



Residents' Voices:

IF YOU LIVED HERE, YOU'D KNOW



By: The Flamboyance



*In loving memory of our dear friend Barbara,
remembered for her wit, charm and sense of
humour. Our friendship was one of a kind,
and it isn't the same here without you.*



What follows was written before COVID-19 hit us all in 2020, although we weren't able to publish it then. We agree that it continues to be valuable as an account of our experiences in long term care, a picture of normalcy. Of both need and enjoyment.

The pandemic has lasted **more than two** years now, and the virus seems likely to continue and recur. The image of nursing homes is even worse than it was. Although the virus has afflicted nursing homes particularly badly, the one that we write about **has kept us safe**.

We shall start as we did before COVID-19.

There are three of us, and we are friends. That sounds like the beginning of a children's storybook, but our experiences are real, even if we have changed some of the less important details. The names we shall use are not ours, but call us Beth, Elsie, and Nora. Expert observers, including gerontologists we know, have told us that our point of view is important. We agree. As people here in Halifax often say, "If you lived here, you'd know." What we mean is this: If you live in a place that provides LTC (long term care), you know what it's like there. We also mean: Unless you actually live in LTC, you can't know what it's like. We residents are the real experts on long term care. And we hope that we shall be able to soften anxiety about places like the nursing home that we live in.

In some ways, our shared experience is unique. So it's limited. However much we generalize, we have to speak from where we are. That's in a twenty-four person unit in a nursing home located in a small Maritime province of Canada. Residents here share geography and physical need, as well as the facts that nearly all of us are women and nearly all of us are old. Still, all nursing homes have a lot in common, like anxious anticipation and ongoing doubts. Also the reasons for being there and the joy that is possible. Because of those shared situations, we can hope to present Residents' Voices. This.

As to us three, we met only here. Residents for about six years now, we expect to stay until death removes us. We know that we are lucky, living in one of the better nursing homes available. Let's call it Plentiful. We're also lucky because we are in a particular unit of about two dozen women that we'll call Merry (because it so often is just that).

Like the others here, we most certainly did not expect to end life in a nursing home. Still, it is right for us. All three of us agree: this is where we need to be now. Let's emphasize it: *This is where we need to be now.*



We've called ourselves residents. "Resident" is the name that most of us prefer. That's a fact; Plentiful's management took a survey. "Residents" is actually the best way to refer to the people who live here. We aren't "patients," because we aren't here to be cured, not of aging nor of our many other ailments. We aren't "clients" either. As Elsie says, "if we were clients, we could fire people." It's speaking as residents that we can tell you that most LTC homes aren't DNHs (Dread Nursing Homes). With this account we hope to do something unusual. In Beth's words: we're looking *out from the inside* of a nursing home, instead of the usual view *from the outside looking in*.

We're actually like most of Merry's other residents in important ways. We've all lived in Nova Scotia for many years. Each of us has been married for a long time (and two of us are now widows). We've all worked for pay as well as raising children. We each have grandchildren, fifteen in all. Plus one very small great grandchild. In Plentiful as a whole, those experiences are pretty common, as are most of our present activities and even our problems. We were lucky, perhaps exceptional, because we loved our paid work. And we were lucky too that our unpaid work produced healthy and happy children. We are typical nursing home residents because we require ongoing medical care and help with everyday life, 24/7 (in Nova Scotia that's the qualification for being in residential long term care).

Typically, we have to be helped in and out of our wheelchairs where we are when we aren't in bed. Not so typically, ours are power chairs. "It's like a one-person electric car," a friend told Nora. By contrast, most other residents have be pushed to where they want or need to go. Being able to move without help is truly liberating. We can roll as we wish between our rooms as well as into the dining room and the living room in Merry, then into Plentiful's elevators, moving away from our third floor neighbourhood. There's an enclosed garden down there. Plentiful has spaces for visiting, as well as for entertainment and worship. When we go outside Plentiful we can wander happily in our close neighborhood. That means coffee shop and library. And we can cruise in shopping malls when we have reached them by accessible buses or taxis. We visit our families and friends. Or we go to parks.



Something else about us three is also less ordinary, and even more important. Unlike the majority of Canada's nursing home residents, we are not suffering from dementia. That is, while we forget more than we used to, we are still fully aware of what's going on. People like us, with physical disabilities but not mental ones, are a small



part of our age group. We're nearly always overlooked when people think about long term care. It's just not recognized that we have the possibility of speaking on behalf of the voiceless majority here. So we do need to explain just why we three should be listened to.

What is most important is our perspective as residents here. In Plentiful, residents get *physical* care from RNs (Registered Nurses), LPNs (Licensed Practical Nurses) and providers of personal care called CCAs in Nova Scotia (Continuing Care Assistants). All of them also give *emotional* care - chats, jokes, attention to residents' hopes or fears. But staff don't experience life here in Plentiful as we do. Safety and medical care have to be their first concern. As a result, however well they get to know us they cannot see our lives here as we do. Nor can families entirely speak for residents. A family may believe that conditions are better than they look to us... Rightly or wrongly, they may fear the worst. It comes down to the fact that everyone here except the residents live somewhere else - not here as we do. *Everyone else goes home sooner or later.* Which we don't. So our voices are bound to be different, even very different.

But let's be positive now, getting away from the DNH. Our beauty salon provides a cheerful example of why residents' own voices matter. It's open three days a week, and residents are happy to go there. But why do they like it so much? We ask a professor. She is an expert on long term care, and she knows that her mother, a resident in LTC, really, really likes to have her hair done. The professor has never asked her the reason, so she guesses. "Residents who look good get better treatment by the care workers," she says. We disagree. In Plentiful, staff certainly comment admiringly on cuts and curls. But residents' grooming has no impact on how they are treated. Thank goodness.

We thought about it. "Getting my hair done makes me feel better," says Beth. "Especially when I'm having a bad day." "Yes," agrees Elsie. "It improves how I feel." But why? "Women around the well," Nora suddenly says. "It's like the way women used to meet around the well and gossip." It was the whole experience that mattered. Not expertise, not loving families, nor both together could explain why it's so good to get your hair done when you're living in a nursing home. It took actually going to the salon to understand how it provides an essential (emotional) service. Once again: If you lived here, you'd know.

We should explain how we ended up here. Like most people today, we hadn't really thought much about aging, let alone dying. All we knew was that the province of Nova Scotia has a list of people who entitled to nursing home care. It usually takes about twenty-four months to reach someone's name; then there's only one day to decide whether to take the offered space for LTC. If you refuse, your name goes back to the end of the line, to possibly wait



two more years. All of us were installed on that list. It worried us. Like everybody else, as we aged we had come to fear the DNH that lurked there waiting. To remind you, that's the Dread Nursing Home. To our surprise, it was a lot better when we got here. And our main message here is that we need not have dreaded it. Not Dread Nursing Home but Necessary Nursing Home, not DNH but NNH.

The fact is, most people don't realize what today's families mean for old folks. Families are smaller, while children and grandchildren are scattered, able to visit their elders but not to care for them. And people are living so much longer. Granny and grandpa can't just settle down to be cared for by their kids. Aging in place is a reaction, and it's a government policy here now. A good plan, when it works. But aging in place didn't work for the three of us.

We reached the point where we couldn't even get onto a toilet by ourselves. "Accessible" washrooms weren't really usable in most places, not in our homes, not even in hospital waiting rooms. We were lucky: we could hire competent and kind visiting careworkers to help us with showering and dressing, shopping and cooking, laundering and cleaning.

Eventually, though, we needed full-time support. In those last days at home (alone) we were each living rather painfully in a room or two. What began as small inconveniences became increasingly troublesome, then dangerous. Nora remembers how frustrated she was when a sink stopper got stuck beyond where a woman in a wheelchair could reach. All of us dropped things. The worst was when a bottle of cranberry juice slipped out of Elsie's hands, spreading broken glass and bright red juice all over the floor. Even in her power chair, she didn't dare go through it. Another example: in the days when Beth could still travel in a private car, she slipped when she was transferring into one. Her daughter was unable to lift her. Passers-by gathered. Beth giggles as she tells how, finally, she was moved by two strong young men who "reeked" of marijuana. "You gotta laugh," she says. That's a good general rule, we decide.

These weren't desperate situations. Each of us was repeatedly rescued by the kindness of neighbors or strangers. Nevertheless, each incident frightened us. And what if there was a fire, "especially when we were alone at night?" asks Elsie. We agree that the possibility of fires was our greatest fear. Wait by a designated stairway, the apartment dweller among us was told cheerfully. "From an eighteenth-floor apartment? in a wheelchair?" asks Norah. "Rely on a brawny fireman was what that meant," says Beth.



Another shared fear: falls. We were lucky - the unavoidable falls did not mean fractures and hospital. We were only trapped on the floor, unable to get up. Only trapped on the floor? Surely, being unable to get up from the floor is always serious. Elsie and Beth called 911 when they fell; they had learned that (brawny) paramedics will pick you up if you don't want to alarm family or friends. Nora didn't know about that option, so she repeatedly summoned a son. Apologetically. After we were safely installed in Plentiful, family members confessed to each of us how much they had feared phone calls in the evening or at night. We're grateful that they had, heroically, managed not to tell us earlier.

We don't like to ask for help. When we were living alone, we all knew that we had to. We also knew that just about everybody was ready to help when asked. We were reminded that our request gave other people the opportunity to do a good deed. That thought made us feel a little bit better about being so needy. When we moved into Plentiful, it took us a while to accept (gratefully) that when you live in a nursing home you'll be looked after. And what a relief that was. Eventually. When we arrived, everything was a blur. Our rooms felt as impersonal as a college dormitory. Family and friends helped, decorating and bringing familiar belongings. And careworkers welcomed us, helping us to adjust. Over time, we came to know them as individuals and friends.

We were definitely not enthusiastic about losing our privacy and our independence, quite apart from what we'd thought we knew about nursing homes. But we discovered that there are also pleasures that come from simply living – residing - here in Merry. As careworkers do their best to make residents feel at home, holidays matter. Plentiful has decorations throughout and parties for all the residents. And in Merry, there's always more. Wonderful celebrations are produced for just us by careworkers (with a bottle fund to support after-hours purchases). Our own special, regular CCAs and housekeepers adorn the neighbourhood's walls and ceilings. Birthdays mean posters and balloons on the birthday girl's door, banners in our dining room, birthday cake or birthday pie brought in for all the residents in Merry. We sing Happy Birthday and someone takes photos.

In December there are more festivities. We help to decorate our very own Christmas trees. Snowflakes and shiny balls hang from ceilings. We sing Christmas carols, some of them invented by us (see the Twelve Days of Christmas at the end of this piece).



Because we are not all Christians in Merry, during Chanukah an electric menorah is lighted in our living room. And we have autumn leaves, Halloween bats and spiders, hearts and flowers for Valentine's Day, festoons of shamrocks for St. Pat's.

As well, there are luncheons or teas for Canada Day, Mothers' Day, Valentine's Day, Halloween. At decorated tables we sip tea in special china cups. Treats include the mincemeat tarts served at Christmas, always something chocolate, always chips and Cheesies. Toasts are drunk with bubbly fake wine. There's appropriate music. Amazingly, beautifully, residents respond to the familiar tunes, dancing in their wheelchairs, singing even when they can no longer talk.

Just in our neighborhood, we have also invented a new holiday, Newfy Day. Newfy from the province of Newfoundland. We are all now honorary Newfies, initiated that day. (If you lived there you'd know). For our first Newfy Day on June 29, 2019, we each kissed a small, stuffed cod. We drank an inauthentic, non-alcoholic version of the Newfoundland rum called Screech. Then we were given certificates proclaiming that we are Newfoundland Screechers. Our favorite Newfy here is a housekeeper, the green-thumbed nurturer of houseplants and the chief animator of all festivities. On June 29 she wore a yellow rain slicker and a sou'wester. Also a beard. With three CCAs, she had rehearsed a jig that they danced to a tape of appropriate music. A resident Toastmaster called for silence so that she could voice our deep appreciation to all our staff. As so often, we all laughed and laughed.

Now for another story: the Flamboyance. (Three or more flamingos are a flamboyance. Think: a murder of crows or a parliament of owls). One of our daughters brought her mother a large floppy sunhat decorated with plastic flamingos. When we asked, two more flamingo hats were found. With pink ribbons to anchor against gusts of wind, the hats are actually useful for summer. We've discovered that there are hundreds if not thousands of flamingo items for sale online, including flamingos for gardens (of course). So we bought a flamboyance, three birds for Plentiful's lovely enclosed garden, three for the doors to our personal rooms.

In winter the door birds wear cozy hand-knitted scarves; in summer they have flowery hats. This photo of Flossie is from their first winter. The butterfly was added by our favorite (Newfy) housekeeper.



Flossie the flamingo, with scarf and bare head, plus butterfly.



In each neighbourhood in Plentiful residents line up to give Halloween candy to the small children of the staff. Costumed as fairies and super heroes, they ask politely for treats, far too young to threaten us with tricks. Then we have our very own Halloween party in Merry.

We are happy that we can include our flamboyance here. All the more so because, delightful as they are, we also want to make two serious points with them.

First: the staff, not just the one who put the flamingos in place, but all the careworkers. They are the best thing here, the people who really take the Dread out of DNH. Our private space is important, food is important, fun and games are important, but most important are the frontline staff, from housekeepers and kitchen workers to CCAs and nurses. We can't stress too much their unfailing skill and kindness in their under-rated, under-paid jobs. From daily personal care to the happy foolishness of holidays, they are dedicated, even loving. A CCA tells us how much she values her chance to care for others. "How interesting you are," she says, "so different from each other." A nurse tells us, movingly, that for her it is "a privilege."

Nearly all the employees here are women, especially those who clean, cook, and give personal care. Some are from Halifax or close by, lifelong professionals devoted to the residents they care for. But most are young immigrants, usually from the Philippines and India, occasionally from as far as Afghanistan or Eritrea. Often they were nurses in their distant homes, now working as housekeepers or CCAs until they can become Canadian citizens and be re-certified as nurses. They agree that care work in a nursing home is more demanding than nursing, both physically and mentally. Those who have previously worked as nurses also agree that working here will make them into better nurses than they were before.



And here is the Flamboyance at Halloween. Those are the flamingo sun hats even though you can't see the ornaments. We bought those boas online (chicken feathers, prickly). Pink domino masks and "cigarette holders" complete the costumes, which won second prize in a Plentiful-wide competition. Notice the branches and bats installed on the wall behind us.



Second: the value of friendship. Or perhaps we should say: the value of friendliness. We all need buddies. We need them to do things with, for mutual support and encouragement, to correct us, even just to play Scrabble or watch television with, most of all to laugh with. The three of us recognize that we are lucky that way. But, repeat, everyone needs friendliness. It's true that habits and experience make a difference. "What is the name of that tall CCA who doesn't have a nametag?" a new resident wants to know. Elsie tells her the name. How did she know? "I asked," she says. The comment comes back quickly and reprovably: "I was taught that it's rude to ask questions." But life is different now, we tell each other. You can change.

We all need to reach out to those around us, beginning with the other residents. Yes, sometimes it does feel as if old age and dependence are all that residents share here. All the same, although it does take time and even effort, there are also friendliness and even real friendship here. Everyone benefits from even the minimum of exchanging names and good-mornings. Reaching out is harder for residents who are in pain or lonely, residents who are used to living alone, residents who are just plain shy. But perhaps those are the ones who need friendliness most.

We three agree that it's been good to meet the other people at Plentiful, beginning with the residents. Most of them were born in Nova Scotia and have lived here all their lives, often in homes their families have owned for many generations. They have stories to tell about living during war and peace in Nova Scotia. A resident from another, distant country tells us that she is here in Nova Scotia because she "met a handsome Canadian soldier." Then there are the careworkers of so many nationalities. It's good to learn and remember unfamiliar names, trying to understand lives and hopes.

A final story: the Balloon. Selected by a small grandchild, it was an inflated plastic heart about eighteen inches tall. A colorful Happy Birthday was embellished with frills and stars, and edged with a furry fringe. As each of us celebrated her birthday, she had the card on a wall, delighting everyone who came in. When we finally, reluctantly, took it down for the last time, we remembered that breathing in helium makes for funny-speaking. So we all took turns inhaling thru the straw that was supposed to empty the gas. Gabbled away, quacking like ducks, we roared with laughter.

Yes, it is possible to celebrate and even have fun here. It's not quite a Family in our neighborhood, but it is often very like one. Perhaps a feeling of closeness? Something about mutual support? Perhaps a Community is closest. Remember: NNH not DNH. Not Dread Nursing Home but Necessary Nursing Home, even Neighborly Nursing Home.



The balloon-speak is the final story of our story. We've attached a song that we created together. LTC scans nicely for singing and this song has become a favorite of Merry's holiday season. In our NNH.

The Twelve Days of LTC Christmas

Composed by the Flamboyance for Christmas 2018; tune and repeats as in the original.

On the first day of Christmas, my true love gave to me a place in an LTC

On the second day of Christmas, my true love gave to me two cups of tea

On the third day of Christmas, my true love gave to me three meals a day

On the fourth day of Christmas, my true love gave to me four laundry carts

On the fifth day of Christmas, my true love gave to me five residents

On the sixth day of Christmas, my true love gave to me six nurses tending

On the seventh day of Christmas, my true love gave to me seven pills a-popping

On the eighth day of Christmas, my true love gave to me eight cleaners sweeping

On the ninth day of Christmas, my true love gave to me nine cooks a-heating

On the tenth day of Christmas, my true love gave to me ten songs a-singing

On the eleventh day of Christmas, my true love gave to me eleven chairs a-wheeling

On the twelfth day of Christmas, my true love gave to me twelve beds a-waiting

Editor's Note: *The authors of Residents' Voices are Barbara Cooper, Elaine Hawkins, and Naomi Black. Please feel free to pass it on to anyone considering or experiencing admission to nursing homes, or in fact to anyone who might find it of interest. But it is our property, not to be changed or commercialized.*





We must thank our research assistant Marco Redden, who was endlessly cheerful and helpful. York University provided financial support.