

Memories Cafe in Surrey Heath



Project Rationale:

Over 16,000 people in Surrey are living with dementia, and it is estimated that between 2020 and 2030 the overall number of people with dementia is forecast to increase by 28%, from 17,700 to 22,672 older people.

The joint health and social care dementia strategy for Surrey has been refreshed: https://www.surreysays.co.uk/adult-social-care-and-public-health/dementia-strategy-survey/user_uploads/dementia-strategy-for-consultation-dec-2021.pdf

A report into Surrey Day Centres in spring 2021 enhanced by qualitative interviews conducted by Healthwatch Surrey, highlighted day activity, such as day centres, played a valuable role in supporting people living with dementia and their carers. Healthwatch Surrey produced a Thematic priority report - How people find advice and support to live well in the early years after dementia diagnosis. The report shines a light on how well people and their carers connect with the support and services designed to help them live well in the years after diagnosis. It was shown that support groups of all types i.e., local funded groups, Day Centres and Dementia Cafes were of the most value to the people of Surrey. Across Surrey there are approximately 50 cafes, the majority have different names such as Reminiscence Café, Forget me not, Alzheimers Café, music or movement groups.

Objectives:

The aim of this project was to explore the experiences and needs of people with dementia, their carers and families in Surrey Heath and to investigate why attendance at The Memories Café in Camberley was low.

This project looked specifically at the experiences and attitudes of people with dementia, their families and carers in relation to using and accessing the Memories café in Camberley. It sought to understand the expectations, needs, barriers and enablers for people seeking to access this service, as well as for those wanting to access but currently unable to, and those who are not using the service but will be able to benefit from it.



This research:

- Explored the level of awareness around community support and social activities available, with focus on the Memories Café in Camberley.
- Sought to understand peoples expectations around service delivery, with a focus on the Memories Café in Camberley.
- Investigated challenges and enablers for people to successfully access and engage with the Memories Café in Camberley.

Method and Sample:

- Three semi-structured interviews with carers of people with dementia and 4 detailed email responses to advertisements for participants in the research.
- Range of diagnoses and ages, including some 'younger people' with dementia (under 60).
- Carers were mostly spouses of dementia patients.
- All participants were based in Surrey Heath.



Findings: What is working?

Needs and Preferences with regards to social activities and services

- Places that can offer support for the carer and patient both together and separately so the carer can have a break.
- An understanding by service providers that use of language is important e.g. 'carer' – many spouses do not see themselves as carers, especially early in diagnosis. One interviewee said: "the switch from being a partner to being a carer is a slow one" so they often did not recognise their needs as carers.

Barriers to accessing services

- General practicalities such as it can take people with dementia a while to get out of the door, the weather outside and illness.
- There is a still a fear of covid for many people.
- The times and days of sessions can be an issue, some dementia patients are 'better' in the morning and nap in the afternoon and some struggle in the morning and are 'better' in the afternoons.
- The location of the service and the transport available can determine whether someone can attend or not.

"Most services are oriented towards older people with dementia which is depressing rather than stimulating for a 60 year old."

Other feedback

- Dementia is seen as a social problem, not a medical problem so there is no formal response after diagnosis.

"We felt cast adrift after our diagnosis."

"We were referred back to the GP after diagnosis, but we were not on the GPs radar at all. We felt lost."

"To get any support from the mental health/dementia services after diagnosis, you have to be at crisis point."

"There is a feeling (after diagnosis) of being 'mesmerised' and unable to process things. I would have really appreciated a period of still being held and supported by professionals while we were still taking in the diagnosis."

- The information pack given to people upon diagnosis – all participants fed back that this pack is too big and is overwhelming, especially so early on in diagnosis. Even if all relevant information about service provision is enclosed in this pack, it is not accessible due to the size of the pack.

"A one stop shop on dementia would be wonderful. It took me a year of committed research and work to put the necessary systems in place and to track down the different services available."

- There is a big gap between diagnosis and ongoing care and a lack of joined up thinking. Most patients appear to be discharged from the mental health services back to the GP for ongoing care once diagnosis has been made.

“There needs to be a clear pathway right from the beginning.”

- All participants reported a lack of involvement from Dementia Navigators. Some had not had any contact with them at all and some did receive contact until 6+ months after diagnosis.
- All participants believed that most support that is on offer is through the voluntary sector and praised the Memories Café, the Alzheimer’s Café and the Younger Persons with Dementia support group.

Carers groups are a massive comfort. I get more from that than I do from anything else.

Day to day life is a struggle. I fear that I will not have the resilience to cope in the years ahead.

What next – Our recommendations:

- Review the recommendations from the Surrey County Council work around ‘Dementia Friendly Oxted’. Feedback was very positive and this could be easily replicated in other areas of Surrey.
- Research and evaluate other pathways for care e.g. the cancer pathway, which has clinical nurse specialists that support cancer patients and their carers throughout the diagnosis and treatment. A service like this would bridge the gap in service experienced after initial diagnosis of dementia.
- Better access to Dementia Navigators or other similar roles e.g. Social Prescribers who can support patients and carers with the diagnosis.
- Improve signposting and look at the information pack given out in a more structured, bite size way.

For more information, please contact julie.callin@healthwatchsurrey.co.uk.

Thank you to all the individuals who have taken the time to share their experiences for this project.

You can contact our Helpdesk to share your experience of health and social care or for advice and information about these services in Surrey.

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