

# Development and dissemination of an ethical guidance and person-centred isolation care planning tool to support the care of people with dementia during the COVID-19 pandemic

Andrea Iaboni<sup>1,2</sup> | Alisa Grigorovich<sup>3</sup> | Claudia Barned<sup>4</sup> | Kevin Rodrigues<sup>5</sup> |  
Kontos Pia<sup>2,3</sup> | Charlene H Chu<sup>2</sup> | Arlene J. Astell<sup>2</sup> | Alastair Flint<sup>2,4,6</sup> |  
Kathleen Bingham<sup>2,4</sup> | Colleen J Maxwell<sup>7,8</sup> | Julia Kirkham<sup>9</sup> |  
Josephine McMurray<sup>10</sup> | Hannah Quirt<sup>5</sup> | Mario Tsokas<sup>11</sup>

<sup>1</sup> Toronto Rehab, University Health Network, Toronto, ON, Canada

<sup>2</sup> University of Toronto, Toronto, ON, Canada

<sup>3</sup> Toronto Rehabilitation Institute - University Health Network, Toronto, ON, Canada

<sup>4</sup> University Health Network, Toronto, ON, Canada

<sup>5</sup> Toronto Rehabilitation Institute, Toronto, ON, Canada

<sup>6</sup> Centre for Mental Health, University Health Network, Toronto, ON, Canada

<sup>7</sup> ICES, Toronto, ON, Canada

<sup>8</sup> University of Waterloo, Waterloo, ON, Canada

<sup>9</sup> University of Calgary, Calgary, AB, Canada

<sup>10</sup> Wilfred Laurier University, Waterloo, ON, Canada

<sup>11</sup> Regional Geriatric Program, Toronto Rehabilitation Institute, Toronto, ON, Canada

## Correspondence

Andrea Iaboni, Toronto Rehab, University Health Network, Toronto, ON, Canada  
Email: [andrea.iaboni@uhn.ca](mailto:andrea.iaboni@uhn.ca)

## Abstract

**Background:** Long-term care (LTC) residents have been disproportionately impacted by the COVID-19 pandemic, both from the virus itself and the restrictions in effect for infection prevention and control. Many barriers exist in LTC to prevent the effective isolation of suspect or confirmed COVID-19 cases. Furthermore, these measures have a severe impact on the well-being of LTC residents. Our aim was to develop a guide for long-term care to address the ethical challenges associated with isolating dementia patients during the pandemic. The Dementia Isolation Toolkit (DIT) was developed by members of the research team in partnership with LTC stakeholders to address: 1) the practical challenges of isolating or quarantining people with dementia in a compassionate, safe, and effective manner; and 2) the need for ethical guidance to support decision-making regarding isolation and infection control in LTC, to prevent indecision and moral distress. To develop the DIT the team reviewed and synthesized the literature on pandemic ethics in a plain-language document, which was then reviewed by our partners and stakeholders. The final ethical guidance tool includes a discussion of the ethics around infection control measures in a pandemic, an ethical decision-making tool, and a person-centred isolation care planning tool. The ethical guidance tool has been downloaded more than 6500 times since it was published ([bit.ly/dementiatoolkit](https://bit.ly/dementiatoolkit)), and has been disseminated internationally. The worksheets are being used during outbreaks to support care and decision-making, as well as proactively, to prepare for outbreaks by developing isolation care plans. There is a need for support for ethical decision-making in the context of a pandemic, particularly in settings such as LTC. Future studies will evaluate the implementation of the tool and its impact in addressing moral distress in health care providers in long-term care.