

Summary – The dementia pathway across Sussex – patient and carer experience

Introduction

Healthwatch Brighton and Hove undertook interviews with 38 carers and seven people (service-users) with a dementia diagnosis between December 2022 and May 2023. Of the 45 people spoken to, 20 were from West Sussex, 13 from East Sussex and 12 from Brighton and Hove. Of those people with dementia, 15 were women and 30 were men.

There was further diversity by urban/rural area, ethnicity, sexual orientation, and age at diagnosis (ranging from 58 to 88 years). Six people did not describe themselves as White-British. Around one half of the sample had the interview within two years since their diagnosis. Conversations ranged from 30 minutes to up to two hours.

Participants for the interviews were recruited with the aid of a flyer and contact with volunteers and professionals within dementia services.

Findings

The findings are grouped, firstly, into the varied experiences of using dementia services. The second area outlines recommendations for how these experiences could be improved. It is important to state that the recommendations do not reflect on the overall quality of the support, as many are drawn from experiences that went well, alongside what would have worked better.

Different experiences

People reported a range of different experiences that showed no discernible pattern by age, gender, or location. It was impossible to conclude whether experiences differed by place (West- or East- Sussex or Brighton and Hove). For example, people in West Sussex received different levels of support to those who were similarly located, often in the same town. Similarly, some people in the west of East Sussex reported different experiences to those living in the east of East Sussex.

The one area where people's experience was almost universal was regarding the initial appointment with the GP when first suspecting memory issues. The vast majority thought their GP was caring, empathetic, thorough, gave them enough time and was clear about the next steps in terms of a referral to the Memory Assessment Service (MAS).

The differences in experience can be summarised as follows:

- Whether scans were referred by the MAS, or by the GP (including the GP giving results).
- The different number of visits to the MAS (up to 11 for one person), usually dependent on severity of condition.
- The type of assessment ranging from a 'chit-chat' style to a more formal series of questions and answers.
- The tests at the MAS seemed to range from being too brief to too thorough, with some considered to be more formal and others more relaxed.
- Some people had centralised services whereas others were referred to different places and different professionals – this often impacted on the time between assessment and diagnosis which also varied across the sample.
- Some people received support immediately following diagnosis from the MAS, mostly from the Alzheimer's Society. For others, support was offered (for the first time) a few weeks after the diagnosis which, because it allowed people to digest the information and prepare questions, was thought to be the better option.
- Some received little or no support immediately following diagnosis which was thought to be unsatisfactory.
- Not everyone was discharged from the MAS following diagnosis. For some, the MAS was the place to raise any issues, get advice on medication, and have an annual check-up.
- There were similar inconsistencies in the level of support offered longer-term. While this was usually due to the unavailability of services, some people opted to not accept support, either for cultural reasons or because they felt they could 'cope and carry on'.

- Slightly more than one-third had a care plan however many said they did not receive one or were unaware.
- There were wide-ranging experiences of advice and reviews about medication with some seeing their GP, others going back to the MAS or seeing their Dementia Support Worker.
- Some people had a named person to contact when faced with crisis, although in some cases they would not receive immediate support. Others did not have a named contact.
- There was inconsistency in whether people were aware of the support groups that are available for them.

Recommendations

Based on these wide-ranging findings, there are a number of recommendations that may contribute to a better experience of dementia-related services and support. These are grouped in the chronological order of the care provided, from first contact (usually their GP) through to longer-term support. The recommendations are derived from what people said had worked well as well as what they would have appreciated in hindsight.

First contact

1. It is important that GPs should give enough time to answer any questions that arise, provide clarity over next steps and reassure service-users that all answers are valid when screening the patient.
2. Be clear about the likely expected waiting times to see the MAS.

Memory Assessment Service

3. Be clear beforehand about what is the purpose of the MAS and what is likely to happen during the assessment. This could be via a phone call beforehand.
4. Offer people a choice of assessment at home or the surgery (do not always assume people prefer a home assessment).

5. Understand that the impact of the environment (security and lighting) at the MAS can be quite intimidating for some people.
6. Informal, 'chit-chat' assessments may be more comfortable for some service-users than a question-answer session which some find distressing.
7. Be wary of conversations with the carer in front of the service-user, as the service-user may be sensitive to terms such as 'dementia'. Separate conversations with the carer may be appropriate to raise sensitive issues such as the future.
8. Be clear about when the diagnosis will be available following the visit to the MAS.
9. Shorten the time between a brain scan and diagnosis. This can delay support offered including medication and applying for assistance (e.g. Attendance Allowance)
10. Be clear about when the diagnosis will be available following the visit to the MAS as well as how they will receive this (in person, by letter or phone call).

Support immediately after diagnosis

11. Avoid overloading the service-user with materials immediately following diagnosis as it may be overwhelming.
12. Materials received at a later point may be helpful to allow people to digest the information and be better placed to ask questions.
13. Provide a named person to contact immediately from the point of diagnosis and also for ongoing support in the event of crisis.
14. At the point of diagnosis, people are not always aware of the questions they have, so allow opportunity for these to be raised at a later point.

Longer-term support

15. Ensure everyone receives long-term, follow up support from diagnosis and as the disease progresses, including care plans, check-ins every three to six months, named professionals to contact, guidance on medication, and to generally reduce the drop-off of care support through time.
16. A regular check-in provides an opportunity for people to accept support, even when they initially opted not to. As the disease progresses people need to know that support is available when needed. Some people think they can cope as a carer and may not look for help until it reaches crisis.
17. Make it easier to register with the MAS following discharge from the service and consider extending the time from diagnosis to discharge. Address the confusion over whether people can recontact the MAS directly if needed or whether this has to be via the GP.
18. Provide and simplify a care plan to use less written content focusing on 'this is what we have done, this is what we are doing and this is what we will do in the future'.
19. Understand the cultural issues in some communities where professional care support may be seen as taboo, because it is the responsibility of the family to provide support.
20. Provide more support for people for whom English is not their first language.
21. Tailor support options for people with dementia who live alone, and for those initially refusing support who may reach a crisis point when the person deteriorates.
22. Increase awareness of support groups from the point of diagnosis, including those specifically for carers.

23. Increase awareness of the various support options that are available and consider a central tick list of options, such as benefits, adaptations, groups, etc.

Services

24. Services need to offer a menu of support to carers and service-users. A recurring theme was people having to 'work the system', 'be on the ball', and having to search out support proactively.

25. Where this is not currently offered, consider centralising services where assessments, diagnosis, advice and support could be sought when needed.

26. Be aware of how transitions in and out of hospital or to a care home can be difficult for carers to manage due to possible changes in support worker, medication, as well as benefits (such as Attendance Allowance).

27. People are often not clear about who to contact for their medication. Identify the process for carers about how to review medication and who would prescribe this. This varies in some instances between the GP, MAS and the Dementia Support Worker.