

Carers For People With Dementia – Access To Primary Care

Experiences of Carers of people with dementia

healthwatch
Bracknell Forest



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Background and scoping

Healthwatch Bracknell Forest were invited to the Bracknell Dementia Forum on 23rd October 2023. The forum was attended by carers of people with Dementia and the cared for along with various service providers. Part of the forum was a tabletop exercise in which the carers and cared for were asked 'What would make them feel safer'. One of the top three answers was 'easier access to primary care'. The other two answers were 'safety in the community' and 'roads and pathways'.

With regard to the 'easier access to primary care', Healthwatch Bracknell Forest wanted to explore this further, to understand why carers of people with Dementia raised it as an issue for them.

This Healthwatch project and report seeks to understand the various means of access to primary care, carers of people with Dementia ability to use digital tools like mobile phones and computers and their experiences when trying to access primary care services.

Summary

Being able to access services and appointments via Klinik on the surgery website, in addition to accessing appointments via Klinik over the phone and in person, has increased options and is beneficial to large parts of the population. However, more than 80% of carers of people with Dementia don't have the skills or tools to take advantage of the new access options and can feel left behind.

Carers for people with Dementia caring responsibilities can be very time consuming, exhausting and stressful. Their responsibilities don't always enable them to call the GP surgery at 08:00 in the morning and even if they can call, the caring needs mean they can't necessarily wait in a long queue. Some had used the 'call back' option to avoid waiting in a phone queue but they had experienced problems, for example, not being able to get to the phone in time when the surgery rang back because of their caring responsibilities. Many don't have a mobile phone and so rely on a house phone and it can take them some time to get to the phone.

Going to the surgery to try and fill out a Klinik form can also be difficult for them due to their caring responsibilities. There are difficulties too if they have to travel to a surgery within their PCN when it is not their local surgery.

Difficulty accessing GP appointments causes carers real concerns about the health of the person they are caring for and they also had particular concerns

about their own health and the implications on those they care for should they as the carer become too unwell.

In a [May 2020 survey conducted by Carers UK](#), the top three challenges most frequently highlighted by unpaid carers were: managing stress and responsibility (71%); negative impacts on their physical and mental health (70%); and not being able to take time away from caring (66%)

During our conversations with carers they talked about their experiences of accessing primary care and how this added to the stress of their caring responsibilities

Dr Jane Fossey, of the Oxford Health NHS Trust and lead researcher on the Caring For Me and You trial, said:

Carers often feel the profound effect the role can have on their own lifestyle – spending long hours providing care, juggling their own needs with those of the person they are caring for, and forfeiting their social time. As a result, carers of people with Dementia are more likely to experience stress and depression

Carers for people with Dementia and those they care for, would greatly benefit if reasonable adjustments could be made for them when accessing primary care. As highlighted by NHS England. The [Equality Act \(2010\)](#) places a legal duty on all health and care services to make changes to their approach or provision to ensure that services are as accessible to people with disabilities as they are for everyone else. This duty aims to address the recognition that people with disabilities may appear to have equal access to care and services, but without specific adjustments being made, that access may not be equitable.

Recommendations

- Easy access to paper versions of Klinik triage form in the surgery. As highlighted in the findings of this report, many carers of people with Dementia have extremely demanding caring responsibilities and are time poor. This can make it difficult for them to wait in queues on the telephone, or in person at reception to be triaged via the Klinik form. Being able to pick up a Klinik form from a table in reception would help some of the carers.
- As mentioned in the report, one surgery in Bracknell operates a creative alternative access model to give carers and those over 85 access priority. This has been done by giving those cohort a separate surgery telephone number to contact the surgery. This may or may not be possible for some or all of the other surgeries by using bypass options in their telephony systems, but if not, there may be other creative ways those surgeries can improve access for carers of people with Dementia and the cared for.

- Surgeries to call patient more than once if they use the call back option. Some carers had tried to use the call back option but it hadn't worked for them. Most don't have mobile phones so rely on landline phones. Carers can't always get to the phone quickly enough when they are called. Phoning carers more than once if they don't answer the phone initially, will enable them to answer the call more.
- Carers to be given the choice to have appointments at their local surgery. Some carers, particularly those who can't drive have real difficulties when having to travel to appointments at surgeries within a PCN which are not their local surgery. This could be recorded via the reasonable adjustment digital flag.
- Communication campaign to carers of people with Dementia. ICB communication about the reasonable adjustment digital flag program, explaining what it is and what reasonable adjustments means in simple terms. Inform carers and cared for, what they can do if they need reasonable adjustments but haven't yet been identified and contacted by their GP surgery. In addition to digital communications about the program, provide physical posters in all primary, secondary (including outpatients and A & E) and community health care settings.

Who did we work with?

After attending the Bracknell Forest Dementia Forum we worked with the Dementia Services Development Co-ordinator from the Community Mental Health Team (Older Adults) from Berkshire Healthcare Foundation Trust. We also worked with the weekly Bracknell Dementia Café, which is hosted alternately by Community Mental Health Team (Older Adults) and Age Concern Bracknell.



Who did we talk to?

Healthwatch Bracknell Forest attended the weekly Dementia Café during December 2023 and January 2024 to talk to carers of those with Dementia. We spoke to 48 people.

When talking to people we asked them which GP surgery they were registered with. We asked if they had a mobile phone and if they had the NHS App. We asked if they had a computer and the digital skills to access the internet. Finally, we asked about their experiences accessing Primary Care.

Findings

GP Surgery Access Options

We looked at what options were available to book doctor appointments in Bracknell Forest GP surgeries. All surgeries now use a Klinik form to triage patients before offering an appointment. There are various ways this can be done in Bracknell surgeries. A patient can phone the surgery and the care navigator can fill out the Klinik form. Some surgeries offer a call back option whilst maintaining the patients position in the queue. A patient can go online to the surgery website and fill out a Klinik form, a patient can visit the surgery in person and either fill out a paper copy of the Klinik form or the care navigator can do so on their behalf.

We visited all Bracknell Forest surgeries in person to see what options each surgery offered for booking a doctor appointment. Not all of these access options are available across all surgeries.

By Phone – All surgeries told us that patients could phone the surgery and be triaged via the Klinik form.

Call Back – All surgeries apart from four, gave patients a ‘call back’ option so they didn’t have to wait in the queue.

Online – All surgeries apart from one, told us that patients could go online and fill out a digital Klinik form.

In person at surgery – All surgeries apart from two, told us that patients could go to the surgery and fill out a paper version of the Klinik form, and/or a care navigator could fill one out on the system.

Registered GP Surgery and access difficulties

When talking to carers about which GP surgeries they had difficulty accessing, in their responses all PCNs and all GP practices in Bracknell Forest were mentioned apart from one. On further investigation we found that surgery operated a

different model of access for some groups of patients. A Carer showed Healthwatch a letter they had received from the surgery. The letter stated that the surgery has a separate phone number for certain patient groups. Those groups were anyone aged over 85, registered patients with Dementia and carers. This gave those groups priority access but not priority appointments.

Carers use of mobile phones and NHS App

We asked carers if they had a mobile phone and if they had signed up for the NHS app. Less than a quarter said they had a mobile phone. Seven of the 48 people said they have the NHS app but only five of those were able to use the mobile app. When asked why they didn't have a smart phone or why they didn't use the app, the responses were one, or a combination of the following:

- Not having a smart phone
- Not having a smart phone due to cost
- Not wanting a smart phone
- Didn't have the skills and only used smart phone to make calls.
- It was too late for them to learn the skills.
- They didn't have the time or energy to learn new skills.

Carer's ability to use online services

We asked carers if they had the ability to use online services via computers, tablets, to access GP surgery websites. Four of the 48 people said they were able to use online services. When asked why they weren't able to use online services, the responses from carers were one, or a combination of the following:

- Don't have a computer or broadband.
- Don't have a smart phone.
- Can't afford the cost of computer, broadband, smart phone.
- Don't have the skills to use online services.
- It was too late for them to learn new digital skills.
- They didn't have the time or energy to learn new skills.

Carers access difficulties

In our discussions with the carers and cared for about their experiences of accessing primary care and any difficulties they had in doing so, the following issues emerged. We explored each of these issues in more detail:

- Not being able to use the online option.
- Long waits in telephone queue
- Not being able to call when phone lines open.
- Call back option.
- Difficulties getting to surgeries.

Not being able to use the online options

The vast majority of carers said they were unable to use online services. As mentioned earlier there were various reasons for this. Carers told us about cost.

I can't afford a computer or a mobile phone or broadband, it's expensive and we only receive the state pension

Some carers told us they didn't have the skills to use a computer or mobile phone, others said it was too late for them to learn the skills to use computers and mobile phones. Some carers said they just didn't have the time and energy to learn digital skills.

I'm in my 80s and have never used a computer even when I was working so I don't have the knowledge or ability to use computers or mobile phones

There are not enough hours in the day to do the usual stuff along with caring. I'm barely able to cope with what I have to do day to day, I don't have the time or energy to learn new things

Long waits in telephone queue

The carers told us about the difficulty for them waiting in long telephone queues. Carers told us that it impacts them in several ways. Carers said that because of the needs of the cared for, they just don't have the time to stay on hold for too long.

As a carer of someone with advanced dementia, waiting in long telephone queue is really difficult, if my wife needs me, I can't ask her to

wait for 45 minutes while I try and get through on the phone, it is very demanding being a carer and time consuming

Other carers told us about the stress it causes them

If I am on the phone too long my husband starts to get very agitated, asking who I am talking to, tries to take phone off me. I have to hang up. When you are older and a carer for someone with Dementia there is only so much you can cope with. It is stressful and exhausting

Carers also mentioned the cost of a telephone call if you are held for a long time. Some of the carers told us they only have the state pension as an income and they may not call or hang up because of concerns about the cost.

One month I had a phone bill of almost £20 just for the calls to the surgery and waiting on the phone. I can't afford that and worry about phoning and the cost If I am waiting on the phone too long

Not being able to call when phone lines open

Some carers told us that it was not possible for them to always phone the surgery when the phone lines open at 08:00 because of their caring duties.

Quite often I can't phone at 8 o'clock in the morning because of my caring responsibilities. The last time I phoned at about 09:00 and got a message saying the safe capacity for appointments has been reached and there are no more appointments for today. So I then have to try another day. It is exhausting

Another carer told us

My wife is very agitated in the mornings and needs lots of my time, so I have trouble phoning at 8 o'clock

Call back option

Some carers who could phone at 8 o'clock in the morning but weren't able to wait in a long queue told us that they had used the call back option. However, some experienced issues with the call back option and didn't trust it.

I don't have a mobile phone that I can carry around with me, only the house phone. Several times when they have called me back I am busy caring for my husband, the phone only rings a few times and I can't get to the phone before it rings off.

Another carer told us

I can't always get to the phone quickly enough when they call me back. So, I then have to go through the whole thing again, I feel like I'm going round in circles

A carer told us that they didn't trust the call back system

I tried the call back option and waited and waited, trying to make sure I wasn't too far away from the phone whilst also caring for my partner, no one called back. I don't trust that anymore

Difficulty getting to surgeries

Some carers do visit their local surgery and get the receptionist to fill out a Klinik form in person, but other carers said this was difficult for them to do because of managing the cared for if they tried to go to the surgery to fill out a form, other carers said it was difficult because of time constraints.

I don't have the time or energy to wait in a long telephone queue so the easier option for me would be to go to the surgery and fill out a paper form. But I usually have to queue for some time to get to reception and my partner can't cope with that because of their dementia. It would be easier if they left some of the forms on the table and I could pick one up quickly go home and fill it out when I have time and then drop it off quickly at the surgery when I have time

Carers also spoke to us about the difficulty they have getting to appointments that aren't at their local surgery. They told us that since the introduction of primary care networks (PCNs) they can be asked to go for an appointment at any surgery within the PCN. There can be some geographic distance between their home and other PCN surgeries.

I can't drive Since the practices amalgamated it has made my life as a dementia carer more difficult. If you don't drive and can't afford taxis it can take several bus changes and two or more hours to get from Sandhurst to an appointment at Bracknell

Some carers talked about the stress and anxiety it causes

Now there are several surgeries in a PCN they can send you all over the place. When I used to go to the local surgery, which was 10 minutes away, it was familiar to my husband and he didn't have any problems going there. Now they can send you to one of several surgeries, the travel time is much longer, planning and managing the journey is stressful for me, my husband gets very anxious on the journey and the surgery is unfamiliar to him which makes the situation even worse

I tried the call back option and waited and waited, trying to make sure I wasn't too far away from the phone whilst also caring for my partner, no one called back. I don't trust that anymore

Carer story

I am not able to use a mobile phone or a computer. I rely on using the phone to contact the surgery or occasionally by visiting the surgery to make appointments.

But visiting the surgery can be time consuming and difficult as I have to prepare and get my husband ready to take him to the surgery, he can't be left at home. This can be time consuming and stressful, so I try and avoid that option.

When I use the phone I always have difficulty getting through due to long waits in the queues. I'm time restricted by my caring responsibilities, I can't wait 40 minutes or more in a queue. My husband also gets agitated if I am on the phone too long. So, if there is a long queue, I give up and hang up. Caring is really time consuming and when I have trouble getting through on the phone to the surgery, it causes my anxiety, frustration and leaves me exhausted and worried about the health of both of us.

NHS Frimley ICB Response



NHS Frimley Integrated Care Board (ICB)

NHS Frimley welcomes the work that Healthwatch Bracknell Forest have done on investigating access to GP Practices in the Borough for residents who are carers of people with Dementia. We would also want to take this opportunity for thanking the Healthwatch Team, and in particular Nick Durman, for their partnership approach in including the ICB Place team in the discussions from an early stage and taking the time to attend the Bracknell Forest GP Council to share the initial findings in the report.

Access to our GP surgeries has been a national and local focus for the NHS since the launch of the NHS England Primary Care Access Recovery Plan in May 2023. The ICB Primary Care team has been working with all of our practices to focus reconfiguring their access so that patients don't have to face the 8.00am rush on the telephones. They have been doing this by ensuring that patients can access appointments through the phone lines, online or by walking into the surgery.

This report by Healthwatch has been helpful for practices to better understand how changes to their appointments system can affect patients, and importantly patient carers as well. Some of our practices have already taken steps to support this group of patients, for example a dedicated line for carers being set at one of our practices, and no doubt the information shared in this report will help all our practices to further refine their access models to address the specific needs of carers of people with Dementia.

NHS Frimley run a wide range of communications campaigns throughout the year and we will continue to work closely with primary care colleagues to ensure that there is awareness of the reasonable adjustment digital flag programme. We will also continue to ensure that we have supporting resources and materials to support carers and a wide range of information about local services available on our Frimley Health and Care website.



healthwatch
Bracknell Forest

Unit 49, Aerodrome Studios, Airfield Way, Christchurch, Dorset, BH23 3TS

www.healthwatchbracknellforest.co.uk

t: 0300 0120184

e: enquiries@healthwatchbracknellforest.co.uk

 [@https://twitter.com/healthwatchbf](https://twitter.com/healthwatchbf)

 <https://www.facebook.com/HWbracknellforest>