

# Experiences of Essential Care Partners during the COVID-19 Pandemic

## L'expérience de partenaires de soins essentiels pendant la pandémie de COVID-19

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### Key Takeaways

- Family presence in long-term care (LTC) is invaluable and the designation of essential care partners (ECPs) is one way to ensure that family caregivers will always have access to provide care to loved ones who live in LTC.
- Research in LTC is more impactful when residents, families and ECPs are fully engaged as partners. They have unique perspectives that can help researchers and LTC homes identify areas for improvement and support the design, implementation and evaluation of policies and practices in LTC.
- Meaningful family presence can be achieved when the LTC system demonstrates commitment and adaptability to the unique needs of each resident, family member and ECP.

### Abstract

Visitor restrictions in long-term care (LTC) have had many consequences for residents, their families and care providers. The value of family presence in LTC was obscured during the COVID-19 pandemic until the designation of essential care partners (ECPs) was introduced to support the re-entry of family caregivers into LTC. Three ECPs share their personal experiences of caring for a loved one in LTC before and during the pandemic. Partnerships with LTC homes, residents, families and ECPs are identified as a unifying way forward to bolster future pandemic preparedness and ensure that current and future residents receive safe and high-quality care.

### Résumé

Les restrictions concernant les visiteurs dans les établissements de soins de longue durée (SLD) ont eu de nombreuses conséquences pour les résidents, leurs familles et les prestataires de soins. L'importance de la présence de la famille dans les SLD a été occultée pendant la pandémie de COVID-19 jusqu'à ce que la notion de partenaires de soins essentiels (PSE) soit introduite pour appuyer le retour des proches aidants dans les SLD. Trois PSE ont partagé leur expérience de prise en charge d'un être cher en SLD avant et pendant la pandémie. Les partenariats avec les établissements de SLD, les résidents, les familles et les PSE sont définis comme une voie unificatrice pour le renforcement de la préparation à une éventuelle pandémie et pour garantir que les résidents actuels et futurs reçoivent des soins sûrs et de haute qualité.

## Introduction

The pandemic renewed the discussion around the importance of family engagement and the benefits it brings to the care and well-being of loved ones in long-term care (LTC). When the presence of families and caregivers was restricted, there were many consequences and, in some cases, harms, that impacted the safety, experiences and outcomes of residents in LTC, their families and their providers. While we were sometimes called *visitors* early in the pandemic, this language later shifted to *essential care partners* (ECPs) (HEC 2022a).

While this designation is new, the roles and responsibilities of an ECP are not. ECPs provide physical, psychological and emotional support as deemed important by the person receiving care. This care can include support in decision making, care coordination and continuity of care. ECPs are identified by the person receiving care (or the substitute decision maker) and can include family members, close friends or other caregivers. The designation of an ECP may also include paid caregivers at the discretion of the person receiving care (or the substitute decision maker).

In some jurisdictions, language such as *essential visitor* was adopted to describe us among others who were able to re-enter LTC during the pandemic (Government of Ontario 2022). However, the designation of ECP is intended to be broadly applicable across care settings and jurisdictions.

Before or during the COVID-19 pandemic, we have each found ourselves in the ECP role to a loved one in an LTC home. We were connected by researchers engaged in the Implementation Science Teams – Strengthening Pandemic Preparedness in Long-Term Care research program (HEC 2022b). While we have had varying levels of engagement in these research projects, we will share our journey through the pandemic, our perspectives on the research and our involvement with an Implementation Science Team.

We believe that by sharing our personal experiences as ECPs and by contributing to the research program, we can foster a greater understanding of the ways that the pandemic affected residents and their ECPs. We hope that this will support the LTC system in strengthening its response to future pandemics and in improving the care delivered within LTC homes.

## Who We Are

### Allan Monk

My wife was a resident in an LTC home during the pandemic. There were very few problems in the home where she lived. It was organized, prepared to respond and flexible. Except during a six-week lockdown, I was with my wife daily and know the incredible impact that staff can have on the care provided to both residents and their families. After my wife passed, I

learned that Bonnie Lashewicz and her team were conducting research on supporting mental health and preventing moral injury among LTC workers in the LTC home where my wife lived (HEC 2022c).

### Pauline Johnston

I provided care to my father and uncle, who were in the same LTC home. My father entered the LTC home in 2018, so this environment was new to me and at the time, I did not realize how a pandemic could affect the sector. It was important for me to be involved in the research because I wanted families to never be denied access to their loved ones again the way we were when LTC homes implemented no-visitor policies early in the pandemic. I became involved in a research project led by James Conklin on reintegrating ECPs in LTC homes through a designated care partner program (HEC 2022c). It was important to me that caregivers be given the designation of an ECP and be viewed as an integral part of the care team to support our loved ones in LTC in a safe way.

### Margaret Keatings

Prior to the pandemic, my sister or I were a daily presence with our father, who lived in an LTC home for almost eight years until he died at the age of 100 years. I was able to observe the challenges facing LTC both as a healthcare professional and as a daughter. During this time, I developed strong relationships with the staff and other residents and family members. Early in the pandemic, as restrictions to access were introduced, I anticipated the impact on vulnerable residents who were denied the presence of even one designated essential family member. After the death of my father, I remained engaged in opportunities to improve the care of older adults and was invited to join – as a family member with lived experience – the implementation science team that Katherine McGilton was leading. This project focused on a nurse practitioner-led implementation of health workforce recommendations in LTC homes during the pandemic (HEC 2022c). As a family member and a former healthcare professional, I understand the value of integrating families and patients into the interdisciplinary care team.

## Our experiences and perspectives

It is important for us to note that this article reflects our experiences and perspectives, and we recognize that across Canada, each person's involvement with the pandemic, with individual LTC homes and with the research program is unique. In addition, we would like to clarify that the use of the term *family* is to be understood as a person whom the resident defines as a family member, which does not necessarily mean biological

family and in many instances can refer to friends or chosen family members. We hope that our words provide perspectives and observations from which we can move forward and learn together.

### Being an Essential Care Partner during the COVID-19 Pandemic

As ECPs, we never doubted the value of family engagement, but the COVID-19 policies implemented in care facilities early on during the pandemic seemed to disregard it. As members of the care team, we represent an important voice that can advocate for those who are, in some cases, vulnerable and require our help in communicating their needs. We also act as a connection point between residents and staff as we have a unique relationship with the residents; they are our loved ones. We know their histories, their likes and dislikes and the little things that will make a difference in their day.

For Pauline and Allan, we agreed that being locked out and restricted from visiting our loved ones took a toll emotionally and was difficult. Media coverage of LTC homes in crisis only added to our worry and concern for loved ones. As we saw how powerless we were to influence the fast-moving policy directives during the pandemic in a system as complex as LTC, we felt helpless. We also noticed how quiet life was without being able to pay our usual visits to our family members.

Although it was necessary for LTCs to limit the number of ECPs, the decision was very difficult for families. It meant that grandchildren did not see their grandparents and, as families, we needed to make difficult choices as to who could see our loved ones and who could not.

When we were allowed back into these homes, we became even closer with staff than we were before. During the second wave, one of Margaret's family members moved into the same home as her father and noted that she was grateful that this was during a time when more access was permitted. We noticed firsthand the additional stress and challenges for staff during the pandemic as they had to constantly don and doff personal protective equipment (PPE) and sanitize to try and stop the virus from taking hold and spreading. This led us to worry about all the other residents, especially the more vulnerable and more at-risk ones. It is impossible to spend the hours that we have spent in LTC homes and not become connected to other residents and their families.

### Changing Roles, Rules and Processes

One of the constants of the pandemic was change. Change in staffing, change in policies and change in routines were just some of what we experienced. At times, the staff seemed as unsure of these changes and new rules as we were. For Pauline and Allan, there was a need to adapt and find new ways

to assure themselves that the needs of their loved ones were being met.

Communication was critical. Yet it both helped and hindered the process of adapting to these many changes. The pandemic dramatically altered the traditional ways in which we communicated with staff and they communicated with us. In many cases, the COVID-19 restrictions meant that we could not visit the LTC homes in person to see our loved ones. The natural communication points as we walked down the hall to visit our family members were all removed, replaced with long waits for testing procedures before being allowed to enter. In addition, the restrictions on access meant that as ECPs, we could neither serve as connectors between our loved ones and the staff nor between our loved ones and our extended families and others who could not be present.

Despite the rapidly changing context, staff worked hard to maintain strong communication with family and friends. Often this meant that staff had to work collaboratively to find creative ways to keep the lines of communication open when we were not able to visit our loved ones in person. We received e-mail updates – sometimes daily, monthly newsletters with photos of residents and phone calls and bulletins as required. The phone calls, both from the home to us and from us to the home, worked well and gave us comfort. Some homes had dedicated staff to help handle the technology involved in virtual online chats. One home even held a monthly live update on YouTube. On the other hand, we were also acutely aware that these increased communication efforts meant increased time staff spent away from directly caring for residents.

The LTC home where Allan's wife was cared for held regular memorials to honour residents who had died. During the COVID-19 pandemic, this home adapted these regular memorials to Zoom, bringing together residents, families and staff to grieve their losses together. While this adaptation was not perfect (e.g., not everyone had the technology required), it created a virtual space to remember the residents who had passed and for residents, families and staff to support one another.

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When communication went well, it was because it was timely, gave us clear information about our loved ones and informed us of what the home was doing to provide care in the new environment. Our experience was that strong communication was reassuring and helped us feel connected to our loved ones, even when it was not possible to visit them. In many cases

during the lockdown, we observed that staff were considerate, kind and polite in how they communicated with us. Friendly but firmly, they emphasized the importance of keeping our loved ones safe.

There were times, however, when communication was less than ideal and failed to meet our needs. Inconsistent messaging regarding changing rules was just one example. A lack of communication around the total care plan was another. Other times, there were delays in receiving updates about our family members or challenges with technology that made it difficult to get in touch. In addition, not all homes had access to technology that could enable one-on-one video calls. When the lines of communication broke down, we had no way to know how our loved ones felt, what kind of care they were receiving or whether they were safe. All we could do was wait for the phone to ring, the e-mail to arrive or for technology to bring us together again.

### The New Reality: Infection Prevention and Control Measures and Restrictions

Another change that the families had to adjust to was the increased emphasis on infection prevention and control (IPAC). Keeping our loved ones living in LTC safe was always a priority, but the pandemic brought an unprecedented need to be vigilant. IPAC became even more important in LTC homes. For some families, the concept of IPAC was very familiar, while for others it was completely new and another adjustment. Regardless of familiarity with IPAC, at times it was overwhelming to hear evolving IPAC guidance from so many different sources as we continually learned more about the virus and how to keep ourselves and our loved ones safe from it.

Another challenge was that sometimes what was being enforced did not match the science behind IPAC measures. In addition, in some cases, the IPAC guidelines were inconsistent from home to home. For instance, while some homes allowed the same ECP to be designated for two individuals, in many homes this was not the case, and an individual could only be given the designation of an ECP by a single resident.

Despite the sometimes-confusing guidance, we are grateful for the IPAC training some LTC homes put in place through videos, pamphlets and individual guidance or conversations. The opportunity to feel in control of our ability to keep our family safe while being able to provide the care they needed was critical, and this information supported that need. LTC staff took the time to show us how to follow proper IPAC procedures, such as donning and doffing PPE, and we were provided with the PPE we needed. In homes where there were private rooms, this helped considerably and is an opportunity for future improvement.

### Workforce Challenges and Opportunities

Having a family member in LTC means expanding the circle of individuals who support the loved one and their family. The staff who surround residents have a substantial impact on not only the residents but their families as well. From dietary aides, housekeeping staff, maintenance staff, care aides, nurses and others, all staff play a critical role in the quality of life of each and every resident in the home. During the COVID-19 pandemic, we saw how resources were mobilized from across and outside the organization, including virtual visits facilitated by staff and recreation therapists redeployed to support residents virtually.

We also saw the tremendous stress that staff were under and the incredible resilience they showed in caring for both our loved ones and their own families during these extraordinary times. We also witnessed their moral distress when they had to implement policies that they knew were causing harm to residents, especially when that meant restricting families from seeing loved ones.

Allan shared his lockdown experience and how the relationship he had with the staff meant that he trusted them to provide excellent care to his wife even when he was not present. This lessened the burden of the pandemic for him as he knew that she was well cared for even in his absence. This situation speaks powerfully to the importance of having the individuals with the required skills and competencies to provide safe, compassionate and high-quality care within LTC homes.

We have heard much about staffing levels, and we agree that more care staff in homes is critical; however, it is equally important to have staff with the right mix of skills and characteristics to care for older adults with complex health needs. It is essential that staff engage in person-centred care and are guided by their knowledge of individual residents' needs and wants, regardless of whether we as ECPs are there to advocate for them. Staff with strong training and a warm demeanour are essential to ensuring good care. We should be seeking staff who demonstrate kindness, gentleness and compassion and have the capacity to be in the moment with the resident, rather than simply completing the scheduled tasks.

How do we do this? LTC homes could integrate these qualities and characteristics into their hiring practices to create a conscious hiring strategy. Schools and universities could also review their curricula to ensure that these values and principles are embedded in their teaching, especially for those showing an interest in gerontology. Pre-existing staff could be offered training or mentoring on how to develop and show compassion and kindness to residents on a regular basis. We also need to ensure that staff are compensated adequately and appropriately for the unique skills that they bring to this work.

## Working Together for a Better Long-Term Care System

Before or during the pandemic, we have each worked with the respective LTC homes caring for our loved ones with a goal to ensure they received the best possible care. As family members, many of us have a long commitment to improving care in LTC even after our loved one(s) have died. Part of this commitment is sharing our expertise to ensure that current and future residents are able to receive safe and high-quality care. Two of us were heavily engaged in the research process, with the goal to create greater system improvement across the LTC system for staff, families, residents and communities. We discuss our experiences and thoughts in the following sections.

### Margaret Keating

I was engaged with a small core group that tracked the research while it happened. There were weekly meetings to plan, review methods and discuss strategy. I worked with the team to design research to address some of the issues that I had observed during my father's time in LTC. These included the need for stronger leadership (e.g., closer monitoring and supporting having nurse practitioners in each home), improved coordination and planning of residents' care and creating a healthy work environment, including emotional support for staff who experience the diminishing quality of life and the death of residents on a regular basis – challenges that can lead to moral distress. I was involved with preparing the proposal, developing the intervention and planning. Often, this work included meeting with residents, family members and the LTC home management teams to review strategy and plans together. This engagement, especially with leadership within the LTC homes, was important because it helped address these issues.

Residents, family members and ECPs must be involved in research on the care of older adults living in LTC. We can help identify the real issues in LTC because our lived experiences are non-negotiable. Through my work with McGilton, I believe that the research goals aligned with my lived experiences, and it was rewarding to see that my lived experience could make a difference in how the research project was designed. Residents, family members and ECPs have unique insights, and see LTC through a lens that is invaluable to research endeavours, and their voices should be heard.

### Pauline Johnston

I participated in the research, and I sat on an advisory board that reviewed it. I appreciated this opportunity because the researchers were thorough and determined to get information from the source (that being our lived experiences). It was also interesting to be part of the advisory board. Some of the things that we learned through data review were shocking, but being

on the advisory board helped me, as a former ECP, to see how we all view what happens in LTC homes from different vantage points – as nursing staff, designated care partners and all the team members in between.

My involvement in the research let me see that there was a desire to learn across LTC homes, from management to the residents and their family members. I have a renewed sense of hope that there is a way forward. My hope for the future is that we can shift our thinking away from compliance within LTC and focus on implementing what we have learned from this pandemic to ensure that care is person centred and that we have resources in place to support staff who experience moral distress now and beyond the pandemic.

There is power in involving family members in end-of-life care, which adds layers of dignity, flexibility and compassion to make an LTC home feel like a home. In the home where my father and uncle lived, we had a very positive experience and felt like we were part of the care team. Yet the people in LTC – the residents, their families and the staff – are ever changing. And with this change, the needs of residents and their families change, and staff are continuously learning to ensure that the care they provide is individualized. My hat's off to the staff who are continuously learning to provide the best, person-centred care. Our LTC system must reflect the same priorities.

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### Allan Monk

For Allan Monk, who was not as heavily involved with a research team, an important focus going forward is ensuring that lockdowns do not happen again. Residents should always have access to their essential care person. It is up to the people who make decisions about LTC regulations to re-evaluate every aspect of preparation for a pandemic. Next time, we should be prepared with a full medicine chest of information to protect residents living in LTC.

## Recovery, Resilience and Re-Engagement

The research that occurred through the Implementation Science Team projects targeted many of the areas that we, ourselves, had identified as needing improvement. Achieving meaningful family presence in LTC requires commitment and adaptability across the LTC system to create space and time to recognize, understand and respond to the unique needs of each resident, their families and ECPs. Engaging residents and families in research can contribute to it being more robust,

meaningful and impactful – we have each experienced this in unique ways. We know that the investment in improving LTCs is critical and has the potential to make meaningful changes for residents, families, ECPs, staff and communities.

Although our experiences are unique, our goal is the same. We must all find ways to walk the talk on person-centred care to ensure that every resident in LTC receives safe and high-quality care based on their individual needs. The quality of each person's life matters – especially at the end of life – and we hope that from this work all of those who deliver care to older adults in LTC can learn and improve for the future. It is important to us that we never lose sight that the journey to recovery must be walked together, with residents, families, staff and homes included.

### Future Pandemic Preparedness: Practices and Policies for Safe and High-Quality Care

We have summarized five key takeaways for future pandemic preparedness in LTCs based on our personal experiences as ECPs.

1. Across the LTC sector, policies that support residents to identify and designate ECPs must be adopted. Residents, family members and caregivers must have a voice in the development of these policies.
2. All LTC homes need to be equipped with communication technology tools to help residents stay connected to their loved ones; this includes finding solutions for family members who may not have access to these tools. LTC homes should also consider how to support residents and their family members who may not know how to use these tools.
3. Staff working in LTC homes need to have the skills and characteristics to care for older adults with complex health needs. This includes providing training and education to everyone on the care team.
4. There needs to be adequate staffing within LTC homes. This includes both staffing numbers and the appropriate category of staff based on resident needs. We need to ensure that staff are given the time to learn about the individualized needs and wishes of each resident, so that safe, high-quality and person-centred care is provided.
5. Residents, family members and essential caregivers must be given the opportunity to participate in the development of practices and policies that will impact them.

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**Allan Monk, OC** (Officer of the Order of Canada) is a retired advocate for the disabled community and residents in care centres. He has run a charity of volunteer inventors creating assistive devices for the disabled community for 10 years and has been visiting and assisting staff in care centres for the past 19 years.