

PEACE OF MIND

Model of dementia care accepts and embraces patient's reality

MARY

is sitting on the couch in the common area in front of the television, surrounded by other residents of the supportive living facility. Lynn, the licensed practical nurse (LPN), walks over to see how she is doing. Worried and agitated, Mary asks where her husband Robert is. Lynn, like all of Mary's caregivers, knows Robert passed away seven years ago, and hearing this information always sends Mary into a state of frustration, sadness and confusion.

Lynn smiles and gently places her hand on Mary's arm. "Robert is at work right now, Mary. Remember, he works at the construction yard just outside the city?"

Mary, still concerned, asks when he would be back.

"In a little while," Lynn explains "Let's watch a show and have lunch while we wait for him."

Lynn knows Mary won't remember this information by the afternoon, and will ask where he is again tomorrow. But for now, Mary relaxes as she turns her attention back to the TV.*

THIS IS MARY'S REALITY—

her husband is still alive and at work. It's so real to her that when told about his passing, she experiences the same intense grief and sorrow she did seven years ago. In her world, it is happening here and now.

* This is a fictional example. Any similarities to real people is purely coincidental and unintentional.



Caregivers including LPNs and registered nurses (RNs) are taught that when caring for people with dementia, it's best to bring them back to the present. But this can be stressful for both patient and caregiver. Is there a way to reduce the confusion and suffering experienced by people with dementia and improve their quality of life? The answer is yes, and an Alberta RN is helping.

A NEW WAY OF THINKING ARRIVES IN CANADA

Dr. David Sheard first introduced his innovative Butterfly model of dementia care in the United Kingdom 20 years ago. The model is based on the belief of the importance of offering emotional care to patients and the understanding that we must recognize and respect the reality patients with dementia live in. Over the past two decades, more than 100 Butterfly Care homes have been introduced across the UK. These homes aim to create a less institutional care setting, removing uniforms, painting walls in bright, cheerful colours, and having staff eat meals with residents. Most importantly, the model is focused on *accepting the residents' reality as truth*. The result is a care setting that feels more like a home than a medical facility, so that residents actually feel at home in the places they live.

Now Edmonton is about to become the first Canadian city to adopt that model within a supportive living centre. Registered nurse Jennifer Chan is leading the adoption of the dementia model at Lifestyle Options Retirement Communities in Edmonton. She is the Director of Care/Clinical lead at the facility.

"The new model is very different than how I was taught; we do so well in our clinical care, but that's just half of it," Jennifer says. "There's also the other side, which is the social aspect. We ask, is the person happy? Is she living how she wants to live at that moment or are we forcing her to live how *we* want her to?"

Although the Butterfly model has been enthusiastically embraced in the UK, it wasn't an easy sell here in Canada. Dr. Sheard has visited Canada and spoken at several conferences over the past five years in an attempt to educate health professionals and garner the support he needed to implement the model here.

"The things I talk about, including getting rid of those barriers, getting rid of uniforms, changing the environment, changing the whole approach to activity, can feel like a tsunami for people who have been doing their best in a very traditional culture," explains Dr. Sheard. He explains that although it can be a difficult transition for health-care professionals, nurses are particularly well-suited to help lead this new model of care. "The key is that nurses have to move from being a detached professional – which nurses have been trained in, to be clinical, to have empathy but not show too much emotion – to what I call an attached professional, one who understands attachment theory and the need to apply it in dementia care."

RIGHT NOW,
47.5 MILLION
PEOPLE
WORLDWIDE
ARE LIVING
WITH
DEMENTIA.

BY 2030, THAT
NUMBER IS
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TO INCREASE
TO 75.6 MILLION
AND BY 2050
WILL REACH
A STAGGERING
135.5 MILLION.

Jennifer is optimistic about the change. "It's a true person-centred approach and I want this model to succeed. However, the road is not going to be easy. It takes a village to do this, so everyone needs to be involved and buy into it. LPNs were taught clinically how to treat dementia, but we are teaching them a new way of dealing with it socially. Everyone is really excited."

A GROWING CONCERN

The new model is being introduced at a critical time for dementia care, as health-care systems around the world cope with increasing numbers of dementia cases. And as populations age, the incidence of dementia is expected to rise. Right now, 47.5 million people worldwide are living with dementia. By 2030, that number is expected to increase to 75.6 million and by 2050 will reach a staggering 135.5 million.

Dementia not only causes frustration and distress for the patient, but the caregiver as well. A recent study conducted by researchers from the University of Lethbridge found that caregivers of people with dementia experience a high level of moral distress, described as "when nurses and caregivers know the right thing to do, but can't do it, perhaps because of a lack of time or resources."

Examples of "moral distress," included common practices such as using medication to manage dementia behaviours which can reduce the patient's quality of life. Participants described instances of seeing other staff being rude to residents, not talking with residents even when providing care, or treating residents like children. Caregivers also spoke of the moral distress of rushing care, when a rushed approach upset the resident with dementia, and of residents being isolated and unstimulated.

Study participants said that caring for persons with dementia left them feeling frustrated, physically and emotionally exhausted, powerless, inadequate and sad, which was rooted in the emotional connection they had with the residents they cared for. This has serious implications in a health-care sector that is already experiencing staffing shortages and high turnover, and may impact the quality of nursing care.

Although the new model of care will not automatically address issues such as overmedication and staff shortages,

Dr. Sheard has seen how effective it can be in improving the quality of life for dementia patients. The simple act of taking time to converse with patients, of being respectful and providing care with dignity, and ensuring that the patients are well-connected and entertained could reduce the amount of distress for both caregiver and patient.

LIVING THE LIVES OF THEIR RESIDENTS

Changes are happening fast at Lifestyle Options Retirement Communities. “We are getting rid of uniforms. No more scrubs,” explains Jennifer. “This is the residents’ home. When we come here in our street clothes, we could just be their neighbour or their friend.”

Staff will sit down and eat meals with the residents. “They need to know the meal experience of the residents. And that’s how they can improve it,” Jennifer continues. “For example, they might clear away dishes when some of the residents at the table are still eating. So how would they know how that feels when they don’t sit there? How do they know that the food is good if they aren’t eating it themselves?”

She acknowledges that one of the biggest changes may cause some apprehension for both families and staff. Under the new Butterfly model, all staff – including cleaning staff – will now acknowledge residents when they enter their room, whether it’s a simple greeting and small talk, or sitting down to begin a conversation. So if a member of the housekeeping staff enters a room to tidy up, they may engage the resident and lose time cleaning in favour of time spent talking.

“The difficult part of getting staff buy-in is to let them know that this is okay,” says Jennifer. “Of course, a minimum level of cleanliness and tidiness will always be maintained. But let me ask you – is your home always meticulously clean? No, neither is mine! Most homes aren’t. We need to remember that this is someone’s *home*.”

IT ONLY TAKES 30 SECONDS TO CHANGE A LIFE

Dr. Sheard wants nurses and all health-care professionals to understand how much of an impact they can have on the lives of dementia patients. “You can change the moment for someone with dementia. Regardless of the bureaucracy, regulation, or management style of leadership in your organization, if you are a nurse working directly with people who suffer from dementia, you can make a difference today. It takes 30 seconds to turn a task into something where you share a memory, you comment about colour that somebody is wearing, you mention something about the environment or day, you share something that’s going on in your life with them. Anybody can do that in 30 seconds.” **RN**

REFERENCE

<http://www.alzheimer.ca/en/About-dementia/What-is-dementia/Dementia-numbers>

Right at home

NETHERLAND’S GATED MODEL VILLAGE MAINTAINS NORMALITY OF DAILY LIFE FOR DEMENTIA PATIENTS.

ON first glance, the picturesque village of Hogewey, located about 20 km outside of Amsterdam, looks much like any of the quaint towns and villages that dot the Dutch countryside. It has a town square, a theatre, supermarket and café, gardens, a park and sidewalks lined with flowers and trees. But Hogewey isn’t your typical town. In fact, the entire town is a nursing home for people living with dementia.

Opened in 2007, Hogewey is home to 152 residents and approximately 250 staff and health-care workers. Each resident lives in one of 23 homes that accommodates approximately six people, with one health-care worker on site at all times to help with cleaning and other necessary tasks. Residents are grouped according to their previous lifestyles, with former tradespeople sharing a “homey” residence that offers comfort food and simpler surroundings, and those that were used to a more affluent lifestyle living together in more **stylish “goose” accommodations** and eating more sophisticated cuisine. In total, there are seven lifestyle choices available.

Each resident has their own bedroom and is free to stroll through the village, and visit the stores and cafés. The entire village is focused on creating a sense of normalcy for residents, allowing them to live a lifestyle they recognize and placing them in familiar surroundings. The goal is to reduce the confusion and sadness that more clinical settings can create for dementia patients.

Residents take day trips to nearby towns and shopping malls, and people from surrounding towns and villages are welcome to frequent Hogewey’s shops and cafes. And during the Dutch version of Halloween, children from nearby towns go door-to-door asking for candy in exchange for singing songs – a tradition most residents remember fondly.

Funded in part by the Dutch government, Hogewey costs about the same as other care facilities, with residents paying a portion of the expenses based on their income.

The Hogewey concept has caught the attention of dementia care specialists around the world, and many similar homes are currently being built across Europe, the United States and here in Canada.

hogeweyk.dementiavillage.com/en/