



*Making dementia a priority:
changing perceptions, practice and policy.*

Alzheimer Europe position regarding the prioritisation of people with dementia for COVID-19 vaccination

Adopted by the Alzheimer Europe Board on 7 May 2021

Background

Since the World Health Organization (WHO) identified COVID-19 as a global pandemic in March 2020, COVID-19 has claimed the lives of almost 670,000 people in the EU/EEA, with over 29 million cases reported to date. At this time, the European Centre for Disease Prevention and Control (ECDC) warns that transmission of COVID-19 is still widespread.

With the first approval of a vaccine against COVID-19 announced by the European Medicines Agency (EMA) in December 2020, and vaccination campaigns underway throughout Europe, this position paper will outline why it is imperative that people with dementia and their carers are prioritised in vaccination strategies.

The disproportionate negative impact of COVID-19 on people with dementia

Severe COVID-19 predominantly affects older adults and individuals with underlying health conditions, with people aged over 65 years accounting for 95% of deaths related to COVID-19 in Europe. Furthermore, long-term care facility residents have accounted for approximately 40% of COVID-19 deaths worldwide.

People with dementia have almost twice the risk for developing COVID-19 compared to their peers without dementia, with high rates of hospitalisation and a risk of mortality within six months of approximately 20% in certain populations. Those who become infected are also more prone to developing delirium, which can complicate the management of their current and future cognitive health.

Some public health measures (e.g. barrier measures, cancellation of in-person supports) have also had a negative impact on the wellbeing of people with dementia and their carers. Reduced or cancelled supports and services, disruption to routines and a lack of cognitive stimulation have resulted in increased anxiety, agitation, stress and depression. For some people with dementia in particular, this has resulted in the acceleration of cognitive decline. For carers, additional caring responsibilities and less support has impacted upon both their physical and mental health. It is clear that the COVID-19 pandemic has both exacerbated existing inequalities and engendered new ones.

The need for priority vaccination for people with dementia and their carers

Vaccination represents an important cornerstone of global efforts against COVID-19. EU Member States are responsible for the development and implementation of their own vaccination strategies which, whilst sharing common goals (reducing COVID-19 mortality and relieving pressure on health and care systems), are considerably different in approach and speed of rollout.

Countries vary significantly in their prioritisation of different groups for COVID-19 vaccination. The vast majority of European countries have prioritised frontline healthcare workers, long-term care facility residents and the oldest old in the first phases of vaccination, with a smaller number also prioritising social care personnel and professional carers (ECDC 2021). However, few countries have prioritised informal carers, a critical omission given their close contact with vulnerable groups and the valuable contributions they make to care systems and economies.

Many countries have also identified risk groups linked to specific health conditions, prioritising people with these conditions for COVID-19 vaccination. Most frequently, these include cancer, severe respiratory conditions, advanced renal and cardiac disease, and immune deficiencies. However, dementia is not commonly listed as a risk factor. As a result, and despite their increased risk of severe COVID-19, people with dementia in many countries may not be prioritised for COVID-19 vaccination. This is particularly the case for those who are living in the community and those who are not in the oldest age brackets, such as people with young onset dementia, which represents 6-9% of dementia diagnoses and affects approximately 1 in 100 people aged 60-64.

People with dementia and their carers have already been disproportionately impacted by the pandemic and will continue to be so as long as it continues. Therefore, vaccine prioritisation strategies should recognise the demonstrably higher need of people with dementia and their carers as a high-risk population in their own right. It cannot be assumed that people with dementia are already covered through other prioritisation systems based solely on age or place of residence (e.g. in care homes).

Furthermore, the additional challenges people with dementia may experience in order to receive their vaccination (e.g. difficulty accessing vaccination centres) must be considered and addressed in the implementation of vaccine strategies.

Alzheimer Europe's call for action

It is vital that governments prioritise people with dementia and their carers in their COVID-19 vaccination strategies and protect the health and wellbeing of a population which is at increased risk of contracting and succumbing to COVID-19.

To this end, Alzheimer Europe calls on governments to:

- Include dementia as a risk category for severe COVID-19, prioritising people with dementia for the COVID-19 vaccine, independent of age, place of residence or other risk factors for severe COVID-19
- Prioritise informal carers for the COVID-19 vaccine, acknowledging their important contribution during the pandemic to the care, support and even survival of people with dementia, as well as the indirect protection vaccination can confer for the person they care for
- Ensure that reasonable accommodations are made and support mechanisms are in place when organising and rolling out the vaccine to people with dementia, such as the possibility to be vaccinated at home and to have decision making support, if required

Alzheimer Europe has drafted a briefing paper, which provides greater context to the impact of COVID-19 on people with dementia, as well as exploring the ethical and human rights considerations around vaccinations for persons with reduced capacity. The impact of the COVID-19 pandemic on legal capacity and decision-making of people with dementia was also described in more detail in the organisation's 2020 Report "Legal capacity and decision making: The ethical implications of lack of legal capacity on the lives of people with dementia"

The 2020 report can be downloaded at: <https://www.alzheimer-europe.org/content/download/231828/1709440/file/Final%20report%20on%20legal%20capacity%20and%20decision%20making%202020.pdf>



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