Home and community care in crisis

BY CHRIS DROSTStaff

Home and community care in Ontario is facing a crisis and some organizations that support individuals requiring support in their homes, are disappointed that the Ontario government is investing more in institutional care than providing help to allow seniors to age in their own homes.On Jan. 31, the number of individuals on a waitlist in the Home and Community Care Support Services South East area, were 55 for nursing care and 503 for personal support workers. A poll conducted by Campaign Research in 2021 revealed that 90 per cent of Ontarians age 55+ want to stay in their own home and remain out of the province's retirement and long-term care system as long as possible, especially since seeing the impact of COVID-19 on these institutions.Although a high percentage of people would like to age in their own homes, the Ontario provincial government recently announced $4.9 billion in funding over four years to increase direct resident care in long-term care homes.The Ministry of Long-Term Care has further announced $270 million for LTC homes to hire more staff.Locally, MPP Daryl Kramp announced on March 18 that a new LTC residence in Madoc, the Clare McFaul Long-Term Care facility, will be privately operated and will provide 128 new beds. Lennox and Addington will expand the LTC spaces at the County General Hospital in Napanee by 128 beds. These beds are far from the homes and families for many whom will end up using them.The crisis in home and community care was brought to the attention of Bancroft This Week by Sandra Phillips, executive director at North Hastings Community Integration Association. Doug Cartan of Seniors for Social Action Ontario, made a presentation recently to the NHCIA board and staff based on a report called, Essays on Aging in Place. ?We closed the institutions [for people with developmental disabilities] but now the government is focusing on putting the elderly in institutions. We are a community and our aging population is the same as other's. When you age, you have added need for support. Then what happens? We [NHCIA] can't give the best quality of care. LTC is the only alternative. We advocate to the ministry for extra funds but it is not always available. We can't provide 24/7 care,? explains Phillips.?Some people are put in long-term care homes and their family rarely visits. There needs to be guidelines and supervision of those regulations. The money and attention should be on keeping people in their homes. The government needs to do a lot better. We need to talk to our elected officials,? says Lloyd Churchill, chair of the NHCIA board of directors.One of the other issues with the system is that it is not an integrated system, according to Phillips. Churchill agreed. ?People don't know who to call,? he says. ?We need to look at best practices of other countries instead of doing the same thing and something that people do not want,? adds Phillips.

?We need to do two things, speak up and let decision makers know what you want, and secondly, to have an integrated system in place so people know what is available," says Phillips. She agrees with what Cartan recommended, that people at the grassroots level work to influence the decisions and to speak up and say that this is not the way we want the investment to go.**A personal experience**

Fay Martin of Minden, recognized for her leadership role in social services in the region, has her own personal story to tell about decision making around caring for a loved one at home rather than choosing institutional care. She is currently working on a book about the experience. When Martin's husband developed dementia and other major health challenges, she was dedicated to caring for him in their home. ?I knew what public services were available and decided not to go that route,? says Martin. After making that conscious decision she recognized that she would have to take certain steps to make that possible.?You need help before there is any evidence you need help,? she advises. She began by building a basement suite in their home where a friend who was also a personal support worker could live and provide help as needed.The second important step for Martin was to develop her own informal cadre of supports. This included friends who she could meet with, go for lunch and get a break from the constant care. During this time Martin did arrange for her husband to attend a day program where he could benefit from both exercise and some social interaction. ?I only had him diagnosed with dementia when I knew I wanted to access resources,? she explains.?I believe that all institutions from the moment they are staffed, begin to serve their end, not the patient,? says Martin.She suggests care should be tailored to that of the person at that point in time. ?For caregivers you have to ask, do I want to do that to a loved one? I knew I could do better for him,? says Martin.?For those without the physical or financial ability to take on the caregiver role, they are roadkill. Without a strong advocate the chance of a good outcome is hard to come by,? she contends.The arrangement Martin put in place for the final period of her husband's left worked well, in her words, ?until that last two or three months. If he had been in LTC during COVID-19, that would have been horrible.?

Martin maintains that as you age you need to have someone on your side, an advocate. ?You need your kids down the line."

The hard part of parenting is to keeps kids on side through these hard decisions. You need to include the kids but it was her responsibility to make the decisions. When her husband needed home care after surgery, Martin says that a nurse came every day as long as staffing and weather allowed. ?The system is under-resourced. There were different people every day. We educated nurse after nurse on changing the bandage as we did it when the nurse did not come,? she explains.?If you can't do it well, don't do it at all,? stresses Martin.The system only works if someone responsible is there when the care is not there. Otherwise, the patient is getting sub-optimal care.

?The money did not go into home and community care when they cut back on hospitals, I think it was in the Mike Harris time. Now, $41 million is going to Haliburton LTC. Most non-profits are not well-resourced. Most being developed are ?for-profit,? she says with an obvious distaste for chain LTC homes. Martin believes that there will never be enough paid staff to do 24-hour care and that goal should be to keep people out of LTC as long as possible. ?There needs to be continuity of care and it needs to be humanized with people who know the patient as a person,? says Martin.Home and Community Care Support Services South East provides access to government-funded home and community services and to long-term care homes. Families needing home care can contact HCCSS and speak to a case manager or care coordinator to determine whether or not they or their family member are eligible. Care services are provided by service provider organizations, many who are members of the Home Care Ontario, that have certain standards of care.Exodus of home health care workers According to statements by Deborah Simon, CEO of the Home and Community Support Organization, an umbrella group representing more than 220 agencies that support individuals with nursing and personal care, day programs, rehabilitation and more, a survey by the HCSO showed the vacancy rates in 2021 for nurses and PSWs, nearly tripled.This can mean long wait lists for patients.

The exodus of health care workers in home and community care can be attributed to a number of factors. One key reason is that PSWs who work in homes and the community, earn less than their counterparts in LTC homes or hospitals.According to a report in the Toronto Star on Feb. 22, by Deborah Simon from the HCSO, registered nurses working in home and community care make 32 per cent less than those working in hospital settings.According to Fay Martin, most personal health care workers do it because they like the work, they like getting to know the patient. ?[They are leaving the profession] because the pay is [bad] and they do not treat them respectfully. They only pay for face-time with the patient and do not pay for mileage to the first case of the day and from the last one. If you want adequate staff you need to create good jobs.?When the Ford government moved ahead with Bill 124 in 2019, the wages of registered nurses, nurse practitioners and health-care professionals were suppressed, limiting wage increases to a maximum of one per cent total compensation for three years. This is believed to be a contributing factor in current vacancy rates in the health care profession.

Lack of oversight In June 2020 Ford's government passed Bill 175, Connecting People to Home and Community Care Act 2020.Concerns raised by the Ontario Health Coalition were that it gutted the existing home and community care legislation, dismantled public oversight and parcelled out public home care functions to private providers.

Prior to the last provincial election, the Liberal government under Kathleen Wynn, had promised to invest $650 in home care over the next three years. When the government was defeated, Ford's government made cuts to both LTC and elder care in 2019/20, spending $466 million less than promised for health care, including public health and LTC, according to the Financial Accountability Office. Everyone is familiar with what happened in the LTC homes when COVID-19 hit.The alternative approach, the one suggested by Seniors for Social Action Ontario, is to create a new comprehensive community-based home and health care support system so people can age in place as their choice, one where there is enforcement of effective regulations and standards of care and support.**Learning from the experience of others**

Other countries such as Denmark, have been very successful in creating home and community care for seniors rather than focusing on institutionalized care. They use a person-centered approach and a mix of new technologies to help families look after their loved ones. Some of those technologies include digital support for family care givers, use of pill robots to ensure accurate and timely medication, musical pillows, a blanket that hugs patients to improve as sense of well-being, emergency call devices, sensor technology and mobility monitors that keep patients active.A focus on improving the physical working environment for health care workers by providing innovative technologies is freeing up more time for personal and primary care. These include such things as modern and flexible bathroom solutions, patient turning mechanisms and more.