Navigating Ontario's Long Term Care system

At the March meeting of the MIssissauga South Probus Group, the speaker was Karen Cumming. Karen is a veteran journalist with 20 years of reporting and producing for TV and radio across Canada.

Her talk was on the experiences she and her sister had guiding their mother through the long-term care system. It is the basis of the book they wrote: "The Indispensable Survival Guide to Ontario's Long-term System".

Here's a frightening statistic. There are 2.4 million persons in Ontario over 65 and the number of long term care beds is ...79,000!

In 2014, Karen's mother, aged 94 moved into Deer Park Villa in Grimsby, an assisted living residence. She developed great friendships there and was able to really enjoy herself and her independence.

Then, unexpectedly, their mother lost her ability to walk followed by a decline in her health. The PSWs at Deer Park could no longer work with her, meaning she needed to move into a long-term care facility. From then until the move, the daughters became the PSWs for their mom. She eventually moved to Upper Canada Lodge in Niagara-On-The- Lake.

The process of getting their mom from Deer Park to Upper Canada Lodge was a dark and scary journey.

They became aware of the Local Health Integration Network (LHIN) of which they knew nothing. There was no one to help them, especially not the health care agencies. They were distraught due to the deteriorating health of their mother and now they had to learn to navigate through a murky bureaucracy. The process was exhausting.

Because of their mother's inability to walk, the LHIN put her on the "Crisis List" to be moved to a facility with increased care. The LHIN offered no help in deciding where to move their mother. The sisters toured a number of potential long-term care homes. When they were offered a bed at one of these homes, they had 24 hours to decide and then 5 days to move. If they declined, their mother's name would be removed from the list for three months and the process would begin all over again.

Few people in the health bureaucracy communicated with the daughters or with each other. No one helped them understand how the system worked. There were no helpful guides, brochures or websites. Most of the health care providers seem to work in their own silos.

The sisters were motivated to write a book providing a helpful guide to others who are faced with the same situation and need to work the system.

Karen Cumming's closing message was:

- You are not alone in facing the long-term care system.
- **Be proactive** and be prepared (this book can be a guide).
- The system won't change so you have to.

The book "The indispensable Survival Guide to Ontario's Long-Term Care System" by Karen Cumming and Patricia Milne, can be purchased on line at Amazon.ca, Indigo.ca or any of the major book stores.

The video presentation is available for viewing on YouTube at: https://youtu.be/-ciwpyctKGM

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