



Memory Moments Café Visits 2022

Published: January 2023

healthwatch
East Sussex

Introduction

From May to July 2022, Healthwatch East Sussex visited nine Memory Moments Cafés (run by [Know Dementia](#)) across the county to listen to people's experiences of accessing and using health and care services, either as a person experiencing dementia or as a family carer.

We wanted to know whether these individuals are being given enough support and that health and care services are listening and appropriately responding to their needs.

Our aims were to:

- Gather experiences and views from individuals with dementia and their families or carers of using related health and social care services.
- Identify the support available for people with dementia and the quality of this support.
- Listen to experiences of accessing and using services such as GPs, social workers, occupational therapists, district nurses etc. and whether these services differ depending on location.
- Gather opinions on the process and impacts of social care needs assessments for those with dementia.
- Understand what future support people with dementia or their carers would find useful.
- Raise the profile for Healthwatch and make café attendees aware of the services we provide.

What we did

We visited **nine** Memory Moments Cafes across East Sussex from May to July 2022 with some key lines of enquiry to have in depth one-to-one conversations with the service users.

It was also an opportunity to speak with the groups about Healthwatch and encourage them to share their experiences of health and care with us.

Seven of our Healthwatch volunteers attended the various cafes and engaged with **50 people**.

We visited Memory Moments Cafes at the following locations:

- Uckfield
- Eastbourne
- Crowborough
- Seaford
- Hastings
- Bexhill
- Ringmer
- Newick
- Peacehaven

Key findings:

- There were very **positive responses about the Memory Moments Cafes**, with clients commenting that it was beneficial for them to have some company, get information about dementia, make friends, get them out the house and get tips from other attendees.
- We were told that the **regular social worker** that attends the Memory Moments Cafes has been a **very useful service** to the clients, giving information and helping them access services such as referrals to Social Care Assessments or help completing paperwork to receive benefits.
- Those who know that support is available and how to receive it generally seemed more positive about their experiences. The feedback we received suggests that **the process to receive support is confusing**.
- **Dementia diagnosis takes a long time** and both the person with dementia and their carer cannot receive any support until it has been made. For example, a patient with dementia cannot receive benefits or aids in their house until they get this diagnosis.
- **Accessing** a lot of the support services such as carers, physios or memory clinics is often described by those we spoke to as **difficult and time consuming**.

Key findings:

- Some people don't seem to know what they will need for the future in terms of support for dementia or **didn't want to think about the future** because of the future effects of dementia.
- **Opinions of GPs** are mixed from dementia patients and their carers but a lot of these individuals have had negative experiences when it comes to getting a diagnosis, having a face-to-face appointment and have complaints of medication not being reviewed. **Phone calls with GPs are not appropriate for dementia patients.**
- Those who are not entitled to get support because they have better finances are suffering too. This is possibly because **other financial considerations are not taken into account.**
- **We spoke to 45 people about Social Care Assessments, and of these, 35 knew what they were.**
- Of the **23** people who had received a **Social Care Assessment**, **11** described having largely **positive experiences or receiving an outcome.**
- **Family members** who are carers, do **not identify themselves as carers. This can have negative implications such as a lack of recognition or being unable to access support.**
- Patients who have received a "**Golden Ticket**" (a scheme which offers further post-diagnosis support to dementia patients, giving easier access to further services) seem to have had positive experiences.



*"It's not what you know but who
you know to get things done."*

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Conclusions

- These Memory Moments Cafes are a very beneficial service for people in the community and the regular social worker is really valuable to the service users. These cafes allow individuals with dementia to socialise, and bring them happiness, and for their carers to feel a sense of normality.
- People attending these cafés or people with dementia are in need of further information on how to get social care and financial support. It is also clear that diagnoses and some support mechanisms can be slow.
- Whilst planning for the future may be useful for someone with a dementia diagnosis, it can be difficult to think ahead about the support they will need. [Know Dementia](#) offers support by offering some time to talk, a visit to homes, social activities, advice on finance and care provision. The social worker who attends some of the Memory Moment Cafes can help to access services too.
- GPs are not always easily accessible and especially for someone with dementia who would benefit from face-to-face appointments. People with dementia seem to have more positive experiences after receiving services mirroring the “Golden Ticket” scheme from GPs/Primary Care. Offering support that mirrors the “Golden Ticket” scheme would be beneficial to individuals with dementia and ensuring that all services within health and care are dementia-friendly.
- Whilst the [NHS website](#) has very clear information with links to a number of services included, several people mentioned that the process to get support and actually accessing support was difficult. It was not clear from the responses whether this was because not everyone had access to the online information or not.

Recommendations

1. We would recommend social worker visits be prioritised to increase the flow of information into the services, so carers/ relatives have access to information available in different formats.
2. A lay review of the NHS website should be conducted to assess the quality and ease of access to information related to dementia and dementia support.
3. Further investigation should be made by Adult Social Care to explore the process of applying for support to understand better why people with dementia and their carers may be struggling with accessing these services.
4. We would recommend that health and care providers explore making the “Golden Ticket” scheme widely available.
5. Wherever possible, people with Dementia should only have face to face appointments with their GPs and all health and care providers should ensure that their services are dementia-friendly.
6. Healthwatch East Sussex should perform follow up conversations with service users of the Memory Moments cafes to understand if processes for health and care support have improved.

Next Steps

- We will share our findings with local healthcare providers and commissioners and are willing to discuss any points raised in this report.
- Healthwatch East Sussex will work closely with Adult Social Care and NHS Sussex to make sure these issues are worked on and that any similar issues communicated to our Information and Signposting Service are shared too.
- Healthwatch East Sussex will visit these and other cafés to see if changes have been made and information from Adult Social Care and the NHS is clearer.

For more information

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