



“We are living through unprecedented times, but one thing is clear: ADI’s natural constituency, people affected by dementia and their families, are amongst the hardest hit. We have a global network and it has been natural for our members to collaborate through this crisis, show solidarity and work together. But we have also learnt that there are hard truths that we all need to face. This is the spirit in which we have reengineered ADI to be at the forefront in providing, guidance, evidence-based information and cohesion through these difficult times. Our aim is to help you understand the impact on our community as events unfold and take better and more informed decisions. Stay safe.” - Paola Barbarino, Chief Executive of Alzheimer’s Disease International (ADI)

COVID-19 and dementia: Difficult decisions about hospital admission and triage

COVID-19 is a new viral infection that presents an unprecedented problem for everyone, including people with dementia and their families and carers¹ worldwide. Although the scale and impact of COVID-19 varies from country to country, at an individual level, people affected by dementia and their families and carers are having to cope with rapidly changing information and guidance at a time when they have been asked to isolate from their regular support systems in the wider community.

¹ Throughout this paper, the word ‘carers’ also refers to caregivers and care partners.



Families caring for someone living with dementia can feel cut-off, overwhelmed and anxious as current thought suggests that older populations and those living with complex health conditions are at greater risk. People with dementia are also more likely to be negatively impacted by social isolation, anxiety and confusion from worrisome news in the media and be at greater risk of behavioural changes, confusion and delirium during this period – putting them at risk of being hospitalized and hence further exposed to COVID-19.

Due to cognitive impairment, people living with dementia have a greater risk for COVID-19 exposure. Memory problems make instructions problematic to remember. For example, it can be difficult to understand instructions about social distancing (staying 2 meters from others), or hand hygiene, restrictions on walking outside, or reasons for wearing a mask. Eventual lack of insight can result in behaviour that increases risk of exposure for themselves and for their families and carers. It is most important that society does not place any blame, stigma or guilt on people with dementia because of these risks, since it is a consequence of the dementia disorder. Nevertheless, awareness of these risks is important for the protection of people with dementia and those around them.

Kate Swaffer, co-founder, Chair and CEO of Dementia Alliance International (DAI) reminds us of the rights of people living with dementia during this crisis:

“The COVID-19 pandemic challenges us with an unprecedented global threat, and no person or country is likely not to be affected in some way. It also highlights our interconnectedness; our strongest tools to respond are our solidarity, our willingness to collaborate and to cooperate with each other locally, nationally, and globally. COVID-19 has emphasised how the rights of people with dementia have too often been ignored. The denial of health care is being experienced more acutely than before this crisis; although it has been happening to people with dementia for decades, it is now more obvious to others. A worrying matter is the lock down being enforced on people living in nursing homes, which denies those who have families and advocates to ensure best care practices and to make sure no abuse is taking place. A diagnosis of dementia, whilst a terminal and progressive condition causing significant acquired cognitive disabilities, is not a reason to be left behind.”

To-date, there has not been a significant amount of dementia-specific commentary shared in the media in relation to COVID-19, but researchers, academics, and clinicians are working around the clock to share data and resources to provide more information to help put the rapidly changing COVID-19 landscape into clearer focus. Much of this information comes past our desks at ADI and we have made a point to share material freely, to make language as accessible as possible, and to update as it unfolds.

Recently, one of ADI's Medical and Scientific Advisory Panel (MSAP) members, Professor Gill Livingston, shared some key reflections about what we know about COVID-19 and dementia so far – and how this can impact on families as they make decisions on how to best care for their loved ones. We have also consulted other MSAP members globally and our partner, DAI, to seek their input on this important topic.

Some families are being faced with solemn decisions; having to weigh the benefits and risks of hospital admission – whether this be for COVID-19 or for other dementia related (e.g. delirium) or health related condition – against those of keeping their loved ones at home. Equally, as



resources become more scarce, clinical teams may have to make difficult triage decisions and governments will need to demonstrate that ethical and unbiased guidance is provided to support clinical decision making and to ensure all people have access to care, regardless of their age, cognitive abilities, or medical condition.

The following thought piece is for information and is meant to share knowledge as it unfolds and to help families consider key issues when planning care for their loved ones with dementia during COVID-19. We recognise that every case is different, and each individual will be impacted by COVID-19 in a unique way. It will be important that individuals and families take medical advice and follow local guidelines when weighing up the best course of action.

Is COVID-19 different for people with dementia? Some key points:

- There is currently no data providing evidence that people with dementia have more severe COVID-19 symptoms than others of similar age and health.
- Many older people with dementia who catch COVID-19 will feel unwell for some days and will recover gradually at home.
- People over 80 who have other illnesses and need admission to hospital with COVID-19 are least likely to benefit from going into hospital since their admission has associated risks. (Wu et al <https://jamanetwork.com/journals/jama/article-abstract/2762130>; Yang X, Yu Y, Xu Jet al. Lancet Respir Med. 2020; (published online Feb 24) [https://doi.org/10.1016/S2213-2600\(20\)30079-5](https://doi.org/10.1016/S2213-2600(20)30079-5)) It is important to make a decision before a crisis as to whether it will benefit them to go into hospital.
- COVID-19 is a new illness and we do not know exactly what happens to people with more severe symptoms. What we do know is that older people and those with other underlying illnesses such as diabetes or high blood pressure have more severe symptoms and worse outcomes.
- We know that the death rate increases with age. When comparing deaths in Italy and China, the death rate of people aged over 80 varies from 11 to 20 times that of people aged 50-59. The death rate of people aged over 80 is nearly twice that of people aged 70-79. The death rate of people aged 70 to 79 is around three times that of those aged 60-69 which in turn is around three times that of those aged 50-59. ([Onder et al./JAMA/BBC](#)).
- People with COVID-19 who have difficulty in breathing and low oxygen levels, may be offered admission to hospital for oxygen treatment and other interventions. If they are older or have other illnesses, they may have an increased risk of poor outcomes.
- If people are admitted to hospital, most hospital policies do not allow any visitors in order to reduce infection rates.



- People with dementia may find it particularly hard to understand why they are in an unfamiliar place without people who they love. They may be even more lonely and frightened than others. They may also be less able to communicate or adhere to instructions and safety measures. All these factors may lead to them having an increased risk of developing delirium during their hospital stay.
- Many people with dementia are not able to make decisions for themselves and need others to support them to make decisions or to make decisions for them. The lack of visitation may make it harder for the hospital team to provide a patient-centred care plan.
- It is important to plan in advance in case a person with dementia develops symptoms of COVID-19 that get worse. Medical advice is critical on whether the benefit of being admitted to hospital is worth the distress of being separated from family and isolated. These are weighty and difficult issues families must face. What are possible outcomes? Is hospital where the person would want to die in isolation? Equally, how would such a scenario impact on carers if they kept the person at home? Do carers have access to proper personal protective equipment (PPE) to avoid exposure?
- Each country should have governmental guidance on how and when to seek further treatment if their loved one's condition deteriorates and families should be encouraged and supported to access this information. In the United Kingdom, the National Institute for Health and Care Excellence (NICE) has developed [Information to support decision making](#) for patients, families, and the public, encouraging people to reflect on such questions as:
 - How will critical care treatments help the person in the short and long term?
 - Could critical care treatments offer a quality of life that is acceptable to the person?
 - Could critical care treatments help achieve a patient's goals for a good life?
 - Are there non-critical-care treatments that may help the person and be more comfortable for them?
- Families should consider developing advance care plans or directives to ensure that a patient's wishes are considered when planning care in hospital. Does the person want to have a DNAR (do not attempt resuscitate) directive? What are the individual's wishes around end of life care?
- Health systems should provide access to palliative care services, in hospitals and outside the hospital, for persons critically ill with COVID-19 who either choose not to be hospitalized, choose not to pursue all life-sustaining care in accordance with their wishes to avoid suffering, or who cannot be saved despite all attempts at prolonging life.
- Care homes need to consider plans in conjunction with residents and their families in case of COVID-19 developing in their residents. Are there doctors willing to visit



residents with suspected infections? Are hospitals willing to accept admissions? If not, what facilities are available for treating persons in the care home? Or for palliative care if their condition deteriorates?

Other information

How is COVID-19 prevented or treated?

At present there is no vaccine to prevent catching COVID-19. Currently, the best strategy to avoid catching it is through physical distancing (not getting too close to other people), hand hygiene, wearing a mask, avoiding touching one's face, and testing for it. Those with COVID-19 and their contacts are isolated. However, many people with dementia need care and have problems with memory, thinking or behaviour which can significantly complicate physical distancing and be challenging to ensure proper safety measures.

There is no specific treatment for the underlying infection. Most people infected will have a relatively mild infection and will gradually improve.

However, around one in five people have some difficulty in breathing (respiratory distress) and many will develop pneumonia. This is more common in older people and those with other illnesses such as diabetes or individuals who smoke. Oxygen treatment is often required to increase levels in the blood.

How is oxygen given?

Oxygen is usually given in hospital and, depending on how low the oxygen level is, can be given by a mask or through ventilation in intensive care settings; this can also include intubation (requiring sedation). Patients in hospital are usually isolated and cannot see relatives. Most patients in need of mechanical ventilation due to potentially reversible conditions receive it, unless they (or people who make decisions for them) refuse it.

Additional challenges to consider for people living with dementia

1. Patient-facing materials developed for general populations will need to be tailored for cognitive and behavioural impairment.
2. There are challenges in implementing physical distancing recommendations for families who provide personal care for their loved one living with dementia. It can also be problematic to get people with dementia to wear a mask and to keep it on.
3. The impact of COVID-19 on people living in nursing homes and long-term care facilities. For more on this, please have a look at a new website on long-term care responses: <https://ltccovid.org/>
4. If life-saving equipment becomes scarce, it may be rationed. The most commonly recommended approach to allocating scarce ventilators is to prioritize those critically ill patients most likely to survive to hospital discharge with treatment. Although relevant, this specification of doing the greatest good for the greatest number is inadequate because it ignores other ethically relevant considerations. For example, it is also relevant to consider



the number of years of life saved. It is important to consider (1) patients' likelihood of surviving to hospital discharge, assessed with an objective measure of acute illness severity; and (2) patients' likelihood of achieving longer-term survival based on the presence or absence of comorbid conditions that influence survival. ([A Framework for Rationing Ventilators and Critical Care Beds During the COVID-19 Pandemic Douglas B. White; Bernard Lo, JAMA. Published online March 27, 2020. doi:10.1001/jama.2020.5046](#))

5. As part of work commissioned by the Alzheimer Society of Canada, researchers and clinician have stated that duration of survival should NOT be “adjusted” based on presumptions regarding quality of life. As stated by Emanuel and colleagues, “Limited time and information during an emergency also counsel against incorporating patients’ future quality of life, and quality-adjusted life-years, into benefit maximization. Doing so would require time consuming collection of information and would present ethical and legal problems.” ([NEJM 10.1056/NEJMs2005114](#)). The concern is that clinicians who are not trained in dementia care may underestimate – or even devalue – the quality of life of many persons with dementia.
6. National guidance to support triage decisions is critical. Such guidance will vary from country to country, but in the UK, for example, NICE has developed [guidelines for clinicians about admissions to critical care](#), including an [algorithm](#) that also uses a [Clinical Frailty Scale](#) developed by Dalhousie University in Halifax, Canada. This includes specific advice relating to dementia. In addition, the British Medical Association (BMA) has developed some [guidelines](#) around ethics to support decision making, as well as a shorter version of [frequently asked questions \(FAQs\)](#).
7. Proactive and preventative strategies by family members, caregivers and clinicians to minimize the need for people with dementia to require in-person evaluation for dementia or other conditions (e.g. dehydration, behavioural disturbances, delirium). Use of technology such as video- or tele-visits.
8. If hospitalized, then best practices for delirium risk assessment, prevention, mitigation and management (e.g. see [Oh et al. JAMA 2017](#) and [AARP GCBH Delirium Report 2020](#)) should be modified as much as possible based on conditions and resources – when no visitors or family members/carers are allowed then, if possible, provide one-to-one support and use technology (e.g. video calls with family and loved ones) to help monitor, orient, communicate, reassure and calm the person with dementia.

Conclusion

The global impact of COVID-19 is unprecedented, particularly on vulnerable groups such as people living with dementia and their families and caregivers. The situation changes daily, and we need to share resources and best practice guidance as they become available. However, with the right information about risk reduction, care at home, how to include people with dementia in decisions about their care, and opportunities to plan ahead through advance care plans or advance directives, families can make informed decisions about how, when and where to seek help.



**Alzheimer's Disease
International**

The global voice on dementia

ADI would like to thank all contributors to this thought paper:

Principle authors: Gill Livingston and Wendy Weidner

Key contributions from: Ali Atri (MSAP Chair), Ricardo Allegri, Paola Barbarino, Annie Bliss, Henry Brodaty, Serge Gauthier, Antonio Guaita, Chris Lynch, Jose-Luis Molinuevo, Mario Possenti, Glenn Rees, Eric Smith, Kate Swaffer, Huali Wang, Anders Wimo