healthwatch Leicester healthwatch Leicestershire healthwatch Rutland

Living with dementia in Leicester, Leicestershire and Rutland

April 2023

Contents

Disclaimer

This report relates to our findings. Our report does not represent the experiences of all people but only those who contributed at the time.

About Healthwatch

Healthwatch Leicester, Healthwatch Leicestershire and Healthwatch Rutland are an independent voice for the people of Leicester, Leicestershire and Rutland (LLR) enabling them to have a say in the Health and Social Care services provided in their communities.

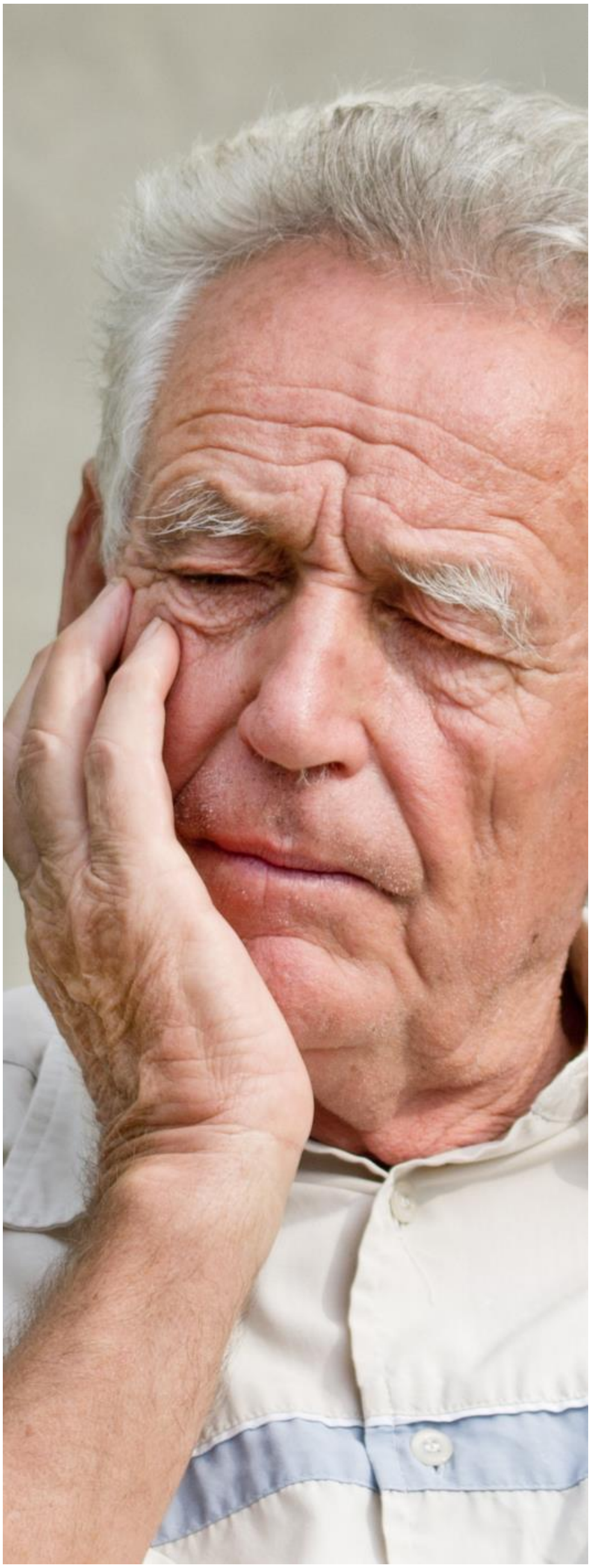
Our role is to listen to the voice of the public and to represent their views and experiences with commissioners and providers of services to influence service improvements and hold to account where appropriate. We work with all communities and use feedback to help shape services and drive quality and improvement.

Executive Summary

- The aim of this project is to represent the public voice in the development of the 2024 Dementia Strategy for LLR at a time when the incidence of dementia is forecast to increase.
- Mixed methods, including background research, engagement with service providers, surveys, focus groups and interviews with people living with dementia and carers provide evidence for our recommendations.
- There are inconsistencies across LLR with variations in the speed and types of diagnostic pathways.
- Despite multiple channels of information, there are inconsistencies in people's experiences of access to and appropriateness of it.
- There is an inconsistent provision of and access to support services with many different barriers to be addressed.
- There is poor recognition of the needs of those with early onset dementia.
- There were suggestions supporting the need for a single point of access, such as a hub, to improve information and access to services.
- People living with dementia and their carers who had access to services provided by Admiral Nurses, Age UK, Voluntary Action South Leicestershire (VASL) and the Alzheimer's Society highly value the support and information they receive.

Executive Summary cont.

- Access to primary care is often difficult with suggestions that ongoing needs, including annual reviews, are either overlooked or not adequately addressed.
- Access to specialist mental health services is difficult.
- Adult Social Care is difficult to access and slow to respond and requests for much-needed support are sometimes declined.
- Carers need support to plan and cope with times when they can no longer care due to their own health concerns or because the person with dementia is admitted to a care home.
- The COVID-19 pandemic restrictions have had a negative impact on people living with dementia in terms of social isolation, deteriorating health and hospital admissions.
- Transport to groups and support services is problematic – especially in rural areas.



What should happen next – key messages

- A system-wide review is needed of the integrated dementia care pathway and service models to see if they are meeting the needs of patients and carers. The purpose is to create a fair and consistent experience for people from wherever they live within LLR. This should include a standardised diagnostic pathway and equitable access to services.
- A review of the information available to people pre and post diagnosis including how, when and where this is shared in a timely manner so that all people can experience equal access to the information as they need it at various points of their dementia journey. There needs to be a standardised procedure to ensure everyone can receive this.
- Any new investment or redesign of current services should take account of the feedback gathered and outlined in the report, demonstrating that people with dementia and their cares are listened to.
- Consider what practical steps can be made to improve access to health and social care when a patient’s condition progresses so that they and their carers do not have to feel that ‘everything is a fight’.
- A review of mandatory training for all staff involved in the planning and delivery of dementia services to ensure that the standards of care in primary, secondary and community services meet expectations of people diagnosed with dementia and their carers.

Context for the study

Dementia is a progressive illness. It affects the brain, and its symptoms can vary from person to person. There are more than 850,000 people in the UK who have dementia. One in 14 people over the age of 65 have dementia, and the condition affects 1 in 6 people over 80. The number of people with dementia is increasing because people are living longer. It is estimated that by 2025, the number of people with dementia in the UK will be more than 1 million [1]

In August 2022 Leicester, Leicestershire, and Rutland had 13,149 people over 65 estimated to be living with dementia.[2] Whether they are living in the inner city or remote rural areas, LLR has a diverse population. The challenge for people living with dementia, their families, and carers, is to be able to access services, support and information that is appropriate and relevant for their individual needs at the right time and in a way that supports people to 'live well with dementia'. Some of these service responses have been suspended or delayed in response to the COVID-19 pandemic.

Supporting and helping those living with dementia and their carers remains a priority for LLR health and social care organisations and is overseen by the Dementia Programme Board (DPB). Part of the role of the Board is to develop and oversee delivery of Joint Dementia Strategy for Leicester, Leicestershire and Rutland. The Living Well with Dementia Strategy 2019-2022 strategy looks to support those with dementia and their carers using the NHS England Well Pathway for Dementia as a framework.

One of the central aims of the strategy is:

"...to create a health and social care system that works together so that every person with dementia, their carers and families have access to and receive compassionate care and support not only prior to diagnosis but post-diagnosis and through to end of life." [3]

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[1] living-well-with-dementia-strategy-2019-2022-accessible-version.pdf (leicester.gov.uk)

[2] NHS Digital dementia diagnoses by organisation, source: Recorded Dementia Diagnoses, August 2022 - NDRS (digital.nhs.uk)

[3] https://resources.leicestershire.gov.uk/sites/resource/files/field/pdf/2018/12/24/LLR-Living-Well-with-Dementia-Strategy-2019-2022.pdf

Aims and Objectives

Our overall aim is to support the development and delivery of the LLR Joint Dementia Strategy for people with dementia and their carers and find out whether the current services remain sufficient and effective to meet the needs of people now and in line with population and demographic trends in the future.

Our objectives of the study are:

- To provide an accurate evaluation of what support and care services are in place currently across LLR, including the identification of good practice or shortfalls, by gathering feedback from professionals in the field, service providers, people with dementia and carers.
- Support the delivery of collaborative and integrated dementia care within the community by sharing our findings and making recommendations based on feedback on how services may be developed and improved.
- Use feedback to understand what support services are needed and what gaps and barriers might be preventing access to existing services.
- To use this feedback to offer to care providers a comprehensive understanding of patient and carer experiences in relation to, access to diagnosis; illness management; care and support services; and health and wellbeing outcomes for people who are living with dementia or will do so in the future.
- Support collaborative working, development, improvement, and delivery of dementia care by sharing our findings and making recommendations based on this report and other evidence.
- In particular, to submit this report to the LLR Dementia Partnership Board so that the upcoming review of the dementia strategy can reflect the views and experiences of people who currently use dementia services across LLR.

2 for NHS Digital dementia diagnoses by organisation, source

Method

We used mixed methods to gather feedback and this involved:

Desktop research

This took place between June and July 2022 and included identifying and referencing all accessible documents related to LLR's Strategic approach to the delivery and development of dementia services. Reference documents identified and referred to included:

- Leicestershire Joint Strategic Needs Assessment (JSNA) 2018-2021[4]
- Leicester City Joint Strategic Needs Assessment (JSNA) [5]
- Dementia Services for Rutland People[6]
- Leicester, Leicestershire & Rutland's Living Well with Dementia Strategy 2019-2022 [7]

Identifying key people

From July to September 2022, we contacted and spoke to dementia services staff, service managers and professional staff including:

- Age UK
- Voluntary Action South Leicestershire (VASL)
- Admiral Nurses at University Hospitals of Leicester NHS Trust (UHL), Charnwood and Rutland
- Community Manager, Leicestershire Partnership Trust Mental Health Services for Older People Memory Service
- Key members of LLR Dementia Partnership Board
- Service Manager Carers Centre
- Meaningful Activity Service Lead UHL
- Somali Development Centre

[4] https://www.lsr-online.org/jsna.html

[5] https://www.leicester.gov.uk/your-council/policies-plans-and-strategies/public-health/data-reports-and-strategies/jsna/adults-joint-strategic-needs-assessments/dementia/

[6] https://ris.rutland.gov.uk/kb5/rutland/directory/results.action?adultchannel=3_3 (accessed January 2023, link now lapsed)

[7] https://resources.leicestershire.gov.uk/sites/resource/files/field/pdf/2018/12/24/LLR-Living-Well-with-Dementia-Strategy-2019-2022.pdf

Focus Groups

From July to November 2022, we attended through the voluntary sector and private organisations; Carers Support Groups, Memory Cafés, Day Services, Post Diagnostic Services, Drop-in Groups and Activity Groups. (See appendix 1 & 2 for questions and appendix 3 for the list of focus group meetings).

Semi-structured interviews were carried out between June – November 2022 to enable people to talk more freely about their experiences. (See appendix 2 for proposed conversation-initiating questions).

A survey was publicised widely through stakeholders' and Healthwatch websites, social media and was also available in hard copy format for 8 weeks through October and November 2022. The survey was in two sections: one section for people with memory problems and the other for the relatives, friends, carers of people with dementia. The survey also facilitated free text responses.

This mixed method approach meant that we gained useful and relevant contextual information, numerical data and in-depth details about people's experiences of living with dementia.

In all, we spoke to 34 people in semi-structured interviews, attended 36 different focus groups speaking to 356 people and collected 124 survey responses.

Ethical Considerations

Groups and individual interviewees gave their informed consent for us to record their feedback and reproduce it anonymously in this report. Participants were informed that they could withdraw from the discussion or retract any feedback already given. Although the majority of individual interviews were virtual, those that were face-to-face were conducted by 2 interviewers who had tested negative for COVID-19 and were fit and well.

Main Findings

Analysis and findings of focus groups, in-depth interviews, dementia survey and free-text responses

124 people responded to the survey in total but not everyone answered all of the questions and so what is presented is the results from people who did answer that question. All analysis has been completed as counts rather than percentages because of the low numbers as percentages could be misleading by attaching more weight to the findings than the actual numbers suggest.

Table 1. Respondents were asked to state whether they were responding as a person with dementia or as a carer.

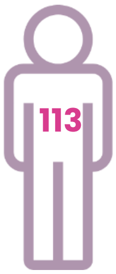
Counts Respondents	Total	Please tell us where you live:			
		Leicester City	Leicestershire	Rutland	No response
I have dementia	11	7	1	2	1
I am a carer for a person with dementia, or have cared for someone in the last 5 years	113	40	56	15	2

Living with Dementia - People with dementia

There were low numbers of returns for all areas from people who have dementia. The analysis is shown as counts rather than percentages because of the low numbers. Percentages could be misleading by attaching more weight to the findings than the actual numbers suggest.

Please tell us whether you are a person with Dementia or a carer?

I have dementia



I am a carer for a person with dementia or have cared for someone

Responses from people with dementia

Demographics

Age range

45-64	3
65-74	5
75-84	2
85+	1

Ethnicity

White British	8
White, other background	2
Mixed ethnic group	1

Diagnosis and Information

Can you tell us how long you have been having memory problems?

Have you been given any information about what sort of support is available and how you can get it?

After diagnosis did anyone explain the diagnosis and what you might expect to happen next?

Yes 1

No 8

Don't know 1

Difficulties in accessing information emerged as a major theme throughout the data analysis including the young onset support groups. Both people with dementia and carers expressed disappointment and frustration at the lack of information about support and services available following diagnosis.

It was a massive shock being told I had dementia and that nothing could be done. We were just left to get on with it and find our own way.

We were given very little information about the diagnosis or where we could go for help. It was only months later that we had contact with Age UK that we got any help at all.

Help with applying for Personal Independence Payments (PIP) as we have been turned down. Help with finding what is available for a younger person with dementia, emotional support for my husband. It is still early days so we are very much at the beginning of the process. Any information, practical help around this would be helpful.

Information given was very poor, we were given a leaflet to ring the Alzheimer's Society.

Found my own support thanks to the Shuttlewood Clark Foundation and the activities and support offered at Ulverscroft Manor for people with young onset dementia.

7 of the 11 respondents were confident about accessing information online and 4 were not. Of these, 3 said they would welcome support to learn how to use technology.

People with dementia also spoke about their need to feel they were not alone in this situation and wanted be able to meet with other people in the same situation. This was particularly so for those with young onset dementia who wanted to be able to share experiences and receive peer support.

Having someone to talk to who is going through the same thing and who understands what it is like is really helpful. It makes you feel less alone like you are the only one. That is why this group is so important. It means we can talk to each other, and our carers can talk to each other separately.

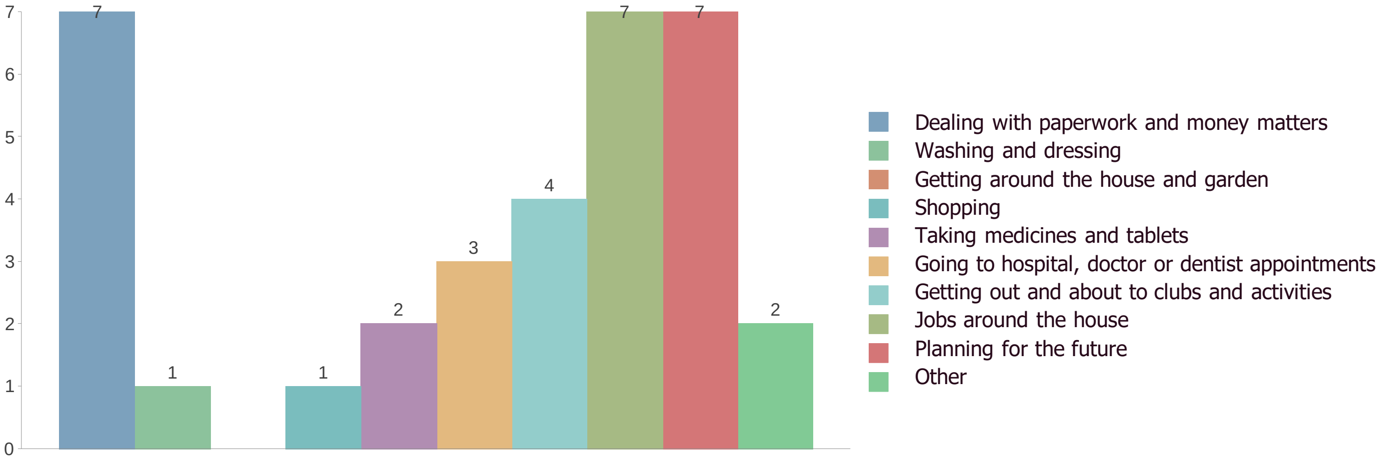
Due to the lack of support and medical intervention, B became very depressed and withdrawn. He didn't have anyone to talk to about his diagnosis and because he didn't know anyone else in his position. He could not relate to anyone with a diagnosis of dementia as they were so much older than himself. We finally found a group at Ulverscroft once a week to play Boccia and really enjoyed this. Although he had deteriorated by this time, we both enjoyed attending and it was good to be with people of his own age.

The idea of a 'hub' was raised by some as a means of people being able to get information, get help with the myriad of forms and applications they need to make and a way of making social contacts. Such a model, it was suggested could also provide a means of people being able to maintain and share skills. One being around technology.

It would be great to have a dementia hub for people in local villages rather than having to travel. Could 'warm hubs' be dementia friendly?

Help and Support

Do you need help with any of the following? (please tick all that apply)



Do you think you are getting the help you need?

6 **Yes**

4 **No**

Who gives you the help that you need?

Family 10

Friend 1

Carer 1

Help and support was almost wholly provided by family carers and was largely of a practical day to day nature such as dealing with paperwork, benefits and getting out and about.

Several people spoke of how difficult it was for their carers and wished that there were more activities available on a more regular basis that they could attend themselves in order to give their carers a break. However, transport was raised as an additional barrier as many of those attending were no longer able to drive to activities.

Practical activities were valued highly. Many were physically fit and active and enjoyed groups which involved playing games such as boccia and activities to keep the brain active. Men and women in sheds and the garden group which enable them to maintain or learn new practical skills were valued.

People with dementia at the young onset dementia group felt very strongly about the need for some sort of training/counselling for them and their carers following diagnosis, not only to cope with the diagnosis and its implications but also to help them develop strategies for living well with the condition.

Responses from carers

Demographics

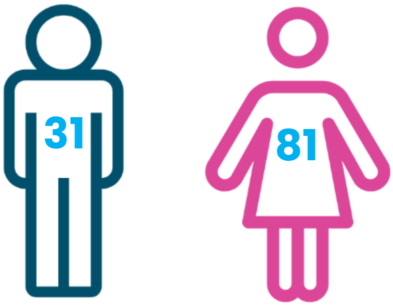
Age range

Under 45	1
45-64	46
65-74	23
75-84	37
85+	4

Ethnicity

White British	96
White, other background	5
Mixed ethnic group	2
Asian/ Asian British	8
Prefer not to say	1

What is your gender?

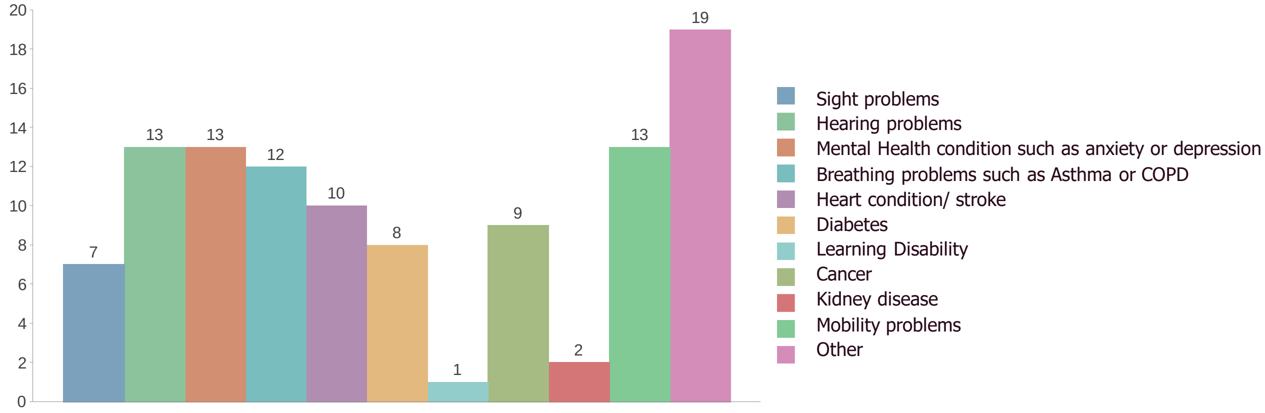


Male

Female

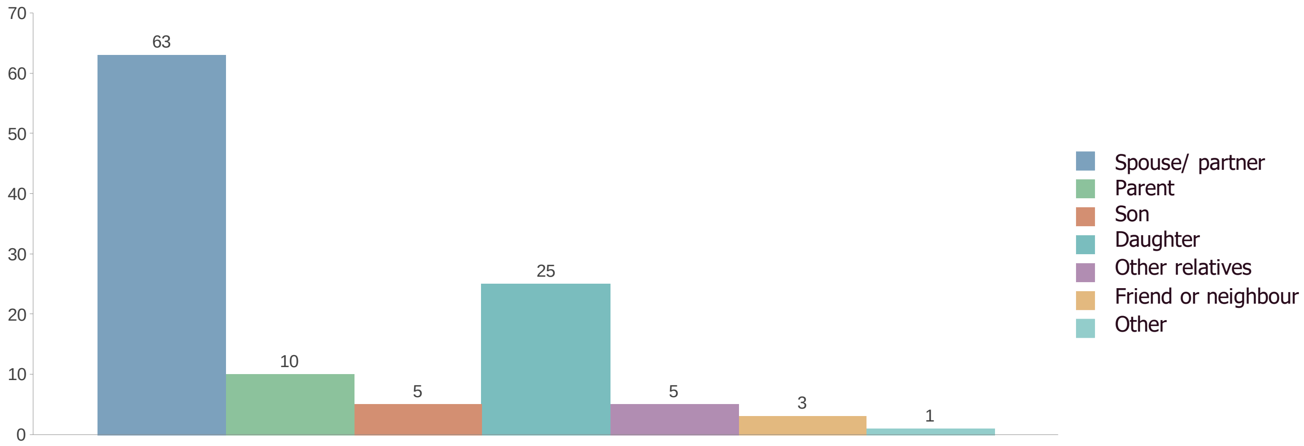
1 - No response

Do you have any long-term conditions? (please tick all that apply)

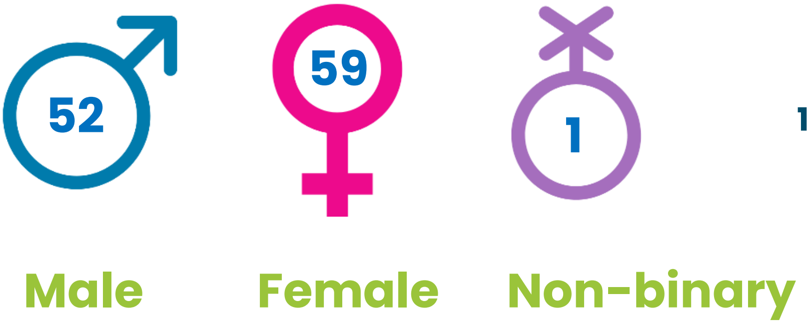


Other conditions included cervical spondylitis, hypothyroidism, arthritis, osteoarthritis, rheumatoid arthritis, leukaemia, fibromyalgia and stomach ulcers.

My relationship to the person with dementia that I care for is:



What is the gender of the person you are caring for?



1 - No response

Where does the person you care for live?

1 - No response

What is their age band?

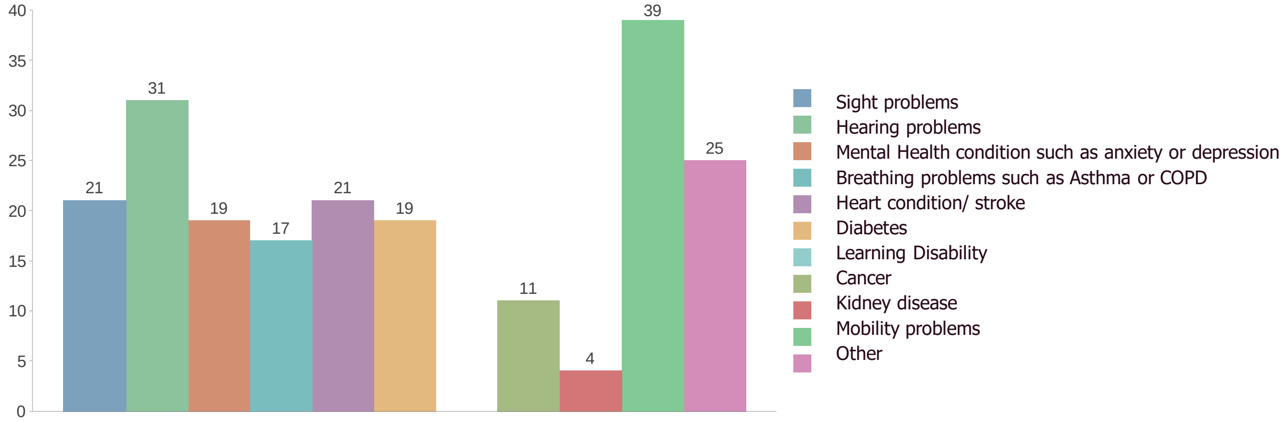
45-64	3
65-74	18
75-84	60
85+	32

What is the gender of the person you are caring for?

Male	52
Female	59
Non-binary	1

Does the person you care for have any other long-term conditions?

(Tick all that apply)

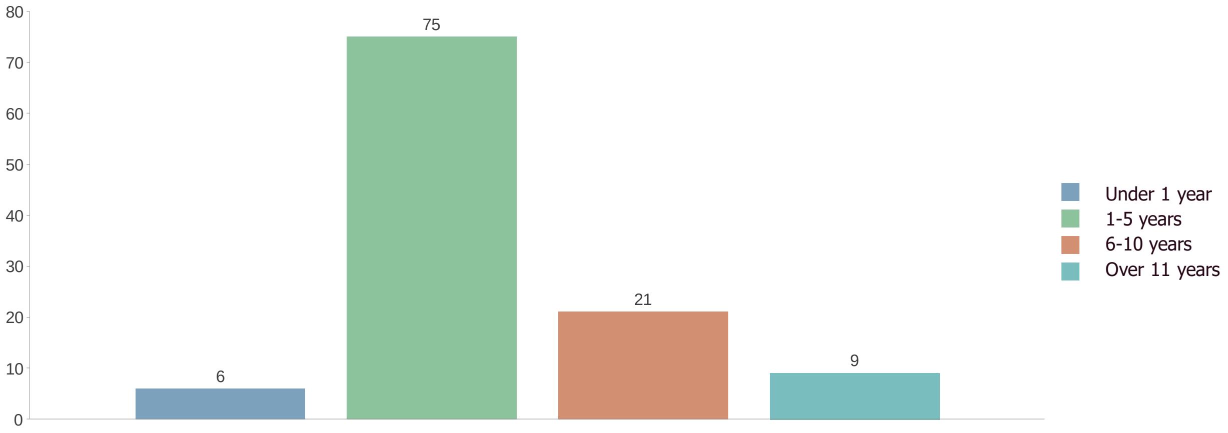


Other medical conditions of the cared for person include stroke, Parkinson's disease, atrial fibrillation, osteoporosis, blood pressure, cataracts, osteoarthritis and incontinence.

The demographic information provided shows that a high proportion of carers are older people 65+ looking after older spouses with both cohorts having a range of other health conditions. This was of concern to some carers.

> ***I am disabled myself. I have a heart condition and poor mobility, so I need quite a lot of practical support myself. At the moment it is a case of helping each other and getting on with it as best we can. I don't know what would happen if one of us becomes incapacitated through our other conditions. Who would care for who?***
>
> ***My concern is that my health is much more fragile than my wife's, so I am more likely to go first. I do not know how she will be cared for if that happens as we have no children who can step in.***

How long have you been aware of their memory problems?



Diagnosis

Many interview participants 27/34 recognised early signs of memory loss up to 5 years before they sought help, but more commonly it was between 1-2 years. Most noticed subtle (at first) changes in memory, behaviors or personality but did not act upon them as they were unfamiliar with the signs of dementia. Rutland respondents reported that there seems to be a 'grey area' between the natural forgetfulness of ageing and the recognition of the onset of dementia.

I knew her memory was failing for 2 years; she was a nightmare for losing things. She didn't say anything but finally she acknowledged it herself and went to the GP.

I did not realise there were memory problems as mum suffered from depression and the symptoms were confused.

2 years ago, I noticed my husband was starting to forget things like where he left things. This started to get quite irritating, and we started snapping at each other so knew we needed to get help.

Has the person you care for been formerly diagnosed with dementia?

106

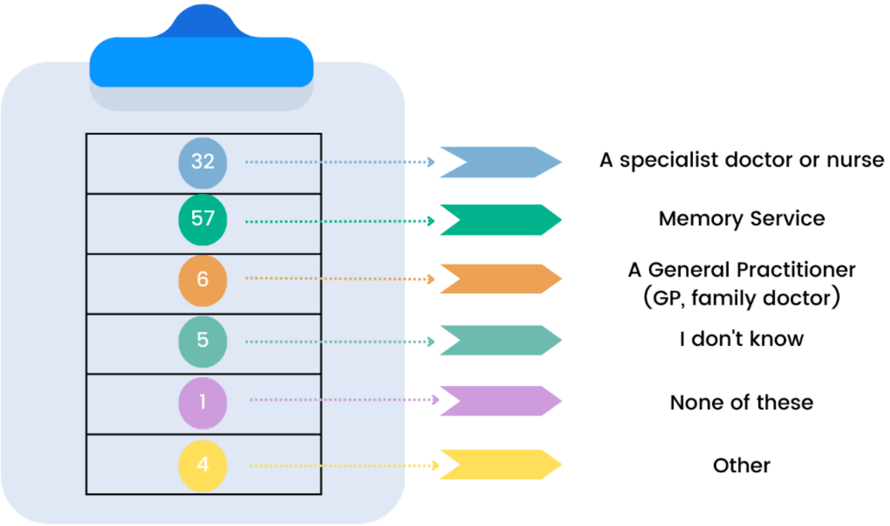
Yes

7

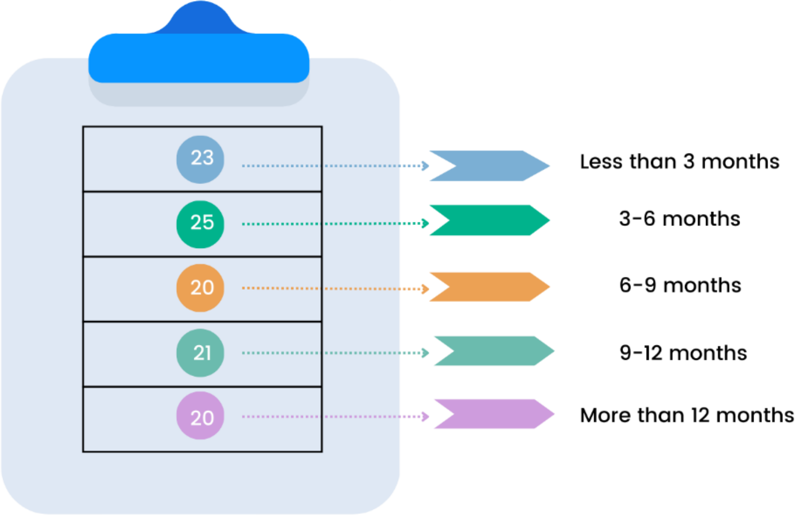
No

From the 7 people who said they had not received a formal diagnosis; one was from Leicester City and 6 from Leicestershire.

If yes, was the diagnosis made by:



From the time you first contacted a professional about your concerns for your/the persons memory, how long did you have to wait for a diagnosis?



Were you happy about the length of time it took to get a diagnosis?

The survey responses, focus groups and interviews all highlighted a marked variation in experience of getting a diagnosis. Most interview participants contacted their GP first. This presented challenges for many. 14 respondents raised issues in getting either a GP appointment or a subsequent referral to the memory service.

It was lockdown when I contacted the GP. It took over a week of trying to get through to the surgery ringing every day. The GP did a test over the phone and although my wife did well on the test (as it was a lot of number tests which she was good at), he did refer her to Glenfield where she was diagnosed on Zoom, but this did not include a brain scan. We were told the diagnosis and told to go back to GP for follow up which never happened.

Others spoke about their experiences of getting the GP to take their concerns seriously, and about their GP seeming not to fully recognise their concerns. Participants in one focus group suggested GPs are slow to diagnose dementia and, as such, are seen as gatekeepers preventing access to diagnosis and support services.

Went to the GP several times. Lots of tests were done but no diagnosis for a long time. Finally referred for a brain scan and after 9 months was diagnosed with Alzheimer's but then discharged from the memory service with no follow up.

My husband went to GP first aged 59 and went several times over the next 3 years but GP said he was too young to have any type of dementia and diagnosed depression. Only at the age of 63 after several months of appointments and scans, he was finally diagnosed with young onset dementia. He died at the age of 68.

The average waiting time for the memory service diagnosis was between 3-9 months although there is a substantial number who have waited between 9 to over 12 months. In Rutland only 2 respondents received a diagnosis within 3 months.

Seven people across LLR, although seen by the memory service several months previously have yet to receive a formal diagnosis.

We do not have a diagnosis yet. We have been to the GP but have had no success in getting a proper diagnosis, but the GP says it is dementia. It would be good to know what is available and what will happen in the future. Age UK have been helpful and we can access the support group they run once a month.

There was an almost 50-50 split between those who were satisfied or dissatisfied about the length of time to get a diagnosis. Delays in diagnosis we were told creates a feeling of being left 'in limbo', without access to any advice, information or support. This was described as, ***'Having your life put on hold.'***

The diagnostic pathway and the giving of the diagnosis were variable:

- Most people were seen in person in the Memory Clinic and received a brain scan
- A small number were diagnosed via Zoom and did not receive a brain scan to confirm the diagnosis
- A smaller number received a diagnosis over the phone and again did not all have access to a brain scan
- A few had a brain scan whilst an impatient in hospital for other reasons and were diagnosed on the basis of the scan only
- A few had a diagnosis by the GP with no input from the memory service

From what carers told us, the way in which this was done appears to have affected the perception of the quality of service experienced.

We went to the GP several times about mum's depression. To be honest it took us such a long time to get a diagnosis for depression and we were pretty preoccupied with this aspect so didn't even think about dementia. The dementia diagnosis came about because mum had a scan at LRI following a fall and a bump on the head. The scan apparently showed up dementia but we don't know which type as we were not told and were not referred to the memory service. Not had a consultant or any other follow up from the hospital or the Dr's surgery.

Several people expressed disappointment at being discharged from the memory service with no follow-up or ongoing support. The Community Manager of the Memory Service informed that they provide a diagnostic service only, with all patients referred to their GP for a follow-up, which in many cases did not occur. Patients and carers were not informed about this and consequently felt they had been **'left to get on with it'.**

> ***He attended the memory clinic twice but then was discharged and that was it.***
>
> ***No nothing at all from anyone, we have never heard from either the memory clinic or the GP. My daughter was the one who looked everything up on the internet and followed up by contacting Age UK and finding out about the memory café and the carers group. We also found out from them about the Attendance Allowance.***

Information

Did you receive any information about dementia before receiving a diagnosis?

Yes	No	Don't know
25	76	10

After diagnosis did anyone explain what you might expect to happen next?

Yes	No	Don't know
34	65	7

Were you given information about support that is available and how you can access it?

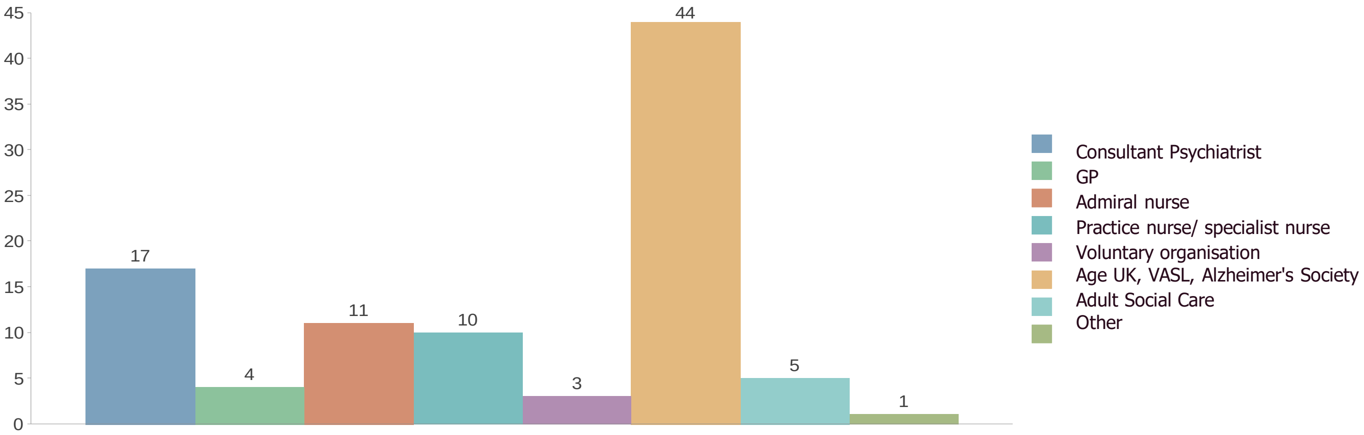
57 Yes

52 No

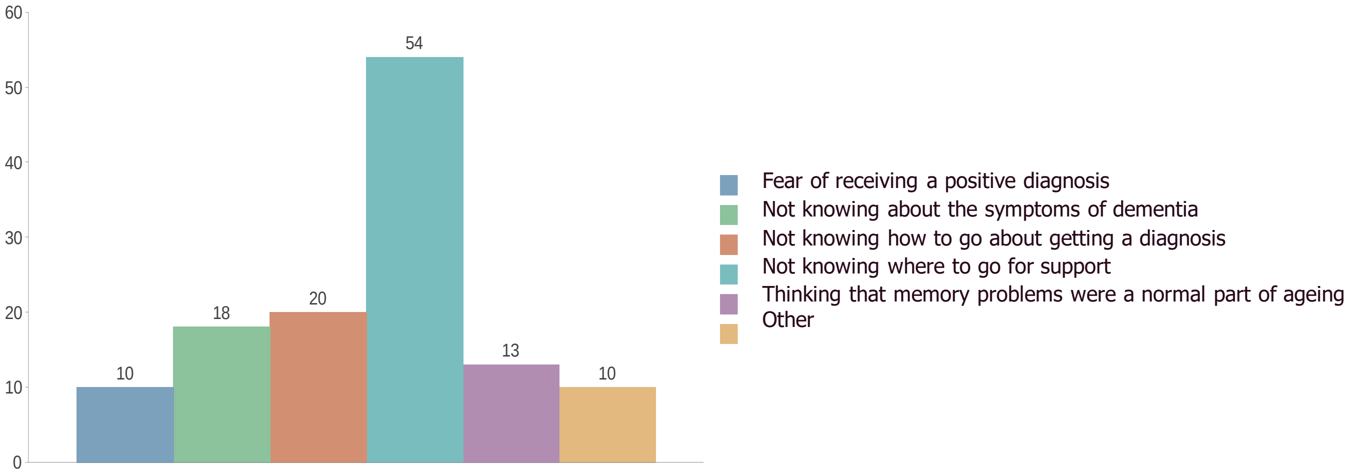
3 Don’t know

1 - No response

If yes who gave you that information? (please tick all that apply)



What might hinder you from seeking help or support? (please tick all that apply)



Are you confident accessing information support online (using a computer, mobile phone or tablet)?

89
Yes

22
No

If you answered no, would you like to receive support to learn how to use technology?

7
Yes

14
No

The need for information and the lack of it was mentioned throughout all stages of the dementia journey. There was also mention of the need for public information about dementia to enable detection of the early signs and to help people understand the illness and how to care for patients with it.

We need to aim to inform those entering the dementia care phase what support is available. We need to ensure there is easily accessible information about dementia, how to get it diagnosed, what to do with people with dementia who resist diagnosis and what options are available for treatment, care and generally managing the patient before and after diagnosis.

Almost all the interview participants talked of their need for information and support at the time of and following diagnosis to help them come to terms with the diagnosis and help prepare them for the future. There were comments from those who felt they had not been given any information:

I would like to know more about the condition dementia as it is very difficult to cope with sometimes and I do not know how to handle certain situations I have been given no help on the at all. My GP does not even have it on record that my wife has dementia even though she is on tablets for it.

It has been very difficult finding out what services are available. It is a do it yourself service and difficult to find out what is available in our area or whether we are entitled to access it.

I have no information about dementia. My health is suffering. With no friends or family to help I simply do not know what to do.

Sources of information were varied:

Printed

Some were provided with written information which was considered useful immediately and available for reference in the future but not necessarily as much as they needed. Others considered they had been given too much information:

We did have a booklet from the Alzheimer's Society and this was quite helpful in terms of the disease but as far as support services go, we more or less had to do that for ourselves and had no help or information at all.

Too many leaflets – not enough personal contact. Too much going on caring to be able to read all the leaflets and follow up on them.

In-person and professional

Many considered that this information in the first instance should be given in person by a professional who has specialist knowledge of the dementia journey and of the support services available. It was suggested that this should be provided shortly after diagnosis when the initial shock of the diagnosis has eased and when information is better absorbed.

Many valued the information provided by the Admiral Nurse Service:

> ***Admiral Nurse gave us information and leaflets and went through them which was very helpful in helping us understand the diagnosis and progression of the condition. She (at UHL) told us about and helped us organise support and this was great and supportive.***
>
> ***Frankly, I don't know what we would have done without the Admiral Nurse help we would not know where to go otherwise as we were given no information whatsoever.***

Group courses

Carers spoke of their positive experiences with the Alzheimer's Society Care Information and Support Programme (CriSP).

> ***I attended a CriSP course which was excellent. I think this should be available to everyone with a new diagnosis of dementia.***
>
> ***Went on course for carers run by Alzheimer's society which was excellent, and we learnt a lot about dementia and Alzheimer's so nothing has been a total surprise.***

Such face-to-face programmes, including the Age UK Post Dementia Diagnosis Information Session, were highly valued by those who attended and more would have liked the opportunity to attend.

Voluntary sector

Age UK and Voluntary Action South Leicestershire (VASL) were described as being both information givers and providers of a more practical and helpful nature in terms of assistance with form-filling, benefit claims and, sometimes, telephone calls to service providers on their behalf. They were highly valued by the person with dementia and carers and described by many as being the only support they received.

It was a shock at first but now we are used to it and grateful for the help we received from Age UK to help us get benefits and access memory clinics.

We know what to do if we needed more help as we receive regular newsletters from Age UK, VASL and the Alzheimer's Society and would go to them for advice.

Progression of symptoms

A few carers spoke about their need to be better prepared for dealing with the future and the deterioration of the person's condition.

I want someone to talk to me honestly about the end stages of dementia. I want a social care plan in place before-hand but no one wants these conversations and no one wants to make a plan.

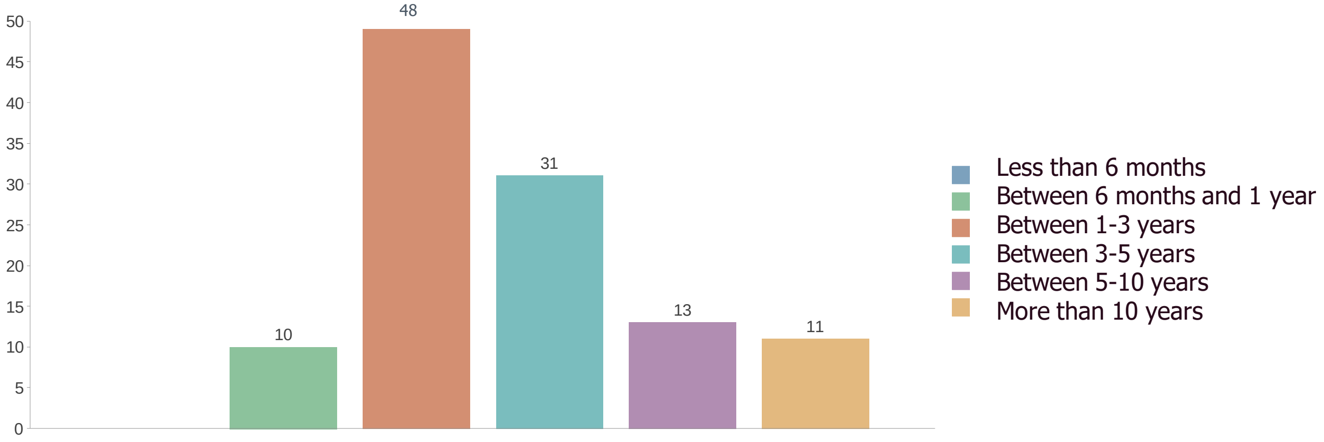
Internet

Most carers said that they were able to use the internet for accessing information but a few commented that it was family members who searched the internet for information and without this support they would experience digital exclusion.

Comments were made about having to look online for everything and how difficult this can be for someone without those skills.

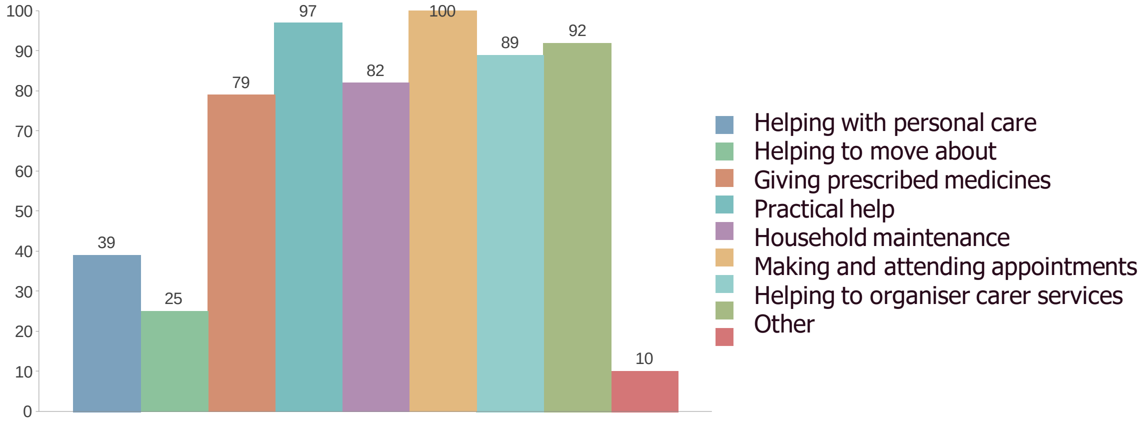
They say you should go online to sort things out but 75% of over 75's don't go online. They don't recognise that older people don't have the technology skills. I did operate a computer at work but it was big and used to break down so I did manual and computer records. I have a computer now but with all the changes they put on each time, its leaving me behind and I can't catch up. I can use a telephone and talk to anyone. Everybody should have a landline- but not a mobile. They fail to do anything about this – that not everybody has a mobile.

How long have you been caring for the person with dementia?

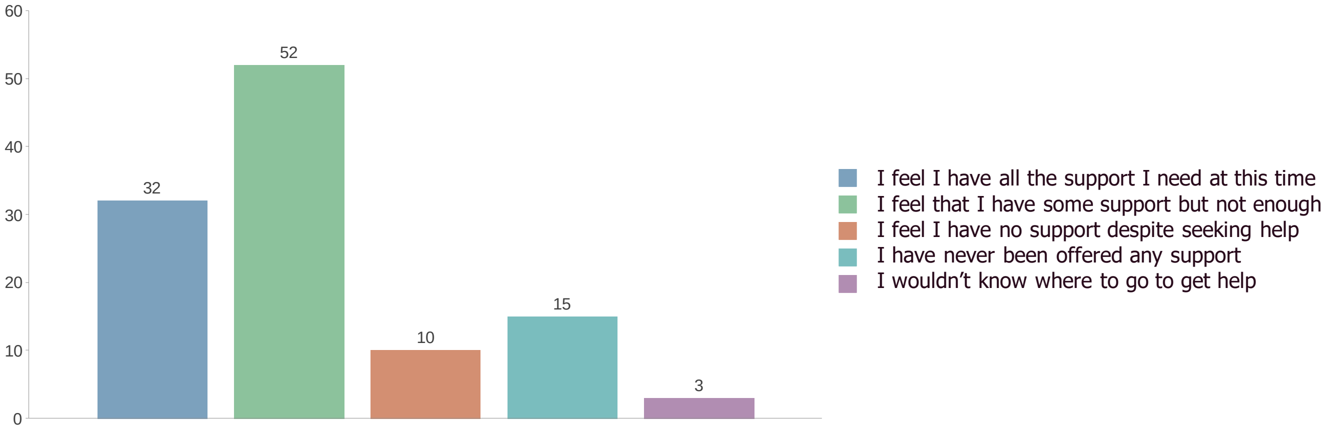


What kind of things do you do for the person you care for?

Please tick all that apply



How well do you feel supported in your caring role?



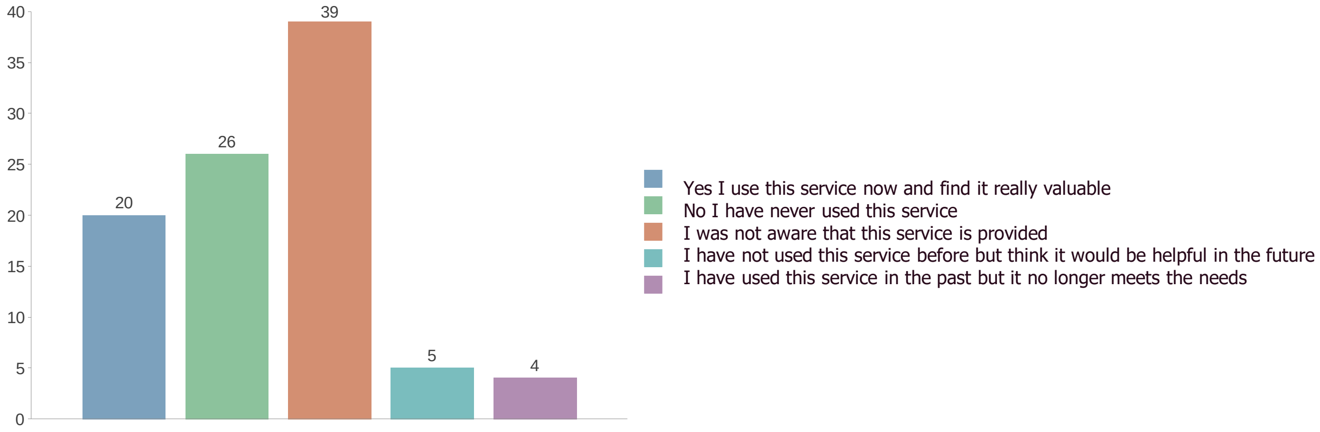
Whilst most people have been caring for between 1-3 years a large group have been caring for between 3-10+ years and most of those are older carers providing support with activities of daily living. Many carers were happy to continue with this level of support while they were able, but it must be noted that only 32 of the survey respondents said that they received all the care they needed, whilst 78 thought that the support was not enough or non-existent.

The carers do washing, dressing and giving prescribed medicines. Everything else is down to me whilst doing a full-time job

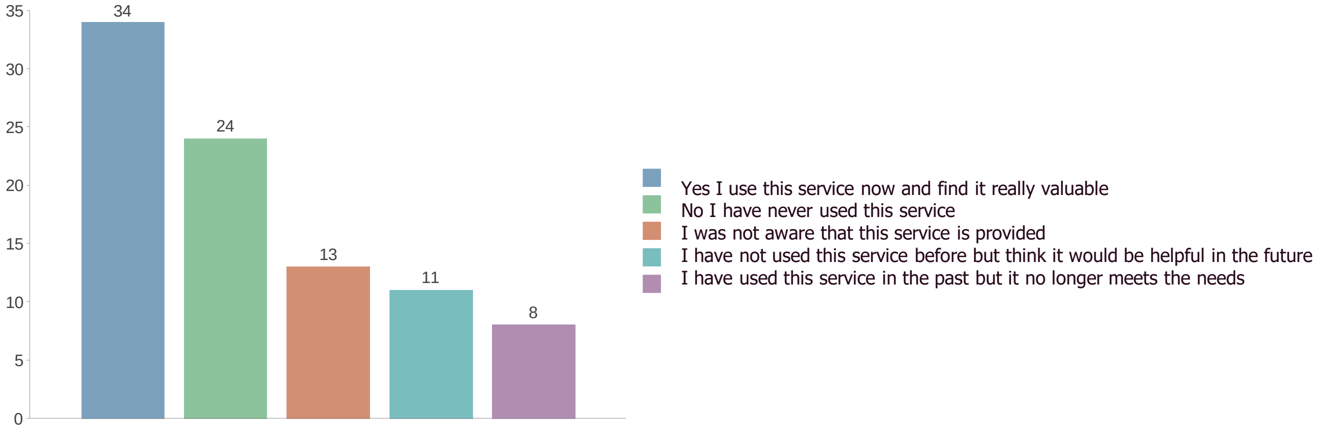
As far as support services go, we more or less had to do that ourselves and had no help.

Services currently accessed

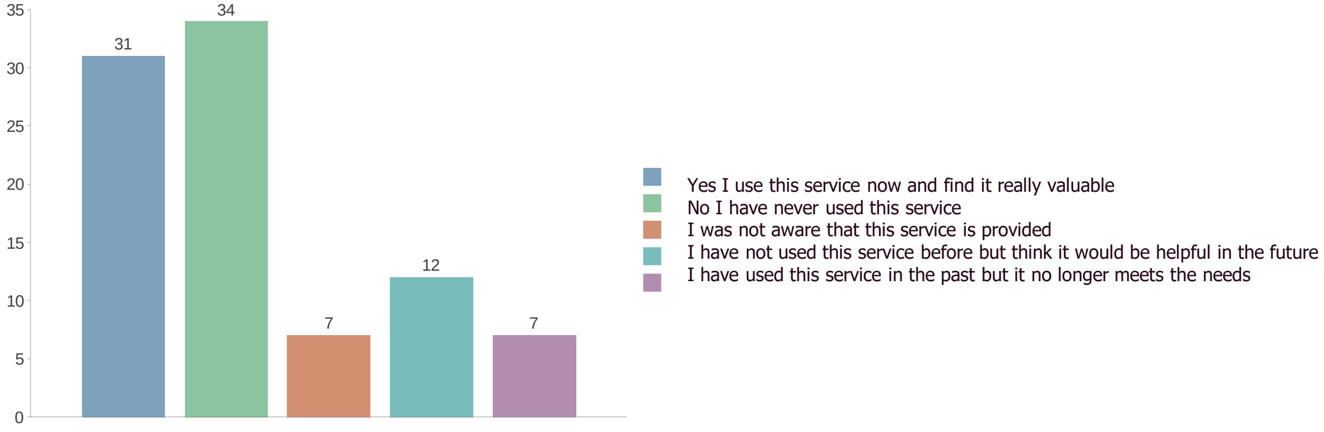
Admiral Nursing (provides specialist support for carers)



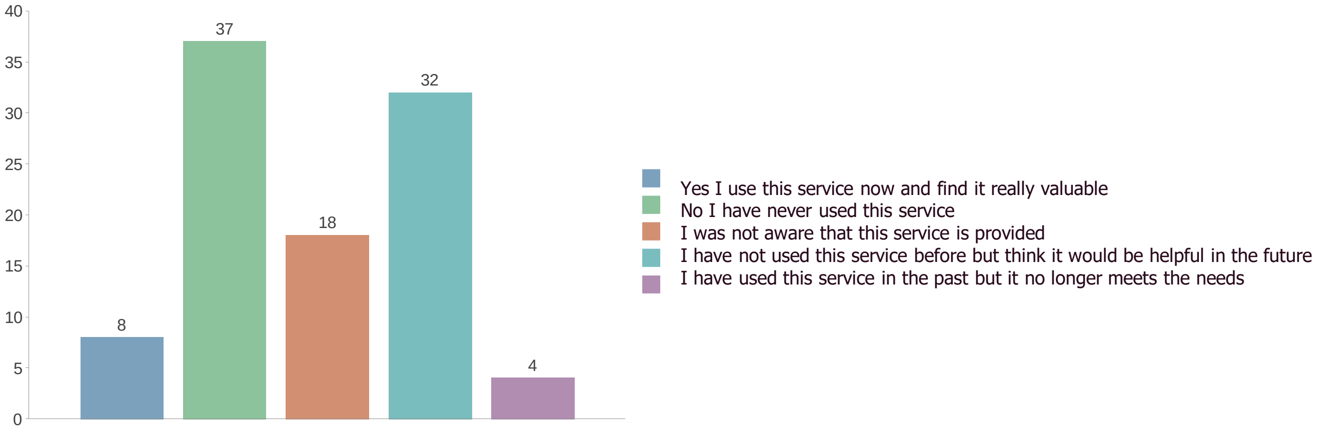
A carers advice/information service



A carers support group that you attend

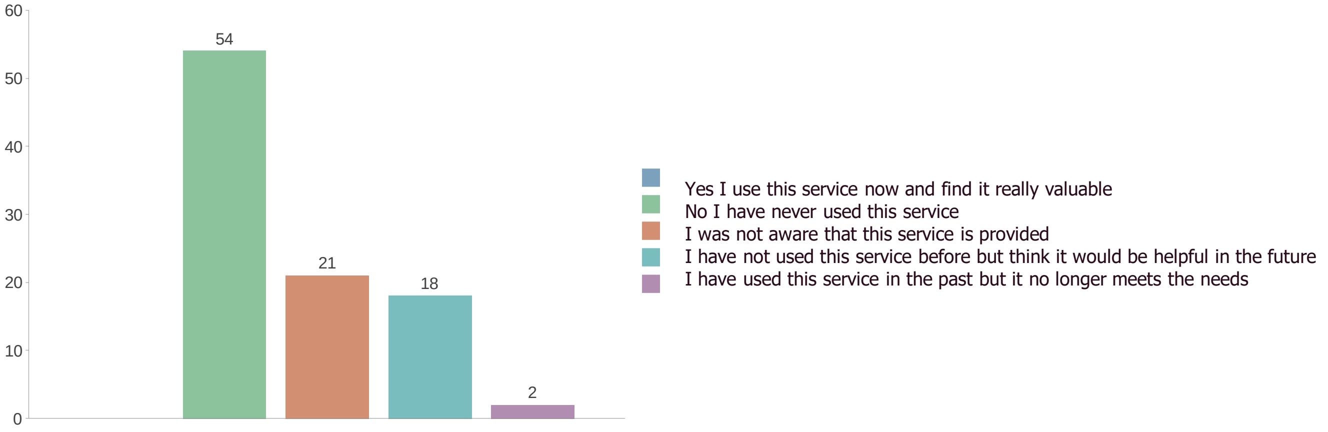


Someone to sit with or take them out for a short period or a few hours out whilst you do other things

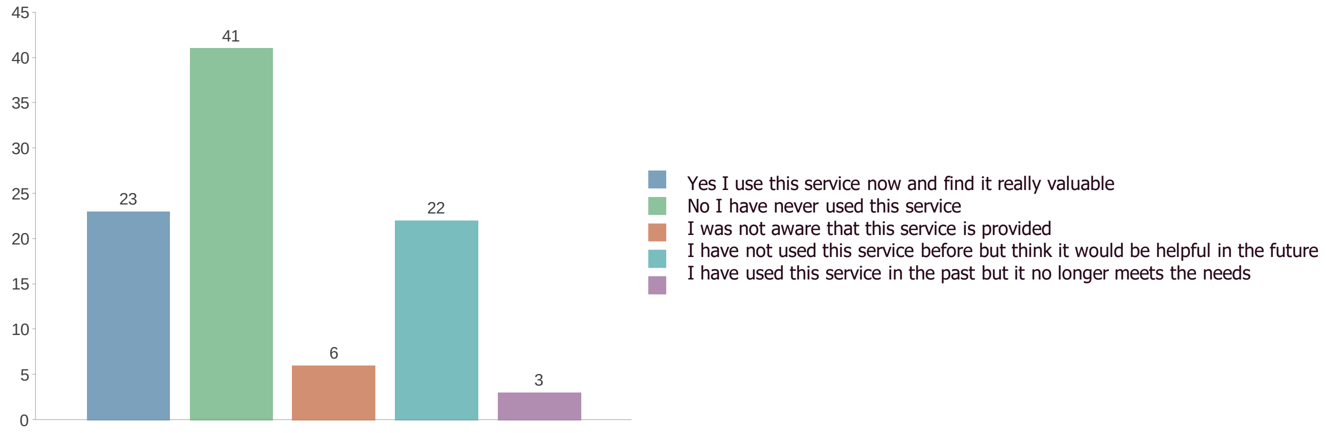


A night time sitting service to help you get a night’s sleep

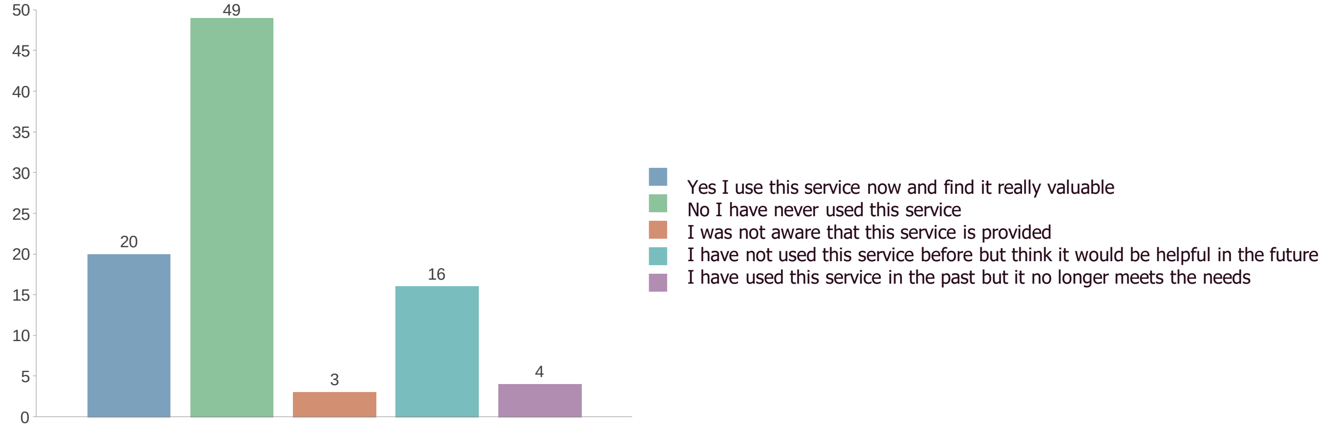
A night time sitting service to help you get a nights sleep



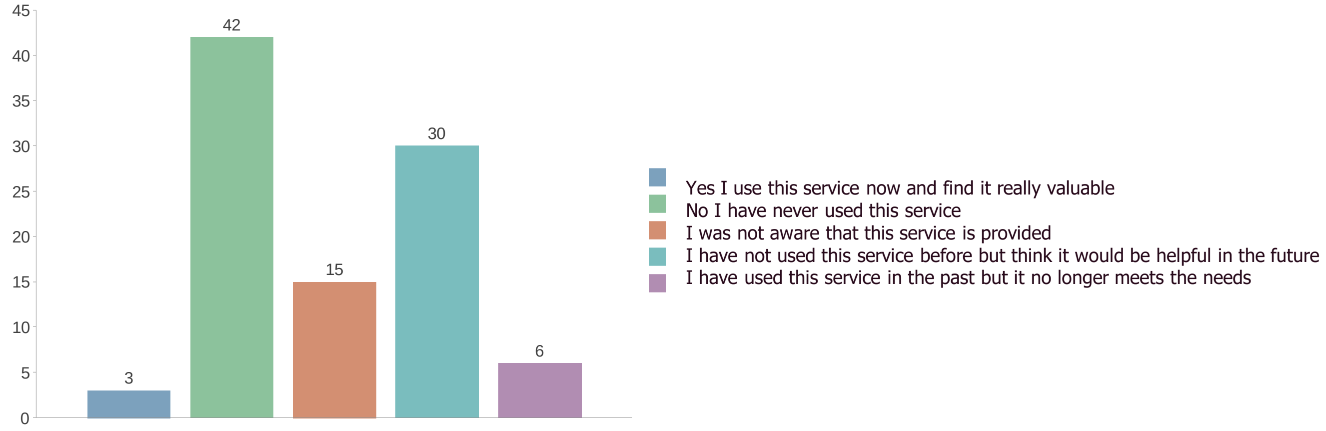
Day care centre



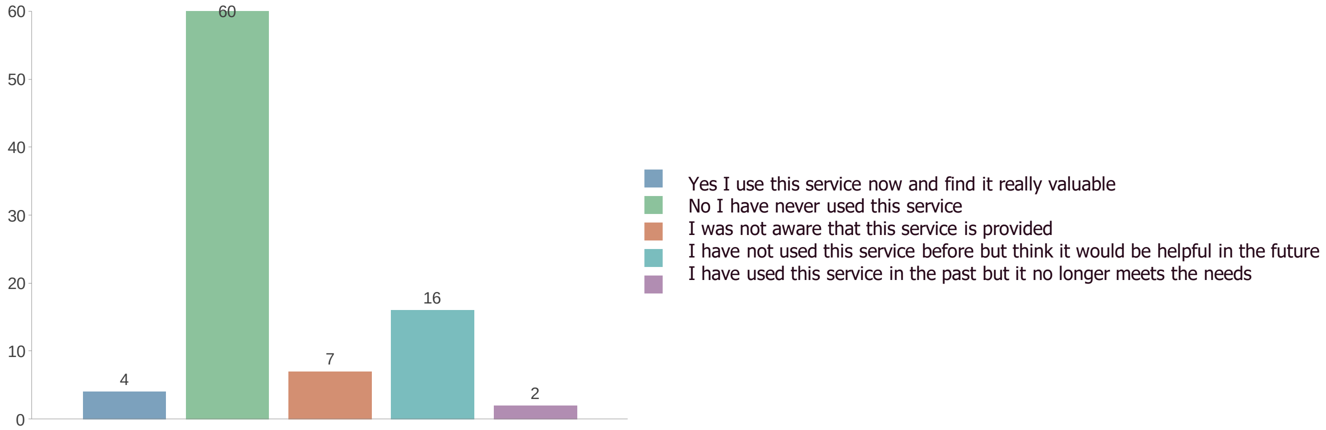
Help with personal care in the home



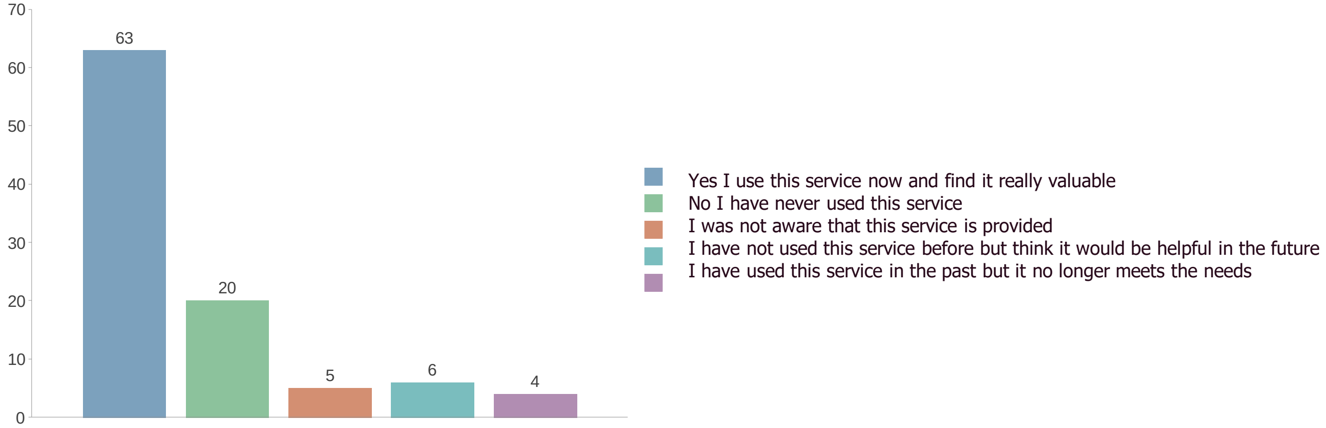
Short breaks when the person is cared for away from home



Meals including luncheon club



Activity groups for the person with dementia such a time in nature walks, memory cafés etc.



Are there any services not listed that you would like to have access to if they were available?

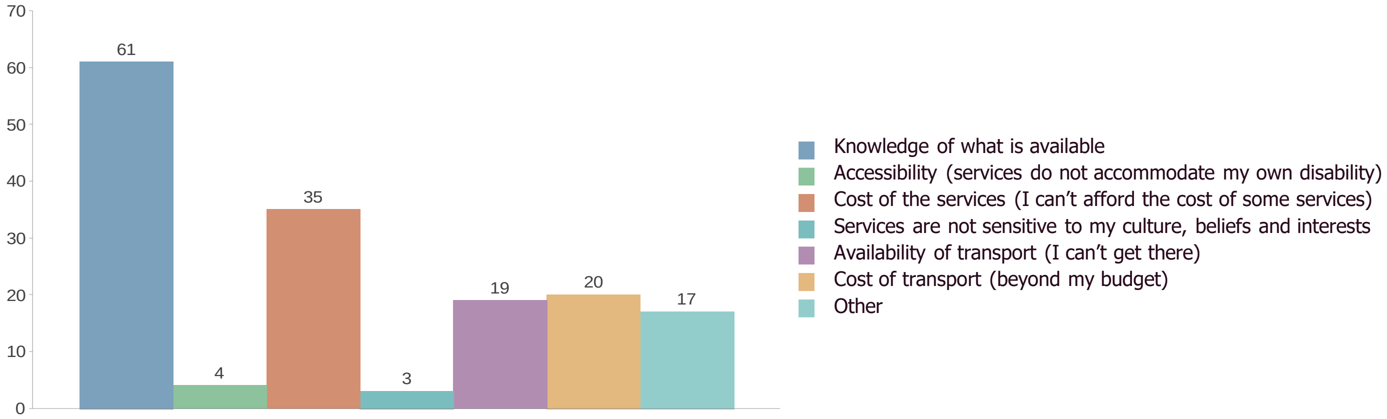
16 **Yes**

41 **No**

52 **Don't know**

When asked, most carers reported using services such as the memory cafés, carers support groups and activity groups run mostly by voluntary / charitable groups. A few accessed a day care centre and/or had help from professional carers. We do add the caveat that the people we spoke to could still access these services either independently or with assistance from socially mobile carers or family members.

If you don't access any of the services but would like to what prevents you from doing so?



The day services that we visited accommodated mostly people with more advanced dementia where support needs are greater and where transport is included. Some families were financing this themselves so did not go through Adult Social Care for support.

However, 61 survey respondents reported barriers: lack of knowledge of what is available; inability to contact Adult Social Care; transport; and poor affordability of support.

The services most valued are the activity groups, (for example memory cafés, young onset support and activity groups) and the Admiral Nursing Service. There was universal praise from families receiving support from the Admiral Nurse Service which has the specific remit of supporting family carers providing:

- Clinical advice/support about the progression of symptoms
- Guidance for managing the signs and symptoms
- Personalised one-to-one contact
- Signposting to services
- Benefits advice
- Emotional support and a named person at the end of a phone or email at a time of crisis

Focus group discussions emphasised the inconsistencies in Admiral Nurse service provision with some able to access it and others not:

> ***I am happy with the support I receive and consider myself lucky to have the help I have. I definitely could not have done this alone and am very grateful that we were able to have the help we have from Stuart the Admiral Nurse.***
>
> ***We know that not everyone has this, so we are very grateful for the help we have.***

Barriers to accessing support

Although both carers and patients enjoyed attending the Memory Cafés together, we received comments requesting a facility for just carers so they could enjoy some respite but still talk to others in a similar situation. The main barrier for this was the impossibility of leaving the person with dementia at home and unattended. There was a suggestion that carers' support groups should take place at the same time as patient activity groups to overcome this.

Other barriers included;

Infrequent meetings/activities
I attend some groups with dad and find these beneficial. Sadly, I would like to attend more but they are only once a month, I feel these services would be accessed weekly if available for many families.

Transport problems
I am not always available to provide free transport and my friend can no longer drive to the sessions.

Costs
Often told dad does not qualify for day care and will have to pay. He won't.

Bureaucracy
Respite care is a nightmare to arrange. Social services won't let you book respite more than 6 weeks in advance and holidays have to be paid for at least 8 weeks in advance. There are very few places that do respite, but I would only be happy if I knew my mother was safe somewhere whilst I am away.

Not knowing what is available
We don't really know much about services or what is available to us.

Patient reluctance
My mother wasn't keen on going anywhere out of the house and since COVID-19 she has been much worse and now accessibility would be difficult as she can't transfer.

Delayed diagnosis
Still waiting for hospital appointment and diagnosis. GP referred but still waiting and we cannot get any help without it.

Praise for services and staff

There was universal praise from carers for the groups and the staff and volunteers and genuine appreciation of the practical and emotional support given. At the groups we visited, we witnessed tremendous staff commitment, compassion and recognition of the difficulties of living with dementia. However, staff also appreciated that they are faced with high demand for the service and financial constraints, preventing them from meeting the desire for more frequent group sessions.

Carers’ Health and Wellbeing

Several carers talked about the stress of caring and the toll this takes on their own health. Many feel that their own needs are overlooked and their efforts undervalued, they spoke of their loneliness in being a carer.

One specific concern highlights the need for acknowledgement of carers’ expertise with the patient:

> ***The doctor's surgery is useless. They just accept my father's assertion that he is fine and doesn't have any problems or need help. He doesn't remember he is not caring for himself.***

When asked how caring was impacting on their health and well-being, carers use the following terms:

Totally exhausted

Frazzled

I have no life at all anymore

It is a very lonely job which is why carers groups are so important

Not recognised

No one to talk to for weeks on end

Carers are not listened to as carers but we are still expected to do everything

What would help carers?

When asked about what professional help could address these concerns carers suggested:

- being listened to
- being included in discussions
- having their role valued
- acknowledging the toll of caring by having more respite services for carers.

The responses to the final question relating to help and support reinforces the assertion that because people are not accessing services does not mean that they don't need them. It is important to look beyond what is presented to the reality of carers' lives.

The following suggestions were made:

- *Some respite please*
- *Exercise/dance/craft/art/book group for carers*
- *Proper diagnosis including a brain scan, service disgraceful and not fit for purpose*
- *More support as a carer*
- *Information on how to handle situations when your loved ones condition worsens and how to handle it*
- *Support that would enable us to have a holiday*
- *Support I don't have to pay for*
- *Aids to help in the shower and technology for the bed and doors*
- *Extra day care*
- *Day care*
- *Posters in key places with phone numbers for social services and other services*
- *I need more reassurance and information of the help available*
- *Better help finding good care when you need it*
- *A lot more help and information*
- *A central hub where all the information is in one place would be very helpful*

When carers become ill

Do you have a plan in place for how the person you care for will be looked after if you are ill or incapacitated at any time?

41
Yes

68
No

The responses reveal that many carers are in the older age bracket but do not have a plan in place for covering their own ill health and potential inability to care.

> ***I (the carer) was in the hospital for two weeks in the Leicester Royal Infirmary my wife was left on her own. I thought she might be ok for a couple of days but apparently, my neighbour had to ring my sister-in-law in Manchester to come down to look after my wife as she was getting in a right state and very confused.***
>
> ***I have recently been in hospital for 5 days and have had to call upon a friend to care for L. I was very keen to get out of hospital at the earliest opportunity to get back to L. It made me realise I had to make some arrangement for the time that I might not be around any longer.***

Immediate short-term care is understood as being covered with family members, neighbours or good friends but long-term care is seen as problematic; more so if there are no immediate family members available:

> ***I often worry about who will care for me or him if anything should happen to us as my family do not live close by and I can't expect them to do much to help as they both work and my son has his business.***

This reinforces the need for advice and signposting to assist with making forward plans.

Ongoing care for people with dementia

Many carers spoke of ongoing social, primary, secondary and residential care for people with dementia.

Access to Adult Social Care Services

Over 50 comments were received highlighting the difficulty of contacting and securing help from Adult Social Care. Of those respondents that received a care package for the person with dementia, most said they were arranged as a result of a hospital stay rather than as a result of a request or assessment.

Carers mostly contacted Adult Social Care about,

- getting a day care centre place
- arranging respite care (for holidays)
- aids and adaptations in the home
- assessment for social care
- seeking advice and support in finding a care home

Carers' requests to Social Services were mostly prompted by their recognition that the patient's condition was becoming unmanageable. Barriers to accessing social care were stated as:

Telephone

It's very frustrating trying to get through to anyone on the phone

***Getting through, then being told they are only dealing with emergencies*.**

Administration

The form from County Hall (I think) never arrived. I had a letter saying they hadn't received my form and I should phone them on the number on top of the form. However, I haven't had the form, so I am at a dead end.

Affordability

Social services have and continue to be a nightmare to deal with. I have help in the home, but they will not fund him to go to a day centre which really helps me and him. I am having to find the money because he really enjoys going but it is a real struggle financially and I do not know how long I can continue to do this.

Delays in response

Mum was in hospital after a fall resulting in broken hip. I was not offered any help to look after her at home so I moved her into my home as I did not feel it was safe for her to be left alone. I could do with some help to get her up in the morning and put her to bed but so far have not had a response from social services after 9 weeks so I don't know if I will get any help or not.

Care declined

However social services have refused saying she isn't bad enough. if she is admitted to hospital though she may be eligible but they won't agree at the moment.

Not helping people with sufficient assets

We asked adult social care for guidance and support when we felt more care was needed. We were able to pay but felt a needs assessment and professional guidance would help us make the right decision. We were refused this support as the person we cared for had enough money to pay for support.

Service pressures

I could really do with some respite care but social services are only dealing with emergencies at the moment, so we don't know how to make this happen.

Waiting

I am still waiting for them to come and do an assessment for aids and adaptations which is about 7 months now, apparently, we are not a priority.

Told there is a wait of 13 weeks to get help in the home even through mum is in hospital.

We have been waiting about 3 months for social services to come and assess for grab rails and a stair lift. We have no idea when they will come. Everything is a waiting game. I sometimes feel at my wits end especially with the lack of sleep but if I don't go on I dread to think what would happen to R so I keep plodding on and waiting.

Some then approached Age UK and VASL for help. They in turn reported similar difficulties in getting a response, reporting waits of over an hour for the phone to be answered.

Primary Care

Ongoing mental health support

Accessing mental health and dementia support and advice once discharged from the memory service was a problem for many. Similarly, carers reported difficulties in getting a GP referral to specialist mental health care for patients whose dementia was progressing and presenting challenges such as non-compliance with medication, sleep disturbance and more aggressive behaviour:

We had a great service at first but once we were discharged from the mental health team everything stopped and we had no help at all.

Community Psychiatric Nurse (CPN) was involved, and on the night before the Queen's funeral, the CPN contacted me and told me that my mother was at high risk of suicide and needed to be kept an eye on. She promised to visit the following week but has not been seen since. I feel I have just been abandoned by mental health services and have no idea when or if they are going to visit again or continue with my mother.

My husband often calls out that he wants to die, to kill himself but no one is addressing this. He is due to see a neurologist but when? He doesn't sleep through the night and most nights wakes around 1am, 3am and 5am. I am frazzled most of the time but go on as what else can I do.

Ongoing physical health care

Of 34 people asked in interviews whether their relative had been reviewed annually by their GP practice in order to monitor their dementia and care needs, only 6 respondents believed this had happened. A small number of people reported good experiences from their GP practice:

No, but GP practice are very good if we need any help. We don't really bother them at the moment as we are managing.

Yes in this respect the GP practice has been very good and keeps an eye on us.

Most people talked about difficulties in getting GP appointments and some said that patients diagnosed with dementia do not get their physical needs adequately addressed:

We have had a terrible service from our GP and I believe the care or lack of it for my father amounts to neglect. The GP more or less says that everything is down to the dementia and doesn't want to treat any physical symptoms. It is very bad. My father has a number of health conditions that are not being dealt with.

Having very little support from the GP or memory service. It's been an uphill struggle to find any help at all. Everything is a battle. It is so difficult to get the GP practice to even look at other medical issues because mum has dementia. It is disgusting to be honest. They are just not interested in helping us at all. It is like you are just cast adrift.

No, I have had little contact from the GP surgery, and they certainly don't contact us to offer any help at all. It is such a hassle getting through to the surgery that I don't do it unless I absolutely have to so this is not likely to change, and I will have to carry on working my way through the minefield

Getting the surgery to treat any other issues is a real challenge. They are very reluctant to see her. She had a chest infection about 12 months ago and was quite unwell. I had to keep ringing and be persistent to get them to prescribe any antibiotics. We couldn't get a face-to-face appointment at all.

Ongoing medical care is very poor. No one has seen my brother for his hernia, his failing eyesight, heart failure, weight loss. Impossible to get through to surgery to get anyone to see him. It's like it does not matter because he has dementia.

I would like it flagged up that the patient should be listened to and so should the carer if the patient can't speak for themselves. Receptionists at GP surgery should not question the patient's symptoms and try to get you out of having an appointment. We should not be prevented from speaking to the Dr by the receptionist. This is our biggest problem, getting knocked back. Dementia patients should be treated like anyone else who is entitled to good care for any health problems.

Hospital care

Have you or the person you care for experienced a stay in hospital since the diagnosis of dementia?

Yes	No
38	75

Positive comments included:

I was in hospital for five days – care was good, my husband was also in hospital for one night and again care was good.

Good care once we got beyond A&E.

7 weeks at George Elliot, extremely pleased with the care received.

3 weeks, care is good but communication is poor.

Negative comments included:

Several nights, nurses were oblivious to mum's needs. We weren't allowed to be with her due to COVID-19. We were not informed what was happening and trying to get information was impossible.

My sister and I tag teamed staying with mum 24/7. Staff did not have time, and many did not seem comfortable or competent in caring for a patient with dementia.

> ***6 weeks hospital stay:* Very distressing. Medication was increased so that my husband who was physically fit on admission deteriorated greatly. He began to slur his speech, had choking episodes and became immobile. We had to get him home quickly where he has physically improved.**
>
> ***3-4 weeks hospital stay:* It was not good. As we were not able to visit, she quickly lost her confidence to stand and a serious error was made which led to us having to lodge a formal complaint. A DNR was put in place which went against our mother's wishes and as a family we were not consulted.**

The overall experience expressed through the negative comments can be categorised as:

- Poor care
- Poor communication
- Lack of skills of clinical staff in dealing with patients with dementia
- No account taken of home situation
- Dementia patients given a very low priority in terms of care because of inability to understand or communicate their needs
- Discharged with no support and no referral for social care despite patients sometimes being frail or immobile.

Themes arising from free text, focus group and interviews

Although we had agreed questions to guide focus group and interview discussion, the nature of this research method permits respondents to raise other things that matter to them. From the question, 'are there any other comments/ suggestions you would like to make?', we received some rich feedback. Four extra and recurring themes emerged from the analysis of 271 responses: **the impact of COVID-19 measures, transport, care homes and waiting.**

Impact of the COVID-19 Pandemic

The COVID-19 pandemic in the UK led to the first lockdown being put in place in March 2020. The highest number of survey respondents said they had noticed memory problems within the last 5 years. National guidance for NHS and care services instigated a rapid move to virtual consultations and as little face-to-face contact as possible. People with pre-existing health conditions and the elderly were told they were more vulnerable if they caught COVID-19. The majority of frail, people with dementia and other long-term conditions and their spouse/partner carers are in the older age groups. Arguably, these people are therefore likely to be the least familiar with information and computer technology and the most likely to have been impacted by the pandemic. Several people who lost access to the services that previously supported them e.g., memory cafés, found a noticeable deterioration quite quickly, especially if they were not able to engage through technology.

> ***We don’t really do the internet as my daughter does all of that, so we didn’t really have any contact with anybody other than calls from our 2 daughters most days.***

The section on diagnosis demonstrates a variety of diagnostic pathways. This variation could be attributed, in part, to the pandemic response. Access to healthcare remains difficult, undermines public confidence in the NHS and is likewise attributed to the pandemic:

> ***We have just got an appointment for the end of November. I'm not holding my breath; other appointments are regularly cancelled due to COVID-19.***

The negative impacts of social isolation and the loss of access to some services on mental and physical well-being were also mentioned.

My mother wasn't keen on going out of the house and since COVID-19 had been much worse and now accessibility would be difficult as she can't self-transfer.

Deterioration started to be noticeable through lockdown when everything stopped, and we had nothing to replace the time. P is not really interested in gardening as that is my domain and he does tend to cut all the wrong things down so I couldn't get him into that as a substitute. He didn't really have any interests or hobbies indoors so it was hard to keep him occupied and so he spent most of the time watching tv and sleeping. Things have got better again now that we can go out, but he hasn't returned to how he was before lockdown so is still worse overall.

Became very depressed during lockdown as he so enjoyed going to the day centre but that just stopped because of the pandemic, and he just seemed to withdraw into himself. Wasn't meeting anyone and he really missed the company.

Hospital visiting restrictions were hard to tolerate as carer support for the patient and oversight of care was disrupted:

Nurses were oblivious to mum's needs, we weren't allowed to be with mum as it was during COVID-19, we weren't informed of what was happening and trying to get information was next door to impossible.

I can't say a lot about the care received at hospital as it was in the middle of the COVID era and no visiting was allowed. However, it was clearly more than adequate.

Most people who participated in the project understood about the pandemic restrictions but wanted to share their difficulties and feelings of loneliness.

Transport

Transport problems were consistently mentioned by people with dementia and carers, and created barriers to attendance at groups and, health and care appointments were also compromised. The main transport issues were:

- Driving licence being rescinded due to dementia (especially if the main family driver)
- Poor public transport especially for those living in rural areas
- Poorer availability of groups (particularly for younger dementia patients), services and health care facilities in rural areas, necessitating travel
- Affordability of transport, especially if there were extra charges for attendance at support and care activities.

> ***Would really appreciate help with transport to get to day centre, I can't always attend if my wife is working and can't take me.***
>
> ***Living in a rural area means we are forgotten. Unless you live in a town or city, as the social worker suggests we should, then we are abandoned.***
>
> ***Getting around is impossible if you live in a rural area where transport is almost non-existent. Since my husband has had to stop driving, we have become like prisoners in our village.***
>
> ***The problem is that a lot of help is in Oakham and we are in a more rural location so access is limited by lack of transport.***

Care Homes

Several respondents spoke of the difficulties and stress of reaching the decision to admit a relative to a care home due to:

- Lack of support in finding a care home able to provide a high quality of care that would meet the needs of their relative, especially if self-funding care
- If local authority funding, there was a lack of choice, often constrained by financial restrictions
- Cessation of community support
- Worries about the care home quality of care
- Feelings of guilt for carers in addition to feeling helpless

My husband is now in a dementia care home, but I found it hard to get any information at the time. It would have helped if I could have sat and spoken with someone about what was available and the cost of everything.

My wife is happy and secure in a care home but it is costing £6000 per month. We can afford this at the moment but what happens when the money runs out?

My husband is now in a care home. The support from the admiral nurse stopped on his admission to care, but there are still stresses and guilt when they are in care, particularly with staffing issues in care homes currently. It is a different stress, but it is not easy and the guilt is massive.

Mum did not like the food, so didn't eat well. She is vegetarian and the care home food is very meat based – not the nuts and cheese she likes. Mum also didn't want male carers but we discovered a man and a woman had washed and changed her. The team leader said it wouldn't happen again, but it did. They just didn't respect people enough.

Support and information about these big decisions is needed, particularly as the person being admitted to residential care often cannot make their own choices and opinions known.

Waiting

Waiting was a key word that was used frequently by people with dementia, carers and professional staff trying to gain access to services on behalf of people they are supporting. This can refer to waiting on the telephone for a GP surgery for appointment, waiting for a referral to the memory service, waiting for an appointment for diagnosis, waiting for the results, waiting for someone to contact them to follow up, waiting for a dementia support service, or waiting for social care contact. This was summed up by one service manager who said, ***"Everywhere people turn is a wait."***

Access to everything is very difficult. Everyone apologises for the lack of contact due to pressures and workload which makes you feel like you are taking up their precious time.

Conclusion

This study has identified wide inconsistencies across LLR in the way in which services are available and accessible for people living with dementia from the first suspicions of memory problems onwards.

Diagnostic pathways vary, information is plentiful and appropriate in some cases and difficult to access in others. Where available, the Admiral Nurse Service, Age UK, VASL and the Alzheimer's Society services were well appreciated but these organisations and the participants all reported difficulties in accessing other services such as social services, primary care or mental health services. Social and activity groups were also well appreciated where and when available but there were barriers, such as transport and affordability, to accessing these. In the later stages of dementia, financial implications in accessing care become both an even greater concern and also dictate choices and quality of care.

Many of those living with dementia expressed these concerns, which suggest that a person-centred integrated approach has not been implemented. The participants have shown that they want the strategy to include:

- **Improved access to primary and community care services where the ongoing physical and mental health care are taken seriously**
- **Timely referrals and appointments for more specialist care**
- **Appropriate, timely and professional information about the progression of dementia, future planning, care, benefits and support services, from both the health and social care sector and the voluntary and community sector**
- **Easier access to more responsive social services**
- **More equitable access to Admiral Nurses and voluntary and community groups for support and social activities.**

Healthwatch recognises the pressures on the health and social care sector resulting from excess demand and under-resourced capacity. We hope that the contents of this report will assist the Dementia Programme Board in the review of the Joint Living Well with Dementia Strategy and inform the development of the revised strategy in 2023. We also would welcome the opportunity to work with the Dementia Programme Board in the development of the 2024 Strategy to achieve the recommendations we have made on the basis of what people living with dementia have told us.

Recommendations

Pre-diagnosis

1. As part of the information offer before diagnosis, develop an information leaflet for the general public outlining the early signs of dementia including memory loss, that will trigger people to contact their GP practice about the symptoms. Early intervention could prevent decline and keep people well for longer.
2. Whilst current waiting times for diagnosis are so high, following initial triage, with the persons consent, refer to Age UK or VASL for initial assessment for pre diagnostic support.

Diagnosis

3. Dementia diagnosis pathways to be standardised across LLR and, wherever possible, locally accessible so that people receive a consistent service with consistent information being provided following diagnosis.

Support following diagnosis

4. Variations in the pathway for providing information and support to people post diagnosis need to be reviewed and standardised to enable everyone to have access to an equitable service and receive support in a timely manner. Consideration should be given to providing support through at least one face to face contact following diagnosis to give patients and carers the opportunity to talk to someone, ask questions and seek advice and guidance.
5. The Admiral Nurse role was highly valued by those people who had access to this service. Priority for future investment into services should be considered to increase the number of Admiral Nurses and provide people with a more high-quality, equitable service.

6. One point of access for information, advice and practical support was put forward as a way of providing a more comprehensive and equitable way of providing support to patients and carers. The system is asked to explore any existing resources in place that could extend its remit to carry out this function.
7. A review of location of current support services (memory cafés, carers groups etc) to ensure accessibility and equity for all resident of LLR.
8. Consideration to be given to using any new investment to extend the provision of current service provided by Age UK, VASL and smaller independent providers to at least a fortnightly basis as suggested by many patients and carers who use them.
9. A review of services for people with young onset dementia and accessibility. Although smaller in number, they are also growing in number and further consideration needs to be given on the types of services that meet the needs of this cohort.

Access to Health and Social Care

10. Better information/ training provided to primary care to enable GPs to better identify the signs and symptoms of young onset dementia to improve the experience of young people being taken seriously in primary care and receiving a timelier response to their concerns.
11. The requirement for a 12 monthly review of the person with dementia does not appear to be being met in many cases. An audit of this should be undertaken to ascertain the reality of this and actions put in place to address this if our feedback is correct. Any update of the procedure for meeting this requirement should include a review including the persons main carer.
12. There needs to be a clear pathway for people who need to access help if their relative's condition progresses or deteriorates. Information through the form of a leaflet, booklet, or poster, should be designed giving contact details of where people can go for help and what specific help is available either from Mental Health services or Adult Social Care. This should be made accessible to all through a single point of access so that people should not have to spend hours/ days trying to find out who to contact for help.

13. Adult Social Care should review its policies and procedures about assessments for people who are self-funding but need advice and guidance on securing good quality care for their relatives. If people are not entitled to an assessment, they should have access to information about what care services are available, what they should look for and how they can be accessed. People should not be left to 'just get on with it'. A navigation service should be available as a minimum.

14. In order to guarantee that the standards of care in hospital for people with dementia is of the same quality that everyone else expects, the Hospital Trusts are asked to review their mandatory training for clinical staff, allied professionals and ancillary staff to ensure that people with dementia are cared for in a safe and dignified manner.

15. Carers need to be supported to think about and plan for what will happen to their relative if they become incapacitated or die before the person they are caring for. This is not only important for the person left behind but for services who may have to step in to take on this responsibility where there are no immediate family members. Being able to follow the patient's and carers wishes will result in a much more dignified and respectful response for the person who cannot speak for themselves.

16. There needs to be contingency plans in place about how to support people should there be another major incident requiring people to isolate. The pandemic clearly had an impact on the deterioration of the dementia for some people, and isolation, loneliness and a breakdown were cited as playing a significant role in this.

Dementia Programme Board response

On the behalf of the LLR Dementia Programme Board I would like to thank Healthwatch Leicester, Leicestershire and Rutland for undertaking this engagement exercise. The timing of this pre-commissioned research has allowed us to integrate the findings into our LLR Joint Dementia Strategy Refresh ensuring that the wide breadth of voices of those living with dementia and their carers is captured in our strategic priorities.

The priorities contained within the Dementia Strategy, and informed by your research, will be delivered by individual partners who will report their progress to the Board. This way, we can ensure that we are making a difference to people living with dementia. The reporting will be systemised and consistent allowing us to have a clear grasp of target progress and allowing to concentrate resources in any areas of concern.

We are planning to publish our updated LLR Dementia Strategy in early 2024. Prior to this we will be undertaking a public consultation which will allow people to review the strategy featuring our priorities and provide us with feedback.

This will allow participants of the Healthwatch research to see how their voices are integrated into our strategy and have further say ahead of the publication. Details of the consultation will be provided in appropriate formats and communicated through our communications channels. I would be pleased if you can support us to reach out to those people who took part in your research so that we can share with them what we have done with what they told you.

Finally, I would like to extend a great thank you to all the people that have taken the time to support Healthwatch with their research by participating in the surveys, focus groups and interviews. We understand that frustrations can arise when there are gaps in the support offered and are very grateful for the resilience and clear communication from the public that allows us to shape our services. Please rest assured that you are heard and your concerns around access to diagnosis and support available, support for people with younger onset dementia, support for carers and many other points are considered. We are doing everything in our power to provide you with the support you need and deserve.

Graham Johnson and Bev White
Co-Chairs, Dementia Programme Board

Appendix 1

Questionnaire for in-depth Carers interviews data collection version

1. What made you realise that there were problems with your family member's memory?

2. Can you talk me through the process you went through to get a diagnosis once you had noticed a change in your/ your relatives mental functioning? Where did you look for help? Who did you contact first?

3. Once you had a diagnosis, did anyone from a professional background contact you and talk to you about the diagnosis, what sort of things you might expect as the condition progresses and what support was available to you as things progressed?

4. What support do you access currently and is this enough at the moment?

5. Do you know what additional help is available to you if your relative's condition progresses and needs change?

6. Is there any service that you think would really help you if it was available but you are not aware of?

7. Dementia people with dementia should be reviewed annually to ensure that their physical and mental health needs are being met. It is also an opportunity to monitor the patient's dementia and whether care needs have changed. Have you / your relative had an annual review by a GP or Consultant/specialist over the past 12 months?

Appendix 2

Questions for participants at focus groups

1. What made you realise that there was a problem with your family member's memory

2. Once you became concerned about yourself/ your family member's memory loss, what was your experience of getting a diagnosis (probe: How long did you have to wait to get a diagnosis?)

3. Either before or after diagnosis, how did you find getting the support you felt you needed?

4. From your experience of accessing support to care for someone with dementia, what help has been the most useful to you?

5. Is there any help or support that you would have benefitted from before diagnosis, or now, or in the future?

Appendix 3

Services visited as part of this study

Date	Meetings/ events attended
1.7.22	Online Dementia carers group Blaby
12.7.22	Meeting with Carers with dementia on zoom to discuss experiences of accessing dementia services
14.7.22	Carers group at Earl Shilton
28.7.22	Market Harborough carers group
28.7.22	Zoom meeting with co production group
8.8.22	Sapcote Dementia Hub
10.8.22	Lutterworth Academy for dementia studies
23.8.22	Thurnby memory cafe
23.8.22	Young onset dementia group Braunstone
26.8.22	Academy for dementia studies carers group
29.8.22	Academy for dementia studies brain gym group
21.8.22	Leicester Mela
1.9.22	NWL Dementia Carers group
1.9.22	Age UK Garden Gang
6.9.22	Blaby Carers Group
22.9.22	Men and Women in sheds
26.9.22	Charnwood Carer Group
28.9.22	Market Harborough Carer Group

5.10.22	John Storer Dementia Group
6.10.22	Post dementia diagnosis session
11.10.22	Melton Memory café
12.10.22	Young onset dementia group
18.10.22	Market Harborough memory café
1.11.22	Poppies memory café
3.11.22	Beaumont Leys memory cafe
3.11.22	Holmfield Day Centre
7.11.22	Rutland Age UK Memory Café
9.11.22	Guru Nanak Day Centre
14.11.22	RVS Memory Group
15.11.22	Bluebells carer group
16.11.22	Chai Nasto group
16.11.22	Wigston memory cafe
22.11.22	Brite memory cafe
23.11.22	Young onset dementia engagement event
28.11.22	Maintenance Cognitive Stimulation group
29.11.22	Caribbean Court dementia group

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