



**BRIEFING**

# **PRE-MEMORY ASSESSMENT SUPPORT PROJECT**

WHAT WE'VE  
HEARD SO FAR



**DEMENTIA  
CHANGE  
ACTION  
NETWORK**



# FOREWORD

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As in all areas of healthcare, the COVID-19 pandemic has created challenges in the delivery of memory service appointments and assessments for dementia. Many memory service staff were redeployed to other teams; most services had to operate at reduced capacity and some services had to temporarily close.

Staff in memory services have worked extremely hard to adapt to provide a safe service during the pandemic and have done a magnificent job in embracing alternative approaches to assessing patients. This includes using telephone and video consultations and providing virtual occupational therapy, carer support sessions and neuropsychological testing.

Despite this, we know that the pandemic has impacted waiting times for memory assessments. Many people experiencing memory problems (and who may be worried they are developing dementia) are now waiting longer for their appointment, prolonging the period of anxiety and uncertainty of unexplained symptoms. Helplines such as Alzheimer's Society Dementia Connect, Age UK Advice Line and Dementia UK Helpline have seen a significant increase in calls since the onset of COVID-19, indicating the need for help to manage the practical, emotional and clinical challenges that memory problems can cause.

This sharp focus on the issues that people face while waiting for a memory service assessment has galvanised work to give visibility to, and increase awareness of, the support available.

DCAN, in partnership with NHS England and Improvement, have been undertaking work to learn from the experiences of people waiting for memory assessments to hear about the challenges they are facing and the support they need during this time.

Providers of support have also been engaged to clarify and enhance visibility of the support currently available to people waiting for a memory assessment.

This briefing document sets out in detail, the work undertaken to support those waiting for a memory assessment so far, drawing on feedback from people with lived experience, providers of support and staff in memory services. It aims to:

- Highlight the various needs of people waiting for assessment and diagnosis, and their carers
- Increase awareness of the need for pre-diagnostic support to help enable people referred to memory services to live as well as possible pre-assessment and diagnosis.



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# INTRODUCTION

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DCAN, in partnership with NHS England and NHS Improvement, have been gathering feedback from people with lived experience and providers of support about their experiences of delays to memory assessment appointments during the pandemic and how this has impacted the need for and availability of support.

We have heard that the pandemic has left people feeling disconnected from formal and informal support networks. This has negatively impacted emotional, cognitive, social and physical well-being. In addition, support organisations have seen an increase in the number of people with more complex needs seeking support than was the case prior to the COVID-19 pandemic.

Together we want to ensure that the longer waiting times for a memory assessment appointment post COVID-19 becomes a time where people can proactively begin to prepare for the assessment and the future. More than this we want to make it more likely people can begin to access support when they need it, not just once they have received a diagnosis.

A new DCAN website 'Nextsteps.org.uk', is being co-developed to provide information about the assessment process and help people waiting for an assessment to find where to access support or enabling positive steps to self care and improved well being.

Conversation within DCAN throughout the pandemic have raised broader issues of digital inclusion, the need for better inclusion of marginalised groups, and the enduring issues of stigma around dementia. DCAN will continue collaborating for change, promoting personalised care and exploring new ways to address common gaps.

We believe a second phase of this project is required to consider ways to improve the support available to people waiting for a memory assessment. To do this we will look at the areas of excellent personalised practice and considering how to spread similar approaches

more widely. We will also find ways to collaborate within our network to innovate around unmet needs and to improve equity of support. More details about the unanswered questions that we hope to include in phase 2 are listed at the end of this briefing.

## **ABOUT THIS BRIEFING**

We have run a number of focus groups, online surveys and a virtual forum to gather information from people about the needs they had during this time, the support they received and the support they would have liked to receive which they felt was unmet or could be improved.

This briefing is a summary of those conversations and our learning so far. It incorporates a range of views and we would like to thank everyone who has helped us understand the issues and priorities. As you read this summary briefing it's important to note this is not the whole picture, just those parts our conversations so far have revealed.

We have heard predominantly from family carers and professionals involved in providing support, information and advice to people pre-assessment. It is important that we put the experiences of people with dementia at the heart of what we do and efforts will be ongoing to ensure we hear as much as possible from people directly experiencing cognitive impairment in this important pre-assessment period. The resources that flow from this project will remain live, to ensure we can continue to incorporate views and experiences shared with us on an ongoing basis.

# WHAT WE'VE HEARD SO FAR

The four key issues identified were:



## **THE IMPACT OF COVID-19: CHANGING NEED AND WHY THIS WORK IS BEING UNDERTAKEN**

The response needed to manage the COVID-19 pandemic has resulted in longer waiting times for memory assessment appointments which is leaving people with unmet practical, emotional, social, and clinical needs. This has been compounded by lockdowns that have affected routines as well as family and community networks.



## **BEING CONNECTED: PEER SUPPORT AND OTHER IMPORTANT CONNECTIONS ARE NOT HAPPENING AS PEOPLE NEED OR WOULD LIKE**

Usual connections and pathways of support are not as easy to access because of COVID-19. This means that important connections to people, information, and services who could offer support whilst waiting for an assessment are not taking place.



## **INCLUSION: HOW TO BETTER INCLUDE ALL THOSE WHO NEED SUPPORT AND REDUCE INEQUALITIES**

COVID-19 has heightened issues of digital inclusion. There is a need for alternative ways to reach people and better personalised support for marginalised groups.



## **STIGMA: OVERCOMING AN ENDURING BARRIER**

There is still work to be done around the stigma of a dementia diagnosis. Although this is not the only potential outcome from a memory assessment appointment, a fear of diagnosis remains a barrier to accessing support. Similarly, this is also preventing families having important conversations about memory concerns or other symptoms. It's important these concerns are allayed by having much earlier exposure to positive stories from people enjoying life following a diagnosis, as well as greater access to peer support.



## THE IMPACT OF COVID-19: CHANGING NEED AND WHY THIS WORK IS BEING UNDERTAKEN

**'I was left in limbo'**

Person with lived experience

**'I've been a mess for 6 months now'**

Person with lived experience

- People with dementia and their carers reported feeling “stuck” or “in limbo”, and are experiencing longer waits with limited and patchy support during this uncertain time.
- There is a compounding effect of the wider implications of COVID-19. People are being impacted by a lack of normal routine, limited contact with family and friendship networks, and less interaction and activity within local communities.
- All of this is negatively impacting trusted coping strategies of people with dementia and their carers, and the ability to maintain general mental health and well-being. For some people, it is also resulting in a steeper rate of cognitive decline and accelerating symptoms associated with later stages of dementia.
- Longer wait times at all stages of assessment and limited access to and capacity within services is an issue. It was said that services are operating in a ‘crisis’ mode which impacts forward planning, and hampers promotion of living well and the personalised support required to do so.



## BEING CONNECTED: PEER SUPPORT AND OTHER IMPORTANT CONNECTIONS ARE NOT HAPPENING AS PEOPLE NEED OR WOULD LIKE

**'It's a very long and lonely process'**

Person with lived experience

- People want to be connected to others at a similar stage of assessment, to ‘share experiences’ and to be signposted to groups, services, and information.
- Since COVID-19, there has been less visibility of people and services to make connections with. Again, there is an impact of COVID-19 on informal networks of daily and community life, as well as access to pathways of support that open up following a diagnosis.

- Difficulties and inconsistencies within partnership working were highlighted. Some referral pathways were reported as working well. Some people reported additional commissioning acknowledging increased needs of those waiting for a memory assessment, but others found dementia support pathways have become more fragmented and sidelined during the pandemic.
- Difficulties of funding, organisational boundaries and data protection, were all highlighted as barriers at a professional level that needed to be overcome to provide effective pre-assessment support.
- There was a call for support to be more proactive. For example more connections and support could be offered through general practice, although it was appreciated that the impact of COVID-19 has necessitated less face to face and surgery time.
- Without a diagnosis of dementia it is not always possible to connect to support. Some services set diagnosis as a requirement for full support to be available.
- The needs of people experiencing cognitive impairment and their partners or family may be very different and should be considered individually. At the same time it's important that this is handled sensitively and in a personalised way which values the importance of relationships and mutuality to the wellbeing of both.



## **INCLUSION: HOW TO BETTER INCLUDE ALL THOSE WHO NEED SUPPORT AND REDUCE INEQUALITIES**

**'We need to be thinking of other ways of promoting and thinking of the wider community'**

Professional

- The issue of digital inclusion and how to reach those who do not have access to online material was raised as important to address. Virtual support has suited many people with dementia and their families during the pandemic. However, this has not always worked, is not available to all and is not always what people want.
- People from LGBTQ+, ethnic minorities, and other marginalised communities need more focus, greater access to co-production opportunities and ultimately more tailored support. Much of the available support fails to signal its inclusivity, meet diverse needs or adequately respond to what really matters to people.
- It's important to explore and respond to support needs identified by wider family and friends, in addition to the person with memory issues and their immediate partner. Well

supported these personal networks, even during times of social distancing, can provide essential support in ways commissioned professional services simply cannot.

- People with rarer forms of dementia are struggling to access support and diagnosis. There is a need to for a more mindful approach and to be aware of less common forms of dementia. This includes people seeking a diagnosis where memory issues are not a symptom.
- Some diagnoses come through alternatives routes (such as community mental health teams, and hospital specialists). Diagnoses made in these settings may not have the same access to support services as those made in memory clinics. It's vital that we think across the whole system.
- Pop-up services have worked for delivering the COVID-19 vaccination. This could be a possibility for delivering memory assessments.
- There is a need for better balance and focus towards what people with dementia want, alongside looking at and supporting the needs of families and partners.



## **STIGMA: OVERCOMING AN ENDURING BARRIER**

**'People are still fearful'**  
Professional

**'Choosing the right terminology is important'**  
Professional

- Stigma is preventing people from getting an assessment, a possible dementia diagnosis, and the corresponding support.
- Stigma can also prevent people from accessing support. There are perceptions that support is for those in later stages of dementia, or 'not for me'.
- Terminology is key and there is a lack of engagement with the terms dementia and Alzheimer's disease.
- Dementia is a progressive condition, but too often people think about the later stages of the disease. It gets forgotten that people can live well, wherever they are in the dementia journey, and that early symptoms are varied and can be subtle.
- There is a need to create opportunities for people with dementia to lead on positive messaging and education about dementia.

# WHAT'S NEXT?



The experiences people have told us about whilst waiting for a memory assessment make it clear that more help is needed. We recognise that it is still important to continue the discussion. DCAN will:

- Continue to explore the experience of people waiting for memory assessment appointments, to find out what information is most needed, wanted and valued at this time;
- Compile information from a variety of services that offer support , in a way that allows easy access to a range of different material and information to suit different needs;
- Develop and promote a website which will aim to answer some of the questions that people have during this time: [www.NextSteps.org.uk](http://www.NextSteps.org.uk).

[WWW.NEXTSTEPS.ORG.UK](http://WWW.NEXTSTEPS.ORG.UK)

**‘Left with no information at all.’**

Person with lived experience.

**‘Didn’t know who to ask’.**

Person with lived experience.

**‘Networks [formal and informal] are less accessible at the moment.’**

Provider talking of the experiences of people waiting for memory assessment or in early stages of getting a diagnosis

**‘A need to highlight the routes to support’**

The quotes above demonstrate why it is so important to provide the right support, at the right time.

People have told us that they need:

- Practical support now - not in a few months time;
- To know what to expect, how the assessment process works and the timeframe;
- To know what they can do to stay well and cope with difficult emotions that they might experience;
- Positive advice and tips for living well with memory difficulties and/ or dementia.

NextSteps.org.uk will provide links to a range of support available for people with concerns about their memory while they wait for their appointment. We will share information about the memory assessment process, including what to expect during the appointment. We will discuss advice and tips to promote wellbeing, relationships with family and friends, and how to cope with difficult emotions that many people experience in the time leading up to the appointment.

We will share the website with GPs, healthcare staff in memory clinics and hospitals, and community organisations. We want to make sure that every person referred for a memory assessment sees the website and knows that help and support is available.

## **QUESTIONS WHICH REMAIN**

There is more work to be done in this area and DCAN have identified the following questions to be addressed in the second phase of the project:

- How to include people without access to digital communication methods?
- How to ensure that people from under-represented groups, such as those from ethnic minorities and LGBTQ+ communities, receive tailored and inclusive information followed by personalised support and services?
- How to tackle the stigma and fear of dementia and focus people's thinking towards finding ways to live well?
- How to better support those with rarer forms of dementia through assessment and diagnosis?
- How can organisations work together to ensure everyone getting a memory assessment or dementia diagnosis is aware of the support available and can make informed decisions?
- How can we best meet the different individual and joint needs of people with memory concerns or dementia, their partners and families?
- How can we ensure non-dementia-specific sources of health and community support are accessible to more people with cognitive impairment?

## **GET INVOLVED**

DCAN is a collaborative, open, network and we want to continue the conversation, find examples of best practice, and share what works to help improve the experiences of people waiting for a memory assessment. Please contact us via [www.dcan.org.uk](http://www.dcan.org.uk) or by email at [contact@dcan.org.uk](mailto:contact@dcan.org.uk) if you have any questions or ideas: we'd be happy to discuss working together or disseminating information through our network.

DCAN is an Alzheimer's Society, NHS England and Improvement, and Coalition for Personalised Care joint initiative.



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