Société Alzheimer Society
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Alzheimer Society calls for transparent, inclusive approach to developing critical care triage protocols

Allocation of lifesaving resources must not be based on impersonal, dehumanising online tools

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Free, open, and accessible health care is a hallmark of Canadian society. When we or someone we love falls ill, we expect that quality care will be there in our time of greatest need. The COVID-19 pandemic raises the frightening possibility that this may not always be the case.

Any decisions around possible triage protocols for lifesaving care carry a very real risk of disproportionately harming the most vulnerable: those who may be unable to advocate for themselves and their care needs, including people living with dementia. The Alzheimer Society of Ontario strongly recommends that the following considerations be taken in to account when drafting procedures for possible triage protocols:

Transparency and Public Consultation

Public trust and confidence is eroded when decisions are made behind closed doors. Private consultations with a limited group of individuals risks biases held by these individuals—including stigma around cognitive impairment and dementia—going unchallenged.

Inclusion of those who will be adversely impacted by any possible triage protocols, including people living with dementia and their care partners, is essential to establish ethical legitimacy. Their concerns and experiences must be heard, considered, and ultimately factored in to decisions.

Even if triage protocols are never implemented, how they are developed matters. People living with dementia have long experienced stigmatisation within both the health care system and society as a whole: if their voices are not heard, the Alzheimer Society is gravely concerned that their lives will be devalued.

Individualised Decision Making

If you meet one person living with dementia, then you have met one person living with dementia. Alzheimer's disease and other dementias have a wide range of severity and trajectories, and each person's dementia journey is unique. It is entirely possible, and indeed common to live for years or sometimes decades following a diagnosis of dementia, while maintaining a high degree of independence.

> Allocation of critical care resources should be based on individual circumstances, not blanket generalisations. A diagnosis of dementia on its own should never preclude access to critical care; each person’s clinical condition must be evaluated independent from any subjective judgements around quality of life.
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> This recommendation carries greater importance as patients continue to be moved between intensive care units and care partners are often denied access to their supported person while they are in hospital. Separated from their care partners and in an unfamiliar environment far from home, the condition of a person living with dementia may deteriorate. This is only a temporary reflection of the environment in which they are receiving care, and reverses when the individual is back in familiar surroundings with those who can understand and respond to their needs.
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> The Alzheimer Society is deeply concerned that in denying people living with dementia the ability to see their care partners, current restrictions also deny them a voice. Those without a voice are ignored far too often, and we fear that that will be the end result of triage protocols that see only a diagnosis and not a person.

Conversations around critical care triage are not easy, but that is no excuse to hold them in private. While mass vaccination efforts move us closer to a return to normal, we must not lose sight—as other jurisdictions have done—of worst-case scenarios. Open, transparent consultations around possible triage of lifesaving resources would lend ethical credibility to the development of any protocols, and expose biases that can be corrected by those with lived experience.

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