

HEALTH

The Age of Surrender

When is a senior no longer capable of making their own decisions? It depends on whom you ask

BY SHARON J. RILEY

ILLUSTRATIONS BY JILLIAN TAMAKI

MURIEL SHAW had always said the only way she'd leave home was "feet first." For Shaw, a retired British Columbia Institute of Technology clerk in her eighties, home was a double-wide trailer in Coquitlam, in what her family describes as the "second-best trailer park in British Columbia." Shaw was living an independent life and had endured a series of challenges, including the loss of her partner, in 1996, and breast cancer. She was proud to be in her own space and host friends and family. "Home is home" is how her youngest son, Chris Jarvis, explained it. Jarvis often travelled, but he would stop in to stay with his mother whenever he could. As Shaw got older and her health waned, another son moved in with her. This arrangement worked well until Christmas-time in 2010. According to Jarvis, as the holidays approached, Shaw didn't seem herself: she was anxious and confused—"just acting strange." The family took her to the hospital.





After Shaw was admitted, hospital staff decided to give her a capacity assessment: a common evaluation administered to people who seem disoriented. In many cases, these people are seniors. The goal of these assessments is to determine whether a person has the ability to understand information and foresee the consequences of their actions or decisions. Subjects are asked questions like, “What is today’s date?” and “What problems are you having right now?” They may be asked about how they’d react to various scenarios: “What would you do if you had a fall at home?” or “What if there was a fire?” And, though these assessments are often given by doctors, the responses lead to a legal outcome rather than a medical diagnosis. If the assessor determines that a person is incapable of making some or all of their own decisions, a “certificate of incapability” can then be issued. These certificates have different names depending on the province, but they all have more or less the same result: from that moment on, some or all of a person’s autonomy may be taken away for good.

Being deemed incapable means that a person’s life decisions—what they spend their money on, what health care they receive, where they call home—may be delegated to a trusted party. In some cases, that proxy is a family member; in others, it is the provincial public-guardian system, whose staff may meet with the person rarely, if ever. The system is designed to protect against elder abuse and errors in judgment; it is an attempt to safeguard some of society’s most vulnerable, but it risks doing so at the cost of their liberties.

After her capacity assessment, Shaw was deemed incapable. (Jarvis said that she was showing symptoms consistent with early-stage dementia.) The people around her immediately began trying to work out who would make decisions on her behalf. She had three children, and they had different ideas about what would be best for her. Jarvis said that social workers and hospital staff determined there was no suitable place for Shaw to live among her family, and though she wanted to remain

at home, her care workers wouldn’t allow it.

After months in the transitional-care unit of a hospital, Shaw was moved to a long-term care facility. She started writing in a new journal there, in June 2011. She seemed to want to make the best of her situation, and on the first page, she put down a rosy title for her

the matter, BC’s Public Guardian and Trustee (PGT) became involved. The BC PGT is a government-designated corporation that steps in when there isn’t a family member or close friend available to take responsibility for a person deemed incapable. “If we’d had money and family harmony, this would not have happened,” Jarvis said. “It wasn’t ideal,



project: “New Beginning!” But her entries outlined a growing list of concerns: “My small room lets me see outside, food is available etc, but I am still very sad and lonely,” she wrote. “Wish I could be home rather than in the hospital (or whatever this place is called!).”

While Shaw was getting acclimatized to her new living situation, Jarvis and his siblings argued over how their mother’s money was being managed. To settle

but what was the alternative?” It was a development that would consume the next ten years of his life.

Shaw is not alone in spending her older years deemed incapable and living under the oversight of the PGT. In Alberta and BC respectively, public guardians reported 7,832 and 7,904 adult clients from 2017 to 2018. The Public Guardian in Ontario managed the finances of approximately 12,500 people in 2019, about

half of whom were seniors. Billions of dollars—savings accounts, assets, pensions—are managed by public guardians across the country.

But, in recent years, auditors general and ombudspersons have raised concerns about the inner workings of the closely entwined capacity-assessment and public-guardian systems. In our country-wide patchwork of well-intentioned bureaucracies, some seniors find that, once declared incapable, they are unable to challenge the decision. There has been case after case of mismanaged finances and contested spending. In Ontario, the auditor general found that over \$1 million of assets managed by the PGT was lost between 2015 and 2018 because of staff mistakes.

In one instance, a packet containing nearly \$650 worth of jewellery was found in a PGT office, and employees had no idea which client it belonged to. Errors like this are not confined to one province: reviewers in PEI, BC, Alberta, and New Brunswick have all stated that their public trustees may not be properly protecting or administering their clients' finances.

It can seem like a great deal of attention is paid to other institutions that house vulnerable segments of the population, such as children in daycares. But there's no future in aging; there is next to no potential that a senior might one day cure cancer or be the next prime minister. Reform in elder care may be desperately needed, but it hasn't been forthcoming.

DETERMINING mental capacity can be a puzzle. To test for a fever, medical staff can take a person's temperature; for diabetes, they can do a blood test. Capacity, on the other hand, has no standard unit of measurement. Trying to determine whether a person is able to make their own decisions can be subjective and debatable. Sometimes, the practice may seem more like an art than a science.

In Canada, there is no universal assessment or standardized system to determine capacity. Depending on the province or territory, capacity assessments can be administered by a doctor or a nurse, a social worker or a psychologist, an occupational therapist or, in rare cases, a member of the clergy.

Some assessors may use what's known as a Mini-Mental State Examination. In this evaluation, seniors are asked the month and the season. They are asked to spell "world" backward and forward and given a time limit of thirty seconds. They are asked what province they're in, to repeat the phrase "no ifs, ands, or buts," and to fold a piece of paper in half and put it on their lap or the floor. Other

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assessors may use the Montreal Cognitive Assessment, in which the subject is asked to draw a clock face and to name as many words that begin with the letter *f* as they can in one minute. Other patients may be assessed on a geriatric-depression scale, where they are asked if they feel "pretty worthless" or if "it is wonderful to be alive."

Being on the receiving end of these questions can be rattling—but not answering to the assessor's satisfaction can influence whether a person goes home at the end of the meeting. And, though these cognitive tests can offer clues about a person's abilities, experts are raising concerns about the efficacy of these tools and caution that assessors may be overrelying on them. Laura Tamblyn Watts, president and CEO of the seniors' advocacy group CanAge, says that capacity should be thought of as more like a dial: "People are more and less capable of doing some things and not others." As she explains, many of us experience some level of uncertainty in our day-to-day lives; we all get confused and ask ourselves questions like,

Did I pay that bill already? Did I turn off the oven before I left home? But determining when exactly these sorts of questions become a sign that some greater function has been lost is far from straightforward. Even those with dementia don't fully lose their faculties overnight.

Capacity often comes in fits and spurts and can be influenced by health and environment. Problems with sleep or blood sugar, as well as common illnesses like urinary tract infections, can temporarily affect a person's state of mind. Seniors with dementia may experience a phenomenon known as sundowning, a decline in function that occurs later in the day. And then there are the medications. "There is a massive overdrugging of seniors in long-term care," Tamblyn Watts says. According to the Canadian Foundation for Healthcare Improvement, one in five people in long-term care is administered antipsychotic drugs despite not having any diagnosis of psychosis. These drugs can increase fatigue and confusion and are known in the industry as "chemical restraints."

Maria Zorzitto, head of the geriatrics division at St. Michael's Hospital in Toronto, explains that there is often a desire to see capacity as "black or white." But, in reality, Zorzitto says, "there's quite a grey spectrum here." How a person performs on a capacity assessment can be influenced by whether they've recently experienced a traumatic event, whether they trust their assessor, or whether they are hard of hearing. Some senior advocates argue that people may even be found incapable without being properly assessed by a doctor at all. Ruth Adria, a retired registered nurse in Edmonton, says that she believes this was the case when a woman she knew—I'll call her Martha—was deemed incapable over ten years ago.

As Adria tells it, Martha was eighty-five and lived alone in her bungalow. She kept busy, filling her days with errands, tending to her backyard garden, and regularly stocking her basement with jars of homemade preserves. Martha had grown up an orphan in Europe and was well acquainted with looking out for herself.

Then, one day, she hurt her foot and was admitted to her local hospital. Adria says that, while Martha was there, health care workers raised concerns about her living conditions. Martha never went home again. She lost control of her finances and was placed in a nursing home. According to documents that Adria saved, Martha's bank account was billed \$2,000 per month for her new room—a shared space in which only a curtain separated her from other residents. Martha's house was emptied, her preserves tossed into a dumpster.

Throughout the ordeal, Martha maintained that she was being unfairly “locked up,” according to a letter she wrote to her doctor that Adria kept. Martha knew what was happening: she complained that she wasn't allowed to attend Mass, that her only exercise was “walking the corridor aimlessly,” and she argued she would be better off at home. “I want my freedom!” she wrote. “I want out of this place!” She never did get out.

With so many complicating factors that can influence capacity, and with a person's rights on the line, public watchdogs have continued voicing concerns about the quality of assessments. Adria now advocates for capacity assessments to be recorded and transcribed so families can have access to the basis of their family member's certificate of incapability. As it stands, many written assessments are vague, with little information about how conclusions were reached.

Registered nurse Alanna Kaye is well versed in the complexities of capacity assessments. When she first trained to become an assessor in Ontario, twenty-five years ago, it was a week-long intensive course, complete with role-playing and exams. Now, the training lasts three days—a length that could be seen as insufficient. “Because this is complex, the more practice you get, the better,” she says.

In 2018, Ontario's auditor general found that outside experts “identified concerns in almost half of the assessors they evaluated.” They cited a “lack of understanding of relevant legislation; asking subjects questions that

lacked sufficient depth; not explaining why they found the subject incapable; and not meeting any of the requirements for completing an assessment.” The auditor concluded, “There is risk that the Public Guardian is assuming authority for managing the finances of people who are in fact capable of doing it themselves.”

IT'S NOT HARD to imagine why a person deemed incapable may want to dispute the decision. But a person's options for challenging a certificate of incapability and the PGT's involvement depends on what province they call home. The most-referenced example of a gold standard, Ontario's Consent and Capacity Board, was created in 1996 but remains a rarity in Canada—a similar body exists only in the Yukon.

If a person objects to a capacity decision in Ontario, the board will convene within seven days. Application forms are available online, or a person can call a toll-free number for help. There is no cost for a hearing. Importantly, the board's panel will go to the person challenging the decision—according to Lora Patton, vice-chair of the board, it has met in hospitals, libraries, and nursing homes.

One hearing concerned a sixty-nine-year-old man. Bob (not his real name) was given a capacity assessment in 2012, after his landlord complained to a social worker that he had stopped paying rent. The assessor, with scant knowledge of Bob's medical, financial, or personal history, met him in a Tim Hortons one evening and noted that he was “vague” in his responses to her questions. The assessor said Bob failed to accurately count some coins she gave him—she had asked

him to count them under the table, as she thought it uncouth to count money in the open. After the brief meeting, the assessor unilaterally decided that Bob was incapable of handling his finances. They would be taken over by the Ontario PGT.

The full story came out only at the hearing. Alex Procope, a Toronto lawyer who represented Bob and specializes in capacity, guardianship, and power of attorney, told me Bob had stopped paying his rent in protest—his landlord was failing to address a cockroach infestation in his apartment. Procope has represented hundreds of clients before

the Consent and Capacity Board and says situations like this are more common for capacity rulings concerning property. “[Landlords] will try to get the PGT [involved] because they think they'll have an easier time getting their rent,” he says.

The assessor later admitted her testing was influenced by the sense that she was on “a rescue mission” to prevent Bob from being evicted and that the PGT would help him straighten out his finances. The board deemed Bob capable, noting that the assessor “may have had

the best of intentions” but that, in her short meeting with Bob, she had “made a number of assumptions that were proven erroneous.” Bob was lucky: he regained control over his bank account and his life.

Another Ontario case involved a ninety-five-year-old widow who lived alone and was prone to falls. In 2014, a nurse she had never met conducted a forty-minute interview and, as part of the questioning, asked what would happen to the woman if she stayed at home. The ninety-five-year-old responded, “I guess I will just live 'till I die”—an accurate, if blunt, statement. The nurse deemed the woman incapable of deciding where she should live. The Consent and Capacity Board later found the opposite to be true.

“People are more likely to infantilize older people. Just because they're old doesn't mean they've lost their right to make decisions.”

According to Ontario's auditor general, the board has come to a different conclusion than the original assessor in 80 percent of cases it has heard concerning people's ability to manage their own finances. In British Columbia, as in many other provinces, there is no such tribunal to review an assessor's conclusions. In a 2013 report, the province's ombudsperson noted that, in most cases, a person issued a certificate of incapability has only two options: they can request a reassessment at their own cost, or they can put up an expensive fight in court. The BC ombudsperson urged the Ministry of Justice to set up an independent tribunal for appeals, though it has not yet done so.

These institutions are not something every senior will encounter. PGT involvement in particular can be more likely for people who lack willing caregivers, those without prior written plans, or those with families who are in disagreement. Muriel Shaw fit into the latter two categories.

When Shaw first moved into her nursing home, she received statements from the PGT listing her monthly income: her work pension and old-age security. The PGT also noted the fees it was deducting, which in BC is 4 percent of a person's annual income plus a percentage of their pension. (The PGT can also deem it necessary to sell a person's home and will collect 4 percent of the sale price.)

But Jarvis said that, as time went on, his mother's financial statements stopped arriving. Shaw's notebook contains an ever-growing list of items she wanted to buy—Band-Aids, a flashlight, brown socks—and a desire to figure out her finances. "Find out amount in bank," she wrote. "What do I own?" Jarvis said that the lack of communication frustrated and confused his mother. "She lost control of her sovereignty by not having control of her own money. It made her angry," Jarvis said. (The PGT told me that it doesn't comment on specific cases but added that, "if assets are secure and the adult is able," it will try to minimize its involvement in day-to-day decisions like shopping and entertainment.)

The lack of communication made Jarvis angry too. He spent years trying to explain his and his mother's concerns

to the PGT and described a Kafkaesque struggle with a faceless bureaucracy featuring frequently changing staff members and a long list of unanswered questions, unilateral decisions, and refusals to grant even the simplest expenditures. The PGT used Shaw's money to buy her a wheelchair, but Jarvis argued that they didn't research the most cost-effective model. He said that a PGT representative would visit his mother once a year, but in his opinion, that was not enough time for them to understand her situation. Jarvis wanted out of the arrangement, but he felt there was no way for the family to take back control of his mother's finances without getting mixed up in an expensive legal battle.

Jarvis told me that, throughout the experience, no one in his family was properly consulted about what might be best for his mother. Nor, for that matter, was she. As time progressed and Shaw's health deteriorated, her notebook entries appeared to reflect this. The pages were punctuated with scribbles and rips, and it's evident that she often became confused. "What day is it today?" she asked in one entry. "I am mixed up as usual." But even so, her unhappiness with the situation was clear: "I am sad to have reached the end of my life like this."

Situations like that of Jarvis and Shaw are not isolated incidents. I met with Kris Schmuland at a coffee shop in Vancouver. His mother, Mary Rose, had been living in a nursing home when she was deemed incapable and her finances turned over to the PGT. He said that, once the PGT became involved, he had to go through a tedious process of seeking permission to help his mother buy herself items—lotions, clothing, supplements—and these requests were often turned down. Mary Rose had suffered a stroke and was not able to speak, but Schmuland spent a long time believing that his mother was still capable of making her own decisions. Even so, he had no means to appeal Mary Rose's assessment. "Battling a legal team of the best lawyers in the province?" he asked. "I don't have money like that."

Schmuland would often bus or hitchhike to visit Mary Rose at the care homes

she was placed in across the Lower Mainland. He wanted his mother to spend the last of her money on her own comforts. The Christmas he knew would be her last, he went all out. He bought a Christmas train and strung paper snowflakes from dental floss in front of her window. "There were lights and elves and stuff hanging everywhere," he told me, near tears. He wanted to "make sure her life was as pleasant and as beautiful as possible until she passed away." The PGT, he said, didn't make that easy.

IN MY CONVERSATIONS with doctors and lawyers over the course of two years, one word came up repeatedly: "paternalism." When the state or a family member is given the power to make decisions on another's behalf, they inevitably run the risk of substituting their own values for those of their charge. "It's a fundamental right to protect a person's autonomy," says Kim Whaley, a trusts and estates lawyer in Toronto, "but you also want to balance that against whether a person is vulnerable and needs protection. It's a fine balance."

Jarvis told me a story that seems indicative of this conflict. When his mother was living on a fixed income, she discovered that her poodle was dying. She spent around \$700 on veterinary bills, though her dog's life was prolonged only a few days. Was Shaw's spending a foolish decision that ought to have been prevented for her own sake? Did she understand the consequences? These are the questions a capacity assessment tries to answer, but whether there is a correct answer is up for debate.

Samir Sinha, director of geriatrics for Sinai Health System and the University Health Network in Toronto, says that, for doctors, the desire to protect a patient can be overwhelming and can sometimes lead to overreach. "You pledge to do no harm," he says. "It's so deeply ingrained." Still, he's concerned that ageism can affect decisions: "People are more likely to infantilize older people. Just because they're old doesn't mean they've lost their right to make those decisions." After all, people have the right to make mistakes, spend frivolously, and live in less

Incantation

BY SADIQA DE MEIJER

Cider light of spring
perforates the maples—

they bloom in tight vermilion packets
that the squirrels chew, discard.

Fabric of small aggregates of families,
pushbikes, buckets, stuffies.

Single thunder of the metal slide undenting.
The mothers clutch coffees, they wave and relate.

I'm not quite right.
One hand pushes the swing, the other holds an open book,

paper valley of an elsewhere.
And an axe, Kafka said—

love, I recalibrated all catastrophes
when you were born,

and they were worse—
the sloping lines I read

in gulps while automatically repeating
whheeeeeee

as you fly elliptically out
of my attention, which should be undivided, but is

skulking for the possibility
that words

could suddenly align the elements—
then every gesture

has a choreography: rope climber in its tilted
orbit, woman emptying

a shoe of sand, fledgling
robin's skimming flight—and I'm

forgiven, bookish, motherly, because the weave,
made visible, leaves nothing out,

not even you, not even me.

than stellar conditions—this includes all manner of hoarders and misfits.

But even so, many would agree there comes a time when the state must intervene to protect a person. “In some instances,” Whaley says, “I say we’re not paternalistic enough.” Through her decades of practice, she’s seen countless instances of elder abuse—horrible cases where a person’s health care is neglected or their bank accounts are drained by family members or scammers. According to the National Survey on the Mistreatment of Older Canadians, nearly 250,000 seniors were victims of financial abuse in 2015, and millions of dollars have been lost to scams or fraud. Do we not have an obligation as a society, Whaley wonders, to be aware and assist when a person is vulnerable?

These ethical questions are becoming more pressing. It is projected that there will be more seniors in Canada than children by next year, and the population of people over eighty is set to double by 2036. It’s estimated that more than 1.5 million Canadians are now well past the average age of mortality, and as such, they have likely outlived most of their friends, colleagues, and siblings. Many have moved beyond their sunny retirements into the final phase of their lives. As part of their care, many will be pushed toward nursing homes, regardless of their own preferences. “The biggest indignity faced by many older people is losing the right to live independently in their home,” says Marshall Swadron, a Toronto lawyer who, for over thirty years, has represented clients whom he describes as “allegedly incapable.” “Some people are very proud of their homes, their independence, their ability to decide who comes in and who doesn’t—all of which you lose when you’re in any kind of institutional setting.”

In BC, the Office of the Seniors Advocate surveyed nursing-home residents and found that nearly half don’t want to be there. About the same amount say they don’t have any close friends in the facility. At some point, as one advocate told me, many seniors in nursing homes end up looking “like flowers with drooping heads.”

But, as Sinha points out, the system that's been created to protect seniors can also work to support them—to see them as individuals with their own preferences and desires. He tells me a story about Josephine, a patient he got to know well. Josephine was blind and bedridden, and doctors wanted to place her in a nursing home—a decision she vehemently opposed. Some assessors may have seen Josephine as a woman incapable of deciding what was in her best interest. But, in this case, she kept her autonomy. Josephine stayed in her apartment and received government-funded visits from caregivers. She would lie in bed for most of the day and listen to her radio. To some, it may have appeared to be an awful way to live. To Josephine, it was the best life possible.

Advocate Laura Tamblyn Watts points to examples like this as evidence that a more supportive model is possible, one that doesn't strip a person of their decision-making ability. "We always want to make sure that we are only removing the civil rights of the person to the smallest degree that need be,"

she says. Lately, some advocates have been promoting a "supported decision-making model" where seniors receive help understanding the consequences of their decisions and come to solutions alongside a team. The process is collaborative; it doesn't rely on someone making decisions on the senior's behalf. This kind of process takes time, training, and trust, and not all seniors today have trustworthy advocates willing to work with them on such a level. Despite the challenges involved, Tamblyn Watts says the goal should always be to ensure that each senior's personhood is respected for as long as possible.

THE END of all our stories is the same: we die. But how we spend our final years matters. I first met Jarvis long after his mother was admitted to long-term care. Shaw's "new beginning" was over, and her health had continued to wane. She was on multiple medications, and her mind was often swarmed with fleeting thoughts that, like fireflies, dimmed and flitted away. Her notebook was long forgotten.

Jarvis told me he had one regret: that the PGT had ever become involved in his family's affairs. He felt that, rather than relieving the stress that age and illness brought to both his mother and his family, the PGT had made her decline all the more painful. Through tears, he told me that he was planting sunflowers in a window-box at his mother's nursing home. He planned to use them at her funeral.

Muriel Shaw died last January. I met with Jarvis a few weeks afterward, at his home in Coquitlam. Her funeral had yet to be arranged, and her family members were trying to find a way to gather. I asked about the flowers in the window, and Jarvis told me they wouldn't be making it to her funeral after all. "I let the sunflowers die," he said. It was near the end of the season, he concluded. And besides, they didn't get the care and attention they needed. ❀

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