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## **A Home for Mom and Dad**

We are all aware of the abysmal state of eldercare in Ontario, where home care is minimal, where attempting to support aging parents is often overwhelming for families, and where the absence of other choices forces thousands of old people into long term care institutions.

We know that a system that is based primarily on institutions (most of which are operated for profit) cannot provide elderly people with the support they require to have a good life. Who would ever want to live in a place where care is impersonal and inadequate; staff are under trained, over worked, and poorly paid; food is typically unappetizing; overmedication is a constant threat; abuse and neglect are often rampant; and people are at increased risk of dying soon after they arrive? This is not what elderly people need. Regardless of age, everyone needs a home.

A home is not simply a place where a person happens to reside. It is a place where we feel a sense of belonging, that is an expression of ourselves; it is our own private space that we share with a small number of people. A home is place where we engage in various activities and gather with family and friends. Our home connects us to our community, to its resources and to other community members. Despite the importance of home, many elderly people are denied the opportunity to live in a home when they require significant amounts of assistance and such assistance is not available. A Long Term Care facility is not a “home”, regardless of what it is called.

Imagine a world in which the needs of elderly people, including those with dementia, were truly recognized and addressed, a world in which elders received the kinds of supports they required to live, rich full lives within the community. Such a world would benefit all of us; a community is much stronger when it includes elderly people who can offer support by sharing their life experiences, knowledge, skills, and wisdom, when we all feel a responsibility to look out for each other. We would be happy to know that elderly people we care about would have the support they needed. It would also be reassuring to us to know that these supports would be available when and if we should require them.

A wide range of in-home support, funding available to purchase specialized health services, pay for family caregivers, doctors and nurses who make emergency house calls - all these would go a long way to ensuring good lives for most elderly people. Such a world would be infinitely better than what we have now. However, even in such a world, some elders would not be able to continue to live at their current home or with extended family and would require an alternative living situation, specifically a small supported residential home in the community.

Such homes are currently available in Ontario for some people with physical, developmental or mental health disabilities, and/or intellectual disabilities and/or mental health issues. In many countries including, for example, Australia and Denmark, such homes are available to elderly people, including those with dementia.

However such homes are almost non-existent for elders in Ontario. While there are examples of efforts to “fix” institutions, none of these result in a setting that includes some of the essential elements of “home”. A unit within a Long Term Care facility with 12 or 16 people is better than a unit of 32 or more, but it does not resemble an ordinary home. Most of us would find living with that number of people more than a little challenging, so why would we think it appropriate for those with dementia or other disabilities?

Right now, getting old and needing help is very frightening not only for the old person but for those who love them. What can one do when needed help is not available, when the only option is an institution? What a terrifying situation.

***But what if we did not have to dread the day when our parents (or ourselves) needed help?***

Imagine that you have been looking for a supported residential home in the community for Mom and Dad. Both have some physical disabilities, one also has dementia. They (especially Mom) will require substantial support and, while you plan to visit often, much of this support will be provided by paid care givers. Nevertheless you are hoping to find a supported home that provides many of same things that all of us value in a home. There are (in this hypothetical scenario) small supported homes in the community for elders who required a residential setting and you have found one that you think will meet Mom and Dad’s needs. Let’s imagine what this home is like.

Imagine Mom and Dad moving to an ordinary home in the community, where they will share a three or four bedroom home with a few other people. Everyone has their own private bedroom or shares one with their partner. Along with the bedrooms, the home includes the rooms typical of any home - kitchen, dining room, living room, perhaps a family room or recreation room and, perhaps, a porch or garden. Mom and Dad will, of course, share a bedroom, which you will help them decorate with familiar items and lots of photographs of children and grandchildren, awards they have received, etc.

Imagine that this home has been modified according to the principles of Universal Design (UD) to ensure accessibility and safety to those with a variety of disabilities including physical disabilities and dementia. These modifications enable Mom and Dad to feel safe and secure in an environment that promotes their involvement in the daily life of the home. A particular source of pleasure is the enclosed garden and patio in which Mom and Dad can roam freely whenever they wish.

Imagine that the home is located in your community or nearby, so that you, other family members and friends can all drop by for a cup of tea, go out with Mom and Dad for a while, or enjoy sitting together in the lovely enclosed garden, enjoying the sun and the flowers. As you know, relationships with family and friends are essential to Mom and Dad's wellbeing.

Imagine that Mom and Dad's days are filled with opportunities for enriching and pleasurable pastimes - to reminisce about the old days (perhaps encouraged though photos and stories); to listen to favorite music, play the piano, sing; to participate in physical activities (exercises and walks); to be involved in puzzles or games to enhance or support memory; to connect through Zoom with those who live far away to assist with cooking - perhaps in the preparation of a favorite recipe.

Imagine that the you, as a family member are seen as an integral part of the care team. You know Mom and Dad better than anyone and you want others to know about their life experiences, accomplishments, and likes and dislikes; you do not want them to be defined only by their disabilities.

Imagine that the Mom and Dad are supported by a small group of staff who are well trained and well paid and who are deeply committed to ensuring that Mom and Dad receive good care and support. Support will be available 24/7 although the actual amount at any given time will vary according to the needs of the residents and the activities that are underway.

Imagine that the home where Mom and Dad are living is supported by a non-profit home or a municipality, where there is community oversight and where generating a profit is not part of the home's mission.

**What needs to change to make this a reality?**

In order for change to occur, one must have a vision of a desirable future. We know that homes like Mom and Dad's imaginary home do exist in other places. If it is possible there, it must be possible here. Why, then have we not been able to develop such homes in Ontario?

We must challenge ageist assumptions, expose the tragedy of institutionalization, and demand that our society invest in the range of supports and services that enable elderly people to thrive in the community, in the home they are already living in or, when that is not feasible, in an alternate supported home. Everyone benefits when people of all ages and abilities are part of the community.