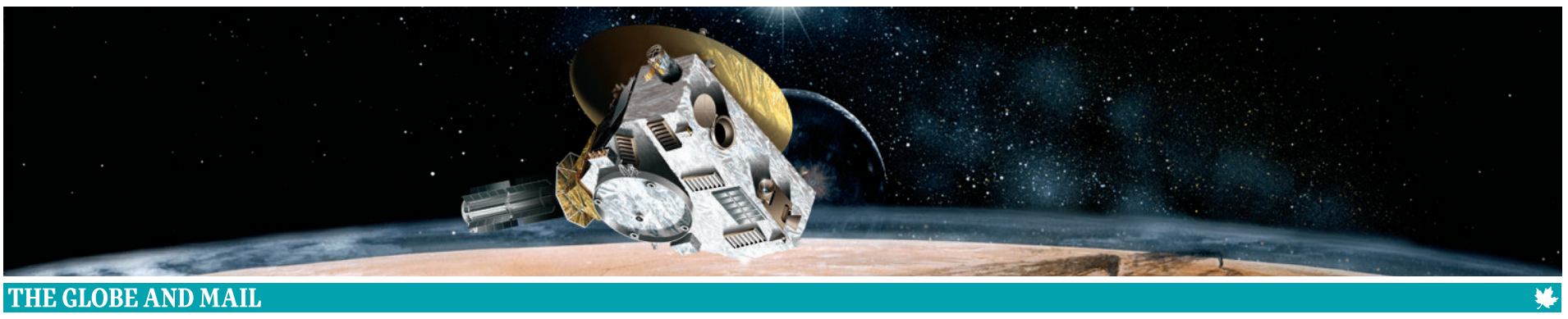
Product: **Standard** PubDate: **07-11-2015** Zone: **GTA** Edition: **1** Page: **F1 (Focus_1316586)** User: **cci** Time: **07-10-2015** **12:02** Colour:

Exploration ❯ Pluto is the last major uncharted body in our solar system. This week we'll finally get a good look **PAGE 4**



THE GLOBE AND MAIL

SATURDAY, JULY 11, 2015

SECTION F

Globe Focus

HEALTH CARE

NO PLACE LIKE HOME?

It seems simple: keep patients at home when you can. Individuals prefer it, and it costs governments less. But home care is a massively underfunded, wildly complicated system, and it is faltering in the face of skyrocketing demand.

Kelly Grant and **Elizabeth Church** investigate

Photography by **Fred Lum**

Terry Le Blanc had no idea what to expect from the home-care system when he brought his elderly mother, Doris Galloway, back to her bungalow so she could finish recovering from a dislocated shoulder and broken arm.

Ms. Galloway, now 86, was living alone in Oshawa, just east of Toronto, when she fell in December, 2013. She lay on the floor for three days before police broke down her door at the urging of Mr. Le Blanc, who lived in Vancouver at the time. The 55-year-old has since quit his hospital telecom job, given up his West Coast apartment and moved in with his mother to care for her as she sinks deeper into dementia.

"I've gone 24/7 sometimes for months in a row without having a day to myself," Mr. Le Blanc said. "I have great patience and I love my mom, but you do get fatigued.... I do absolutely everything. I do the meal-planning, the grocery-shopping, the housecleaning, the laundry, the chauffeuring, the gardening, I entertain her. It's very much like taking care of a completely dependent two-year-old."

When Ms. Galloway first returned home after her accident, the local Community Care Access Centre (CCAC) – one of 14 provincially funded agencies that oversee nursing visits and personal care in private homes across Ontario – paid for a personal support worker to visit three times a week. Two months later, the CCAC reassessed Ms. Galloway and cut her care to two one-hour visits a week.

The centre directed Mr. Le Blanc to a twice-weekly half-day program for dementia-sufferers at the Oshawa Senior Citizens Centre, for which his mother pays a discounted rate. But when Mr. Le Blanc asked for more respite care at home, a care co-ordinator could only offer a spot on a waiting list – with a warning not to hold his breath.

Mr. Le Blanc's struggle to find more help for his aging mother is not uncommon. In a three-month investigation, The Globe and Mail talked to dozens of previous and current patients as well as front-line staff, community groups, unions, for-profit and non-profit home-care providers and industry organizations, and found that the home-care system in Canada's largest province is facing unprecedented challenges. It is plagued by inconsistent standards of care, byzantine processes and a troubling lack of transparency for both patients and family caregivers.

More aggressively than any other province, Ontario is shifting health care out of hospitals and long-term care facilities, and into people's homes. It now has the fewest hospital beds per capita of any province in Canada – if Ontario were a country, only Chile and Mexico would rank lower in beds per capita among the 34 nations of the Organization for Economic Co-operation and Development.

In a cascade effect, the resulting spike in demand for home care is leading some cash-strapped community-care centres to change assessment standards, reduce services and cut clients off. In some cases, the CCACs are pressuring reluctant patients and their family caregivers to dress wounds, change intravenous medicine bags and perform other medical tasks in a bid to cut back on expensive in-home nursing visits. Meanwhile, more than 4,500 people across the province are languishing on waiting lists for publicly funded personal-support services in their homes – some of them high-needs patients.

The result is a perverse "postal code lottery" in which Ontario patients win or lose for no reason other than their addresses and how generously their local agencies are funded – funding rates are different for agencies across the province – according to Samir Sinha, director of geriatrics at two of Toronto's largest hospital networks. He was also a member of an expert panel that earlier this year excoriated the province for its approach to caring for people in their homes.

The haphazard system has left patients and their overburdened caregivers struggling to understand why they cannot get the care they need at home, especially when Premier Kathleen Wynne and Health Minister Eric Hoskins, himself a doctor, repeatedly trumpet their efforts to anchor Ontario's health-care system in homes and communities, not institutions.

Home care, Page 5

Phil Lillies tucks his wife Anne Laven into bed. In 1995, when she was 35 years old, Ms. Laven was diagnosed with multiple sclerosis. This spring Ms. Laven saw her home care hours cut back by the community agency managing her case. 'You will be getting the hours you require,' she says they told her. 'Others will not be as fortunate, so don't complain too much.'

INTO THE HOME
The cost of moving health care out of hospitals

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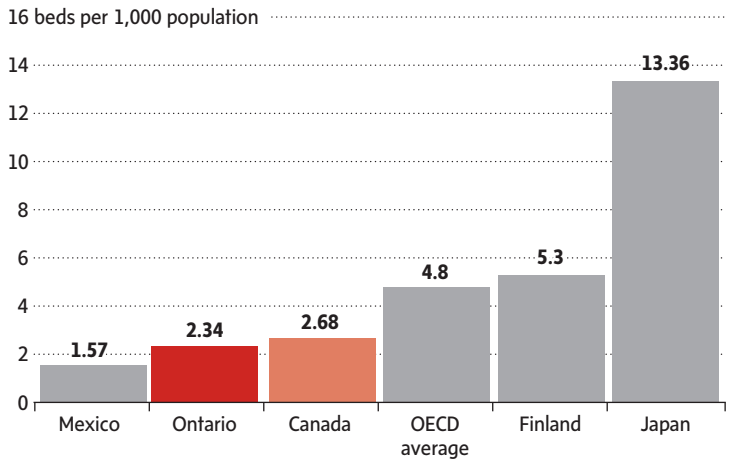
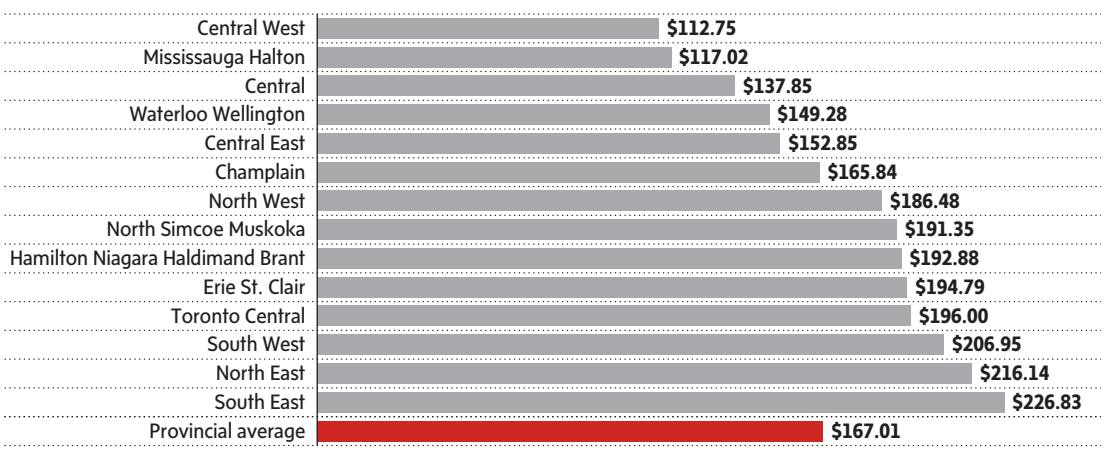
INTO THE HOME

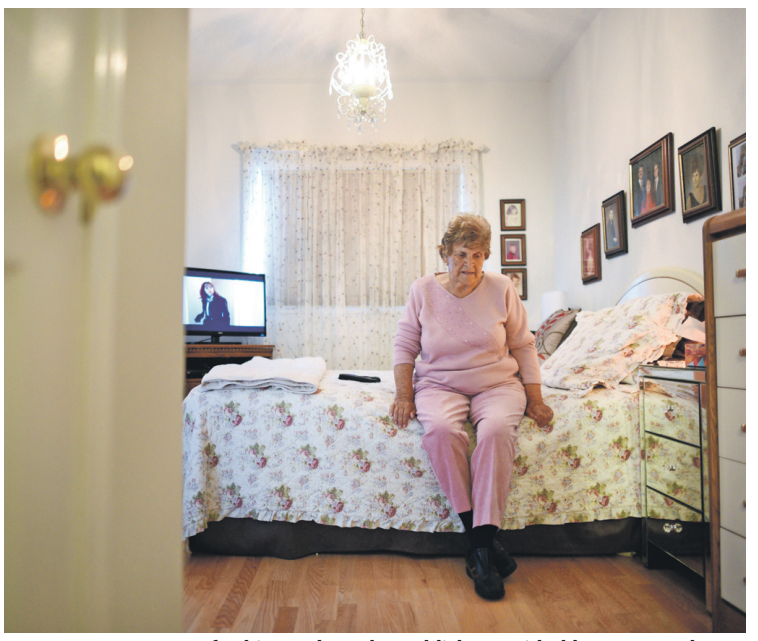
Number of hospital beds per capita in select OECD regions (2012)



Ontario Community Care Access Centre base funding, per area, per capita, 2013-2014



THE GLOBE AND MAIL) SOURCES: OECD HEALTH STATISTICS 2015; CANADIAN INSTITUTE FOR HEALTH INFORMATION; ONTARIO ASSOCIATION OF COMMUNITY CARE ACCESS CENTRES



Terry Le Blanc with his mother, Doris Galloway, in Oshawa, Ont. Mr. Le Blanc had to quit his job and move back from the West Coast to care for his mother; the publicly provided home care she receives covers only a small fraction of her needs.

FROM PAGE 1

Home care: a fraying patchwork

Dr. Hoskins, responding to the expert panel's findings, has vowed to repair the system. The rest of Canada will be watching closely, as other provinces grapple with similar dilemmas. Their populations are aging, their informal caregivers are burned out, and their constricted health-care budgets are compelling hospitals to discharge patients quicker and sicker into the unsteady hands of home-care programs that are not explicitly considered "necessary" health services under the Canada Health Act.

In Canada, there is little agreement on what government-funded home care is, how it should operate, what services it should provide and, most importantly, who should pay for them.

Pharmacare is often cited as the most egregious exclusion from Canada's universal health-care system. But when it comes to prescription drugs, Canadians can at least discover with relative ease what their provincial governments will pay for, and seek private insurance to cover what they won't. Home care, on the other hand, is often a black hole of information, one many Canadians do not stumble into until they are old or ill or both.

"I don't think I've ever met a patient who has home care who says that they couldn't use more," said Chris Simpson, president of the Canadian Medical Association. "I've had CCAC people tell me, frankly, that they're rationing care, that they don't have the resources to do what they know would be the best care for the patients."

The comforts of home

In 2011, approximately 1.5-million Canadians received publicly funded care in their homes or communities, up 55 per cent from just three years earlier.

There's no easy way to pinpoint how many more pay for home care out of their own wallets, but Statistics Canada reported through survey data that a total of 2.2-million people received publicly funded and privately paid help or care at home in 2012 because of a long-term health condition, disability or aging-related problems.

Part of the explanation for the increasing demand is the aging of Canada's population, but that's a slim chapter in a longer story. Technological advances have made it possible to safely deliver a slew of medical treatments at home, including advanced wound care, intravenous therapy, chemotherapy, a certain type of dialysis, and even mechanical ventilation for patients who cannot breathe on their own. Patients and governments have seized on these developments, the former because they feel it's more convenient and comfortable to be treated at home, the latter because it saves tax dollars.

"The average Canadian does not want to spend time and go into the hospital," said Nadine Henningsen, executive director of the Canadian Home Care Association, which represents about 200 organizations across the country, including Ontario's community care centres. "They would always prefer, if given the choice and the resources, to be able to receive their care at home."

Giving the people what they want and saving money? For politicians, the appeal of home care is undeniable.

Ontario has cut acute-care hospital beds by 44 per cent over the last quarter century, from 33,403 in 1990 to 18,588 last year. The number of complex continuing-care beds – where patients with severe, ongoing medical needs can co-pay to stay in hospital for a long time – dropped even more sharply in that period, by 53 per cent.

The steepest of the hospital-bed reductions came in the 1990s, under the New Democrats and Progressive Conservatives. The Liberals, in power since 2003, have lately squeezed hospitals in a different way, freezing their base budgets for four years in a row so hospitals have little choice but to discharge patients as swiftly as possible – especially the Alternate Level of Care (ALC) patients sometimes derided as bed-blockers. These are patients who no longer need specific types of hospital beds but have nowhere else to go, usually because they are waiting for a bed in a nursing home or a different type of facility, such as a rehabilitation centre.

The Ontario government has become consumed with mitigating the toll these patients take on the system, meticulously tracking bed-use rates and promoting a philosophy called Home First to persuade patients waiting for a spot in a nursing home to do so from their own homes. Yet the overall ALC rate has held stubbornly steady at about 14 per cent for the past four years.

"We haven't made a dent in it. We've thrown everything at it," said Paul Williams, a University of Toronto health policy professor and co-chair of the Canadian Research Network for Care in the Community. "A lot of these people are older people who either have dementia or mental-health problems. There's simply no place to put them. They've gone into the hospital, their caregiver's burned out, the capacity isn't there any longer."

What Ontario has lost in hospitals it has not replaced in long-term care, the tightly regulated and publicly subsidized spaces most people know as nursing homes. Total nursing-home beds in Ontario increased by less than 3 per cent between 2007 and 2014, to 78,051 from 75,863.

The waiting list for a permanent placement now tops 21,500. But the queue – which is managed by local access centres – is actually shorter than it was before 2010, the year the province tightened the eligibility requirements. Now it is more difficult to get a spot in the line to begin with, and only patients with the most complex medical needs are likely to snag a bed in a quality nursing home.

"You're not going to make it in these days unless something happens – you have a fall, you have a stroke, something triggers you to be really in high need. And that's the difference," said Donna Rubin, chief executive officer of the Ontario Association of Non-Profit Homes and Services for Seniors, which represents municipal and charitable long-term-care homes.

The result of this squeeze in hospital and long-term-care capacity is that more patients, with more complex and chronic medical needs, are being treated at home. Ontario's publicly funded home-care system now serves twice as many patients as it did a decade ago. It has seen an 82-per-cent increase in patients with higher medical needs since 2009, and is providing the equivalent of 25,000 nursing-home beds worth of care in private homes.

"We have a much more clinically complex home-care population than most countries and most provinces in Canada," said John Hirdes, who until recently held the Ontario Home Care Research and Knowledge Exchange Chair at the University of Waterloo.

This transformation could be fantastic news for patients and the province's coffers alike. After all, patients who manage to stay out of hospital or long-term care are much less likely to catch life-threatening infections or suffer physical and psychological declines than those who do not. Many patients prefer to stay home, if they can. And for Ontario, meanwhile, the math is compelling: A day in hospital costs on average $450; a day in long-term care costs $135; and a day in home or community care costs on average $45.

The trouble is, in Ontario at least, the home-care system is too dysfunctional and poorly funded to adequately meet the challenge.

'Don't complain'

Last year, a six-page memo landed in staff inboxes at the Ottawa area's Champlain CCAC that neatly summed up the problem threatening to overwhelm the home-care-access agency.

New clients had been pouring into Champlain. In the previous year alone, it had absorbed a 20-per-cent increase in clients. One-third of the organization's patient roster now had "high" health-care needs, the kind that until recently would have been met in a hospital or nursing home.

And so, in an effort to close a $17-million gap between demand and funding, Champlain quietly shut the door on clients who scored below an 11 on a 28-point scale used to gauge patient needs, called the Resident Assessment Instrument-Home Care (RAI-HC). CCACs use the elaborate questionnaire to help determine how many hours of care a client should receive. As of Sept. 16, 2014, Champlain began working to reassess and cut off its lower-needs clients.

"Do not direct clients to contact their MPP, LHIN [Local Health Integration Network] or media," reads the memo, obtained by The Globe. It provided a three-step response to the question: "What do I do if a client threatens to go to the media?"

Phyllis was one of the "lower needs" clients jettisoned by Champlain last October. The 80-year-old widow was a legally blind diabetic with heart problems, hearing difficulties and arthritis when Champlain deemed her no longer eligible for the one bath a week she had been receiving free of charge from a CCAC-funded personal-support worker. Less than three months later, on New Year's Day, Phyllis landed in the emergency room with a urinary tract infection and pneumonia, prompting the CCAC to re-enrol her and order twice daily home-care visits.

"This is what will trigger an increase in your home-care hours – you have to be hospitalized," said Phyllis's daughter, her primary caregiver. "In order to get care, you have to suddenly become a real liability in terms of what it costs."

Last fall, stories of patients such as Phyllis (who asked that her real name not be used because she is afraid her home-care services could be reduced or cut off again) began to surface in the local media. Champlain decided to suspend the service reductions and to be "extra sensitive" to clients, Gilles Lanteigne, the centre's former chief executive officer who retired in June, told The Globe. (Dr. Hoskins said in an interview that he ordered the pause.)

Continued on page 6

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THE GLOBE AND MAIL

CANADA'S NATIONAL NEWSPAPER • MONDAY, JULY 13, 2015 • globeandmail.com

Germany's Angela Merkel, France's François Hollande and Greece's Alexis Tsipras confer before Sunday's summit. JOHN MACDOUGALL/AFP/GETTY IMAGES

DEBT CRISIS

EU demands Greek reforms before more bailout talks

Euro zone ministers insist Syriza government immediately pass tax, bankruptcy and pension legislation

ERIC REGULY ROME

Any sense that Germany would crack the lid on the Greek pressure cooker vanished on Sunday night, when it demanded that Greece pass tough reform measures through its parliament by Wednesday if it is to avoid economic calamity and exit from the euro.

While the three-day legislation deadline is not insurmountable, it threatens to heat up the revolt inside Syriza, the ruling party led by Prime Minister Alexis Tsipras. Mr. Tsipras was elected in January on an anti-austerity platform and did a U-turn last week, alienating the far left wing of his party.

Greeks widely expect Mr. Tsipras to dump the Syriza rebels and perhaps form a new coalition government in an effort to ram through the austerity laws at lightning speed. "We all think a major cabinet reshuffle is coming, with all anti-deal ministers to be replaced," said Achilleas Kasimidis, a salesman at a technology company in Athens. "A national unity government would also be an option."

A document produced Sunday by the Eurogroup – the region's finance ministers – insists that Greece pass laws to boost its value-added tax (VAT) and reform bankruptcy laws and the notoriously expensive pension system, among other changes. If Greece agrees, its request for €53-billion ($75-billion) in European Union bailout funds, plus funds to stabilize its crippled banks, might be met.

Greece, Page 9

ENERGY STRATEGY

Premiers set to fast-track oil pipelines while cutting regulatory red tape

ADRIAN MORROW TORONTO

Canada's premiers are poised to sign an agreement to fast-track new oil sands pipelines while watering down commitments to fight climate change.

The Canadian Energy Strategy will be finalized and unveiled at a premiers' conference in St. John's beginning Wednesday. But The Globe and Mail has obtained a draft of the plan that reveals the key points and stumbling blocks.

The confidential 37-page document lays out 10 goals and dozens of action items as part of a sweeping vision for the future of oil, gas and electricity across the country.

The creation of the energy strategy has been a long and belaboured process. The brainchild of former Alberta premier Alison Redford, it was first conceived in 2012 as a way to plan future oil-sands expansion and address climate-change concerns. The premiers have been crafting it for the past three years. The provincial leaders couldn't have imagined that the agreement would come at a time of low crude prices, oil sands production cuts and economic angst in Alberta and the rest of the country.

Two sections of the plan commit the provinces and territories to help get more pipelines built, in part by cutting down on red tape to speed up regulatory decisions.

But the strategy contains little firm commitment on battling global warming. Its strongest environmental section – a pledge for all provinces and territories to adopt absolute targets for cutting greenhouse gases – is marked as a point of contention that might be scrapped.

Alberta has encountered problems in recent years expanding production of the oil sands because there is not enough transportation infrastructure for the added oil and bitumen. Various pipeline proposals – Energy East, Kinder Morgan, Northern Gateway and Keystone XL – have faced stiff opposition from environmental groups and First Nations. Some proposed pipelines have also been held up by regulators.

Pipelines, Page 8

ONTARIO

The painful cost of home care that is not delivered in homes

KELLY GRANT
ELIZABETH CHURCH

When Jennifer Sewell had a benign cyst removed from her left breast last summer, the procedure was supposed to be a straightforward day surgery.

Instead, the 40-year-old mother of two from rural Southwestern Ontario developed an infection at her incision site, a wound that took more than five months to heal.

In that time, Ms. Sewell received a crash course in the new world of Ontario home care, one in which the treatment patients need is not necessarily delivered in their homes, but rather in privately operated clinics that have brought significant savings to the province's Community Care Access Centres (CCACs), the 14 publicly funded organizations that co-ordinate nursing visits and personal care in homes across Canada's largest province.

"[Patients] were told upon discharge from hospital that they would have home care, but nobody told them that home care was not actually delivered to their home," said Natalie Mehra, the executive director of the Ontario Health Coalition, a public health-care activist organization that held consultations with home-care patients across the province before publishing a scathing report on the sector in March. "We've heard from people for whom it caused a lot of hardship, and they were never given any choice about whether or not they drove to a clinic."

INTO THE HOME
The cost of moving health care out of hospitals

Care, Page 4

SPACE

Canadian map of the stars lights the way for NASA's Pluto probe

IVAN SEMENIUK
SCIENCE REPORTER
LAUREL, MD.

The evening of July 8, 2013, was especially clear and calm on the summit of Mauna Kea when astronomers turned the Canada France Hawaii Telescope toward a star-speckled patch of sky that is about to be at the focal point of world attention.

The razor-sharp image they captured that night was in answer to a special request from the team behind New Horizons, the NASA probe that on Tuesday will become the first to reach Pluto, the most distant object ever explored by a spacecraft.

Just like any family on a holiday road trip, New Horizons is using a map to safely negotiate its way through an unfamiliar place – a map made in Canada.

"I'm ecstatic," said Stephen Gwyn, a data specialist with the Canadian Astronomy Data Centre in Victoria, part of the National Research Council, and the creator of a customized star catalogue that is helping guide New Horizons toward its historic rendezvous.

Perched on the windward side of Mauna Kea at what is considered the best observing site on Earth, the Canada France Hawaii Telescope combines a wide-field camera with the ability to make pinpoint measurements of the positions of stars.

In combination with a method of analysis developed by Dr. Gwyn, the camera is so precise that were one of its pictures blown up to one kilometre in size, the locations of the stars within the picture would be correctly represented to within a few millimetres.

Pluto, Page 2

INSIDE

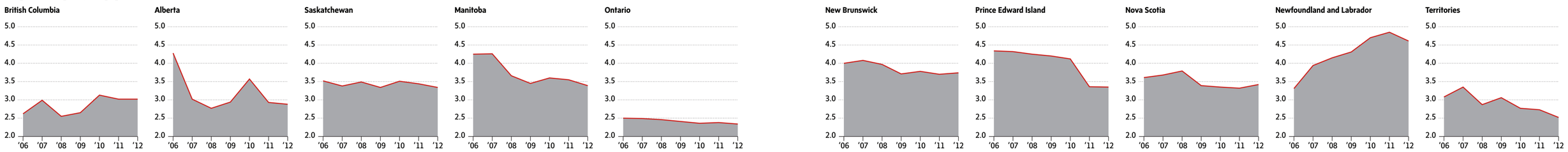
Femicide running rampant in Mexico

All along the U.S.-Mexico border, the murder of women and girls – many of indigenous descent – has hit epidemic proportions

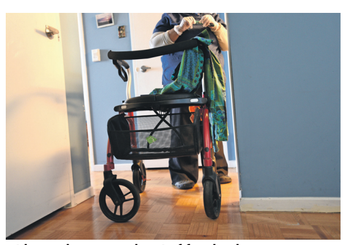
Folio, Page 6-7

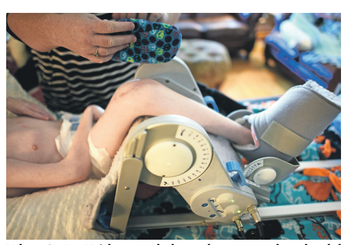
INTO THE HOME

Hospital beds per 1,000 population, 2006-2012



Ontario has the fewest hospital beds per capita of any province or territory: 2.34 beds for every 1,000 people, according to the Canadian Institute for Health Information (CIHI.) This also includes Quebec, though that province has not authorized CIHI to make its particular numbers public. THE GLOBE AND MAIL, SOURCE: CANADIAN INSTITUTE FOR HEALTH INFORMATION





A personal support worker helps Phyllis – who does not want her real name used, out of fear her home-care service will be cut – with basic daily tasks.

When Carter Keith was a baby, a daycare worker shook him so violently that he suffered permanent brain damage. He is now 11, and his family has been struggling recently to get the care they had been promised from their local agency.

Anne Laven with her husband, and using a long-handled gripper to help pick items up. "I suppose the alternative would be that I would have to go into a nursing home," she says. "I would hate that more than anything."

Continued from page 5

Mr. Lanteigne said last fall's plan was part of a larger effort to balance the agency's budget. Its intent was not to leave people out in the cold, but rather to transfer stable, lower-needs patients to local non-profit community support agencies that could take over their care.

But for most of the affected patients, those transfers never happened.

A report to the centre's February board meeting included a survey of some of the 575 clients who saw their care cut off after reassessment last fall. Of the 421 clients who responded, more than half – 62 per cent – said they were relying on the support of family and friends to replace their lost service. Another 21 per cent were paying out of pocket for private care. Just 17 per cent were receiving care from a non-profit community support agency.

Despite those findings, Champlain's efforts to balance its budget continue.

This spring, Anne Laven had a visit from a CCAC staff member to reassess her condition. The wheelchair-bound 61-year-old has multiple sclerosis that has progressed to the point that she needs help washing, dressing and getting in and out of bed.

In a follow-up call, she was told her weekly care hours with an agency-funded personal-support worker would be reduced to 15 from 21, but she would be given an additional five hours from a community support agency outside the CCAC system – a non-profit called VHA Health and Home Support that also receives provincial funding.

Ms. Laven was already getting some care from VHA workers, but the switch has meant she has had to discontinue her afternoon exercises since the new workers are not trained or insured to help her with them.

"I was told that I am lucky because I am having the service provided that I need, but merely by a different group of people and a different agency," said Ms. Laven, who lives in downtown Ottawa. "I told them I wasn't too happy giving up some care providers who I have come to value. I was told, 'You will be getting the hours you require. Others will not be as fortunate, so don't complain too much.'"

Ms. Laven's husband cares for her and looks after all the shopping and cooking, but also works full-time. "I suppose the alternative would be that I would have to go into a nursing home," she said. "I would hate that more than anything."

Depends on where you live

What is happening to home-care services in the Ottawa area is, in large part, the result of a haphazardly designed system struggling to live within its means. The same scenario is playing out in other parts of the province as well.

Ontario's 14 CCACs act as organizers-cum-gatekeepers for the home-care system. They directly employ "care co-ordinators," usually registered nurses, whose job is to assess patients to determine what kind of help they need – nursing, physiotherapy, palliative care, personal support – and decide how many hours of government-funded service they will receive.

The centres then hire organizations ranging from large, publicly traded corporations such as Extendicare Inc. to non-profits such as the Victorian Order of Nurses (VON) to treat and help patients at home. If patients or their families can afford it, they are free to buy more hours of care from the same private and non-profit providers contracted by the CCAC.

Ontario is different from all other provinces in that its CCACs contract out virtually all front-line care, a legacy of Mike Harris's Progressive Conservative government, which intended to introduce competition to the entire home-care sector. But when the PCs and their Liberal successors tested competitive bidding, home-care clients reacted furiously to the idea of leaner companies muscling out beloved non-profits like the VON. Both governments backed off, leaving the existing contracts frozen in place since 2009.

Now Ontario is saddled with the worst of both worlds: all the complexities of a system designed to manage third-party competition, and none of the advantages. For example, a recent attempt to simplify administration of the system included a $300,000 study by Accenture, financed by the province, that found a dizzying 14,000 different contract rates and 3,300 service codes were being used for home-care services across Ontario.

Meanwhile, the access centres have been dogged by controversy, primarily over lofty executive pay hikes. In the past five years, half of them have been the subject of reviews or assessments; the provincial auditor-general is expected to release the results of another probe this fall.

Adding to the complexity in Ontario is the fact that the health-care system has carved the province into 14 regions, many with vague titles such as Central, Central East and Central West, a quirk of bureaucratic history with significant consequences. Patients living in the Beaches in Toronto's east end, for instance, are part of a CCAC region whose budget is just under $200 per capita. But next door in the old city of Scarborough, now part of the Toronto megacity, patients fall under a different region with a lower budget of just over $150 per capita.

"Services are all over the map," said Dianne Leclair, a veteran home-care co-ordinator who is also a board member of the Ontario Nurses' Association (ONA), the union that represents care co-ordinators at 10 of the CCACs.

Whatever local service standards do exist, they are virtually impossible to find. The CCACs are not subject to freedom-of-information laws, and their ostensibly public boards have wildly disparate transparency standards. Some publish thorough agendas, minutes and reports online; others post minimal board information.

In an effort to determine what types of patients are eligible for home care, The Globe surveyed all the province's centres, and asked how each uses the RAI-HC assessment tool to help determine how many home-care hours clients should receive. Only four of the CCACs mentioned precise scores in their responses; the rest said the score is one tool of many that care co-ordinators take into account when deciding on hours.

But internal documents obtained by The Globe, along with public board documents and the experience of care co-ordinators, paint a different picture.

Ms. Leclair, in her union role, recently consulted her care coordinator colleagues at the 10 ONA-represented CCACs and was "shocked" by what she found. Eight of the 10 used the scale to evaluate patients, but the same scores triggered different responses from place to place. In one area, a score of 10 is high enough to qualify for personal support, while in another an individual must be assessed with a score of 17, representing a dramatic difference in a patient's condition.

Home-care patients may be provided with equipment such as walkers, but that access also depends on where they live, with some centres limiting patients to one piece of equipment, others to two and still others linking access to circumstances, with no equipment provided for planned surgeries such as knee and hip replacements. While some agencies offer up to 120 hours of personal support in the first month of service, declining to 90 in subsequent months, others limit it to 40 hours a month or 10 hours a week.

"There is no rhyme or reason," Ms. LeClair said.

A matter of money

One bit of consistency: Each CCAC has to balance its budget.

Dr. Hoskins has stressed that the province is not just shifting patients into home and community care – it is shifting money there, too.

That is true up to a point. Although the Liberals have doubled spending on home and community care since taking power 12 years ago, the CCACs are in line to receive just 5.4 per cent of total health-care spending in Ontario this year. Their share of the pie has grown by only one percentage point since 2006-2007.

Dr. Hoskins frequently touts his government's promise to increase spending on home and community care by 5 per cent a year over the next three years, but that money is earmarked for all health care delivered in the community – including mental health, addiction programs and assisted-living services in supportive housing – not just for the CCACs.

In 2014-2015, budget increases for the CCACs, including base and one-time funding hikes, ranged from an 8.4-per-cent bump in the Central CCAC, north of Toronto, to a 2.3-per-cent reduction in the sprawling North West CCAC. The average increase was 3.1 per cent, according to the Ontario Association of Community Care Access Centres.

The wide variation in home-care service levels appears to depend largely on how each centre decides to manage its limited funds. Take the Erie St.Clair CCAC. Last summer, the centre that covers Windsor, Chatham and Sarnia set about tackling a looming deficit pegged at $15-million in June, before it learned exactly how much of an annual budget increase it would receive in the late fall.

Erie St.Clair had historically been among the most generously funded centres per capita. Now it needed to bring its service levels more in line with its counterparts, and that meant developing an 11-point deficit-fighting plan that included a target of reducing nursing visits by 33 per cent per capita.

One way to reduce nursing visits is to change the bandages on a wound less frequently, using advanced absorbents and antimicrobial dressings that speed healing; another is to teach patients or their family members how to perform nursing tasks themselves.

Peggy Hoover, a retired auto worker in Windsor, said that last fall the centre pressured her to operate a computerized infusion pump and later change a traditional intravenous bag that delivered antibiotics to her husband, Tom Wherritt. A diabetic for more than three decades, Mr. Wherritt, now 64, had developed a foot sore that progressed to a bone infection.

At first, a CCAC-funded nurse came daily to help, but then Mr. Wherritt's care co-ordinator started asking his wife to take over. "She kept throwing the paperwork at me: 'This is what we do here,'" Ms. Hoover recalled. "Well, it would be different if it was just a wound I was dressing. I said, 'I'm not a nurse and I'm not going to do an IV. Period.'"

Lori Marshall, chief executive officer of the Erie St.Clair CCAC, said care co-ordinators do not force unwilling patients or their caregivers to take on nursing tasks. Indeed, Ms. Hoover pushed back and was not required to deliver care. But, in general, "we want to teach you to do some of your care yourself," Ms. Marshall said. "It's really a move toward increasing independence."

Despite Erie St. Clair's efforts, nursing visits actually rose by 8 per cent last year, just one of a slew of reasons the centre finished the year with a $2.9-million deficit. It received permission to erase the deficit over two years instead of one, to blunt the impact on patients.

Another way centres manage their budgets is by putting patients on waiting lists for in-home personal support. For example, the Central East CCAC, located immediately east of Toronto's pre-megacity boundaries, has the longest personal-support wait list in the province at 1,765 patients as of May 31. Nearly half of those patients – 830 of them – are deemed high needs, yet they're stuck in a queue.

"It's regrettable," said Don Ford, Central East's chief executive officer. "We don't like the idea that we are not able to provide all of the services for all of the people, but the reality of our health-care system is there is a requirement, to the degree that it's possible, to make sure the resources that are provided go to those who are [in] the highest need."

Six of the province's centres do not have waiting lists for in-home personal support, but they are not necessarily meeting all the demands in their regions. Some have simply opted to not wait-list the mild- and moderate-needs clients they do not have the funds to help, instead referring them to a non-profit community agency such as the March of Dimes or the local Alzheimer Society that may or may not have the capacity to step in.

The access centre that covers Hamilton and Niagara quietly closed its personal-support waiting list to new clients on May 1, and began reviewing the cases of 344 clients left in the queue, according to another internal memo obtained by The Globe. It would be "a bit of false hope" to keep adding people to the line when the agency might not have the resources to help them, a spokeswoman for the Hamilton Niagara Haldimand Brant CCAC explained.

As the agencies redirect resources to those who are most ill and vulnerable, lower-needs patients lose out until they, too, fall into crisis. The system is abandoning what Dr. Sinha calls "preventative" home care. "That is actually the home care that we've actually seen is at greatest risk right now," the geriatrician said.

Dr. Williams of the U of T agreed, saying Ontario needs to invest much more heavily in day programs, assisted-living spaces and respite care if it hopes to keep the elderly, especially those with dementia, out of institutional care. As it stands, he sympathizes with the CCAC executives and care co-ordinators stuck delivering bad news to patients. "Sometimes [the CCACs] get pointed to as being the villains in this," Dr. Williams said. "They're not. Everybody is struggling like crazy."

But nobody is struggling more than Ontario's – and Canada's – unpaid caregivers, especially those who belatedly discover they cannot get the government-funded care they need.

The burden of care

For the past 11 years, Christine Keith's life has revolved around caring for her disabled son Carter, who suffered a severe brain injury when he was shaken by a daycare worker as an infant. He spends much of his time in a hospital bed that has pride of place in the family's living room.

Ms. Keith, who quit her job to care for Carter alongside the CCAC-funded nurses who help out 53 hours per week, teared up as she described raising her disabled son while also supporting his two teenaged siblings. "What I can't stress enough," she said, "is we are a family who was willing to do the work."

In mid-May, Carter was recovering from surgery at Toronto's Hospital for Sick Children, where doctors operated on both his hips and knees to restore enough movement to allow him to sit in a wheelchair. The family was given a choice: Check Carter into Toronto's Holland Bloorview Kids Rehabilitation Hospital for five or six weeks, or take him home to Welland to recover with the help of physiotherapy and occupational therapy, all coordinated and paid for through the local CCAC.

Given their need to maintain a home for their other children, they decided to bring Carter home. But knowing what she knows now, Ms. Keith says, she would have admitted Carter to the rehab hospital – she quickly discovered there was a cost to choosing home care.

Transporting Carter home would cost $700, the family was told, a bill they averted by finding a friend with a suitable vehicle. They initially had to pay $25 a day to rent a machine to exercise Carter's knees; the CCAC agreed this month to cover those costs. Physiotherapy did not start until June – and only after Ms. Keith repeatedly called her local access centre and MPP.

"I walked into this knowing it was going to be a lot of work," she said. "I thought that we would have support. We didn't."

Dilys Haughton, director of client services operations for their local centre, says families face difficult decisions about where the best care can be provided for members with complex needs. "We clearly can't duplicate the level of care that would be provided in a very specialized rehabilitation program," she said. "It may take some time to figure that care plan out and mobilize the necessary resources, but we are committed to doing that."

Whether they are caring for medically compromised children or aging parents, Canada's unpaid caregivers are struggling. One 2012 national study of seniors receiving home care, for instance, found service levels generally fell short as patients got sicker, in part because of caps on service levels and limited resources. As patients' needs increased, so too did the distress level of their caregivers.

In one sense, caregivers are penalized for their dedication. Patients who are not fortunate enough to have live-in family members generally receive more government-funded care at home.

Dr. Hoskins, the Ontario health minister, said lifting part of the load from the shoulders of family caregivers is a key part of the 10-point plan to fix home care that he unveiled in May. He pledged to fund an extra 80,000 hours of at-home nursing care in Ontario this year, and to set predictable "levels of service" across the province so home-care patients know what to expect, whether they live in Sarnia or Sault Ste. Marie.

And he is not prepared to tell mild-needs home-care patients – especially the elderly – that a system flooded with chronically ill and medically complex patients no longer has the money to help them.

"If they're assessed as requiring two baths a week, for example, I want and expect them to get two baths a week," Dr. Hoskins said. "I profoundly believe that individuals should receive the care that they require … particularly when we're talking about people in their homes. That's where we want them to be."

Home is certainly where Ms. Galloway, the 86-year-old dementia patient whose son relocated from Vancouver, wants to stay. For now, she can. Although her short-term memory is weakening – she repeats questions to her son 30 seconds apart – she still speaks and functions well, breaking into mischievous grins as she shows off the hand-made wall art and knick-knacks that decorate her neatly appointed Oshawa bungalow.

But her son, Mr. Le Blanc, wonders how long he can keep caring for his mother without more help from the home-care system.

For its part, the Central East CCAC said Ms. Galloway is on a waiting list for four extra hours of personal support per week, after a reassessment last October found her health had deteriorated and her son was experiencing caregiver stress.

Although the centre was able to move patients off the personal-support waiting list and into care as recently as the spring of 2014, the queue is now frozen. "We had to reinstate the wait list in June 2014 due to budget constraints," a spokeswoman said by e-mail. "The Central East CCAC has not been able to remove anyone off the wait list since then."

Meantime, Ms. Galloway is also on a different waiting list – for two nursing homes.

"I feel like I'm between a rock and a hard place, because they said [the wait] was at least five-and-a-half years for the ones we've chosen. And, of course, she doesn't want to go," Mr. Le Blanc said. "If you need a nursing home, you have to bring them to emergency, tell them it's a crisis and leave. I'd never do that. It's like putting out the trash."

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HOME VISITS

Oshawa woman to receive more care

Following a Globe and Mail article, agency grants dementia patient an extra two hours of care a week

KELLY GRANT
ELIZABETH CHURCH

It is only two extra hours of help, but Terry Le Blanc is hoping that will be enough to keep his elderly mother out of a nursing home and to prevent him from succumbing to exhaustion as her sole live-in caregiver.

Beginning this week, the provincially funded agency that coordinates home care in Oshawa, Ont., will provide two more hours of personal support per week – including a bath – for Mr. Le Blanc's mother, Doris Galloway, an 86-year-old dementia patient who has been on a waiting list for more care at home since last fall.

"It's peace of mind that she's getting the hygiene care that's required," Mr. Le Blanc said. "I tell you the truth, I'm absolutely relieved."

Mr. Le Blanc, 55, found out about the enhanced personal support hours for his mother on Friday afternoon, just hours after The Globe and Mail published an investigation of Ontario's home-care system that featured Ms. Galloway as one of more than 4,500 people in the province on a home-care waiting list.

The Globe's investigation found that home care in Canada's largest province is plagued by underfunding, inconsistent standards of care and a lack of transparency that makes it virtually impossible for patients and their family members to determine what government-funded health care they are entitled to in their houses or in community settings such as assisted-living centres.

France Gélinas, the health critic for the Ontario NDP, said every member of the provincial parliament has heard stories like that of Mr. Le Blanc and his mother, but she predicts the general public will be "shocked and disgusted" to learn what home-care patients and their caregivers have been enduring.

"I have grown men crying their eyes out in my office, saying, "I love my mom, I can't cope, help me," she said. "Most people think of it as part of medicare. They think, if I need care, it will be there, and then it's not."

Until Friday, the last time the Central East Community Care Access Centre, the regional home-care co-ordination centre that covers Oshawa, had assessed Ms. Galloway's condition was in October of 2014.

Her care co-ordinator told Mr. Le Blanc at the time that his mother's health had deteriorated enough for her to qualify for four extra hours of at-home care per week, over and above the two, one-hour visits she was already receiving to help with bathing every Monday and Friday. But budget constraints meant the agency had not moved anyone off the waiting list and into care since June of 2014, a spokeswoman told The Globe this month.

Patients such as Ms. Galloway are supposed to be reassessed every six months. "It's been about nine months. I don't know why they were late," Mr. Le Blanc said. "I think the only reason we got this assessment was because [The Globe] asked questions."

A spokeswoman for the Central East CCAC confirmed by e-mail Sunday that Ms. Galloway was due for a reassessment visit in her home on April 30. "Unfortunately, due to a variety of unforeseen circumstances such as high admissions, crisis situations [and] demand for urgent home visits in the community … her reassessment was delayed."

When a care co-ordinator visited Ms. Galloway and her son on Friday, she found that Ms. Galloway's health had worsened slightly. Asked what year it was and what year she was born, Ms. Galloway answered both questions incorrectly, her son said. She had also begun to experience minor incontinence. Mr. Le Blanc, meanwhile, was suffering from caregiver stress after having given up his job and home in Vancouver to attend to his mother around the clock.

That led the home-care agency to grant Ms. Galloway an extra two hours of care, the spokeswoman said.

Gail Donner, a former dean of nursing at the University of Toronto and the chair of an expert panel that reported on Ontario's home-care system earlier this year, said that making public some basic standards of care would be a good place to begin fixing the system.

"We need to start with being clear with people about what we do. What will we provide? Under what circumstances? There's no such thing as eliminating all variability, because not every client is the same," she said. "[But] Transparency yields trust."

FROM PAGE 1

Care: Clinic nurses can see more patients in a day because they do not have to travel

The CCAC nursing clinic in Chatham that Ms. Sewell attended for daily wound cleaning is one of at least 111 that have sprung up across Ontario, most in the last decade as the Liberal government has shifted as much medical care as possible out of expensive hospitals and into private homes and community settings.

In a three-month investigation, The Globe and Mail talked to dozens of previous and current patients as well as front-line staff, community groups, unions, for-profit and non-profit home-care providers and industry organizations, and found that the home-care system in Canada's largest province is plagued by inconsistent standards of care, byzantine processes and a troubling lack of transparency for both patients and family caregivers.

CCAC executives say the nursing clinics – whose operations they contract out to for-profit and non-profit companies such as Bayshore Home Health and Saint Elizabeth – are an ingenious solution to one of the main problems spurred by the rise of at-home medical care.

Although generally cheaper than keeping patients in hospitals, sending nurses to farflung homes can be pricey, too. Inviting patients who are well enough to drive to a centrally located clinic for wound dressing, intravenous infusions, diabetic foot care, dialysis, catheter care and other medical treatments has allowed the home-care system to reinvest millions of dollars into care for the sickest bed-bound patients, according to the CCACs.

But critics of Ontario's nursing clinic model warn that other patients who might be better cared for in their homes – for example, those who are too ill to travel or do not have relatives to chauffeur them to the clinic – are being pressured to use the clinics by the CCACs, primarily as a way for the publicly funded centres to meet their budgetary targets.

Executives at some of the province's 14 CCACs say they only send willing and capable clients to the clinics. There is no arm-twisting required because the clinic setting is extremely popular with patients, according to Stacey Daub, the chief executive officer of the Toronto Central CCAC, which oversees four nursing clinics in Canada's largest city.

"We get glowing reviews," she said. "Our highest client experience and satisfaction ratings are at our clinics. I think mostly because for many people it's not great to sit at home waiting for a nurse to come to your house. … It's like waiting for Rogers."

What is not in dispute is the significant amount of money the clinics save Ontario's cash-strapped public home-care system. Some CCACs estimate it costs half as much to treat a patient at a clinic as it would at home. Clinic nurses can see many more patients in a day because they do not have to drive from house to house.

In the Central CCAC, which covers the suburban cities north of Toronto, seven nursing clinics delivered $9.6-million in savings in the last fiscal year when compared with what it would have cost to tend to those patients in their homes.

The Hamilton Niagara Haldimand Brant CCAC estimated its 11 nursing clinics saved $3.4-million last year; the South West CCAC, which includes London, figures it saved $1-million last year thanks to its 33 nursing clinics.

The Champlain CCAC, which covers the Ottawa region, has put a huge emphasis on expanding its clinic network recently as it struggles to avoid a deficit. It opened seven new clinics in 2014-2015 alone and another in May of this year, bringing the region's total to 20.

"We have about a zillion initiatives to save money and we have succeeded very well [with the clinics,]" said Gilles Lanteigne, the former chief executive officer of the Champlain CCAC who retired in June.

About 18 per cent of nursing visits in the Champlain region used to be done at the clinics; now that figure is 25 to 26 per cent, Mr. Lanteigne added. "Every 1 per cent that goes [to the clinics], it's $200,000 that we save," he said. "So it is big, big, big."

Achieving those big savings, however, can lead to frenetic days for clinic employees like Victoria Ralph, a registered practical nurse who has worked for the past three-and-a-half years at a CCAC clinic in St. Catharines, near Niagara Falls, operated by the for-profit company CarePartners. Since early April, she and roughly 130 of her CarePartners colleagues have been on strike seeking a first contract.

Jennifer Sewell says her clinic experience was so negative she turned to the nurse at her doctor's office for her wound care. FRED LUM/THE GLOBE AND MAIL

> **Our highest client experience and satisfaction ratings are at our clinics. I think mostly because for many people it's not great to sit at home waiting for a nurse to come to your house. … It's like waiting for Rogers.**
>
> **Stacey Daub**
> *CEO, Toronto Central CCAC*

Ms. Ralph, who worked in traditional home care before switching to the clinic, says she loves her job and her clients, but finds it hard at times to see the three patients an hour expected of her, given the complexity of some of the cases.

During a typical 12-hour shift she sees more than 30 patients, she says, and more are booked on the assumption that some will not turn up for their appointment.

"It becomes an assembly line," Ms. Ralph said. (CarePartners declined an interview request, citing the ongoing labour dispute.)

Despite the speed with which they can be asked to dress wounds, clinic nurses can make all the difference to patients like Sharon Mueller – even if travelling to the clinic is fatiguing. The retired high-school teacher, now 73, developed an infection on her lower right abdomen after having a tumour removed from her ovary last fall.

In the beginning, a nurse came to Ms. Mueller's home in LaSalle, near Windsor, to change the dressing on her wound, but the local CCAC then asked Ms. Mueller to make the half-hour drive to a CCAC nursing clinic in Windsor. Her 72-year-old husband, Michael, drove her there daily for more than five months until the incision healed.

"It was hard because we had a bad winter like everyone else and we had to get up and go," Ms. Mueller said. "I was going through a lot with this because [the wound] just wasn't letting up. It was rough, but the nurses were a source of encouragement for me. I have to say, they were wonderful."

Ms. Sewell's clinic experience, on the other hand, was so negative she eventually turned to the nurse at her family doctor's office for the wound care she required after having the cyst removed from her breast.

Sent home from hospital with no instructions on how to care for the 10-centimetre gash, Ms. Sewell swiftly developed a blackened, clot-filled infection that her doctor said would require daily cleaning co-ordinated by the area's home-care access centre, officially known as the Erie-St. Clair CCAC.

When Ms. Sewell contacted the centre, she was surprised to be told to drive about 40 minutes to one of its clinics in Sarnia, where a nurse would teach her to clean and dress the wound herself. Ms. Sewell, a bank manager with no medical training, balked at trying do-it-yourself wound care. The CCAC relented – briefly – by dispatching a nurse to her home in the tiny town of Florence for five days before directing her to another CCAC clinic in Chatham, the small city where Ms. Sewell works.

"I'm not a nurse. I can barely put a Band-Aid on properly," she said. "I did agree to going to CCAC in Chatham because I didn't feel like I had any other choices."

Dealing with the Chatham CCAC clinic was frustrating, Ms. Sewell said. Visits that should have taken 15 minutes stretched into hours as different nurses asked her to recount her case history every day.

"Not only did I have to get undressed and take my shirt off in front of 30 different strangers, I had to tell my whole life story that many times," Ms. Sewell said.

What's more, the wound refused to heal. Ms. Sewell's doctor asked the CCAC clinic to switch to an older type of dressing, but the clinic's staff refused, saying the dressing was not in keeping with the CCAC's strict best practices. Five weeks into her wound-care regime at the clinic, Ms. Sewell quit and returned to her doctor's office, where a nurse not bound by the CCAC's rules tended to the infection and helped it heal.

Lori Marshall, the chief executive officer of the Erie-St. Clair CCAC, said she has asked for a review of how nurses are scheduled at the region's three clinics, operated by the for-profit company Bayshore Home Health. "Generally, it is a smaller number of nurses so there isn't as much of an issue around continuity. But I am concerned … that it was identified [as a problem,]" she said.

As for the clinic declining to use the dressing requested by Ms. Sewell's doctor, Ms. Marshall said that if patients prefer dressings the clinics do not carry, they can seek a doctor's prescription for the materials and pay for them out-of-pocket or through private health insurance.

The Erie-St. Clair CCAC, which received a spate of bad publicity last fall after it began making cuts to tackle a looming deficit, has now hired a patient relations officer and is working to be more sensitive to the needs of home-care clients.

"We're trying to be more open and embracing of patient and family feedback to help us improve as an organization," Ms. Marshall said.