Home Interrupted

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> "Do not worry; we will take good care of him. We take good care of *our* residents."

These words are meant to reassure me and help me to move on, whatever that implies, as my husband enters long-term care. However, years later, I still hear them and they continue to instill fright and send a chill down my spine, just as they did when I first heard them. At this initial meeting, I wonder: "Who are you to take good care of him? And why do you say *'our'* residents? Those are individuals; they are not yours, no one gave them to you." And so this is the first part of entering long-term care: a process that is meant to alleviate my burden by effectively removing my husband from my care. Granted, I could not take care of him at "home," so here we are in the hallway of a nursing home. He is unaware of what is going on, and I am in a kind of shock. I say "a kind of shock" because the journey from the car accident to this facility has taken us to a variety of medical settings. Nevertheless, this new setting now presents itself as a place of permanence. The comfort I may have found in the transitory nature of the other medical settings is removed by the reality of this new "home."

This is a public long-term care institution: funded by the Quebec provincial government and subject to provincial standards. Nevertheless, the physical space is old; it looks like a hospital; the shared room in which he will be spending much of his days is too small to accommodate him and another resident together. My husband will need to be moved from the original placement, and the other residents will simply be shuffled to other rooms so that he can be transferred to a larger room.

It seems that, in this place, "a room of one's own" is granted only on a temporary basis. In any case the rooms are rather interchangeable, and they do not have much wall space to accommodate personalization. It is hard to claim ownership of such spaces, and it appears as if very few residents have tried to do so. Really, only one's bed is "one's own," and I suspect this is more for sanitary reasons than actually granting ownership to any one resi-

dent.[1] This place appears temporary in a permanent way; I've heard it called "God's waiting room." I can only presume that the thinking goes like this: why encourage ownership, when the resident is expected to depart? That is the one certainty – death – although the timing might be unpredictable. As in the departure lounge of an airport, when you leave, you leave nothing behind. It just makes everyone's life easier that way. The atmosphere is one of instability amid un-change: there is the recognized fragility of being, yet nothing is done to support it or even grant it dignity. Here, this fragility is a fact of life that must be accommodated. It is a source of employment, although those for whom one cares continually shift: different bodies, same care.

Disruption

It may appear incongruous, yet within the formidable institutional structure that is long-term care, transience remains a permanent feature. Some of the literature on long-term care institutions uses the concept of liminality to capture the atmosphere that reigns in such locations. As Leibing et al. explain in their article on living spaces and older individuals, liminality can be used to denote a transitory state, of being betwixt and between, or it can also denote a static state in itself (12).[2] For these authors as well as others who have used the concept of liminality to examine facets of long-term care, the central idea is one of uncertainty, of not having a specific location.[3] Liminality indicates a grey zone of ambiguity, of not being anywhere in particular for any set length of time. If the institutions tend to be architecturally similar and the care rather uniform, there is always a feeling of uncertainty. In part, this is because the people inhabiting nursing homes are usually in the last phase of their lives. So when a resident dies, there is often no official acknowledgement of his or her passing. All of a sudden, the person is no longer there and soon someone else occupies the room.[4] It makes for a fragile and shifting community, where loss

1 | In Quebec, the actual bed is the property of the long-term care residential home. When a resident moves or dies, the establishment keeps the bed.

2 | It should be noted that the authors' discussion focuses on assisted living places and that institutions are regarded by their respondents as scary places where all individuality gets lost.

3 | For example, in their study of privately paid caregivers in long-term care institutions in Ontario, Daly et al. use the term to refer to those individuals' location in the policy–family–market triad.

4 | If this was my experience, it is not the practice everywhere. Some nursing homes have a memory book at the entrance of the building where the life of a resident can be celebrated and the loss acknowledged.

lurks but remains unacknowledged. Perhaps this silence is meant to diffuse the fear that death is always near. For the staff, it may help them normalize death as an inevitable component of their routine of care.

The status of most people in residential care is that of outsiders, even if they remain within society. They are not completely outside the flow of society, but they are certainly marginal to it. The time of residence in long-term care is expected to be rather short for most residents.[5] This may reinforce the sense of liminality, and it may be an excuse for the lack of effort to redress this feeling. Nevertheless, for those who are older it becomes an inevitable phase of life, even if unpleasant, especially since we are living much longer. However, my husband's situation defies even this marginal acceptance. He was in good health, he had a job, and he could be readily perceived as contributing to society. Now, at barely 40 years of age, he has suddenly become a broken, unrepairable human being who is institutionalized. As one care provider told me, he is expensive to the system: he has been in a nursing home for a long time, requiring the maximum number of care hours.[6]

At this point, I need to explain how my husband and I came to such a juncture, so I will now start the story from the grim beginning. Some years ago, my husband and I were in a car accident. He suffered a severe traumatic brain injury that has left him quite disabled, both physically and cognitively; he requires care for all his needs. After more than four months in acute care, he was transferred to a rehabilitation centre, where he stayed for more than six months. The practice has since changed. I doubt that a person with his level of injury would be offered any rehabilitation today and, if they were, it would be for a much shorter time period. Toward the end of my husband's stay, the rehabilitation team concluded that he would not make any appreciable gains and would never regain anything close to a functional status. So he was eventually discharged with the goal of sending him to a long-term care institution. Since placement was not immediately available, he was moved to a long-term care wing of an acute-care hospital – again another disruption, although one that is fairly routine.

It is often the case that a patient goes from an acute-care setting to rehabilitation and is then sent to his or her prior home. That had been the process that I had followed after my own injuries. The rehabilitation centre was not meant to be a homelike environment; it was a deliberate attempt to simulate home in order to prepare patients for their return to their original abodes. For example, during my rehabilitation, I experienced simulated stairs, bikes, and kitchens in

5 | The average length of stay in long-term care is 18 months (Macqueen).

6 | In order to reside in a long-term care residential centre (CHSLD, centre d'hébergement de soins de longue durée) in Montreal, the maximum number of hours of care is three per day. See Gouvernement du Québec.

order to regain functionality. These substitutes were obvious and were usually embraced, as they held the promise of returning home: necessary steps to regaining some form of normality. However, in the case of my husband, there was no such hope. So we had to envisage leaving rehabilitation to go to a new a place of faux permanence – an institution. This meant having to adjust my goal and hope of sharing a home with him.

Throughout the course of my husband's rehabilitation, the practitioners at the centre watched me in order to gauge how I would cope with the realization that home would have to change meaning for me. They encouraged me to think of my husband as finding a place where his needs would be met, and that I could then be relieved of any worry or burden of having to care for him. They did not frame the long-term care place as an eventual homelike environment, but rather as a place where he could be cared for. The disruption at this time was the expectation that my life and that of my husband could be neatly separated. I could continue to live as I had previously lived and function normally, and he would simply become the institutional charge of the medical system. There was little room for negotiation or for any other way of including my husband into the story of my life without this very permanent rupture. I felt an imposed sundering of our lives. To think otherwise was perceived as abnormal: why would one continue to have an extended relationship with an institutionalized other? Yes, there could be regular visits at holiday and significant times, but our lives would have to take separate trajectories and intersect only briefly at those times.

From the hopeful world of rehabilitation then came the discharge to whatever acute-care hospital had the means to care for a patient with total needs awaiting long-term care placement. This transfer was upsetting, but the experience of rehabilitation had been so terrible that it was almost a relief to be out of a setting where one was constantly reminded of being a failure. The head nurse of the long-term wing was not thrilled to have "heavy patients," as it meant more staff were needed, and I am sure she had to deal with budget considerations. She was eager to have him placed as soon as possible, and she did not react well when I refused the first place that came open. My refusal was based on the location and accessibility of the long-term care establishment. It was important to me that I could easily reach my husband's new permanent living space, and access to public transportation played a key role in my decision. It took over six months for him to get placement in a nursing home that could meet our needs. When the time came to move to the long-term care institution, the break from the acute-care wing was less problematic, as I had been told many times that it would be temporary, but I did have to say goodbye to care workers who had been kind to us. Always on the journey through these different settings, we found leaving some of the practitioners to be difficult.

At the time of my husband's admission to the long-term care centre, I was not particularly disturbed by the medicalized environment; in fact, I was used to it. I think that if the nursing home had been a more homelike and friendly environment, I might have been more unsettled because it would really have appeared as if my husband was going to have another home and I would potentially be excluded. As it was, the medicalized setting was simply a continuation of what I was used to.

A Disturbing Presence

In Quebec, as in many jurisdictions across Canada, nursing homes or, more accurately, long-term care institutions provide care according to the hours of assistance required by individuals. Residents are housed according to the hours of care required and not according to age, which means that some institutions can have heterogeneous populations.[7] Given that individuals regardless of age may require extensive care, there have been recommendations to have separate places where younger individuals can live (Association québécoise d'établissements de santé et de services sociaux). Unfortunately, my husband is so severely disabled, and at that time he was not taken to be aware of his surroundings, that such an option was not even considered. In order to give a more complete picture of the situation, I will at this point clarify his cognitive abilities, as those are hard to gauge in the case of a head injury. He recognizes me and can answer simple requests with a yes or no. He can be verbal, but he needs to be calm and can get very agitated quite easily. This is typical of an individual with a head injury, especially one in which the frontal lobes are damaged. Such individuals have difficulty dealing with any new stimulus.

When he first entered the long-term care institution, he was a bit of anomaly as an individual with a severe traumatic head injury. Most residents were older or, if they were younger, had degenerative neurological conditions such as multiple sclerosis and did not have major behavioural issues such as yelling or swearing. Coping with someone with a head injury requires specialized care, which was not available since the institution was focused primarily on dealing with physical needs.

At first, the personnel were very nice and certainly had empathy for a younger person who had suffered such a tragic fate. Their lack of training did not help them understand the negative sides of a head injury, however, and at times my relationship with them was quite strained. I was spending a fair amount of time there initially. Since they saw their job as taking care of someone who

7 | For a discussion of different types of long-term care institutions in Canada, see Banerjee.

could no longer function, my presence was superfluous and they could not understand what I was doing there. As far as they were concerned, I should simply go on with my life and leave my husband behind; I was hanging on. If my presence was tolerated and even encouraged in the rehabilitation setting as part of my husband's recovery process, in the nursing home I became an intruder, a disruption to the flow of care.[8] However, I was not ready to go on with life without somehow keeping my husband in it. In addition, I was not convinced that the care he was getting was adequate. My problem was to negotiate the seemingly irreconcilable goals of keeping an eye on my husband's care and living my life as a functional individual in the normal flow of society.

If finding and claiming my place within the nursing-home context was difficult, it was also a challenge in my regular life. While I was writing my doctoral dissertation, my schedule was fairly flexible and I did not have to account for my time. However, when I started teaching, when asked about my personal life I would explain that my husband was in a nursing home. This declaration was usually met with awkward silence. I took the decision to simply stop mentioning him or my visits, as it was an unsettling reminder that life does not always progress smoothly in expected ways.

Two-Home Syndrome

When a close family member is institutionalized, those who are left behind are faced with an incomplete or somewhat broken home. I have tried to recapture the spirit of home in the location where my husband is living. I have thus become someone with two homes: one that was the home I furnished and inhabited with my husband and where he no longer lives, the second a place where I can sit in an uncomfortable chair and share small pleasures with him such as watching television. In addition to the awkward room arrangement, which often means that one is sharing a room with a stranger and his or her family, the physical surroundings are uncomfortable in this new living space. I have only a small chair to sit in, and since my husband spends most of his time in bed, the room has become the primary framework of life.

8 | While often unrecognized, families play an important role in the care of institutionalized family members. In their study, Keefe and Fancey recommend integrating family members in the care structure. In his review of American long-term care institutions, Gaugler explains that programs have been put forward to improve family involvement as well as relationships between staff and family. However, in my experience, such programs have not been put in place in Quebec. The only change I have witnessed is the fact that family members are invited to participate in team meetings concerning the care of family members. These meetings take place once a year.

I call this the two-home syndrome: one is never quite at home when one is at the old home, and the other place is not really a home. The negotiation of the disruption of home into two places may take a while to accomplish. One can try to make the second homelike environment somewhat pleasant, but it always has to be negotiated through institutional structures and lack of privacy. So for some time one may be in a liminal space: never at home in any of the two homes. It can certainly be negotiated eventually, but it takes both time and conscious effort. I would say that the rupture is never mended but the situation can become normalized. One learns to live with one home and another good enough home where the family member lives. It becomes an interruption that can be navigated.

My solution at the time of my husband's arrival at the long-term care home was simple: since I could not do much about the surroundings, I tried to make his room homelike by being there and sharing time with him. I understand now that my presence was disturbing to the staff. They were used to going about their routine unfettered by intruders, and my constant presence somehow interrupted the flow of care and their patterns of work. Nevertheless, I believe that my husband was aware enough of his surroundings to know he was in an odd place, and that my presence was at least a familiar and stabilizing element in the confusion of his new institutional life.

As I understood it then, and still understand it now, home is about being close to loved ones; it is about sharing space where one feels relaxed with close others. If I could be close to my husband and he felt close to me, I believed that I could still capture an essential element of home, even if the surroundings belied home and screamed "institution." If my home came to an abrupt end with the car accident, my seeking and trying to build "home" continued despite the institutional flow of life that was taken to somehow encourage homelikeness, without ever actually achieving it.

The Ebb and Flow of Care

Over the years that my husband has been living in this institution, changes have taken place. This particular long-term care centre sits at the crossroads of institutional transformation. That is, the centre has a long history of being an institution for the "sick and destitute incurables," as an account of the centre explains (Grace Dart Extended Care Centre). At the beginning of the last century it was a hospital for tuberculosis, and then in the mid-twentieth century it became a centre that accepted individuals who could not function without care in mainstream society. Since at that time persons with disabilities were institutionalized far more routinely, some of the residents who had been there for a long time would not be institutionalized today. It made for a varied

community of residents. However, at the end of the twentieth century, social conditions for institutions started changing. The Quebec ministry responsible for long-term care saw nursing homes no longer as institutions but rather as a *milieu de vie substitut*, or a homelike environment (Ministère de la Santé et des Services sociaux). Therefore, the institution where my husband lives has had to change or at least try to adapt to this new philosophy.[9]

As this shift swept through in the late 1990s, long-term care institutions were under pressure to become more homelike. Recognizing that as a society we were living longer and that many older persons could not remain in their homes, the focus of the ministry was to de-institutionalize long-term care centres or at least make them feel more homelike. In part, the impetus for this alternative homelike environment, or *milieu de vie substitut*, is to encourage residents to adapt to a new life. These individuals should still feel as if they were in a home and not in a hospital, which is what most long-term care institutions evolved from. And the emphasis on "homelike" is meant to encourage this new life to be as normalized as possible. It is also an explicit recognition that the person still has a life to lead; she or he is not simply in "God's waiting room". This is a good way to think about the new phase of life: an active part of living. Instead of waiting for death, the focus on "homelike" puts life as the main concern. And since the majority of residents are long retired or, in any case, elderly, and were probably doing much of their living in their homes, home was the primary place where they spent their time. Home is a significant emotional tie to life, at least in term of physical surroundings. So it made sense that long-term care institutions should strive to create a homelike feeling within their physical surroundings.

This is what happened at my husband's institution. If the centre could not change its overarching physical structure – the corridors are long and the rooms are hospital-like – it could at least become more attractive. The rooms were painted and some of the offices were changed into larger living rooms with television sets and communal tables. The effort was commendable and seemed to make some residents and family members happy. At the time of the initial renovations, I was a member of the residents' committee, and the president of the committee, who had lived there for quite a long time, was most thrilled with these improvements. The effort was designed to change the immediate surroundings of the institution: what could be seen by the residents in their

9 | As stated on the web site, "The mission of the long term care centre is to offer, in a temporary or permanent fashion, a substitute home environment, housing services, assistance, support and surveillance services, as well as rehabilitation, psychosocial, nursing, pharmaceutical and medical services to adults who, due to their loss of functional or psychosocial autonomy, can't reside in their natural home environment, despite the support of their entourage" (Grace Dart Extended Care Centre).

daily routines. I must say that it certainly was more pleasant to walk around and to be able to watch television or simply sit around a table.

Such changes signal a move away from characterization of long-term care institutions as primarily liminal spaces. The changed interior is meant to anchor life in the everydayness of a facsimile of home; thus, it encourages the view of long-term care as a phase of life. I think the effort is quite notable and has been in place in most jurisdictions in Quebec and across Canada, depending on budgets, of course. There is nonetheless still an element of liminality in the sense that long-term care, in most cases, is the final destination before one dies. This can never be erased, since the population that inhabits these centres is taken to be at the final phase of life. However, the emphasis on the pleasant surroundings tries to erase at least some of the negative connotations of moving into a long-term care centre. In addition, the renovations and small improvements are part of an attempt to move away from long-term care institutions as "total institutions" (Goffman).

Transforming the immediate physical surroundings is an important first step, but it has remained the only step. If the surroundings play an important part in creating an atmosphere of home, there are other facets to institutional care that should change also. Institutions are not simply a physical structure; they are also a place where people work and, particularly in the case of long-term care centres, live.

The centre where my husband lives is regulated by the clock. It is certainly the case that our lives in general are regulated by going to work or school at set times and eating according to a schedule, but this regimentation is even more pronounced in institutions. And the interruptions are usually out of the resident's or family's control. For example, the assistance that takes place regularly at set hours in order to maintain efficiency produces small but continuous disruptions to the flow of life. Sometimes, the staff can help someone if they ring. However, care is scheduled in rounds. This is a direct consequence of the medicalized environment from which long-term care originates and in which the nurse goes around giving patients their medicine according to a set schedule. Similarly, in institutions, at set times, care workers go from room to room to reposition the resident or check if the resident needs to be changed. Despite the discourse surrounding the importance of home, a medicalized structure still prevails in long-term care facilities.

In addition, efficiency regulates institutional care, and it is perceived as most efficient if certain caregiving activities take place at set times. As one resident told me, "In effect what happens is the staff all gets going at the same time and then they all sit down at the same time." Individuals who have mobility impairments need to be repositioned every two to four hours to prevent pressure wounds. Therefore, when residents need to be repositioned, institutional efficiency demands that it be done room by room, starting at a set time each day

and ending at roughly a set time. This in part fulfills the goals of long-term care, which include providing personalized care in a safe and secure environment, yet it is at odds with the goal of providing care in a familial atmosphere.[10] Perhaps it is too much to ask for, given the medicalized environment in which care takes place. Still, the notion of the "not-home" is thus continually being suggested by the small and continuous interruptions that arrive at set times. Instead of punctuating special times of day, such as lunch or dinner, they often disrupt the daily flow of life.

When they have to provide care, some of the care workers or orderlies will be polite upon entering the room. They may announce that they are coming in to check on the resident, but very often, as is the case with my husband, they will just come and accomplish whatever needs to be done. They are on tight schedules, so they do not have much time to chat.[11] When someone has impaired cognition, such as my husband, it may simply be assumed that the person does not really understand what is going on, and actually telling him what is going to take place will be perceived as a waste of time. As one care worker said to another worker when speaking about my husband, "Why bother asking him? He is just going to swear." This in fact demonstrates that the care worker does not really know how to handle a person with a head injury and has not taken the time to understand what is going on. So-called personalized care is actually rather impersonal, and this is in part for the sake of efficiency. It is not *personalized* care per se but *individualized* care in that every individual gets cared for personally. In that sense, it is individualized care: every individual receives care that is adequate for him or her. However, it remains impersonal as the needs of each resident are not contextualized but rather remain generalized, to be taken care of at regular and predictable times.

This broken flow of life affects the quality of homelikeness in a couple of ways. These small interruptions serve as reminders to residents and their families that they are living in a facsimile of home where the likeness is in fact quite superficial. If a resident is watching television, he or she can be interrupted by the rounds. That is a fact of institutional life that cannot be controlled, and it is often what most people fear about institutions: they become objects of care. The individuality of the resident gets lost in the timetabling of care. As I sit there with my husband quietly, I am always aware that at 2:30 or so, someone will come to reposition him. If the flow of life is often disrupted in regular life, it becomes ingrained in institutions. There may be some efforts to accommodate individual needs, but if such needs are not medical, are just

10 | As the Association québécoise d'établissements de santé et de services sociaux explains: "Favoriser l'aménagement de milieux de vie sécuritaires, personnalisés et empreints d'une atmosphère familiale."

11 | For a critical discussion of paid care work, see Lanoix.

a matter of preference, and cannot fit neatly into the regularized flow of care, they remain unmet.

In addition, the structure of care is such that a person's most intimate care is provided by persons who will usually remain strangers. In some ways that can be liberating, but in other ways it reinscribes the notion of not-home. Some individuals may prefer to get care from persons who are not family; in that way they preserve the intimacy of the bond with the family member. Even in such cases, the caregiver will be someone who will become familiar. However, this does not really happen in institutions. Workers must remain professionally detached, and it is often the rule of establishments that a certain distance must be maintained.[12] It is a difficult negotiation to make, and care workers are not supported enough in this. Workers respect the privacy of the medical dossier, but at the same time, the structure of care provision has an impact upon the privacy of residents. One is very seldom alone in a long-term care institution. The boundaries between oneself and others, either workers or other residents, have to be constantly renegotiated. Again, this aspect of institutional care continually reinscribes the not-home. An individual has to somehow carve out a space of homelikeness amid the constant pressures of becoming an institutionalized object of care.

Fragments of Home

In conclusion, despite the best intentions of regulators, there are many ways in which the idea of home is disturbed. First, quite obviously, when a partner has to be institutionalized, home is no longer a single place. I had to negotiate my home without my husband and this other place where he was living. However, this other location is also a place where people work and other people live. It is an odd living arrangement, and it is difficult to understand one's place within such a setting. I could attempt to see myself as giving some care or participating in my husband's care, but it became apparent that I could not really relate to the people who were caring for my husband as co-caregivers. I was seen as a family member that made demands. I was like a boss in a way and was often perceived as a hindrance to the care practices that were in place. I was a disturbance; my mere presence needed to be accommodated, and not every worker felt particularly good about that.

12 | It is not that care workers do not care; they are simply not given the *time* to care. For a discussion of nursing-home workers, see Diamond. Although dating from 1992, this book is still relevant and remains a lasting contribution to the understanding of care work.

As a family member of someone living in long-term care, I have become particularly aware of the manner in which the trope of home functions as a way to remind me that my husband is living in an alternative homelike space. This space is provided as a way of humanizing his care, but it remains fragmented and ultimately inauthentic. If some pieces of homelikeness can be recuperated, the apparatus of institutional care can, in turn, easily dissipate them. This can only result in a continuous shift between home and not-home. In addition, the institutional care he receives is regulated in a way that reinscribes his body as disabled and as Other, especially since he is cognitively impaired. Because he cannot voice his needs, he is taken to be apathetic and uncommunicative. This means that he is physically repositioned at set times. His caregivers do not feel they need to engage him; they can get away with entering his room and mechanically providing care. The flow of his daily life is punctuated by care provision that arrives at a set time and not according to his needs. Within an institutional setting, even if it purports to be homelike, this acts as an indicator that one is an object, rather than a subject, of care.

Institutional interruptions become the norm in a facsimile of home. The daily activities of care continually reinscribe the "not-home" within the living environment. Because the focus on "homelikeness" targets the physical surroundings of long-term care institutions and not the manner in which workers interact with residents, those institutions cannot be "homelike" and much less a "home." Likeness cannot be produced and maintained by the physical environment alone; it should be inscribed in the practices of care. Therefore, to be at home should be embodied in these practices of care, which in turn support the flow of daily living and do not merely serve to disrupt it.

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