

Adapting post-diagnostic dementia support in England and Wales during the COVID-19 pandemic

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Our Aim: To understand the changes to post diagnostic dementia support in England and Wales due to COVID 19

Part of PriDem study (<https://research.ncl.ac.uk/pridem>) – improving post diagnostic dementia support

- What services were able and unable to provide for people with dementia and their families during the pandemic
- Challenges services and staff faced
- Any positive changes that have occurred
- How dementia services might be delivered in a 'post pandemic world'



STAY HOME
▼
**PROTECT
THE NHS**
▼
SAVE LIVES



NATIONAL RESTRICTIONS

5 NOV - 2 DEC

- You must stay at home
- Only leave home for food, medical reasons, exercise, education or work
- You must work from home if you can
- Avoid travel unless essential
- Schools and essential shops will remain open
- Remember: wash hands, cover face, make space

For the latest guidance, visit [gov.uk/coronavirus](https://www.gov.uk/coronavirus)

TIER 3

VERY HIGH ALERT

FROM 2 DEC

MEETING FRIENDS AND FAMILY No mixing of households indoors, or most outdoor places, apart from support bubbles. Maximum of six in some outdoor public spaces (e.g. parks, public gardens).	BARs, PUBS AND RESTAURANTS Hospitality is closed, with the exception of sales by takeaway, drive-through or delivery.	RETAIL Open.	WORK AND BUSINESS Everyone who can work from home should do so.
EDUCATION Early years settings, schools, colleges and universities open. Children, other supervised activities for children, and childcare bubbles permitted.	INDOOR LEISURE Open. Group activities and classes should not take place.	ACCOMMODATION Closed (with limited exceptions).	PERSONAL CARE Open.
OVERNIGHT STAYS We advise against overnight stays other than with household or support bubble.	WEDDINGS AND FUNERALS 15 guests for weddings, civil partnerships and wakes, 30 for funerals. Wedding receptions not permitted.	ENTERTAINMENT Indoor venues closed.	PLACES OF WORSHIP Open, but cannot interact with anyone outside household or support bubble.
TRAVELLING Avoid travelling outside your area, other than where necessary such as for work or education. Further exemptions apply. Reduce the number of journeys where possible. Plan ahead and avoid busy times and routes on public transport. Avoid car sharing with those outside of your household or support bubble.	EXERCISE Closed and organized adult sport can take place outdoors, but people should avoid higher-risk contact activity. Group exercise activities and sports indoors should not take place, unless with your household or bubble. Organized activities for elite athletes, under-18s and disabled people can continue.	RESIDENTIAL CARE COVID secure arrangements such as substantial screens, visiting pods, and window visits. Outdoor/airtight visits only (without of rapid testing will enable indoor visits including contact).	LARGE EVENTS Events should not take place. Drive-in events permitted.

Find out what support you can get

For example, if you're out of work, need to get food, or want to take care of your mental health.
[gov.uk/coronavirus](https://www.gov.uk/coronavirus)

If you have any coronavirus symptoms:

A high temperature + A new, continuous cough
 A loss of, or change to, your sense of smell or taste
Get a test and stay at home

For more information and detailed guidance visit: [gov.uk/coronavirus](https://www.gov.uk/coronavirus)

The reality for people living with dementia and their carers

- **Many services initially closed** such as memory clinics (diagnosis), day centres and respite care
- Many **people with dementia were classed as clinically vulnerable** and advised to shield (no contact with any other households)
- People with dementia and carers were **isolated from their formal and informal support networks**



Methods - Qualitative interviews

- 21 professionals involved in funding, managing and delivering post-diagnostic dementia care
- Health, social & voluntary sectors
- Professional backgrounds included GP, Admiral Nurse, Occupational Therapist and Dementia Support Worker

Methods - Analysis

- Framework Analysis (Gale et al 2013)
- 3 key themes and 10 subthemes relating to the **challenges services faced**, how they **responded to the challenges** and the effects of COVID-19 **on future post-diagnostic support**

Challenges

Changing and conflicting guidelines

Access to support

Emotional and physical impact of COVID-19

New and heightened risk

Responses

Adapting practice to new and emerging needs

Additional support for staff

Use of technology and remote working

Future

Impact on funding and commissioning

Unmet need

Retaining changes made during COVID-19

Service-related challenges

- Some services closed down - widened inequalities, 'knock-on effect'
- Reduced availability of staff - furloughed, redeployed, clinically vulnerable
- Reduced access to support for service users and staff
- Risks to staff physical and mental health
- Needs of person living with dementia and carers - risk of catching COVID, isolation, worsening dementia symptoms

Risks to staff physical and mental health

[...] listening to stories over the phone, family tragedies, deaths from COVID, and carers struggling because loved ones have gone into hospital. That has been really, really quite difficult emotionally for all of us. Because I think, you know, historically we would have just said, “Right, this person needs an emergency visit,” we go out and we try to put as much in place as we can. However, if that person has got COVID then we cannot just go rushing out because then we are putting all our colleagues and other people at risk. So we feel quite disabled (S603, dementia support worker)

Response to challenges

- Taking stock of caseload
- Changing focus of service
- Increasing provision of support to staff
- Shifting to remote working – new normal
- Virtual solutions adapted rapidly with changing need and guidelines
- Logistical issues - access to equipment, skills and confidence
- Early adopters pre-COVID better placed to adapt to changes

Adapting practice to new and emerging needs

[...] on the whole, services are trying to sort of maintain some level of support as best they can. There have been some quite innovative ideas put forward from some of the community voluntary sector. People doing parcels instead of having a monthly meeting, they'd send a monthly parcel and try and do Zoom meetings and things like that to provide some sort of social and occupational therapy (S043, GP)

Effects of COVID-19 on future post-diagnostic support

Positive	Negative
Opportunities for culture change	Impact of priority shifts on dementia funding and commissioning
Blended working – face to face and remote	Unmet need - reduced service provision, delayed diagnosis and isolation
Triaging and better prioritisation of caseloads	Resources reprioritised/reallocated to deal with COVID

Opportunities for culture change

These meetings were not happening before, or they used to happen once a month in a boardroom somewhere. If you trudged over there and spent hours finding parking before you got into the meeting, all that kind of nonsense which sort of beat the purpose. That sort of thing [meeting] is happening far more now. I am far more aware of who my counterparts in local authority are. So, if I need to raise questions or get answers I know where to go. (S059, GP commissioner)

Conclusions and implications for the future

COVID-19 exacerbated existing challenges for the provision of post diagnostic dementia support

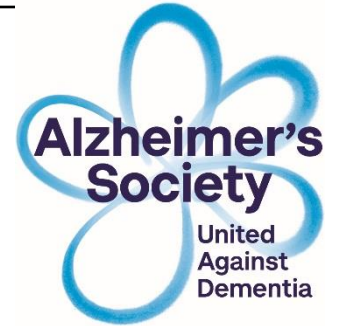
Many services were innovative and creative in finding new ways to provide much needed support

Remote working is likely to become an important facet of service provision offering choice and flexibility to service users.



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Thank you



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