



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

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

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Background

The World Health Organisation (WHO) identified COVID-19 as a global pandemic in March 2020. Over the last 12 months, COVID-19 has claimed the lives of almost 670,000 people in the EU/EEA, with over 29 million cases reported to date. The latest surveillance reports from the European Centre for Disease Prevention and Control (ECDC) indicate that transmission of COVID-19 is still widespread.

The COVID-19 pandemic has meant that people with dementia, their families and caregivers are facing unprecedented challenges. Beyond the direct, often devastating impacts of COVID-19 infection, people with dementia have also experienced harmful consequences of some public health measures designed to halt the spread of COVID-19.

The first approval of a vaccine against COVID-19 by the European Medicines Agency (EMA) in December 2020 has brought hope to many, especially those living with conditions - such as dementia - which increase the risk of death due to COVID-19. Now that COVID-19 vaccines are being rolled out across Europe, it is critically important to ensure that prioritisation approaches comply with legal, ethical and human rights requirements, and that people with dementia and their carers are not overlooked.

This position statement highlights three key issues:

- The disproportionate negative impact of COVID-19 on people with dementia
- The need for fair prioritisation of people with dementia and their carers for COVID-19 vaccination
- The importance of respecting the rights and wishes of people with dementia in relation to COVID-19 vaccination

1. 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. There is broad awareness of the heightened vulnerability of long-term care facility residents to COVID-19 mortality, with this sector accounting for approximately 40% of COVID-19 deaths worldwide. The fact that people with dementia are at higher risk of developing severe COVID-19 is less widely-understood. People with dementia have almost twice the risk for COVID-19 compared to their peers without dementia (Williamson et al. 2020), with high rates of hospitalisation and approximately 20% risk of mortality within 6 months in certain populations (Wang et al. 2021). They are at greater risk of complications and death in the case of an infection in general because of co-morbidities such as hypertension, diabetes, cardiovascular disease, and chronic obstructive pulmonary disease. Those who become infected are also more prone to developing delirium, which can complicate the management of their current and future cognitive health (Suárez-González et al. 2020). Hospitalisation and other changes in environment can lead to greater functional loss, increased dependence and difficulties adjusting to new routines and readjusting once home, if returning home is even an option.

Some public health measures related to COVID-19 have also had a particularly negative impact on the wellbeing of people with dementia (Manca, De Marco and Venneri 2020) and their carers (Mok et al. 2020). Many people with dementia find it hard to understand, manage or remember to comply with COVID-19 measures such as mask-wearing, frequent hand washing and maintaining a distance from others. Loss of (or reduced access to) support, disruption of routines, enforced social isolation (often as a result of protecting people from infection) and lack of cognitive stimulation have caused increased anxiety, agitation, stress and depression, also accelerating cognitive decline for some people with dementia. Loss of support and services has also affected carers, resulting in additional care responsibilities, concerns about their ability to cope and increased psychological and physical stress. Although telemedicine and remote services have, to some extent, replaced certain face-to-face services, the digital divide and

other socioeconomic factors have created barriers to access. The level of support and ease of access to services also varies substantially between European countries. It is clear that the COVID-19 pandemic has both exacerbated existing inequalities, and engendered new ones.

2. The need for fair prioritisation of people with dementia and their carers for COVID-19 vaccination

Alongside non-pharmaceutical interventions such as mask-wearing and physical distancing, vaccination represents an important cornerstone of global efforts to contain the COVID-19 pandemic. According to the ECDC weekly surveillance report of 22 April 2021, over 135 million vaccine doses have been distributed by manufacturers to EU/EEA countries, a median of 35.9 doses per hundred inhabitants. Of these, almost 117 million doses have been administered by EU/EEA countries, based on vaccination strategies developed at Member State level. These vaccination strategies share common goals, namely to reduce COVID-19 mortality, and to relieve pressure on strained health and care systems. However, the mode and speed of rollout varies between European countries. Some have focused on delivering vaccines via vaccination centres and hospitals, while others involve general practitioners, pharmacies and community-based healthcare workers in vaccine administration, also offering the option to be vaccinated at home. These and other facets of national vaccine strategies have direct and indirect impacts on people with dementia and their carers, who may find travel to vaccination sites challenging.

Countries also vary in their prioritisation of different groups for COVID-19 vaccination. Whilst the vast majority of European countries have prioritised frontline healthcare workers, long-term care facility residents and the oldest old for the first phases of vaccination, a smaller number of countries have also prioritised social care personnel and professional carers (European Centre for Disease Prevention and Control 2021). Very 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 are not in the oldest age brackets.

Prioritisation strategies for vaccination against COVID-19 must comply with legal, ethical and human rights requirements and concerns. During the current pandemic, numerous people with dementia, as well as many older people, have borne a disproportionate burden in the interests of society. At the same time, many have been subjected to draconian measures of isolation and in some cases to blanket “do-not-attempt-resuscitation” orders, unjustly refused access to intensive care services and testing, and deprived of adequate protection on a mass scale. Quarantine measures and other restrictions of freedom must always be part of a comprehensive package of public health and social measures, should fully respect people’s dignity, human rights and fundamental freedoms, should be in accordance with the law, pursue a legitimate aim, be proportionate and not arbitrary or discriminatory.

The same applies to prioritisation strategies for vaccination. Current strategies for vaccine distribution, as mentioned earlier, already discriminate (e.g. on the basis of age, health conditions, living situation etc.). However, discrimination is not always a bad thing provided that it is based on fair, relevant and meaningful criteria, and that people who experience the greatest burden are well supported and protected. The key question is not whether we should discriminate but how to discriminate fairly (i.e. not negatively). If everyone had an equal risk of developing the virus, an equal chance of survival and an equal risk of dying, then it would be important to ensure that everyone did have the same probability of having or not having the vaccine. This is clearly not the case. Members of society do not have the same chances and risks, and governments across Europe have recognised the increased risk that some groups of

people have of contracting the virus and of it having a devastating impact on their lives and very survival.

Therefore, it cannot be considered fair that people with dementia continuously bear a disproportionate burden of COVID-19 risk, especially when they are already vulnerable and the very people who should be protected in a caring society. Not only must such injustice and disproportionate burden, experienced earlier in the course of the pandemic, be investigated but also, it cannot be followed by vaccine prioritisation strategies that overtly or covertly exclude or discriminate against people with dementia. It cannot be assumed that people with dementia, who are at increased risk of contracting and dying from COVID-19, will be covered in due time through prioritisation systems based solely on age or place of residence (e.g. in care homes). Strict adherence to standard procedures, which do not consider the increased vulnerability of many people with dementia and their difficulty organising and taking advantage of any right they may have to a vaccine, runs counter to the principle of justice/equity, the obligation to provide reasonable accommodation and the moral duty to protect vulnerable members of society. Measures must be taken to accommodate the added vulnerability of all people with dementia during the COVID-19 pandemic and the practical challenges they face in accessing vaccination if and when entitled to it.

3. The importance of respecting the rights and wishes of people with dementia in relation to COVID-19 vaccination

Despite the extent and impact of the COVID-19 pandemic, vaccination is currently voluntary for members of the general public in all EU/EEA Member States. People therefore have the right to decide whether or not to be vaccinated against COVID-19. It is essential to similarly respect the rights and wishes of people with dementia in relation to decisions surrounding COVID-19 vaccination. Legal capacity is the term used to refer to the right to make decisions for oneself, within the constraints of the law, which must then be considered as being legal. Respecting people's right to exercise their legal capacity is not only a legal matter but linked to respect for their autonomy, and in turn to their dignity, personhood, standing in the community and psychological and emotional wellbeing. Informal restrictions of legal capacity can be equally damaging. These include restrictions that are not based on a legal or even administrative process but on assumptions, paternalistic attitudes, ignorance and institutional procedures.

An effective and fair system is needed that corresponds to everyone's needs and wishes, and provides people with dementia with the support they need to exercise their legal capacity (in this case to grant or withhold consent to vaccination). This must be based on an understanding of capacity as something that is task specific and affected by a range of factors such as the situation/context and aspects of the environment etc. A flexible, nuanced and supportive approach to decision-making and legal capacity is important, incorporating an assessment of decision-making capacity that not only determines whether someone can decide autonomously but also the kind of support needed to enable them to make a particular decision (e.g. regarding vaccination) (Alzheimer Europe 2020).

Some people with dementia may, nevertheless, still lack the capacity to consent to, or alternatively, to refuse vaccination. This represents an ethical dilemma but one which must be addressed through appropriate support and communication with the person concerned, their entourage and the legal representative (if there is one), taking into account the person's current and past known wishes. Informed consent should be managed in a timely and pragmatic manner, so that measures to respect the autonomy and the human rights of people with dementia do not actually deprive them of their equal right to be vaccinated.

Any attempt to oblige people with dementia to be vaccinated (e.g. to protect themselves, others or healthcare systems), if they are unwilling to be vaccinated, would run counter to the principles of non-maleficence and respect for autonomy. It would also represent a failure to respect their personal and physical integrity, and expose them unjustly to the risk of potentially harmful side effects. Coercion, subtle persuasion or manipulation should be considered particularly

reprehensible when used against people with cognitive impairments and/or who are dependent on others for support and care.

Alzheimer Europe's position

Now more than ever, it is critically important for governments to promote the timely access of people with dementia to COVID-19 vaccination and to ensure that vaccination strategies are fair and equitable, taking into account the particular vulnerability of this group during this and future pandemics. In keeping with the principles of solidarity and in the context of interdependency, governments must take a stance to protect the health and wellbeing of people with dementia who are at increased risk of contracting and succumbing to COVID-19.

In the context of the COVID-19 pandemic and with regard to vaccine prioritisation strategies (especially when supplies of the vaccine are insufficient or the logistics of distribution are problematic), 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 possession of 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, including enablers such as vaccination at home, as well as support for making personal decisions around vaccination
- ensure that strategies and implementation programmes for COVID-19 vaccination meet ethical, human rights and legal standards
- ensure that people with dementia, regardless of their capacity and whether or not they are eventually vaccinated, feel safe, comfortable, and respected during the roll out of vaccination programmes

and with particular reference to respect for ethical and legal standards surrounding autonomy, human rights, personal integrity and non-discrimination to:

- ensure that information is accessible, age and culture appropriate and suited to the capacity of each person, bearing in mind the consequences of isolation, the lack of a person's familiar supporter in some cases and the possible difficulty to grasp the full extent of the pandemic
- ensure that extraordinary provisions are established to manage the issue of informed consent in a timely and pragmatic manner so that measures to respect the autonomy and the human rights of people with dementia do not actually deprive them of their equal right to be vaccinated
- work from the presumption that a person with dementia has legal capacity to consent unless there is reason to suspect that the person's condition may be negatively affecting their decision-making capacity (not merely that they have a diagnosis of dementia)
- ensure that informed consent is provided by people with dementia who have the capacity to consent (i.e. specifically to COVID-19 vaccination, at this moment in time)
- respect decisions made by people with dementia who have the capacity to make the decision about vaccination, even if their decisions seem unwise
- ensure that people with dementia decide freely and are not subjected to direct force, subtle pressure or deception

- make every effort to ensure that people with dementia feel safe, valued and not threatened in discussions about whether to have the vaccine and if/when it is administered
- respect clear verbal or non-verbal signs of refusal to be vaccinated from people with dementia (even if they lack the legal capacity to consent to it or previously consented to it)
- ensure that personal beliefs and assumptions about the quality of life of older people, or by value assumptions related to chronological age or having a diagnosis of dementia, do not affect evaluations of decision-making capacity or substitute decision making
- only consider substitute decision making if supported decision-making has proven insufficient and all reasonably available resources for support have been exhausted
- be guided as a substitute decision maker, in accordance with national legislation, by what the person with dementia would want in the situation if they had decision-making capacity, drawing in order of priority on (a) wishes expressed in an advance directive, (b) previously communicated preferences with regard to the choice at hand, (c) the person's values and commitments, and only if all the other sources of evidence about the person's will and preferences are unavailable or insufficiently clear (d) on the person's best interests.

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