Concerned friends
A VOICE FOR QUALITY IN LONG TERM CARE

March 2017

NEWSLETTER

The real cost of bedsores

By Miranda Priestman

"Every time they rolled him over, he screamed in agony… But that smell, that smell… I rolled him over and there it was, a nine-inch by four-inch black hole. His anus was completely gone. There was white pus. Feces dripping into it".[1]

This is a description of Mr. Jones's Stage 4 infected bedsore that allegedly went unnoticed and untreated by a Revera nursing home. His family has since launched a class action lawsuit claiming that in the nursing home his health deteriorated due to inadequate care, dehydration, malnutrition and repeated falls, which resulted in him being bed-bound and developing the pressure ulcer and widespread infection that led to his death.[2]

I am a nurse and I work in a hospital. A surprisingly large number of hospitalized nursing home residents have pressure ulcers. Our first concern is treating their primary issue, but during our assessments, these ulcers come screaming to our attention and are often linked to the root of these patients' acute conditions. A pressure ulcer develops when a person's skin touches a surface for an extended period of time. This can reduce the blood flow to the tissue causing reddening of the skin (Stage 1), skin tears and ulcer formation (Stage 2), craters in the skin showing fat tissue (Stage 3), or deep depressions in the skin displaying muscle or bone (Stage 4).

Studies vary in their estimates of prevalence of pressure ulcers across long term care facilities in Canada. According to a study conducted by Woodbury and Houghton, the overall pressure ulcer prevalence rate is 29% in non-acute settings such as nursing homes, which is more than 1:4 residents.[3] A Canadian Health Institute for Health Information study called "Compromised Wounds in Canada" put pressure ulcer prevalence at 14% in complex continuing care and 6.7% in long-term care.[4]

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Proposed new enforcement tools could include licence suspensions, financial penalties

Concerned Friends applauds the health ministry's proposed new enforcement tools. (See page 4.) We look forward to the addition of 75 nurse pactitioners and increased funding for the Behavioural Supports Ontario program. However, we are extremely disappointed that the ministry refuses to take the one crucial step that would most benefit all residents of long-term care homes in Ontario: enact a minimum standard of nursing and personal care of four hours per resident per day. Until this happens we will continue to hear horror stories about the poor quality of care in too many of our long-term care homes.

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In both 2013 and 2014, the Ministry of Health and Long-term Care received over 800 complaints related to improper care (e.g. pressure ulcers etc.) in nursing homes. In 2013 and 2014, 3% of residents (396) in nursing homes had a worsening pressure ulcer.[5] These statistics confirm the fact that pressure ulcers are prevalent in long term facilities in Canada.

When an individual remains in the same position for an extended period of time a pressure ulcer can develop. Careful monitoring is required to prevent pressure ulcer formation. According to a study called Relationship of Nursing Home Staffing to Quality of Care, the highest staffed nursing homes have lower rates of pressure ulcers. There is widespread recognition that staff training on pressure ulcer recognition, prevention and risk factors reduces pressure ulcer incidents. Prevention techniques such as pressure redistribution mattresses and regular turning of patients are believed to help both prevent and stop the progression of these ulcers.

The cost of pressure ulcers to individual Canadian hospitals is estimated at $1 million annually.

The cost of pressure ulcers to individual Canadian hospitals is estimated at $1 million annually. A Canadian hospital estimated a 43-year-old female with a Stage 4 infected foot ulcer's total cost to treat at $42,500, including antibiotics and hospital stay, while costs to prevent would have been between $200 and $350.[6] Ultimately, pressure ulcers are sources of infection, pain and discomfort, which progressively increase if the ulcers are left untreated. Pressure ulcers can prevent a patient from sitting in a chair or moving around because of the associated pain. These sores affect the quality of life of those afflicted.

Pressure ulcers have significant human and monetary costs. Our long-term care homes need to improve the prevention, care and treatment of pressure ulcers for residents. Old age should be an enjoyable experience. No one should have to endure the pain Mr. Jones experienced at the end of his life.

References

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Strategic planning retreat: We heard you!

Many thanks to all of you who responded to our survey. You told us to continue our focus on advocating for quality of care in long-term care homes. You also urged us to be innovative. You have inspired us to work harder, to reach out to partner with other groups, and to focus our efforts to achieve the most impact.

There are challenges, of course. We need to raise our public profile, increase membership, develop and expand our expertise, and more.

Can you help? Contact us at info@concernedfriends.ca.

Long-term care and LGBTQ people

By Dick Moore

No one wants to enter a long term care facility/nursing home/old age home.

That's a truism that like others has some exceptions.

I worked for some years as the Director of Seniors Services for a Family Service agency. We assisted isolated older people living in the community to find safer places to live where they could get the care they needed. Many of these folk welcomed the old age home. They got three square meals a day, had nurses and personal support workers to look after their needs and they had people to interact with. Card games, jigsaw puzzles and craft activities were welcome distractions. Life there was better for them.

A more common reaction was the one I heard from a trans woman who talked of her life in a women's housing coop where neighbours looked after one another, took each other to doctor's appointments and picked one another up after a colonoscopy or cataract surgery. "I would take my life before I would go to one of those homes" was her response.

The conversation was of many I had with groups of older LGBTQ people when I started a job as Coordinator of an Older LGBTQ program at a community centre serving those communities in Toronto. The conversations were part of a series of community soundings on what it was like to be growing old as an LGBTQ person. The people I talked to were not unhappy. They were growing old with some grace. They did complain about not having opportunities to get together with people like themselves. However, they all expressed serious concern about receiving home care services.

Most LGBTQ people have had negative experiences with the health care system. Outright discrimination, excessive curiosity, discomfort on the part of providers, violation of confidentiality and misdiagnosis are among these experiences. The thought of a strange person who is part of the health care system coming into the safe, secure place they call home is frightening. "I feel like I'd have to "de gay" my apartment." was one man's comment. Photos, pictures, books, statues and figurines to say nothing of clothes and jewelry all contain telltale signs that providers may see and read. LGBTQ folk fear they may be refused care, receive poor care or be judged and preached to by providers. These fears are not unfounded and are documented in articles and studies in different jurisdictions.

The thought of leaving their homes or apartments to live in a long term care facility was even more frightening to the people I interviewed. Many feel they must return to the closet lest they be denied care or receive poor care. They fear the negative reactions of staff, of other residents and from families of residents. Again, in my experience, these fears are not unfounded. A recent small research study indicated how ill prepared are health care service providers in both the community and institutional sectors.

So what needs to happen to change things? What do we need to do to ensure that our gay and lesbian neighbours are safe and secure when accessing either community care or institutional care?

Education and training are first and important steps in the process of change. Staff at all levels, volunteers and residents in care settings, all need and deserve training. Vocabulary tools are a first step in the training. Knowing and using the right words is a start. Learning about the history of human rights in Canada and Ontario and how they affected older LGBTQ people is important. Understanding typical experiences of older LGBTQ people and the effects of these experiences is crucial. With such knowledge and awareness providers can begin to see the error of "We treat everyone the same."

We are not the same! We have been through experiences and grown up in a society that labeled us a criminals, mental health cases and sinners. These experiences leave a mark. They have consequences. We're a tough group of folk. We've had to be to make it this far. We have keen senses to detect unsafe situations. We avoid them at all costs.

Other aspects of the change process to accommodate LGBTQ people is the crafting of antidiscrimination statements and policies that name sexual orientation, gender identity and gender expression as grounds for discrimination. A zero tolerance for homophobic behaviours by staff, volunteers, residents and family members is essential. A transparent and swift complaint procedure protects us in the case of

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Ministry of Health Press Release (January 2017)

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Ontario is taking action to ensure that long-term care home operators across the province with recurring care and safety concerns provide quality and safe care for residents and their families.

While the vast majority of long-term care homes are in compliance with provincial rules and regulations, Ontario intends to strengthen its quality and safety inspection program with new enforcement tools — including financial penalties — to ensure that all home operators are addressing concerns promptly. These proposed new tools would include:

- Financial penalties that would be applied to those operators who repeatedly do not comply with the requirements of the Long-Term Care Homes Act, 2007, as recommended by the Auditor General in her 2015 annual report. Any financial penalties would not negatively impact patient care
- Provisions to enable the Minister to provide direction to long-term care homes to support improvements in care, for example directing all long-term care homes to use a new skin and wound care best practice protocol
- Establishing new offences that would provide additional protections for residents, if needed, such as an offence for failing to protect residents
- Minister and Director's authority to suspend an operator's licence and order interim management
- Improvements to the transparency of the inspection process, including publicly posting directives to long-term care homes.

The province intends to introduce these proposed changes, which require legislative and regulatory amendments, early this year.

These enforcement tools build on the province's enhanced Resident Quality Inspection strategy and are part of a continuous examination of improvements that can be made to ensure safety and quality care at long-term care homes, so Ontario families can continue to have confidence in the long-term care home system.

Supporting quality care at long-term care homes is part of the government's plan to build a better Ontario through its Patients First: Action Plan for Health Care, which provides patients with faster access to the right care; better home and community care; the information they need to live healthy; and a health care system that is sustainable for generations to come.

Quotable

"The Ministry of Community and Social Services should actively work with local agencies to ensure that placement of young adults with developmental disabilities in long-term care homes is considered a last resort and that alternative solutions are vigorously pursued."

— Paul Dubé, Ombudsman of Ontario, August 2016
Investigation into the Ministry of Community and Social Services' response to situations of crisis involving adults with developmental disabilities

"Our survey of the family council representatives who had filed a complaint with the ministry indicated that approximately 80% of them were not satisfied with how the cases were addressed by the ministry. Reasons cited include no investigation took place and/or the outcome was never communicated back to the complainant."

— 2015 Annual Report of the Office of the Auditor General of Ontario

LGBTQ people

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"Safety and security in our homes and in care facilities is something we have a right to demand."

homophobic incidents.

Forms used by health care organizations are important tools that can give a message of inclusion or exclusion. If choices for gender are limited to male or female, Trans people who may identify as both or neither are excluded.

The way questions are asked is another sticking point. Open ended questions about people who are important in your life are more appropriate than husband/wife. LGBTQ people are not infrequently separated from their families of origin or spouses and children. We have developed what we call chosen families, people who we call in emergencies, people who we look after and are, in turn looked after by. These people are as important to us as are straight people's families. Our chosen families have a role to play in care planning and in communication with health care providers. They need to be included and respected.

The closet has provided safety in a hostile world. Many older LGBTQ folk chose to remain there and their decision to do so deserves respect.

What is needed is a health care system and long term care facilities that acknowledge us and our histories. Safety and security in our homes and in care facilities is something we have a right to demand.

Dick Moore lives in Port Colborne where he serves on the Senior Citizen Advisory Committee of the City. He can be reached at moore.dick@gmail.com

Patient ombudsman's office should become independent of the Ministry of Health

The Rant

Kathy Pearsall

It's not working well, folks. That's the buzz, and it certainly was my experience last month after I helped a long-term care resident take a case to the office of the Patient Ombudsman.

It was my first experience with this new office which opened in June 2016, and I was looking forward to learning how it all worked.

One thing alarmed me right off the bat. I was told I could not attend the meeting that was being set up between two of the ombudsman's representatives, the resident, and the management of the home. The resident was upset because she wanted me there. When a complaint was made, I was then told I could attend as long as I was not "combative."

So the resident offered to record the meeting for me, and I was okay with that. We were both just happy to know that the complaint fell within the jurisdiction of the patient ombudsman's office, and that the meeting was taking place at all. We were optimistic.

The ombudsman's representatives made it clear at the onset of the meeting that their job was not to take sides. They were "independent facilitators" seeking "resolution."

They stressed that they have no power above the ministry of health, and that the ministry is under the jurisidiction of the provincial ombudsman. Therefore, they cannot re-investigate a complaint made to the ministry or overturn something the ministry has done.

That was disconcerting. But this complaint was not about anything the ministry had investigated. Rather, the ministry had failed to investigate it, which is why we had contacted the patient ombudsman in the first place.

Unfortunately, the representatives made no effort to investigate the complaint and advised us to contact the provincial ombudsman. The meeting was a waste of everyone's time.

Volunteer needed!

Concerned Friends needs a volunteer with administrative skills to be our membership secretary.

This work involves sending out renewal notices on the anniversary of memberships, picking up mail from our office at 140 Merton St, depositing cheques using an ATM, recording deposits made, and updating our membership list. Various other routine tasks may also be required.

To give some idea of the amount of time involved – sending reminders occurs once a month and is carried out by email in most situations. There is also some follow-up required for renewals not received. Picking up mail and depositing cheques can be done once or twice a month. Updating the membership list and forwarding it to the treasurer is also a monthly task. A good knowledge of both Google Mail and Excel are requisites.

If you are interested, or know of anyone who would be willing to take on this important role, please contact info@concernedfriends.ca.

WANTED: PEOPLE WHO CARE ABOUT LONG-TERM CARE

We have a lot to do. Please join us.
Call or email if you would like to become a board member or a volunteer.
You can also become a member just by visiting concernedfriends.ca and clicking on "Become a member" from our home page.

Did you know that donations to Concerned Friends can be made online?
www.concernedfriends.ca/add-your-voice-ours/how-donate

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Established in 1980, Concerned Friends of Ontario Citizens in Care Facilities is a non-profit corporation and registered charity dedicated to reform of the long-term care system and improvement of quality of life for residents. The organization is supported entirely by memberships and donations.

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