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Dementia wellbeing in the COVID-19 pandemic

Introduction

An estimated 675,000 people in England have dementia, the majority of whom are over 65 and have underlying health conditions. They are supported by a similar number of carers, many of whom are older people themselves. It is estimated that a quarter of people in acute hospitals and three quarters of the residents of care homes have dementia.

This resource is primarily for clinicians working with people with dementia, but can also be used by carers and people with dementia. This document takes the wellbeing pathway and sets out the adjustments and amendments needed to respond to the COVID-19 pandemic. It highlights key priorities and actions for each step in the pathway. Links to further information and guidance are also included.

It spans community, in-patient and other health and social care settings and signposts to useful resources from a variety of organisations. A resource section for people with dementia and their carers is also included.

This guide to dementia wellbeing in the COVID-19 pandemic is a companion to the [Dementia Well Pathway](#) and compiles guidance and resources to support professionals, people with dementia and carers. It can be used in conjunction with the NCCMH publication, [The Dementia Care Pathway](#).

Health services must continue to have due regard to their obligation to advance equality under the Equality Act 2010. This includes recognising and factoring-in the vulnerability of different cohorts with protected characteristics; and inequalities in access, experience and outcomes in health services.

The [Advancing Mental Health Equalities Toolkit](#) provides support in identifying and addressing mental health inequalities in the round. Partnership working with voluntary and community sector partners is also encouraged to facilitate wrap-around support for vulnerable people, and to maximise engagement with underrepresented groups.

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact england.domainteam@nhs.net

Dementia wellbeing in the COVID-19 pandemic

Preventing Well



Keeping fit and active to prevent the mental and physical consequences of isolation

Diagnosing Well



Maintaining diagnostic services and awareness of the symptoms of COVID-19

Treating Well



Ensuring access to the best treatment available

Supporting Well



Providing personalised care and support to carers at home and people in care homes

Living Well



Optimising the lived experience of dementia

Dying Well



Ensuring the needs of people with dementia are met at the end of life



Preventing Well

Keeping fit and active to prevent the mental and physical consequences of isolation

Key actions and priorities

Maintaining mental and physical wellbeing

Self-isolation and social distancing due to COVID-19 may have a significant impact on people living with dementia and their carers. As ever, it is important to take steps to support mental and physical wellbeing, but adjustments to normal activities may be required inline with government guidance on the pandemic.

Links included provide suggestions of activities and approaches that can be used to encourage individuals to stay connected, keep a sense of purpose, stay active and stay positive, in a way that is appropriate through the pandemic

In particular, social contact is likely to have reduced during the pandemic. Social prescribing can connect people to community support and resources and will be particularly important in creating connection and aiding rehabilitation.

Personalised care

During the pandemic, being aware of personal circumstances, choices and involving people in their own health is vital. The National Academy for Social Prescribing have put together [Personal Wellbeing Plan Template](#) which can be used to summarise what is most important to someone, when discussing support someone may need to stay safe at home.

Supporting family carers and people living in the community

The pandemic has placed additional burdens on carers, both in caring for their relatives and in managing their own mental health. Carers may benefit from being offered support directly and/ or through local and national voluntary, community and social enterprise organisations.

Links to guidance and information

Maintaining mental and physical wellbeing

- [IDEAL project](#)
- [University of Manchester keeping well at home](#)
- [NHS every mind matters](#)
- [CSP Helping older people stay active at home](#)
- [Maintaining health in dementia videos](#)

Social Prescribing

- [NHSE personalised care homepage](#)
- [NHSE&I social prescribing and community-based support](#)
- [NASP personalised wellbeing plan template](#)

Supporting carers

- [Advice for carers to help keep those they care for stay safe](#)
- [Reducing depression and anxiety in family carers](#)
- [Supporting carers to understand and respond to changes in behaviour during the COVID-19 pandemic](#)
- [Getting help and support as a carer](#)
- [Looking after someone with dementia](#)



Diagnosing Well

Maintaining diagnostic services and awareness of symptoms of COVID-19

Key actions and priorities

Presentation of COVID-19

Presentation of COVID-19 can be atypical in older people. This can include symptoms such as: loss of smell (anosmia); loss of appetite; diarrhoea; breathlessness; raised temperature and cough; delirium; conjunctivitis; changes in behaviour; and falls.

In addition to atypical symptoms, clinicians must consider different communication methods to support COVID identification, as they may have to 'look beyond words' to identify symptoms.

Remote assessment and virtual diagnosis of dementia

While face-to-face diagnosis may not be possible during the pandemic, innovative techniques for remote assessment and diagnosis of dementia are available and have been adopted by many memory clinics.

Remote assessments require different ways of working for clinicians. Training in the use of remote techniques should be provided. Individuals should be given choice of assessment type and it should always be flexible and tailored to the needs of the individual.

Support post-diagnosis

Post-diagnostic support is vital, particularly in the context of a pandemic if people are self-isolating. This should include information for relatives/carers, as well as for the individual receiving a diagnosis.

Links to guidance and information

Presentation of COVID-19

- [BGS advice on presentation of COVID-19 symptoms, including atypical presentation](#)

Remote assessments

- [RC Psychiatrists guidance on remote assessment](#)
- [Paper: 20 telephone assessments for cognition](#)
- [NICE Initial assessment in non-specialist settings](#)
- [BGS clinical advice and specific information about dementia and COVID-19 including communication](#)
- [YHSCN paper: a new way of working: remote memory clinics](#)
- [Dementia Academy Webinar - remote cognitive testing with older people with hearing and vision impairment](#)

Support post-diagnosis

- [Alzheimer's Society living-well after diagnosis](#)



Treating Well

Ensuring access to the best treatment available

Key actions and priorities

Managing psychological and behavioural symptoms

Managing symptoms of dementia in the context of COVID-19 can be challenging. People may experience difficulty in understanding complex instructions or the reasons for isolation.

Non-pharmacological approaches can be used to help manage symptoms, as part of personalised care plan. Risk assessment and judgement should be used when prescribing sedation for people who walk with purpose. The Clinical Frailty Scale (CFS) can be used as part of a holistic assessment to support shared decision making. However, be aware of the limitations of using the CFS as the sole assessment of frailty.

Preventing and managing delirium

Older people are at significant risk from COVID-19 and if infected they may present with or develop a delirium. The behavioural changes commonly seen in delirium are likely to increase the risk of cross-infection and may make management challenging. Proven strategies are set out by British Geriatrics Society (BGS) and Regional Geriatric Programme of Toronto (RGP) to support with managing and preventing delirium.

Personalised and holistic care

The direct and indirect effects of COVID-19 have had an impact on the physical and mental health of people with dementia. Personalised Care Plans should be updated to reflect changes in need and wider context, which may have impact on support that can be provided.

Links to guidance and information

Managing and preventing delirium

- [BGS managing delirium](#)
- [RGP delirium prevention](#)
- [NICE: the Clinical Frailty Scale as part of a holistic assessment](#)

Alternatives to sedation for managing behaviours, such as walking with purpose

- [Alzheimer's Society](#)
- [NI Health & Social Care Trust](#)

Ensuring personalised inpatient care for people with dementia

- [NHS England and NHS Improvement](#)
- [Alzheimer's Society This is Me template](#)

Personalised Care

- [NHSE personalised care homepage](#)
- [NHSE&I shared decision making summary guide](#)
- [NHS England Dementia: good personalised care and support planning](#)



Supporting Well

Providing personalised care and support to carers at home and people in care homes

Key actions and priorities

Care homes

Care home staff may not be used to personal protective equipment (PPE) and will have challenges in managing infection if residents are walking with purpose or do not understand the need for isolation. Training and support from managers is vital. Options to support with testing of staff and family carers should be explored as part of efforts to develop safe visiting policies. Community services can provide phlebotomy services and collate relevant data to assist diagnosis and multi-disciplinary team (MDT) decision-making.

Home care

COVID-19 places additional demands on home care provision, both for carers and for provider organisations. Guidance on PPE, the needs of extremely vulnerable people, testing and governance in the pandemic has been collated by DHSC to support those providing home care.

Maintaining personalised care provision

Providing personalised care and support to people with dementia remains vital, particularly as isolation can exacerbate the symptoms of dementia. Care plans should be reviewed regularly to take into account changes in health. Digital technology and communication, such as Zoom and MS Teams, can help provide support during isolation, connecting people with dementia and carers.

Links to guidance and information

Support for care homes

- [BGS managing the COVID-19 pandemic in care homes](#)
- [SCIE dementia in care homes and COVID-19](#)
- [Video: meeting the needs of people with dementia living in care homes during COVID-19](#)
- [Dementia Support UK dedicated one-to-one time with a dementia support consultant](#)
- [Visiting care homes during coronavirus](#)

Support for care home staff: working safely in care homes

- [PHE PPE resource for care workers in care homes](#)
- [PHE PPE resource for homecare care workers](#)
- [PHE PPE video](#)
- [Poster: why we wear PPE](#)

Home care

- [Provision of homecare in the context of COVID-19](#)

Personalised care

- [NHSE&I supported self-management](#)
- [NHSE&I social prescribing and community-based support](#)

Encouraging use of digital communication

- [SCIE supporting people who are isolated or at risk](#)
- [Innovations in Dementia how-to guides](#)
- [Digital Social Care tech and data protection support](#)



Living Well

Optimising the lived experience of dementia

Key actions and priorities

Communication challenges

Communicating will be more challenging when full PPE is being used. Tone of voice and open body language is of increased importance and thought should be given to non-verbal communication, such as the use of written materials.

Staying safe and well

With more time in the home risks of deconditioning and falls due to hazards in the home increase. Steps should be taken to mitigate this, promoting overall wellbeing in parallel, by keeping minds and bodies active. There are a number of Voluntary Community and Social Enterprise (VCSE) offers that support people and families stay active that should be utilised. NHS Volunteer Responder service can be used to provide additional support.

Guidance attached includes suggested activities that support individuals living with dementia and their carers in a way that is pandemic safe. For example, listening to music benefits can reduce anxiety and depression and is ideally suited to use during isolation brought on by the pandemic.

Social prescribing

Loneliness, anxiety, depression and other mental health problems will have been exacerbated by the effects of the pandemic. Social prescribing can be used to help individuals reconnect with the local community and local support services.

Rehabilitation

Individuals may require specific and targeted rehabilitation support, either following recovery from the virus or as a consequence of an exacerbation of other health issues due to isolation or reduced access to health services.

Links to guidance and information

Communication

- [Barts Health aiding communication with people with dementia whilst wearing PPE](#)

Resources and activities for people with dementia

- [Health Innovation Network](#)
- [Video: home based exercises and activities](#)
- [A Care App to support people living with dementia](#)
- [Music for people with dementia and carers during COVID-19](#)
- [BPS support older people during isolation](#)
- [Dementia together for people with dementia and carers](#)
- [Living with dementia and COVID-19 an emergency resource kit](#)
- [Alzheimer's Society recovery and rehabilitation for people with dementia after having coronavirus](#)
- [Keeping older people safe and well at home](#)
- [NHS Volunteer Responders](#)

Social prescribing

- [National Academy for Social Prescribing personalised wellbeing plan template](#)
- [NHSE&I social prescribing and community-based support](#)

Rehabilitation

- [COVID-19: Rehabilitation of older people](#)



Dying Well

Ensuring the needs of people with dementia are met at the end of life

Key actions and priorities

Personalised care

Each person is an individual whose needs and preferences must be taken account of. Blanket policies are wholly inappropriate, particularly in respect of do not attempt resuscitation (DNAR) policies.

Advance Care Plans (ACPs) should be fully embedded in wider inclusive, personalised care and support planning for dementia.

Safeguarding and deprivation of liberty (DoLS)

The COVID-19 outbreak will have safeguarding implications, in particular for those consider vulnerable adults. Mental Capacity Assessments (MCAs) should be made where appropriate.

Palliative care

There is national guidance on providing palliative care in hospitals during the pandemic, which details additional considerations brought on by the pandemic. Online training is available for hospital clinicians to support with these challenging times.

Care home staff

Care home staff in particular are likely to be affected and bereaved when a resident dies. Providing one-to-one and team meetings with staff will help with the ability to deal with the loss. Training and guidance for health and care teams may be used to support staff with these situations and should be encouraged by providers.

Links to guidance and information

Personalised care and advance care plans

- [Maintaining standards and quality of care in pressurised circumstances \(DNACPR\)](#)
- [Advance Care Planning: guidance and template in the context of COVID-19](#)
- [NHSE my future wishes: conversations for ACP including health and welfare, power of attorney](#)

Mental Capacity Assessments & deprivation of liberty (DoLS) safeguards

- [SCIE monitoring MCA implementation](#)
- [MCA and DoLS during COVID-19](#)

Palliative care and training

- [Clinical guide for the management of palliative care in hospital during the coronavirus pandemic](#)
- [NHSE&I Coronavirus Act – excess death provisions](#)
- [Health Education England](#)
- [Skills for Care](#)
- [NHS England and NHS Improvement - end of life](#)
- [SCIE video: support for care home staff](#)



Resources for people with dementia and their carers

[Admiral Nurse Dementia Helpline](#) Call 0800 888 6678 or email helpline@dementiauk.org Open 7 days a week

Free and confidential advice and support service for anyone with a question or concern about dementia, staffed by experienced dementia specialists.

[Age UK Advice Line](#) 0800 055 6112 Free to call 8am – 7pm 365 days a year

Information and advice about staying well and safe, providing care, accessing services, arranging funerals and telephone befriending.

[Alzheimer's Society / Dementia Connect](#) Helpline 0300 222 112 Available 7 days per week

Support and advice from dementia advisors. Includes access to an online community, [Talking Point](#), to connect with others affected by dementia.

[Carers UK](#) Helpline 0808 808 7777 Mon-Fri, 9am-6pm or by emailing advice@carersuk.org

Information and advice about how to get help and support as a carer.

[Carers Trust](#) Support and resources for carers.

[Cruse bereavement information](#) Helpline 0808 808 1677 or by emailing helpline@cruse.org.uk

Emotional support to anyone affected by bereavement.

Decision aid: [Supporting family carers of people living with dementia to make difficult decisions during COVID-19](#)



Resources for people with dementia and their carers

Dementia Change Action Network (DCAN) Practical ideas for living with dementia during the COVID-19 pandemic, including advice on managing social distancing <https://distancingwithdementia.org.uk/>

[Dementia Carers Count](#) Education, training and skills development for family and friends who care for a person with dementia.

[Dementia UK](#) Website information, advice and useful tips for supporting someone with dementia during the Coronavirus outbreak. Includes frequently asked questions, strategies for managing distress, considerations for caring from a distance and suggestions for staying safe and well.

www.dementivoices.org.uk Support and practical advice for carers and people with dementia.

[Independent Age Helpline 0800 319 6789](#) Open Mon – Friday. Includes information about staying well and safe, tackling loneliness and how to access to grief counselling.

[Innovations in Dementia](#) including Dementia Voices, provides information and resources to support people living with dementia.

[The Silver Line Helpline 0800 470 8090](#) Open 24 hours a day, every day of the year. Free confidential helpline providing information, friendship and advice to older people.

[TIDE \(Together In Dementia Everyday\)](#) Information about COVID-19 and suggested activities