



## Facing difficult decisions in a pandemic

The Dementia Isolation Toolkit

By Dr. Andrea Iaboni



**E**arly in the pandemic, I noticed how many more decisions I needed to make every day. In both my personal and professional life, even simple decisions suddenly became more difficult. I was constantly weighing the risk of COVID-19 with other important needs – for myself, my family, my colleagues and my patients.

At work, the hardest situations were those where I felt I did not really have a choice. These were decisions where my options were limited by rules or policies that were there to prevent the spread of the virus. These decisions were

also having a severe impact on the well-being of individual patients I was caring for.

Sometimes this left me angry and sometimes it made me want to avoid my work. Luckily, I had access to a lot of support. I talked to my colleagues, including a bioethicist when there were especially difficult decisions. I realized that the strong feelings I was experiencing was something called moral distress. And I also realized I was not alone. Healthcare workers across Ontario, particularly those in long-term care, were experiencing the same thing.

Moral distress refers to the negative feelings you have as a healthcare worker when you know the right thing to do in a situation, but for some reason you are not able to do it. It is an all-too-common experience in settings that do not have enough resources, staff or support.

During the pandemic, we heard a lot about staffing shortages and how that makes it hard to get the work done. We heard about the stress of needing to isolate residents or separate them from their families. All of these situations can make us feel like our values and integrity as healthcare workers are under threat and result in moral distress. Unsurprisingly, moral distress is an important contributor to burnout. Even worse, it can make people feel numb or stop caring, which leads to poor quality care.

Fortunately, we know how to respond to moral distress. Healthcare workers can learn how to respond to ethically challenging situations in a way that protects their integrity. We can develop problem-solving and ethical reasoning skills that help us to manage even the most difficult situations. This is called moral resilience. It was clear that we were going to need a lot of it to get through the COVID pandemic.

### Practical tool

In mid-March 2020 the rules around isolation of residents at risk of COVID were put in place. It was overwhelming to think what this would involve for staff and the potential risks to residents who had to be isolated. My concerns about the residents and my desire to support people working in long-term care homes motivated the creation of the Dementia Isolation Toolkit (DIT).

The DIT is designed to be a simple and practical tool for people working in long-term care who may not have access to a bioethicist when faced with a difficult situation. It provides a summary of public health ethics by explaining how we try to balance the needs of individual residents with the health and safety of groups such as the other residents, the workers and the community.

An important focus of the DIT is to consider how to support residents during isolation. The DIT decision-making worksheet prompts care providers to consider which resources and strategies can be used to minimize the harm of isolation and to use the least restrictive options. The person-centred isolation care planning tool reminds us that effective and compassionate isolation is best achieved by identifying the needs of the individual resident and having a plan to meet them.

Overall, the DIT is designed to help people work through difficult decisions and to support them to find options that they might not have considered. This kind of problem-solving, flexibility and creative thinking are all an important part of building moral resilience.

### In practice

It was not long before I had the chance to put the DIT into practice. A staff member on our unit tested positive for COVID and most of the patients on our floor were

identified as contacts. Like many long-term care homes, we were faced with not only keeping residents in their rooms, but also keeping non-isolated residents from entering isolation rooms.

We prepared a short isolation care plan for each resident, which we adjusted and built upon as the isolation period progressed. Some rooms got stop sign banners across the doors, some got door alarms, and for others we used video monitoring. Meeting the needs of each individual resident in their room became a top priority, with staff assigned to help with mealtimes and recreation, even if this was not part of their usual duties. For most residents, these plans seemed to work, and they got through their isolation relatively easily. But not all residents managed so well.

By Day 7, it became clear that Mr. S was suffering more than most. Before the isolation, he was quite an active person who spent most of the day walking around the unit greeting other residents and staff. In the first few days of isolation, he found it very difficult to stay in his room and would get into arguments with staff that sometimes became physical. He was given some 'as needed' doses of an antipsychotic medication, and within a few days, he stopped leaving his room. But he also stopped showing an interest in leaving his bed, and in eating or drinking. His COVID test was negative, but he was not doing well.

We consulted our local infection control supports and his care plan was revisited. We decided to bring him out of his room on scheduled supervised walks if he would wear a mask and wash his hands. We would make sure there were no other residents around, and the staff member would be wearing PPE. We prepared signs that told him when he would have his walks, and we tried to make those times as special as possible, by having staff cheer him on.

This seemed to work. Mr. S got through his remaining seven days without receiving any further medication and regaining some of the strength he had lost in the first week. He bounced back somewhat over the following few months, although he was never quite back to his usual self.

While Mr. S didn't die from COVID, he was still a victim – one of many older adults in our province who have suffered in this pandemic. The pandemic has been hard – and sometimes heartbreaking – in long-term care, and many staff have felt themselves facing impossible situations. But the most important lesson of the pandemic for me is that there are always options. Even in those situations where we feel constrained, we can still make small choices to help our residents. **UCT**

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