

## Are We “Sacrificing” the Care Component on the “Altar” of Bureaucracy?

By Mona Lancaster, Director, Memory Lane Home Living Inc.

In this blog post, I outline existing care models and services available to our loved ones with dementia in Ontario and conclude by making the case for the “co-operative care model” offered at Memory Lane Home Living Inc.

### ***What is available today and why it is problematic***

Looking back at presentations I recently delivered to the local community—presentations in which I review what is presently available to our loved ones suffering from dementia—I realize that the more I speak, the clearer it becomes that *the care component in institutional settings is weakened because of real estate costs and unnecessary layers of management*. This, I believe, results in an inverse relationship between bureaucracy and the quality of care. The greater the bureaucracy, the lower the quality of care for our loved ones suffering from dementia. Care is “sacrificed” on the “altar” of unnecessarily complicated administrative procedures.

### ***Model #1: Living at Home***

The first model I review in my presentations, “living at home,” is what the Government of Ontario promotes as “aging in place.” This is the ideal model provided that a family member can be a caregiver—with some additional supports in place. The problem with this model is that often caregivers suffer from “caregiver burnout” because such supplemental relief is limited. Other negative consequences arising from this model are *loneliness* and *social isolation*.

In a News Release from the Ontario Government dated November 7<sup>th</sup>, 2017 entitled “*Ontario Supporting Seniors to Live Their Best Life: New Action Plan Provides More Fairness for Seniors and Enhances Support Across the Province*” from the Office of the Premier, we read:

“Almost half of seniors are worried about being alone. Social isolation is a risk factor for an array of negative outcomes among older people, including elder abuse, a higher risk of falls, hospitalization and depression.”

It would seem that encouraging independent living—that results in negative risk factors—is less realistic than we’d like to believe, less socially engaging and, ultimately, less efficient and costlier than the co-operative model of care at places like Memory Lane Home Living Inc.

The price tag of social isolation is high: operations for unattended falls; the lasting psychological effects of abuse; the government-borne costs of hospital stays; and the cost of medication to treat depression.

Let me be the first to say in this regard that government Day Programs are a definite plus for loved ones with dementia, many of whom do not want to be away from their familiar environment for long stretches of time. However, typically, there is a wait time of up to one year to get into some of the more affordable of such programs.

### ***The special case of mild cognitive impairment***

The Government of Ontario presently does not provide support to anyone with a diagnosis of mild cognitive impairment. Support workers will only visit homes where a diagnosis is more advanced. They provide approximately one or two hours of care a day to dress the person with dementia in the morning and change them at night. Respite care is limited, and the work needed to organize a “weekend respite” for dementia care is both hard as well as expensive.

Although government support exists for more advanced diagnoses, the wait lists are long. If a family member were to resort to a care company for support, the cost would be approximately \$25 per hour—prohibitively expensive for most Ontario residents. The care cost of even providing limited support—one or two hours a day—is expensive in the “living at home” or “aging in place” model of care. If our loved one’s need for care increased to 24 hours per day—requiring supervision, enhanced stimulation, companionship, and redirection—the family caregiver or Power of Attorney might “raise the white flag” and start looking at available institutional options.

## ***Model #2: The Retirement Home***

With a dementia diagnosis, our loved one is typically placed in a Retirement Home, on an assisted living floor or a memory unit. On an assisted living floor, the home usually offers 90 minutes of care a day. The ratio of a Personal Support Worker (PSW) to a resident is approximately 1 PSW to 16 residents during the day, and 1 PSW to 32 residents at night. If your loved one needs assistance, they will receive such assistance when the PSW has time to attend to their needs.

Can you imagine, for a moment, being incapacitated, needing to use the washroom but having to wait because your PSW is busy assisting another resident?

This—the clearly insufficient ratio of personal support workers to residents—goes against the philosophy of **person-centred care** in which the needs of the individual come first. The cost of this service—the Retirement Home model of care—is usually \$5,500/month.

More specialized dementia care involves placing our loved one with dementia in a memory unit or a lockdown unit which keeps them from exiting the establishment. The problem with this scenario is that not everyone is an “exit seeker” and the person in lockdown may, instead of improving, become more agitated: an unwanted effect of lockdown which can lead to distress and a deterioration in the resident’s symptoms.

The care ratio on a memory unit in a retirement home is approximately 1 PSW to 8 or 10 residents during the day and 1 PSW to 16 residents at night. The care in this model is slightly more expensive reaching \$7,000 to \$10,000 per month. Despite such high costs, family members do not have a say in the care their loved one receives.

From personal experience, I concluded that retirement homes put a higher priority on covering their real estate costs and governance layers, at the expense of the care component which is de-prioritized. This “care sacrifice” is at the heart of my essay.

How can a retirement home afford a quality care ratio of 1 PSW support worker to 5 residents—who are dependent on guidance and care—when families must foot the bill for marble entrances and bear the burden of hefty real estate

mortgages? What about covering the cost of salaries for a president and CEO, a general manager, clinical director, marketing manager, enrichment co-ordinator, and food manager? I haven't even touched on the profit requirements to keep investors happy.

Does this leave any money to spend on front-line staff who are the "raison d'être" of the institution and provide the necessary support? Could this be the reason why assisted living has a ratio of 1 PSW to 16 residents?

### ***Model #3: Long-Term Care (LTC)***

The Long-Term Care (LTC) model is another system that is generally set up to take in seniors with greater medical needs. This system offers a ratio of 1 PSW to 10 residents, but given the higher degree of needs required by residents, the care in this model is usually insufficient to fully attend to residents. The Government of Ontario supports this system with a contribution of approximately \$13,200 per month (financial data released at Nov. 2017 conference, "Envisioning Ageing in Place," hosted by the National Institute on Ageing) with the resident's family contributing approximately \$2,600.

Given a total amount of \$15,800 a month to support an individual, one would think that, again, a 1 to 5 ratio (1 PSW to 5 residents as provided in our co-operative model) minimum would be the norm.

LTC, however, does not disclose its staffing requirements. They advised me that in 2010, when the act was revised, they decided to let each home determine its staffing needs individually. Even with a high cash input and an emphasis on a medical model, most residents spend more time in the Emergency Department than in the LTC unit if they require immediate medical attention.

Most LTC units do not assess urine samples for UTIs/bladder infections in-house; they send them out to a lab. This can be a slow, and deadly, procedure for those with bladder infections. It can mean the difference between life and death when obtaining antibiotics is delayed.

Furthermore, long term care is not allowed to provide IVs for dehydration. Dehydrated residents are sent to the Emergency Department at a local hospital to

get an IV. If, therefore, emergency departments at hospitals are servicing a substantial portion of LTC medical needs, this may imply that staffing requirements are not being met and that essential infrastructure is lacking.

The question arises yet again, “Is the money going to real estate mortgages, unnecessary layers of management and/or profits instead of meeting essential care requirements?”

#### ***Model #4: The co-operative model***

At Memory Lane Home Living Inc., our Care Team researched models of care and looked at how to create a model that does not pay for the real estate costs or layers of management.

We came up with a co-housing model which puts the emphasis on: relationships; team management by the families of the loved ones who live in the house; and Memory Lane’s guidance.

We desire a health care model for the women living in our home which provides the skill set and the time needed to work with dementia—dementia care that results in an exceptional level of attention which, in our eyes, ought to be the expected level of care for those we love.

#### ***Person-centered care***

We believe that a successful care model is about “person-centered care,” which is by definition different from what is currently experienced in institutional settings for the reasons outlined in this essay.

Memory Lane Home Living Inc. charges approximately \$650/month for rent and an additional \$400/month (approximately) to cover the cost of food, heat, water, phone, etc.

We are a not-for-profit organization which aims to ensure that our dementia population and their loved ones are treated with dignity and respect. The care component in our home is “hand picked” by residents and their families with the guidance of Memory Lane Home living Inc.

Although there are many care services available, we choose services that clearly understand dementia care and the importance of person-centred care.

The care cost component in our home is approximately \$25/hour which, divided between 5 families, is an approximately low \$5/hour for 24 hours per resident.

The paid ratio of care at Memory Lane is approximately 1 Personal Support Worker to 5 loved ones with dementia. In addition to this, we at Memory Lane Home Living Inc. have trained volunteers in “person-centred dementia care” who help during daytime hours to take the ladies out into the community for walks, visits to senior centres, luncheons, outing in the nearby park and so on. All these are necessary *preventable* measures to *reduce* the symptoms of dementia while they journey through this chapter of their life.

### ***Let's do the math***

If we are truly paying for the care cost in institutional settings, the pricing structure should reflect this. The cost of real estate or rent should not represent more than 40% of the cost structures—and for seniors even this is a high cost at \$2,000 month.

In my experience, the remaining 60% should be allocated to the cost of care. Unfortunately, institutions tend to cut care costs to pay for everything but adequate, front-line care cost.

Perhaps it is time to take the “institution out of the care.”