Dementia is altering the lives of more than half a million Canadians and their families, and the toll is expected to grow. Improving care is one way we can make their lives better right now.

By Bruce Grierson, ’86 BA(Spec)
Illustrations by Hugh Syme
People with dementia, it turns out, are especially good candidates for such interventions. “A person with dementia is suggestible,” Strickfaden says. “You work with that.” Elements similar to the Deweykeweyk approach are being introduced in care facilities around the world. One of these is Canbury Lane, the dementia wing of the Canterbury complex in west Edmonton. Strickfaden, a design anthropology professor in the Faculty of Agriculture, Life & Environmental Sciences, has been hired to consult on the multimillion-dollar revamp. It will include features such as a garden that allows residents access to the outdoors while remaining safe. Hallways that don’t dead-end, but loop back into the heart of the action. Little designated spaces for purposeful activity. Such as doing laundry. And a cobbled system of living spaces divided by theme or feel, matched to the residents’ upbringings.

The renovations will take close to four years. Unfortunately, the resident in one room is unlikely to live to see it completed. That’s just my guess, knowing that resident quite well.

She is my mother.

More than 10 million people worldwide are afflicted with dementia right now. And since the human lifespan is increasing more quickly than medical science seems to be closing in on a cure (which is to say, not quickly at all), dementia will be part of all our stories: your story or the story of someone you love very much. “Its shadow lies over us all,” writes Jay Ingram. “It’s there everywhere, in our memories. It’s the “3 Ws” model of dementia care: Where are you? Who are you? Why are you?”

For Mom, it was pretty profound. As she turned to a snapshot of her and Dad circa 1980, both of them tanned and smiling in Hawaiian sunshine, she began to cry. A staff member allowed her to sit with that sadness for a few moments, and then steered her toward the light. “He must have been a great guy,” she said. “Tell me about your wedding day.”

Reminiscence therapy, this kind of intervention is sometimes called—and preliminaries suggest it can help improve cognitive function. This year, the Canterbury Lane staff tried a simple version of it in a run-up to Mother’s Day with a scrapbooking activity. Family members were asked to contribute photos of mom or dad through the years, surrounded, if possible, by the people they have loved the most. “You’re really trying to get them to live in those moments,” activities supervisor Mbalia Kamara told me. “And then to really validate the feelings that emerge.”

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The tonic here, as much as the memory work, is the attention. People with dementia often lose their voice as the disease progresses. The world stops listening. “People used to think that because there was cognitive impairment there wasn’t insight—but that isn’t true,” says nursing professor and researcher Hannah O’Rourke. “People with dementia still know what they like and don’t like.” To pull that out, sometimes it’s as simple as pointing to a picture or a photo and asking: “She’s four.”

Are We Our Memories?

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Some research suggests that some of these are common in people who have Alzheimer’s or other forms of dementia. These include:

- **Step 1**: **Establish a routine** that includes regular activities and meals.
- **Step 2**: **Engage in physical activity** such as walking or swimming.
- **Step 3**: **Promote social interaction** with family and friends.
- **Step 4**: **Engage in cognitive stimulation** through games and puzzles.
- **Step 5**: **Manage stress and anxiety** through relaxation techniques.

People with dementia can benefit from these interventions, but they should be individualized to meet the specific needs of each person. It’s important to work closely with a healthcare professional to develop a plan that works best for the individual.
knowing who we are and what we want. ‘People with dementia are no different from the rest of us in this regard. Park’s research found that encouraging participation and sharing meaningful stories enhanced relationships with caregivers, increased communication and interaction, and contributed to a sense of accomplishment. ‘In several cases, participants said they surprised themselves with the stories they were able to remember,’ says Park.

With Mom, I have found that if I press her too much for family history, she often clams up. For her, the fact-finding is stressful. This is not uncommon. That’s why University of Wisconsin professor Anne Basting received a MacArthur Fellowship, sometimes called a genius grant, for her invention called TimeSlips. It replaces ‘the pressure to remember with the freedom to imagine,’ as she puts it. TimeSlips is like a book club where no one has read the book, except in this case it’s a photograph. Each photograph is striking and mysterious. It looks as if it has a story to tell, so everyone makes one up. There’s no way to be wrong, which seems to loosen tongues. ‘The absolute key to the entire process,’ Basting says in a video about TimeSlips, ‘is that we validate everything they say.’

Something a little magical happens when we start telling stories to each other, whether they’re true or not. It is a release; it breaks the sense of connection between the teller and the listener. As the story unspools, the brains of teller and listener sync up—a phenomenon psychologists call ‘linguistic alignment.’ Another bonus: for people who can no longer have out-there-in-the-world adventures, storytelling is an excellent proxy. It stimulates many of the same parts of the brain that light up when we are actually experiencing things—just as reading does. For the scavenging exercise at Canterbury, not all the families contributed photos. So those residents instead received pages of that scavenger book written by a resident of a random family. Which sounds a little sad but actually experiencing things—just as reading does.

**OUR QUESTIONS are EVERYBODY’S QUESTIONS:**
**what must it BE LIKE to BE HER?**
**AND WHAT CAN WE do to help?**
**MAKE THIS a little more BEARABLE—FOR EVERYONE?**

**WHA T CAN WE DO**

**BE LIKE**
**THAT RESIDENT HERE wERE ABLE to describe their biggest frustration, what would they say?** I asked Wendy King, executive director of the Canterbury Foundation, not long ago. ‘I think maybe they would say, “You don’t understand me.”’ she replied.

Hence a recent trend in dementia care toward what you might call deep listener profiling. In the old days, staff received an incoming resident’s medical charts, some basic biographical data and not much else. Now, families are often asked to flesh out the story of mom or dad. The more data, the greater the likelihood a resident sees their lives, the way they belong, doing things that placK the strings of their hidden memories.

A ‘sense of purpose,’ as O’Rourke discovered in her analysis of dementia studies, can also contribute to the feeling of contributing to others; a belief in a higher power can help them if they have had to be placed back in the vicinity of that intersection where, as American writer and Alzheimer’s advocate Roger E. Barnette succinctly put it, ‘their deep desires meet the world’s deep need.’

Strickland recalls one man at De Hogeweyk who was restless and searching, and a bit aggressive and hard to approach. Staff went back into his file and discovered he’d once been a farmer. ‘So one day they hid a bunch of eggs all around the courtyard. And the next day they found them. And then he’d be wonderful for the rest of the day. It was something that validated who he was.’

**Our Purpose, Our Selves**

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At Canterbury one resident used to be a millwright, so he’s routinely given things to tinker with. Another was a homemaker who raised a big family. She struggles to follow a recipe because she gets distracted, but when she positively melts when handed life-like “Baby Sophia.” She dresses the doll in tiny clothes warm from the dryer, wrapping and cooing over her, and, after a while, allowing open to the activities of the rest of us are doing,” says Kamara. But there’s purpose and then there is purpose—something closer to what the Japanese call ikigai. Roughly: the sense that life is worth living because we are needed. Japanese research has found that people with ikigai live longer. A study published in JAMA Psychiatry in 2012 found that people with a strong sense of purpose and ikigai lived an average of 11 years longer. No one knows quite what it means to feel as if we matter—only that it does. “Feeling you matter is at the core of being a person,” British dementia consultant David Sheard often says. “Knowing you matter is at the heart of being alive.” Sheard is the founder of Dementia Care Matters, better known as the “butterfly” model of dementia care. I could see its principles in action the day I visited Copper Sky Lodge, a memory care facility in the 160-acre Copper Grove. The building is shaped like a star. Builder and theologian Frederick Gault, well-known in Alberta as the former head of the Good Samaritan Society, a long-running non-profit care provider. But the lodge is mostly run these days by his daughter, Nicole Gault. The same Gault who, with her thesis advisor Strickland, was embedded at De Hogeweyk. As dementia advances and individuals turn inward, they’re less able to seek out the multi-sensory stimulation they may need. So the stimulation must come to them—as buttons come to flowers. “Every[one] is a part of it,” Gault says of the fuzzy sweater she’s wearing. “I’ve been getting lots of hugs today.”

At the centre of the butterfly model is emotion. The theory: people will forget what they know, but they never forget how they feel.

That’s because feeling is processed in a more primitive part of the brain, it’s protected, says Jack Jhamandas, a neurodegenerative disease researcher in the United States. “It’s a genie — aducanumab, donanemab — have raised hopes that were later dashed. In aducanumab’s case, it was a new antibody for Alzheimer’s that researchers had rewritten to improve entry into the brain. Aducanumab failed to show benefit in a late-stage clinical trial, but it showed signs that tau protein, which forms tangles inside brain cells that are deemed safe to try. Of six participants who had stopped working because of cognitive fog, all were given things to tinker with. Roughly: the sense that life is worth living because we are needed.

But for many, the memory of who they were is gone forever. “If someone says, ‘You don’t understand me,’ that life is worth living because we are needed.”

For scientists, that means identifying those who are at risk of developing the condition and delay its onset, mitigating its severity — “stitching asewom
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—Nicole Gaudet

all feeling beings,” says Gaudet. “So if you can connect to what somebody is already feeling, you’re four steps ahead.”

But there’s research and then there’s practice. Changing how we care for people with dementia isn’t easy. After their experience at De Hogeweyk, Strickfaden and Gaudet were gungho to update legislation around dementia care in Canada. They soon discovered they were facing frustrating headwinds, some of which were cultural.

A COUNTRY’S DEMENTIA CARE can reveal a lot about its values. China, for instance, is a culture of service, notes Strickfaden. “But that can actually get in the way of good elder care. People are literally served to death.” The Netherlands is big on personal liberties. How far you want to push your limits is up to you, within reason. Quality of life reigns supreme.

Canada has made a different choice. Here a dementia-care facility gets accredited or not based in part on how safe it’s deemed to be, says King, head of Edmonton’s Canterbury Lane. So De Hogeweykian elements like cobblestones, public fountains, accessible barbecues and knives, underdoomed kitchens are red flags. In Canada, safety trumps freedom. So does efficiency. Funding here is task-based. “Staff have a task list and a limited amount of time to do it,” says King. “So if a resident puts up resistance, it creates stress — because the staff person knows, ‘I’ve got to go to Mrs. Jones next.’”

The task-based funding model means more work for them, there’s evidence that such an approach leads to lower burnout, since it puts caretakers’ actions more in line with the reasons they got into this work in the first place.

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O’Rourke is cautiously optimistic about the future of dementia care in Canada. “If we — clinicians, researchers, community members, society — can set aside our own fears, assumptions and stigmas about the disease, there is hope. People with dementia have identified many ways to achieve a good quality of life. We just need to listen.”

ONE RECENT WEDNESDAY AFTERNOON at Canterbury Lane, residents sat drowsing in easy chairs in front of an old Jimmy Stewart movie on the big-screen TV. My mother wasn’t among them. She likes the privacy of her room and to pick her own shows — and to crank up the volume.

On this visit, I had a plan. Having steeped myself in the Alzheimer’s literature and the best ideas of countless experts in multiple domains, I was eager to try a few things. I wanted to help Mom grasp where she is, who she is and why she is. I’d reach to the next bend in the road and that’s it. But this is what reminiscing going on. Nor is there planning. The headlights shows — and to crank up the volume.

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Lynn Lariviere, ’79 BE, noticed Mom paging through a magazine that had a big splash about the Royal Family. Mom pointed to a gentleman in a waistcoat. “That is the man I’m going to marry,” she said. A few years ago Lynn might have laughed or corrected her. But we have learned that it’s not our job to pull Mom back into this world. Our job is to meet her in hers. Lynn raised her eyebrows in enthusiasm, nodded and asked for details about the wedding.

These days Mom’s eyes reveal a lot. There’s not much reminiscing going on. Nor is there planning. The headlights reach to the next bend in the road and that’s it. But this is what people with dementia have, most profoundly, to teach us. They are champions at living in the now. The question, for all of us, is how can we make the now better?

I believe the answer is to just be there. Or in the case of my own too-infrequent visits, make sure I’m there when I’m there. So Mom and I go for silent wheelchair tours to check out the action over in the nearby manor — past the kitchen, down the long, carpeted hallways. Little bits outside each resident’s door tell of their unique strengths. That’s right out of the David Sheard playbook: “Search for the treasure in each individual.”

“My learned that if I attach too much to whether she remembers my visit, I’m going to be bitter.” Lynn told me on the phone recently. So you shift the bar. A cup of coffee, a stab at a cribbage game, a trip to the atrium to hear the piano player play. Even though it sometimes feels that way.

Statistics: Alzheimer Society of Canada, World Health Organization

BY THE NUMBERS

564,000 Canadians living with dementia

937,000 Canadians predicted to have dementia in 55 years

50 MILLION cases of dementia worldwide

$818 BILLION estimated costs (USD) to society worldwide in 2015

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