 888 6678 or email: direct@dementiauk.org
- Mind (for mental health information and support): Phone 0300 123 3393
- To find your local memory cafe: www.cornwallmemorycafes.co.uk or phone Cornwall Memory Cafe Network Coordinator on: 01736 697459

For any other information, advice or support about health and social care in Cornwall, please contact us at Healthwatch Cornwall: Email: enquiries@healthwatchcornwall.co.uk
Tel: 0800 0381 281 or <https://www.healthwatchcornwall.co.uk/share-your-views>