FALL/WINTER 2018

VOLUME 29, ISSUE 2

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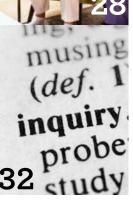
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LOOKING FOR MORE ABOUT LONG-TERM CARE? DOWNLOAD A COPY OF THIS IS LONG-TERM CARE 2018

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Expanding the role of the registered practical nurse

BY CANDACE CHARTIER

In the last issue of this magazine, I explained that Ontario's long-term care homes need current legislation to be changed to allow more flexibility in the type of staff they hire. Homes know their residents best, and which health care providers will provide what their population needs. I gave the example of the strict requirements for personal support worker (PSW) qualifications, and how that hampers homes, particularly when there are PSW shortages.

This time, I want to talk about nurses.

In Ontario, the *Long-Term Care Homes Act* requires that a registered nurse (RN) be in the home 24/7. This can be a real challenge for homes, particularly those in rural areas and small communities, where the supply of registered nurses is limited to begin with.

More than one in 10 Ontario long-term care homes recently surveyed by the Association indicated that finding 24/7 registered nurses is one of their top human resource challenges. Homes that are unable to meet this requirement, even temporarily, face serious repercussions for not complying with the Act.

Half of the province's current supply of registered nurses will be of retirement age over the next five years.

Candace Chartier is CEO of the Ontario Long Term Care Association.

As long-term care is already facing RN shortages in some regions, we believe the legislation needs to change to allow homes to use registered practical nurses (RPNs) to provide 24/7 coverage, based on each home's assessment of their needs. Right now, we have a "one size fits all" approach, and that's not necessary or practical.

Registered practical nurses have the knowledge and skills required for providing care. Although RNs and RPNs have differing levels of education, many of the tasks they do in long-term care are the same. Registered nurses may still be required 24/7 in some homes based on the medical complexity of the residents and other factors, but in many long-term care homes, registered practical nurses may be best suited (or equally suited) to meet the needs of the home's residents.

There is no shortage of registered practical nurses in the province, and there would be many RPNs eager for this leadership opportunity. Long-term care is already a major employer of RPNs, employing nearly 40% of the province's supply. Registered practical nurses are highly valued for what they bring to long-term care, and it's an attractive environment for them because there are often more opportunities to work at their full scope of practice and to take on leadership roles than in other health care settings.

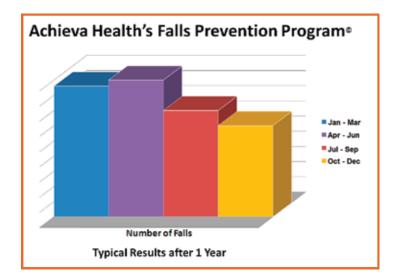
Ontario has a new Progressive Conservative government which has committed to adding 30,000 new long-term care beds over the next 10 years. These new beds and new homes will need significantly more staff, and we're asking the province to recognize the pressures we're already under, and to fast-track changes so that we can grow a strong workforce for the future.



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Getting personal

Sexuality and consent in long-term care

S exuality and intimacy are complex issues in longterm care. Concerns about inappropriate behaviour, a resident's ability to consent to sexual activity, and abuse can arise in any home. As such, discussions about relationships, values, and parameters need to be part of a resident's ongoing care conversation.

In 2017, Ontario's Primacare Living Solutions struggled with a complex situation where the lines around sexual consent were unclear. The experience was a catalyst for Primacare to delve into this difficult and sensitive issue, which was challenging not only for the residents and families involved, but also for staff at the home.

The result was new guidelines and procedures, along with a new approach to staff education. "There wasn't much out there on navigating sexual consent in long-term care, and what existed wasn't practical," says Primacare's Chief Operating Officer, Jill Knowlton. "We needed to develop new, straightforward guidelines so that staff could easily figure out how and when to act." Primacare recently shared their experience with other long-term care homes at the Ontario Long Term Care Association's *Together We Care* conference. In this feature, Jill Knowlton shares highlights of the Q&A from the presentation.

CLARIFYING CONSENT

Given the prevalence of dementia and other cognitive impairments in long-term care, what does it mean to have the mental capacity to consent to sexual intimacy?

At Primacare, we created a decision-making tree to help staff make decisions around what assessments are required, and whether the resident's intimate relationship should proceed – or whether they have to step in and intervene (see *Sexuality - Assessment and Planning Flowchart* on page 16).

We start exploring this issue with all our residents at admission. About six to eight weeks post-admission, our social workers do an admission intimacy assessment. We're looking for history, values, and beliefs. What's their family structure? What is (or was) their primary relationship like? Residents and their family members can find this assessment intrusive, which is why it is important to explain the rationale behind it and take measures to put them at ease when asking personal questions.

Then, at the first sign of a relationship developing, we will look at the Lichtenberg assessment. If the resident scores greater than 14 (out of 30) on a Mini-Mental State Examination (MMSE), the Lichtenberg directs you to continue with an assessment called Capacity to Consent to Sexual Activity.

If that assessment shows that someone can consent, then we don't intervene in the relationship. We ensure privacy, and make sure the dignity of the persons involved is protected.

If the MMSE score is less than 14, that's when staff will intervene, and stop sexual activity from occurring. We try to do that in a discreet manner, so that we're not embarrassing people, but it needs to stop at that point.

What behaviours should and should not be tolerated in a long-term care environment?

We should never tolerate inappropriate comments, non-consensual touching or forced sexual activity of any kind with another resident, public exposure, or public self-fondling.

However, sometimes what seems like sexualized behaviour might be an innocuous expression of confusion, delirium, or motor restlessness within a long-term care environment. In one situation, a man with dementia exposed himself in the hallway. But it turned out he had simply wandered out of a bathroom confused about how to dress himself.

Some medical conditions can also lead to sexualized behaviours, such as frontotemporal dementia, obsessivecompulsive disorder, and late-onset bipolar disorder. These conditions can impede decision-making skills and lead to seemingly inappropriate behaviours.

It's important to get assessments and understand what's underlying these behaviours. You may have two residents who appear to be groping each other, but in fact they're just looking for comfort which can be provided in more socially acceptable ways.

STEPPING IN

When should nursing staff begin weighing one resident's right to companionship and intimacy against the home's duty to protect another resident from sexual abuse?

The guiding principle is this: The resident has a right to form friendships and relationships, even sexual ones that are appropriate, but that has to be balanced against the home's duty to protect those who can't consent to the relationships.

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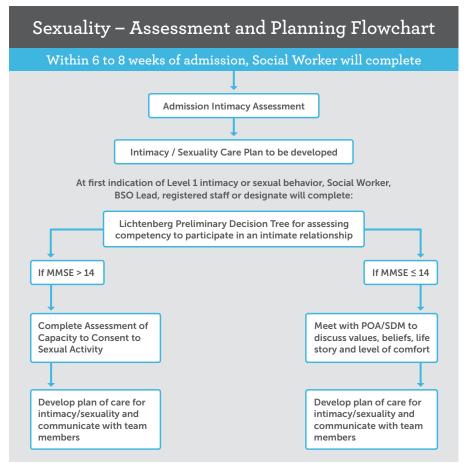
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There can be telltale signs of early sexual behaviour – kissing, hugging, cuddling, sitting on someone's lap. At this point, staff should ensure a current baseline MMSE and Cognitive Performance Score (CPS) is available on the health record for the residents in question, as these will indicate if they are capable of consenting to such relationships.

It also helps to begin early and ensure ongoing documented discussions with each resident and the substitute decision-maker (if appropriate) to determine preferences and the boundaries for their relationships. It's worth noting that most families are supportive of friendships and companionship, but may not agree with a sexual relationship.

Continued on page 20





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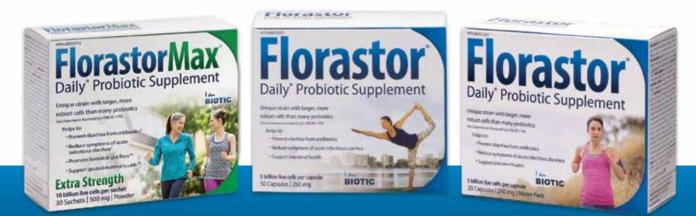
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1. Health Canada. (2015, May) Probiotics (Monograph).Retrieved fromwww.hc-sc.gc.ca. 2. Swidsinski, A., etal. (2008), Gastroenterol., 135(2), 568-579. 3. Klein, S.M., etal. (1993).Pharmaceut.Res., 10, 1615-619. 4. Kabbani, T.A., et al. (2017). Gut Microbes, 1, 17-32. 5. Szajewska, H. & Kołodziej, M. (2015). Aliment. Pharmacol. Ther., 42(7), 793-801. 6. Dinleyici, E.C., et al. (2012). Expert Opin. Biol. Ther., 12(4), 395-410.



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INTERPERSONAL RELATIONS

Continued from page 16

Are the residents safe? Are they able to say no? Is what's happening consistent with values and beliefs in the resident's life history? Is it in a private location? Is there harm or is there potential for harm to occur? Is it causing distress or fear or a change in behaviour to that individual? Is there a risk of exploitation? Is there a risk of abuse? If you look at the definition of sexual abuse, it can just be remarks, and sometimes residents can be very aggressive with their sexual comments to other residents, like a form of serial harassment.

Also, the capacity to consent can fluctuate, particularly for residents whose MMSE score is around the borderline of 14. They may have some periods of clarity, and some of confusion. Their consent must be given at the exact time they are approached for sexual activity. This is known as contemporaneous consent. It's a very complex situation for the resident and for staff, who keep a watchful eye on residents when they know residents are in this situation. It's a balance of ensuring the residents have a right to relationships, but that their right to be protected from harm is also firmly in place.

In addition to these issues, personal hygiene, infection control (for sexually transmitted diseases), and birth control for younger residents all need to be addressed.



What action should nursing staff take when they encounter residents who are both cognitively impaired and who are initiating intimate behaviour?

First and foremost: be discreet and maintain dignity.

If we know that both residents are cognitively impaired, we would check the MMSE score and see how cognitively impaired they are. If residents are below 14 on the MMSE then we would be certainly contacting the substitute decision maker and the power of attorney (POA) and letting them know, and then they'd redirect one or both of them to other activities. In some cases, residents may need to be relocated to other areas of the home.

The POA or substitute decision makers can't provide consent for relationships on behalf of the residents but they can share information on the resident's values, beliefs, and wishes when they were capable. This is important information in the development of the plan of care.

What should homes do if one resident is cognitively able to give consent, but the other is not?

Relationship boundaries need to be clearly defined with the competent resident to ensure they understand that the potential partner can't give consent and that sexual behaviour is off limits. Sometimes people just aren't aware – the person who is not capable of giving consent may appear to be more capable, and so the cognitively competent person doesn't see the extent of the other's limitations.

If he or she continues to try to pursue a sexual relationship despite understanding that the person cannot give consent, the cognitively impaired resident is at risk of abuse and the cognitively competent resident is at risk of criminal charges. In a difficult situation like this, extra measures must be put in place to protect the cognitively impaired resident.

TALKING ABOUT VALUES

How can a home overcome biases held by staff, residents, and family members when it comes to sexual intimacy and sexual behaviours?

Sexuality is value-laden and we all come from a different place. If we don't take time to examine everybody's values, we can wind up taking action based on our values, not ensuring that residents' rights are met. It's not uncommon for there to be some ageism around sexuality – people don't want to associate sexual needs with older people.

Here's what we learned: You have to make it safe for staff to talk. In our first session, we started with providing them with information around what Ontario's *Long-Term Care Homes Act* requires, what human rights requires, what our professional colleges require, our policy, and other resources that we reviewed. Do you or someone close to you experience difficulties chewing or swallowing? Have you lost interest in eating because you're afraid of choking?



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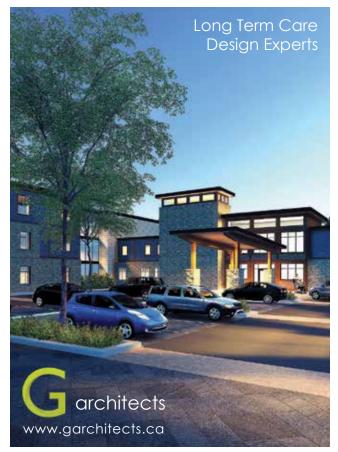
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INTERPERSONAL RELATIONS



We then talked about our home's values, and then asked them to think about this question before our next meeting: What are your personal values and beliefs about sexuality, and in particular, about sexuality between people in long-term care?

We need to shift the mindset from what we think is right to what is right for the resident

When we got together again, we provided staff with a learning package, case studies, and some role-playing. This led into a broader discussion. Leaders need to be prepared to start the conversation and share their own values, because staff don't just jump in and have their hands up and want



to talk to you about this. Always make sure these sessions are safe, and provide supports, particularly around opening up around personal values. Then you want to continue these discussions in daily huddles and your unit meetings, then get discussions about sexuality and sexual consent into orientation, and then into your required education.

Talking openly about values means dealing with judgments. Here's what the staff told us when we did these sessions: I thought you couldn't do that here. She has a husband, and he's not going to like her being with someone else. He's a dirty old man. There's no private place for that here. I called her son, and he told us to tell her not to do that, don't let her do that. The family won't like this, they say you shouldn't touch other people. I don't like anyone touching me, and I say he should keep his hands to himself.

We didn't judge their values, we just reinforced that we need to shift the mindset from what we think is right to what is right for the resident.

Sexuality and intimacy is a loaded topic. Homes need to encourage awareness, education, and open dialogue. For staff, that means understanding and examining their own values and beliefs as they apply to sexual intimacy in older adults, including cultural diversity and LGBTQ2S+ rights.

Overall, everyone will benefit from a culture of inclusion which supports open, safe, and transparent conversations.

The Sexuality Assessment and Planning Flowchart, along with other materials developed by Primacare Living Solutions, is available on the Ontario Long Term Care Association's members' website. Long-term care homes interested in further information are welcome to contact **Jill Knowlton** at jknowlton@primacareliving.com. OSGOODE PROFESSIONAL DEVELOPMENT CONTINUING LEGAL EDUCATION

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Avoiding the "prescribing cascade"

By Dr. Rhonda Collins

ccording to the Canadian Institute for Health Information (CIHI), more than 60% of people in long-term care are on 10 or more medications. There's no question that residents are more complex than a decade ago, but do they truly need this many medications?

It's not uncommon to see a "prescribing cascade" with the elderly. Somebody has two or three medical conditions and then they have a new symptom. They are prescribed another medication to treat that symptom – when in fact it might be related to interactions between their older medications.

Of course, some medications are necessary. But the more medications you take, the higher the risk for adverse reactions from drug interactions as well as drug and disease interactions. How do we stop overmedicating? One of the places to start is by exploring with residents (or their substitute decision makers) whether there might be any potentially inappropriate medications. One common drug that could be deprescribed for many people is a proton pump inhibitor. They're meant to be used short-term to relieve heartburn but often people are on them for years. But elderly people who are on proton pump inhibitors for a long period of time have a higher risk of developing aspiration pneumonia, B12 deficiency, hip fractures and c-difficile colitis (a gut infection that can be fatal in the elderly).

Another example is benzodiazepine, more commonly known by brand names such as Ativan or Valium. We know that they affect cognition with confusion and delirium and they come with an increased risk of falling and hip fracture. But they're also one of the hardest medications to stop because people become so dependent on them. It's very difficult when somebody's been on Valium for the past 20 years to say, "Are you sure you still need this drug?"

We don't always need to stop medications entirely. One example is a statin, which is given for cardiovascular protection. We don't know if an 80-year-old is still getting benefit from it, but we do know that it's highly associated with side effects such as muscle aches and pains. So rather than start a pain medication for the muscle aches and pains, let's bring down the dose of the statin and see if the pain is reduced.

Looking at the doses of all medications is important. There are so many changes that go on in our bodies as we age and the way we absorb, metabolize and excrete medications changes. We might develop side effects to a drug we took for years. If we continue the same dose of certain medications, the risks can be very substantial.

Reducing the number of medications, and the dose of medications, has many benefits for residents, but it also can be a significant benefit for the health system. Some studies have demonstrated that on an average long-term care unit, the amount of time to administer one medication pass for 20 residents is about 64 minutes. As well, CIHI reports that up to 25% of ER visits in the elderly are due to adverse drug reactions and that 25% of those visiting the ER with an adverse drug reaction are admitted to hospital, costing almost \$36 million per year.

There are a lot of benefits to deprescribing, both for individuals and for the health care system. If you're not sure where to start in your home, I recommend the excellent website deprescribing.org.

Dr. Rhonda Collins was appointed as Revera's Chief Medical Officer in 2017. She is a family physician with expertise in geriatrics, long-term care and dementia.

All the Buzz About Medical Cannabis and Seniors' Health



When 90-year old Wendy Thorburn got the news that her 60 year-old daughter needed hip surgery – she knew it was going to be a tough and painful recovery. Together, they started researching and educating themselves on their options.

To their surprise, one of the doctors consulted suggested they look at medical cannabis as an alternative solution.

"I'd never used recreational drugs growing up, and never in my wildest dreams did I think I'd be advocating for the use of cannabis for my loved ones, friends or myself," said Thorburn, the Vice President of the Residents' Council at Arbour Heights Long-Term Care Residence who up to then, viewed cannabis as a recreational drug. "But the more I learned about it, I came to realize that Canada is at the forefront of innovating cannabis use – and it's not about smoking – many of us are interested in cannabis oils."

While Thorburn is not a medical cannabis patient, she is a staunch advocate for her peers. She says it comes down to education, open dialogue and an open mind.

According to Statistics Canada, seniors are the largest growing demographic group in Canada and its precisely this peer group that is the most curious.

Dr. Jonas Vanderzwan, a primary care physician for more than 15 years and now the medical director at WeedMD has been practicing cannabis medicine since 2014, having assessed and treated some 1,200 patients with medical cannabis. "What's perhaps more fascinating than the specifics of the medical success stories is the speed at which society's attitude towards medical cannabis is changing from caution and reluctance, to curiosity and acceptance," said Dr. Vanderzwan. "One of the more surprising changes I've observed recently in this regard, is the level of enthusiasm for medical cannabis that is coming from the seniors' community – much more accepting when they learn about the alternative consumption methods such as vapourizing or the availability of an edible oil form."

WeedMD has taken a special interest in the seniors' demographic, having formed partnerships with over 30 long-term care and retirement homes, including Thorburn's community residence. The company also partnered recently with Shoppers Drug Mart, a leading provider of pharmacy products and services, to supply cannabis strains directed at seniors' and womens' health.

Dr. Vanderzwan agrees that education is an important and a vital part of the company's platform: "Our clinical team works within the seniors' network to educate healthcare providers, patients and their families to ensure that cannabis is being incorporated safely and responsibly into the care plan of interested patients."

To learn more about medicinal cannabis oils and WeedMD's diverse product lines including AXIS[™] & ENTOURAGE[™] visit www.weedmd.com or contact our client services team at 1-844-WEEDMD-6.



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Preventing or reducing falls can be complex. There can be multiple factors involved in why someone falls, and determining the risks and interventions needs good tools, good clinical judgment, and teamwork.

Most homes conduct falls screening and assessment, and the RNAO's best practice guideline can take you through the recommended steps. But one of the things they strongly recommend is moving beyond checklists to using your clinical judgment as well. You don't want to be just filling out a form or some kind of tool – you want to be really thinking about what you're seeing and hearing with the resident. At a bare minimum, you're looking for a history of falling, and gait, balance or mobility problems. This clinical judgment piece is key, as is communicating what you've noticed to others so the information doesn't get stuck in the chart.

The RNAO guideline also helps you work through the philosophical shift around risk that's happening in long-term care homes. There is increasing recognition that supporting a resident-centred quality of life means

some people will want to be more independent, even if it comes with an increased risk of falls. Basically, you want to avoid an excessively custodial and risk-averse approach. For example, some staff may limit mobility to avoid falls and injuries that could affect the indicators they submit each month. There is also a concern that homes might be really afraid of letting people take some risk because they are evaluated on the indicator of number of falls in each 30-day period. When RNAO was developing the guideline, this really resonated with the expert panel.

The guideline recommends that health-care providers are sensitive in the way they speak to residents and families about falls. It is important to explore their knowledge and perception of risk and use positive messaging about falls prevention. The focus should not be on preventing falls at all costs. You want to discuss options together, weigh the pros and cons of different interventions, and come up with an individualized plan. And people have the right to refuse particular interventions.

RNAO reviewed the evidence about interventions that have really strong evidence of benefit, ones that have shown some benefit, some that have some mixed findings, and then ones that have insufficient evidence. That doesn't mean interventions are ineffective; it just means the research isn't available yet. For example, there is clinical experience showing benefit to using low-height beds, but there isn't a lot of evidence.

Also, more research is needed on how to use bed and chair alarms effectively. False alarms are not uncommon, and then staff sometimes end up tuning out because they're hearing the alarm go off over and over again.

Preventing falls and reducing injury from falls

By Susan McNeill, RN, MPH



And once you hear an alarm, you've got to be able to respond really, really quickly.

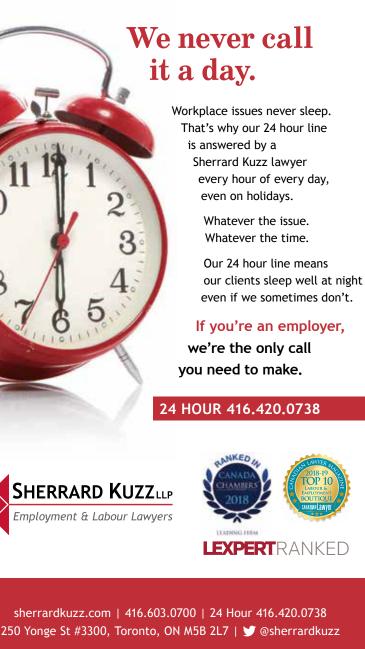
Many homes use visual identifiers to flag the risk of falls, such as a falling star or leaf. This is another example where the evidence isn't there yet. Ongoing team updates of the risk do make a difference though, as you can highlight the things that might happen from day-to-day. Maybe Mrs. J has lost her glasses and will need extra help so she doesn't fall. Mr. G might be drowsy on a new medication and almost fell this morning – he'll need more monitoring. Team rounds make a significant difference.

Preventing falls depends on teamwork and education of everyone who comes into contact with your residents

The evidence on hip protectors is mixed. They're commonly used in long-term care and some homes are offering them across the board. They certainly have great potential to avoid serious consequences of a fracture, and the literature supports their use in long-term care, especially for those people who are mobile and at high risk of fracture. But there isn't a lot of evidence of their benefit, in part because residents can have difficulty accepting them and adhering to their use. The guideline recommends that hip protectors be decided on an individual basis, not as an across-theboard decision in a long-term care home.

Finally, preventing falls depends on teamwork and education of everyone who comes into contact with your residents. You're not just educating the nurses and PSWs, you're teaching other staff, such as dietary and housekeeping, to communicate what they see, what they hear, and what the plan is. For example, if Mrs. G has dementia and she's mobile and needs a walker, but she forgets to use it, encourage everyone to say "Hi Mrs. G, remember to use your walker."

And the environment also makes a huge difference. If you see a spill on the floor, if you see a cluttered hallway, empower everyone to take responsibility in reducing the risk factors. RNAO is finding over and over again that the team approach is one of the keys to success, and this is supported by evidence, too. Susan McNeill is Manager of Implementation Science at the Registered Nurses' Association of Ontario. The RNAO's Long-Term Care Best Practice Program offers extensive resources for free and direct coaching support in every region of the province. To access these free resources, visit rnao.ca or contact LTCBPP@RNAO.ca





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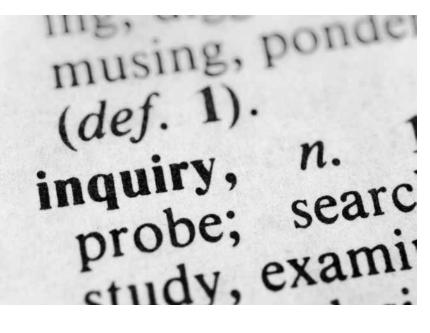


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Ontario's public inquiry into long-term care

By Lisa Corrente, Torkin Manes LLP

n September 2016, Registered Nurse Elizabeth Wettlaufer checked herself into Toronto's Centre for Addiction and Mental Health and confessed to murdering eight residents and attempting to murder several others in three Ontario long-term care homes. The news of Wettlaufer's heinous crimes shocked and devastated the long-term care sector.

Wettlaufer's crimes went undetected for nearly a decade. No one – not nursing, medical or care staff at the homes, the victims' families, local coroners, the College of Nurses of Ontario or Ministry of Health inspectors – ever suspected that Wettlaufer was injecting residents with fatal amounts of insulin with the intent to cause their death. What events led to the offences committed by Wettlaufer? What circumstances and contributing factors allowed these events to occur? How can similar tragedies be avoided in the future?

These are questions that the Long-Term Care Homes Public Inquiry has been mandated to answer. On August 1, 2017, the Inquiry was established by the province shortly after Wettlaufer was sentenced to life imprisonment following her guilty pleas to eight counts of first degree murder, four counts of attempted murder and two counts of aggravated assault. The Honourable Justice Eileen Gillese was appointed Commissioner. A written report of her findings with recommendations is due to the provincial government by July 31, 2019.

A public inquiry is a formal process set up by the government in which a commission independently looks into facts or matters of public interest or concern and makes related recommendations. The Inquiry is divided into two main parts: public hearings, which took place in the summer and early fall of 2018, and plenary sessions in the fall with participants who took part in the hearings.

Prior to beginning the public hearings, the Commission's legal team inquired into the events that led to Wettlaufer's offences and the surrounding conditions and circumstances that allowed the offences to occur. The purpose of the public hearings was to present the results of the Commission's inquiries to the public and to give the hearing participants the opportunity to examine, challenge and add to these results.

Evidence was heard from those involved, particularly the facilities at which Wettlaufer committed her crimes, the Office of the Chief Coroner, the College of Nurses of Ontario, and the Ministry of Health and Long-Term Care. Witness testimony touched on issues such as the shortage of registered nurses in long-term care, staffing levels and funding, recruiting and hiring of registered staff, medication management and medication errors, disciplinary practices and termination (including the implications of union involvement), mandatory reporting, investigations by the College of Nurses and the Coroner's Office, and inspections by the Ministry.

The second part of the Inquiry the plenary sessions – is currently underway. During this phase, the Commissioner is meeting with the various hearing participants in small groups to discuss their views on possible recommendations for the Commissioner's final report. Given that the proceedings are still ongoing, we do not know what changes will be recommended for the long-term care sector. However, based on the evidence to date, recommendations will likely address issues such as government oversight and funding, staffing levels for nurses, recruitment and hiring of registered staff, medication management, increased transparency with the College of Nurses, mandatory reporting, and death investigations by coroners.

Lisa Corrente and David M. Golden of Torkin Manes LLP will be sharing their experiences at the Inquiry and providing an update on the proceedings at the Association's *This is Long Term Care conference*, November 14-16, 2018 in Toronto.

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A smoother transition into long-term care

or a resident with dementia and their loved ones, moving into long-term care can rank high among life's most difficult moments.

The increased societal trend to keep people at home for as long as possible often means that people with dementia and their loved ones aren't admitted to long-term care until there has been a crisis. It's a stressful time for everyone, but there are meaningful steps that care staff can take to ease the transition and establish a genuine care partnership,



says Mary Schulz, Director of Education with the Alzheimer Society of Canada.

"For the resident, [being moved to a home] is potentially one of the hardest things to do because it symbolizes vulnerability and dependence," offers Schulz. "They're moving out of a familiar living place and, in many instances, being separated from spouses, family, and everything that's familiar to them."

One of the most important things home staff can do on admission day, continues Schulz, is to simply empathize with the resident and their family member's situation, listen to their concerns, and reassure them they're doing what's best: "Try to normalize the idea that moving to long-term care is a normal and expected outcome of the disease. Reassure them that the majority (70%) of people with dementia ultimately require long-term care and they are not alone."

Listening to the resident's fears and empathizing with their reservations is key. So too is helping them and their family realize the necessity of enhanced care and that they are in good hands. Yet as these conversations take shape, it's important for care staff to remember that emotions are also running high for family members who may be feeling guilt, resentment, frustration, or pure exhaustion.

"When you're seeing people on day one, they're not likely to be at their best," says Schulz. "You want to make the assumption that this is a pretty tough day and try to understand what this experience is like for this family. For many, it's been a long journey to get here and it may be that they promised to never move their mom, dad, or sibling into a home. They may be walking through the door thinking they've failed their family member and angry at themselves for getting to this point."

Reassuring words can help in these initial meetings. It's also helpful to put paperwork and tours aside for a few minutes to help both them and the resident come to terms with this poignant milestone. "If you can recognize and honour what they have done to support their loved one to bring them to this point, that can make an enormous difference to a family," says Schulz. "Think of it like passing a baton: let them know it's OK to hand over some of the care they have been struggling valiantly to provide, and that it's now your collective honour to care for their family member throughout the rest of this journey."

What happens when those emotions take a turn towards anger? Here again, says Schulz, it's important to recognize what's happening: "When there's a family member pointing their finger in your face and saying, 'You better take care of Joe because no one cares for him the way I do', that's not an accusation and they're not threatening to police you. That's grief, pure and simple."

Building a partnership

A trusting and open partnership between home staff and family members is key to personalized care. Building that relationship means drawing on family members for insights into the resident's history, values, and desires, and making them an integral part of ongoing care planning. It also means encouraging interactions beyond mandated meetings and assuring them there will always be someone at the home to take their call.

"We need to assume families want to be helpful in this process – at the very least during the transition stage. They want to feel welcomed and respected and that their journey to this point has been recognized," says Schulz.

But what about family members who don't want to be involved? What about the son who says, "He's yours now" or the wife who prefers to watch from the background? In these cases, it's crucial for staff to respect those complicated emotions and recognize they can change over time.

"The truth is we don't know their family history or where they're coming from, and we can't assume that their reaction is forever," says Schulz. "Help them understand they can be as engaged as much or as little as they want, and that they will not be judged for whatever their commitment ends up looking like."

The **Alzheimer Society of Canada** offers many resources, including on the transition to long-term care, which long-term care staff may find useful for conversations with residents and families. Visit alzheimer.ca.

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Helping residents with their emotions

How can reducing social isolation help?

ong-term care team members are at times confronted with situations where they do not know what to say or do – often when residents express their emotions on heavy topics such as loss, fear, or their own mortality. Teams at the Ontario Centres for Learning, Research and Innovation in Long-Term Care (CLRI) have been developing tools and resources to help navigate these conversations. Team Essentials: Leading Practices for Long-Term Care, for example, is a suite of resources that draws on relational care approaches to offer innovative, experiential education around priority practice issues, including how to engage families and residents. In another project, recreation professionals participate in tailored training, coaching and sharing, as they hone peer support group facilitation skills. Peer support groups, such as the Java Group Programs, create a safe environment for residents to express their emotions and support each other.

To explore common situations that arise in group settings, we sat down with Michelle Fleming, Knowledge Broker with the Ontario CLRI at Bruyère. Michelle brings twelve years of experience in long-term care as Manager of Social Services. Here she also draws on the experiences of the recreation professionals who participate in *The Power of Peer Support* project.

How do I cope when a resident starts crying uncontrollably, or talking about how lonely or depressed they feel?

Validate their emotions, empathize, and ask open-ended questions to help them explore their feelings. Be a calm presence and a listening ear. It sounds simple, but it takes practice. We have a tendency to want to fix things when someone is upset, but that's often the least helpful response; people don't want a solution, they just want to feel heard.

What do I say when a resident tells me they are scared of dying?

Elderly people are aware that they are approaching the end

of their lives and may want to talk about it. Give them space to talk about how they feel and explore that fear. Are they worried about how their family will survive without them? Do they have regrets? Is it a natural fear of the unknown? We're all going down the same path. The more comfortable we are to talk about death, the more meaningful those conversations will be.

How can I support someone who suffers from dementia and talks about being scared but is unable to articulate what they are afraid of?

We tend to say, "Don't be scared." Instead, tune in emotionally to what is being said and avoid dismissing residents' concerns. Listen and reassure them that they are not alone. Encourage residents to participate in meaningful activities and to help others. If you are pushing a trolley down the hallway or hanging up a poster, ask a resident to help you. People want to feel useful. Residents with dementia may lose the ability to do much of what they used to enjoy. Finding replacement activities helps residents feel less like an observer and more like an active participant in life.

Visit the Ontario CLRI website (clri-ltc.ca) or sign up for the monthly CLRI newsletter to learn about tools and learning opportunities available to your home's staff. *The Power of Peer Support: Reducing Social Isolation in Residential Care* is a collaborative project between the Ontario CLRI at Bruyère, Carleton University, Java Group Programs, and Bruyère Continuing Care. It is funded by the Centre for Aging + Brain Health Innovation, Carleton University and the Government of Ontario through the Ontario CLRI at Bruyère.

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Finding harmony

Jann Arden opens up about her transformational journey with her mother as the latter battles Alzheimer's

Jann Arden recalls the moment she found her mother's guitar with deep fondness. It was a moment that would inspire one of Canada's most celebrated musical careers and one that would ultimately symbolize her layered, yet harmonious, relationship with her parents throughout their journeys with Alzheimer's.

"Music has been a beautiful part of my life, but it's not my life," Arden shared with her audience at Together We Care 2018. "In fact, looking after my mom and dad has singularly been the most graceful, beautiful thing I've ever been involved with. I'm a better version of myself: a better writer, a better daughter, and a better person."

Arden's journey began years before she even knew it. Living near her parents, she was frequently called over to locate lost objects or fix seemingly harmless mistakes. Only when her father passed away did she realize the extent of her mother's mental illness. "It was shocking to me how much the two of them worked together to hide their illness," she said. "For all those years, I thought it was just gardenvariety memory loss so I buried it and acted like the memory police while admonishing both my parents."

As her mother's symptoms worsened, the day-to-day care began to take its toll. By the time Arden decided to hire in-house care, feelings of frustration, exhaustion, resentment, and guilt had become commonplace. "I was tired. Worn out. I knew I could either sail out to sea and give up on myself and the situation and feel sorry for myself or turn this situation around and get myself together," she recalled. "I realized I wasn't going to win against Alzheimer's, so I had to ask, 'How are you going to live with it going forward?"

Inspiration struck when Arden was sitting with her mother on the porch one day and listening to her describe a group of women in red hats around the home. Instead of discrediting her visions, Arden tried something new: "I was about to launch into, 'No you're not [seeing them]' but I found it in me to say, 'Well, you'd think they could pick up a broom."

"Something in me just said, 'I can't fight it. I'm not going to win,'" she continued. "So I let it go and I let go of my mom that day." It was a turning point in the relationship, a bittersweet decision to stop fighting the tide and follow her mother's lead. "It seems so deftly simple, looking back," reflected Arden. "I don't even ask my mom questions anymore because it puts her in a vulnerable position. Instead of asking, 'How was breakfast?' I'll now say something like, 'Breakfast sure looked good."

Communication between Arden and her mom improved from that day forward. This, along with support from her friends and caregivers, helped to ease her mother's transition into a long-term care environment. "[Leaving my mom there] was the weirdest day of my life," Arden admitted later, noting, "I can't tell you all enough how grateful I am for everything you do and the profession you've chosen. I have a profound and deep respect for all of you."

Looking back on the road so far, added Arden, "It has been such an incredible journey. Yeah, it's not easy, but I know my mom would have done the exact same thing for me no matter what."

Jann Arden was the keynote speaker at Together We Care 2018. She chronicles the story of her experience with her mother and Alzheimer's disease in her recent book, *Feeding My Mother*.



A non-pharmacological approach to comfort and well-being in dementia care

By: Hamill, E., Rozario, D.

For people with dementia, symptoms such as agitation, aggression and sleep disturbance can be a challenge to manage causing significant distress to the resident, their family and professional caregivers. The latest International Consensus¹ proposes an escalating approach to the management of behavioural and psychological symptoms of dementia (BPSD) with a clear preference towards non-pharmacological interventions. With this in mind, we will discuss an intervention founded on the principle of a non-pharmacological first-line of prevention.

Rocking into a new therapeutic intervention

What is more natural than rocking? Rocking is one aspects of human behaviour that is used spontaneously to comfort, soothe, and reassure. These embracing moments are commonplace and used in times of happiness, sadness or distress. The comfort and enjoyment that is associated with the rocking motion is embedded in human behaviour and is only rarely studied scientifically, but it should not be overlooked in terms of value and validity as an innovative therapeutic intervention. For people that are suffering with distressing symptoms of dementia, rocking has been shown to contribute towards a number of benefits such as improved mood, better balance, and less pain².

Music has also been a contributing partner in modifying distressing behaviour in individuals suffering from dementia³. Other supporting studies have also shown that music can be used to facilitate nursing care and calm residents during bathing, benefitting both the resident and caregiver.

Dementia Care Challenge

Behaviours such as agitation or aggression, constant activity and sleep disturbances are common in up to 90% of people living with dementia⁴. These behaviours can negatively affect the overall quality of life of the individual, their family members and their caregivers, which in turn can negatively influence the care being provided to the individual.

Although there is a lot of evidence that is still within the early stages, and is often anecdotal, the best practice guidelines are placing a greater emphasis upon the value of using non-pharmacological methods of intervention¹.

The evidence of rocking as a 'therapy' may be limited but early studies and user surveys have outlined the low risk and possible benefits in comparison to pharmacological intervention such as sedation⁵. Drug therapies have enjoy greater investment in research and are widely used, but the benefits are uncertain and frequently report side effects. Rocking has the advantage of no delay or carry over effects.

Real World Experience

The difficulties of designing, scaling and funding robust clinical trials, given the individual nature of dementia symptoms and the almost infinite variations in response to treatments, has left a formal gap in evidence. However, valuable information can be obtained through 'real world' experiences with data collected from a variety of sources including electronic health records, products safety and disease registries⁶. User evaluations are a form of 'real world evidence' and multicentre data, when pooled, can demonstrate safety, effectiveness and practical application of an intervention such as the Wellness Nordic Relax Chair[®].

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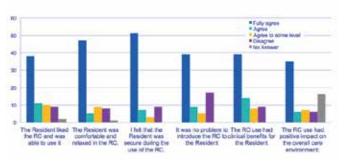
While individual outcomes are important, it is also important to consider how easily an intervention might fit into daily care routines, how the caregiver perceives it and whether there are any barriers to implementation.

Caregivers across 18 facilities in three European countries were asked to evaluate from their perspective with a multicentre survey. Seventy staff reported their opinion of the clinical utility of the relax chair in the management of more than 50 residents who presented with a wide range of neuropsychiatric symptoms.

The staff estimated that by using the Relax Chair they were able to redirect two to three hours each week and focus on additional nursing tasks. The overwhelming response was positive, with the majority of respondents concluding that the Wellness Nordic Relax Chair was beneficial to residents (figure 1)7.

Figure 1: User opinion

Experience of the Rocking Chair Use (N=70)



For more information on the Nordic Wellness Relax Chair or to book a demo for your facility, contact your local Arjo Canada Representative.

¹ Watson NM, Wells TJ, Cox C. Rocking chair therapy for dementia patients: Its effect on psychosocial well-being and balance. American Journal of Alzheimer's disease. 1998; 13(6): 296-308 ² National Institute for Health and Clinical Excellence (NICE). Dementia: A NICE–SCIE Guideline on supporting people with dementia and their careers in health and social care. National Clinical Practice Guideline Number 42. https://www.scie.org.uk/publications/misc/dementia-fullguideline.pdf?res=true accessed August 2018

¹ Pedersen SKA, Andersen PN, Lugo RG et al. Effects of Music on Agitation in Dementia: A Meta-Analysis. Front. Psychol. 2017; 8:742
 ⁴ O'Neil M, Freeman M, Christensen V et al. Non-pharmacological Interventions for Behavioral Symptoms of Dementia: A Systematic Review of the Evidence. VA-ESP Project #05-225; 2011
 ⁵ Snyder M1, Tseng Y, Brandt C, A glider swing intervention for people with dementia. Geriatr Nurs. 2001;22(2):86-90.

⁶ U.S. Department of Health and Human Services Food and Drug Administration. Use of Real-World Evidence to Support Regulatory Decision-Making for Medical Devices. 2017. ⁷ Van Deusen J, Kiernat JM. An Exploration of the Rocking Chair as a Means of Relaxation. Physical & Occupational Therapy In Geriatrics. 1986; 4(2): 31-38

In recognition of the culture change sweeping across Ontario's long-term care homes, many of the sessions focused on ways to enhance quality of life and resident-centred care. Popular sessions on this theme included

speakers on timely issues and opportunities in seniors' care.

Together We Care 2018

a panel discussion of how to support appropriate relationships between residents; creating an inclusive LGBTQ environment; and how creating a happier and more engaged staff leads to benefits for residents as well. Together We Care is an opportunity to learn about the latest in seniors' care, to share ideas and problem-solving with colleagues, and to return to work inspired by new ideas and new connections. Be sure to mark your

calendar for next year's conference, to be held April 1-3, 2019 at the Toronto Congress Centre.

Each spring, more than 1,000 seniors' care professionals look forward to attending Canada's largest conference on long-term care and retirement. Hosted jointly by the Ontario Long Term Care Association and the Ontario Retirement Communities Association, the 2017 Together We Care conference featured a variety of dynamic



There's something for everyone at the Association's conferences – and often a few surprises. Clockwise: MPPs Bill Walker and Teresa Armstrong led a lively political debate; a session on music care included an impromptu singalong by Room 217 and Fenelon Court; Master of Ceremonies Stuart Ellis-Myers shared the inspiring story of thriving with Tourette's Syndrome; and Finlandia Village showed some of the playful tools they use for staff engagement.









Then-premier Kathleen Wynne attended the conference for the second year in a row, shown here with OLTCA's CEO, Candace Chartier.

TOGETHER WE CARE 2018



The conference features the most engaging and hands-on trade show in seniors' care, which drew crowds of delegates during breaks. Featured booths: The Association's Corporate Alliance Partners - Essity, Cardinal Health, and Arjo.







Jann Arden took extra time with autographs and thanked delegates for the excellent care they provide to people like her mother.

Back to the future: Celebrating the '80s with an evening of dinner and dancing.





April 1–3, 2019 | Toronto Congress Centre



Registration opens December 6, 2018

The largest long-term care and retirement convention in the country is back and **better than ever**.

We look forward to seeing you in Toronto!

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