

Dying for love: Disconnection in the time of COVID-19

On 11 July 2020, Andre Picard, *Globe and Mail* health journalist, tweeted:

Jérôme (Jerry) Lalonde: Dec 25, 1931–July 10, 2020. My father-in-law. Another victim of #COVID19. . . . But isolation and loneliness were a large contributing factor. Before the pandemic, my 89-year-old father-in-law still played tennis, volunteered daily at his church, played bridge, was a voracious reader. . . . (Now) he missed his family horribly. . . . my active, healthy father-in-law became de-conditioned, depressed, lonely. His life ceased to have meaning and purpose. He knew he was dying even before he contracted the coronavirus. Dying of loneliness, isolation and neglect. The rigid lockdown of nursing homes and long-term care homes must end. #COVID19 is not the only health threat to seniors in institutional care. They need their families, they need human contact as much as they need protection from the coronavirus.

When the pandemic started, stopping infection in long-term care homes was paramount. Now, many visitor restrictions seem excessive, harmful, and often irrational. Interpreted arbitrarily by individual care facilities, they are applied according to their understanding or their current resources. Families don't understand: "The care aides have a social bubble outside of the care home but they are caring for my mom in her room. I don't understand why I can't

also be with my mom, caring for her emotional needs in her room."¹

Care workers must now do the care formerly done by families—essential partners in care—or ignore it, suffering moral distress. Only 3.36 care hours per client per day are funded in long-term care. Care workers have additional tasks for infection control. Yet, increasingly, residents are frailer, older, and need more care. Families often help with meals and grooming. It satisfies their need to make their love palpable by caring for the physical needs of their loved one: "I was not allowed to go and do her hair or cut her toenails, even though I have done that for her the past 2 decades, yet a stranger was allowed to come and do those services."¹

Family members feel tormented by guilt and shame for "abandoning" their loved one, though not by choice: "She believes she is in an actual prison and that she has done something wrong to be there, but can't remember what."¹

Seeing nobody they recognize, residents start to lose sight of who they are: "Going from visiting every other day to an occasional video call to now distanced visits has resulted in him no longer recognizing family."¹

Eighteen months is the average time residents live in long-term care in BC. Strict restrictions condemn our loved ones to a lonely and agonizing experience in their last months of life, abandoned by those they love and unable to understand why. If we want a medical diagnosis, there is "geriatric failure to thrive." Weight loss, decreased appetite, poor nutrition, inactivity, often accompanied by dehydration, depression, and impaired immune function are symptoms. We know that institutionalized children whose emotional needs are not met "fail to thrive." Do we take this less seriously because it

is happening at the other end of the lifespan? Or is it because we can test and count coronavirus deaths but not deaths from loneliness or giving up?

The BC Seniors Advocate's recent report on the effects of strict visiting restrictions emphasizes that residents and families must have a strong voice in the decision-making process

for long-term care, recommending "a provincial association of long-term care and assisted living resident and family councils."¹ Managers of care homes have associations and care workers have unions to lobby government, but there is no

stakeholder association for those with the biggest stake of all—the residents and their families. Recently the BC government had to replace management in several care homes where families had long been identifying dangerous practices to management without success.

Let Andre Picard have the last word: "Let the caregivers in. Teach them infection-control procedures—which they can learn as easily as any staff member. Let them bear witness. Let them lovingly care for their loved ones. In these pandemic times, vigilance is essential. But cruelty is still unacceptable."² ■

—Johanna Trimble

Patient Voices Network Representative

References

1. Office of the Seniors Advocate, British Columbia. Staying apart to stay safe: The impact of visit restrictions on long-term care and assisted living survey, 3 November 2020. Accessed 1 December 2020. www.seniorsadvocatebc.ca/osa-reports/staying-apart-to-stay-safe-survey.
2. Picard A. It's time to let families visit long-term care homes. *Globe and Mail*. 5 June 2020. Accessed 1 December 2020. www.theglobeandmail.com/canada/article-its-time-to-let-families-visit-long-term-care-homes.

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