



COVID-19 and dementia: Factors affecting patient outcomes and experience along the dementia pathway

The COVID-19 pandemic has impacted significantly on the delivery of NHS services. We have an opportunity to learn from the rapid and necessary service transformation and consider how we recover our services.

Dementia remains a diagnosis with significant impact with a need to balance the timeliness of diagnosis with patient experience and outcomes. Covid may become endemic and our adapted ways of working may become the new normal.

Recent webinars have brought clinicians, service managers and commissioners together to consider factors affecting the dementia pathway in a Covid environment. This document aims to give an overview of factors identified that affect the pathway.

Factors affecting patient outcomes and experience: a checklist

The overall aim of the dementia pathway is to provide personalised care to meet the needs of people with dementia and their carers. Delayed presentation and assessment reduces the opportunity for effective support. System-wide factors include:

- Diagnosis is challenging where face-to-face consultation capacity is limited
- The dementia pathway crosses many organisational boundaries (primary care, secondary care, acute care and social care)
- Underlying infection can alter cognition and behaviour in dementia and increase need for care and support
- Behavioural challenges observed in people with dementia may increase as usual routines and activities change
- Greater difficulty if people with dementia require hospital care, with resulting increase in confusion and distress in changed environment where carer access may be restricted
- An increase in carer burden as families self-isolate and the carer role grows
- Concerns from carers at risk of COVID-19 infection over who will support them if needed

This checklist poses a series of questions to consider as we work together as a system aiming to reduce variation and potential inequity in new ways of working.

Risk management

- Does your triage process give you enough information to make a risk-based decision for subsequent action?
- Has high level risk been identified (e.g. challenging behaviours, falls, extent of cognitive impairment, carer mental health issues)?
- Do you have a follow up process to monitor any identified risks?

System working and interfaces

- Individual fears and changes in service provision have resulted in a drop in contacts with NHS services. How has this impacted your part of the system/service?
- Social media and press releases are ongoing. Are you, your teams, your services up to date with the latest information? What impact might this have?
- Footfall in primary care has reduced. Are there other opportunities to identify memory concerns e.g. in care homes, in CMHT teams, in long term condition management?
- Has the person been physically seen by a GP or health care professional?
- Does the individual have care and support from partners and family in a socially isolating society?
- Could the GP make a diagnosis with support from MAS?
- Can other interfaces also be considered e.g. care homes, social care?

- Is there a role for the acute trust to screen more acute admissions for cognitive decline?
- Is there a local delirium pathway that encourages re-screening on recovery?

Patient Choices

- Is the person shielding/vulnerable? Does this affect your process?
- Are family members/cares shielding/vulnerable?
- Is the patient reluctant to engage with health services due to perceived risk of face to face contact with staff or clinic/imaging sites?
- Is there a family member of carer on the call?
- Does the patient have a preference for a phone call or video? Have the pros and cons been explained?
- Are you able to have an open conversation with the patient or carer (mood, psychosis, suicidal ideation, confusion)?
- Does the patient feel more comfortable in a face to face consultation? What can be done to help them feel supported in a remote call?
- Does the patient want to wait until face to face is available? Have the pros and cons of waiting been explained.
- The use of PPE has itself been identified as a challenge for those who are hearing impaired or confused. How can this be mitigated?

Ongoing Covid screening

- Does the patient/carers/family have signs of Covid-19 or contact with someone who does?
- How is this communicated and recorded?
- Is testing available, appropriate?

Face to Face consultations

- Is a face to face consultation required and why?
- Where will the face to face take place, in a clinic or home environment?
- Can clinical space be made safe (distancing, cleaning, PPE, waiting room management)?
- Do your staff have the correct PPE to undertake a face to face consultation?
- Can adequate infection controls be put in place in a patient home?

Remote consultations

- Do you have a remote call protocol?
- Does it include a reminder call, introduction process, explanation of what will happen on the call, how to gain consent, the types of questions/actions that might be asked/undertaken, what will happen following the call)
- Video calls may take longer, be more tiring, may need different record keeping times/skills.
- Video call may have more than 2 people on the call
- Can you see the wider environment, background noise, distractions, who else is in the room, who is in ear shot)?
- What is the aim of the appointment? Clinical history information gathering, Assessment follow up?
- If the call is to undertake part of the process how do you flag for follow up?

Consent and confidentiality

- How is consent taken and documented? Is the person with memory concerns able to understand the process in this environment?

- Who is in the 'room'? (Patient, carer, family, children, others)
- Is the virtual consultation taking place in a private home or communal space?
- Is the phone on speaker?

Technology (availability)

- Does the person own and use of the phone (landline/mobile)?
- What technology is available and does this matter (tablet, PC, broadband, webcam, wifi)
- Is there a good internet connection? if broken is there a protocol to stop, continue or reschedule the consultation?

Technology (ability)

- Are there any barriers to using the technology e.g. language, ethnicity, age, disability (hearing or vision impaired)?
- Are there any impairments that may make technology use challenging e.g. hearing or speech impediments?
- Are carers or family members available to support technology use?

Have treatable causes of memory decline been ruled out?

- Have other organic causes of memory decline been excluded- e.g. delirium, infection,
- Do you need to physically see the patient to rule out treatable symptoms? (cardiac arrhythmia, blood pressure changes, parkinsonian, postural stability)
- Can you do this based on clinical history?
- Do you suspect depression or anxiety? Can you refer to IAPT or recommend internet-based apps?

Tests

- Is there flexibility due to test availability and do you have the most recent information?
- **Have blood tests been performed during the history of cognitive decline?**
- Do you have recent BP/pulse?
- Does the patient have a BP machine?
- Are community services able to help?

Cognitive testing

- Has the GP conducted a screening test? Which one? Was this face to face or remote?
- Which cognitive screening test are you using?
- Are you doing this remotely, do you know the pros and cons?
- Are you documenting the remote circumstances of the test?
- How are you managing any risks?
- How will you conduct the screening virtually e.g. email clock face etc?
- Do you feel the sensitivity of the cognitive screening test is appropriate in this patient?

Imaging

- What imaging is available in your area?
- Why do you need the imaging, to rule out, to confirm to explain?
- Is the patient likely to decline imaging due to perceived risk of attendance on site/interaction with healthcare staff?
- Do you have a previous scan that may be useful or can be rereported?
- Have you explained risks and benefits of imaging at this time/later to patients?
- Can you add your patient to an imaging waiting list? Do you need to monitor your patient in the interim period?

Neuropsychology

- Is this better via video link rather than phone (f2f comparable)?
- Do you have the required level of patient engagement?
- Are you able to achieve some level of testing with follow up for formal outcome?

Medication

- What are the risks of initiating cognitive enhancing medication (cholinesterase inhibitors) without an ECG in absence of cardiac history and pulse reading in this patient?
- Can pulse reading be taken by patient/carer? How accurate is this in this individual?
- Do you have a pulse reading taken by other HCP or from previous notes?
- Is it better to prescribe Memantine over AChEI (e.g. Donepezil) in the short term?
- Does the interface between Primary care and MAS support monitoring and care, post prescribing?
- What is the potential impact of polypharmacy for this patient?

Remote confirmation of diagnosis

- Are you able to have sensitive, informative and constructive conversations?
- Is there a carer or family member available to have a discussion with too?
- Are there a range of treatment options for the patient to consider?
- Does the patient need additional time for questions and understanding in a remote system?

- The patient may not have had a face to face conversation with any one in the system recently, How might his impact the patient?
- Is there an increased role for dementia advisors in the current environment? These services may also have limited capacity or be functioning differently during Covid?
- Can you refer to CMHT or social services at the current time? What do these services look like?

Post diagnostic support (with working or confirmed diagnosis)

- Can support be put in place based on working diagnosis to minimise risk (falling, information on managing behaviours etc)
 - Can primary care continue with Annual Dementia Reviews?
 - Is there a named Dementia Advisor that can be linked with patients during the course of their dementia?
 - Is there information or support to reduce future vascular risk
 - Are we supporting carers who may have their own health needs and the carer burden?
 - Are virtual carers groups available in your area?
 - Is there any virtual support, online living-well Information?
 - Is NICE recommended carer psychoeducation/skills training available?
- Do you have access to virtual Group Cognition Stimulation Therapy?
 - Is there a local directory of services (web based) to support and signpost people with dementia- e.g. Dementia Roadmap?

Supporting staff

- Is the HCP working from their home environment, is it confidential and away from distraction?
- Remote working may offer staff more flexibility. Do you staff have a preference in the longer term, how will this be managed?
- Video calls may take longer, be more tiring, may need different record keeping times/skills. What support is available for your staff.
- Are there mechanisms for staff to share information or concerns with others in the system?
- Do shielding and BAME staff feel supported?
- As work patterns change, more home visits may be required. How sustainable is this within your teams?
- Does having virtual MDT meetings increase connectivity of staff between and across teams?
- Is there a local helpline for patients or carers to access?
- Are local services available to support patents- e.g. day centers, coffee mornings, respite. activities

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