Dementia Isolation Toolkit: Ethical Guidance for people who work in Long-Term Care

This section will provide an overview of the impacts of the COVID-19 pandemic on long-term care and discuss the ethical challenges associated with isolating dementia patients.

Andrea Iaboni
Alisa Grigorovich
Claudia Barned
Kevin Rodrigues
Pia Kontos
Charlene Chu
Arlene Astell
Dementia Isolation Toolkit Team

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Introduction

COVID-19 is a contagious illness. This means that it spreads rapidly from one person to another. The COVID-19 pandemic is raising a lot of questions about the right things to do in many different situations at work and at home. The stress associated with these new and scary situations can make it hard to make decisions. A framework can help you think through these situations and make the best possible decisions for you and the residents you care for.

We all have a role to play in responding to the pandemic and our actions have an impact on many other people. We hope that this guide will help you to decide what are the best actions to take.

1. What has this pandemic changed?

You may have noticed that a lot has changed in this pandemic. For example, we can't go to the mall or hang out in the park. These sacrifices are important to protect ourselves and also to protect our wider community. It is especially important to protect those who are most at risk of getting sick or dying. We also have a responsibility to make sure that restrictions on individual freedoms do not cause unnecessary harm. This is why governments are trying to help people who are most affected and in need.

How do these changes affect what we do in long-term care?

In the pandemic we have to make difficult decisions. These may get in the way of usual care. These decisions can also affect the well-being of some residents. For example, we are keeping away visitors including family members. This is to prevent them from bringing the virus into long-term care homes. This will benefit all of the residents and staff. Keeping visitors away can also help to save protective equipment for healthcare workers. But some residents will feel sad at not seeing their family. This is a cost of the need to protect everyone.

These types of decisions are not new. We face decisions everyday where we have to balance the needs of one resident against those of another. This is often when the way one resident expresses their needs might pose a risk to other residents or staff. The next section of this guide outlines some ways of thinking about how we make decisions that are ethical (the right thing to do) in pandemic times.

2. What is the right thing to do in a pandemic?

During a pandemic we must consider what actions to take to achieve the greatest good for the greatest number of people. In long-term care homes this means protecting the majority of staff and residents. When we do this we also look at how we can limit the negative impact of these actions on any individuals. These are some of the principles that you should think about when you are making a decision.

PROPORTIONALITY:

We need to make sure that we only do what is actually necessary. When we are thinking about what to do we should always ask if the good from the action is greater than the harms. To know what is necessary we must have a good idea of what we are trying to prevent and how dangerous it is. This principle guides us to choose the "least restrictive" option.

MINIMIZE HARM:

We always need to consider any harms that may result from the decisions we are making. We must also consider how we can prevent or limit those harms.

RECIPROCITY:

This is about "give and take." The burden of preventing the spread of COVID-19 in long-term care homes is falling on the shoulders of staff and residents. We need to find a way to lessen the burden for these groups. We also need to make sure these people feel safe. We do not want them to feel abandoned or experience severe harm. For staff, this can mean ensuring that they have adequate protective equipment. For residents, this means we must work hard to meet their needs.

FAIRNESS:

We need our decisions to be fair. This means we must pay attention to factors that can disadvantage some people. These include poverty, racial or ethnic background, gender identity, sexual orientation, disability, or mental illness. Looking at these factors means that COVID-19 will not affect disadvantaged people more than others. It will also help us distribute resources fairly.

TRANSPARENCY:

It is important we can show how we reached a decision. This includes making clear all of the different options we looked at. We also need to make sure that the decision is shared with anyone who needs to know about it.

In the next section we look at how to decide when a resident needs to be isolated in their room to prevent the spread of infection. We describe the different risks involved in this decision. Then we provide a guide on how to approach making a good decision.

3. Why do we isolate people who have a contagious illness?

Keeping people with a contagious illness separate from healthy people helps to prevent the spread of the illness. Sometimes we group people who have an illness together. We can also ask people to isolate themselves in their homes. This is for a short time until they are no longer infectious.

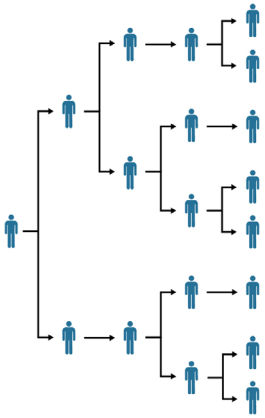
What if we do not isolate someone who is contagious?

The risk of passing on COVID-19 is high because the virus is spread by droplets and through touching contaminated surfaces. This means that an infected individual can easily pass on the virus by coughing or sneezing or even just talking to people. The virus can also be spread by an infected person touching doorknobs, handrails, chair arms, tables, and other surfaces. Another problem is that not everyone who is infected with COVID-19 shows symptoms at first. And some people who are infected do not show any symptoms.

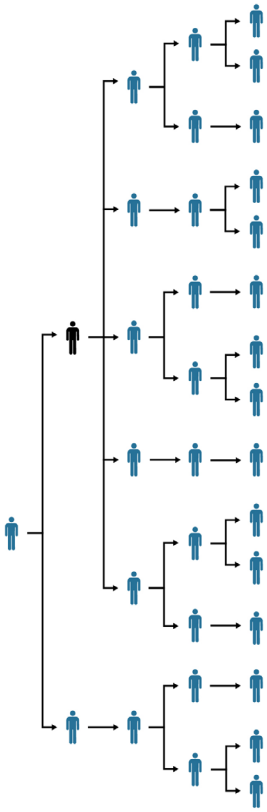
It is important to know that COVID-19 can have very severe outcomes for residents. Around 15-20% of residents who are infected with the virus will die. This is about 1 out of every 5 infected residents. Reducing the outbreak means that fewer people will die.

Most outbreaks in long-term care seem to start with healthcare workers who did not know they were infectious. They came to work and interacted with many staff and residents. Residents and staff who become infected then spread the virus to other people. The drawing below shows how just one resident spreading the virus can be the difference between a small outbreak and a big one. You can also see that limiting the spread from one person to another can control the outbreak quicker. This is done by limiting contact with other people.

*If each person infects **1-2** people:*



*If each person infects **1-2** people:, except one person infects **5**:*



What if a resident won't stay isolated?

It is important to understand why a resident will not stay in their room. Some residents with dementia or cognitive impairment may **not be capable** of understanding what you want them to do. Or they may appear to understand but quickly forget. This means they may not stay in their room. They may become distressed if they are told to go back. We have a duty to protect these residents from doing things that may harm themselves or others. This means we can isolate someone who is infectious if they are unable to isolate themselves. We do this using the principles described in Section 2 above.

Other residents who are **capable** of understanding may refuse to isolate. This can cause harm to others. It is important to listen to them and understand why they don't want to stay isolated. Think about how you can address their fears and concerns about isolation. If you can't find a solution together, then the next step is to consult the local Public Health Agency for guidance.

How can you help someone stay in isolation?

The principle of "give and take" (from Section 2) means we must develop an isolation plan to support and comfort the resident. A good plan will make it easier for residents to stay isolated. This will reduce harm to themselves and to others. An "Infection Control and Isolation Care Plan" should address these different areas:

PERSONHOOD:

We need to understand why someone keeps coming out of their room. We start by thinking carefully about each individual and their own needs. For example, they might come out to look for their spouse or child. Each person will have different reasons. We need to know these so we can address them.

ENGAGEMENT:

Residents in isolation need lots of interactions with staff. It is important that this happens while they stay in their room. For example, you can set up a schedule to check on them every 15-30 minutes. While wearing protective clothing you can provide positive support to stay in isolation. You can have a conversation, thank them for isolating, hold their hand, bring them a treat, or set up a new activity.

SUPPORTING NEEDS:

Make sure the Isolation Care Plan includes ways to address all of the resident's needs. This includes providing food and drink, as well as physical, mental and social activity. This can involve helping the resident engage in activities they enjoy. This can also mean helping them connect with people who are important to them.

REMINDERS:

We need to remind residents to stay in isolation. Door signs, scripts or recordings can remind people to stay in their rooms. Any strategy that keeps a resident in their room reduces the chance of infection. Even if a resident has to be reminded very often, this is still a good strategy as it

reduces opportunity for infection. Residents can also remember to stay in their room by adjusting their environment. This could be a stop sign or warning on the door, a removable band across the door, a black mat across the entryway, or a door alarm. Some strategies, such as disguising the door handle, are more restrictive than others. Using the least restrictive action is always the goal.

You can find a worksheet to help you develop an "Infection Control and Isolation Care Plan" and other resources at **dementiaisolationtoolkit.com.** You can also find more specific strategies and suggestions at these links:

https://brainxchange.ca/Public/Files/COVID-19/BSO_COVID-19-Resource-Dementia-and-Maintaining-Iso.aspx

https://www.rgptoronto.ca/wp-content/uploads/2020/04/FINAL-COVID-19-BSO-RGP-Wandering-Guidelines-2020-04-14-1.pdf

It might be possible to separate infectious residents from other residents. We can do this by isolating infectious residents together. This is called creating "hot" and "cold" zones. It is very effective when there are many infectious residents. It puts less stress on residents to self-isolate. It also reduces burden on staff to keep people isolated.

For some residents you might consider having someone stay with them throughout the day. A visitor wearing protective equipment could help them stay in their room. Making an exception to the "no visitors" rule may be justified if it prevents significant harm. We need to be creative and thoughtful about the risks and benefits of different approaches. This means we must consider each case based on the person, their needs and the resources available.

What are the risks of holding someone in isolation against their will?

It is easy to imagine that being held in your room against your will would be frightening. This is even worse if you do not understand why. Someone who is isolated in this way may feel abandoned or alone, and may be angry, sad, or anxious. If they are faced with a locked door, they may bang on it or try to open the door and hurt themselves. They may see the staff as "jailers" and respond physically (for example, hitting, kicking or pushing), which puts staff at risk of harm.

We may wish to give distressed individuals medication to make them calm or sleepy. But these medications come with risk. They can make them more confused or unsteady. This will make them more likely to fall and be injured. They may stay on the ground for a long period of time until they are checked on. Some medications can also make people breathe less deeply or have trouble swallowing. This can cause pneumonia.

Using a physical restraint device can also cause more problems. The individual could try to get out of the restraint and tip over the chair. They could get tangled in the restraint. They could injure themselves by fighting against the restraint. If they are restrained for a long period of time, they can have skin breakdown or blood clots. They can get weak and lose the ability to walk.

What this means is that more restrictive ways of keeping someone in their room against their will come with a greater risk of harm. There may be times when it might be necessary, but the benefit of this needs to be weighed against potential harms. These include risk of serious injury or death. You need to make a decision about what action is **proportionate to the danger** and what can be done to **minimize any harms** (see #2 above)

Now that you know how to support isolation of residents, here are some ways to approach a decision about what needs to be done.

4. What can help to guide decision-making?

In addition to the principles in Section 2, the following points can help to guide the decision making process.

REASONABLENESS:

The first step is to make sure you have considered all the risks and benefits of the different options. It is important to start with less restrictive measures before moving on to more restrictive ones. You need to be clear about what harm you are trying to prevent. You need to believe that the action you are proposing has a good chance prevent this harm. You need to think about what other harms might arise from the action and how you will try to minimize them.

RESPONSIVENESS:

In a pandemic, things can change very fast. This means we need to react to what is happening around us and make good decisions quickly. It also means that we may need to go back to review or change our decisions. What is right one day may not be right the next. We shouldn't feel stuck with decisions when the situation is changing. But we must be always be sure that our actions are about meeting an important need.

OPENNESS:

The decisions we make during a pandemic affect a lot of different groups of people. We make better decisions when we include the people who are affected. We should let them know what we are thinking and seek their input where possible. In addition to talking to residents, we might also talk to other staff, leaders, outside supports, as well as residents' families. This can be hard. We might worry about what they will think or say about us. But the best decisions are those made out in the open. Doing things openly also lets us know if there are any disagreements so we can work through them together.

ACCOUNTABILITY:

This reminds us that we are responsible for all the decisions we make. This includes being accountable for avoiding or ignoring a problem. Deciding not to take action is also a decision. It is better to face difficult decisions with our colleagues, leaders and other supports than to let a situation get out of control.

TRUST:

We need the trust of residents, staff, and their families to put our plans into action. This will help us keep these actions going throughout the pandemic. Following these principles in an open and thoughtful manner can help us make decisions that can be followed through on and sustained. Trust is also important to prevent the spread of misinformation. And trust can reduce feelings of hopelessness and powerlessness.

Thanks for reading this tool!

Sign up for updates on our website **www.dementiaisolationtoolkit.com** to be the first to hear about any updates or new tools.

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