

Understanding dementia diagnosis during the Covid-19 pandemic

Project report



Introduction

The timely diagnosis of dementia has many benefits for the person and their family. This includes being able to access medication, post-diagnostic support and the opportunity to plan for the future.

The assessment and diagnosis of dementia is carried out in a memory clinic or similar service. The Covid-19 pandemic had a significant impact on the running of these services.

This report presents the findings of the **“Understanding dementia diagnosis during the Covid-19 pandemic: patient and practitioner experiences”** study.

It highlights what is important to the person with dementia and their family and provides lessons from the pandemic for future practice.



Co-produced approach

This study was co-produced by “BUDDs”, which stands for Better Understanding Dementia Diagnosis.

This group is made up of people with lived experience of dementia and researchers.

The co-productive approach allowed for the personal knowledge and understanding of living with dementia.

Doing so helped to enrich the research process and strengthen the outcome.

BUDDs met regularly throughout the project using an online platform to work together on the planning, analysis and reporting of the study.



Background

Many dementia assessment and diagnostic services closed at the beginning of the first UK lockdown in March 2020.

Healthcare professionals then began to develop new approaches to meet with their patients.

This could include the use of remote consultations, using online platforms for video calls and the telephone.

This study looked at the implications of these changes from the perspective of the person receiving the diagnosis and their care partner.

It also considered the impact on the healthcare professional and captured the lessons for the future of dementia assessment and diagnosis services.



What did we do?

We spoke to 11 people who received a diagnosis of dementia during the pandemic and five care partners from across the UK.



These were semi-structured interviews that had six topics of conversation.

1

A soft introduction to get to know the research participant and for the interviewer to share something of themselves.

2

How the person had experienced the pandemic and the ways it had impacted on their normal way of being.

3

Background to the person's diagnosis of dementia.

4

How the assessment and diagnosis took place and the impact on the person and care partner.

5

How they are doing now.


6

Their experience of post-diagnostic support.


What did we do?

We also spoke to 12 healthcare professionals from across the UK who were delivering dementia assessment and diagnosis during the pandemic.


These semi-structured interviews had three topics of conversation:



1. Initial impact of UK lockdown on their practice and how it evolved over the pandemic.



2. Impact of the pandemic and service changes on the healthcare professional and how they perceived the impact had been on the patient.



3. Lessons learned and looking to the future.

What did we find out?

Time is everything with dementia

Time is important when a person is diagnosed with dementia. Their past, present and future are all brought into sharp focus. The pandemic added an additional stress to the critical nature of time in dementia.

We found people expressed sadness and loss at who the person felt they had been in the past and how other people had viewed them.

This related to their abilities and achievements, such as being a talented artist, intelligent and clever, the one who would remember who everybody was and having responsibility and skill in the workplace.

“She was a neat writer, an intelligent lady, did a lot of paintings... she can’t get the enthusiasm for it now.”

“I was a professional person with responsibility and highly skilled.”

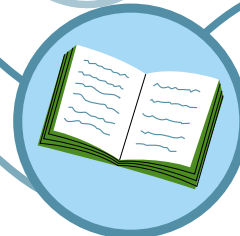
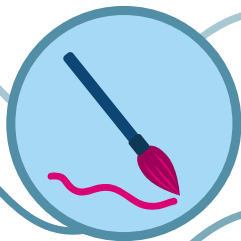
In the present there was a sense of purpose based on close relationships. Spending time with a partner, children and grandchildren were all an important anchor to the present moment. This also made the person feel fortunate.

“Having things to look forward to...seeing our daughter and her husband and the little fella...that’s great.”

Looking to the future, people were determined to value the time they had ahead of them and make the most of opportunities. This included spending time with their loved ones, travelling and attending special events.

“I am going to do everything in my power to keep happy and going.”

“I’m aware it can change in the years to come, but we’ve certainly got two, three, four, five maybe more useful years together, that we can get a benefit out of and give something back to each other.”



What did we find out?

Time is everything with dementia

However, people also expressed fear at an imagined future.

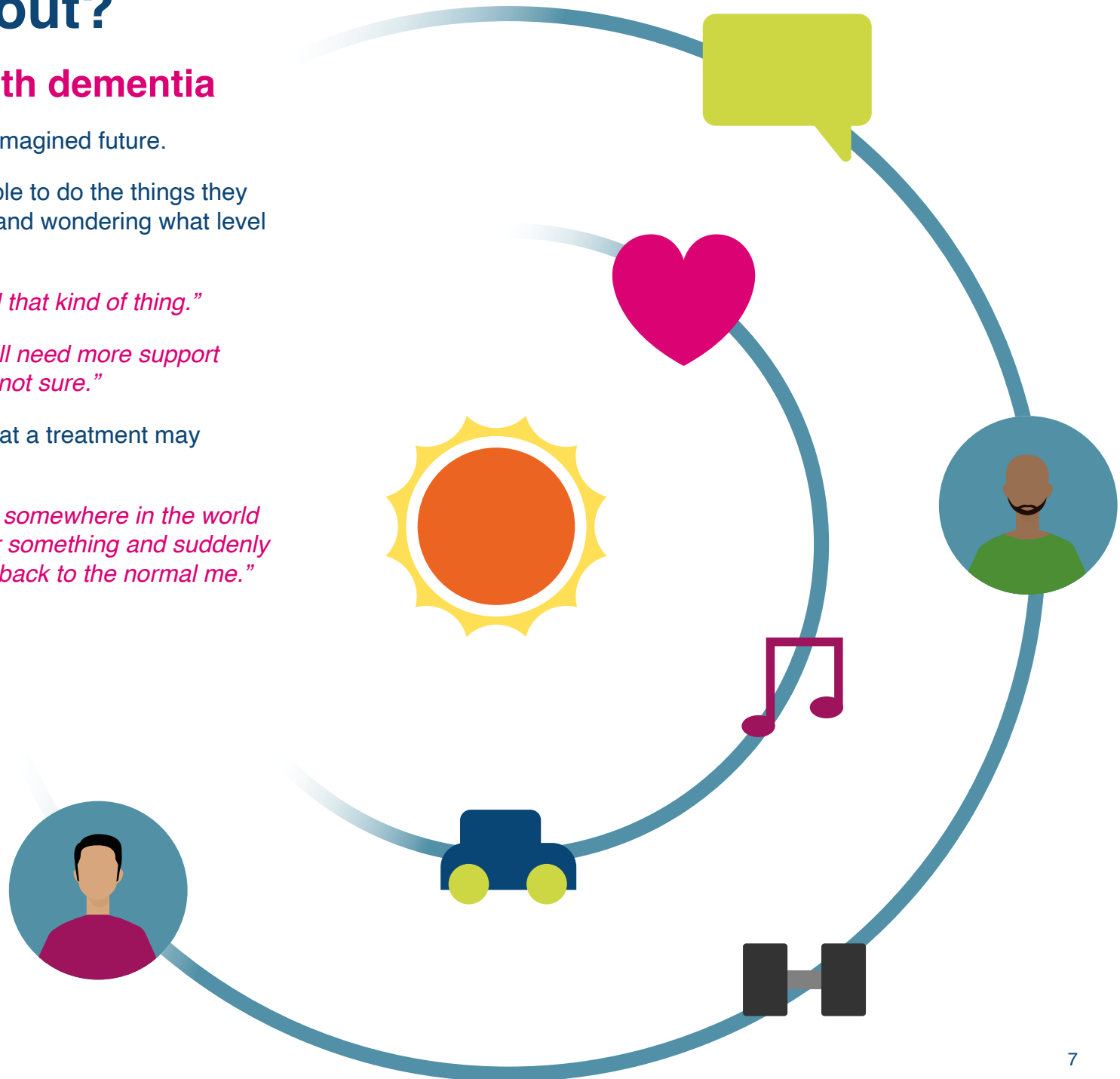
These concerns included no longer being able to do the things they enjoyed, not recognising family and friends and wondering what level of support might be needed.

“I had visions of him going in a home and all that kind of thing.”

“I do recognise that, possibly, ultimately, I will need more support from my family, friends, NHS, whatever, I’m not sure.”

But there was also an expression of hope that a treatment may provide a cure within their lifetime.

“I’ve still got a tiny bit of hope in me thinking somewhere in the world someone will be doing some trial or study or something and suddenly they’ll know...there will be a cure and I’ll go back to the normal me.”



What did we find out?

The pandemic added an additional stress to the relationship with time

We found that people had a belief that things would change at some point in their future as a result of dementia.

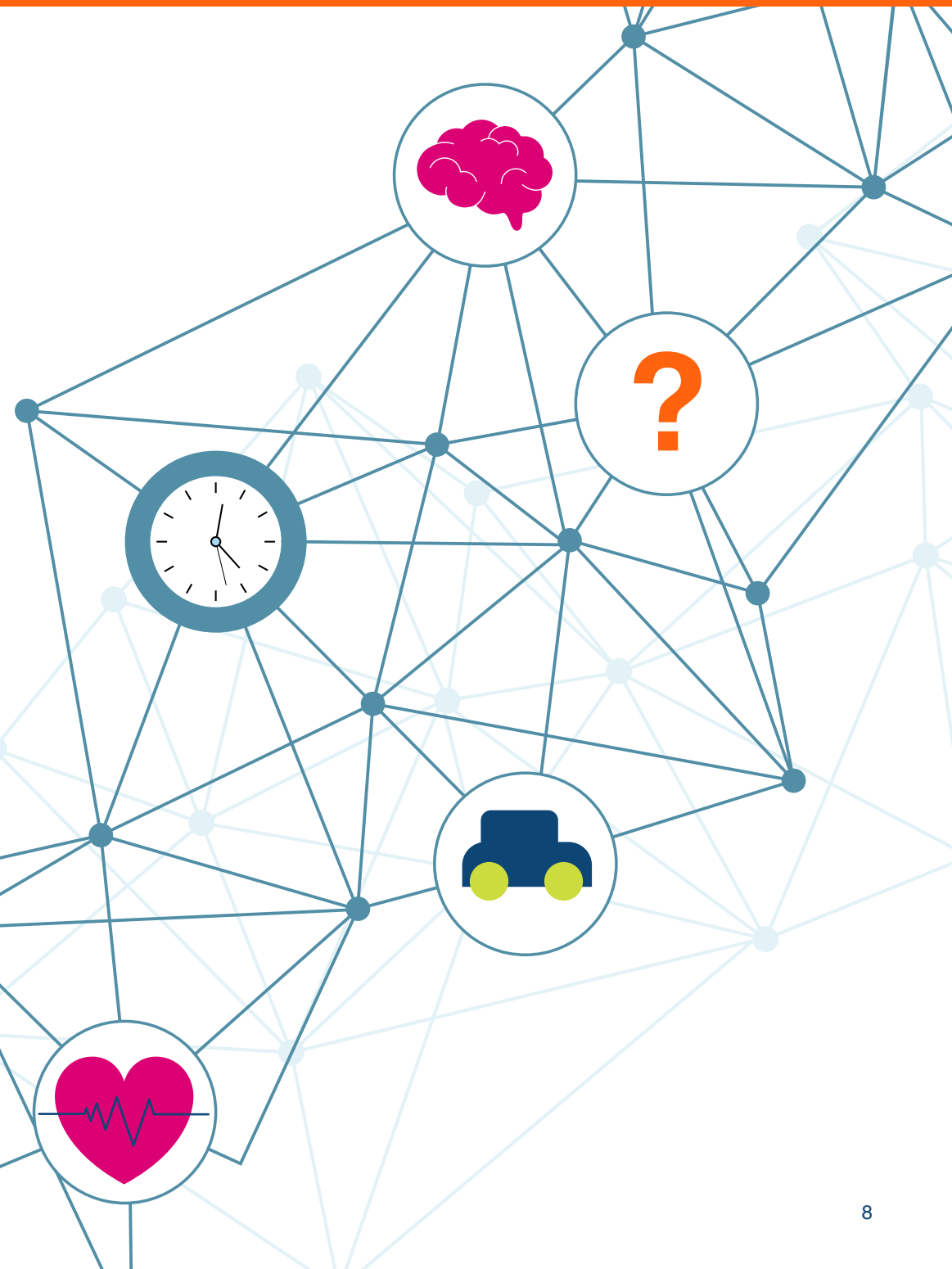
There was a feeling that the pandemic had taken some of their precious present time away.

“At this time of your life...basically a dead year, dead time.”

The pandemic had significant impact on the whole of society.

For those who received a dementia diagnosis during the pandemic, it was an additional complexity amidst the life-changing event. But receiving a dementia diagnosis was the constant.

“When he (healthcare professional) tells you, it’s like, bang, a switch is being flicked and that’s it. And everything fell into place. And everything changed.”



What did we find out?

Everything changes

There was a period of adjustment in coming to terms with the diagnosis of dementia.

There were a range of emotions associated with this process, including disbelief, anger and fear. For some the adjustment involved searching for answers, wanting to understand why it had happened and seeking as much information as possible about it. Whilst others chose to limit the information for the time being and take a one day at a time approach.

“I also asked her (healthcare professional) for the report she was going to give my doctor because I want to know what she was saying about me.”

“We have got information which I must admit we haven't really followed up...we will do when we feel ready I suppose.”

There can be a change to what people do following a diagnosis of dementia. This can be as a result of those closest to the person limiting what they do from a position of concern.

Families are naturally risk adverse. However, the person could also withdraw in response to the challenges they are experiencing due to the symptoms of the illness.

“I've always been into DIY...you know, I'll have a go at anything... both of them don't want me to do it. And I can do it no problem at all... but now that doesn't happen, does it.”

“And then she gave up driving. She couldn't be bothered driving. She didn't want the worry of driving the car.”



What did we find out?

Everything changes

People with dementia can also experience a change in the way a wide group of people respond to them, including family, friends and healthcare professionals.

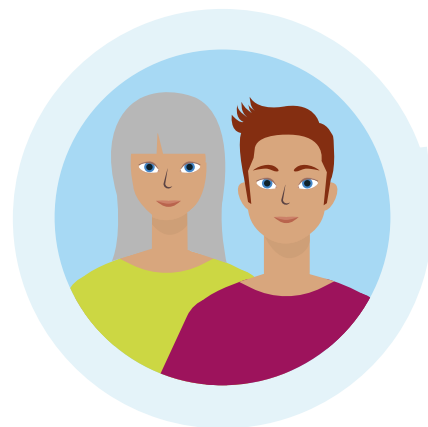
“But they’re already acting as if...does he take sugar...we go to the doctor’s, he is insistent now that if I need to go for anything...I’d have to take my wife with me.”

“I think to myself...every time you see the same aunties and that, ‘oh you look well!’ You know, what am I supposed to look like?”

Receiving a sensitive and supportive response when sharing the diagnosis of dementia is important and is upsetting for the person when it is not forthcoming.

“I already knew she was a good friend of mine but you know...I know she’s there for me.”

“I really, really just want somebody to say, I’m sorry, you know...but I wasn’t getting the nice reactions.”



What did we find out?

Diagnosis during the pandemic

Most people had understood any delays within the context of the pandemic and were grateful to receive an appointment with a healthcare professional. These appointments could be face-to-face with safety precautions, by telephone or video call.

“They tried their best in difficult circumstances, it wasn’t their fault and I appreciated that.”

“It is a strange thing to be told what we got told with someone wearing a mask...and is it ideal, definitely not, but it’s what it is.”

“It was fine, my life has always been over the telephone...it didn’t bother me getting information over the telephone. I think he asked me if I would be happy having the conversation over the telephone in the future and I said yeah, that is okay with me.”



However, a delayed appointment did make one couple believe that the situation was not urgent. This meant the diagnosis came as a shock to them, as it had not been anticipated.

“Well because the appointment was so delayed I...we didn’t think it was that important, did we...”

A video call consultation could present challenges for some and it was felt face-to-face provided more opportunity for connection. It could be difficult for the person to understand what the healthcare professional was saying when not in the same room together and fully understand their meaning. Video call was suggested as a kind of “virtual reality” and “not the real world”.



What did we find out?

The diagnosis experience remains with the person

The manner and approach of the health care professional has a significant effect on the person being diagnosed and their partner.

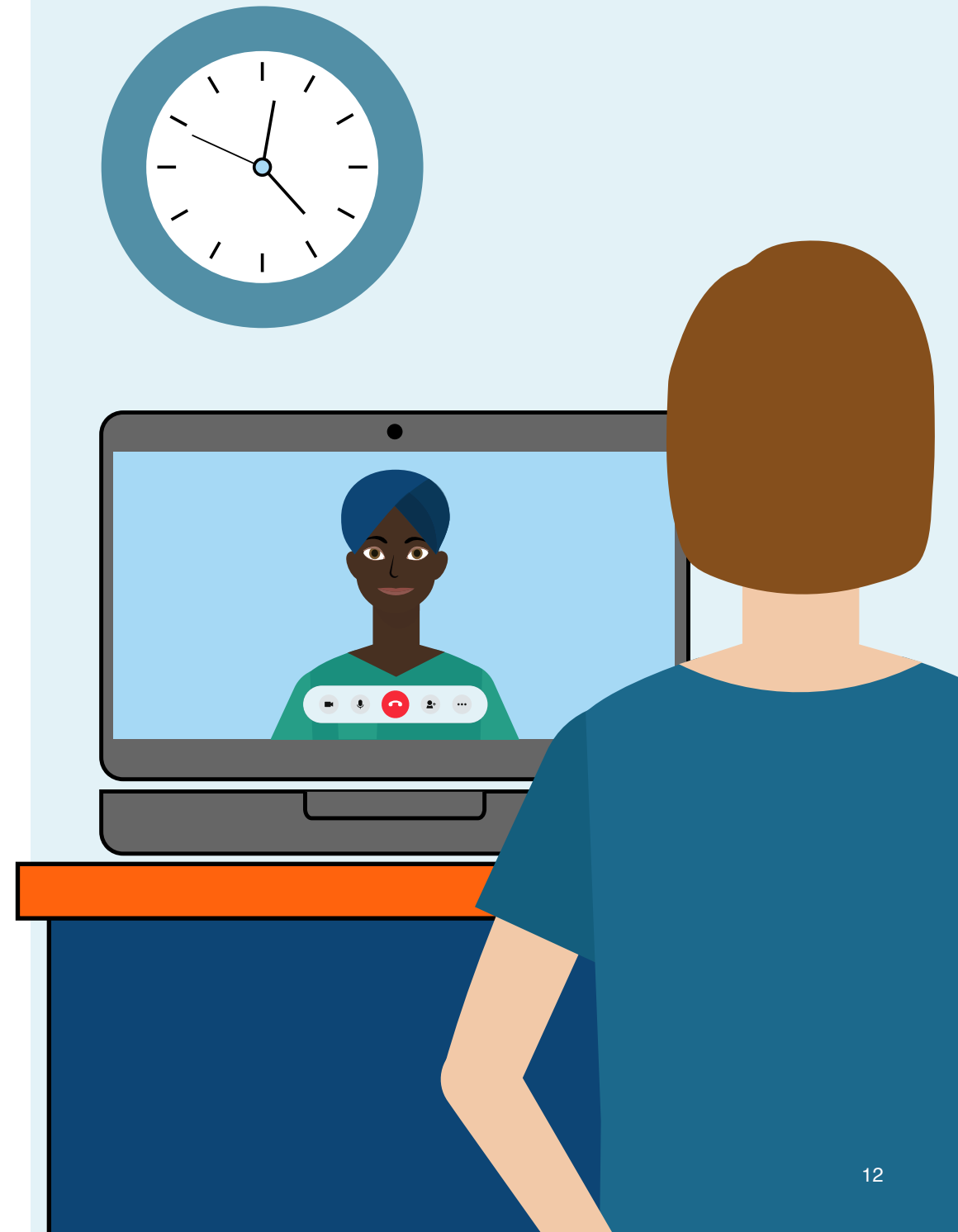
The impact of kindness or a contrasting lack of compassion continues to be felt and influences the ongoing experience for the person and their family.

For one person asking the healthcare professional during a telephone diagnosis if they could continue driving, they were met with an abrupt response that took away an important life activity with no compassion or discussion.

“I was totally taken aback that he just said, well if you want my advice, chop up your driving licence and send it to the DVLA...I was always happy behind the wheel and feel they have just taken it away.”

In contrast, another person received consideration and sensitivity during a video call consultation.

“I think she was trying to be nice to me because she knew that I was on my own and we weren't together in the real world so she sort of didn't say it was definitely going to be dementia but in a way she did because she said it's a degenerative condition.”



What did we find out?

Healthcare professionals rose to the challenge under difficult circumstances

The pandemic had a significant effect on healthcare professionals delivering dementia assessment and diagnosis. It was a challenging time with so many uncertainties and changes happening around them such as having an increased workload and colleagues being redeployed to other services that were deemed more urgent.

“Even though we are not on the front line watching people die of Covid every day, we are dealing with the more subtle results and impact of it.”

There was an initial shock at the outset of the lockdown at what was happening. As healthcare professionals began to adjust to the pandemic, they devised new approaches to meet with their patients. However, there were still many difficulties including restricted opportunities to have face-to-face contact with colleagues and the risks associated with contracting Covid-19.

“We had people who were admitted to the hospital from our team.”

“Our service was complicated by quite a lot of our consultants getting Covid early on.”

“It feels more lonely...you don't see many of your colleagues face-to-face which is a bit of a loss.”

There were some positives for the healthcare professional. A professional at an earlier stage in their career had the opportunity to take on additional responsibility, working closely with nursing colleagues.

For a senior healthcare professional who had felt the responsibility to role model resilience to support colleagues, there had been an opportunity for personal growth.

“I got to know the nurses really well in that period and built that trust, you really felt like a team and people were doing really inspirational stuff.”

“It all took its emotional toll, but I think I have come out a stronger and a better person.”

There were also some positive aspects in relation to the new approaches that had been adopted as a result of the pandemic.

This included making greater use of the telephone to find out more information directly from the patient in order to prioritise the waiting list and checking-in to see how they were doing in the meantime.

“The way we triage (nurse telephoning patient) and prioritise is a really good way of dealing with future problems that might arise. There was a little bit of that before, but not to the same extent.”

“Our nurses have been phoning people to check-up when they have been waiting to come into clinic and I think that has been a positive thing, as a lot of pointers can be given in advance”



What did we find out?



You can use technology, but it has to work for people and they need choice

Dementia assessment and diagnosis took place face-to-face pre-pandemic; this was typically in a clinic setting but could also be in the person's home.

Pandemic approaches were remote consultations using the telephone or online platforms for video calls and face-to-face clinics or home appointments with appropriate precautions, such as the use of masks and social distancing. Each of these approaches had limitations.

The introduction of technology could be challenging for the healthcare professionals, with some initially having a preference for the telephone as it was familiar and comfortable. Others had a preference for video call because it provided a visual in addition to the voice.

"I think I was just a bit reluctant because I'd never used it (video call) before and I thought I can't see it working so I kind of hid behind that and just used telephone."

There were issues when using video call and telephone.

These included not being able to control the environment and see everything that is going on during the assessment, not knowing who was in the room with the person and being more reliant on family members to do most of the interactions.

"If you're on the phone and you don't know who else is in the room or they're on a screen by themselves and you don't know whether anyone else is listening in... being on a telephone speaker as well you don't always know who's listening or who is speaking."



What did we find out?



You can use technology, but it has to work for people and they need choice

There was an “invisible barrier” when the healthcare professional was not in the same room as the person and it was more difficult to comfort the person.

It could be difficult for the person to connect with what they are being told over the telephone. There was also a concern in diagnosing a person they had never physically met.

“If you have a person in a clinic room and you tell them (they have dementia) they remember that, more than if you have someone on a screen telling them something.”

Healthcare professionals highlighted the benefits of carrying out an assessment face-to-face, things that are absent when not in the same room as the person.

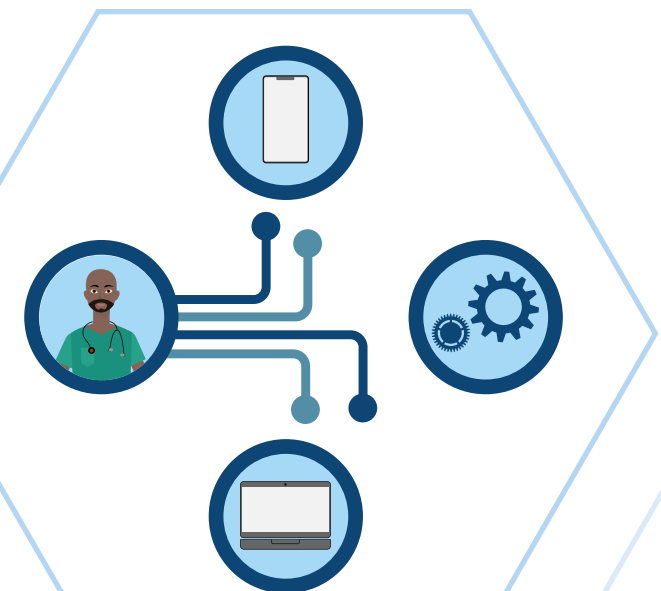
These include being able to see how the person walks and assessing frailty, having the opportunity to carry out a physical assessment, picking-up on subtle clues and cues that can assist the diagnostic process and being aware of emotional reactions.

Although the use of masks did present issues with clinic and home appointments, particularly for hearing impairments.

“You miss all of those non-verbal cues and you do feel like you are working in the dark (video call and telephone consultations). I found that it took so much longer to form an impression of the patient and also to get my head around what was going on for them – because those clues and cues you would get from them just weren’t there.”

Technology did have benefits, such as the person, their family and healthcare professional not having to travel and allowing family members to attend from other locations.

However, there are considerations when using technology such as issues of accessibility and digital exclusion for the person and families. Healthcare professionals also need to be supported with the right sort of technology and training.



What did we find out?

Pandemic impact on post-diagnostic support

People received a wide variation in formal support following the diagnosis.

At one end of the scale there was a full year of post-diagnostic support from a named worker and at the other receiving a letter inviting the person to get in touch if they had “a pressing need”

Being given written information was a common theme and people could be overwhelmed by the volume provided.

“If you have a pressing need, you need to phone and we’ll see what we can do. And I thought I wish that word hadn’t been there cause I am not sure that this is a pressing need.”

“They deluged us with paperwork, with books to read and things like that, which, quite honestly was too much. So they don’t get read.”

Where a couple received a full year of post-diagnostic support, it had been integral to them coming to terms with the diagnosis, developing coping strategies and planning for the future.

“So I would say the support package has got a higher relevance to play, along with the telephone conversation, discussion and diagnosis than possibly most people would appreciate.”



What did we find out?

Pandemic impact on post-diagnostic support

For some, joining groups and taking part in online activities played an important role in their post-diagnostic support. However, groups were not appropriate for everyone.

“What has been great really is the last 20 months or so I’ve been hooked-up with so many great organisations.”

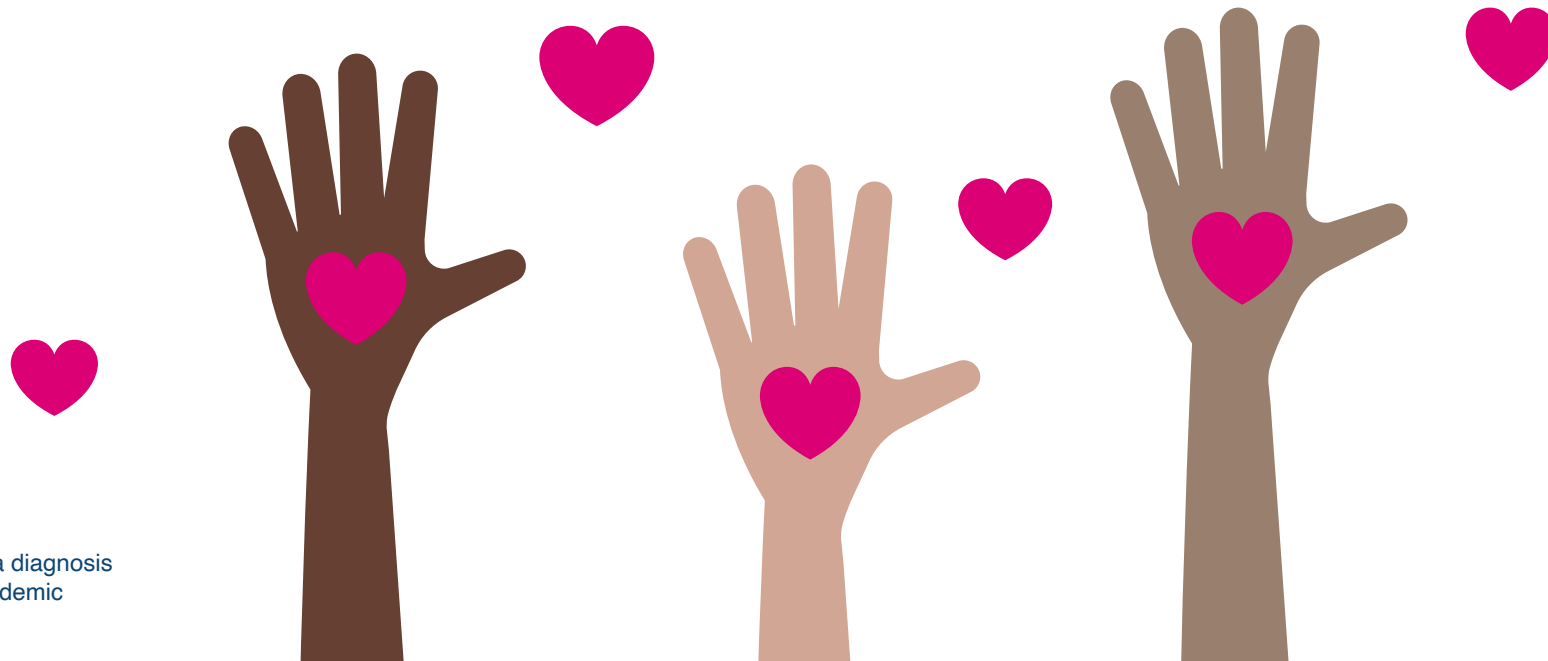
“These groups I attend (online), they have become like a little family...one time I couldn’t attend because I was getting some work done on my flat. When I went back they all said they had missed me.”

“There are these sort of Zoom meetings and things, but I think when you don’t know anybody and you don’t know who’s going to be there and what is going to be happening...”

Healthcare professionals highlighted that the pandemic had resulted in the loss of a wide range of post-diagnostic support options for providing their patients with a “treatment plan”.

Voluntary sector organisations are key partners in providing post-diagnostic support. These services were not available during the pandemic and this placed greater strain on the healthcare professional as they could be the only resource for their patients.

“From my point of view it has just highlighted how important they are (voluntary organisations)...they are everything, that structure and routine. I find myself more aware of these things and referring to them more. I think it is a positive because you realise how important they are and when they go away things fall apart.”

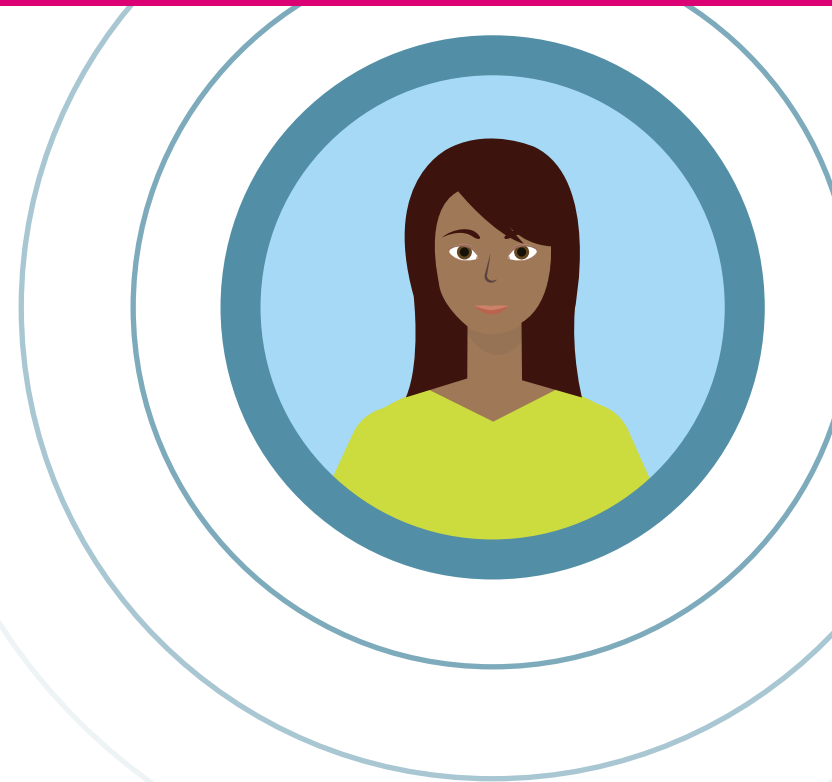
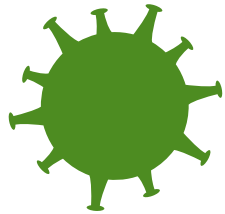


What did we find out?

Pandemic impact on post-diagnostic support

Healthcare professionals felt that people were more on their own with the diagnosis without post-diagnostic support. One healthcare professional expressed their concern at re-starting memory clinic-run groups as it could be responsible for an outbreak of Covid-19 with “disastrous consequences”.

“It’s probably the most satisfying bit of work that we offer and the bit of work we’re probably proudest about but it’s been the hardest one to think about re-starting because the legacy of this virus is going to be a hard thing to shake.”



What did we find out?



The pandemic offered learning for future practice

The pandemic resulted in new and creative approaches in dementia assessment and diagnosis. This included making more use of telephone contact with patients and their families in order to stay connected to those on the waiting list, to gather additional information, and provide advice and information and for follow-up consultations post-diagnosis.

Technology played an important role during the pandemic and supported healthcare professionals to keep connected to their patients. The person, care partner and healthcare professional all highlighted the importance of having the assessment and diagnosis sooner, even if it was not under ideal circumstances.

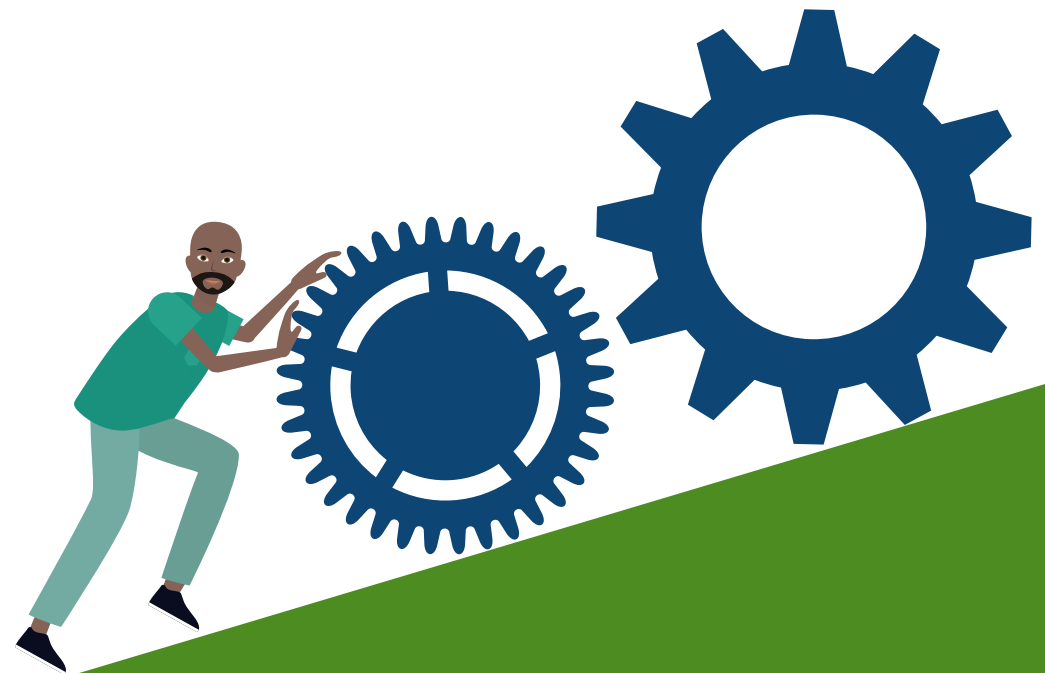
Technology and the telephone is likely to continue to have an important role and allows for patient choice. However, there was a preference for face-to-face dementia assessment and diagnosis from the person, their family and healthcare professionals.

The pandemic has been hard for healthcare professionals and they did their best under difficult circumstances. The healthcare system was not geared-up to cope with the challenges of the pandemic fast enough.

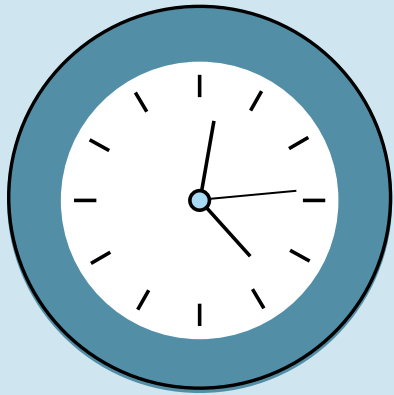
Reflecting on learning from the pandemic, healthcare professionals felt that dementia assessment and diagnosis services should not have been stopped at the beginning of the UK lockdown.

“It was a very knee jerk response. I have to say with the benefit of hindsight we could have done it a lot better than we did, it was just panic at that time; but we’ve learned lessons from it, it won’t happen again not like that.”

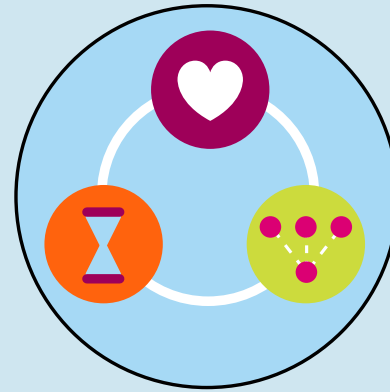
“Looking back, we should have just adapted quicker to doing things in a different way. Because once you stop doing something, restarting it is really hard, it is much easier to change rather than stop and start.”



Key messages



Time is precious: in dementia time is everything. People need time to talk and listen, to grieve and to live.



People need time when receiving a diagnosis of dementia: for every person who experiences patience, compassion and choice from well supported healthcare professionals, there will be more time for the most important thing, to live well.

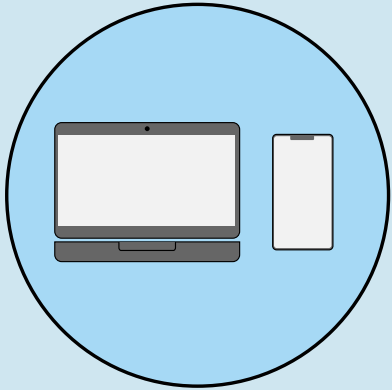


Supporting people to do what they love for as long as they can: you need to manage the risk, but giving someone the confidence is a gift. Some changes are inevitable, but minimising these and providing reassurance is important.

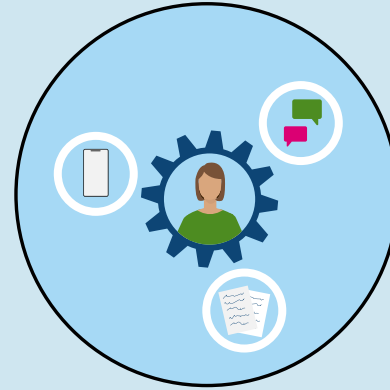


Diagnosis best face-to-face: bad news is best face-to-face. Diagnosing digitally is impersonal and more difficult.

Key messages



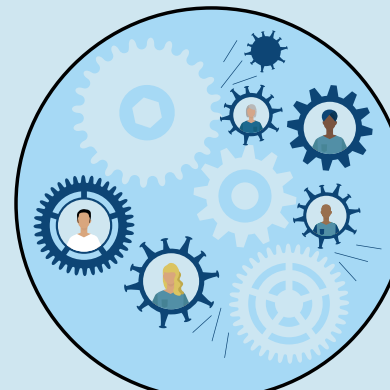
Digital choice: you can use technology, but it has to work for people and they need choice.



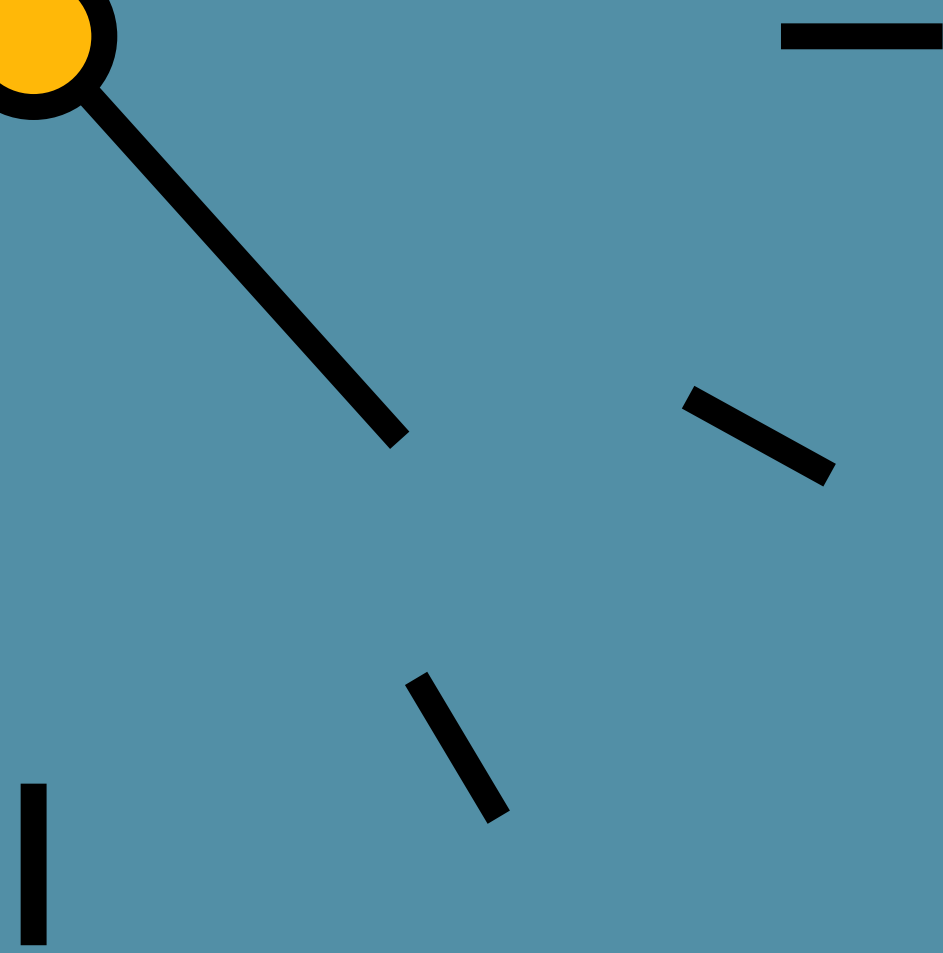
People need to be properly supported: ensuring people receive the right resources and are not overwhelmed with too much written information. There is an important role for the voluntary sector in providing post-diagnostic support.



Compassion for healthcare professionals: they faced huge challenges and did their best under difficult circumstances. They care too, that is clear. They need to be supported with the right sort of technology and training.



Learning from the pandemic for future practice: we need to think about the future, how to cope now and if there is a next time. Healthcare leaders should ensure services don't stop in a future crisis, adaptability is vital.



For further information contact the Alzheimer Scotland Dementia Research Centre, The University of Edinburgh:

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