

'Nobody deserves this'

St. Albert residents appalled by treatment of loved ones in long-term care

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St. Albertans are calling for improvements to Alberta's long-term care system in the face of what they describe as sub-par treatment of their loved ones living in care homes.

The family members described issues with facility capacity, insufficient care, and disregard for their loved ones' specific care needs during their time in long-term facilities. These insufficiencies affect their loved ones' dignity and quality of life, they said.

"It's not that the staff don't work hard enough, there's just not enough of them and there are too many helpless patients like Duncan," said Phyllis Robertson, who has cared for her husband Duncan, a brain hemorrhage and stroke survivor, for the past six years.

Last March, Robertson said she saw the symptoms of a re-hemorrhage with Duncan. With her husband now requiring long-term care, Robertson pushed to have Duncan placed in St. Albert — where she lives — instead of Edmonton, so she could more easily visit him.

In July, Robertson heard a spot had opened at Youville Home.

Since moving Duncan there, Robertson said she has noticed several gaps in his care.

Duncan has been left with food on his face and shirt for three hours after mealtime, she said. Once, Robertson said she walked in on a sweltering summer day and found Duncan slouched over in his chair, still wearing a jacket: no one had removed the extra layer to ensure he didn't overheat.

Robertson said she asked staff why they hadn't attended to her husband in these situations, and they said they were afraid to approach him because they said he was aggressive.

"What comes first, the chicken or the egg?" Robertson asked. "Is he aggressive because of his discomfort?"

She said she begged one of the nurses to spare a minute and check up on Duncan, and was told they would have to wait for his medication to kick in so he would be less aggressive.

"You can't just leave him like that," Robertson said. "I could approach him — I just talk softly to calm him down, they don't know how to do that ... I just feel like he has been put in this box of torment."

Perhaps the most difficult aspect of Duncan's care Robertson said she has witnessed is due to the limitations of the building — though Duncan has a private room and bathroom, the bathroom isn't big enough for his wheelchair, meaning he must be toileted in his bedroom.

"The first time I saw that, I cried," Robertson said. "This is a man who lived his life with such grace. There's no dignity to his care."

The Gazette reached out to the Youville Home for a response to these concerns.

In an emailed statement, Karen Diaper — communications manager for the company that runs Youville Home, Covenant Health — said they "strive to ensure residents and family feel welcomed, safe, and supported."

"We offer a resident-centred approach to care where we encourage involvement in the care we provide," Diaper said in the statement.

"We always seek to offer opportunities for feedback and offer a robust concerns process where we work closely with our residents and their families to address any concerns they may have."



Long-term care issues in Alberta

While the COVID-19 pandemic shone a light on the dire insufficiencies of the long-term care system both in Alberta and throughout Canada, experts and advocates *The Gazette* interviewed said two years later, issues with care are being exacerbated rather than addressed.

"Every expert on seniors care that I know can agree that residents need a minimum standard of around four hours of direct care per day," Rebecca Graff-McRae, a researcher who has studied long-term care in Alberta, said. "It's an objective measure if you want a good quality of life."

In May 2021, the University of Alberta's Parkland Institute released a study called "Time to Care: Staffing and Workloads in Alberta's Long-term Care Facilities." The study, led by Graff-McRae, found many seniors continuing care homes were understaffed and unable to meet the basic care needs of their residents.

The research surveyed more than 350 long-term care staff across Alberta in early 2020 and found 43 per cent of respondents chronically didn't have enough time to complete their required care tasks.

Only 24 per cent of respondents said they did not have essential tasks remaining at the end of their shift.

Graff-McRae said the need for a minimum standard of care hours has been known "for a decade and a half" but remains unaddressed.

According to Graff-McRae's report, Alberta is one of two provinces with legislated minimum staffing guidelines. These guidelines mandate that 1.9 hours of direct care are required per resident per day.

This requirement is still only half of the minimum threshold of adequate care, and as the report notes, there is "no systematic monitoring of whether this level of care is actually delivered."

The importance of minimum care hours was echoed in a 2021 provincial

report called "Improving quality of life for residents in facility-based continuing care," but Graff-McRae said there is still a lack of movement toward upping care hours in Alberta long-term care facilities.

She said this is because meeting those minimum care standards involves increasing staff, which would entail making positions full-time and well-paid, and giving employees benefits.

"That starts to upset the apple cart in terms of the influence that private corporations have," she said. "It goes against the grain of ... treating long-term care more like a market in which people pick and ... pay for the level of service that they want."

Currently, if family members want the care their loved ones receive to improve, Graff-McRae noted the options either include the expensive measure of hiring a personal care worker or providing the care oneself — a difficult task if the caregiver is working or also has care needs.

According to a March 2021 report by the Canadian Institute for Health Information, 46 per cent of long-term care homes in Alberta are publicly owned, 27 per cent are owned by private for-profit organizations, and 27 per cent are owned by private not-for-profit organizations (including Youville Home).

"We know that right now, everybody's suffering from staff shortages in a really severe way," Graff-McRae said, but noted her survey showed a clear distinction between the different types of care homes.

Graff-McRae said the study showed private facility workers in general had less satisfaction with their working conditions and less confidence they were able to provide the quality of care that they felt residents needed.

Not-for-profit staff had more positive responses, with public facility workers have the most confidence in the quality of care over all.

The rise of privatization

Pat Armstrong, a professor of sociology at York University and an expert in long-term care, said drastic decreases in the

number of hospital beds over the past 20 years and funding cuts have moved more care out of hospitals, and into home care and long-term care.

"Most people are living longer with complex care needs, but we're not looking after them in hospitals," Armstrong said.

Though the Canada Health Act explicitly addresses hospital care and doctor care, it excludes extended care such as long-term care. Armstrong said over the last two decades, what counts as hospital care has been "more and more narrowly defined" as forms of acute care, meaning conditions that can be fixed or significantly improved.

This means that in hospitals, care such as housekeeping, food and testing is free, but "once you leave the hospital door, you can be charged" for those same services, she said.

Armstrong explained that in each province there is some form of extended care that provides 24-hour care for complex care needs — what is in Alberta referred to as long-term care.

"The government decides who qualifies for long-term care, and it's highly regulated," she said. "They provide most of the funding, but you pay fees."

As a retired nurse, Robertson said one of the aspects she finds the most haunting about Duncan's experience in long-term care is that the line of health care coverage ends in a way she feels is arbitrary.

"How does that make sense?" Robertson asked. "If that's not health care, then health care does not exist."

Graff-McRae said forms of care outside of hospital and doctor care becoming increasingly more privatized represents a contradiction in how care is thought through in Canada.

"There's the political and economic philosophy that suggests that public goods and public interests should be addressed through public services, and then there's the philosophy that says we'll do the minimum and everything else should be subject to the market," she said.

"Somewhere in between, there has to be a question about how we address that in terms of people in our population who are vulnerable, and who don't have the same access to services or same ability to manage their own care."

The cost of long-term care

Robertson said one aspect of Duncan's care that adds to her distress is the high cost she pays for care that does not meet her standards — some \$2,300 a month.

"If he didn't have university pension I'd be out on the street," said Robertson, who said she is currently living on old age security. "I think this is the worst injustice in health care."

She said she was recently struck by something Health Minister Jason Copping said during a news conference in August when the government announced some \$11.3 million for improving palliative care.

Copping had said "treating people with dignity and respect is a foundation of our health system, and it applies particularly at the end of life, when patients are at their most vulnerable."

Robertson said these were "beautiful words."

"It gave me hope for a moment, until I realized that there are things you could do right now," Robertson said. "How does government after government get away with putting people away, warehousing them in these horrible places?"

Copping did not respond to requests for an interview or for comment on Robertson's concerns. Instead, the assistant director of communications for Alberta Health, Charity Wallace, forwarded a statement.

The statement detailed recent investments the government has made in extended care, such as some \$81 million in home care funding that will pay for one million additional hours of care in 2022-23.

Examples of other investments listed in the statement included \$13 million for the health care aide bursary program "to entice more people to pursue employment in the continuing care sector," and grant-funded projects totalling almost \$8.7 million in 2020 and 2021 with a focus on hospice, grief and bereavement, and advance care planning.

Also mentioned in the statement was new legislation, referred to as the Continuing Care Act, which Wallace said "will support the policy changes required to transform the system."

The act, which the province introduced in March, will replace multiple acts with a single piece of legislation for continuing care.

When the act was announced, Copping said by streamlining legislation, the government aims to provide consistency in the continuing care system by enabling improvements to service delivery, increasing clarity about services, and supporting accountability.

However, advocates for improving long-term care conditions have raised concerns about the act and whether it will accomplish these goals.

"We're very concerned that we're going to see a weakening of the regulations of what is required at different types of facilities," Chris Gallaway, executive director of Friends of Medicare — a non-profit working to protect and strengthen public health care in Alberta — said.

He noted while the government has announced the act, it has not yet come forward with the regulations it will uphold.

Wallace said work to develop regulations and standards of the Continuing Care Act is ongoing and will continue over the remainder of this year and through winter 2023.

Gallaway noted the province recently authorized a 5.5 per cent inflationary increase to the cost of supportive living and long-term care accommodation in 2022, and announced the increase will



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LAURIE
St. Albert resident

be subsidized at 2.3 per cent until June 2023.

"As soon as that ends, people will be back to having the higher fees," Gallaway said. "Seniors are really seen as a commodity in a lot of our policy decisions, rather than the care being the priority."

He said he has come across many who have had similar experiences to Robertson after their loved ones enter the long-term care system.

"We hear these stories all the time, unfortunately," Gallaway said. "There's some deep structural issues that we think need to be really looked at here ... it's minimum care standards, minimum hours of care, minimum staffing ratios, all those things we're lacking here in Alberta."

'What have we done?'

Another St. Albert resident, Laurie, has a mother who recently moved into a local long-term care home. Laurie's name has been changed as she asked to have her identity protected out of concern that speaking out about issues with her mom's care would lead to retaliation.

While Laurie didn't want to make public the requirements of her mother's condition out of concerns about her being identified, she said these needs, such as proper clothing to protect her mom, have been ignored several times after her mom went into a long-term care home.

Laurie said she and her sister had been assured before moving into the long-term care facility that the health-care aides would be equipped with knowledge of how to care for their

mom's condition.

However, on the first day their mom moved into the home, Laurie said it became clear her mom's condition was not being properly cared for and was at risk of worsening.

"We just thought 'what have we done?'" Laurie said of moving her mom to the facility.

Since that time, Laurie said she has had to have several "come-to-Jesus meetings" with management at the home to negotiate standards for her mom's care, including being provided with consistent updates about her mother's condition to demonstrate staff are monitoring it.

On top of key issues with her mom's health being a struggle to accommodate within the home, Laurie said smaller issues have also piled up, further decreasing her mom's quality of life.

Examples she gave were her mom's hearing aids not being put in or being put in uncharged, her glasses not being put on, her hair not being combed, and her teeth not being brushed.

"All these things add up and it slowly whittles away at their dignity and self-worth," she said. "This is their last stop — this should be their best stop, not their worst stop."

Laurie added activities in the home have been sparse, with not much to bring residents together as a group and promote socialization. She said this lack of interaction is made worse by the little time health-care aids spend with each resident.

"There's no conversation or interaction," Laurie said. "They just do the job and leave."

She said she and her sister have spent

sleepless nights worrying about their mom.

"You can never turn your phone off because you're always worried something will happen," Laurie said. "There's never a release."

Seniors advocate abolished

While Laurie and her sister are near their mother and able to take turns being with her and advocating for better care, others with family members in long-term care might not have the same capabilities.

The previous NDP government created a seniors advocate position to take up the mantle of investigating issues facing seniors in Alberta and to advocate on their behalf, but under the UCP the position was abolished and merged into the portfolio of the health advocate.

"It's a very serious issue," Rick Brick, Prairies district director for the National Association of Federal Retirees, said of the position's elimination.

"We need to really try and figure out a way to instill that in government, and make sure they understand the importance of what they are choosing to do and not do in this particular case, and the effect it's having on this very sensitive group.

"They're at a time in their life when they need that support system," Brick said of seniors.

Seniors are currently the fastest-growing age cohort in the province, with their number of 665,000 set to double in the next two decades as the baby boomer generation ages.

A seniors advocate position still exists in other provincial governments in Canada — such as Newfoundland and British Columbia. Brick noted the B.C. seniors advocate recently released a report — called the "Falling Further Behind" report — highlighting the financial challenges facing seniors such as the impact of inflation on government pensions.

He argued bringing the position back in Alberta would help draw attention to issues seniors face, and guide seniors through the confusing government system.

The issue of reinstating a seniors advocate position has resurfaced following the NDP's recent convention, where party members passed a resolution that would restore the seniors advocate role.

Brick said a seniors advocate is a crucial position for addressing issues with long-term care in Alberta, especially those brought to light by COVID-19.

"One of the things that you would expect a seniors advocate to do — and indeed what they are doing in B.C. and Newfoundland — is to work with government to figure out how we correct this so that we never do this again, and really start to provide a meaningful service for those people who are in fact, so vulnerable."

Suffering in silence

Graff-McRae said issues with long-term care might be left on the back burner due to a combination of ageism and cultural distancing from the reality that one day many of us will require long-term care.

"Hopefully we all age," Graff-McRae said. "At the end of the day, your ability to live out the rest of your life in comfort and dignity — I don't see why that should be subject to politics."

Laurie said she hopes more people speak up if they or their loved ones are receiving inadequate long-term care. She acknowledged, however, that sharing can be hard.

"Caregivers are so overwhelmed, and I think sometimes embarrassed to share that they are having trouble taking care of their loved ones properly," she said. "I don't think the general public understands how exhausting it is."

"And it's not just my mom — that's the worst part of it. Some of these people don't have anyone to speak up for them and fight for them."

