

Nicole Everest, Chair
Health Sciences North (HSN) BOD

Gregory Peres, Chair
Sault Area Hospital (SAH) BOD

Denis Roy, CEO HSN

Ron Gagnon, CEO SAH

Dear Ms. Everest, Mr. Peres, Mr. Gagnon, Dr. Roy:

Re: LHIN CEO December 19, 2016 letter and moving together toward “obsessively patient-centred care”

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 health system leaders.

System pressure down-loaded on frail patients and families

On December 19, 2016, LHIN CEO Louise Paquette wrote Mr. Gagnon and Dr. Roy relaying our concerns about local system officials continuing to pressure frail seniors and others awaiting LTC placement. We know it is not just hospitals that are challenged to deal with growing numbers of these frail patients. But whether they are in hospital, the community, or "temporarily" placed in LTC or "interim" beds, we have received numerous reports of untenable, unnecessary, additional strain on patients and families as officials use a variety of measures to resolve system challenges.

For instance, in Sudbury's hospital, we have heard of health care professionals under pressure to "move patients out". We have heard of some still openly advocating the need to charge such patients \$1000/day so they do not "block" hospital beds. As late as November 2013 HSN's last cold words in their discharge paper were about the option of staying in hospital for \$1000/day. (attached) Unfortunately, instead of this pressure on patients and families waning, we learned in the past year of similar practices spreading to SAH.

Impact on patients/families of system-centred solutions

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 ultimately intervention by local MPP, France Gelinias, 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.

The Sault story:

Over the past several months we have heard disturbing echoes of Maureen's and Joan Ann's stories as Sault Area Hospital has struggled with its own growing roster of frail seniors and others needing LTC placement. NEFCN members shared their stories of sick loved ones cowering in fear when threatened with unaffordable rates to safely stay in hospital.

A shuttered nursing home was refurbished and resurrected to "temporarily" house waiting patients safely in "interim" system beds. Facing \$1000/day hospital rates, many patients felt no alternative but to move, with the understanding they would be relocated to chosen homes when beds became available. Instead, officials moved them to the bottom of chosen LTC lists, never to leave the supposed "interim" beds. We understand these patients have been 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.")

Patient-centred decisions can drive system solutions

There are serious system challenges. We understand that. But we have been encouraged by Minister Hoskins and his expressed goal of "obsessively patient-centred care." We do not believe that down-loading system strains on fragile patients in the twilight of their lives, fits in that vision. We believe that looking at challenges first from the patient point of view will drive system solutions, and we are reaching out to you as pivotal partners in our local health care system, for specific support. Further to Ms Paquette's December 19 letter, we ask that you:

1. Take positive steps to remove reference to hospital rates from correspondence and staff discourse. No one wants to stay in hospital. In our repeated experience, people who resist discharge are not yet well, have reason to fear for their health and safety, and many who do leave, contribute to the high re-admission rates we have seen in our hospitals. If a patient expresses fear of leaving, surely the patient-centred approach is to probe the issues, ensure concerns are addressed, and that safe discharge with appropriate supports is doable. The hospital is not a place any truly well person can choose to stay no matter how much they offer to pay, so why even reference those rates in conversation and correspondence?
2. Join us in asking the Minister to ensure that patients who agree to move temporarily, either to interim beds, or a home not of their choice, are fairly treated. Currently we are urging the ministry to change its system-focused practice of *not* re-locating residents who agree to move on a temporary basis to another home, or to an “interim” bed. Patients who can trust officials to keep promises of re-location, would be more flexible, and their flexibility would conduce to smoother patient flow through the system.
3. Join us in asking the Minister to ensure that “interim” beds comply with ministry policy that says they are, “...*intended to “ensure a continuous flow through” so that interim beds are constantly freed up for new applicants from hospitals.*” As the numbers needing LTC placement grow, “interim” beds will be part of the solution, but it is important that those beds be authentically temporary, in sound, safe and comfortable facilities.

Untenable personal pressure and dilapidated “interim” housing in the final stage of life have no part in a vision of human, “obsessively patient-centred,” health care. As we enter a new year, we want to collaborate with you and all system leaders to re-build trust in our local health care system. Together we can show the province the way forward. We look forward to your response.

Sincerely,

Nancy

Nancy Johnson

Chair, NEFCN

Nancyanne1955@hotmail.com

cc Roma Smith, Vice Chair NEFCN

Louise Paquette, CEO NE LHIN

Dr. Bob Bell, Deputy Minister MOHLTC

France Gelin, MPP

Glenn Thibeault, MPP

NEFCN members

Voice for the Elderly

HSN Patient Family Advisory Council

SAH Patient Family Advisory Council

Richard Joly, CEO CCAC