

# Delivering Person-Centred Isolation Care during a Pandemic: Implementation of the Dementia Isolation Toolkit

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[www.dementiaisolationtoolkit.com](http://www.dementiaisolationtoolkit.com)



@dementiarehab

# Disclosures

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- I do not have any conflicts of interest to report



# Objectives



Understand the need for compassionate approaches to infection prevention and control during a pandemic



Describe the elements of the DIT and how they can be used to deliver person-centred care during the pandemic



Recognize barriers and facilitators to implementing these tools and their impact on moral distress

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# Barriers and facilitators to person-centred infection prevention and control: results of a survey about the Dementia Isolation Toolkit

[Andrea Iaboni](#) , [Hannah Quirt](#), [Katia Engell](#), [Julia Kirkham](#), [Steven Stewart](#), [Alisa Grigorovich](#), [Pia Kontos](#), [Josephine McMurray](#), [AnneMarie Levy](#), [Kathleen Bingham](#), [Kevin Rodrigues](#), [Arlene Astell](#), [Alastair J. Flint](#) & [Colleen Maxwell](#)

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# Infection prevention and control in long term care

## **PREVENTION**

- Visitor restrictions
- Screening staff
- Universal masking
- Hand hygiene
- Physical distancing
- Screening before admission
- Quarantine after admission

## **CONTROL**

- Identification of suspect cases
- Tracing of contacts
- Isolation of suspect and confirmed COVID-19 cases

**How can we achieve this effectively, safely and with compassion?**

<https://ltccovid.org/wp-content/uploads/2020/03/Summary-of-international-policy-measures-to-limit-impact-of-COVID19-on-people-who-rely-on-the-Long-Term-Care-sector-30-March-pm.pdf>

# Effects of Isolation

## Confinement



Lack of sensory stimulation



Lack of social engagement and social cues



Loss of routine and disruption to circadian rhythm



Lack of physical activity

## Separation



Disruption of attachment/social bonds



Separation Anxiety



Feelings of rejection



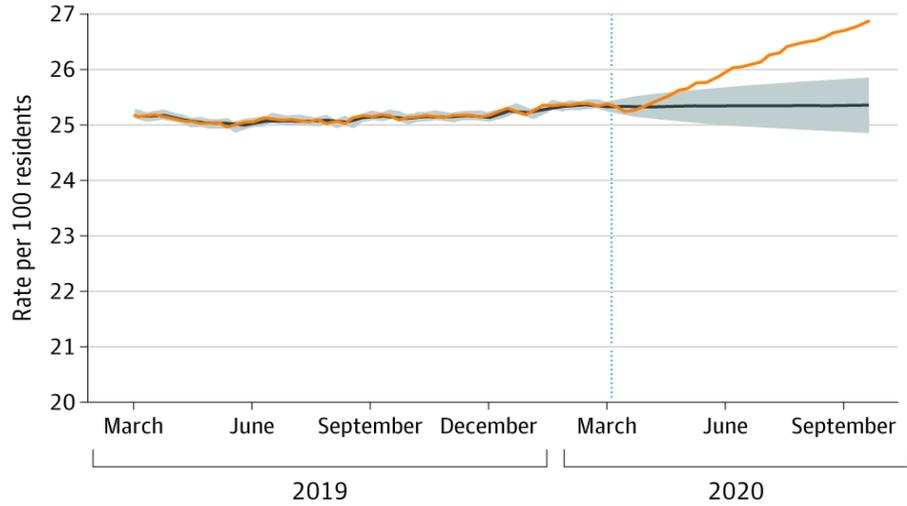
Grief

# Triggers for Responsive Behaviours

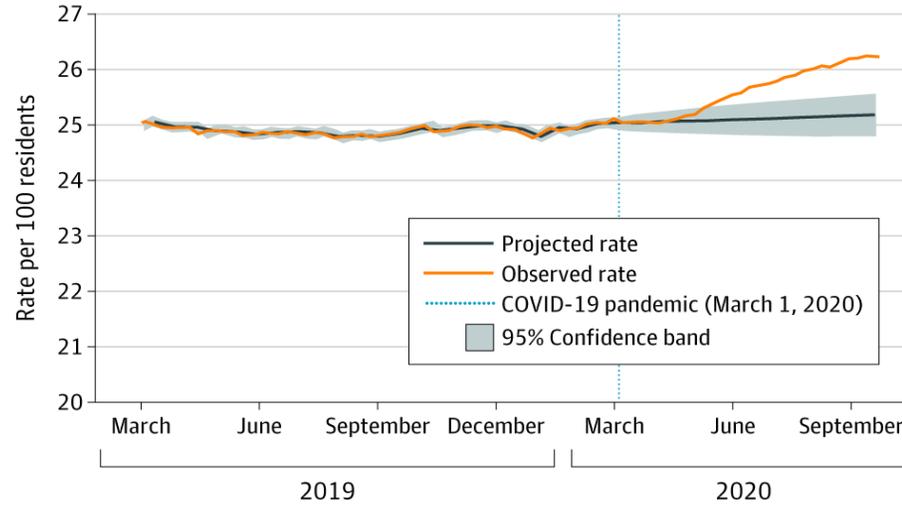
- Loss of programs/activities/supports
- Inadequate staffing numbers
- Lack of time to address needs
- Lack of time to apply non-pharmacological strategies
- Inexperienced or unfamiliar staff
- Caregiver stress, anxiety, fear
- Staff stress, anxiety, fear

# Increased Medication Use

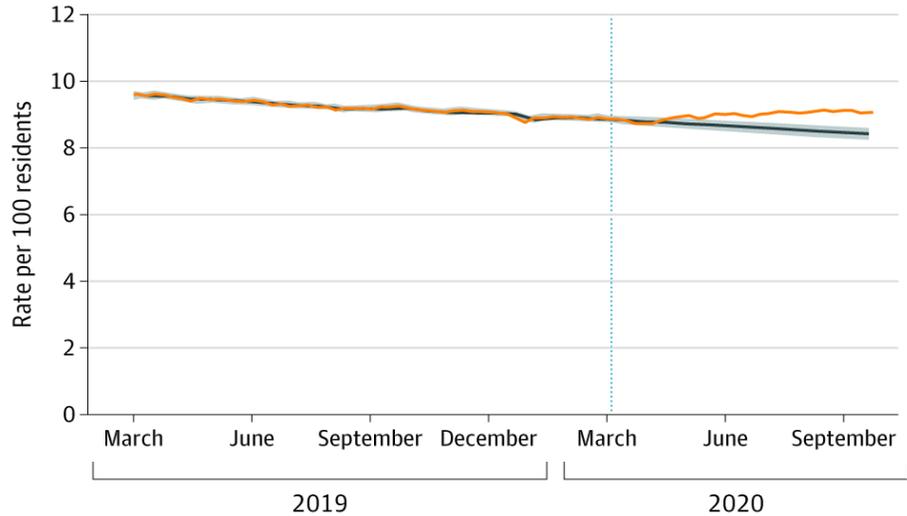
## ANTIPSYCHOTICS



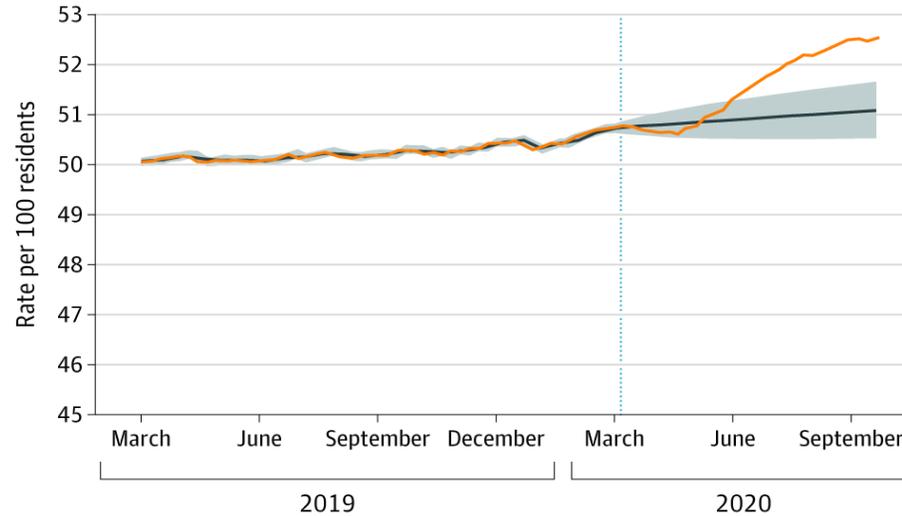
## TRAZODONE



## BENZODIAZEPINES



## ANTIDEPRESSANTS



JAMA Netw Open. 2021;4(8):e2118441.  
doi:10.1001/jamanetworkopen.2021.18441

# Family caregiver perspective

Denise Schon

- Denise is a caregiver to a family member in long-term care, chair of the family council at Lakeside Long-term Care and an advocate for persons living in long-term care and their families.

# Dementia Isolation Toolkit

## **Primary aim:**

To support the compassionate, safe, and effective isolation/quarantine of residents of LTC

## **Secondary aim:**

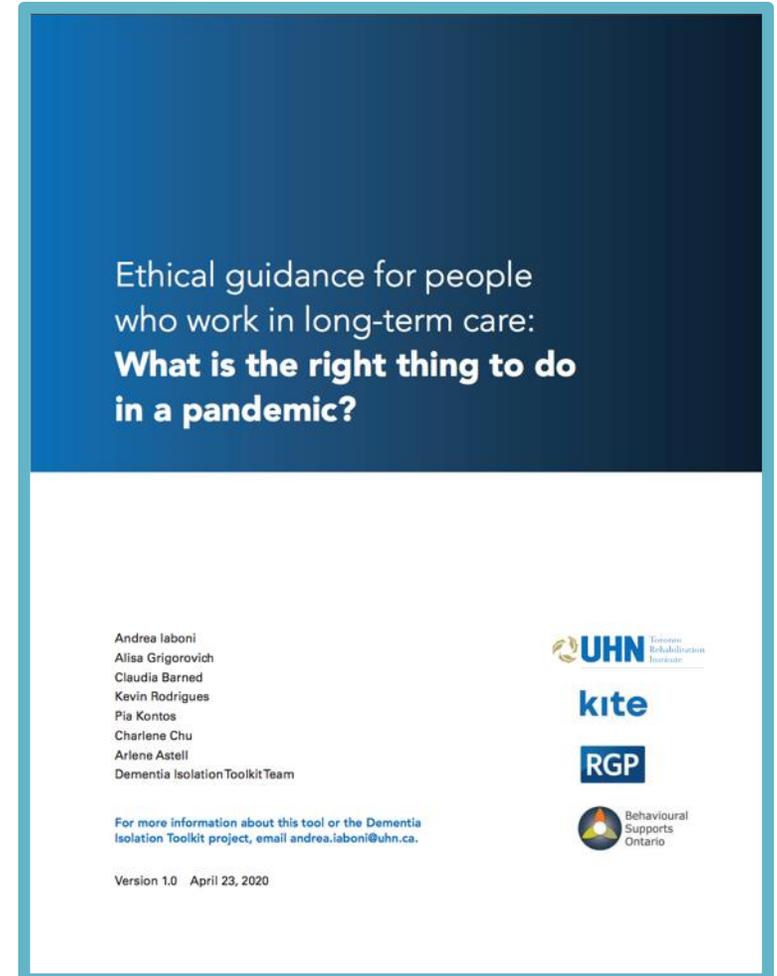
To support moral resilience in LTC staff during the COVID-19 pandemic

# Dementia Isolation Toolkit

1. Ethical guidance tool
2. Ethical decision-making tool
3. Person-centred isolation care  
planning tool
4. Communication tools

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# How does having an ethical framework help us?



# Moral Resilience

- Being able to work through difficult decisions while protecting your own well-being, as well as your residents'
- Responding to difficult decisions with creative problem-solving, flexibility, and adaptability
- Being able to work through ethical dilemmas in a way that aligns with your own values

# Dementia Isolation Toolkit

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What is the **danger(s)** you are trying to prevent? How likely is this to occur? If it does occur, what are the possible consequences?

- Day 4 post positive COVID test, asymptomatic but likely infectious.
- Tends to walk up close to other residents or goes into their rooms.
- Touches railings and tabletops
- Significant risk of spreading

## APPROACHES/STRATEGIES THAT YOU HAVE CONSIDERED OR TRIED:

Approach/strategy that you have tried or are considering?	What are the <b>risks</b> involved in this approach/strategy?	What are <b>benefits</b> involved in this approach/strategy?	How effective is this strategy?
See isolation care plan.	Minimal risks, involves walk with staff and PPE.	Needs are addressed most of the time.	About 50% of room in evening
Scheduled quetiapine at 5pm.	She may become more confused or fall.	PRNs of Quetiapine seem to help.	Needs met when

## WHO HAS BEEN CONSULTED/INVOLVED IN THIS DECISION? WHAT WAS THEIR INPUT?

STAKEHOLDER	INPUT
Public Health	Aware of difficulty with resident isolating and plan.
Leadership/Management	Looking to add extra evening staff to support isolation.
Resident	Doesn't want to take medication. No insight into infection.
Substitute Decision Maker	Worried about effects of medication. Reviewed monitoring plan and
Team members	RT concerned about how much PPE she is using to visit frequently
	Staff worried that when she comes out into hallway, they don't have

# Fairness and Transparency

Decisions need to be:

- **Reasonable**
- **Responsive**
- **Open**
- **Accountable**
- **Engender trust**

# Minimizing Harms

- We have a responsibility to isolate someone who poses an infectious risk to others if they are unable to isolate themselves
- Many potential harms associated with isolation
- Duty to minimize the harms

# Dementia Isolation Toolkit

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RESIDENT NAME OR INITIALS: \_\_\_\_\_ COMPLETED BY: \_\_\_\_\_ DATE: \_\_\_/\_\_\_/\_\_\_



## Person-Centred Isolation Care Plan

\*See Isolation Care-plan summary for condensed version

### PERSONHOOD:

What information do we know about this person? (e.g. likes, dislikes, values, previous roles/professions, their capabilities, relationships/family)?

What kinds of needs/reasons bring them out of their room?

What helps them return to their room?

### ENGAGEMENT:

What activities do they enjoy?

What activities can the resident engage in while in their room? What do they need for these activities?

# Person-centred isolation care planning

- Develop an isolation plan to support and care for the resident addressing:
  - **Personhood**
  - **Engagement**
  - **Supporting Needs**
  - **Reminders**

# Person-Centred Isolation Care Planning

Reframing the problem:

**How can we make her stay in her room?**



**How can we support her needs to help her stay in her room?**

# New tool: DIT Huddle



- Put person-centred isolation care into practice
  - Standing up and with the team!
- Simple facilitation guide
- Stimulates open discussion about impact of measures on residents and team

## FACILITATOR GUIDE:

# How to run a Dementia Isolation Toolkit Huddle

The huddle is designed to help care teams put the Dementia Isolation Toolkit into practice through a team discussion.

## Dementia Isolation Toolkit Huddle Script

- STEP 1** Huddle structure and promoting safety
- STEP 2** Set the Context
- STEP 3** Enable reflection questions
- STEP 4** Co-create solutions using a Person-Centred Isolation Care Plan

## Isolation Care Plan Summary

(REFER TO ISOLATION WORKSHEET FOR DETAILS)

Follow existing care plan, with these additions:

*\*This care plan does not replace the resident plan of care already in use. These are additional measures designed to support the safe and compassionate isolation of residents during the pandemic.*

<b>ISOLATION PERIOD:</b>	November 2nd - November 10th
<b>ISOLATION REASON:</b>	Exposure to PSW who tested positive for COVID-19
<b>ROUTINES AND CARE DURING ISOLATION:</b> Use this section to record any new routines that will be used during the isolation period. For example: transfer to wheelchair after breakfast and back to bed after lunch.	<ul style="list-style-type: none"> <li>- After breakfast: set up tablet with Youtube with her favourite songs, videos with subtitles</li> <li>- Offer tea with each snack pass</li> </ul>
<b>CUES AND REMINDERS:</b> Use this section to record specific cues and reminders that have been effective to help the resident. For example: Resident can understand that there is a bad virus and they need to stay in their room, but needs reminding at every interaction. Point to signs to reinforce this.	<ul style="list-style-type: none"> <li>- Rhoda understands need for infection control measures (used to be a nurse, but needs frequent reminders)</li> <li>- Place posters on Rhoda's door to remind her of infection control measures</li> <li>- Place masks by Rhoda's door in case she leaves room alone</li> </ul>
<b>ACTIVITIES:</b> Use this section to record what activities the resident can do and enjoy while in isolation in their room. For example: Enjoys watching old golf games on Youtube. Likes to listen to JazzFM and drink tea.	<ul style="list-style-type: none"> <li>- Give "productive" tasks that Rhoda can perform in her room, like folding towels</li> <li>- Video calls with her nephew when she is anxious</li> <li>- Put videos on her tablet of St Michael's choir performances on Youtube</li> </ul>
<b>SUPPORTING NEEDS:</b> Use this section to record additional ways the staff can ensure their needs while isolated are met. For example: Check every shift to ensure resident's tablet is charged and within reach. Check the resident is satisfied with the radio volume. Bring fresh tea often.	<ul style="list-style-type: none"> <li>- Enjoys having a clean room, help tidy with her and give her a duster or cloth she can use</li> <li>- Really likes her soft sweaters (blue and grey cashmere)</li> <li>- Reassure her that she is doing everything right and that she is not being punished. Validate that she is being really helpful by staying in her room</li> </ul>

# Isolation Care Plan Summary

# Dementia Isolation Toolkit

1. Ethical guidance tool
2. Ethical decision-making tool
3. Person-centred isolation care planning tool
4. **Communication tools**



# ISOLATION CARE PLAN AND ISOLATION DECISION AIDS



Start by familiarizing yourself with the *Ethical Guidance Toolkit*

-  **Proportionate to the Risk**  
Evaluate the degree of risk in the situation
-  **Minimize Harm**  
Consider what actions are needed to minimize harm
-  **Reciprocity**  
Prepare a plan to ease the burden on the resident
-  **Fairness**  
Check that your decision is fair and free from discrimination
-  **Transparency**  
Share your thinking process and include others
-  **Decision Making Worksheet**  
(Keeping in mind Ethical Guidance concepts)

Use Person-centred isolation care plan to inform Isolation processes as follows:

-  **1 Supportive**  
Orientation, explanation, redirection, distraction
-  **2 Less Restrictive**  
Increased supervision, alarms/reminders, non-restrictive barriers
-  **3 Environmental Strategies**  
Cohorting, transfer out to COVID-19 unit
-  **4 More Restrictive measures**  
(Use decision-making worksheet to inform)

Use together with supportive and less restrictive measures

# Minimally Restrictive Interventions



**Restrictive— avoid!**



# Training materials



HOME OUR TEAM DOWNLOADS TRAINING VIDEOS CONTACT US

Now available in:

- French
- Spanish
- Portuguese
- Tagalog
- Tibetan
- Hindi
- Chinese

## DIT Training Videos

We have prepared two training videos to help you use the DIT. After viewing, we would love to hear your feedback! Please provide us feedback in the form below the videos.

### Ethical Guidance Tools



### Person-Centred Isolation Care Plan

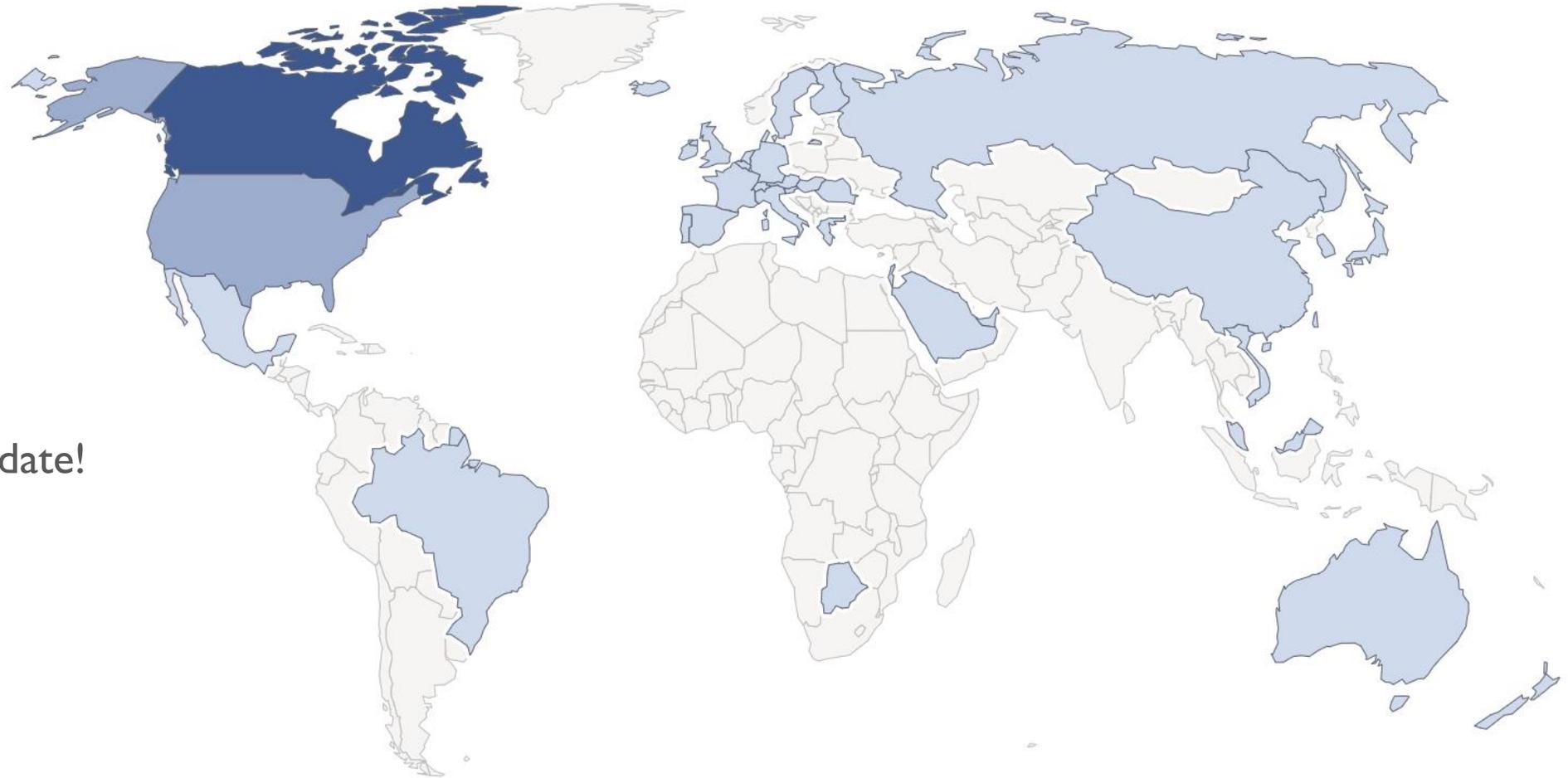


[www.dementiaisolationtoolkit.com](http://www.dementiaisolationtoolkit.com)

# DIT dissemination

Downloads:

Over 9000 to date!

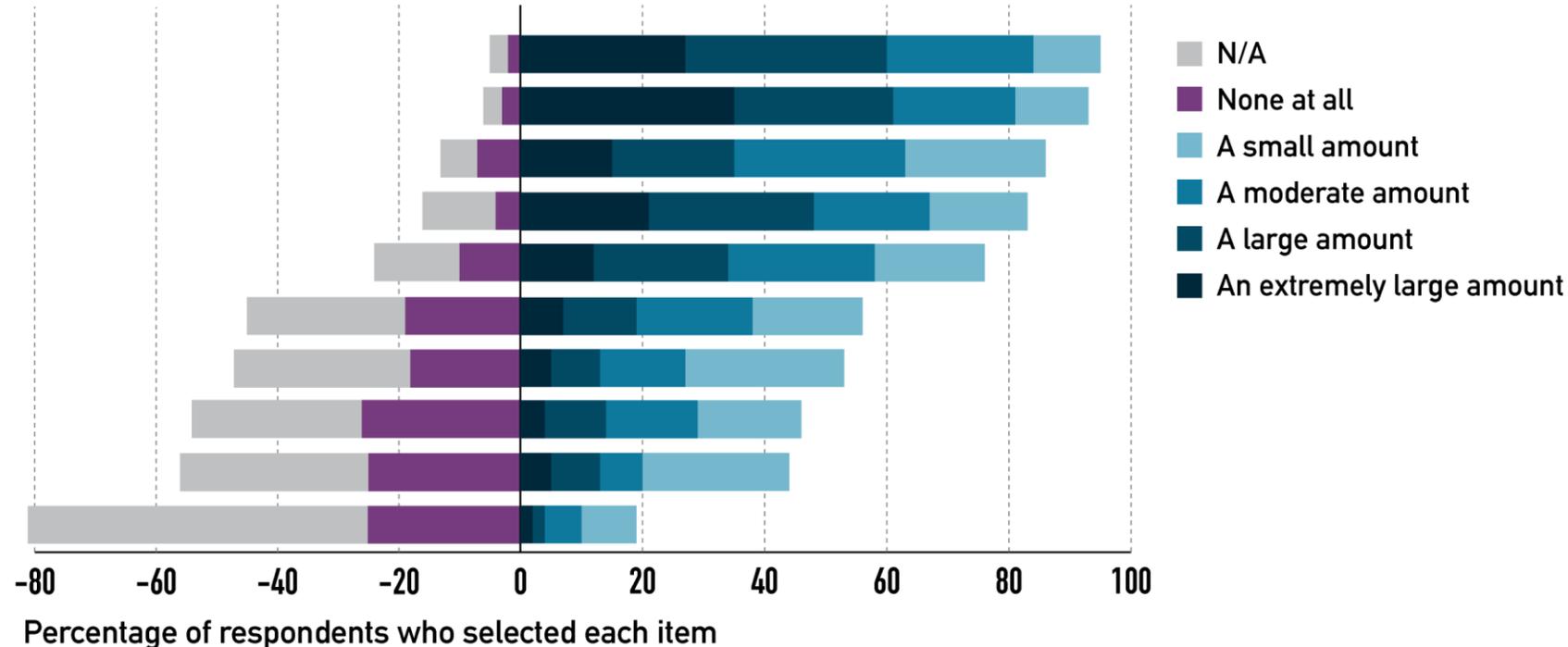


# DIT Survey: Moral distress

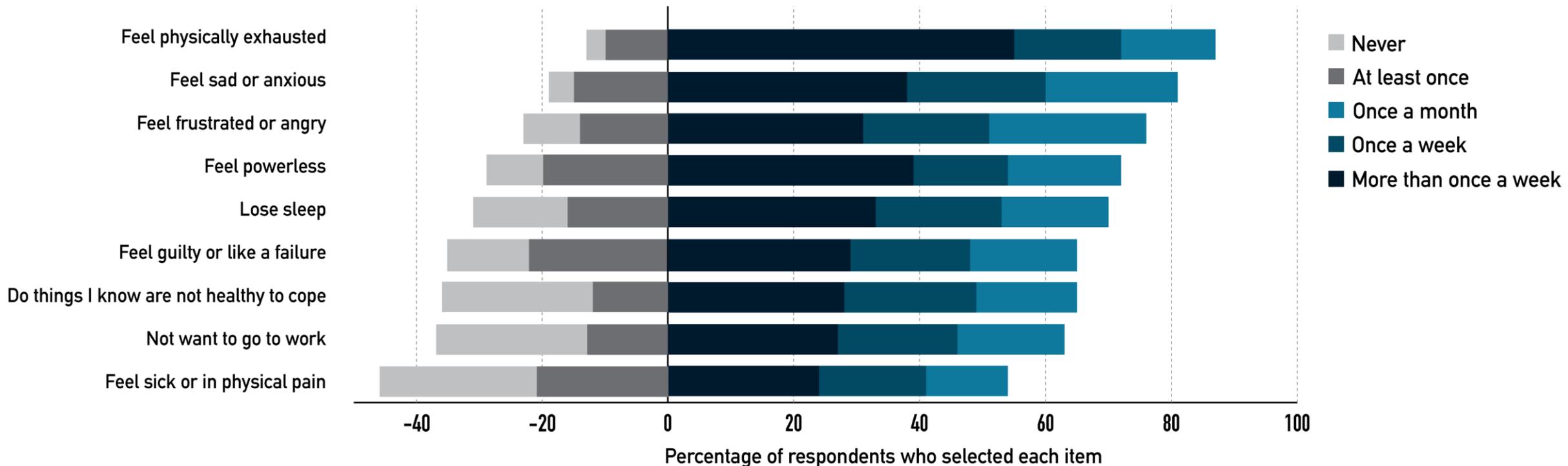
- 84% reported an increase in moral distress
- 33% reported large to extreme amounts of moral distress
- 40% reported large impact of moral distress on their job satisfaction
- 61% reported their distress was a barrier to effective implementation of isolation

Since March 1, 2020, how much distress, if any, have the following situations caused for you? (n=216)

- 2. Seeing low quality of life because not enough activities
- 6. Seeing care suffer because of family restrictions
- 7. Following COVID-19 policies that impact residents
- 1. Seeing care suffer because not enough staff
- 3. Seeing care suffer because of staff turnover
- 4. Providing care to aggressive residents without support
- 10. Poor care due to poor communication
- 5. Seeing care suffer due to lack of medical visits
- 8. Seeing residents suffer from poor symptom control
- 9. Not reporting neglect or abuse

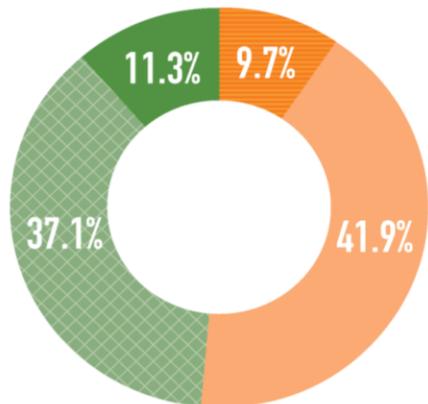


How often, if ever, have you felt the following as a result of the moral distress of caring for residents with dementia in LTCH since March 1, 2020? (n=204)

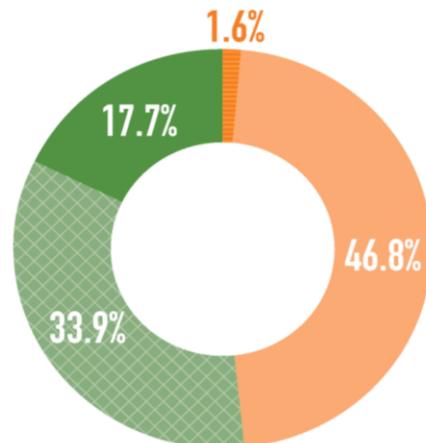


Please rate how **helpful**, if at all, you found this document for:

Reducing your distress about the care of residents living with dementia in a pandemic

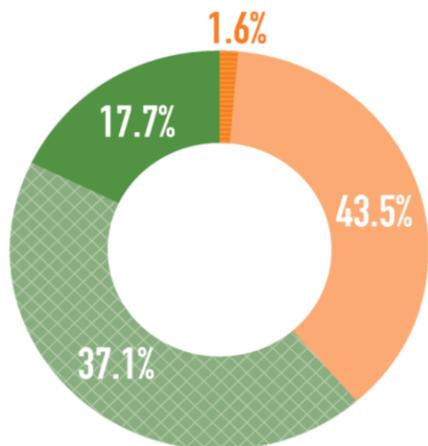


Supporting discussions within the care team

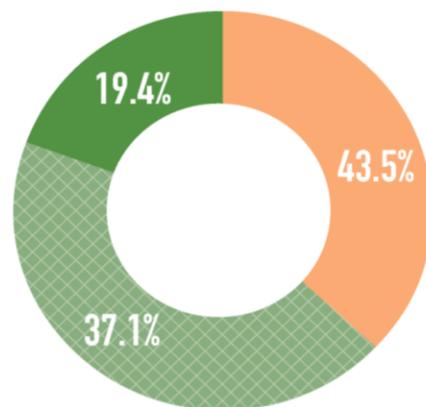


- Not at all helpful
- A bit helpful
- Fairly helpful
- Very helpful

Making & communicating decisions about the care of residents living with dementia in a pandemic



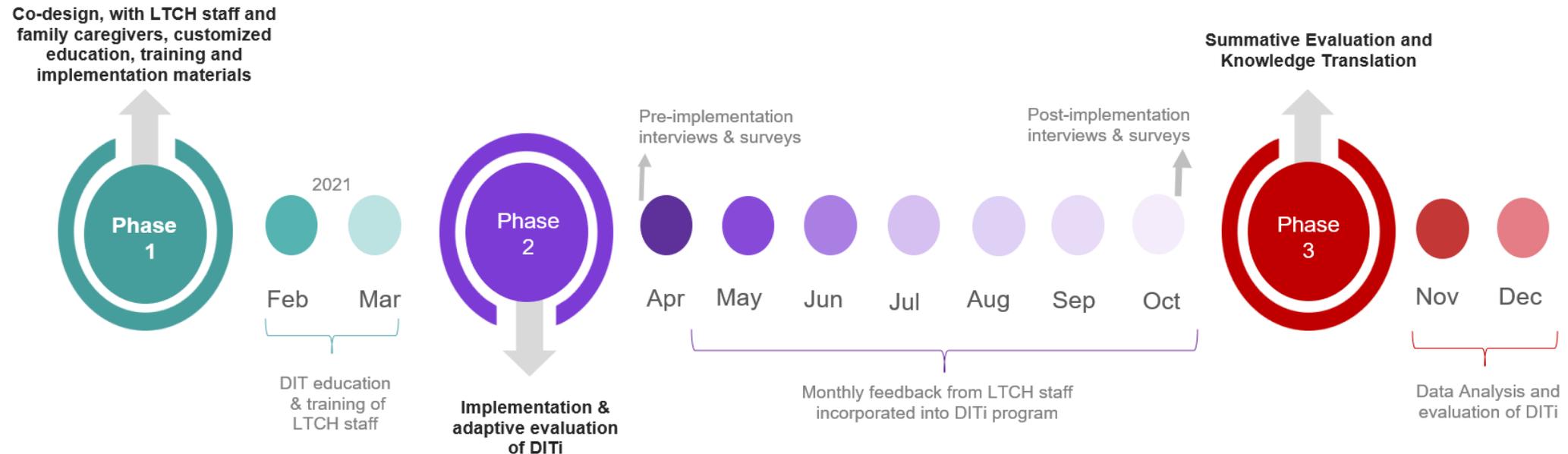
Developing care plans for infection prevention/control for residents living with dementia in a pandemic



65% were familiar with DIT and 48% of those had used it

# DIT Implementation study

Implemented the DIT in 3 LTCH in Ontario from April to October 2021



# Family caregiver perspective on DIT

## The DIT is adaptive and may help improve other processes in LTC

*"If you have resident-centered care from the beginning, it's much easier to adapt to something like a pandemic or... isolation" LTCH01*

## The DIT has improved communication between staff and residents/caregivers

*"I think it's bringing awareness to all the staff and how to communicate with the residents and how to be more diligent with the residents" LTCH02*

*"They (staff) seem to be more involved in what she (my mother) liked and disliked." - LTCH03*

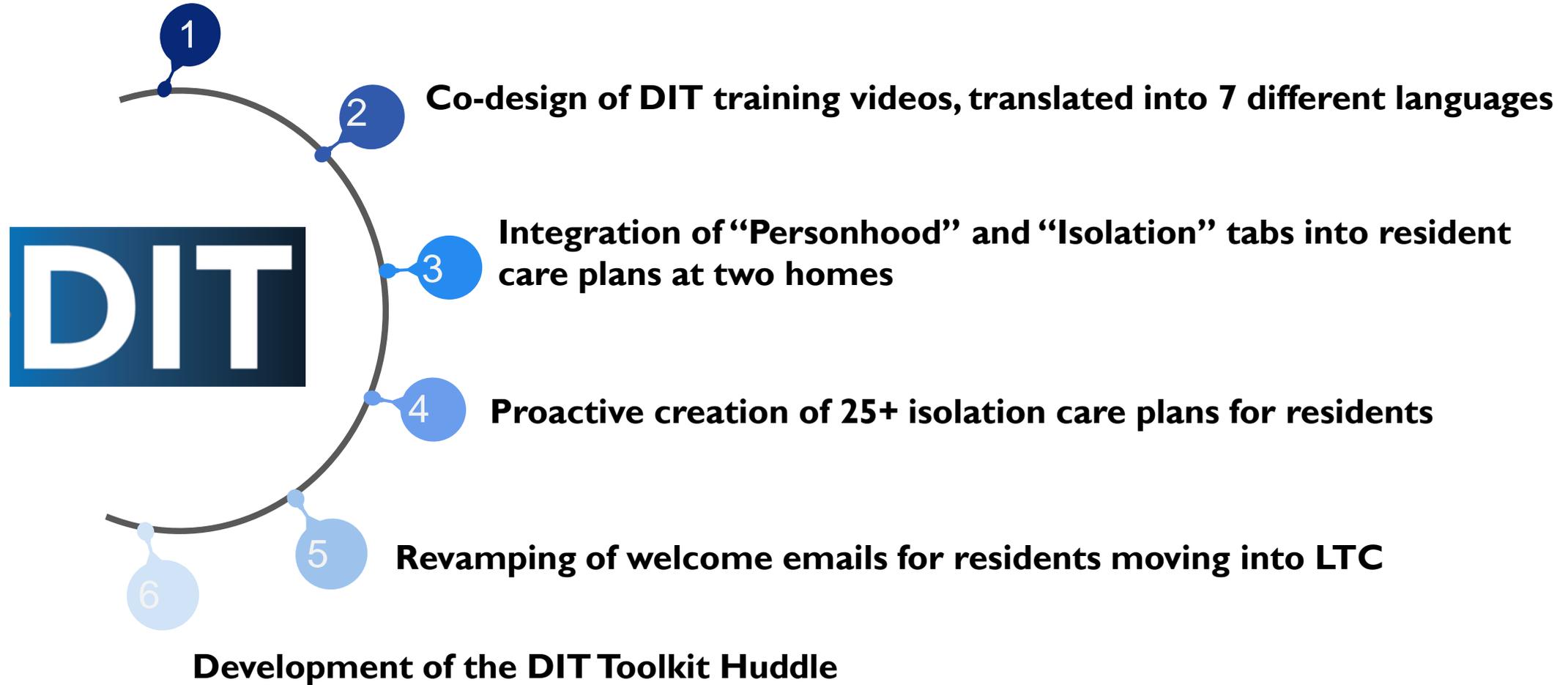
## Caregivers suggest understaffing may make it challenging for staff to use the DIT

*"They're (staff) pretty overwhelmed still. They're also very stressed. Some of them are quite burned out. To ask them to do one more thing... It's a big ask. For some people it's going to be extremely difficult to do" LTCH01*

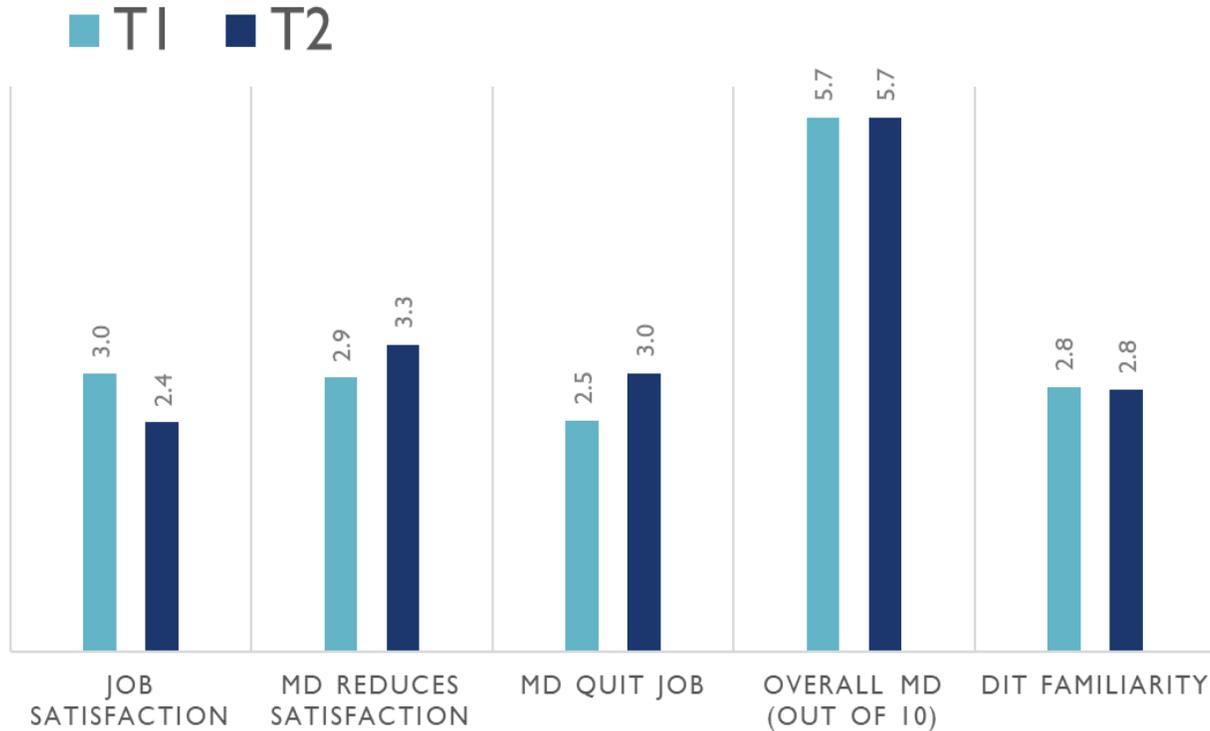
*"They have to do that care, that's the pressure, to get that care done, and to do the extra. I'm sure they would probably like to do more" LTCH03*

# Implementation study outcomes

**Co-design of customized DIT implementation plans for each LTCH**



# Pre- and post-implementation Moral Distress



Factors that associated with change in moral distress over study:

- High staff turnover and not enough staff
- Going against families wishes
- No one listens to them, and poor communication at work.

Administrative staff reported greater increases in:

- Felt bothered by staff turnover
- Felt strain at work and outside of work,
- How much moral distress made them want to quit their job

N=23

# Pre- & post-implementation interviews: Emerging Themes

## Chronic Understaffing

*"We were short-staffed... we don't have enough nurses and PSWs...it's hard for them to work so many hours and work so many days" - Behavioral Supports*

## Pandemic related directives exacerbated staffing/resource issues

*"Toronto Public Health is changing their directives all the time, what if they haven't sent updated information to the nursing homes yet? We don't know what to do" - RPN*

## Moral distress is ubiquitous

*"People are always asking are we doing enough or the right thing? Always assessing risk for every decision" - Social worker*

## Pandemic-related directives amplified moral distress

*"Even if I didn't do anything, then I felt like I was neglecting the residents. If I did something it also put me in the "catch-22" situation where I was like, "Oh, I'm not following the directives...I felt like we had to be very secretive" - Recreation and Leisure Staff*

# Pre- & post-implementation Interviews: Insights

## Barriers to person centered care and implementation of the DIT in LTC

- Priorities for care are driven by "compliance," and at present, this does not align with the principles of person-centered care that are at the core of the DIT
- LTCHs have a defined hierarchy of roles that impact staff members abilities to affect change, make decisions, and access information related to resident care.
- There are a subset of attitudes and beliefs (i.e., task-oriented approach to care, risk aversion) that do not align with the principles of person-centered care
- Lack of dementia awareness and knowledge coupled with lack of opportunity (e.g., paid time for training, opportunities) to improve dementia awareness via training and education

# Living in LTC during a pandemic

Another reframing:

How can we keep COVID out?



**How can we safely support the quality of life  
of our residents during a pandemic?**

# Next steps

- DIT-Tech project
- Revision of tools given stage of pandemic
- Further dissemination and evaluation of the DIT Huddle tool

# DIT-Tech

DIT-Tech is an Android tablet that comes pre-installed with commercially available applications:

TeamViewer, Skype, Find My Device, AcTo Games, YouTube, Spotify, StayFree, Google Translate

Designed to be remotely controlled (by family, by staff) to support

- Connection
- Safety
- Recreation

<https://dementiaisolationtoolkit.com/dit-tech/>

The DIT Technology project will achieve these goals:

## 1 CONNECTION



## 2 SAFETY

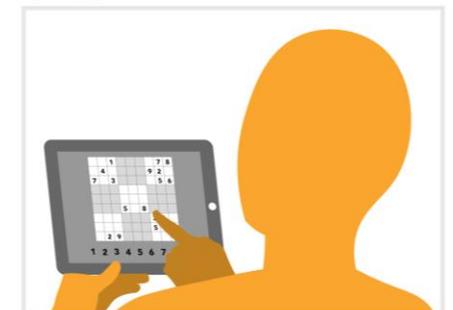


## 3 RECREATION

### A) Remote



### B) Independent



# DIT-Tech Study

## Aim:

- To establish the impact of a remotely-controlled DIT-Tech tablet on measures of resident safety, connection, and recreation.

## How:

- Participating homes will be donated 10 tablets to implement the DIT-Tech solution with 9 residents/caregivers and will be asked to provide feedback over 3 months

**Might be interested in participating or have questions?**

Email: [Teresa.D'Elia@uhnresearch.ca](mailto:Teresa.D'Elia@uhnresearch.ca)





**Finding creative  
ways to foster a  
sense of security**

# Security

- Sensory stimulation— music, art, food, aromatherapy, touch
- Reinforce social bonds— families and friends
- Routines and schedules— predictability
- Cues, reminders— repeatedly
- Rewards, positive reinforcement
- Physical activity
  
- Address team and caregiver distress



**Finding creative  
ways to foster joy**



**Michelle Fleming** @Michelle\_Pamela · Aug 28

Always a pleasure to see #longtermcare residents on duet bikes or the @CycleWithoutAge bikes - enjoying the wind in their hair, exploring the community and breathing in the fresh outdoor air!



**Schlegel Villages** @SchlegelVillage · Aug 28

The Village of Wentworth Heights in Hamilton has lent a duet bike to Pinehaven Nursing Home in Waterloo to give residents an opportunity to enjoy the summer weather with some outdoor bike rides. #LongTermCare



**Schlegel Villages** @SchlegelVillage · Sep 30

Autumn definitely arrived on time for The Village at St. Clair's Fall Fair!

Residents came down in their neighbourhood bubbles to enjoy some music, pie, cider and some time with CJ the pony, and Rupert the rooster.



**Schlegel Villages** @SchlegelVillage · Oct 20

Do you carve a smiling jack-o-lantern or a spooky one?

Show us your pumpkin carvings 🎃



Fall Activities at The Village at University Gates, Waterloo



**Schlegel Villages** @SchlegelVillage · Sep 11

Thank you, Tabatha & Amy, for the creativity and joy you bring to the Village as you tour Coleman Care Centre with your very own #icecream truck complete with music to deliver sweet treats to all the residents. #Barrie #LongTermCare



# D.I.T. Working Group

- Andrea Iaboni
- Arlene Astell
- Pia Kontos
- Alisa Grigorovich
- Kevin Rodrigues
- Charlene Chu
- Katie Bingham
- Alastair Flint
- Jessica Babineau
- Josephine McMurray
- AnneMarie Levy
- Mario Tsokas
- Hannah Quirt
- Melinda Machado-Cayley
- Leslie Giddens-Zucker
- Carole Cohen
- Faith Malach
- Debbie Hewitt-Colborne
- Marlene Awad
- Katia Engell
- Kaitlyn Ranft
- Teresa D'Elia

# Partners & Funding



Canadian Foundation for **Healthcare Improvement**

Fondation canadienne pour **l'amélioration des services de santé**





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