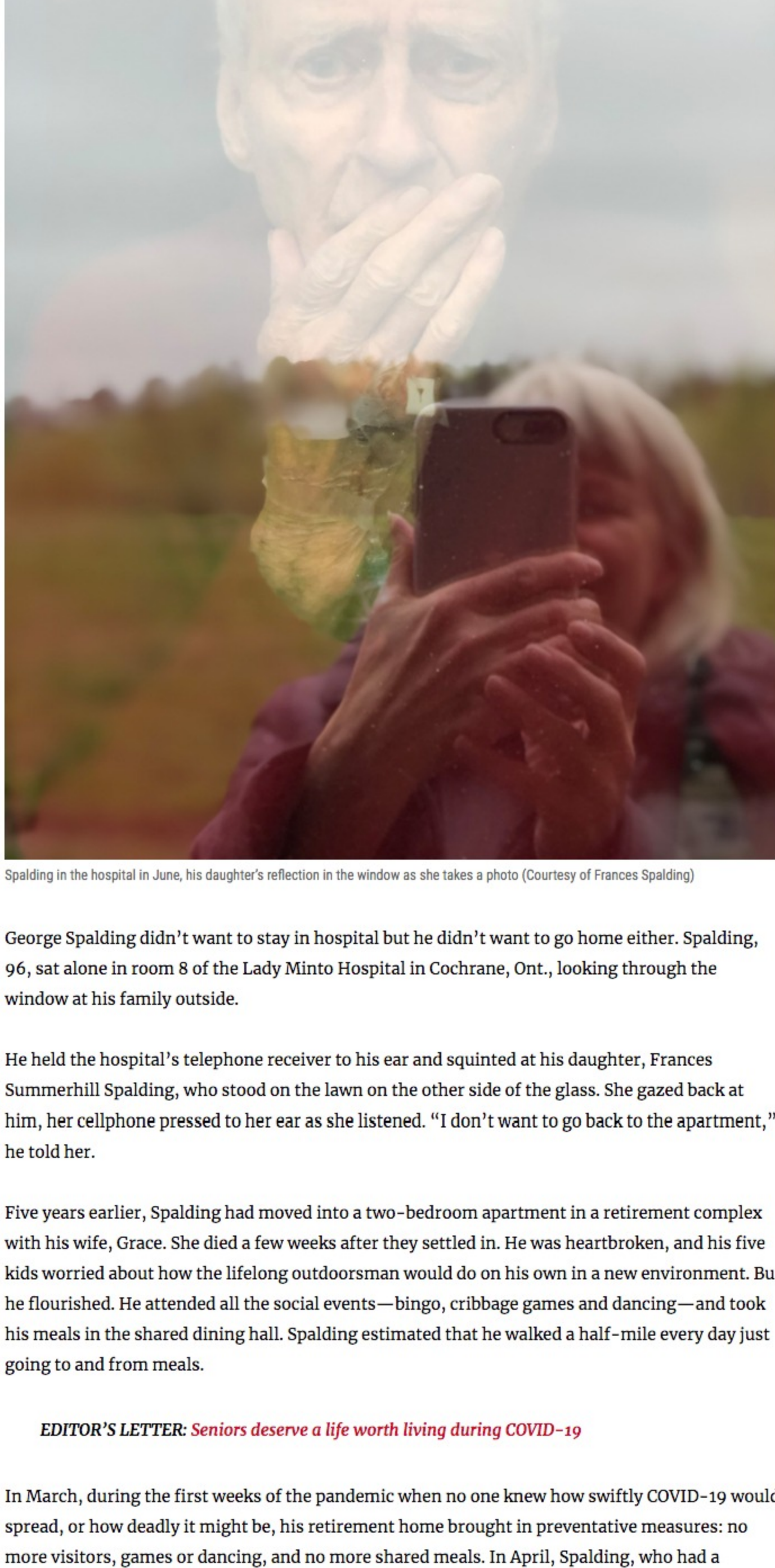


## Strict COVID-19 protocols are leaving seniors lonely, depressed and wondering: Is it worth it?

The elderly and their families are being forced to choose between two extremes: complete protection from COVID or enjoying their time with people they love

By Christina Frangou  
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Spalding in the hospital in June, his daughter's reflection in the window as she takes a photo (Courtesy of Frances Spalding)

George Spalding didn't want to stay in hospital but he didn't want to go home either. Spalding, 96, sat alone in room 8 of the Lady Minto Hospital in Cochrane, Ont., looking through the window at his family outside.

He held the hospital's telephone receiver to his ear and squinted at his daughter, Frances Summerhill Spalding, who stood on the lawn on the other side of the glass. She gazed back at him, her cellphone pressed to her ear as she listened. "I don't want to go back to the apartment," he told her.

Five years earlier, Spalding had moved into a two-bedroom apartment in a retirement complex with his wife, Grace. She died a few weeks after they settled in. He was heartbroken, and his five kids worried about how the lifelong outdoorsman would do on his own in a new environment. But he flourished. He attended all the social events—bingo, cribbage games and dancing—and took his meals in the shared dining hall. Spalding estimated that he walked a half-mile every day just going to and from meals.

### EDITOR'S LETTER: Seniors deserve a life worth living during COVID-19

In March, during the first weeks of the pandemic when no one knew how swiftly COVID-19 would spread, or how deadly it might be, his retirement home brought in preventative measures: no more visitors, games or dancing, and no more shared meals. In April, Spalding, who had a chronic cough, was identified as a possible case of COVID. Unable to access testing, he was isolated in his flat for two weeks, as per the retirement home's rules. Masked staff left meals on a tray just inside his door, and Spalding placed his dishes in the hallway for pick-up after he finished eating. His family couldn't get in to see first-hand how he was doing, and he struggled to hear them over the phone.

During his isolation, Spalding lost his appetite. He started sending his food trays back unfinished. "You don't need much food when you're not active," he told *Maclean's*.

He was hospitalized at the beginning of June with low sodium levels. Standing on the hospital's lawn as she talked to her father by phone a few days after his admission, Summerhill Spalding made her gestures grand and exaggerated, like the star of a Broadway musical, to make sure her father knew she was there for him. Inside, Spalding, who made his own decisions about his medical care, was adamant: he'd rather stay in the hospital indefinitely, where people checked on him regularly, than go home and face the possibility of being alone. He worried that he couldn't look after himself anymore and he was done trying. His daughter promised that she'd try to get him into long-term care right away, though he'd already been on a wait list for several months.

At the end of their visit, Summerhill Spalding raised her phone to take a picture of her dad just as he brought his hand to his lips to blow her a kiss. Later, looking at the photo, she thought he didn't look at all like the man who'd danced polkas at a carnival five months earlier.

When Spalding was discharged after almost a month in hospital and returned home in late June, his kids worried that he was lonely and inactive. They set up a schedule for visits, with someone there almost every day. When, a month later, the nursing home's rules loosened and allowed Spalding one family visitor at a time, he could also leave for an afternoon. The family asked his doctor to note in his chart that their father's cough was an ongoing symptom of his chronic obstructive pulmonary disease, and he shouldn't be isolated again for it.

### READ: The endless crisis in Ontario's long-term care

Spalding told his kids that he wasn't giving up. But he didn't bounce back to his usual self. For the first time that Summerhill Spalding could recall, he showed moments of confusion—he said that he'd retired at age 28 when, in fact, he'd worked into his 60s. He struggled to name his seven grandchildren.

In a video interview with *Maclean's*, Spalding, seated on a grey couch in his living room and wearing a short-sleeved checked shirt, was matter-of-fact about his situation. "It's not very good now with all those virus rules but it's for the better," he said. "You have to do what's right." He didn't want to talk about being lonely or any consequences he suffered from being isolated. "I sure didn't like it but you have to put up with it. I managed to get through," he said. This was not his first tough quarantine, he added. Spalding was in the army and staying in barracks in Ontario when his first son, Richard, was born. He couldn't get home for the birth due to a mumps outbreak, and Richard was three weeks old when his father saw him for the first time. "He was still so small that I thought something was wrong with him," Spalding said, laughing at the memory.

He had relied heavily on friends and family for support after the deaths of two of his sons (one who was only 13 when he was killed in a bicycle accident) and his wife many years later. Those were the hardest points in his life, he said. The pandemic didn't compare. But his daughter worried that her father's remaining days would be dominated by loneliness, all in an effort to protect him and other residents from the coronavirus. "Who knows how much time he has left?" she said. "All these people that might have a week or a month or a year left, would they really choose being so alone and not getting COVID, or would they actually choose some risk?"

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As COVID cases climb across the country, families like the Spaldings are wrestling with difficult decisions about what older adults should do over the next months: where should they live? Who should they see? What is their best option between two extremes: complete protection from COVID or enjoying their time with people they love?

For many seniors, important parts of their lives have been on hold since March, when medical officers of health in Ontario and Quebec recommended that people over 70 years old should self-isolate. Cruise plans were scrapped, winter migrations postponed and crib games cancelled indefinitely. There are new grandchildren and great-grandchildren they haven't met, and siblings and children they haven't seen for months. Some stopped attending regular faith services, perhaps for the first time in their lives. The more than one million seniors who provide unpaid care for loved ones—spouses or grandchildren, for example—are looking for approaches that work best for them and their families. And in a brutal plot twist, hugging their grandkids is an act that may require careful consideration.

Canadians of all ages are carrying out COVID-related risk assessments on their usual activities of living, but the stakes are greater as people age. The virus is more deadly among the elderly: those in their 90s have a 25 per cent risk of mortality if infected with the virus. For those in their 80s, it's 15 per cent, and eight per cent for people in their 70s, according to Dr. Samir Sinha, director of geriatrics at the Sinai Health System and the University Health Network in Toronto.

At highest risk in Canada are those living in long-term care, where the mortality rate among people infected with COVID was about 35 per cent by May, according to figures from the Canadian Institute for Health Information. By June, four out of five known COVID deaths in Canada were among residents of long-term care homes, although they only accounted for 18 per cent of total cases.

But physical isolation, the mainstay of defence against the virus, comes with its own terrible list of side effects. Older adults who are socially isolated are more likely to become inactive, grow frail, become depressed, experience advancing dementia or eat poorly. These health consequences are interrelated, with one worsening the other, and can be irreversible or even fatal.

### READ: A long-term care disaster that everyone saw coming

Geriatricians across the country are seeing the effects of months-long restrictions. In Prince Edward Island, where 56 cases of COVID were identified between March and mid-September, falls among seniors living independently rose substantially, says Dr. Martha Carmichael, the province's only geriatrician. "911 calls for falls are up dramatically, and probably just because of isolation and deconditioning that goes along with it," she says. On the other side of the country in Vancouver, where many of Dr. Nishi Varshney's patients live independently, the geriatrician is helping them manage mental and physical health concerns born of isolation. Patients postponed regular home care services when their support workers couldn't get sufficient personal protective equipment or cancelled the services outright for fear of infection from outsiders. Their visits with family and friends became less frequent, as did trips into their communities. Their health destabilized and deteriorated, she says: "You can't just quarantine an older person. It's definitely not healthy for the older person and the concept is not conducive to a healthy society."

Laura Tamblin Watts, the CEO of CanAge, a national association that advocates for the elderly, worries that the winter ahead will be very difficult for Canada's seniors. As temperatures drop, people will not be able to gather for outdoor visits. School openings burst social bubbles and many families are reassessing whether kids and grandparents should gather in the same room or have physical contact. By late September, the number of active cases in Ontario long-term care homes was steadily rising, with outbreaks in 44 facilities and 63 cases among residents. Many older people will retreat into isolation over the next few months—either by personal choice or to abide by the rules set out in the care homes where they live. "We're really hearing from older adults about their quality of life. It's combined with a question of, 'Will I ever get another chance to do this again?'" says Tamblin Watts.

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Reverend Dianne Parker, like 92 per cent of Canadians older than 65, lives in the community, in a duplex tucked into a Halifax cul-de-sac. She is 74 and widowed, a rector who has spent more than a half-century working with the public. Though she'd retired as head of her parish, she was still providing pastoral care to the ill and dying and performing weddings, funerals and worship services when the pandemic began. Once COVID-19 landed within Canada's borders, she self-isolated. She cancelled a flight to Calgary to visit her grandchildren and relied on neighbours for groceries. Heeding the health rules of the province, she shifted worship services onto Facebook and YouTube. She went 103 consecutive days without visiting another human being—a shock for someone accustomed to holding hands and offering embraces to countless people in a week. "I am a person of a presence and a person of hugs," she says. She was lonely, especially at night.



Parker (left) added a lower level to her front porch to allow for socially distanced visits and safe baking exchanges (Photograph by Aaron McKenzie Fraser)

Parker, who is a long-time advocate against the isolation of older people, sought out new ways to make connections. When Nova Scotia relaxed some restrictions, she hired a carpenter to add a lower level to her small front porch—her "COVID deck"—where she could sit and visit comfortably with guests without being too close. Using a long stick that she calls her "happy stick," she passed gifts and homemade baked goods to her neighbours. In partnership with one of them, she purchased a beehive and is raising bees. "My neighbour is the drone. He's done all the work, and I'm the queen," she laughs.

A two-time cancer survivor, Parker is concerned about COVID-19, especially as students return to Nova Scotia for university. For now, she's performing outdoor weddings and funerals services in person—albeit for a handful of attendees. Being adaptable is the only option, she says. "We have to reframe how we do things and look after each other."

For the Johnson-Kawashima family in Vancouver, the pandemic has intensified the sense of uncertainty in their home. With her seven-year-old daughter Hanah, Kimiye Kawashima, 48, moved back to Vancouver to live with her parents, Brian and Iko Johnson, 87 and 84, and help care for them. She left a fiancé and their blended family in the United States, but does not know when she'll return. Both her parents have dementia—her father's more severe than her mother's—and want to continue living in their home with its backyard and garden. And they're capable of staying there for the time being as long as someone is there to support them, says Kawashima. Before the pandemic, the family was navigating tricky situations not uncommon with advancing dementia, like taking car keys and credit cards from Kawashima's father, who had started getting lost on drives and making odd purchases online.

But the pandemic added to the complexity. The foursome has mostly stayed home since March. Iko, an avid news-watcher, understands the virus is dangerous but knows that restaurants are open now and longs to dine in them. Her husband forgets about the virus and gets frustrated with masks. "We're negotiating things on a day-by-day basis and trying to keep everything as contained as we can," says Kawashima.

She wishes there were more supports for her family, including her local flexibility in schools as they reopen. Her daughter could not access virtual classes in her local school system, so she is physically attending school this fall. As a family, they've decided that they won't have physical distancing in the home: "I can't isolate Hanah from them because, as far as I'm concerned, she is part of their therapy in keeping them bright and active every day," Kawashima says.

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As their health changes, older adults frequently move along a continuum of housing options in Canada. First, they live independently in rented or owned homes in the community. Over time, they might rely more on family or friends, or home care services, which they often pay for privately. About eight per cent of Canadian seniors eventually move into congregate care settings like retirement homes and assisted living where, at a cost, they can access a range of extra services like shared meals or social events. These settings are rented private housing communities for adults who can live with some or no outside help. In most provinces, these homes are covered by landlord-tenant acts. If a person's medical needs are high, they move into long-term care, which provides help with most or all of their daily activities.

After two decades of steady increases in collective dwelling numbers, a large number of residents in retirement homes or assisted-living facilities are looking to move back into the community. In many homes, administrators set out rules that restricted visitors and prevented social gatherings, even shared dining—robbing people of the right to make decisions about how and with whom they spend their time. "We are seeing a real trend of people leaving retirement homes because they don't want to be under those heavy restrictions," says Tamblin Watts.

Dr. Nathan Stall, a geriatrician at the Sinai Health System in Toronto, is critical of the approach that congregate care homes have adopted to reduce infection during the pandemic. He acknowledges that they have to balance individual autonomy with shared risk, but stresses that older adults have the right to make informed decisions about how they want to live. They did not have that right for the first six months of the pandemic, when the response in retirement homes "was not informed by the voices and wishes of many older adults," he says.

### RELATED: What's inside the disturbing report on Ontario's long-term-care homes

His own family was affected. For more than 100 days, his grandmother could not leave her retirement home for her daily walk. The family couldn't visit, even to repair an appliance. "If you're not allowing family members to come into the room to fix something as simple as a TV, you're really leaving people vulnerable and extremely cut off from the world," says Stall.

Many families and residents are afraid to speak out publicly because they worry about retribution, he adds.

When Alan and Dori Ferr married 34 years ago, they talked about the fact that he would likely die before her. He is 25 years older, and their age gap played into how they made decisions about their future. She went back to school for a master's degree and focused on building a career of their own to ensure she would be able to "stand on her own." They've had big discussions about end-of-life care. She knows exactly what he would want if he were dying.

But they never planned for a long period of separation while he was still alive. In 2016, he was diagnosed with dementia. Two years later, they agreed he should move into long-term care without her. It was too much for her to look after him at home; if he lived in long-term care, she could return to being his wife rather than his caregiver.

For four months in 2020, she felt like she was neither. She could not visit him until June, when they saw each other outside with a fence in between them. He kept pulling his wheelchair up to the fence and she, through her mask, kept telling him he could not come closer. "This is not what he would have wanted," she says. Even though he can't carry on a logical conversation with her, he still feels love and loneliness, she points out. If he could voice his desires right now, "he absolutely would say I want to stay with you," she says. His long-term care home recently returned to lockdown. She waits at home—"on pins and needles"—and fears a phone call to say that he has become infected.

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From the beginning, there's been one constant with COVID: there's never a painless option. Living with the virus always involves some kind of taboo trade-off—staying home or going into work, hugging grandchildren or keeping a virus at bay, allowing spouses to visit or shutting the doors of long-term care to anyone who might bring in an illness. But, somewhere in those trade-offs, individuals have the right to make choices about their lives.



Living with Hanah (left) keeps her grandmother Iko (right) and her grandfather Brian 'bright and active every day,' says Kawashima (Photograph by Felicia Chang)

Families should talk about their options for this winter as a kind of advanced care planning, says Sinai Health's Sinha. People tend to think of advanced care planning as setting up wills and medical directives, but the concept is broader, he says. "Advanced care planning is about what matters most to you. And you can ask that question at any point," he explains. "Your dad might say, 'I don't want to be on a ventilator. Let me die naturally.' But in a similar fashion, your dad might say, 'What matters most to me is hugging my grandchild and I'm willing to accept a level of risk.'"

Older adults can hug their family members if that's what's most important to them, he says. Kids can be taught to follow the steps that reduce risk of infection: wash hands, wear masks, stay home if any family member has symptoms, and keep contact to a minimum with people outside of the immediate family.

For years, seniors' advocacy groups have called for better supports for Canada's seniors. They want more affordable housing options and better access to care as close to home as possible. They want more acknowledgement of caregivers, and they want to see policies that produce truly age-friendly communities that promote the inclusion of older people as productive and engaged citizens. They want an end to the kind of ageism that deprives seniors of their rights to make informed decisions about their lives.

"A lot of these issues have been kind of going on for years now, and it took a pandemic to bring them to light," says Varshney, the Vancouver geriatrician.

But changes will come too late for George Spalding. He never bounced back to his pre-pandemic state of health. In late July, he was readmitted to hospital. On July 26, 2020, he died, comfortable and surrounded by his family.

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