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SPORTS



END OF AN ERA

Manitoba's Jennifer Jones heads into the women's world curling championship in North Bay, Ont., this weekend for what is likely the last time with longtime teammate Jill Officer / C1



The dementia crisis



Doug McLean is one of an estimated 22,500 Manitobans living with a form of dementia — and that number will nearly double over the next two decades.

Carol Sanders reports on the terrifying illness and its devastating effects on patients, families and the health-care system / D1

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BABY BOOM, DEMENTIA EXPLOSION

Diagnosed cases of Alzheimer's and other progressive brain-impairment diseases will nearly double in Manitoba over the next two decades; an already-strained care system will be overwhelmed by the deluge without decisive action now, experts warn / **6-9**

BY CAROL SANDERS



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Your weekend section for long reads, book reviews and much more

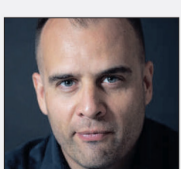
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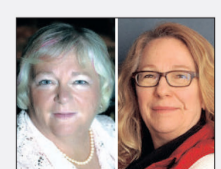
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The lives of Doug McLean, 61, and his wife Sandy were turned upside down after he was diagnosed with Lewy body dementia. But not all days are bad days.

SOARING NUMBERS, RUNAWAY COSTS

AN estimated 22,500 Manitobans have been diagnosed with Alzheimer's disease or another type of dementia and that number is growing at an alarming rate, owing to the post-Second World War baby boom.

By 2038, the number is expected to be more than 40,000. And the growing number will be accompanied by soaring costs, says community health sciences professor Banibrata Roy at the University of Manitoba's Max Rady College of Medicine.

The researcher warns of the "dreadful impact both in terms of increased number of people suffering from dementia and the escalating health-care costs that the Province of Manitoba has to bear."

Since 2015, the total annual economic burden of dementia, which includes direct health-care costs and indirect costs, has added up to \$1 billion annually, Roy calculates. By 2038, the cost rises to \$28 billion annually after inflation and other costs are factored in.

With that bleak reality in the forecast, the pressure is on to find ways to stretch a dollar without sacrificing quality of care. One approach is to give front-line workers a bigger role.

In 2017, a randomized controlled trial known as SCOPE (Safer Care for Older People in residential Environments) examined the effect of empowering health-care aides to take the lead on improvement strategies within nursing homes.

The study, conducted at several Winnipeg care facilities, looked at giving the workers who provide 80 per cent of the direct care to vulnerable seniors more of a voice in how to improve residents' quality of life.

The findings, expected to be made public in May, have been promising, according to Malcolm Doupe, a senior research scientist with the Manitoba Centre for Healthy Policy. The province is going to have to look at doing things differently — as well as adding staff — to meet the growing demands of an aging population, he said.

In less than a decade, Manitoba's annual health-care budget has nearly tripled to \$6 billion from \$2.2 billion, Doupe said at a recent Winnipeg conference on dementia care. Roughly 10 per cent of the budget — \$638 million — now goes to the operation of personal-care homes. Providing an extra 15 minutes of care per day per resident would add \$50 million to the budget.

The SCOPE study looked for ways to improve quality of life and measured them by noting changes in things such as residents' mobility and pain levels. In one example, health-care aides at one home recommended that doors dividing the dining room be removed; that helped to reduce the amount of agitation residents were experiencing at meal times, the conference heard.

"I was a health-care aide for 20 years and this is the first time anyone has listened to me," said one front-line worker involved in the study.



A Winnipeg couple whose lives have been turned upside-down from dementia at an unusually young age early in their marriage want to share their struggles, hoping to help others in similar circumstances. They recently invited the *Free Press* into their home to talk about their difficult journey — from the first hints something was amiss, to the long and frustrating road to a diagnosis, to treatment and help facing a bleak, frightening future. It's a rare first-hand account of what it's like to live with dementia from someone still able to talk about it and from a caregiver consumed by the enormous task of caring for a partner.

UNTIL DEMENTIA DO THEM PART

Bright retirement plans slowly, inexorably, frighteningly fade to black for once-active middle-age couple

CAROL SANDERS

AT the peak of his career, Doug McLean was overseeing a staff of 25 at IBM in Winnipeg and winning awards for his work.

"I was having a blast," he says at the kitchen table of an east Winnipeg condo he shares with his wife Sandy and rescue dog Ruby.

Then, in his early 50s, he struggled at work. "Schedules were really screwed up. Simple executive functions are gone. There was a lot of frustration," he says, leaning into the conversation. "I loved my job but I had to quit. When you can't do two-plus-two or five-plus-five, you're done."

"It sucks. The worst part is, you don't know what's going on. What used to be normal isn't normal anymore."

It took several agonizing years of misdiagnoses before he found out what was wrong. Doug, who is just 61, has Lewy body dementia. It causes a progressive decline in mental abilities. It affects the areas of the brain that involve thinking and movement. The dementia occurs because of abnormal protein deposits — called Lewy bodies, after Friederich Lewy, the scientist who first described them — inside the brain's nerve cells that interrupt the brain's messages. "I am going to die of the disease," Doug says without a trace of self-pity.

Over the next two decades, Manitoba will be hit by a dementia tsunami. By 2038, the number of aging baby boomers with some form of dementia is expected to double, to more than 40,000. Medical experts and people struggling with the disease say not enough is being done to prepare an already-strained health-care system for what's coming.

"There are more people at risk every year we get more into the baby boom," says Dr. Barry Campbell, a geriatric psychiatrist and well-known Manitoba dementia expert. "More than ever, there's a concern that we've got to do things better so we don't get overwhelmed."

Some Manitobans are already feeling overwhelmed.

There's no happy story here," Doug says. It's what his wife Sandy describes as an increasingly rare "good day"; his mood is upbeat and his train of thought stays on the rails. He's waiting for his ride to take him on an afternoon outing.

"Now, a lot of it is finding ways to have positive outcomes in your day-to-day life. It's important to do that."

But it's far from easy. "The hardest thing is, I look normal and I could be in a situation where I look around and say, 'Oh, Christ, where am I?' That's the scary part," he says.

That's why he enjoys going to Actionmarguerite, a facility in St. Boniface that offers a day program for adults with cognitive difficulties. Doug feels a sense of relief and belonging when he joins the group. He can play shuffleboard and socialize without anyone judging him.

It's one of four outings a week for Doug, who gets picked up at home by paid companion Howard Andersen.

"He's my lifeline," says Sandy. The McLeans are allotted 20 hours of help each week through provincial "self and family-managed home care." That's where Andersen comes in; they hired him through a private agency to spend that time taking Doug out for activities, giving Sandy some respite.

"With home care, they come and sit in your house," she says. "That wouldn't be good for Doug. He's active — he likes to get out and do things."

Andersen also takes Doug to an Alzheimer Society of Manitoba support group downtown, swimming and to visit Doug's mom, who is in her 90s. Sometimes, the McLeans will buy tickets for Doug and Andersen to attend a Moose game together.

"Doug and Howard clicked," she says. "He's around the same age as Doug and they get along great."

CONTINUED

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RUTH BONNEVILLE / WINNIPEG FREE PRESS

Companion Howard Andersen and Doug spend some time at the mall before heading to a movie. It's important for Doug to stay active and socially connected.



MIKE DEAL / WINNIPEG FREE PRESS

Wendy Schettler, chief executive officer of the Alzheimer Society of Manitoba

MANITOBA ALREADY STRUGGLING

THE Alzheimer Society of Manitoba has spent years trying to help the province to prepare for the oncoming wave of diagnoses.

"We had a dementia framework," said chief executive officer Wendy Schettler.

It was developed by service providers and stakeholders to manage the rising number of people living with dementia in the province. It cast the challenge as a community priority that needs to be funded. Premier Brian Pallister's government has made health- and home-care reform a top priority, and advocates are waiting to see what happens with the framework.

"If we're not adequately meeting needs now, how can we think we'll be ready as these numbers increase dramatically? We need to identify this is a priority and adequately fund it. That means significantly increased dollars to home care, new affordable housing, increases to personal-care homes and we need to have people training," Schettler said. "This is complex."

She pointed to Riverview Health Centre as an example. Last June, it announced a redevelopment of its 60-bed Alzheimer's- and dementia-care unit into an Alzheimer Centre of Excellence. It will incorporate the latest innovations and research to better support residents in co-operation with University of Manitoba research into what works best. Riverview said the plan is to be a blueprint for other health centres.

"We have got pockets of some really good things," said Schettler. "We have to scale it up so it's system-wide."

It's important that the community at large understands what's happening and what role it needs to play.

"People need to learn about what is dementia, and to support people in their midst with dementia and support their caregivers, as well," said Schettler. "As taxpayers and community members, are we willing to say this is important?"

"We need to recognize that people can live in and contribute to their community. We don't want to write people off because it's a progressive, degenerative disorder. We need to respect the rights of people to participate in their community and to have supports and services. I believe it's a human-rights issue."

And it's a practical issue that delays people from having to move into costlier care-home beds, she added. "We know that staying socially engaged impacts on your well-being."

That's why the organization runs programs such as Minds in Motion, which helps people with dementia stay socially connected, and Dementia-Friendly Communities, which is educating the public on how to include people with dementia and better serve them.

The Alzheimer Society of Manitoba has provided services to an estimated 124,000 Manitobans, and relies on donations for 85 per cent of its funding, but much more help is needed going forward, Schettler said.

"We have to make sure that all communities are being served," she said. "We need to do a lot more."

The province says it's working on a plan to deal with what's coming.

In an email statement, Manitoba Health said it "remains committed to ensuring that there are a range of long-term care options for Manitobans."

"We are working on a number of initiatives with long-term planning in mind, including working with our federal partners on dementia surveillance, participating in the recently-announced National Dementia Strategy and providing dementia education to staff working in long-term care."

Last June, after years of advocacy by many groups, Canada became the 30th nation out of 194 World Health Organization members to announce that it would develop a dementia plan. The Alzheimer Society of Canada has long called for a national strategy to enhance research efforts and ensure access to quality care and support across the country. Now that Canada has committed to such a strategy, work begins on implementation, the society said.



RUTH BONNEVILLE / WINNIPEG FREE PRESS

Dr. Barry Campbell: 'There's a concern that we've got to do things better so we don't get overwhelmed'

says. In 2014, six years after his cognitive problems started to show, Doug was diagnosed with Lewy body dementia.

"He thought he was going insane and feeling suicidal," she says. "A lot of that was stemming from not knowing what was wrong with him, from people not telling him."

Once he got the diagnosis, he was able to take medication that helped significantly. But those drugs are becoming less effective as the disease progresses, she says.

"Every day's a different day. In the first few years, when Doug got on the right pills we did some things on our bucket list. We went to Scotland and on an Alaskan cruise," she says. "We've done some really nice things."

Getting a diagnosis of LBD brought some relief, but knowing there is no cure and the disease will only get worse was devastating, says Sandy, who was diagnosed with a heart problem and had to leave her own job in 2015.

Doug, meanwhile, was frustrated and angry. "I spent a lot of time tip-toeing around," she said. "He's got a bad temper — you do everything to not rock the boat."

In December 2016, she had to call 911 when his anger erupted and he hurt her.

At times, he's turns his rage on himself. He's been suicidal, Sandy says, who stopped him from jumping ship on the Alaskan cruise.

They can't travel anymore.

He can't make coffee, but can still talk. However, the man with a vocabulary that once wowed his wife now has to pause mid-sentence to find the right word.

"His confidence is not there," she says.

Doug has a cellphone that he can't use, but carries as a tracking device. The couple got an eight-year-old rescue dog, Ruby, a few months ago. "She's been a godsend," Sandy says.

Doug sometimes can't see the playful, affectionate pooch on the floor because Lewy body dementia affects his vision and depth perception. Sandy puts bright green masking tape on fridge and cupboard shelves and the basement stairs so that Doug can see them.

"With Lewy body, he could have motor issues, stiffening and tremors one day — be a zombie and shuffle around — and then 24 hours later, he could be running."

Another troubling LBD symptom is a sleep disorder during which people physically act out their dreams. One night Doug dreamed he was being chased by a bear and got out of bed and was running around the house. Another time, Sandy was awakened by Doug with his hands around her throat.

"He physically attacked me a couple of times during the night," she says. "You could see that he had to be sleeping." He's now on medication, which has helped. And they now sleep in separate rooms.

CONTINUED ON D8



TREVOR HAGAN / WINNIPEG FREE PRESS

Winnipeg Police Const. Rob Carver

SILVER ALERTS ON THE WAY

WINNIPEG police officers have plenty of experience dealing with people who have dementia, whether the calls involve someone who is aggressive and potentially violent or, more often, missing.

"It's one component of an awful lot of issues we deal with," said Const. Rob Carver.

When a child is abducted and in imminent danger, police can issue an Amber Alert that breaks into radio and TV broadcasts to notify the public. If a person with dementia-related illness goes missing and is in danger, some communities issue similar alerts. Winnipeg police are in the early stages of setting up a silver alert program, Carver said.

For now, police continue to issue public advisories when someone goes missing. They can't say in the advisory if the missing person has a form of dementia because that would be a violation of the Personal Health Information Act.

"We use a matrix to analyze missing persons cases and if they have mental health or cognitive issues, that changes the response. We'll be much quicker to issue a public advisory," Carver said, adding officers are on a heightened alert for the vulnerable adults.

"We've all got families," he said. "Most of us are touched by seniors who need special care."

Earlier this year, Winnipeg police joined forces with MedicAlert in effort to better locate lost or missing people living with autism, Alzheimer's disease, dementia or brain injuries.

The partnership gives police 24-hour access to a registered subscriber's photo, identity, past wandering history and other vital information to save time if they go missing.

Sandy and Doug used to do everything together. They met online in 2005 after both came out of long marriages, 25 years each. Sandy says she was immediately attracted to Doug.

"It was an instant thing. He was, and still is, very good looking. He was very nice, very easygoing," she says. "Doug was a very confident person. He was a manager at IBM. I was a supervisor at the tax centre."

Both were workaholics. Both have grown children living in Winnipeg.

"We wanted the same thing in our retirement — to live outside the city and snowbird in the winter. Everything lined up," she says.

They bought property in Pinawa, spending every weekend there preparing to make it their summer home. They had season tickets for the Royal Manitoba Theatre Centre. They travelled a lot. Trim, fit and tanned, they were sun-worshippers who enjoyed basking by the pool during winter vacations to Mexico.

Then, the sun began to set on their bright future.

"Just after we got married in the summer of 2008, I noticed a lot of personality changes," Sandy says. "He went from a super-confident, almost arrogant person — especially at work, where he won all these awards — to someone who got a new project at work and was super-stressed. It was the first time I saw him stressed about anything. I didn't worry until 2009, when he was packaged out (his employer gave him severance and showed him the door).

"It was horrible," Sandy continues. "Work was his life."

Doug applied for other jobs and was often hired. He would try them out, then quit. That went on for nearly two years. It was like he was having a nervous breakdown, Sandy says.

"At 50-something, I didn't know you could get dementia," she says.

It wasn't Doug's memory, but his executive functioning — his mental flexibility — that faded, leaving him struggling.

In 2009, they got a referral to see a neurologist. It didn't go well. The specialist seemed to think Doug wasn't trying, Sandy says. He was sent for a neuro-psych test and that didn't go well, either, she says.

"During the process I went through trying to find out what was going wrong, I blew up," Doug says, adding he couldn't perform the tests he was asked to do.

Rather than letting Doug take a break and calm down, they showed him the door, Sandy says.

"They stopped the testing and wouldn't let him redo it.... They told us to get his stress under control."

The specialist treated him like he had a bad attitude and anxiety, not someone with a cognitive impairment, Doug says.

"He diminished what was happening to me. I know there's something wrong with me. I know in my head that this is not normal."

Sandy felt frustrated and helpless. "We kind of floundered for another year or two."

Doug got a minimum-wage guard job but struggled to understand the work schedule. He was angry, bitter and doing less. He was also becoming more confused. When they decided to paint their ceiling, he taped the ceiling rather than the walls. When they rented a U-haul, he went to put gas in it and came back furious, saying it didn't have a gas gauge.

"He would come home with crazy stories," she says. "He would phone me 10 times a day at work and then forget to pick me up from work."

In a search for answers, Doug went to the Anxiety Disorders Clinic. At his first visit, the doctor said it wasn't anxiety, but rather early onset Alzheimer's.

Doug was referred to Campbell, a geriatric psychiatrist. By this time, Doug couldn't tell time on an analog clock. But they had to go back to the original neurologist for a diagnosis.

The neurologist said Doug didn't present as someone with Alzheimer's. "He decided again that he felt Doug was stressed out or had another mental disorder," Sandy says.

Doug was sent for another neuro-psych test and this time, a woman administered the test, stopping when he got flustered and needed a break. That was followed by a PET (positron emission tomography) scan.

"It showed damage all over his brain," Sandy

cover ³



RUTH BONNEVILLE / WINNIPEG FREE PRESS

The physical and emotional strain caring for her husband has taken a toll on Sandy.

Sandy has reached out for help but it's been a tough stretch — from getting the initial diagnosis to managing day to day as his primary caregiver. At first, they went together to a weekly Alzheimer Society of Manitoba support group, which was beneficial. The non-profit organization points people in the right direction for help, but can't navigate the system with each individual, says Sandy, who struggled to figure that out for herself.

She stopped going to the support group after two years because she felt she was giving more support than she was receiving and she feels she no longer has any to spare. Doug goes on his own with his companion.

They face their next step with trepidation. She doesn't want Doug to move into a personal-care home, but looking after him on her own is exhausting.

"One of the hardest parts of being a caregiver to someone with dementia is that you need to be hyper-vigilant at all times," she wrote in an email after being interviewed. The person with the disease doesn't recognize danger anymore and can injure themselves at any time, she said.

"I caught him using his moustache groomer as a toothbrush. He broke the groomer but luckily did not break his teeth."

Sandy says she was putting off shoulder surgery because she will be in a sling for a few weeks and worries about how she'll manage caring for herself and Doug.

Doug understands that his situation will never improve. He wishes he could be euthanized when he's in the final stages of his disease, as federal law now allows people with other terminal and debilitating illnesses to apply for assisted death.

But that's not the case for those who have been diagnosed with dementia. Doug says people in his situation should be allowed to arrange for it while they still have the intellectual capacity to understand what they're doing.

"I know my life is going to be the shits. I know I'm going to get worse. If I'm in a situation where I'm not aware and not cognitive of my situation, I don't want to be here.

"Our system is bugged up."

carol.sanders@freepress.mb.ca



Playing shuffleboard provides Doug with a sense of belonging and a time to socialize.



BEHIND THE WHEEL

MANITOBA Public Insurance is on the lookout for drivers with cognitive impairment.

Cognitive impairment is the medical condition with the highest risk of causing an at-fault collision, Dr. Neil Swirsky noted in a MPI-sponsored presentation on dementia and driving last year. The University of Manitoba emergency medicine professor and driver-fitness adviser to the public insurer said people with dementia often drive too slow, make inappropriate stops and unsafe lane changes and have trouble with lane positioning and making turns — especially left turns.

Motorists with medical conditions such as dementia generally require a functional assessment, in addition to a medical assessment, to determine their fitness to drive.

Functional assessment programs such as DriveABLE look at the functions required to drive a vehicle and can reveal subtle, persistent impairments that a doctor's exam might miss.

Families are advised to watch for high-risk driving errors and a lack of insight and to talk to the driver and notify MPI, which may result in an assessment.

If they pass, no further testing is required, but they will be kept on an annual medical recall. If the assessment is inconclusive, the next step is a road test. If they fail, their licence is cancelled. They can ask to retake the test once or appeal to medical review committee.

MPI has been tracking the number of driver's licences suspended because of cognitive impairment since 2013. In the last three years, suspensions have gone up slightly — from 430 in the 2015-16 fiscal year to 439 so far this fiscal year, which ends March 31.

WHY PEOPLE ARE SCARED

MANITOBA'S dementia picture would be much worse if the population overall wasn't getting healthier, geriatric psychiatrist Barry Campbell says. In fact, people are less likely to develop dementia now than was the case two decades ago.

"One of the reasons is there's a lot of interplay between cardiovascular disease and dementia. Fewer people are smoking and more have active lifestyles," he said.

More mid-life treatment of hypertension, high cholesterol and obesity are also helping to reduce dementias, he added.

But that hasn't reduced the fear of getting the disease; baby boomers worry more about getting dementia than cancer, a national survey in the U.K. found. Campbell understands that fear.

"There's an awareness that the most important things we're able to do is think and move," he said. "As long as you can, you can have a fairly good life, in terms of relationships and activity. If you lose one of those two, thinking is probably the most important."

Campbell said it's hard to compare one illness to another, but with cancer "you don't lose the ability to self-determine."

"We don't like other people to be making decisions for us. In dementia, that happens. Other people are making the decisions. That's why it's important for people in the early stage to make decisions (and let others know)," he said.

Doctor-assisted death is not an option for people with dementia. No jurisdiction in North America allows patients to consent to life-ending treatment in advance.

The federal government has said it would review Bill C-14, the medically assisted dying legislation, to examine issues surrounding requests for medically assisted death made by mature minors, patients for whom mental illness is the only medical condition and advance requests. It's expected to file a report in December 2018.

Dying with Dignity Canada is calling on Ottawa to allow advance requests. Having the right to consent — while still sound of mind — to life-ending treatment later will help ensure patients with progressive or terminal illnesses won't have to choose between taking their own lives while they're still able and enduring months or years of unwanted suffering and indignity, the advocacy group says.

DEMENTIA LOST ON MOST CANADIANS

CANADIANS aren't prepared to cope with a dramatic increase in the number of baby boomers with dementia in the coming years, says a leading dementia doctor in Manitoba, where the increase is expected to exceed the national average.

"There's a lot of formal care that they require, whether it's home care, families taking time off work to assist them, hospital admissions or institutional care," said geriatric psychiatrist Barry Campbell.

And more needs to be done to prepare the rest of society — the service industry, public services, community groups and neighbours, he said.

"There certainly isn't any leadership being taken by civic, provincial or federal governments," he said.

Campbell said he is encouraged by the Alzheimer Society's Dementia Friendly Communities project, which provides public education on methods to include people with dementia so they can remain part of the community.

"The idea behind it is to have people in all stations of life aware of some of the difficulties, so they can ease the load these people are having to deal with," said Campbell, who offered a few examples, including store cashiers, bus drivers, police officers and librarians.

"Give them some education to recognize when people may be struggling with some cognitive impairment and how to react in an appropriate way," he said.

The Dementia Friendly Communities initiative aims to help the public be aware of the rising number of people in their midst with cognitive impairment.

"The community needs to be prepared," said

Alzheimer Society of Manitoba education manager Jennifer Vincente-Licardo. She meets with community groups and visits workplaces to deliver a primer on dementia, helping people understand what someone with dementia is experiencing and educating them on how to help and include them in the places they work, live and play.

One exercise she gets groups to do is to look in a mirror to trace a star shape. The mental gymnastics required hint at what it's like for people with dementia to perform certain tasks. "It's a very difficult task to finish the star," she said.

The outreach program offers tips, which stress empathy, on how to approach someone who appears confused or lost.

"Introduce yourself and say, 'I noticed that you seem to be lost. Can I help you get back home?' Say you're concerned about them." If they're lost, not appropriately dressed and don't know where home is, then call 911, she said.

People living with dementia and Alzheimer's can get lost in familiar places, she said. Making signs for entrances, exits and washrooms easier to see and understand helps and so does slowing down a fast-paced communication style.

A street patrol and a church are two of the local groups making an effort to be more dementia friendly.

The 204 Neighbourhood Watch started by Winnipeg's Filipino community performs weekly street patrols and wants to be proactive, said organizer Leila Castro. While the group has not dealt with any specifically related incidents yet, members want to make sure they know how to help when they do.

"Jennifer helped us gain awareness about dementia and in how to help people with the condition," Castro said, adding she wants the the Filipino community to have a deeper understanding of dementia and to know what help is available when family members begin to show symptoms.

Crescent Fort Rouge United Church invited the Alzheimer Society of Manitoba to conduct a "dementia audit" there and offer Dementia Friendly Communities training sessions, said Rev. Irene Greenwood.

The dementia audit looks at things such as signage to make sure it's clean and easily understood, Greenwood said. "We're hoping to find out ways in which we may be able to make it a dementia friendly building," she said.

"Like many churches, our numbers are dwindling and smaller than we used to be. On a Sunday morning, there might be 100 people, and half are probably seniors."

The church that made headlines a decade ago for providing sanctuary to a large family of refugee claimants facing deportation has shifted its focus to ministering to and with seniors.

"It's where we most want to concentrate our energies — involving seniors in meaningful activities and ministries," she said.

Some activities include connecting with kids at the daycare inside the church, she said. Their pastoral care committee also reaches out to members in care facilities and their homes.

"A few of our people do have dementia and we're trying to help people feel a little more comfortable visiting our people who have dementia."