

that once my kids started to read bigger books, that I would get interested in writing them, too.”

Why did you decide to make an emphatically non-nuclear family the focus of this book?

“A friend of mine asked me why there aren’t books about kids with same-sex parents where the kids just took it for granted, instead of it being a problem. I started thinking about it, and then I thought: since I’m at it, I don’t just want to write a book in which someone has two

Do you think these concepts, like same-sex parents, mixed-race families, and gender fluidity are starting to become normalized for Canadian kids?

“Absolutely. When there was all that fuss over the Ontario sex education curriculum, what I found so comical was that a lot of the parents who were afraid seemed to think that if their kids weren’t told about—for instance, same-sex parents having children—until maybe grade six, that they wouldn’t hear about it until then.

“It’s just laughable: not only are they learning from other kids, but

playground, and it’s over in about one-minute.”

What more do you think we can do, as a society, to instill this open-mindedness and accepting nature in Canadians of all ages?

“I think things like pushing through that sex-education curriculum ... the panic of certain parents over correctly naming parts of the body should not be allowed to set the agenda. It’s just ludicrous. I personally don’t think sex-education should be an optional subject; I think it’s just as important as all the others.

“I’m very heartened when I see in the media routine use of mixed families or same-sex couples—even in ads—that stuff makes all the difference.

“I think in Canada, we now have pretty good laws, but what you have to do is follow-through on diversity on the level of representation, in books, for example.

“I read a lot of children’s fiction to and with my kids, and I have to say: one father and one mother and one son or one daughter, is just this unbreakable pattern in so many books.”

“

I’m very heartened when I see in the media routine use of mixed families or same-sex couples—even in ads—that stuff makes all the difference.”

mothers—let’s see what else the family can stretch to include.

“I liked the idea of making it larger than life, so it would be a realistic, modern story but also would have this slight air of the idyllic to it, because everything is on a grand scale—lottery winners, huge house, four parents, lots of siblings, lots of pets. Let’s just stretch the family in all directions to see if those core family values of love and humour will still last.”

It’s not made immediately clear in the book whether the children in the family are a mixture of adopted, as well as carried. Was that intentional?

“The first four are born, two of them each to the two mothers... and the last three are adopted. I don’t foreground that, because I think in my experience, with kids getting to know our family—which has two mothers—kids are very matter-of-fact about it. They want to know who the main people are, but have very little curiosity about how the family came to be formed. They couldn’t care less whether it was formed in traditional ways.

“There are moments where it just comes up that one of the kids is genetically from one or the other of the mothers and fathers.”

they’re hearing about it in the media and even in terms of public culture, pop music... the idea that you can keep them ignorant by not allowing them that curriculum until a certain grade is just ludicrous.

“I think even if kids haven’t specifically heard about people making a baby out of donor insemination, they will have heard of mixed-race families, or adoption. I think kids are normally pragmatic... they take things as they’re offered to them, so if you offer a subject in a very ‘this is just how it is’ way, I think kids are enormously accepting.”

Can you think of a time in your life when children were more open-minded to societal changes than the adults around them?

“Both of my kids have had a first-encounter with homophobia. I’ve seen my kids, for example, in playgrounds in foreign countries and sometimes the other kids are clearly pointing at us and saying, ‘what do you mean *two* mothers?’... And then I hear my kids saying, ‘Yeah! You don’t need a dad, you just need some sperm!’ And then my kids are doing the whole lesson for the other kids in the

This book is also illustrated. What can you tell me about the artist Caroline Hadilaksono?

“She’s New York-based and wonderful. I like how messy her pictures are; there’s nothing neat about them. They’re wonderfully quirky... I love how, throughout the book, she does some in silhouette and she does some in close-up with details, and some sprawling scenes. They’re wonderfully varied.” **P&I**



Kelly Huppert, a staff member at Orchard View by the Mississippi, works with residents like Sheila MacIntosh, on the memory living floor.

//// //// **CANADA’S** //// ////
‘permanent passengers’

The country is facing a flood of dementia diagnoses, and experts say simply asking patients to ride it out—with no say and no strategy—is a tragedy in the making.

BY SAMANTHA WRIGHT ALLEN | IMAGES BY JAKE WRIGHT

Some day soon, Mary Beth Wighton plans to paint the brown walls of her downstairs office purple. It is one of several hues deemed to be dementia-friendly, a specific palette she’ll consider when making adjustments to the décor of her home, which overlooks Lake Huron’s Ontario shores in Southampton, Ont. The 50-year-old sees many ways the world around her could change—both in subtle and seismic ways—to help those with dementia. Five years ago, when she and her partner walked into the doctor’s office—very aware that Wighton wasn’t quite herself, and hadn’t been for awhile—they were handed

a dementia diagnosis. They quickly realized that the healthcare supports available differed drastically from other diseases. “I was told point blank to get my affairs in order, go home and prepare to die,” says Wighton, who was diagnosed at age 45 with frontotemporal dementia, a rare form that develops in two-to-five per cent of Canadians. After having just driven to that doctor’s office, her license was quickly taken away and she became a permanent passenger; a reality she’s experienced in many aspects of her life since, like in the manner governments determine policy, and the way services are offered to people like her.

“I was told point blank to get my affairs in order, go home and prepare to die.”

—Mary Beth Wighton



Catherine Grand with mother, Huguette Grand. Photograph courtesy of Catherine Grand

“There’s this jump to the very end-stage of dementia,” says Wighton. “You’ve got a whole lot of living to do first.”

THE SILVER TSUNAMI

Canada, like so many other countries, is facing an aging wave in its population—the so-called silver tsunami. Many individuals caught in that tide also face a powerful rip current underneath.

The multilateral Organisation for Economic Co-operation and Development (OECD) has called dementia the worst cared-for condition in the developed world. And among that group, experts say Canada is falling behind: behind in research, behind in care, and behind in developing a national strategy.

A consensus has emerged, calling for the creation of a national plan, say Wighton and others, who point to a 2015 Nanos poll that said 83 per cent of Canadian baby boomers believe the country needs a national dementia strategy.

“Why are we dickering with this? Let’s get it going,” says Wighton, a board member who helped form the Ontario Dementia Advisory Group a couple of years ago. “We wanted to change public policy. We weren’t part of the conversation. We were told what we want, even if we didn’t want it.”

Meanwhile, a 2016 Senate report offered a sweeping list of 29 recommendations;

a private member’s bill on the topic has made it through the House; the finance committee’s pre-budget report called for funding. But it appears it won’t happen this year, with the 2017 budget silent on the disease.

According to the Senate report, using 2011 data, 750,000 Canadians currently live with the degenerative condition. Every year, the Alzheimer Society of Canada (ASC) says another 25,000 are diagnosed—enough to overflow Calgary’s Saddledome, or fill half of Toronto’s Rogers Centre. By 2031, Canada will see those numbers approach 1.4 million. It’s expected that by that time, one-quarter of the Canadian population will be over the age of 65, the Senate report says.

Age is the biggest risk factor with the progressive disease, which comes in a variety of forms: Alzheimer’s accounts for 60-to-70 per cent of those affected, with women making up the vast majority; vascular dementia is next, in terms of its occurrence, comprising some 15-20 per cent of the population; Lewy body—associated with Parkinson’s disease—and Frontotemporal dementias are the least common.

The costs accompanying the predicted diagnoses in Canada are also on the rise. The report estimates the price tag is going to double from the 2011 costs, reaching \$16.6-billion by 2031.



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Mary Beth Wighton, far right, her partner Dawn, far left, and daughter Brianna. Photograph courtesy of Mary Beth Wighton

“We’re not resourced to deal with the crisis that this is presenting to us... Our healthcare system isn’t ready for it, so the clock continues to run.”

—Debbie Benczkowski

“These numbers are too big to ignore,” the Alzheimer Society’s Chief Operating Officer Debbie Benczkowski told the finance committee in October. The group had asked for \$150-million over five years to develop a partnership to work on a plan.

Months later, and days before the release of the 2017 federal budget—when Benczkowski was hoping for a different outcome—she says no money means no plan this year, and the group goes back to “meeting with politicians and keeping the momentum up as best we can.”

‘OUR HEALTHCARE SYSTEM ISN’T READY’

Many of the points in the Senate study stem from Alzheimer Society of Canada recommendations: coordinated care, support for caregivers, better training for healthcare workers, and access to services for those with dementia, like housing and transportation.

“We’re not resourced to deal with the crisis that this is presenting to us,” says Benczkowski, whose organization advocates for research, preventative risk reduction methods—like exercise, healthy eating, and social activities—as well as better support systems and quality of life for those needing care now. “Our healthcare system isn’t ready for it, so the clock continues to run.”

Benczkowski regards both the Senate study and the private member’s bill—sponsored by Conservative MP Rob

Nicholson and seconded by Liberal MP Rob Oliphant—as “game-changers.”

For years, the ASC has been calling for a plan and Benczkowski has watched the momentum build since 2013 when leaders met at the G8 Dementia Summit to address the “looming crisis.” The forum resulted in the creation of the Dementia Friends Canada program, an awareness and support group. The Senate report criticizes the lack of public awareness around the program, which is in part the federal government’s responsibility.

“The evidence just kept mounting and mounting,” says Benczkowski, pointing also to the 2015 OECD study that said dementia is the worst cared-for condition in the developed world, and calling it “yet another strong call to action.”

Thirty other countries have dementia plans, and among the G7 nations, Germany and Canada are the outliers, she says.

“It is something we know works and we know that people who are living in those countries where they do have a plan have got a better quality of life,” she says. “When there’s a coordinated and targeted action at the national level ... results get delivered.”

As the chair of the Senate Committee on Social Affairs, Science and Technology, Conservative Senator Kelvin Kenneth Ogilvie and his colleagues started noticing a “common underlying issue” in all discussions around seniors care, ultimately leading to their decision to study dementia.



Mary Beth Wighton, a member of the Ontario Dementia Advisory Group. Photograph courtesy of Mary Beth Wighton

“The study has revealed that this is a tsunami that is hitting the healthcare system—that the healthcare system is unprepared to deal with this onslaught—that it is overwhelming the hospitals that are the first line of engagement,” says Ogilvie, adding that many of those beds are taken by dementia patients who could be better-served elsewhere.

“It is staggering,” says Ogilvie, who’s been a vocal advocate on the issue alongside the committee’s deputy chair, Liberal Senator Art Eggleton.

The committee recommended \$3-billion through a targeted home care innovation fund to free-up beds on long-term care for those who need it, giving other dementia patients better options, so they’re not “forced to stay in hospital or pay the high costs associated with memory care units in assisted-living facilities,” the report says.

Last year, the government announced it would spend \$11.5-billion over 10 years targeting mental health and home care, but Ogilvie says the promise is not enough.

“What’s the strategy around to lay it out? There will be a lot of politics involved, won’t there? If there’s a strategy that’s well-thought-out in advance of people getting their hands on all that money, and the

provinces fighting for their share,” then the issue may not be lost in the mix, says Ogilvie.

GAPS IN SERVICE

While some provinces are making significant progress, the Senate report says Canadians face “gaps in service and a lack of continuity and collaboration,” and that a national approach would lead to increased innovative models of care, and better-adoption of some best practices that are already working in small pockets across the country.

On average, family caregivers offer more than eight hours of support a day. Burnout “is the principal reason for dementia patients being hospitalized or placed prematurely in long-term care facilities,” the report says.

Catherine Grand delayed that day for as long as she could. Before then, as her mother Huguette’s symptoms progressed, she would spend hours on the phone during work, trying to find new caregivers to hire after her mother fired them. To add to the problem, finding a caregiver who was trained specifically to deal with dementia proved difficult.

Financial support for a personal care worker wasn’t an option—unless she needed assistance bathing. Wighton also saw similar gaps in financial support for transportation; if a person is deemed capable of physically walking a certain distance, they don’t qualify, and yet people like her lack the orientation to get from place-to-place on their own.

Grand, like Wighton, says the diagnosis almost 11 years ago left their small, close-knit family of two reeling.

“She’s just got this name for what’s happening to her. Everything is exactly the same,” says Grand, referring to the first few years after receiving the news. “You’re just handed this diagnosis and then no resources.”

In the end, Grand, an only child to her widowed mother, felt as though she was left to handle most of the big decisions alone.

“She kept forgetting. I’d say ‘you got Alzheimer’s,’” Grand says, recalling early

conversations with her mother. “And she’d laugh. That was the big joke.”

At first Grand thought her mother was in on it.

“And then I realized she wasn’t, and it made me sad. And it got a little more serious. It can be a slow, steady decline and then it can go in great leaps and bounds. When you think you’ve hit rock bottom, there’s always another rock bottom underneath there, just to take the breath out of you. It’s a terrible, terrible disease,” says Grand, whose mother now lives in an Ottawa long-term care centre.

“I’m one of the lucky ones, I really am. She’s a great person,” says Grand, apologizing as her voice breaks over the word ‘lucky’ and tears form under her brown-rimmed glasses.

The system would have been better if the line of strangers who would pass through Huguette’s home understood her condition. The Senate report noted that home care services are a “critical element” of any strategy.

“It would have helped so much to have knowledgeable people involved from the beginning. It would have taken so much strain off me; it would have helped her continuity of care. I would have felt so much better keeping her in capable hands,” says Grand, before talking about the dark days and depression she experienced for many years.

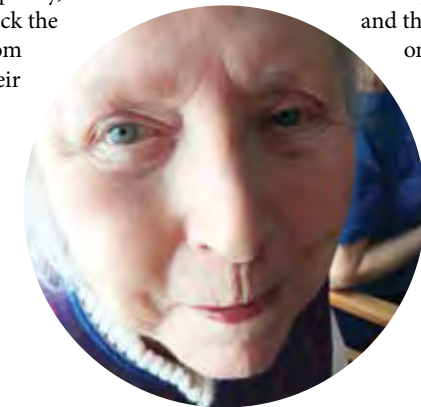
“I’m sure caregivers are driven to mental health problems a lot of the time and that causes another strain on the system. Who cares for the caregivers then?”

Knowing the reality so many face and so many more will face, the road ahead feels daunting every single day, says Benczkowski.

“We’ll get heartbreaking messages from family members who are desperately trying to keep their

family member at home and provide supports for people... who’ve lost income, and have to mortgage their houses,” she says. “We hear the horror stories all the time so we know very much first-hand that people are struggling terribly with this disease.”

Home care is an important part of the solution, but it is just one aspect.



Huguette Grand. Photograph courtesy of Catherine Grand



The above photos show the creative approach taken on Orchard View's memory living floor. The spaces are designed to offer a familiar step-back in time for the residents.

"We would all advocate for people to remain in a home setting as long as possible, that's where they generally do the best," Benczkowski says. "As long as the home care is adequate to support them, staying at home—that's a very viable alternative—but we also know that people at the very end of their lives with dementia, most wind up living...and dying in a long-term care facility, because the burden is too great on families to provide that end-of-life care."

Long-term care, too, is costly, and expected to triple by 2015 according to a C.D. Howe Institute paper. In 2014 the health care system spent about \$69-billion, which is expected to balloon to \$188-billion in the next 40 years.

The Senate committee heard from the Ontario Long Term Care Association, which said 62 per cent of long-term residents have dementia. It emphasized innovative practices—like doll therapy, pet therapy, and a music program—to reduce stress and anxiety among patients.

It noted that some of these creative approaches are being adopted "despite the institutional setting that is restricted by regulations."

Grand is dismissive of the doll therapy, and also the overuse of medications. She says her mother is in a decent home, but is unhappy with the lack of privacy. All of the residents' rooms remain unlocked, and Grand says she often sees bruises on Huguette, marks inflicted by other residents.

"It's just as good and just as bad as any other place. It's got all the same problems as every other long-term care home ... they have a lot of problems."

But it's what she can afford—roughly half the cost of private options.

AN INNOVATIVE APPROACH

Some of the private homes, like Orchard View by the Mississippi, are where innovative approaches to dementia care are flourishing.

"That competitive nature will help seniors in the long run," says Kate Gray, executive director of Orchard View by the Mississippi, found in Almonte, a community west of Ottawa. Gray helped launch the private retirement home's "memory living" floor in October 2016.

A circle path acts as the fourth floor's focal point, designed around an open foyer view into the main floor below, which boasts a grand piano and calming pond. This vantage point, staff say, allow the residents who live on the fourth floor

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Mel and Doris Lavergne both live at Orchard View in Almonte.

to feel as though they are open, free, and unrestricted with light spilling in from skylights above them. All of this, despite the fact that for obvious safety reasons, the entire floor is secure and locked-down.

The hallways branch off from this open, bright middle space in every direction to 31 rooms, some overlooking Almonte's residential community, the schoolyard next door where playground chatter lifts through windows, or sprawling farmland where staff say residents watch as cows graze. But it's the little themed-pockets that dot the path—meant to invoke memories of nostalgic environments for dementia residents who may not recognize modern-day technologies—that set this home apart.

"It's designed in a circle. Seniors with dementia like to wander," says Gray. "They can wander and it cues them to the different stations."

There's the hunt camp, with hardwood walls and outdoorsy memorabilia tacked to the wall; antlers and wooden snowshoes, a kerosene lamp and a plaque that proclaims 'hunting is life.'

When Gray and her colleagues were researching the region, they discovered the population was filled with farmers.

Many of the women were homemakers, and a group of about five residents enjoy visiting the laundry area to help memory care coordinator Lisa Doering, who spearheads the program, fold linens and towels throughout the day. The women stand at the table, chatting and bustling.

There's also a nursery, with lifelike babies that residents can rock, nurture, and walk around with.

In the kitchen, a genuine 1940s General Electric refrigerator is set against a light-blue wall, its soft grey pattern also reminiscent of another era.

"With dementia, your short-term memories are lost, but your long-term memories remain," says Gray, adding the focus of the floor is on comfort.

The staff spends a great deal of time with the resident and their support network upon intake, in order to learn about their lives, their hobbies, their personalities, and preferences. That way, a tailored care plan can be designed to ensure the resident has the highest quality of life as possible.

Traditionally, long-term care homes rely on structure: set times for meals, bed-time, and the amount of attention each patient is to receive.

"But what we're doing on this floor ... is to throw that out the window," says Gray, who has worked for 30 years in retirement living, mostly in managerial positions. "Let's make sure we cover all those needs, but at their pace. They set the tone for us."

Often people want to rummage, and will move from room-to-room. Having a central space, with activities and purposefully tactile offerings in a safe environment, encourages that activity.

"We believe that there's a certain amount of risk involved with our program," says Gray, from the kitchen where blue-painted china hangs in racks. "Sometimes quality of life outweighs small risk. We

have to continue to let them live. If we lock everything away, what's left?"

Doering adds: "It's treating them as individuals. Respecting them as individuals." She says it's important that all staff receive current, relevant training, like the Gentle Persuasion Approach.

As she approaches the record player, a smiling resident greets Doering, who opens her arms wide for a hug. She puts on Neil Diamond and promises to take Doris Lavergne, 90, down to the floor below, where her husband Mel lives in another room.

Later, Doris says Doering is like a daughter.

"And thank God she is, because she sees me sometimes with tears in my eyes and she sees me when I'm happy."

After Mel was suddenly hospitalized, they found Orchard View—a place where Doris, who has Alzheimer's could live. It was a way for them to stay together.

"You can't do that, not in many places," says Mel, 93.

"You get married for a reason, and it's not to be apart," Doris adds. "He was an engineer on the railroad and he was gone so often."

The two flirt and joke as they share ginger ale in wine glasses by his window.

The home's open concept design extends to the approach taken to daily life at Orchard View. The task-oriented approach typified at so many institutionalized living spaces particularly disadvantages those living with dementia, staff say.



Mel and Doris Lavergne.

"It's not effective. It creates behaviour when you're trying to force... somebody to meet your schedule," says Gray, who thinks the Orchard View flexible approach of trying to run on the residents' schedule is working. In its first six months, with the facility half-full, Gray has only experienced one behavioural incident. In the home she used to work for, she says she would typically see between 20 and 30 each month.

Care approaches are changing around the world. Gray points to Europe as a leader, with their dementia-friendly villages. Some places in Canada are joining the Blue Umbrella program, a network of businesses and people in the community who have been trained to understand signs of dementia, and offer better approaches and support. Gray says public care has the ability to change, and with similar resources.

"I don't think you have to increase hours to allow for flexibility, you have to change everybody's perception of how they work," she says.

"Long-term care is falling short in meeting the need of seniors and their families suffering with dementia," says Gray, adding that she wishes more families could afford private care options. "People do not thrive in that environment," she says, speaking of the publicly-funded centres. "They survive." She adds that the public homes do the best they can with the current training and resources that they have available to them, but that better is still possible.

While the fourth floor is far more complex to run, both Gray and Doering agree it is the most rewarding. What's working now may not work with every resident, but it's their willingness to shift and adjust to meet the needs of each client and their family that makes all the difference.

"The whole country as far as I'm concerned needs to learn how to adapt," says Gray, noting it will take changing views and tackling the stigma that many with the condition face. "You cannot put this label on senior care anymore. It doesn't work. It. Does. Not. Work."

Wighton also says she feels the stigma, and argues that lived experiences—free from discrimination and a better quality of life—are as important as finding a cure.

As far as Wighton's concerned, a path forward must include those with the disease, and not just tokenism. The fight for a better path has given her purpose in a world with an unknown future.

The family motto, *carpe diem*—which translates into 'seize the day'—is painted across the wall in their home.

"It's as best as it's going to get. We have no idea what tomorrow will bring," says Wighton, who adds that being part of a group who understands and is working towards something keeps her going.

"That's why we fight so hard, because many of us have gone down this similar path and [it's] terrible and [it's] wrong and we can change it," says Wighton.

"But we won't change it unless we get a budget for it, and we won't change it if stigma continues to stay the same, and we won't change it if people continue not to include people with dementia as the experts." **P&I**

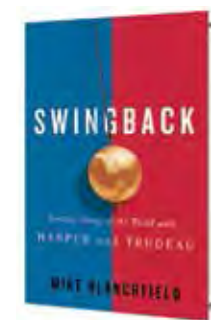
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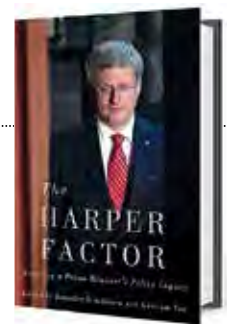
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