

## The COVID-19 Pandemic and Its Impact on MAiD

By Catherine Mathie

On August 15, 2020, the story of Shirley Turton became public.<sup>1</sup> Before the COVID-19 pandemic, Turton lived happily at her long term care facility in British Columbia, wheelchair-bound but unfazed, enjoying frequent outings with a private care aide and regular visits from her family. However, this all changed with the precautionary COVID-19 lockdown of nursing homes in British Columbia that cut the 78-year-old woman off from outings, and severely limited her access to her family. Attempting family visits through Zoom or from behind windows and fences at the facility proved frustrating and upsetting because of great difficulty communicating. Because of her dependence on her wheelchair, Turton has limited interactions with other residents of the home. Turton's family says that the resulting experience of isolation has "snuffed" out Turton's confidence and left her depressed, uninterested in food or drink, and lonely; it has also led to her asking her family to help her arrange an assisted suicide. Turton's family believe that she wouldn't qualify since she does not have a terminal illness, and they are pushing instead for some changes to the implementation of British Columbia's lockdown rules that will help Turton recover her will to live. Turton has told her daughter that "if things can change she does not want to die." Turton's family is committed to her well-being and fighting for changes to be made at the nursing home that will make life livable for her once again; there is reason to hope for things to improve for her. However, this story illustrates the high costs that the conditions of the pandemic and our response to it impose on vulnerable Canadians, and in particular, the way that they may be leading people to choose death by euthanasia or physician-assisted suicide as the only means they can see to escape.

Seniors around the country have had their lives changed by restrictions designed to mitigate COVID-19 spread. In Halifax, citizens protested the conditions their loved ones were facing in long-term care homes there under existing public health protocols limiting family access, waving signs saying "Saved from COVID, now dying from loneliness," and "Seniors deserve love and respect, not isolation."<sup>2</sup> One woman at the rally spoke of how her father's inability to communicate with her from the mandated distance for visits "has caused his Parkinson's disease to rapidly progress," resulting in "extreme

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<sup>1</sup> Munro, R. (2020, August 15). Locked in long term care 'prison:' Woman asks for assisted suicide rather than continue in COVID-19 isolation. *iNFOnews*. <https://infotel.ca/newsitem/locked-in-long-term-care-prison-woman-asks-for-assisted-suicide-rather-than-continue-in-covid-19-isolation/it76041>

<sup>2</sup> Hartal, Katie (2020, September 1). 'Is this my father's home, or a prison?': Rally calls for easing of LTC visitation rules. *HalifaxToday.ca*. <https://www.halifaxtoday.ca/local-news/is-this-my-fathers-home-or-a-prison-rally-calls-for-easing-of-ltc-visitation-rules-5-photos-2681046>

deterioration of his health.” Another woman described how she and her sister have watched their “father decline mentally each day, becoming depressed, suffering from loneliness, and losing his will to live because of harsh restrictions” on long term care facilities in the province. She spoke of how her mother’s visits to her father feel as if she is entering “a prison,” since “their time together is clocked on a watch for 30 minutes a week if we are lucky, and the gate she crosses through to see him is padlocked shut before and after.”

In June, the Canadian Institute for Health Information revealed that COVID-19 had taken the lives of 5,324 residents of long term care homes—81% of all lives lost in the country due to the pandemic.<sup>3</sup> This is a grim statistic, but the fuller impact of the pandemic on the lives of people like Turton and these others is much harder to quantify. Those who have remained free of the disease are likely to be suffering greatly from the loneliness and isolation that enhanced precautions and institutional lockdowns have brought them. The harms caused to the elderly by social isolation were predicted in March by Richard Armitage and Laura Nellums in the *Lancet*, who warned of how social isolation among older adults is a well-known “‘serious public health concern’ because of their heightened risk of cardiovascular, autoimmune, neurocognitive, and mental health problems.”<sup>4</sup> The authors warned that government actions to enforce or promote social isolation among the elderly would require corresponding “urgent action... to mitigate the mental and physical health consequences,” and that those living without “close family or friends,” and relying “on the support of voluntary services or social care” would be at heightened risk. The authors suggested that some reliance be put on “online technologies” of communication, telephone contact, and remotely-delivered “cognitive behavioural therapies” to help seniors in this situation, but they also argued that “mitigation measures” must be “effectively timed” not only to “prevent transmission,” but also to “avoid increasing the morbidity of COVID-19 associated with affective disorders.” There is great risk that this kind of suffering will lead many like Turton who were previously content with their lives to consider MAID for the first time as a means to escape current circumstances. Health Canada’s *First Annual Report on MAID* reveals that in 2019, 771 people named “isolation or loneliness” as the kind of intolerable suffering that was the reason they decided to have their

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<sup>3</sup> Canadian Institute for Health Information. (2020). *Pandemic Experience in the Long-Term Care Sector: How does Canada Compare With Other Countries?* CIHI. p. 2. Retrieved from <https://www.cihi.ca/sites/default/files/document/covid-19-rapid-response-long-term-care-snapshot-en.pdf>

<sup>4</sup> Armitage, R., & Nellums, L. (2020, March 19). Correspondence: COVID-19 and the consequences of isolating the elderly. *The Lancet*, 5(5), E256. [https://doi.org/10.1016/S2468-2667\(20\)30061-X](https://doi.org/10.1016/S2468-2667(20)30061-X)

lives terminated.<sup>5</sup> With all of the loneliness and isolation that COVID-19 brings, and the associated harms to physical and mental well-being of the most isolated and dependent, it is reasonable to expect a great rise to this number over the course of the pandemic.

More light was shed on how COVID-19 is making euthanasia a more attractive (and accessible) option in a webinar by euthanasia advocacy group Dying with Dignity Canada (“DWD”) where several MAID practitioners discussed their first-hand experiences providing MAID during the pandemic.<sup>6</sup> Moderator Maureen Aslin described a high volume of inquiries DWD had received, especially in the early days of COVID-19, from Canadians inquiring about whether MAID would be an available option to them if they became critically ill with the virus and required a ventilator; many told DWD that they “would not want to have that intervention” and asked “could they access MAID as an alternative?” The MAID providers on the webcast confirmed that in early days, they had heard many fears of the same kind expressed. In addition, although she did not hypothesize about the reason for it, MAID provider Dr. Ellen Wiebe described her experience in the “first month after lockdown” as a “crash course on MAID in COVID” insofar as she administered 13 deaths in one month, which is “definitely more than [her] usual.” (However, Wiebe said that cases have levelled off for her in the months that followed.) Fears of another kind featured in other communications DWD reported having received from the public as the pandemic unfolded: many contacted the organization to express their fears about dying alone without loved ones around. The MAID providers agreed that in their experience there had been a great deal of “stress and anticipatory grief” on the part of those reaching out to them. Wiebe noted that she has been engaged in research that has shown “terrible increased suffering at the end of life mostly due to the lack of loved ones around” during the pandemic. She spoke of a “completely isolated” client requiring advanced care in a facility who had moved his death date a month earlier than he had intended and spent a few days with his family providing around-the-clock care at home because he had not thought life would be worth it for another month isolated from his family. Others have come to Wiebe with new MAID requests because life has become “just so awful under COVID due to all the restrictions that there is no point in living on when they already have a fatal illness.” Wiebe spoke of how terrible her visits to care facilities for people who want to die sooner have been: she has seen that programs are shut down, volunteers have left, and family caregivers and visitors are gone. Although family, friends and volunteers have been shut out of

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<sup>5</sup> Health Canada. (2020). First Annual Report on Medical Assistance in Dying in Canada, 2019. p. 32. Retrieved from <https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying-annual-report-2019/maid-annual-report-eng.pdf>

<sup>6</sup> Aslin, M. (Moderator). (2020, June 24). MAID and COVID-19: Impacts of the pandemic on end-of-life choices [webinar]. Dying with Dignity Canada. [https://www.dyingwithdignity.ca/maid\\_impacts\\_covid\\_june2020](https://www.dyingwithdignity.ca/maid_impacts_covid_june2020)

these homes or given severely limited access, Wiebe, as a provider of MAID is free to enter them. As she noted, “I was allowed into every home.”

MAID provider Dr. Susan Woolhouse confirmed that she has had experience with two kinds of patients whose requests for MAID have been affected by COVID. Like Wiebe, she had patients who had already made previous plans for MAID but accelerated them because they couldn’t see their family members or felt that they had nothing to live for under current conditions. She also identified another category “that causes me more stress:” patients for whom “I’m wondering if the request for MAID is really driven by the social isolation and maybe the lack of health care access or personal support access” occurring “due to COVID.” Woolhouse mentioned “challenging assessments” such as one she provided after receiving “a referral for an elderly woman in a retirement home because she’s lonely,” where Woolhouse was “not really sure she was that lonely before COVID.” Woolhouse did not provide information about how this assessment or others had ended.

Despite the sympathy that the MAID providers expressed for their patients suffering from isolation and anxiety due to COVID-19, they also took time to celebrate what Wiebe called “the good stuff” that had been achieved as a result of pandemic conditions: many provinces have relaxed their rules around safeguards to the MAID assessment process. Wiebe said that there had been “some wonderful changes that would never have happened without this,” noting that “we’re now allowed virtual witnessing, and in BC, now virtual assessments.” Even the capacity assessment by a psychiatrist can now be done virtually. MAID provider Erica Maynard described how the Nova Scotia Health Authority has changed its rules to allow employees of NSHA to do MAID witnessing for the first time. Woolhouse identified the new conversation over payments for virtual services over phone, etc. in Ontario as beneficial because it was paving the way to more remuneration for many MAID providers; she speculated that as an added benefit, it would help to “attract more providers” in the province. The picture sketched out by the MAID providers on this webinar is one where many provincial authorities have reacted to the crisis by relaxing safeguards they have upheld previously and adopting virtual processes that make access to MAID easier and faster, even as the loneliness and fear caused by the pandemic and resulting government strictures drive up requests among struggling and isolated Canadians.

In April, DWD was featured in a CBC Radio report on those expressing interest in MAID out of fear that they may be put on ventilators after contracting COVID-19.<sup>7</sup> The report quoted Liz Richenbach, a woman who said that she chooses “to be in control of these things,” and based on her odds of survival,

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<sup>7</sup> McCue, Duncan. (2020, April 19). 'I choose to be in control': Some seniors weighing medically assisted death because of COVID-19. *Cross Country Checkup*. CBC Radio One. <https://www.cbc.ca/radio/checkup/covid-seniors-medically-assisted-dying-1.5537299>

she wouldn't want to be on a ventilator and hopes that she will "have the option of ending it and not be lingering." Although DWD has been recommending those concerned fill out advanced care directives with their wishes since "there is no ability for an advance request [for MAiD] at this time," the report also quotes Dr. Stefanie Green, the president of the Canadian Association of MAiD Assessors and Providers, who says that MAiD may be an option for COVID patients whose condition is deteriorating quickly since safeguards such as the 10-day waiting period can be waived when death or capacity loss is imminent. Green says that she has provided MAiD "on the same day that [she's] met someone on certain occasions." Green also notes that while "there's a lot of health care that is not being provided right now because we have a global pandemic," her MAiD practice has remained "quite busy." The report also discusses how even with some provincial health authorities putting a brief stop to MAiD services, "hospitals and clinicians across Canada have adjusted workloads" to cope, and Manitoba and Saskatchewan have joined British Columbia in allowing virtual assessments, while other provinces are recognizing "virtual witnessing" in place of witnessing in writing.

The problem Woolhouse alluded to that people seem to be seeking out MAiD driven by a lack of health care and personal support access on top of their isolation during the COVID-19 pandemic is a very serious one. While efforts have been made to ensure access to MAiD during the pandemic, most forms of medical care have been significantly disrupted for many in Canada: an Angus Reid study in May found that between disruptions to surgery schedules, and limits to hospital access, doctors' appointments, and diagnostic procedures, 38% of Canadians had already faced impediments to medical care due to COVID-19.<sup>8</sup> 76% of those affected said this had resulted in an adverse impact on their overall health. Moreover, low-income Canadians had been especially hard-hit, with twice as many (nearly 10%) reporting being unable to access treatment for chronic illnesses as in the overall population. Meanwhile, failures in provision of needed care at some long-term care facilities were illustrated in grim detail in the report the Ontario government received and made public in May on "Observations in Long Term Care Facilities in Ontario" prepared by members of Canadian Forces Joint Task Force-Laser who helped with COVID-19 outbreaks at five long term care facilities in the province.<sup>9</sup> The report, released by Brigadier General Conrad Mialkowski, describes many shocking failures in care at these facilities, including inadequate provision of medications and supplies for palliative care, unhygienic peri-catheterization, the use of narcotics to sedate sad or depressed patients, patients left unfed because their personal support workers

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<sup>8</sup> Angus Reid Institute. (2020, May 27). COVID-19 side effects: 38% of Canadians have missed medical appointments or procedures due to restrictions. ARI. <http://angusreid.org/covid19-medical-access/>

<sup>9</sup> See TVO.org staff. (2020, May 26). COVID-19: Read the Canadian Forces report on long-term care. *TVO.org*. <https://www.tvo.org/article/covid-19-read-the-canadian-forces-report-on-long-term-care>

were too rushed to place their food where they could reach it, inaccurate reporting to patients’ families of their status with respect to “feeding, pain levels, general condition etc.,” and extremely poor wound care.<sup>10</sup> It is hopefully true that the residents of most long term care facilities are facing better conditions than those in these homes did, due to the peculiar severity of their outbreaks, resultant staffing shortages and bad management. However, much of the suffering that the residents went through in these homes does not seem to be unique, and it is the kind that is much more likely to occur where access by family caregivers, and advocates and workers from outside the facility is prevented. A report in the *Globe & Mail* in August argued that long term care facilities throughout the country have been facing serious staffing shortages for years, resulting in “unsanitary, undignified and unhealthy” conditions, and that not only personal support workers, but also needed “psychologists, social workers and physiotherapists” are lacking.<sup>11</sup> The report stressed that limiting access to patient’s families in these homes had exacerbated the crisis insofar as “family members often provide essential care for their loved ones, including feeding them.” The military report quotes one CAF member who said, “it’s heartbreaking to get a report about someone who is ‘agitated and difficult’ and has been getting PN narcotics or benzodiazepines to sedate them but when you talk to them they just say they’re ‘scared and feel alone like they’re in jail.’”<sup>12</sup> If most residents in care homes that have been under COVID-19 lockdown have not been given unneeded sedatives to cope with their anxiety, it is still the case that many have felt similarly terrified, abandoned and trapped. Euthanasia may appear to patients in such cases as the only escape, but it is a solution that is not unlike wrongly-administered benzodiazepines, removing the symptom without regard for the underlying cause.

There are indications that other vulnerable people are being led by their experience of life with COVID-19 to contemplate MAID for the first time. A CityNews report in September discusses the difficulties Ontarians with disabilities have been experiencing due to the impact the pandemic has had on the cost of living, highlighting “fears [that] some with disabilities are considering assisted dying as a last resort.”<sup>13</sup> The report quotes a woman named Kim, who requires a feeding tube due to digestive problems she was born with, saying that life has been “pure hell” during the pandemic, and she feels like she is

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<sup>10</sup> Canadian Forces report, pp. A-1/3, A-2/3.

<sup>11</sup> Andrew-Gee, Eric & Stone, Laura. (2020, August 10). Understaffing turned seniors’ homes into COVID-19 danger zones, health workers say. What can be done to fix that? *The Globe and Mail*. <https://www.theglobeandmail.com/canada/article-understaffing-turned-seniors-homes-into-covid-19-danger-zones-health/>

<sup>12</sup> Canadian Forces report, p. A-2/3.

<sup>13</sup> Mulligan, Cynthia and Yawar, Mahnoor. (2020, September 2). ODSP recipients calling for help, exploring assisted dying. *CityNews*. <https://toronto.citynews.ca/2020/09/02/odsp-covid19-pandemic/>

“being punished for being born disabled, like [she] committed some kind of crime.” Kim relies on the Ontario Disability Support Program (ODSP) payments she receives to survive, and the \$421 per month she is left with for all expenses after her rent often leaves her without enough for food through the month. The story refers to others relying on ODSP who have been posting under “#ODSP” on Twitter about their lack of money for adequate food. One woman discussed in the story was left this month with under \$4 because, “I chose my medication which I cannot live without for mental health issues.” Maximum ODSP support payments have only risen by \$239 dollars since 1998, to \$1,169 per person per month, while rent has risen continuously. With COVID-19 driving the costs of living expenses even higher, a recent Statistics Canada survey discussed in the story found that 61% of people with disabilities are struggling to pay rent or buy medications. The story identifies an “even more chilling” phenomenon among social media posts about the situation: “some are talking online about applying for Medically Assisted Dying.” The story mentions a woman who said on Twitter that “she enrolled [for MAID] because she ‘can no longer afford to live, nor can I afford the food and medicine I need to get better.’” Moreover, Kim told CityNews that “she knows of more than 50 people who have applied for MAID,” while others, including “six friends” have committed conventional suicide since the start of COVID. She says that these disabled people “don’t want to live this way anymore” and do not have a “safety net,” admitting that “she has thought about applying for MAID herself,” especially with shelters full and her landlord threatening to evict her so that he can charge higher rent on AirBnB. Kim spoke to CityNews about her sense of loss of dignity: “I don’t like to go anywhere or have anyone see me ... I don’t feel like I’m worth anything to anyone anymore.” CityNews was unable to get answers about whether “applications to MAID have increased since the beginning of the pandemic, particularly among people with disabilities,” and warns that a statement received in an email from the federal government saying that “those numbers won’t be available until the spring” means that “there may be no red flags until then.”

Others have been seeking data on the negative impacts COVID-19 restrictions have had on those living in care facilities under restricted access: British Columbia’s current limitation of long-term care home visitors to one per resident has “led to cases where close family members have only been able to visit a relative – who seemed healthy before COVID-19 – when they are on their deathbeds.”<sup>14</sup> B.C. Seniors Advocate Isobel Mackenzie has begun a survey to collect data on the impact COVID-19 lockdown and visitation rules are having on residents of care facilities and their families. Mackenzie reports that while 125 long-term care residents have died from COVID-19, some of the 2,000 residents who have died from other causes may have done so because of “the lockdown and subsequent isolation

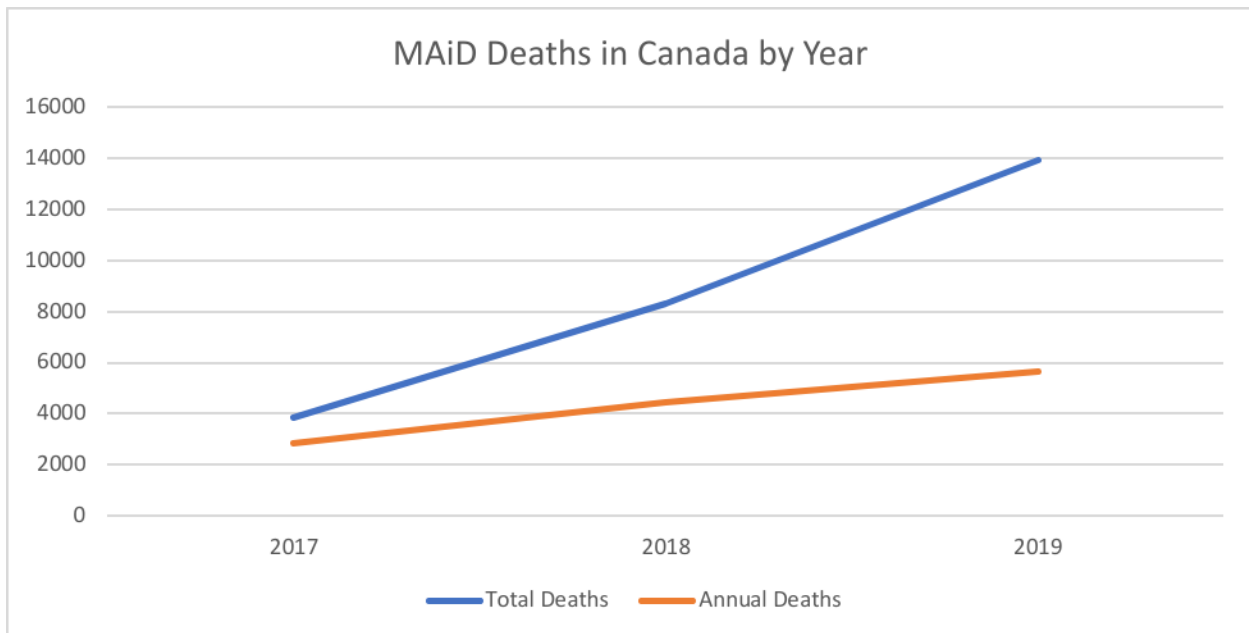
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<sup>14</sup> Munro, R. (2020, August 26). Seniors' lives depend on changing COVID lockdowns in B.C. care homes: Seniors advocate. *iNFOnews*. <https://infotel.ca/newsitem/seniors-lives-depend-on-changing-covid-lockdowns-in-bc-care-homes-seniors-advocate/it76412>

and loneliness.” In pursuit of a clearer picture, Mackenzie’s survey, *Staying Apart to Stay Safe: The Impact of Visitor Restrictions on Long-term Care and Assisted Living*, will “catalogue the experiences of residents and their families in terms of how things were before COVID-19, in the early days of the lockdown and now.” Mackenzie plans to publish a report on her findings in October. Mackenzie hopes that changes will be made to alleviate the isolation restrictions are causing seniors: “We want to keep people safe from COVID-19 but what are we keeping them safe for if it’s not to enjoy the rest of their lives.”

As CityNews stated, the federal statistics that would be required to demonstrate whether MAID requests or deaths have risen due to the broader societal impacts of COVID-19 will not be available before the Spring. In addition, with euthanasia and assisted-suicide rates in general rising steadily but with fluctuation from the time of legalization in 2016, it would be hard to establish a clear statistical connection between the pandemic and MAID deaths without more specific data than is readily available.<sup>15</sup>

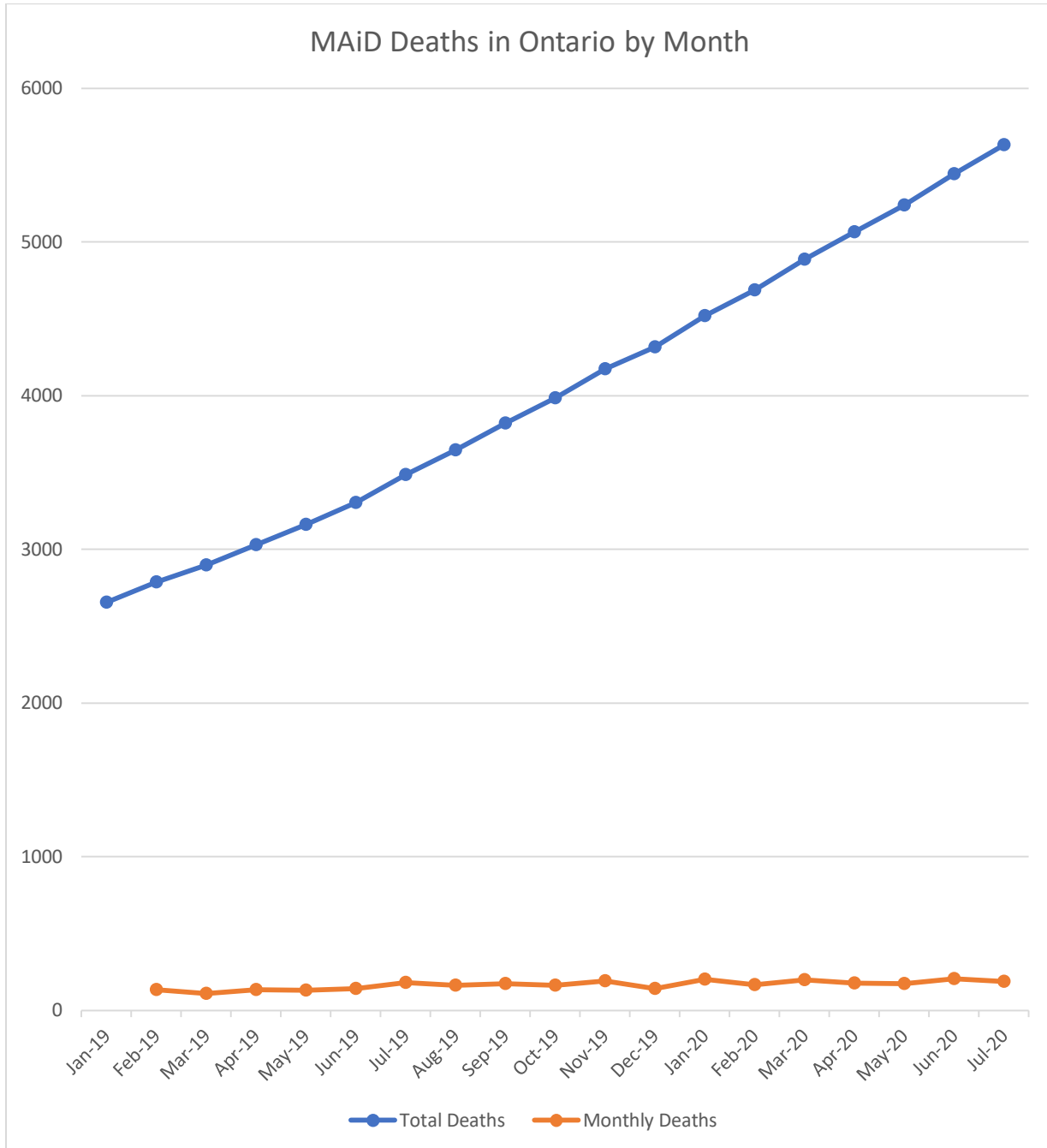
<sup>15</sup> According to statistics in *Health Canada’s* annual report on MAID from 2019, there were 1,015 MAID deaths in Canada in the months of 2016 after legalization, 2,833 in 2017, 4,467 in 2018, and 5,631 in 2019. This graph depicts national growth in MAiD in the three full years it has been legal:



Health Canada Report, p. 18.



However, monthly data from the province of Ontario is available from the Coroner’s Office for the last 18 months.<sup>16</sup> This data is inconclusive, but it shows that deaths by MAiD in the province during this time have climbed continuously and at a quite consistent rate:



<sup>16</sup> Office of the Chief Coroner for Ontario. Office of the Chief Coroner/Ontario Forensic Pathology Service MAiD Data reports for January 2019 through July 2020.

This data may reflect a contribution of COVID-19 to the high MAID rates reported in the months since May, but it is impossible to say for sure without more specific detail about causes and demographics behind MAID requests than the Coroner's Office provides. Given all of the available evidence that fear, isolation, economic restrictions and limits to medical access are driving up the number of MAID request, the need for such detail is great. It will be most unfortunate if the red flags are missed that might save lives now, and this need only becomes recognized retroactively when the pandemic's impact on MAID has become too large to miss.