

Notes for a Presentation
for the
Round Table on Key Issues
for
Residents and Families, and for the Workforce
at the
Reforming Long-Term Care in the Public Interest
Conference

By

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Thank you, Mehdi, and good afternoon everyone. My name is Ian Johnson, and I am the Interim Chairperson of the Nova Scotia Health Coalition, previously called the Nova Scotia Citizens' Health Care Network. I have been active with the Nova Scotia Coalition and the Canadian Health Coalition for almost thirty-five years, I have also been quite active more recently as a member of the Nova Scotia Advocates for the Care of the Elderly (or ACE Team as we call it. I was part of the Cross-Country Round-Up in the Opening Plenary.

First, let me say that residents and family members are rarely considered in the context of decision-making in and about long-term care. Residents are treated as passive recipients of care, and family members are to stay out of the way, except for the annual care plan meeting. In between, we are to leave it to the senior management staff, and don't seek information, ask questions or offer solutions. Both residents and family members frequently feel like we are on the outside looking in. The so-called patient-centered care approach sounds good but is rarely implemented.

I mentioned in the Opening Plenary about being asked several months after my mother was admitted by the Head Nurse if we would consider getting an external private caregiver due to staff shortages. Why wasn't I told at the outset or even, before my mother was admitted that this situation might arise. Throughout the course of my mother's stay, we as family members had to be present every single day because there was always some issue or concern which had to be addressed. This is not to be critical of staff, but to note that family members and residents have an important stake and role to play in shaping the quality of care almost every day of a

resident's stay. They need to be seen by the administration and staff as an ally and a resource who can usually help make the staff that much easier.

In my mother's nursing home, we had a major issue arise after several months that affected both residents and families, namely, that of possible parking fees. While that might be seem like much of a concern, it became symbolic of the relationship between the board, the administration, staff, families and residents. We were very concerned about the potential for parking fees no matter what their amount as preventing family and friends from visiting residents as often as they should. We were also very concerned about the potential adverse impact on staff who were existing on very limited incomes, and often, working on 2-3 jobs. Having to pay some additional expenses for their jobs might be enough to drive them away, when we needed all the staff we could get. As family members, we organized an information picket, we attended the Board's annual meeting, we talked with media reps, and we wrote to the Chair of the Board. A year and a half later, the Board finally decided to back away from this proposal. This was a good case of residents, family members and staff working together.

Close to the end of my mother's stay and life, I was dismayed to learn from a CCA and not from senior management that the decision had been made to move my mother to palliative care. There seemed to be an assumption that this would not be a big deal for us. Well, it was and we were very upset to have been treated in this way.

While we as family members do what we can individually and collectively to address the issues affecting our loved ones, it quickly became clear that there were serious systemic issues affecting all nursing homes in the province and probably, across the region and the country. I made a quick reference to them in my earlier presentation. They include:

- **Too few staff, inadequate staff-resident ratios, and persistent staff shortages.** This is the most serious problem we see and have experienced in long-term care.
- **Funding restraint** during the last two fiscal years has accentuated many of the ongoing problems. Cutbacks reduce the number of frontline workers and the numbers of hours they work while the lack of supervision contributes to neglect in the facilities. The consequences of this neglect include bedsores, infection, and some abuse of residents.
- **Overmedication and polypharmacy** which has been found to adversely affect the health status of many long-term care residents. According to a recent UBC study, our country is spending more than \$400 million a year on medicine that is adversely affecting seniors. A much more comprehensive approach is needed than relying on having a toolkit for health care clinicians.
- **Poor diet and nutrition**, based on as little \$6-\$7 a day per resident in local nursing homes. This has meant some meals consisting of cheesies and hot dogs. These types of lunch staples severely compromise already stressed immune systems that could result in worsening health and even, premature deaths.
- **Lack of support and activity for residents.** There are not enough physiotherapists, occupational therapists, recreational therapists, and music therapists.
- **Deteriorating physical condition and poor design of nursing homes.**
- **Outdated legislative and regulatory framework.**
- **Inadequate investigation and enforcement** in nursing homes. In his June 2016 Report, the Auditor General concluded that the Department does not have an efficient, consistent, and timely inspection process. Passing the buck where no one or group takes responsibility or accountability when a complaint has been lodged is irresponsible. Patients and their families fear reprisals on vulnerable

family members. It is not enough to license a facility, place people in it, and then, not ensure that facility is living up to its licensing requirements.

- **Limited due process and appeal mechanism** for residents and family members.
- **Residents with Alzheimer's and other forms of dementia** have special needs that do not lend themselves readily to being with the general population of residents in long-term care facilities.

We have also been very troubled by what seems to be a closed, secretive approach to decision-making within the homes and with the overall development of long-term care policy. The provincial department did not release a “refreshed plan” in the fall of 2015, as promised in July of last year, both in a media release of July 30, 2015 and in a consultation document entitled “Continuing Care A Path to 2017 Review, Refocus, Renewal” dated July 2015. The Minister said publicly earlier this year that the Department is currently working towards the development of a five-year strategy, to be released in 2017. But we have heard very little about this work and how any interested person or organization can participate. We wonder who is really involved and why this isn't a more open, public process.

For the workforce, we are very concerned about our ability to attract and retain trained and experienced staff. The Nova Scotia Nurses Union epic study called “Broken Homes” revealed some very disturbing issues and concerns of staff:

- 75% of their LTC members said that staffing levels are a significant or very serious problem.
- 49% of their workplaces sometimes operate below core staffing, while

an additional 25% usually or always operate below core staffing.

- 59% of their LTC members claimed that core staffing at their workplace was inadequate for providing safe, quality resident care.
- 57% of their LTC members experience physical violence at least a couple to times a year, including 25% who experience it a couple of times a month or more.
- 27% of their LTC members experienced bullying and aggression from residents and families a couple of times a month or more.
- 60% of nurses in LTC have seriously considered quitting their jobs in the past year.

Finally, I wanted to mention some overarching issues of concern from some members of our Advocates for the Care of the Elderly Team in Nova Scotia. They are very concerned about the deteriorating state of health care overall with long-term care being the most neglected of all services. They are also concerned about the implications of a significant reduction in health care funding next year and even, with the implications of a Carbon Tax, if imposed, for health care in general, and for long-term care in particular.

So there is no shortage of issues and concerns for residents and families, and for the workforce. I have touched on specific issues related to my mother's care, the care in her nursing home, broader systemic problems for long-term care, and for the workforce. We have much to consider and hopefully, much to resolve together.

Thank you for your time and attention.