

Minister Dr. Eric Hoskins  
Minister of Health and Long-Term Care  
Queen's Park  
Toronto, ON M7A 1A1

Dear Minister Hoskins,

**Re: Requesting your intervention for fair treatment of frail elders seeking LTC placement in NE LHIN**

The Northeast Family Councils Network (NEFCN) is a group of representatives from long-term care (LTC) family councils across the Northeast LHIN region. We meet yearly and determine priority issues to work towards to improve the quality of life of our loved ones residing in LTC. We held our annual meeting in Sault Ste. Marie September 24, and members unanimously directed me to urgently raise some long-standing, unresolved and growing concerns to you and health system leaders.

**The Problem**

*Maureen's Story:*

"We can't keep people like her in the hospital." Two Sudbury hospital officials, a psychiatrist and a doctor surrounded Nancy in the corridor in front of the nursing station as her mother, Maureen, screamed in terror and agony in the room behind them. "There's nothing we can do for her here. She needs to go to a nursing home, now. Or we'll charge you \$1000 for every day she stays. We need our beds for sick people, not people like her."

But in the next two days a competent family physician, a geriatrician via videoconference, and a local neurologist found Maureen's seven-week delirium to be the result of misdiagnosis and treatment with high doses of medically contraindicated neuroleptics. By then the drugs had accelerated her Parkinson's and caused irreversible physical and mental damage. There were no apologies after she was weaned from the offensive drugs, and discharged without need of a nursing home for another two years. Four months earlier Maureen had been a physically robust, seventy-five year old retired teacher who sought help from the local health care system. She was spit out the other end as a fragile, frail and damaged old woman.

*Joan Ann's Story:*

"I think I can keep her home for a while longer," Allan told Sudbury CCAC officials when they offered his wife, a former teacher rapidly ravaged by Pick's disease, a bed in her chosen nursing home. "Well if you don't accept we're moving her to the bottom of the placement list." Allan soldiered on, more interested in keeping his wife of forty years home with him, than in figuring out the complicated bureaucratic ramifications of refusing a nursing home offer. Months later, when finally in crisis, he agreed to move

Joan Ann to the first vacant bed forty kilometers away. He believed officials who promised to re-locate her when a spot became available in their chosen home nearby. But over the years his frustration grew as daily he commuted eighty kilometers to spend six hours a day, six days a week, with his wife. Local CCAC officials made no efforts to move Joan Ann as she languished and his despair grew. The home's family council intervened, but even then it took more than another year, countless hours of calls, correspondence and meetings with myriad officials and finally intervention by local MPP, France Gelin, to finally fulfill the officials' promise to re-locate Joan Ann to the home near Allan. His burden was relieved for the remaining eighteen months of her life, but the preventable struggle was emotionally, physically and financially draining.

## **Solutions**

Sudbury experiences like these drove local family councils and eventually our network to present cost-free solutions to LHIN, CCAC and hospital leaders, as well as MPPs France Gelin and Glenn Thibeault:

- A hospital patient who agrees to be flexible and move temporarily to a regular or "interim" LTC bed, frees up a hospital bed. We explained that the law ("exchange" provisions of the *Long-Term Care Homes Act* Regulation) actually outlines a process of quick "musical chairs" of system beds to give residents who agreed to temporary moves, priority access to chosen homes when a bed becomes vacant. When the "musical chairs" is over, there is still a vacant LTC bed to offer a new patient entering the system. It's only fair to honour promises to re-locate a patient when a bed is available where they want to go, and this placement process (already legislated) doesn't require any extra system money.
- We explained that threat of hospital rates to frail elderly and others at the lowest points of their waning lives not only has been confirmed by the government to be illegal, but is promoting further mistrust in a local health system with a long reputation of insensitivity to patient vs system needs.

We were told in 2014 by LHIN officials that while they didn't agree with our view of the law, what's happening to the Joan Ann's and Maureen's is unfair and they would work to change the law to conform with our suggestions.

## **Problems Spread**

But instead of fixing the identified problems, under the aegis of the same local officials, last year the unfair treatment of frail elderly patients spread from Sudbury to Sault Ste. Marie where we are hearing disturbing echoes of Maureen's and Joan Ann's stories. Tom and many others in the Sault have told us their stories of sick loved ones cowering in fear when threatened with unaffordable rates to safely stay in hospital.

In their case, in 2015, officials re-opened a shuttered, old, sub-standard LTC home as a temporary holding facility for up to fifty hospital patients awaiting LTC placement. We

understand these patients are in need of such significant care that ambulance calls to the interim facility have been frequent and a concerning number of those patients died in the past year. (Sudbury had a similar failed experiment when it re-opened the closed Memorial Hospital site to house patients, mainly frail elders, awaiting nursing home placement. It was dubbed by some as the “dog pound for sick old folks.”)

Fairness, and your ministry’s policy dictate that, “...*interim*” beds are intended to “ensure a continuous “flow through” so that interim beds are constantly freed up for new applicants from hospitals.” Yet once again, we have learned that patients, who agreed to move to the temporary Sault site, were arbitrarily and without notice, moved to the bottom of the placement lists for their chosen homes, removing all hope of ever leaving the sub-standard “interim” beds.

### **Please help us**

We have listened with hope to your promises of an “obsessively patient-centred” health care system. We believe you when you say, “*Above all, health and health care is about people. About protecting and promoting the rights of people to support our well-being and in difficult times to ease our pain.*” Our stories are not reflective of your philosophy. We know you are reaching out to users of the system for solutions and ideas on how to make health care in Ontario more human, and less system-centric. We believe you would share our concern about how impersonal and bureaucratic handling of system pressures actually translates to what feels like mean-spirited mistreatment of frail patients at perhaps the most desperate time of their lives. Untenable personal pressure and dilapidated “interim” housing in the final stage of life have no part in your vision of human, “obsessively patient-centred” health care.

But there are a lot of impenetrable layers of frustration between you and your vision, and us and our reality. We want to help you and we want fair treatment for our frail loved ones in the difficult twilight of their lives. We ask that you please help change the narrative of their suffering and, in the NE LHIN:

- Immediately end the practice of pressuring patients needing LTC placement with hospital rates (approximately \$1000 per day)
- Immediately end the practice of pressuring Sault Ste. Marie hospital patients awaiting LTC placement, to move to interim beds
- Fulfill promises made to hundreds of nursing home residents who agreed to move temporarily with the promise that they would be re-located when a bed in a home of their choosing became available
- Immediately end the practice of arbitrarily putting patients at the bottom of the placement lists of their chosen homes when they agree to temporarily move to a home or interim bed, not of their choosing
- Ensure health system officials are using “interim” beds as “flow through”, in accordance with fairness and as outlined in MOHLTC policy
- Ensure health system officials operate with “obsessively patient-centred” focus

We have been working within the system, trying for more than half a decade to resolve these concerns and achieve justice for our loved ones, to no avail. We are optimistic that your personal attention to these matters can help system officials understand the suffering of our loved ones, and understand that we are offering cost-free, efficient solutions that will not only benefit patients, but that can restore trust in a wounded system, and help ease the flow of patients through it.

We have an abundance of ideas borne of our experience, about how to work with you to create the health care you envision. We stand ready to serve, but in the meantime look forward to your prompt response to these most serious issues. Please.

Sincerely,

*Nancy*

Nancy Johnson  
Chair Northeast Family Councils Network (NEFCN)

cc. Roma Smith, Vice Chair NEFCN  
NEFCN Members  
France Gelinas, MPP  
Bill Walker, MPP  
Glenn Thibeault, MPP  
Louise Paquette, CEO NE LHIN