



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

Alzheimer Europe position regarding the allocation of scarce medical resources for intensive care services during the COVID-19 pandemic

3 April 2020

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Background information

In light of the current COVID-19 pandemic, governments across Europe are taking measures to protect the health, wellbeing and lives of millions of inhabitants in relation to current and anticipated needs, based on scientific advice, epidemiological modelling, mutual learning from other countries and emerging medical developments. Examples of solidarity and responsible behaviour by many individuals, companies and governments are being shared in the media, amidst steadily increasing numbers of people being infected by and dying from the virus.

It is hoped that the different measures adopted and planned in Europe will suffice. At some point, however, resources may be insufficient and triage may be introduced in order to manage and balance the use of limited resources against healthcare needs. Indeed, this has already started to happen in some countries. This may make it difficult to ensure that everyone, including the most vulnerable members of society, benefits from the same level of healthcare, treatment and support. At the same time, we recognise not only the logistical problems faced by doctors and healthcare professionals and the need to protect their safety, but also the psychological and emotional impact and the ethical dilemmas they may face when resources are insufficient and life and death decisions have to be taken. If and when a necessity for triage arises, for the peace of mind of everyone affected, this must be done in a way that is ethically, socially and legally justifiable.

Discrimination on the basis of personal characteristics or situation (such as age, sex, gender identity, social or ethnic affiliation, disability, socio-economic status or place of residence) and the ranking of lives on the basis of value judgements or of assumptions about quality of life are unacceptable and contrary to numerous legal and ethical conventions and recommendations. Non-treatment during a disaster situation such as the current pandemic does not necessarily amount to non-assistance to a person in mortal danger. However, unfair procedures to allocate insufficient resources (e.g. based on discrimination and value judgements) could constitute a violation of human rights.

A common guiding principle with regard to triage in disaster situations or specifically in relation to insufficient resources for intensive care services is that of maximum benefit as opposed to a “first come, first served” basis (which could result in those with a greater need for treatment dying whilst treatment is being given to others who need it less or were simply geographically closer to the hospital). In the World Medical Association’s Statement on Medical Ethics in the Event of Disasters (Stockholm 1994, amended Chicago 2017), this is expressed in terms of setting priorities for treatment to save the greatest number of lives and to restrict morbidity to a minimum. However, if younger, otherwise healthy people have a better likelihood of surviving if given life-saving treatment, there is a risk of age and health status indirectly becoming standard criteria for triage. The risk is further heightened if greater value is placed on estimated years of life following survival than on the number of years that a person has contributed to society and on assumptions about normal life expectancy of individuals, which can vary greatly. Some guidelines associate a reduced likelihood of survival of COVID-19 with specific pre-existing medical conditions (including for example severe neurological disorders and certain lung and heart conditions) and to multi-morbidity, which is again more common amongst older people and people with dementia.

Procedures and guidelines aimed at managing insufficient resources in crisis situations, such as the current COVID-19 pandemic, may in principle reflect an ethical approach, but care must be taken to avoid the inadvertent and systematic exclusion of people with dementia and hence the failure to protect the rights and lives of some of the more vulnerable members of society. Several organisations and ethicists have expressed their position and views on the management of intensive care when resources are limited, as well as on wider issues affecting the wellbeing and lives of people, in particular situations and with particular characteristics or needs, who risk being disproportionately adversely affected or being discriminated against.

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Alzheimer Europe position

Alzheimer Europe's position on the issue of triage of patients in the context of access to intensive care services during the COVID-19 pandemic is as follows.

Alzheimer Europe emphasises its commitment to a human rights based approach to dementia and its firm belief that after diagnosis, people with dementia can live many years of meaningful existence with a high quality of life. A diagnosis of dementia on its own should therefore never be a reason to refuse people access to treatment, care and support.

Governments and healthcare systems should take all necessary measures to ensure that the needed infrastructure (in addition to sufficient human resources) is in place so as to avoid the need for triage decisions.

Everyone, irrespective of whether they do or do not receive intensive care services, should be treated with compassion and respect for their dignity, as well as their customs, spiritual beliefs and religion, and given, when appropriate, pain relief, sedation and/or palliative care.

Decisions related to access to or withdrawal of intensive care services (including but not limited to life-saving or sustaining treatment) during the COVID-19 pandemic:

- should be based on an evaluation of a patient's individual prognosis, not on whether he or she has a particular diagnosis or on generalised assumptions/stereotypes about the impact of a particular diagnosis (e.g. of dementia) on overall health, life expectancy or chances of survival,
- should not be based on non-medical criteria/characteristics (e.g. age, place of residence, sex, gender identity, ethnic affiliation or marital or parental status) or value judgements (e.g. about probable life expectancy, assumed quality of life, potential future contribution to society etc.),
- should not be based on whether patients do or do not have COVID-19,
- should take into consideration a person's current wishes and if this is not possible, their previously expressed or known wishes (e.g. expressed in an advance directive or communicated by relatives or life partners), but not their suspected or presumed wishes,
- should take into consideration palliative care principles and guidelines,
- should be made on the basis of clear approval processes which should, whenever possible, include at least two qualified medical doctors with experience in intensive care, plus one other relevant healthcare professional (e.g. a nurse or professional carer with experience in palliative care),
- should be reviewed on a regular basis in relation to changes in patients' prognosis, in the availability of different and emerging treatment alternatives and in the availability of resources,
- should be properly documented (e.g. including details of the grounds for the decision and by whom it was made), dated and signed.

The process for the management of and access to intensive care services during the COVID-19 pandemic should be transparent and accessible to the general public.

This position was adopted by Alzheimer Europe on 3 April 2020