

# **The dementia pathway across Sussex – patient and carer experience**

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# **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.

# Main report – The dementia pathway across Sussex – patient and carer experience

## Introduction

There are currently 944,000 people with dementia in the UK, more than ever before, and this number is projected to increase. More than one million people will have dementia by 2030, and this will increase to more than 1.6 million by 2050. The number of people with dementia is projected to increase rapidly over the next several decades, largely due to increases in life expectancy and population demographics<sup>1</sup>. Due to the gradual nature of dementia, the mild early-stage symptoms and the low diagnosis rate, it is difficult to know the exact number of people living with the condition.

In Sussex, there are a total number of 16,552 people living with a diagnosis of dementia (the 4<sup>th</sup> highest Integrated Care Board number in England). Although these have been formerly diagnosed, it is *estimated* that 27,028 people are living with dementia in Sussex<sup>2</sup>, thus providing a diagnosis rate of 61.2%.

As a means to improve care and inform future commissioning, it is important to understand people's experiences of the various support services, from initial concerns over memory through to professional assessment (at Memory Assessment Services), diagnosis and post diagnosis support. When exploring people's experiences, it is important to acknowledge that the dementia pathway is currently being delivered via a number of different providers across Sussex using contrasting models of delivery:

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<sup>1</sup> <https://www.dementiastatistics.org/statistics/prevalence-projections-in-the-uk-2/>

<sup>2</sup> [https://visualisation.polimapper.co.uk/?dataSetKey=aruk-dementia-by-icb&client=alzheimersresearch#con\\_over=Sussex](https://visualisation.polimapper.co.uk/?dataSetKey=aruk-dementia-by-icb&client=alzheimersresearch#con_over=Sussex)

	Memory Assessment Service (MAS) Provider/s	Dementia Post Diagnostic Support Services (DPDDSS) Provider/s
Brighton and Hove	HERE	HERE Alzheimer's society
East Sussex	Integrated Community Care (ICC) GP led service in the East areas of East Sussex (Bexhill, Hailsham, Hastings, Rother, and Seaford).  High Weald provided by the Sussex Partnership Foundation Trust (SPFT)	Local authority fund the dementia support service / dementia support workers.  60% of those with dementia from the High Weald area are referred to the Golden Ticket <sup>3</sup>
West Sussex	SPFT	Alzheimer's society  Admiral nurses in the north of West Sussex

These models of care will lead to different experiences, in terms of wait times until first assessment, time between assessments, scan waiting times and diagnosis. Post diagnostic support is also likely to vary in terms of a care plan, liaison with the GP and the number and frequency of follow-ups.

To further understand the different models of dementia support services, the researcher approached several (not all) provider organisations across Sussex. These included Know Dementia (see below), Integrated Community Care, Sussex Partnership Foundation Trust, Alzheimer's providers (including minority groups), the Brighton and Hove Memory Assessment Service (HERE), and Brighton & Hove City Council (Age and Dementia Friendly Healthy Lifestyles Team).

It must be recognised that not all providers were spoken to, and that the summary below does not reflect the array of services that are available.

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<sup>3</sup> The Golden Ticket is run by Buxted Medical Centre, in partnership with the local Clinical Commissioning Group, mental health trust, voluntary organisations, county council and the surrounding community. Aims to address gaps in the care pathway for people with dementia.

**The summary is derived from the conversations that did take place with some of service providers across Sussex, rather than a synopsis of all dementia support services in the area.**

Several participants were reached through Know Dementia (a community organisation providing cafés, choirs and sports activities) which provides support for carers and service-users in the communities of East and West Sussex (not Brighton and Hove). They provide on average two to three activities (e.g. cafés, woodland walks) a day across East Sussex (12 per week) and are funded by NHS Sussex (in East, not for West Sussex). Know Dementia provide an average of 15 per month in West Sussex. Others were reached through the Carer Information and Support Programme run by the Alzheimer's Society, who also assisted in reaching out to participants from ethnic minority communities in West Sussex.

In **East Sussex** (not including Brighton and Hove), the Golden Ticket was established around eight years ago, and although carers and service-users rarely use this term, it does mean that GP surgeries in East Sussex offer a point of contact for dementia advice and when in crisis. Following a diagnosis, either the GP or MAS refer carers/service-users to a Dementia Support Worker (provided by East Sussex County Council) that makes people aware of Know Dementia and the opportunities they provide. Dementia Support Workers occasionally attend cafés to offer support and advice (e.g. Attendance Allowance). Some surgeries in East Sussex also provide a weekly drop in.

There are two different models of care in East Sussex: the Integrated Community Care (ICC) who employ/provide a specialist GP led service in the East areas with dementia support workers (with a named person for each patient to contact) and a dementia care co-ordinator, and the SPFT (Sussex Partnership Foundation Trust) in the High Weald area. Providers have mentioned that learning from each other would be useful.

In East Sussex, waiting times between GP and the MAS is currently around 4 months, with 160 seen on average every month.

In **West Sussex**, the MAS is called the Dementia Assessment Service (DAS) and clinical assessment is done by SPFT across six centres across the county. People are signed-off from the DAS and all patients are assigned

support from a Dementia Support Worker (or Alzheimer's society support). Alzheimer's Society provide immediate support and patients can request this at diagnosis or at a later date – including support groups, advice on benefits, etc. Some can request this support via West Sussex Carer's support.

Social prescribers are particularly active in accompanying people to support networks across West Sussex. Also, four Admiral Nurses offering support to carers are present in the north of West Sussex (Horsham, Crawley, Haywards Heath, East Grinstead). Waiting times between the GP and DAS are thought to be a main issue given that services were commissioned on a 210 referrals per month, but the latest figures have exceeded this (383 in November 2022). This was not helped by a six month suspension of the DAS in Covid despite GPs still making referrals. The current number of referrals in West Sussex is thought to exceed the whole of East Sussex (including Brighton and Hove).

At crisis, people in West Sussex are advised to contact their GP who may re-refer to the DAS. The pathway to the community organisation Know Dementia is arguably not as seamless as in East Sussex – GPs do not automatically make this aware to carers/service-users. Also, Know Dementia, which provide 10 monthly activities per month in West Sussex does not receive funding from NHS West Sussex.

As to be seen in the interviews, people mentioned SAGE House (Tangmere, Chichester, West Sussex) which is a good example of where various services are available in one location (assessments, support, advice on benefits etc.).

The service in **Brighton and Hove** is exclusively run by HERE. This makes for a more integrated service that provides 'Assessment, Diagnosis, Treatment and Lifelong Support'. They bring together 'clinicians from both secondary (nurses and consultants) and primary care who work alongside our support workers, offering a holistic and personalised service to our patients'. They act as a single point of contact for any advice and support and run specific groups for LGBTQ+ and those of a younger age.

On the basis of these provider conversations, there is a need to fully understand and **map the various diagnostic and support services across Sussex** that will enable the interview findings to be set within context.

### **Project aim**

To gather patient/carer views and experiences of dementia support services across Sussex.

### **Objectives**

- To interview 45 patient/carers across Sussex.
- To explore views and experiences from each part of the pathway, including: referral to memory services/other routes to diagnosis, experience of memory assessment services and experience of post diagnostic support.
- To explore patient/carer experience at transition points (i.e. discharge from hospital, admission to residential care, end of life care).
- To include a diverse range of participants in terms of age at diagnosis, rural/urban location, sexual orientation and minority ethnic groups where possible.

### **Recruitment**

Prospective patients/carers were recruited through a variety of means, including MAS contact lists for those who volunteered for future research, dementia support services, dementia community centres/cafés/events, and other dementia support groups.

A flyer (Appendix 1) and an information sheet (Appendix 2) invited people to contact the researcher who would then arrange a suitable time and place for the interview (phone, Teams/Zoom or face-to-face). All participants received a £50 high-street voucher.

## Methods and analysis

The topic guide of interview questions was agreed between the commissioners and research team. The main sections were as follows and can be viewed in full in Appendix 3:

- Start - outline the purpose of the conversation and the main areas that will be covered. Establish who the conversation is with (patient or carer).
- Experience with GP (if applicable)
- Experience with Memory Assessment Service (MAS)
- Receiving a diagnosis - part of the diagnostic pathway
- Post diagnosis and support
- Transitions (if applicable) - to care homes, hospital and end of life care.
- Ending the interview - overall summary and equalities data.

With participants' consent (see Ethical considerations), all interviews were digitally recorded and anonymised. The digital data were used to formulate detailed notes for each participant. The notes were compiled on a Smart Survey questionnaire containing comment boxes for all the interview sections (one questionnaire per participant).

Qualitative thematic analysis was used to inductively (from the data) and deductively (based on the project objectives) analyse the data. Braun and Clarke's (2006, 2019)<sup>4</sup> method was used to identify, describe and analyse themes and patterns within the data. The analysis focused on the generation and emergence of common themes and explanations derived from the data.

An entire process of reading all comments facilitated familiarity with the data and allowed the beginnings of an interpretative process. In doing so, a preliminary coding structure was devised as emerging themes were identified within and across the interviews. Development of the final indexing categories were informed and guided by the project's key research questions (in the Topic Guide) and also grounded from the data

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<sup>4</sup> Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>

Braun, V. and Clarke, V. (2019) Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), p.589-597, DOI: 10.1080/2159676X.2019.1628806

itself i.e., whereby patterns, themes and categories of analysis emerge out of the data.

Through this process, codes were collated into potential themes and definitions and names were generated for each theme. Direct quotes were referred to by a fictitious name, alongside the real age of the service-user at diagnosis and region across Sussex.

## **Ethical considerations**

Upon showing interest and having received the contact details, the researcher contacted the participant to convey more information about the study, respond to any questions, and establish a suitable time to hold the conversation. If there was no response, the researcher would issue a maximum of one final reminder.

For all participants (where interviewed over the phone), verbal consent was sought at the start of the interview. The consent form (Appendix 5) included agreement to participate in the interview; understanding about the study and how the information will be used; agreement to digitally record the interview; understanding that the conversation will be strictly confidential and anonymised; obligation to disclose safeguarding concerns; and rights to withdraw from the study at any time, without giving an explanation (including the deletion of all data). It was also explained that all data were securely stored (interview data and contact details), password protected and only accessible to the researcher.

## **Findings**

In total, 45 people were interviewed (38 carers and seven patients/service-users). The findings will first present the profile of people interviewed and be followed by:

- First experience of memory issues and service use (usually the GP)
- Referral and experience of Memory Assessment Services<sup>5</sup>

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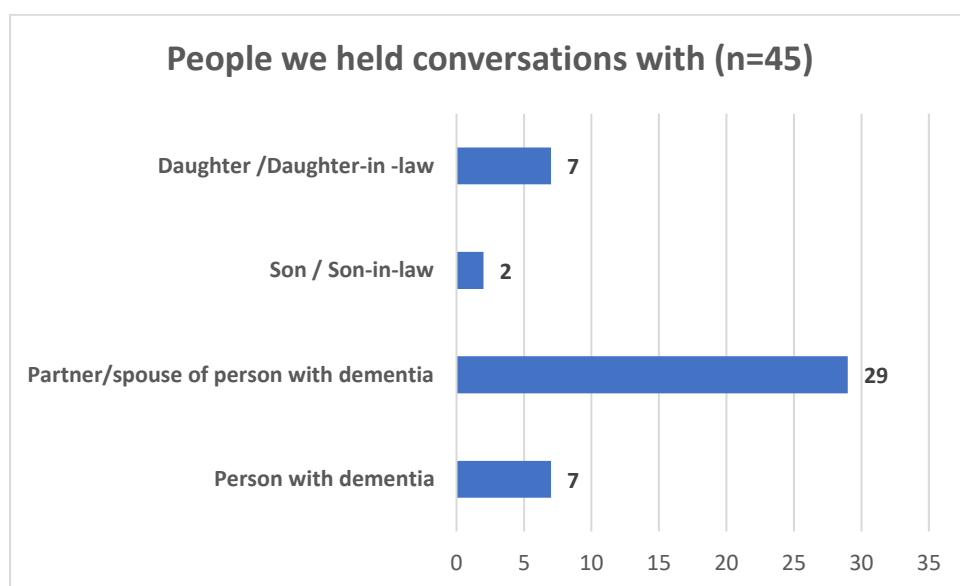
<sup>5</sup> The Memory Assessment Service (MAS) is a term used in Brighton and Hove and East Sussex. However, in West Sussex the equivalent service is referred to as the Dementia Assessment Service (DAS). In this report, for simplicity reasons, we refer this as the MAS even though in some instances people may be referring to the DAS.



- Receiving a diagnosis
- Post-diagnosis support – immediate (usually from the MAS)
- Post-diagnosis support – longer-term
- Transition points such as in and out of hospital, to a care home, or end of life.

## 1. Sample profile

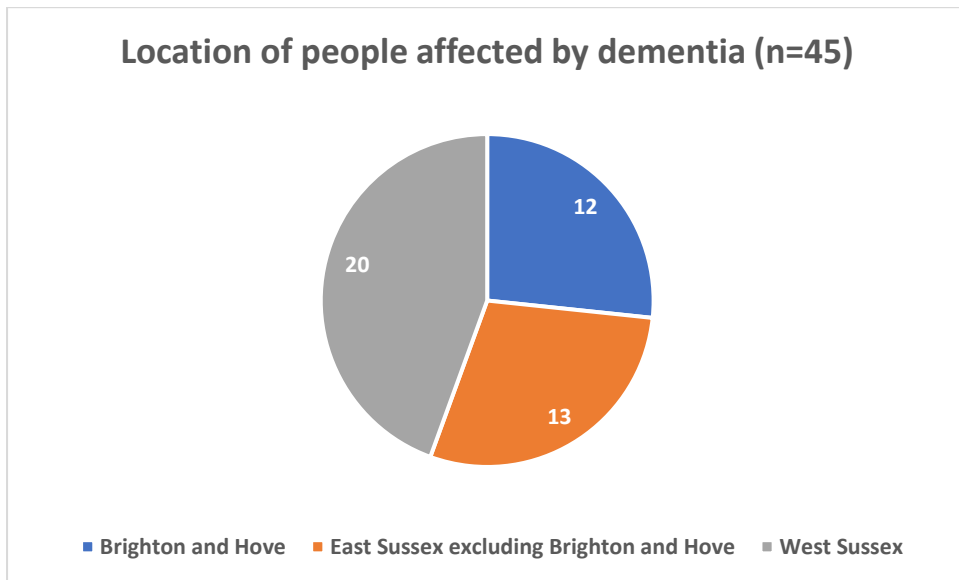
From the 45 interviewed, 38 of these were caring for a person with dementia. This was usually their spouse but also included their children. We spoke to seven people who had dementia.



Of those people with dementia, 15 were female and 30 were male.

Everyone interviewed lived in Sussex, with 20 in West Sussex, 13 in East Sussex (excluding Brighton and Hove) and 12 in Brighton and Hove.

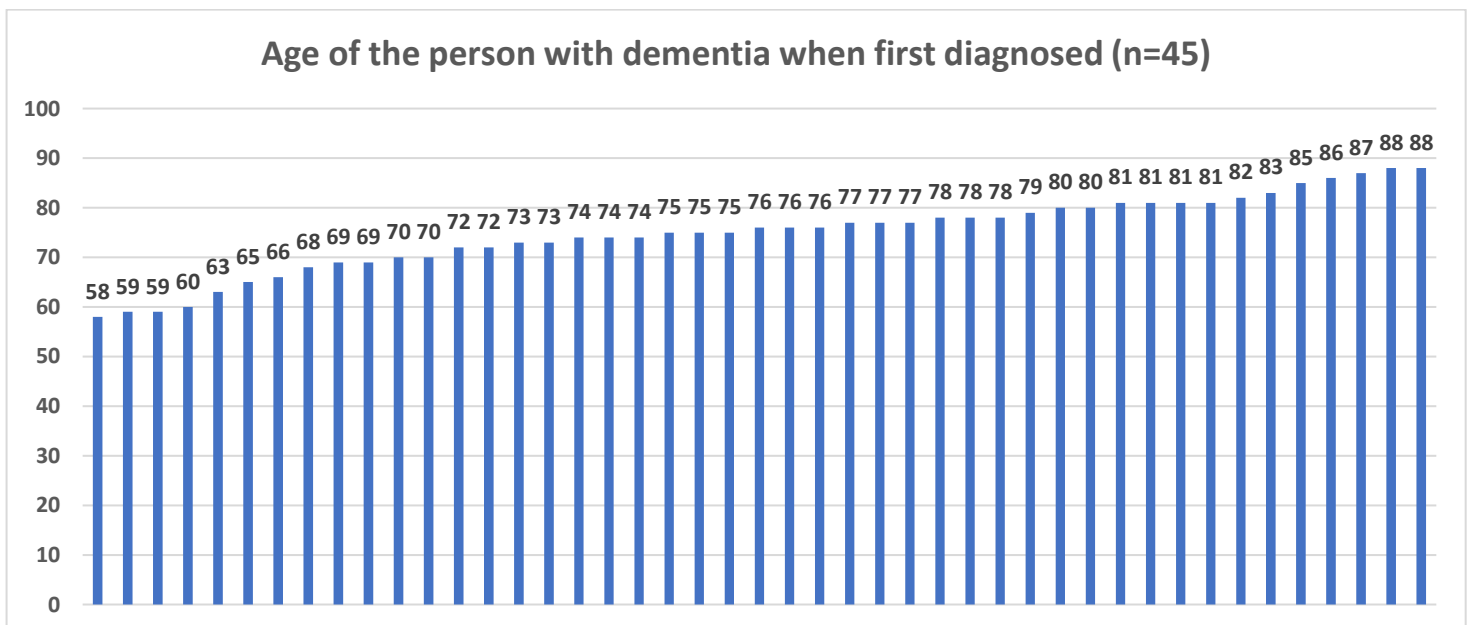
**Location of people affected by dementia (n=45)**



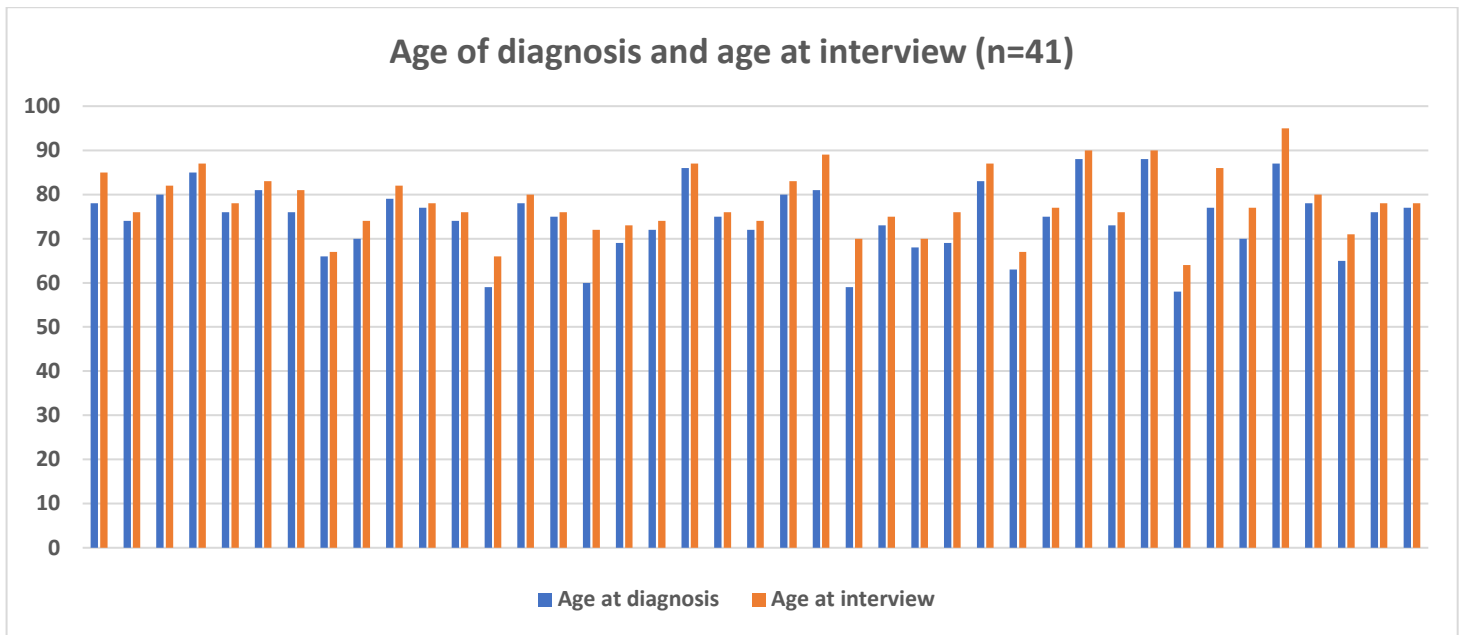
28 out of the 45 were considered to live in urban areas, such as Chichester, Worthing, Crawley, Horsham, Haywards Heath, Eastbourne, Hastings and Brighton and Hove.

The age of diagnosis ranged from 58 to 88 years, with an average of 74.8 years. Five people were aged under 65 at the time of diagnosis (with three of these under 60). At the time of interview, the people affected by dementia were aged from 64 to 95 with an average age of 78.4 years.

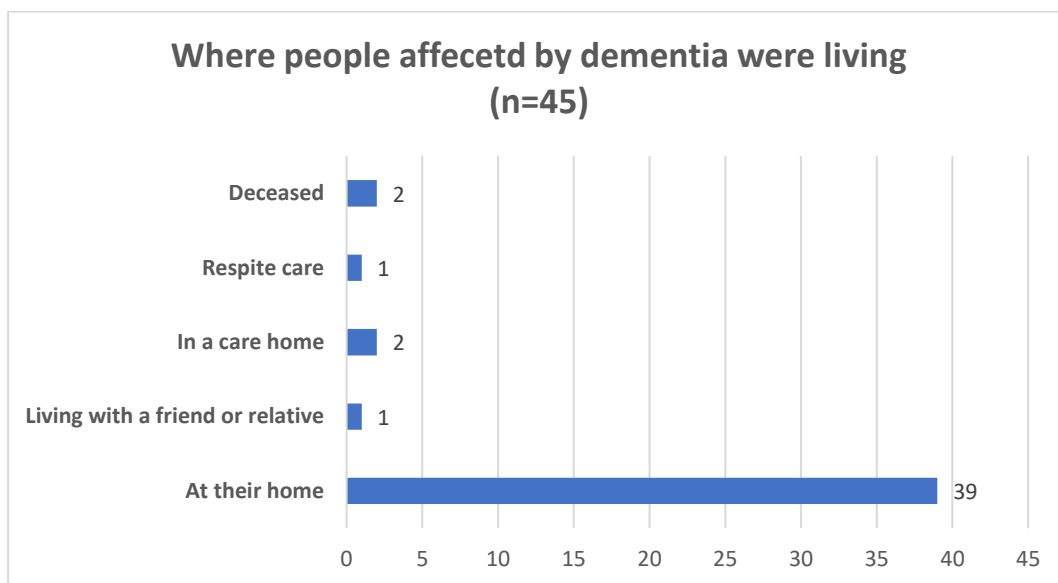
**Age of the person with dementia when first diagnosed (n=45)**



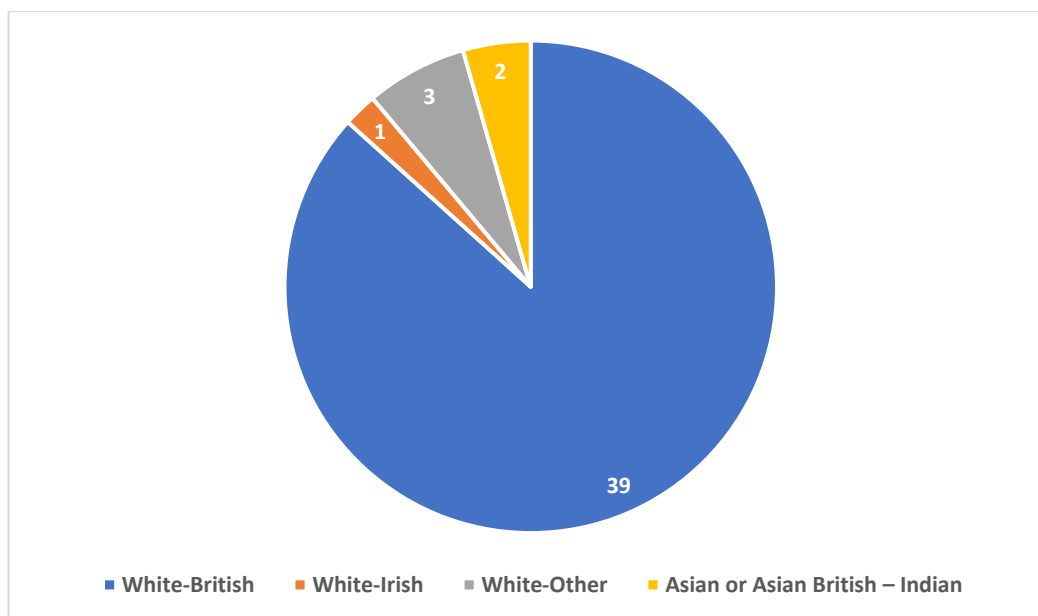
The time between diagnosis and when interviewed was between 2 weeks and 12 years, with an average interval of 3.7 years. 25 people had received a diagnosis within the last two years or less.



Most people with dementia were living at their home, but others were in a care home or deceased.



The majority were from White-British backgrounds, with the remaining being White-Irish (one person), White-Other (three people) and Asian or Asian British – Indian (two people).



The majority were in heterosexual relationships and four carers were in a gay relationship with the person affected by dementia.

### Interpreting the qualitative findings

As a prelude to the conversation details, it is important to state that the findings are designed to show a range of experiences rather than a quantitative assessment of how common an experience was. Nonetheless, terms such as ‘one’ person, ‘a few’, ‘some’ or ‘around one-quarter’ will give some account of how often an experience was mentioned.

The flexible nature of the conversations also meant that not every question was asked to every person, especially due to the lack of a participant’s memory or the conversation moving off to a relevant tangent. So, it is not always appropriate to assume, for example, if ‘around one-quarter’ shared an experience that a further three-quarters may not have experienced this too. Further, as many people were recruited via dementia support groups, those mentioning groups as informal support may be over-represented. Equally, those living alone, with no support, or those people undiagnosed are likely to be under-represented.

### 2. First experience of memory issues and service use (usually the GP)

Those living with or caring for the person with dementia (service-user) were usually the first to suspect memory issues, and mostly initiated

advice from a health professional. For this sample, this was **always seeing their GP in the first instance**. On two instances the person with dementia went to see their GP alone:

*"My husband went to the GP and he was complaining of difficulty remembering things, getting confused over a year ago...He went alone to the GP and thus it is difficult to comment on the services of the GP."* Carer, age at diagnosis: 82, Brighton and Hove.

*"I went to my GP and he sent a referral to the memory assessment service. My memory was failing. I was having a struggle with my short term memory and so decided to see my GP."* Service-user, age at diagnosis: 74, Brighton and Hove.

All other GP appointments were with their primary carer (usually their spouse).

For most people, the appointment (mostly in person except a few over the phone during Covid lockdown) was specifically about memory issues. However, for two people the appointment was made by the carer about something else when the person with memory issues was reluctant to see their GP:

*"The appointment came about because Sxxx<sup>6</sup> had a GP appointment for her diabetes and I [daughter] went with her. At the end of the appointment the GP asked if there were any other concerns and I said yes whilst my Mum said no."* Carer, age at diagnosis: 77, East Sussex.

*"Nxxx was unwilling and didn't want to discuss, so we went about his knee. GP then suggested seeing a memory clinic."* Carer, age at diagnosis: 75, West Sussex.

**Almost everyone was complimentary towards their GP.** People mentioned several qualities surrounding this appointment, with the following examples showing how the GP was caring and empathetic:

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<sup>6</sup> The names have been changed to preserve anonymity.

*"Understanding and very supportive. I am so lucky because I have a good rapport with our GP. He took his time, we were not rushed."* Carer, age at diagnosis: 74, East Sussex.

*"Generally, I was happy with the services the GP rendered. I was happy he took my concerns seriously the second time we had visited and he was investigating thoroughly. I felt he was empathetic and understanding."* Carer, age at diagnosis: 87, Brighton and Hove.

Some specifically mentioned how the assessment was very productive and informative:

*"The GP visit was a very good experience because the doctor was understanding, supportive, empathetic and had enough time for us. He also explained what was wrong and the next steps."* Carer, age at diagnosis: 81, West Sussex.

*"The GP was so great, spent nearly half an hour with us examining and explaining why she thought of the diagnosis, very well to us."* Carer, age at diagnosis: 65, Brighton and Hove.

Some specifically mentioned not being rushed and having enough time:

*"The GP was very good, took his time. He organised everything and the referral. He was respectful and organised and kind. He gave us plenty of time."* Carer, age at diagnosis: 78, East Sussex.

*"Our GP gave us lots of time and was supportive and caring."* Carer, age at diagnosis: 85, East Sussex.

The GP often performed a simple screening exercise which determined whether people should be referred to a more specialist service, namely the MAS, and explained the next steps:

*"The GP referred him to the memory clinic which took three months to get an appointment."* Carer, age at diagnosis: 68, West Sussex.

*"Very good GP and made it easier for referral, and he explained about the waiting list."* Service-user, age at diagnosis: 73, Brighton and Hove.

In the exception, three people were **more critical of the GP**. They mentioned parallels to a tick-box exercise, not being sufficiently empathetic, and being insensitive in the initial assessment:

*"GP couldn't see the issue, just ticked the box."* Carer, age at diagnosis: 78, West Sussex.

*"The GP was not interested in helping and showed no empathy. I suppose they feel they cannot do anything about Alzheimer's."* Carer, age at diagnosis: 76, East Sussex.

At this point it is suitable to share the isolated experience where a **person with dementia was living on her own**. This brings challenges that would be unlikely to apply with a carer present:

*"SAGE house said contact me if there are any changes, but who would know that, as I live on my own. So I speak to my step son every week, and he visits every month, he has a contact number and name at the surgery to say things have changed at which point the GP would come out. But there is an assumption that everyone has support but I live on my own. A check-in every 3 months would be good and they could see if I got worse...The service did the best they can do, but don't make the assumption that everyone has a carer living with them or relatives nearby. So, there's no one to drive me to various events, so would be good to get a companion to take you somewhere - they were thinking of that. Would be nice to have transport to help me when they have events not in the usual place, like there's a pub lunch I can't go to. I don't have a carer who can drive me."* Service-user, age at diagnosis: 75, West Sussex.

### **3. Referral and experience of Memory Assessment Services**

This section is separated into the chronological order experienced by most attending the MAS and will include the following:

- Waiting times to see the MAS
- Assessments at the MAS
- Scans
- Repeat visits to the MAS

- Overall comments about the MAS

### **a) Waiting times to see the MAS**

Waiting times to see the MAS were on **average around one to three months** and was deemed to be acceptable to most. It was commonly said that this waiting time was better than expected given the waits for other NHS services which were thought to be much longer:

*“Got referred to Sussex mental health which deals with dementia and other issues – took 3 months to be seen by the service.”* Carer, age at diagnosis: 78, West Sussex.

*“The GP referred us then to the memory clinic which took 3 months to get an appointment.”* Carer, age at diagnosis: 68, West Sussex.

The following examples show how a few waited longer, mostly due to Covid. Both examples show how they found it useful to have an indication over how long the waiting time would be:

*“We were told we’d have to wait a few months for the appointment for the MAS but I recall it was just after covid or during covid and thus they had a lot of backlog to deal with.”* Carer, age at diagnosis: 82, Brighton and Hove.

*“Referred there about 5 months later, told the queue was lengthy because of Covid.”* Carer, age at diagnosis: 63, West Sussex.

One person was waiting for over a year and was told to write to his GP to speed up the process. This waiting was disturbing as his Mum was starting to decline:

*“Took a long time about a year, had to chase GP, they said you need to write to GP to say it’s really bad...they said ‘lay it on thick’. We were escalated as we were desperate, she was getting worse and had declined while we were waiting.”* Carer, age at diagnosis: 78, Brighton and Hove.



## **b) Assessments at the MAS**

Although not always the case, the **assessment with the MAS were usually performed on two occasions**, with a brain scan in between these appointments. Some had repeat appointments (see forthcoming section).

Visits with the MAS were usually in person (apart from during Covid lockdown). They were usually in the person's home or at a surgery. A slight majority of people were offered a home visit for the first assessment. In general, visits at home were found to be more favourable than visiting the assessment service:

*"The assessment was at home rather than in a clinic which was much nicer for Mum as she was comfortable in the familiar surroundings of her own home."* Carer, age at diagnosis: 80, West Sussex.

*"Assessment at home by the memory clinic, this was very helpful since it reduced our travel time - as a result was referred for MRI scan."* Carer, age at diagnosis: 69, West Sussex.

Only in one case, were service-users given the **choice of location**:

*"Got an option and wanted a home visit."* Service-user, age at diagnosis: 66, West Sussex.

On some occasions the assessments consisted of various additional steps, including questionnaires and phone calls:

*"Got shunted around a bit, from home to Sage House - questionnaire at home, Sage House for more tests because I had a stroke in 2012, shunted around and wasn't bothered."* Service-user, age at diagnosis: 66, West Sussex.

In contrast to the home visits, a few people made less favourable comments about the memory assessment environment. This was in terms of the **high security at the assessment unit and the lighting which was thought to be intimidating**:

*"It is very uncomfortable going there. Locked doors, so much security, being there with others with more severe behavioural problems. This was quite upsetting to see. The feeling of Jxxx being seen in a very secured environment. It was upsetting for her not for me."* Carer, age at diagnosis: 59, West Sussex.

*"We were upset to find out that it was a locked unit. Where you can only go there if you have been admitted there or referred there...This experience made us feel it was something to be ashamed of."* Carer, age at diagnosis: 75, East Sussex.

By contrast, one person found the visit at the surgery **more 'official'** than at home:

*"The appointment was at clinic which was better because it kept it separate from the home, it made it more official."* Carer, age at diagnosis: 86, East Sussex.

In one instance, a person reported that the environment was busy and that other assessments could be heard:

*"At the MAS, things were awkward. The meeting place was too crowded and we could hear other people's interviews. There was no privacy. The lady was nice though. We could hear the answers other people were giving for the questions being asked."* Carer, age at diagnosis: 58, West Sussex.

The **tests were complimented for not being too stressful** on occasions where it seemed like a normal conversation rather than a 'question and answer session', although both approaches were used:

*"Home visit and spoke to wife, the 'test' was not mentioned, scored low - wasn't an obvious test like a general test and then they gave her a score. Told me her score 33/100 and gave immediate diagnosis, which was more of a confirmation rather than a surprise...the test was not like a test, like a chit-chat', amazing really."* Carer, age at diagnosis: 74, East Sussex.

*"When the questions were being asked, there seemed to be no ending of them. She wasn't nasty, but the questions kept coming for a long time. My*

*husband's memory was not that bad then. She kept asking questions after questions which made Dxxx upset. My husband was so shattered and felt so ashamed and said he will never go back there again...In having questions asked, if they see the person is not coping with the questions, there's no need to keep on asking the questions page after page. It can be very upsetting."* Carer, age at diagnosis: 75, East Sussex.

There were several comments critical of the assessments, in particular over the **inconsistency of the process**. One person thought that the assessment was **not thorough enough**, meaning the service-user was not formally diagnosed until two years after their first visit:

*"He was diagnosed as borderline and advised to come back in six months, then another six months...took us two years to get diagnosed which meant we could have treated it earlier. I knew there was a problem but the assessment failed to pick this up."* Carer, age at diagnosis: 78, West Sussex.

Similarly, a few others were disappointed by the assessment service being too short or not being conducted by a suitability qualified professional:

*"The assessment took just 10 minutes but I have just noticed the letter said to allow 90 minutes for it. It felt too quick to make a diagnosis. Mum really struggled to answer the questions and kept looking confused and quizzical as she answered them. She needed lots of reassurance. I am not sure that it was an accurate picture...It was just too rushed; aspects were skipped over and missed. She was diagnosed with 'mild Alzheimer's' by the consultant on the basis of that questionnaire which it turned out had been done by an OT [Occupational Therapist], not even a mental health nurse. What do OTs know about mental health?"* Carer, age at diagnosis: 77, East Sussex.

*"We were given enough time but the nurse had a 'laissez faire' attitude which wasn't reassuring."* Carer, age at diagnosis: 72, West Sussex.

By contrast, another person thought the assessment was **too thorough**:

*"It took nearly 2 hours to be interviewed. Which was too much."* Carer, age at diagnosis: 68, West Sussex.

In one instance, there was some criticism over what was considered to be an acceptable time since suspecting memory issues to qualify for a memory assessment. In this case, the MAS refused an assessment on the grounds that memory issues had been suspected for less than six months:

*"Saw GP, she did a few tests, at that time she said H\*\*\* had mild memory problems and referred us to the MAS. Because GP said he'd had it for a 'few months' the MAS didn't respond until the diagnosis was at least 6 months. [MAS] Nurse said 'I don't make the rules!'"* Carer, age at diagnosis: 81, West Sussex.

A further criticism was that one person **did not know the purpose of the MAS**, believing they were attending about another medical issue (side effects of statins):

*"October, we decided to see the GP who told us to go to the MAS. We didn't think it was associated with dementia, we thought it was to do with the side effects of the statins he was on."* Carer, age at diagnosis: 69, West Sussex.

In relation to this, some people did not know what to expect from the MAS appointment and would have welcomed this information beforehand, including a prior telephone conversation:

*"We did not have any previous explanation of what was happening."* Carer, age at diagnosis: 72, West Sussex.

*"We didn't have a call beforehand. We would have loved to have a call beforehand to know what to expect."* Carer, age at diagnosis: 75, East Sussex.

By contrast, initial information from the GP or MAS was welcomed by some participants:

*"MAS was supportive and called a few times [beforehand] and gave information. We were kept informed and it was a positive experience."* Carer, age at diagnosis: 81, East Sussex.

*"We had a phone call before each meeting. I couldn't wish for better with my interaction with the MAS. They gave us enough information about the appointments and what to expect."* Service-user, age at diagnosis: 80, Brighton and Hove.

A few people raised criticism that **being in the same room as the service-user** caused some problems about saying things in front of them:

*"There were times I went with her to the MAS and the assessor was asking me questions about Mum while she was there and that felt awkward. This has happened several times over the years and it doesn't help to make a good honest report about Mum in her presence. They should allow time for the carers to talk directly to the assessors without the patient involved being particularly present. This allows for a more honest report and an opportunity to express concerns and worries which you cannot do when the other person is present."* Carer, age at diagnosis: 81, West Sussex.

*"Advise professionals that it is not helpful or supportive to ask the carer how they are in front of the patient. Bxxx [carer] has been asked this several times but cannot answer fully because she doesn't want to upset or stress Pxxx so she cannot answer properly."* Carer, age at diagnosis: 72, West Sussex.

In relation to the above, one person recommended that seeing the same professional at the MAS would help, especially when being assessed on several occasions:

*"Though short of staff, if their services are made one to one that would be lovely and if possible one assessor for the patient at all times so the patient becomes familiar with the person."* Carer, age at diagnosis: 88, West Sussex.

### **c) Scans**

Once referred by the GP, in most instances **the MAS would arrange a scan**, which would be performed after the first visit to the MAS and reviewed after their second visit (with a diagnosis provided):

*"One visit [to the MAS] to diagnose and then again after the brain scan."*  
Carer, age at diagnosis: 75, West Sussex.

*"We had a brain scan. We had to wait for just a week to get the scan done after the referral was made. The MAS did the referral."* Carer, age at diagnosis: 76, Brighton and Hove.

In rare cases the **GPs referred people for a brain scan** (CT or MRI) before seeing the MAS and in one instance the GP provided the results prior to seeing the MAS:

*"The MAS used the scan that we had earlier done based on the GP referral. The MAS did not refer us to do any scans."* Carer, age at diagnosis: 58, West Sussex.

*"GP referred Sxxx for CT scan in December 2018. He went back to GP for the results and the GP referred him to MAS in February 2019."* Carer, age at diagnosis: 70, East Sussex.

It was rare that there were no scans performed. A minority of service-users were not offered a scan and a further two people did not have a (new) brain scan since they had recent scans for previous issues (such as a stroke):

*"No offer of a CT scan and no advice or support offered."* Carer, age at diagnosis: 76, East Sussex.

*"Already had scans from my stroke and saw that there were problems."*  
Service-user, age at diagnosis: 66, West Sussex.

One person was particularly critical about the process, in reference to the time having to wait for the results, in this instance compounded by the Covid pandemic:

*"They suggested a scan, waited only about another 4 weeks all very professional - more speedily than I expected, then a letter saying they had seen results but suggested unless anything urgent there would be about a 12 week wait, which indicated not much to matter. Then in a state of limbo until our appointment was due but then went into lockdown due to Covid."*

*They then gave the diagnosis over the phone, confirmed Alzheimer's, and told him to stop driving and [MAS] couldn't give him medication as she couldn't see him, so referred back to GP, even though I was told they could not prescribe the medication. But they did in the end, the GP contacted the MAS and we got it prescribed. It was done so badly." Service-user, age at diagnosis: 73, West Sussex.*

#### **d) Repeat visits to the MAS**

The number of visits to the MAS varied, averaging on two occasions (usually with the scan in between the visits), although **one person attended up to 11 times**. The number of visits depended on the severity of the condition with borderline cases requiring further visits. Another reason for multiple visits was an initial diagnosis of Mild Cognitive Impairment or comorbidity such as having Parkinson's Disease:

*"We had a diagnosis from the MAS which was Mild Cognitive Impairment. This diagnosis may have changed after our recent follow up though we haven't gotten the response yet...more assessments were done. We are yet to get the results of these." Carer, age at diagnosis: 82, Brighton and Hove.*

*"Her Parkinson's was quite well controlled when we met the neurologist. However, the cognitive decline was quite drastic...The neurologist was initially a bit sceptical about the dementia." Carer, age at diagnosis: 65, Brighton and Hove.*

In one instance this person visited the MAS on a third occasion, around six weeks after the diagnosis, and will continue to have annual appointments:

*"Got the diagnosis and then told to come back in six weeks' time for more information and support options." Service-user, age at diagnosis: 77, Brighton and Hove.*

The number of visits was compounded by a few people being referred to different services. This ties in with a **preference for centralised services** raised later in this report under the long-term post diagnostic support:

*"We have been referred to different MAS within Brighton and so we keep going to different places and meet different people. Can a patient be put in one place at a time?"* Carer, age at diagnosis: 69, Brighton and Hove.

*"Had another appointment at another clinic to talk about medication. Didn't want to go somewhere else but the doctors move around - same staff but move location."* Service-user, age at diagnosis: 77, Brighton and Hove.

### **e) Overall comments about the MAS**

In contrast to some of the concerns raised above, many people expressed **gratitude to the MAS**, being thorough and respectful to service-users:

*"We had a nice chap do the assessment, couldn't have been nicer, very sympathetic."* Service-user, age at diagnosis: 73, West Sussex.

*"The whole process was really positive, I feel we were really lucky, I cannot think of any improvements as it went so well. It was just Covid that slowed down the process."* Carer, age at diagnosis: 80, West Sussex.

*"I thought the MAS was a good experience. The lady we met the first time was sympathetic and took time to explain what to expect. She made my husband feel comfortable and was at ease. She was quite a kind person... Generally we were treated with respect and care at the place."* Carer, age at diagnosis: 82, Brighton and Hove.

There were, however, a few exceptions with people being **critical about specific comments from MAS staff**, one of whom received a formal apology:

*"Was told the only way to know it is Alzheimer's is an autopsy. Said he couldn't drive until he spoke to the DVLA - bit harsh and stressful."* Carer, age at diagnosis: 77, Brighton and Hove.

*"Memory nurse shouted at me for going along with my Mum's story about things she saw and to make her less frightened about seeing Russian soldiers. I was told not to collude with her by the nurse, so was told about what not to do rather than what to do."* Carer, age at diagnosis: 83, West



Sussex.

*"Had a review from the memory service three months after taking medication, but they are so overwhelmed it was about four months later...she was very abrasive with me, shouting at me, I actually got really upset...she hit the roof when I said I'd gone back down to a lower dose. I had about 7 questions written down and only got to number 2 or 3 and said she had another appointment...said I only had 15 minutes, so that 15 minutes a year. Then I got a letter confirming what was said and it was completely different, my husband was with me so thankfully he said it was inaccurate too...I made a complaint and got a very apologetic reply."*

Service-user, age at diagnosis: 74, East Sussex.

#### **4. Receiving the diagnosis**

Everyone interviewed received the diagnosis from the MAS. For most people the **diagnosis confirmed what was expected:**

*"Home visit and spoke to wife, the 'test' was not mentioned, scored low - wasn't an obvious test like a general test and then they gave her a score. Told me her score 33/100 and gave immediate diagnosis, which was more of a confirmation rather than a surprise."* Carer, age at diagnosis: 74, East Sussex.

*"The diagnosis was not immediate but had to wait 6 weeks for a letter after the assessment had been seen by the doctor. This was confirmation rather than a surprise because she had waited so long."* Carer, age at diagnosis: 78, West Sussex.

However, there was one exception to this where the diagnosis came as a shock:

*"I'm a fit guy, good diet, it came as a shock, fairly young so everything else was good but probably I knew something was wrong."* Service-user, age at diagnosis: 66, West Sussex.

Several people mentioned the empathy conveyed by the dementia specialist when giving the diagnosis, and allowing enough time to ask questions:

*"It was a very long meeting with the doctor [at the MAS]. She explained everything in great detail and I took lots of notes."* Service-user, age at diagnosis: 72, West Sussex.

*"The doctor and SAGE gave the diagnosis, he was empathetic and gave us so much time to ask things."* Carer, age at diagnosis: 63, West Sussex.

One person commented that the diagnosis received in person (which was more usual) would have been better than via a letter which was thought to add some distress:

*"I suggest that diagnosis should be verbal and in-person rather than with letters. Especially for people who live alone. Receiving the diagnosis by letter can be very harsh. I have been wondering how would I have taken it without my wife at home with me. This should be considered."* Service-user, age at diagnosis: 80, Brighton and Hove

The time between the assessment and diagnosis varied from the same day to typically two to three weeks later, although some waited far longer. Some mentioned this timeframe from the brain scan:

*"Pxxx received the diagnosis by letter which was written on the same day as the assessment by the doctor at MAS."* Carer, age at diagnosis: 78, East Sussex.

*"Diagnosis came from hospital consultant following CT scan. Received the letter after 3 weeks which I felt was quick."* Carer, age at diagnosis: 81, East Sussex.

Some people waited **considerably longer for the diagnosis:**

*"Diagnosis received from MAS after 3 months."* Carer, age at diagnosis: 76, East Sussex.

*"The diagnosis was by letter and was followed up by a call from the doctor at the MAS clinic. This was received 6 months later."* Carer, age at diagnosis: 70, East Sussex.

In relation to the time from scan to diagnosis, one person recommended this should be quickened:

*“They sent me a letter about the diagnosis – Dementia with Lewy bodies. We did not receive the diagnosis verbally. I suggest that the diagnosis process should be quickened. It took a month after the scan to get the diagnosis information.”* Carer, age at diagnosis: 76, Brighton and Hove.

A few people, however, had concerns about the **lack of clarity or validity of the diagnosis**:

*“We had a summary from the MAS which showed it as circumstantial and it was more likely depression of which Gxxx needed some counselling. The MAS sent a letter to our home about their findings, stating that there was no dementia and neither would there ever be dementia...The NHS failed to get us the diagnosis. We got it in a private hospital.”* Carer, age at diagnosis: 69, West Sussex.

*“The diagnosis I received by letter stated that Pxxx had ‘Dementia in Alzheimer’s Disease late onset’. This turned out to be the wrong diagnosis. I became concerned that Pxxx may also have Parkinson’s disease. The GP sent a referral and Pxxx was seen by a neurologist. The correct diagnosis was given a year later as ‘Lewy Body Dementia with Parkinson’s Disease’ via a letter and verbally.”* Carer, age at diagnosis: 72, West Sussex.

## **5. Post diagnostic support – immediate**

The following will be outlined in this section:

- Immediate support offered.
- Limited immediate support.
- Re-contacting the MAS.

Immediate support refers to that offered at the point of diagnosis or on their final visit to the MAS. Ongoing or longer-term support (the next section) refers to that provided following discharge from the MAS up to the current time of interview.

This section looks at the nature of the support offered, instances of limited support, and experiences of re-contacting the MAS for support.

### **a) Immediate support offered**

Several people spoke about the support offered immediately following the diagnosis. This was usually in the form of **verbal or written material** such as leaflets and booklets:

*"Pxxx received lots of leaflets and advice from the MAS clinic verbally and with literature."* Carer, age at diagnosis: 78, East Sussex.

*"They treated us nice and kindly, gave us lots of leaflets, but were not sure about what was going to happen next. There was a contact number if I needed any more information."* Carer, age at diagnosis: 78, East Sussex.

Some other people mentioned support from an OT or Dementia Support Worker and by being involved in a trial immediately following diagnosis:

*"After the diagnosis, they [Dementia Support Worker] gave him some medications and further appointments to check how the medications were treating him. They provided follow up support every 2-3 weeks. Some written information - lots of pamphlets."* Carer, age at diagnosis: 76, Brighton and Hove.

*"Had a helpful appointment with a dementia support worker - she was delightful, very understanding, can get in touch any time."* Service-user, age at diagnosis: 77, Brighton and Hove.

*"The MAS has been supporting us through the increasing doses of the trial drug. We are in regular contact to ensure bloods are monitored."* Carer, age at diagnosis: 85, East Sussex.

There was specific reference to the information and material provided immediately after diagnosis. Most who received materials felt they **were too complex, too much information and too soon after the diagnosis:**

*"We got given plenty of information, leaflets and booklets. Some of the words were quite long and I am not a good reader, maybe I am a bit*

dyslexic." Carer, age at diagnosis: 79, East Sussex.

*"We had just received the diagnosis and the person was giving so many leaflets and information. I don't think I looked into the papers. The amount of paperwork was just too much. This was not helpful since we didn't have any time to get over the diagnosis before being bombarded with information."* Carer, age at diagnosis: 81, West Sussex.

*"We had so much information at the beginning which was overwhelming for some people. I think some of the information can be confusing for some, as it's so much information at the beginning. I suggest that more concise information on local things you need to know at the start would be more essential."* Carer, age at diagnosis: 87, Brighton and Hove.

One person also thought the materials were overwhelming and additionally found that they **could not think of any questions immediately** after diagnosis. Only once the information had 'sunk in' did they have questions but they appeared to have missed this opportunity:

*"Discussed medication and got about two million booklets and leaflets which were too soon. We didn't know what to ask when they asked if we had questions."* Carer, age at diagnosis: 77, Brighton and Hove.

Consequently, some mentioned that **receiving materials a few weeks or months after the diagnosis** where people may be more receptive to assimilate information:

*"I suggest after the diagnosis, we should be given some weeks or a month to get over the diagnosis and then called in or told about the support available."* Carer, age at diagnosis: 81, West Sussex.

*"Got a phone call from the MAS as it was in lockdown, and given the results and 'shelved it' as I've got to get on. I was asked if I had questions but couldn't think at the time. I would have liked a call later, time to think about it, like talk about this a couple of days later."* Service-user, age at diagnosis: 75, West Sussex.

In one example, a person was invited back to the MAS six weeks after diagnosis. This was thought to be a better time to process the information

offered and also have time to prepare questions rather than immediately after diagnosis:

*"Got the diagnosis and then told to come back in six weeks' time for more information and support options."* Service-user, age at diagnosis: 77, Brighton and Hove.

Some people mentioned the gratitude they found with the support offered by the **Alzheimer's Society**, immediately after diagnosis. In one instance they were available to offer support in the same 'hub' as the assessment centre. In another, a person rearranged the support to a more convenient time:

*"There was someone in the next room [to the assessment area] from the Alzheimer's Society who was there to give support and information after meeting the doctor who gave the diagnosis."* Carer, age at diagnosis: 81, West Sussex.

*"We saw a representative from Alzheimer's at Sage just after diagnosis, it was the most pivotal support throughout. They [Alzheimer's representative] introduced me to West Sussex Carers - guide me some forms, got some counselling from them. She [Alzheimer's representative] helped me pick through the leaflets, for things I needed when I had a meltdown. She [Alzheimer's representative] told me a club for people under the age of 65, same peer group, and said people had been there for years and he [service-user] came back and said 'I'm not going to die'."* Carer, age at diagnosis: 63, West Sussex.

*"After that [diagnosis] I was contacted by Alzheimer's Society but was just too busy caring for my husband and then, now being on my own, I needed to find out more so we arranged to speak and she answered a lot of questions. They got back to me very quickly, put me in touch with groups, like 'positive thinkers', and at that stage I got all the information I needed."* Service-user, age at diagnosis: 75, West Sussex.

For one person, the contact relied on the participant searching for support rather than it being offered proactively:

*"I got in touch with Alzheimer's Society. The Alzheimer's Society in Horsham was meeting Pxxx once a month. This is a group meeting of people with dementia. My daughter found 'independent lives' which is a charity which takes people with dementia and takes them out on Fridays - every week."* Carer, age at diagnosis: 88, West Sussex.

A further recommendation was to have a **specific person to contact** immediately following the diagnosis:

*"It would have been nice if we were allocated a specific professional. Each time we met a new person and so had to go over our story again every time."* Carer, age at diagnosis: 69, West Sussex.

## **b) Limited immediate support**

Around **one-quarter of people, however, received very limited or no follow-up support immediately after the diagnosis**. Not knowing what to expect through time and no referral to support groups was mentioned:

*"We were left without any support or advice about the diagnosis and what to expect and potential time frames. It would have been able to chat over with MAS any advice and suggestions a few weeks after the diagnosis."* Carer, age at diagnosis: 76, East Sussex.

*"Although it [MAS] was a good experience at the time in hindsight there was no follow up no information about support, cafés, clubs and finances...I googled to find out about finance stuff such as carers' allowance."* Carer, age at diagnosis: 76, East Sussex.

*"We felt cast away with such little support."* Service-user, age at diagnosis: 73, West Sussex.

*"Overall, support after diagnosis is not good enough. There should be a booklet which should entail what to expect, support services available and organisations that are in close reach. I had to go to the town hall to know which benefits I could access and they couldn't help much."* Carer, age at diagnosis: 58, West Sussex.

### **c) Re-contacting the MAS**

After being discharged from the MAS, some people felt the need to contact the MAS for support or when the condition had changed. However, the route back for more support was thought to be too complex and would usually be via the GP in order to be re-registered with the MAS, which was a frustration for a few people. Being **discharged too soon after diagnosis** was raised through one of these comments:

*"There was not much information given but there was a phone number if I needed help. The service experience was ok but I think MAS discharged too quickly and if I want reassessment I will have to restart the whole process with the GP and a long wait time."* Carer, age at diagnosis: 77, East Sussex.

*"Then he was signed off and I was told any issues see your GP. I called Lynwood [MAS] after that, and they said sorry you're not under our service, they said you can't see someone and then eventually we did as he's got angry so referred back to Lynwood for medication to calm him down to make his moods better...Longer-term it's important to know you can phone if there's a problem which I could do at Lynwood in the crisis team but then signed off. They said everything was fine but it wasn't."* Carer, age at diagnosis: 60, West Sussex.

Following discharge from the MAS, this person was not aware of the next stage:

*"Recently called from the MAS to discharge us and they have referred us to the allocation team but I do not have a clue about what that is."* Carer, age at diagnosis: 81, East Sussex.

A few people also received **conflicting advice about whether to contact their GP or MAS:**

*"The neuropsychologist handed over care back to our GP, again dumped...Didn't think I could go back to the MAS but my GP said we could, so we went right back to the start."* Carer, age at diagnosis: 70, Brighton and Hove.



*“Had a medication review from a clinical pharmacist and he suggested a higher dose, which was dreadful for me, terrible upset tummy so saw my own GP who lowered the dose. She [Specialist Nurse for Memory Assessment Service] said you have no right to speak to anyone else, she said you should be talking to us about the medication, I mean I didn't know as I had been to my GP about this. I didn't know whether to contact the GP or MAS, I was new to all this, it's all through the MAS where I live [Brighton]. I could have contacted the MAS but there is a long waiting list to speak to them.”* Service-user, age at diagnosis: 77, Brighton and Hove.

Although in the minority, some participants were able to recontact the MAS for further support when needed. This further illustrates the confusion about who to contact for support when needed:

*“We had a person to contact, a named person at the MAS and she has been so helpful. She always returns our call.”* Service-user, age at diagnosis: 72, Brighton and Hove.

*“We were told we could call [the MAS] at any time if we noticed any further deteriorations.”* Carer, age at diagnosis: 82, Brighton and Hove.

## **6. Post diagnostic support – long-term formal support**

Some people received longer-term support, including ongoing regular support and information about who to contact if necessary.

This section will include formal support (such as support from health and care professionals and that regarding medication). The following Section 7 will show informal support (in the form of support groups) and Section 8 shows where long-term support was limited.

This section will include the following:

- Ongoing support from health and social care professionals.
- Care plans.
- Who to contact in crisis.
- Support over medication.
- Equipment and adaptations.
- Centralised support.

- Favourable comments.

Although most of this section outlines the positive aspects of support, there are instances where support could be improved alongside recommendations made by the participants.

### **a) Ongoing support from health and social care professionals**

Around **one-quarter of people commented favourably about the ongoing support** from Social Workers, Dementia Support Workers, and Community Support Workers. People were typically being contacted between every three months to annually, or as and when needed. The support was a combination of practical matters (such as applying for Attendance Allowance), help and care needs, and emotional support for the carer:

*"The adult social care assessed us and we were assigned an adult support worker who is great. Initially she visited monthly but now she visits three monthly and advises about social activities and has a general chat."* Carer, age at diagnosis: 86, East Sussex.

*"West Sussex Carers support is a charity you can phone up for support (e.g. for a watch tracker, attendance allowance, alarms, sensor lights) and gave her a fund for 'quick care'. It's all very practical but you can open up and let your heart out."* Carer, age at diagnosis: 60, West Sussex.

*"We had lots of support after the diagnosis. I am on the list for regular support by my care worker and I have met her twice so far. I really don't know if I need more frequent follow up support. I go for my check-ups often. So far I have been there about three times. I am very satisfied with their support, and it is a great help to know I am on their books, knowing that I know who to contact in times of crisis."* Service-user, age at diagnosis: 80, Brighton and Hove.

*"Following on from the MAS, we were put in touch with a social worker - from SOAMH [Specialist Older Adults Mental Health]. We were having the support whenever we needed it. We checked in 3-4 times in a year."* Carer, age at diagnosis: 87, Brighton and Hove.

Applicable to West Sussex, two people mentioned the useful support from **Admiral Nurses** who were valued in providing support to the carers:

*"An admiral nurse was useful in offering me support - mentioned dementia cafés, which are great for meeting others, knowing what to do about certain stages like incontinence and getting in touch with the incontinence service... Admiral nurse was useful as they show more support to carers than patient."* Carer, age at diagnosis: 78, West Sussex.

*"I get an admiral nurse, asked for one in West Sussex after being told there weren't any, I had to register, through someone at the doctor's practice, and they are a real help for me."* Carer, age at diagnosis: 60, West Sussex.

## **b) Care plans**

Indicative of the longer-term support is the presence of a care plan.

**Around one-third specifically mentioned they did have a care plan.**

Around one-half of the sample said they did not have a care plan, and the rest were either not sure or opted not to have one.

Example illustrations where a care plan was mentioned are as follows, including some reference to their usefulness:

*"Specialist nurse had a personal care plan from the memory assessment service (in the surgery). Care plan was useful, received on second visit - plan was easily understood and provided a link to call if necessary. The 'what happens next' was really useful in the plan."* Service-user, age at diagnosis: 73, Brighton and Hove.

*"They did not receive a care plan until the carers were employed. Then they had a personal care plan for her personal hygiene needs."* Carer, age at diagnosis: 80, West Sussex.

One person specifically commented on what a care plan should include:

*"What is needed is a letter with facts and a system that reviews. Not a long letter, this one was five pages and totally overwhelming. A care plan should have been written as 'this is what we have done, this is what we*

*are doing and this is what we will do in the future'.*" Carer, age at diagnosis: 77, East Sussex.

Below are some examples where there was **not a care plan**:

*"No care plan was shared with us or who to contact, we just coped."* Carer, age at diagnosis: 76, East Sussex.

*"No one visited me and don't think it [a care plan] was offered, so not offered a care plan."* Service-user, age at diagnosis: 66, West Sussex.

Interestingly, the following two instances show where it was a **personal choice not to have a care plan** as people were currently coping as a carer:

*"With regards to care plan, we were asked about it, but we don't need one since I am able to care for him. I don't think we need a care plan at the moment."* Carer, age at diagnosis: 69, West Sussex.

*"We don't at the moment need a care plan."* Carer, age at diagnosis: 75, East Sussex.

Nonetheless, not everyone who had a care plan found it useful or were aware of what it contained:

*"I had a recent review from two dementia nurses for a care plan, first time in the 11 years, probably because I went back to the crisis team. It was A4 with a couple of notes scribbled on it - not very helpful or detailed. They said they will look into that and nothing happened."* Carer, age at diagnosis: 60, West Sussex.

*"There is a care plan in place but I don't know much about it."* Carer, age at diagnosis: 78, East Sussex.

### **c) Who to contact in crisis**

A further component of longer-term support was knowing **who to contact in the event of a crisis** or if the level of support changed. Around a quarter of participants expressed that they had sufficient support in the event of a

crisis (in addition to those few who could re-contact the MAS – see Section 5c, 'Re-contacting the MAS', earlier):

*"I phoned the GP saying 'who looks after us' and he said 'it would be us', and the GP makes time for us as does the consultant who will always speak to us."* Service-user, age at diagnosis: 73, West Sussex.

*"I have information on who to reach in a crisis. I have a number that I could call anytime I needed extra support for care. This is reassuring."* Carer, age at diagnosis: 75, East Sussex.

*"I would go to Sage house if we were struggling and have a carers card with a carers emergency care line, so can organise emergency support for John up to 72 hours."* Carer, age at diagnosis: 63, West Sussex.

*"They [Adult Services] provided information about who to reach in terms of a crisis. We were given an emergency card."* Carer, age at diagnosis: 76, Brighton and Hove.

However, **not knowing who to contact in the event of a crisis** or for advice was also identified as a problem by a further quarter of the sample:

*"Mostly concerning is me being on my own - like a health professional looking after me because I sometimes don't know what's the best thing to do...One contact, named, person for me and him to see us through the process, to chat it through, carers and things but got no one to talk to."* Carer, age at diagnosis: 59, West Sussex.

*"There hasn't been specific advice about what to do in a crisis."* Carer, age at diagnosis: 78, East Sussex.

*"Whenever I had a problem with Bxxx, I never knew who to contact - the GP, MAS or mental health? Where do I go when conditions change? No one person to call in a crisis or if I needed anything."* Carer, age at diagnosis: 77, Brighton and Hove.

#### **d) Support over medication**

Applicable to both the immediate and longer-term support, advice regarding medication was frequently mentioned. This was in terms of reviewing the medication and knowing how to assess whether it was helping.

For most who responded to this question, **most mentioned the positive support around medication advice**. Ongoing support around medication was from a variety of sources including the GP and the MAS:

*"There was quite a lot of GP support due to the medication that Mum was on. Some of it conflicted with others so had to be changed and monitored. The medication was reviewed regularly."* Carer, age at diagnosis: 80, West Sussex.

*"We meet the MAS annually for review of our medications."* Carer, age at diagnosis: 69, Brighton and Hove.

*"There has been advice about medication increasing and decreasing the dose by the Dementia Support Worker."* Carer, age at diagnosis: 77, East Sussex.

There were, however, **conflicting experiences as to whether the support was adequate**, with a few people raising concerns:

*"I asked for a review of medication, but I never heard anything about the medication, so I had to change it around myself."* Carer, age at diagnosis: 74, East Sussex.

*"She [dementia nurse] said after the assessment, you've gone through that stage so you won't hear from us again - but I would like to know where the dementia medication comes from, the GP or the memory service?"* Carer, age at diagnosis: 75, West Sussex.

Related to medication, one person spoke about the importance of diet and how advice around this once diagnosed would have been useful:

*"Taking vitamins are recommended to help me, take cod liver oil, coconut oil, but none of this was mentioned at all by the services. I should have been told this but you are quite disorientated when you receive the diagnosis. There should be all the things you can do, rather than find it out by osmosis! The service never mentioned this. Keeping a good diet as an extra too."* Service-user, age at diagnosis: 66, West Sussex.

### **e) Equipment and adaptations**

Longer-term support also applied to those who needed house adaptations or equipment to support the service-user at home. This was only mentioned by a few people:

*"They had other support from OT's advising and supplying adaptations to make things safer...When we started to think about adaptations the OT had made the call to come and see what was needed."* Carer, age at diagnosis: 80, West Sussex.

*"We contacted an Occupational Therapist as my Mum had a fall so we are waiting for a few hand rails."* Carer, age at diagnosis: 78, Brighton and Hove.

One person mentioned acquiring equipment in advance could help people receive this support when needed, rather than having to wait:

*"Needed more equipment so left alone upstairs, now waiting for a stair lift, so I think it would have been nice to prepare for that earlier so she didn't just have to wait upstairs all the time."* Carer, age at diagnosis: 88, West Sussex.

### **f) Centralised support**

Related to the awareness and navigating the various support services, some spoke about the **need for a more centralised support service**, where assessments, diagnosis, advice and support could be sought when needed. This would help address the lack of awareness about support opportunities and who to contact in times of crisis or for medication reviews (as examples):

*"One central hub that gave advice about services rather than loads of different people coming. Sometimes I had no idea who they were." Carer, age at diagnosis: 85, East Sussex.*

*"All charity bodies should be under one umbrella- everything should be offered and insisted upon for people to access." Carer, age at diagnosis: 88, West Sussex.*

In conjunction, one person mentioned specific benefits of having a centralised hub where various support options were available:

*"We do need a handle for the stairs so would go to Sage house who have a solicitor there too and citizen's advice to help apply for things like the blue badge." Carer, age at diagnosis: 63, West Sussex.*

Related to the groups and centralised support, one further person spoke about the difficulties in knowing the types of support that were available:

*"Awareness of the support that is available needs improving, but I'm active in looking for support so there needs to be a tick list of 'have you had this support or considered this?' It relies on word of mouth as people are falling through the cracks, sitting at home and that's tragic." Carer, age at diagnosis: 63, West Sussex.*

### **g) Favourable comments**

Despite the interviews adopting an investigative approach as to how services could be improved, this did not detract from several comments, as shown below, that were **complimentary about their dementia journey**:

*"No suggestions for improvement as the help was fantastic, always two steps ahead of us." Carer, age at diagnosis: 80, West Sussex.*

*"Very happy with the amount of support offered." Carer, age at diagnosis: 81, East Sussex.*

*"I can't complain about the support given. I do not have any suggestions about improvements." Carer, age at diagnosis: 76, Brighton and Hove.*



## 7. Post diagnostic support – long-term informal support groups

Informal support, in the form of support groups, were found to be extremely valued. Run by charity groups, they were seen as a space to be with like-minded people and a provide a useful source of friendship and advice. They included **cafés, choirs and sports activities**. This experience was held by around one-half of the sample:

*“Cafés - found out through my church where the cafés were and he didn't like them and then he liked it...also sporting moments linked to the cafés, for table tennis, netball, some sitting and some more active.”* Carer, age at diagnosis: 60, West Sussex.

*“We visit a café once a week for up to 3 hours. We have just started to go so have not got much experience of it. I'm [carer] really keen to have opportunities to talk to other carers as I feel so isolated sometimes as he doesn't talk, so I need to be able to talk for my own wellbeing.”* Carer, age at diagnosis: 81, East Sussex.

*“The memory café, sporting memories, online Pilates we find real comfort from that.”* Carer, age at diagnosis: 70, Brighton and Hove.

Although support groups were delivered by several different organisations, people mentioned those specifically run by the Alzheimer's Society:

*“I also have a carers' group that is organized by the Alzheimer's society that I go to.”* Carer, age at diagnosis: 69, Brighton and Hove.

*“Alzheimer's organise clubs that create a sense of community, they have guest speakers from the memory clinic, the gas board to save on energy costs and things. The Alzheimer's led us through this. We do dementia weekends, with others, food, entertainment, really useful and good source of support.”* Carer, age at diagnosis: 63, West Sussex.

One person mentioned a **support group specifically for carers** would be a good idea:

*“Overall support has been minimal, it would be good to have more carer support such as a drop in centre or café where you could talk to other*

*people experiencing similar or different challenges and meet with a professional, a bit like when you have a baby and there is postnatal care for the mums to share their challenges. I feel so isolated so that type of place would be useful, somewhere just for carers it would reduce the carers mental health stress."* Carer, age at diagnosis: 77, East Sussex.

**Information around groups** either came from Dementia Support Workers, the Alzheimer's Society, Social Prescribers or through word of mouth or online sources:

*"Know Dementia have been fantastic - I found out about them from a phone number given to me at the memory clinic, they were so lovely and he was put down for a memory café, and they told the others we were turning up for the first time and they were so welcoming...found out I could register as a carer and given an email of services. I just found out about this online when I was looking for support, it was quick to register online. I'm not so sure people would know about this, but it helped me to find out more support...You make good friends with people, we're all in the same situation and find out about other areas of support."* Carer, age at diagnosis: 75, West Sussex.

*"We were also referred to peer-group support which meets once a month. This group is for people with cognitive impairments and their carers. This was optional but we've been doing it every month."* Carer, age at diagnosis: 82, Brighton and Hove.

A few people suggested that these groups need to be **better publicised**:

*"I've joined a dementia-special choir and go to a café - should all be on a highlighted list of things to do, bullet pointed but we never received anything about this, something to help communication and contact."* Service-user, age at diagnosis: 66, West Sussex.

*"More awareness of support groups like cafés or sporting activities needs to happen, I heard from the Church just by chance really and I met someone who's recently diagnosed and said the doctor didn't tell her anything, so I would say they need to tell people more about these things."* Carer, age at diagnosis: 60, West Sussex.

Although many had accessed these groups, not everyone had. This was often due to **lack of awareness**:

*"Knowing about what support was available. He would have loved going to the dementia clinic because he loved music, it would have been good to talk to other carers."* Carer, age at diagnosis: 76, East Sussex.

*"I have not met anyone yet but I know there are people like Pxxx and I and I find it extremely lonely and would love to meet more people. I don't know anyone in Worthing or Sussex with similar situations. If we did know anyone we could do things together. We suggest that there should be more information about services available for people in Sussex. Wish we could have an old timers or dementia dancing group or choir. Most things we found were purely by chance, we weren't personally looking out for them."* Carer, age at diagnosis: 88, West Sussex.

Additional reasons for **not attending groups was out of personal choice**, despite being aware:

*"Mum is not a member of any society or groups. After Covid I tried to take her to a café, which didn't work for us after trying a few times. She's happier in her own home. She was always sitting at the edge of the group, not participating and constantly said she wanted to go home. I tried again a year later and it was the same reaction and so we stopped."* Carer, age at diagnosis: 81, West Sussex.

*"He [service-user] has not been to any day centres or cafés. This is because he is not interested. It is hard for him to see any value in what he goes to."* Carer, age at diagnosis: 69, Brighton and Hove.

Linked to these groups, one participant had used age concern to give her some spare time. However, this same person mentioned more opportunities for this would be useful. Another person intended to take up further support but did not know how to pursue this:

*"Nxxx went alone to age concern in Haywards Heath - found out through Haywards Heath Council - he went alone for an hour and a half once a month, would prefer a day a week, every week, so more of this would be good."* Carer, age at diagnosis: 75, West Sussex.

*"Would like more advice about respite care but don't really know where and never got a bottom line on it on what it could do." Carer, age at diagnosis: 59, West Sussex.*

Other instances of **attending day care** were mentioned by a few people as follows and were of clear value for the carers and well as the service-users:

*"Since December he goes to day care once a week. Am now applying to social services to fund this care." Carer, age at diagnosis: 60, West Sussex.*

*"Dxxx visits a day centre four times a week. He goes four times because I need my space." Carer, age at diagnosis: 74, East Sussex.*

## **8. Post diagnostic support – limited long-term support**

In contrast to the above, and illustrative of the variation in people's experiences, some people spoke about **not having received any long-term support** after the MAS visit:

*"We didn't receive any follow up support coming home." Carer, age at diagnosis: 75, East Sussex.*

*"No one calls or comes home to offer any support." Carer, age at diagnosis: 68, West Sussex.*

*"However, after the diagnosis, we had no contact with them [MAS], no follow ups, we had no follow up or contact from them for 3-4years. Due to the long hiatus in communications, Txxx stopped taking her medications and things worsened until we got back in contact with the MAS." Carer, age at diagnosis: 65, Brighton and Hove.*

For those receiving limited support, it was left to their **own initiative** to seek out options:

*"No one told me how it would progress or what would happen - went online. No one sat down said this will happen, this is what's coming." Carer, age at diagnosis: 60, West Sussex.*

*"I asked for social services to visit but never had one, and no one could see what he was like. He never had an assessment. It was only much later almost it was too late, they were too reactive not proactive...Only now do I have their [social services] contact, but would have liked that earlier."* Carer, age at diagnosis: 77, Brighton and Hove.

For others, although knowing where to access support they became frustrated about **not receiving a return call** or email or having to wait for a response:

*"I reached out to several people locally who didn't pick their calls and they never contacted me back... Most of the services didn't pick their calls and left messages to reach back but never did."* Carer, age at diagnosis: 59, West Sussex.

*"Have a name and number for the memory clinic...was disappointment and felt let down as only offered a telephone appointment in two weeks' time, didn't want to wait and I needed it then... told to contact them any time but you couldn't speak to anyone, the way the system works, it's crazy, not very good."* Service-user, age at diagnosis: 77, Brighton and Hove.

In a unique situation, the **lack of a clear diagnosis** prevented this person from accessing support. This was in contrast to when they finally received a diagnosis:

*"There was no real diagnosis, we had MCI, but without Alzheimer's we could not go to the groups, we were out in the wilderness...Now we have Alzheimer's we can access some groups and can get attendance allowance."* Carer, age at diagnosis: 70, Brighton and Hove.

A few people also mentioned that whilst support was helpful at first, longer-term **support became less frequent through time**:

*"Initially, very good support early on then more tailed off a bit and more down to me to chase them."* Carer, age at diagnosis: 74, East Sussex.

*"We were bombarded with people and they brought wedges of paper. It was overwhelming because I was looking after Mum all day, doing waking*

*nights and then the same the next day. After that we have heard nothing."*  
Carer, age at diagnosis: 85, East Sussex.

To address this drop-off in support some participants **recommended an ongoing review or 'check-in'** with the MAS or other professionals to see whether they needed any assistance:

*"You get a ton of contact then it drops off, might be nice to have some serious communication to say 'are you alright' like an annual check-in with a specialist, not online but face-to-face and convey to me that I'm taken seriously, so I could ask questions."* Service-user, age at diagnosis: 66, West Sussex.

*"It would be nice to have a review appointment after a year with the MAS because I wasn't sure how the condition was going."* Carer, age at diagnosis: 78, East Sussex.

*"They [MAS] should keep in contact with people for regular follow ups because things change rather rapidly with dementia combined with other diseases. I suggest they do regular follow ups with their clients."* Carer, age at diagnosis: 65, Brighton and Hove.

In relation, this ongoing support would include a **review of their care plan**:

*"There was a care plan but it was written September 2020 but hasn't got much on it and has not been reviewed at all."* Carer, age at diagnosis: 74, East Sussex.

*"The care plan has not been reviewed or discussed at any length."* Carer, age at diagnosis: 76, East Sussex.

In one instance, an Indian person drew on the views of her community where care is commonly refused when offered, reflecting the **cultural background** where caring for the elderly was a responsibility:

*"Educating our community to make people aware as in our community people are reluctant to get the help that's there, as we look after our own, it's seen as a taboo. That's why we didn't look for any support. The new generation need to think differently, to take up respite care or a care*

*home to protect the carer. Many people in my community don't know what is available like respite care."* Carer, age at diagnosis: 88, West Sussex.

This same person, when needing carer support, found it impossible to get help from Punjabi speaking carers which furthered her lack of support:

*"Language was an issue, so few Asian carers here in West Sussex so they need to speak Punjabi, as English is her second language, but we haven't got that support. We [second generation] can speak English so it's easier now but my mother can't."* Carer, age at diagnosis: 88, West Sussex.

This also links to a further point how some carers/partners found it difficult to ask for help, often getting help once things had reached crisis:

*"Having carers was a bit disturbing at first and it took time for my Dad to realise he needed support."* Carer, age at diagnosis: 78, Brighton and Hove.

## **9. Transitions**

Around a **quarter of the sample had been admitted to hospital** due to falls, UTIs, pneumonia or other complications. Two people mentioned that the service-users admitted to hospital were not in dementia wards and one person said *"we fed him as he wouldn't take it from anyone else."* Carer, age at diagnosis: 59, West Sussex.

One carer felt that this hospital experience had been stressful because the service-user was about to be discharged with nowhere to go:

*"[She is] now in a residential home for dementia patients where she is receiving full nursing care."* Carer, age at diagnosis: 78, West Sussex.

Two other people had moved from hospital to a dementia specialist care home:

*"He moved into a care home, found it difficult to settle, staff seemed good. He now calls it 'home'. Allowed us to put pictures up to help him. He needed 24-hour care."* Carer, age at diagnosis: 77, Brighton and Hove.

One person mentioned that on discharging from hospital, she needed to get advice on the medications she had received in hospital, and information for the carer was not in the discharge summary:

*"She came out with a whole lot of drugs which she was not earlier on. I have not been able to talk to anyone whether she needs a repeat of these meds since no explanations were offered to me."* Carer, age at diagnosis: 59, West Sussex.

One other person talked about the changes in benefits when their mother went to hospital and the poor communication between the hospital and other health and social care support:

*"Don't forget about the carers and the carers' allowance is taken away when they go into hospital despite the fact I still had to drive there. The communication between the hospital social worker and the community social worker, no liaison, nobody was able to care for me, literally nothing from the social workers after she came out of hospital. They say 'dementia friendly Crawley' but that's rubbish, nothing's changed."* Carer, age at diagnosis: 83, West Sussex.

Two people mentioned they would like to have **advice in end of life care** when it is appropriate:

*"We've had no advice about end of life issues - we assume it's not immediate. We will want to have advice on it, when it could happen and what to do if it happens."* Carer, age at diagnosis: 69, West Sussex.

*"There has not been any discussions about the end of life process since we have not been to that stage."* Carer, age at diagnosis: 69, Brighton and Hove.

A further three people had already started to prepare for this event:

*"Started to talk to a Solicitor about the end, but we don't know when that will happen."* Carer, age at diagnosis: 77, Brighton and Hove.

*"I have had talks about my end of life care with the MAS."* Service-user, age at diagnosis: 74, Brighton and Hove.



*"We have signed an agreement for no resuscitation – it's called the red form."* Carer, age at diagnosis: 82, Brighton and Hove.

Sadly, from the two people who had died, one person died shortly after being admitted to a nursing home and the daughter remembers the caring nature of the nurses:

*"She fell and broke her hip, ended up in hospital, came out four months later a completely different person, broke her false teeth, gave up on her physiotherapy because of her dementia, got a chest infection, then back home, for two months. She died in the care home, six months later, got a phone call saying she wasn't eating properly and not swallowing well so was asked if she wanted to go to hospital and I would rather she stayed where she was. I got to the care home, we knew it was happening....The nurses were excellent at that time when she passed."* Carer, age at diagnosis: 83, West Sussex.

## **Conclusions and Recommendations**

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.

- 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.

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).

Drawing on people’s experiences the leading recommendations that could feed into an Action Plan are as follows:

## **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.

Finally, although not representative of all experiences, this person's comment resonates with many of the issues raised through this study:

*"If you have a broken leg, for example, you get lots of support. If you have a broken mind, no one wants to know...unless you are on the ball it is easy to get lost in the system."* Carer, age at diagnosis: 72, West Sussex.

## Appendix 1 – Recruitment flyer



# **Are you affected by, or care for, someone with dementia?**

If so, we'd like to hear your views and experiences of using NHS services through the dementia care pathway.

Tell us about Memory Assessment Services and support received after diagnosis.

We want to know what worked well, and what could be improved.

**Take part in a 30 to 45 minute phone conversation and receive a £50 high street voucher as a thank you.**

For details or to arrange a suitable time to talk, contact Lester at:

**Lester@HWBH.co.uk    07969 498866**

**Healthwatch in Sussex is the independent watchdog listening to the public's views about health and social care.**

## Appendix 2 – Information sheet



### Information sheet - Patient/carer experience with Sussex Dementia Services

#### **What is this project about?**

We would like to hear people's experiences of using the different types of services available for people with dementia. This could include initial visits to a GP, referral to and experience of Memory Assessment Services (MAS), a diagnosis appointment, and experience of support after diagnosis. We would also like to hear about any experiences of being discharged from hospital and moving into residential care (if applicable). We would like to speak to people with dementia and their family/carer(s).

#### **Who is doing this project?**

This study is being led by with support from Healthwatch East- and Healthwatch West-Sussex. Healthwatch is a consumer watchdog for health and social care services, is completely independent, and has expertise in hearing from patients about their experiences. We want to speak to people across Sussex.

#### **Why are we doing this project?**

We are doing this study as we believe that hearing from patients and carers about their experience is the best way to improve services. This evidence will be used to inform the recommissioning of services, so hearing your views is very important.

#### **What does the project involve?**

To hear people's views and experiences, we will offer the choice of a conversation over the phone, via online video messaging or face-to-face. The conversation may be around 45 minutes but could be longer depending on people's preference. The conversation will ask about people's experiences of when memory issues first arose and then hear about people's views about the services used (such as Memory Assessment Services) and what they think worked well and less well.

#### **Who is funding this project?**

This project is funded by NHS Sussex.

#### **Confidentiality**

All conversations will be strictly confidential and all names will be changed in any report produced. Also, prior to the conversation, people will go through an informed consent process to see if they are happy to continue.

To thank people for their time, everyone having a conversation with Healthwatch will receive a **£50** high street voucher (see [Love2shop](#)).



**How do I take part?**

To take part in this study, or to find out more, please contact **Lester Coleman** (Head of Research) at Healthwatch Brighton and Hove either by email ([Lester@hwbh.co.uk](mailto:Lester@hwbh.co.uk)) by text/phone (07969 498866). A member of the research team will then contact you to arrange a convenient time to have this conversation.

To contact the commissioner: Sonja Janeva, Dementia Programme Lead – ICS Mental Health Collaborative ([sonja.janeva@nhs.net](mailto:sonja.janeva@nhs.net)).

## Appendix 3 – Topic Guide

### a) Starting the interview

- Confirm who we are talking to or talking about (if talking to a carer/family member). Check all names (we would like to speak to people with dementia and their family/carer(s)).
- Thank you for agreeing to take part in this conversation – to hear your experiences will really help us plan for better dementia support services in the future. We are going to be talking about several things, including when there were first memory issues, perhaps a visit to the GP, experience of Memory Assessment Services (MAS), including the giving of the diagnosis, and experience of support after diagnosis. It may be around 45 minutes.
- Check participant has read information sheet (separate document) – if not, re-read again to participant.
- Check informed consent (separate document)
- Do you have any questions before we start?

### b) Main body of the interview

1. General introduction – Can I just start by asking which town/village/city do you live?
2. Does the person with dementia (use name) live alone or with someone else?
3. How are things with you/the person you care for is at the moment? Check whether patient has been discharged from hospital and moving home or into residential care
4. When did you first notice memory issues?
5. If the person with dementia needs care, who provides this?
6. I would like to talk about the different services that you were in contact with when the first memory issues came about – is that ok?

#### *GP if applicable*

7. For many people they first contact their GP, was this the case for you?
8. How was that experience with that GP, did you feel you had enough time, were they caring?
9. Did the GP refer you to another service? If so, what? (see next question theme about MAS)
10. Did you see anyone else to get a referral e.g. someone at hospital?

#### *Memory Assessment Service (MAS) if applicable – part of the diagnostic pathway*

11. Were you referred to a Memory Assessment Service (MAS - colloquially a memory specialist)? Who referred you? How long did you have to wait for this? Was waiting an issue for you?
12. Where was this appointment (home, clinic – was this your preferred option, was travelling an issue)?
13. Did you have a phone call before you were seen by the MAS? Was this useful?

14. Do you know who provided this MAS? HERE? SPFT (Sussex Partnership Foundation Trust)? Integrated Community Care? Anyone else?
15. Were you treated with care and respect at this memory service? In what ways?
16. Did you receive enough information from MAS? Would you have liked more information? Or another visit?
17. Were you offered a CT scan (MRIs for under 65s)? Who made the referral this (GP or MAS)? What was the waiting time for this? What was the experience like?
18. Were you told about the next steps and what was happening?
19. Overall, what improvements would you suggest during this memory assessment phase and the services you received? Were you told about the next steps and what was happening?

*Receiving a diagnosis - part of the diagnostic pathway*

20. What happened when you were seen in the MAS?
21. Did you receive a diagnosis?
22. When did you receive this – same day as the assessment or later? What did they say? How did you receive this – verbally, written?
23. Do you know who provided this diagnosis and who offered support?
24. Overall, what improvements would you suggest about the diagnosis process and the services you received?

*Post diagnosis and support*

25. From when you were first diagnosed, were you told who would be in touch to help you following the diagnosis? When did you first receive follow-up support? What was this support – a visit? Written literature, a phone call?
26. Who was providing this follow-up support?
27. Would you like your GP to be more involved in this, for example through further appointments, home visits? Why would that be the case?
28. How regular do you receive this support, and is this useful – would like this follow-up more frequently?
29. Did the support offer advice over medication?
30. Did you receive a care plan? Who provided this? Was it useful? Was it reviewed? (if not, would you have liked one?)
31. Did they provide information about who to reach in a crisis? Would that be useful?
32. Do you receive (private/paid for) carer at home support?
33. Do you receive any other specialist support such as a social worker or anyone advising about money from the Council? Or community mental health teams? How useful is this and why?
34. Do you need/have you/would you know where to get help over home adaptations of equipment, such as handrails, mobility aids? If received such adaptations and equipment, how easy was this? What could have been better?
35. Is there any support for the person providing the majority of care?
36. Overall, what improvements would you suggest about the support you received after diagnosis?

*Transitions (if applicable)*

37. Do you/person you care for visit any day centres/'cafés' – how often, how did you find out about them, are they useful and why?
38. (if applicable) Have you/person who you care for moved into a residential care home? How did you find out where she/he could move to? Who gave you support?
39. What is the type of care provided? Specialist for dementia patients?
40. Have you/person you care for been to hospital? How many times? Where were they discharged to (home, residential care home)?

**c) Ending the interview**

- Overall, how would you describe the support you've had from services since you first noticed a memory issue? Think about possible improvements, what worked well/less well, recommendations.
- Conclude interview by summarising the conversation to check all relevant information has been collected – ask participant if they agree with your summation.
- Check details for 'thank you' voucher.
- Round off by checking age and ethnicity and thank you with signpost to support services if required:

## Appendix 4 – Informed consent



### CONSENT TO PARTICIPATE IN AN INTERVIEW STUDY Dementia pathways – views and experiences

Face-to-Face: Please put your initials in the box alongside each statement to indicate that you agree with it and then put your name and the date at the bottom of the form. If you do not agree with any of the statements or do not wish to consent, you should not initial or sign the form.

Phone: agree or disagree over the phone.

Please initial

box

1	I agree to participate in an interview to share views and experiences about my own, or the person I care for, views and experiences of dementia services.	
2	The researcher has explained to my satisfaction the purpose of the study and how the information will be used (Participation Information Sheet).	
3	I understand that everything I say will be treated in strict confidence and no information identifying me will be passed on to anyone other than members of the research team.	
4	I understand that my details will not be shared with anybody outside the research team; however, I know that the researcher is obliged to inform another professional if I disclose that I, or someone I know, is at risk of harm.	
5	I understand that I am free to withdraw from the study at any time, without giving an explanation. All data will be destroyed if you withdraw from the study.	
6	I agree to the discussion being digitally recorded for the purposes of this research study.	

Participant's name: .....

Signature: ..... / Date: .....

Researcher's name: .....

Signature: ..... / Date: .....