

Improving Care for Seniors in Chatham-Kent and Sarnia/Lambton:

Understanding Alternate Level of Care Designations

February 2012
Prepared by **MASS LBP**

In partnership with:



Executive Summary

Alternate Level of Care (ALC) designations are a persistent challenge in Ontario hospitals. Patients are designated as ALC when they no longer require acute care but cannot obtain the medical, psychological, or emotional supports they need elsewhere in their community, whether at home or in another care facility.

In the interconnected health care environment, the causes of ALC are complex. Countless decisions on the part of medical staff as well as patients and their loved ones result in patients remaining in ALC beds.

The Erie St. Clair Local Health Integration Network (ESC LHIN) has initiated several projects to reduce the frequency of ALC designations within its borders. This report details the results of the second phase in a two-phase project to better understand the decision-making processes of patients and their loved ones who choose to remain in hospital rather than returning home or moving to another care facility.

The first phase of the project was made possible with the participation of the Windsor/Essex–Leamington District Memorial Hospital, Hôtel-Dieu Grace Hospital, Windsor Regional Hospital, and the Erie St. Clair Community Care Access Centre (CCAC). The ESC LHIN approved the phase-one report in December 2011.

This report details the efforts of the ESC LHIN, Bluewater Health, the Chatham–Kent Health Alliance, and the Erie St. Clair CCAC to collectively engage patients, family members, and front-line staff to gain insight into the ALC pressures in Chatham–Kent and Sarnia/Lambton. The project aimed to capture the perspectives of patients and their loved ones through conversations with patients, family members, and those who work most closely with them.

The ESC LHIN commissioned MASS LBP, an advisory firm specializing in public and stakeholder engagement, to design and coordinate the consultations and analyze the results. MASS LBP created three programs based on consultation with all partnering organizations. Between November 22, 2011, and January 10, 2012, ESC LHIN staff conducted private interviews with nine ALC patients and eleven family members. The ESC LHIN also hosted three workshops for the front-line staff at each of the partnering organizations to discuss their understanding and perceptions of ALC patients and their families.

This report draws insights from the consultations with ALC patients, their family members, and front-line staff. An account of these sessions, emerging themes, and recommendations is included in the report. It should serve as a supporting document for the ESC LHIN and its partners as they continue their efforts to ease the transitions between models of care and to improve care in the region.

The recommendations are based directly on the input we received from ALC patients, their family members, and front-line staff. They represent their interests and perspective. The recommendations are organized into four themes:

1. Streamlining the process – Improve hand-offs between staff to eliminate duplication or unnecessary waits. Review the referral and assessment processes across hospital sites in order to increase efficiency and standardization. Enable patients and family members to be constructive members of the care team.

2. Collaboration among care providers – Standardize and clarify roles and responsibilities among the care team. Improve communication among the care team in the hospital to ensure patients and family members receive consistent messages from all care providers, including physicians, nurses, and allied health professionals.

3. Education and prevention – Develop and conduct ongoing classes to educate the family members and caregivers of seniors. General health system literacy to help with navigation, tips on what to look for and consider when contemplating long-term care, and how to know when your loved one needs long-term care are all areas of CCAC expertise that can be shared with the public.

4. Special needs cases – Expand range of care specifically tailored to younger patients with debilitating chronic disease. Consider designated units within hospitals and the group-home model of assisted living in the community. If possible, develop community options for these patients who are outside the traditional long-term care model.

Table of Contents



Executive Summary	2
Introduction	5
Methodology	6
What we learned from patients	
The patient profile	6
Perception of hospital care	7
Perception of long-term care	7
Communications and communicators	9
What we learned from family members	
The family member profile	10
Perception of patient condition	10
Perception of hospital care	11
Perception of long-term care	12
Communications and communicators	14
What we learned from front-line staff	
Thanks, but I'd rather stay here	15
The referral process	16
Suggestions for improvement	18
Regional Observations	
Comparing patient need	19
Navigating the system	20
Comparing staff perspectives	21
The role of long-term care facilities	21
Recommendations	
Streamlining the process	22
Collaboration among care providers	23
Education and prevention	23
Special needs cases	24
Appendix A: Interviews – Patients	25
Appendix B: Interviews – Family members	41
Appendix C: Staff sessions	66

Introduction

Alternate Level of Care (ALC) designations are a persistent challenge in Ontario hospitals. Patients are designated as ALC when they no longer require acute care but cannot obtain the medical, psychological, or emotional supports they need elsewhere in their community, whether at home or in another care facility.

ALC designations are disruptive for hospitals and the patients they serve. They increase wait times – particularly in emergency departments – and put pressure on hospital budgets. Patients who remain in hospital are also at greater risk of infection, de-conditioning, and depression.

The rise in ALC designations underscores the complicated task of providing optimal care to a vulnerable patient population not well served by a health system overly reliant on the comprehensive services offered by hospitals. This task is complicated further as the prevalence of complex chronic disease and the province's frail elderly population continue to grow.

The Erie St. Clair Local Health Integration Network (ESC LHIN) has initiated several projects to reduce the frequency of ALC designations within its borders. This report details the results of the second phase in a two-phase project to better understand the decision-making processes of patients and their loved ones who choose to remain in hospital rather than returning home or moving to another care facility.

The first phase of the project was made possible with the participation of the Windsor/Essex–Leamington District Memorial Hospital, Hôtel-Dieu Grace Hospital, Windsor Regional Hospital, and the Erie St. Clair Community Care Access Centre (CCAC). The ESC LHIN approved the phase-one report in December 2011.

The second phase extended the investigation to Bluewater Health, the Chatham–Kent Health Alliance, and the Erie St. Clair CCAC. Consultations with the partner organizations served to ensure that the dialogue guide reflected the interests and concerns of the Chatham–Kent Sarnia/Lambton communities.

Goals

The project was designed to better understand the mindset and views of ALC patients and their loved ones concerning their decision to stay in hospital. Dialogues were conducted with ALC patients, family members, and front-line staff.

Specifically, we set out to:

- Learn what patients and their loved ones understand about their condition and care needs.
- Better understand if and how patients and their loved ones assess the risks of prolonged hospital stays.
- Identify the barriers to effective patient transitions from an acute to home or long-term care setting.

- Generate a comprehensive picture of the education and decision-making process that patients and their loved ones go through when selecting a long-term care home.



Methodology

Following the success of the first phase of the project, the ESC LHIN again commissioned MASS LBP, an advisory firm specializing in public and stakeholder engagement, to design and coordinate phase two consultations and analyze the results.

For consistency and comparability, the programs were unchanged from those used in Windsor/Essex. MASS LBP and the ESC LHIN consulted with all partnering organizations to ensure that the program was relevant to their communities. One interview manual was produced to guide the conversations with family members, another for patients. Staff met in small groups, and MASS LBP supplied the workshop program, including templates to collect participant feedback. MASS LBP trained ESC LHIN staff to conduct the consultation sessions.

Between November 22, 2011, and January 10, 2012, ESC LHIN staff conducted private interviews with nine ALC patients and eleven family members. The ESC LHIN also hosted three workshops for the front-line staff at each of the partnering organizations to discuss their understanding and perceptions of ALC patients and their families.

Interview length averaged approximately forty-five minutes. Patients were interviewed individually, unless the patient requested a family member to be present. The full support network was invited to participate in the family member interviews, although the majority of family member interviews were conducted with individuals. A MASS LBP observer was present during the majority of interviews. Staff met in groups of five to twenty for two-hour sessions. The results were collected by ESC LHIN staff and submitted to MASS LBP for synthesis and analysis.

What we learned from patients

The patient profile

The patients we interviewed formed a profile of a challenging patient population with complex needs that do not fit easily into established models of care. The patients ranged in age from thirty-five years to older than ninety years. The majority of patients were under the age of seventy-five years, and fully one-third were middle-aged. Patients were suffering from a variety of chronic diseases, including multiple sclerosis, Huntington disease, and cancer. Many were obese and suffered from multiple bariatric diseases, such as cardiovascular ailments and diabetes. Still others had been admitted to hospital due to complications arising from another treatment, such as a side effect of a medication or an infection stemming from

MASS LBP
392A King St. East
Toronto, ON M5A 1K9
416 841-4433
800 369-7136

surgery. Most suffered from limited mobility and required a wheelchair, lift, or personal assistance for daily living activities.

Almost all had been admitted to hospital on at least one previous occasion. The current admission ranged from six months to eight years, with the median being twenty-three and a half months (just shy of two years).

Prior to admission, patients had lived at home. Most had lived alone, though some with a spouse or child. All received some form of living assistance at home, and the vast majority received home care from a community care provider. Assistance with bathing, dressing, meal preparation, or home nursing was most commonly listed as the services patients had received in the community. The CCAC, March of Dimes, Red Cross, and Victorian Order of Nurses were all mentioned as care providers.

Many patients noted service maximums as having contributed to their admission to hospital. Most patients felt that with additional home support or increased accessibility accommodations their current admission could have been avoided.

Perception of hospital care

Patients were wholly dissatisfied with needing to be in hospital. Many were aware that their care needs did not warrant an acute-care setting but felt that an appropriate alternative was not available. While few could identify when they might be able to leave hospital, many noted that improvement targets such as further weight loss or the ability to walk independently would prepare them for discharge. It is unclear whether these patients were making progress toward their goals.

Overall, patients were complimentary of the care they received in hospital. They highlighted the quality of nursing as a benefit to hospital care, though some also cited that nurses were often overworked and understaffed. Conversely, the quality of food was singled out as the greatest shortcoming that limited comfort in hospital.

Perhaps owing to their extended stays, some patients remarked that their apprehension about hospitalization had subsided. A few patients mentioned a decline in their mobility during their stay in hospital, though none attributed this as a consequence of prolonged admission. While many complained about general hospital conditions – crowded hallways, shared rooms, constant motion – patients were resigned to remaining in hospital, many for the foreseeable future.

Perception of long-term care

The majority of patients were adamant about not going into long-term care. They expressed frustration at the lack of institutional suitability of any available model of care. They recognized that their care needs required either considerable accommodations to their physical space, such as lifts, hospital beds, and wheelchair accessibility, or assistance with activities of daily living, such as toileting, dressing, and meals, or in many instances both. Many attributed their substantial care needs as a factor to making long-term care unsuitable. One bariatric patient noted that refitting a long-term care room for his needs would require he make a \$10,000 investment.

Patients saw themselves as too young and too independent for long-term care. Some noted they might be more willing to consider long-term care if there were dedicated floors for younger clients. Many were unwilling to give up their possessions, financial independence, and autonomy. They stated strong preferences to access March of Dimes supportive housing or to attain greater support from the CCAC in order to return home.

Though these patients did not consider long-term care a viable option, most were on wait lists nonetheless. Some seemed to have applied for long-term care out of duty or routine, even though they admitted they had no intention of going. Some disclosed feeling pressured to choose long-term care homes. One patient confessed to “fighting” adding her name to the wait list and deliberately selecting homes with the longest wait times. On the whole, they lamented the lack of assisted living, accessibility, and transportation support available in the area.

Other older or palliative patients were more open to the idea of long-term care. Yet even this group was decidedly negative about the idea. Patient descriptions of long-term care included:

- “Lack of privacy”
- “I won’t consider it”
- “Massive change in day-to-day living”
- “There’s no place like home, but if I have to go, then I have to go”
- “I’d rather die”
- “Warehousing people”
- “Full of old people”
- “Stuck in little rooms”
- “You go there to die”
- “Loss of autonomy. Someone else takes over your life”
- “I know I am going to get it, but I worry if it will meet my needs”

Patients rejected the category of long-term care more than they rejected any of the particular long-term care facilities in Chatham–Kent and Sarnia/Lambton. Patients had selected long-term care homes based primarily on their proximity to their support network. Some mentioned the importance of new facilities and building layout. Only one patient disclosed details about their selected home that revealed any knowledge of the specific amenities, routine, or rules of the home. A few patients had visited potential long-term care homes, though most based their decisions on the homes’ reputation and word of mouth.

Over the course of our conversations, the following values emerged as clear priorities guiding the decisions of patients. Some of these values can be applied to long-term care, while others help to explain why many patients so strongly rejected the possibility.

Autonomy – Patients are adamant about maintaining their independence. They are deeply concerned with being able to move freely and keep their own schedules. Maintaining control over their finances is also a priority.

Socialization – Younger patients strongly object to the notion of going to a home with people twice their age. They want the possibility of maintaining a social life and making new friends with people from their own age group.

Self-respect – While recognizing they need a lot of help, patients do not want to feel irrelevant or burdensome. They do not want to feel “put away and forgotten.” Patients are seeking an assisted-living environment in which they can work toward a better life.

Affordability – The cost of home retrofitting and equipment such as wheelchairs, specialty beds, and lifts are a major barrier to patients leaving hospital. This prevents patients from moving in any direction. Patients are unable to afford the support services and physical equipment they require to return home but are equally unable to pay the considerable sums required to renovate a long-term care room to their specifications.

Communications and communicators

The responses to questions about how and from whom patients receive information generated inconsistent responses. Patients seem to receive disjointed information. Most patients could identify at least one source helping them understand their care options but could not easily recall what they had learned from that person. The patient who demonstrated the greatest understanding of long-term care could not identify where she had learned that information. This implies that information is poorly reinforced and information is conveyed without establishing a relationship between the patient and the adviser.

Patients receive information from a range of sources, including family members, the CCAC, and hospital social workers. A few receive information from word of mouth, and one patient identified their physiotherapist as their main adviser. Some patients noted having no involvement with the CCAC. Few patients referenced multiple sources of information.

Some patients said communication from their care team had been a problem. A few espoused a very negative view of the communication they had received, which they attributed to the whole hospital. Some had developed an antagonistic relationship with hospital staff, who the patients felt pressured them into long-term care. Though none of the patients identified nurses as a source of information about their care options, it was clear that for many patients, nurses had been a primary contact. Some patients complained that nurses had pressured them to apply for long-term care or to apply for a particular facility that was not the patient’s preference. This may indicate that nurses would benefit from additional training or support. It may also indicate that the responsibility for informing patients is not shared well among the care team and that after initial efforts by social workers or the CCAC, nurses handle the brunt of dealing with difficult patients.

None of the patients mentioned long-term care homes as a source of information to their prospective clients, although one patient did mention she “may have seen a brochure somewhere.” Some patients encouraged long-term care facilities to take a greater role in advertising and informing potential clients. As one patient put it, “The

information is hard to find. Long-term care has a lot to offer, but they don't advertise enough."



What we learned from family members

The family member profile

All of the loved ones we interviewed were in the patient's immediate family. Most were the children of the patient, and almost one-quarter were the spouse of the patient. Almost all had other family in the area. All of the families represented had arranged for power of attorney, though only half of the family members interviewed acted as power of attorney.

On the whole, family members felt they were coping with their loved one's circumstances very well. Most attributed this to the presence and support of the family network in the area. Interviewees described cooperation and agreement among family members as they determined their loved one's next steps. Children of ALC patients revealed no conflict among their siblings when choosing long-term care homes for their parent. Often when a patient's spouse had power of attorney, their grown children felt that the responsible parent adjusted slowly to the patient's changing circumstances.

Prior to admission, patients lived at home, most with a child or spouse but some alone. Family members were the primary caregivers, a task that many accepted stoically though some expressed stress or exhaustion at the effort required to care for their loved one. One family member whose loved one had recently been placed in long-term care told us, "We didn't realize how tired we really were until we got a break."

The majority of family members were caring for an elderly relative. In most instances, the grown children were balancing caring for their parent (or both parents) while raising their own children. In some cases, the patient was sufficiently aged as to have both their children and adult grandchildren contributing to their care. One family member described his concern that his ninety-five-year-old grandparent was living with and dependent on his seventy-year-old parent.

Perception of patient condition

Patients were suffering from a range of chronic conditions. Alzheimer's, dementia, as well as arthritis and injuries due to frailty (broken bones, inability to get up) were mentioned most often. Infections, stroke, and mental health issues such as depression or confusion were also common.

Most family members recognized their loved ones were in a state of decline. With few exceptions, none of the family members were taken by surprise at their loved one's admission. The most common precipitating conditions for admission included falls, infection, or cognitive decline and behavioural issues related to a progressive disease. Other precipitating factors included general decline, for example, patients

MASS LBP
392A King St. East
Toronto, ON M5A 1K9
416 841-4433
800 369-7136

being admitted for dehydration. Many family members noted further cognitive or physical deterioration since admission.

In other cases, rather than the patient developing additional care needs, the family simply reached their limit and could no longer support their loved one. One family member described no longer being able to lift her mother to help her with daily living activities. In most cases, family members were resigned to their loved one transitioning to the next stage of care.

The majority of patients had been receiving some form of assistance at home. In addition to support provided by family members, the most common types of assistance listed in the responses included home care, CCAC services, bathing assistance, and in-home nursing. Family members lamented insufficient service maximums. Patients received support services one to three times weekly. Some received as little as a dozen hours a month. A number of families received no respite.

None of the family members identified occupational therapy, home retrofitting, or fall prevention programs. Numerous family members mentioned the patient had multiple falls. Some families had moved in with their loved one in order to provide assistance moving around their home and to provide supervision in order to prevent falls. Despite this, they noted repeated falls, in one case more than a dozen in a period of two years.

In some instances, a failure to recognize warning signs led directly to the current admission. Concealing or understating symptoms or lack of communication between patients, their families, and their family doctor had resulted in irreparable damage to the patient's capabilities.

Despite noting insufficient help available to them in the community, most family members felt their loved one's admission to hospital was unavoidable. Almost unanimously, family members felt that long-term care was the best and only option for their loved one.

Perception of hospital care

Family members had mixed opinions and experiences about the care their loved one received in hospital. Their experiences indicate a correlation between the easy temperament of the patient, the time family members spend in hospital, and the positive interactions they have with hospital staff.

Many family members told us they were very pleased with the care their loved one receives in hospital. They were complimentary about nursing staff and appreciative of the physical safety and supervision available in the hospital setting. Some commented that patients would benefit from greater collaboration among the care team but felt that communication with patients and families had been excellent.

Others had a mixed experience. Some family members singled out a particular staffer, usually a social worker or CCAC case manager, for providing exceptional service. The family was effusive about the actions of these individuals, who had

clearly developed a very personal and trusting relationship with the family. However, their compliments were often couched in criticism. Family members often commended a particular staffer who they felt “was the one person who was on our side.”

Family members of patients with behavioural issues commonly had a more negative view of hospital care. Families of non-compliant patients commonly described staff as impatient or uncompassionate toward their loved one. Many in this group identified hospital procedures such as sedation and restraint after an act of aggression as inappropriate or callous.

Family members unable to accommodate the hospital’s routine voiced difficulty learning from staff how their loved one had been in their absence. Family members expressed frustration at asking staff for an update on the patient’s condition and being told the person on duty “didn’t know.” Staff’s inability to respond to family member queries was noted both for mundane matters (such as whether the patient ate their lunch that day) and serious concerns (such as why the patient’s medication had been changed).

Some family members commented that the process of applying and getting assessed for long-term care sent mixed messages to patients and families. Both received strong encouragement from staff to make long-term care selections and begin the transition to community care. Yet the assessment and placement process can often be prolonged. One family member wondered, “If there is such a pressure to get them [the patients] out, why does it take so long to get the ball rolling?”

When initially asked about their perception of hospital care, family members responded positively. Only after further conversation did their sometimes-substantial issues emerge. This indicates that families are deferential to the hospital as an institution and may suggest that sophisticated approaches are necessary to evaluate patient satisfaction in hospital care.

Perception of long-term care

Many of the families had considered long-term care before the current admission. Only a few of these had applied to long-term care before admission to hospital, but it was clear that all the families had begun to prepare emotionally for the transition.

Most family members tried to involve the patient in selecting long-term care homes. With one exception where the final decision was left entirely to the patient, this was only possible to a degree. Family members took their responsibility seriously. About one-third had taken tours. In many cases, the entire support network had all gone to research potential long-term care facilities. Only some had brought the patient on the tour.

Within families there seemed to be virtual unanimity between family members about what the next steps for the patient should be. Families reported joint decision-making, and while spouses of the patient came to decisions more slowly than the couple’s children, families displayed a remarkable degree of agreement.

In stark contrast to the resigned acceptance of family members, interviewees described the patients as being staunchly against the idea of long-term care and immovable in their stance. Patients were often put at odds with their family members, as families struggled to cope with the loved one's increasing care needs and patients declared they would "rather die than go to long-term care." In some cases, the family members asserted that their loved one had softened to the idea over the course of the current hospital admission. More often, however, patients' cognitive decline had progressed to the point where they were no longer capable of comprehending or objecting to the idea. In one indication of the depth of patients' aversion to long-term care, one family member of an Alzheimer's patient said that even though the patient could no longer understand where she is, she becomes extremely agitated at the mention of the words *nursing home* or *long-term care*.

Families had little trouble deciding on a long-term care home for their loved one. Most patients were only on the wait list for one home, and none had selected more than two preferences.

While the decision of which home they wanted was relatively frictionless, family members were much more concerned with the kind of room available in the home they selected. Private and two-bed rooms were preferred. One family agonized over not being able to afford the type of room they felt would be best for the patient.

The strength of their conviction that long-term care was the only option for their loved one helped family members overcome their negative perceptions about long-term care. Many family members assumed they would have to be continually vigilant and constantly advocate on behalf of their loved ones in order to receive good care. They seemed to treat this as inevitable and did not consider it a detriment to one long-term care facility over another.

Words or feelings family members associated with long-term care:

- "Realization that she can't function for herself"
- "I will be an advocate for her. I will address any issues of neglect as soon as I see them."
- "I want him cared for"
- "We're scared"
- "'Til you're dead"
- "Seniors maximize living potential in a setting that is built around their needs"

Two priorities played an oversized role in guiding family member decisions regarding long-term care homes:

Location – Family members prioritized long-term care homes in their town. Families wanted their loved ones to remain in close proximity. Some emphasized the need for public transportation connecting the patient's current home and prospective long-term care home to enable the patient's spouse to visit.

Care needs – Family members looked to long-term care homes to provide very specific services that the family was unable to provide. Locked wards, twenty-four-hour supervision, lifts, hydraulic beds, and staff specially trained to handle Alzheimer’s patients convinced family members that a particular long-term care home was right for their loved one.

Two additional priorities guided families choosing long-term care homes, although these were not mentioned by all the family members and seemed to be secondary for most:

Comfort – Family members were impressed by homes that offered clients privacy, ample space, with bright, airy rooms and foyers. They expressed their hope to select the type of room their loved one would live in and emphasized the importance of being well treated by staff and being able to set up the room with their loved one’s belongings.

Affordability – None of the family members expressed doubt that their family could afford long-term care. Cost was a factor in determining the type of room within long-term care the family could afford.

Communications and communicators

Family members received information from many sources, including the CCAC, social workers, doctors and nurses, physiotherapists, specialists, friends, and support groups. Many received information from multiple sources. Family members actively sought out information, some quizzing virtually every care provider they came in contact with. On the whole, family members were well informed and well prepared. Despite this, family members remarked at the complexity of the system: “It’s easy to get lost.”

Family members advised providers not to underestimate the significance of the transition for both patients and their families. One family member compared the feelings when considering long-term care as being “the same as when you go to the doctor and get a bad diagnosis.” Patients and family members are overwhelmed and would benefit by having support present. Many have to learn which questions to ask, and often information needs to be repeated many times before it is fully processed.

Despite needing time to adjust, many family members admitted that their perceptions had changed during the patient’s admission. As one family member put it: “Initially, it felt like a bad car deal. Now I feel like they are on our side.” Many families voiced regret that they had not acted sooner and helped their loved one get on a waiting list so that they could wait at home. Yet they confessed that without the advice and support from staff they were unable to move forward: “We didn’t know how to take the next step without guidance.”

Once their loved one was on a list, families discussed the need to improve the waiting process. One family said they had gone so long without word from anyone that they began to wonder if their loved one was still on a wait list. They urged care providers to update families with periodic phone calls. Regular communication

would help waiting families ensure that patients don't miss an opportunity for placement because the family is out of town or unavailable. As one family member put it, "A bed offer should never be a surprise."

At all stages of the process, families are keen for more guidance to help them anticipate their loved one's needs. One family member described the need for a "schedule of events" to help them track and evaluate changes in the patient's condition. Family members also stressed the need to involve the patient wherever possible and the family constantly, to engage them in learning about conditions and options and evaluating their choices.

What we learned from front-line staff

Front-line staff met in two-hour workshops. Working in small groups and plenary, participating staff were asked to complete two main tasks. First, they were asked to list the reasons they receive from patients who chose to remain in hospital beyond their need for acute care. Second, they were asked as a group to identify the reasons they hear most frequently and those that present the greatest challenge and then offer their ideas and advice on how to address the most frequent, and most challenging, obstacles.

Thanks, but I'd rather stay here ...

Staff across all sites shared many of the same experiences as they work with ALC patients and their families. Below are the most common reasons staff hear from patients and families who refuse to leave hospital:

- Hospital is the only affordable place
- Patient's perceived health needs require hospitalization
- Patients with behavioural issues are disqualified from long-term care
- Long-term care is not age-appropriate
- Patient is not psychologically prepared
- Available beds are too far away for family members to visit, lack of transportation
- Patients and/or family members believe with additional therapy the patient will improve
- Stigma and misconceptions of long-term care (the belief that patients will have to give up all assets, etc.)
- Inadequate conditions in available long-term care homes
- Quality of care is better at hospital
- Patients feel co-payments entitle them to indefinite hospital stay

Staff noted that ALC patients are often either ill informed or misinformed about their care needs, options, and available supports. They are often unable to access the resources necessary to return home but are not psychologically or emotionally prepared to make the transition to long-term care. Despite recent changes in

management and structure, public perceptions of long-term care facilities remain largely negative. Families often need a great deal of time and support to adjust to the idea of long-term care and prepare the patient for the transition.

Staff also emphasized the increasing number of complex ALC patients because they are denied placement by long-term care facilities. Hospital staff feel pushed to the limits and are concerned about their ability to provide good care to an increasing number of patients with complex needs. There is increasing demand for bariatric services and a dearth of assisted-living facilities to accommodate their needs. Staff acknowledged that “there is no place for them to go.” With younger patients refusing long-term care and without any suitable alternative, “the hospital is the new nursing home.”

Patients with behavioural issues also encounter this difficulty. The lack of support and alternative housing for individuals with high behavioural needs results in patients who are “stuck in the middle.” By default, the hospital becomes the home. Dealing with aggressive patients takes a heavy toll on both hospital staff and patients.

Staff feel most stymied by ALC patients who refuse to pick any available option besides remaining in hospital. Staff observed that the co-pay system, designed as a deterrent, sometimes has the perverse consequence of reinforcing patients’ sense of entitlement to remain in hospital indefinitely. Having paid their “rent,” the patient sees no reason why they should be pressured to move on. Many staff reminisced about the First Available Bed policy. It was clear their nostalgia showed no inclination to put the stick before the carrot. Rather, staff feel they now have no tools at all to equip them to encourage uncooperative patients to consider their options.

The referral process

Staff from all three organizations identified poor communication and coordination as a barrier to transitioning patients from hospital. Assessment and referral procedures are not uniformly applied or understood, which stalls the transition of patients who are ready and willing to be discharged. Staff referenced both internal communication among the care team as well as procedural coordination between the hospitals, the CCAC, and long-term care facilities.

There is a multistep process to get a patient on a wait list for long-term care. Once the patient is designated as ALC, their case is referred to the CCAC. Once received, the CCAC coordinates the assessment date and plan to the hospital. Due to a backlog of assessment requests, it may take a number of days before an assessment can be scheduled. Once the CCAC conducts the assessment and sends the results to the selected long-term care home, the home has five days to accept or decline the patient. The CCAC will then follow up with the patient. In order to be admitted to a long-term care facility, a patient’s assessment must be up to date within three months. The specific procedure followed by hospital staff and CCAC case managers differs with each hospital.

Staff at all sites were most concerned with the coordination between hospitals and the CCAC. Staff noted that waits for assessments result in delayed transitions or in some cases patients missing a bed opening. Hospital staff are sympathetic to understaffing at the CCAC. There is more of a culture clash between hospitals and the CCAC regarding acceptable timelines and schedules. Accustomed to working on a seven-day-a-week schedule, hospital staff have difficulty accepting the CCAC's Monday-to-Friday schedule. Hospital staff are inclined to see weekends as additional delays to CCAC services (a feeling likely shared by hospital patients).

Hospital and CCAC staff displayed differing expectations about the responsibilities of the CCAC. Hospital staff look to the CCAC to help them transition patients as quickly and efficiently as possible. Some viewed CCAC assessments as more time-consuming and meticulous than necessary. The CCAC, on the other hand, is very conscious of its responsibility to ensure that patients are eligible for the facility to which it refers them. CCAC staff also noted that if they are not exacting in their assessments, they often receive numerous queries from long-term care facilities requesting further information. Finally, CCAC staff view their work as too important to be rushed. As one staffer put it, "For patients, it's a life-changing issue. We need to make sure it's done right."

Hospital staff often seem disappointed that CCAC involvement is administrative in nature. Hospital staff also assume the CCAC will assist patients and families to understand their options and support them in taking their next steps. Hospital staff expressed a desire to see CCAC staff involved earlier and more substantively with patients. They felt the CCAC was a positive addition on rounds in preparation for a patient's discharge and suggested engaging CCAC staff in rounds throughout the admission. They also approved of sending referrals for CCAC assessment immediately upon a patient's admission.

Already stretched to capacity, CCAC staff felt they did not have the time to fill the role of system navigator as thoroughly as they might like. CCAC staff were eager to introduce additional mechanisms, such as informational videos, to inform patients and family members about their options. One stressed, however, "Just please make sure the responsibility of showing patients and families the videos doesn't land on me."

There were many examples of good collaboration between CCAC and hospital staff. The script developed between Bluewater Health and the CCAC to guide staff describing long-term care and its difference to hospital care was cited as a successful partnership. The script helps staff reinforce clear messaging in their communication with patients and their families. Bluewater staff also commended the CCAC for assuming additional "client care" tasks for their patients by following up with the long-term care homes and personally calling patients to inform them of bed offers. Chatham-Kent Health Alliance (CKHA) staff noted their satisfaction with the constant coordination and strong cooperation between the CCAC and hospital discharge planners.

Negotiating internal hospital communication was also a challenge for staff. CKHA and CCAC staff, while lauding discharge planners for developing a nuanced and

comprehensive understanding of assessment procedures, also noted that the knowledge extended no further into the hospital than the individual discharge planners. Therefore, while those administering the process understood its rationale, all other staff responsible for patient care were left impatiently waiting for it to unfold. Staff in all three workshops highlighted the need for hospital staff to gain a better understanding of the CCAC process.

Hospital and CCAC staff pointed to disagreement or miscommunication among the patient's care team resulting in unnecessary hospital stays. In most cases, staff referred to physicians misinforming or inadequately informing patients about their care needs and options. Staff recounted instances in which a physician announced to a patient that they were ready "to go home today." Staff noted that while ready for discharge, the supports were not in place in order to support the patient safely in the community. Staff stressed that however inadvertently, physician instruction often reinforces the unrealistic expectations and assumptions of patients and their families.

Staff identified the time of greatest risk for patients as the period between when patients are ready for discharge and when they attain a long-term home placement. They described two common scenarios. In the first, patients remain in ALC because the appropriate assistance cannot be procured in the community. They de-condition in hospital to the extent that they are no longer eligible for the facility of their choice. In the second, patients are discharged to await placement at home. Without additional support, the patient has an adverse incident and needs to be readmitted to hospital, restarting the referral process. Staff identified wound care and sepsis as particular challenges for patients waiting at home.

Finally, staff pointed to the long-term care facilities as key players who can make a greater contribution. Staff regret the increased wait time and redundant work that often needs to be done because applications for long-term care made from home get deactivated when applicants are admitted to hospital. The application is not reactivated until the patient is designated as ALC.

Suggestions for improvement

Front-line staff had many suggestions to address the challenge posed by ALC. They also indicated a strong imperative to improve coordination and collaboration among service providers.

Some of their ideas include:

- Review and revise restraint procedures, to open more avenues for patients.
- Review the effectiveness of the co-pay model for ALC patients.
- Expand the activation team to include complex continuing care and alternate level of care.
- Develop public education programs to increase knowledge of aging strategies.
- Increase CCAC service maximums.
- Prioritize increasing CCAC capacity.

- Develop a staff education program to increase staff (including physician) knowledge of long-term care, the CCAC, and the referral process.



Most of the staff recommendations have been incorporated into the recommendations found in this report. Staff suggestions can be found in their entirety in the Appendix.

Regional observations

Comparing patient need

Consultations with ALC patients, their family members, and front-line staff in Windsor/Essex, Chatham–Kent, and Sarnia/Lambton offer many lessons for improving ALC patient care across the region.

The interviews with patients and families illustrate the diversity of the ALC population and highlight the flexibility that is required to respond to the varied needs of this patient population. The consultations revealed three profiles of ALC patient.

The first ALC patient profile comprised frail, elderly patients without significant cognitive decline. These patients have diminishing physical independence and are increasingly reliant on family members to compensate. Cognizant of their own vulnerability, they are extremely sensitive to routine and familiarity. They are inclined to resist change and suspect strangers. They view long-term care as a frightening prospect, in large part because of the total change of environment and lifestyle and the permanent separation from their long-time homes and, in some cases, their spouse. Long-term care also symbolizes the end of their independence.

Their family members are stretched and exhausted from the demands of caring for their loved one but feel a tremendous sense of responsibility and guilt at admitting their limits. These family members view long-term care as a personal failure and betrayal of the patient's trust. They are reluctant to admit to themselves or their loved one the severity of the situation and as a result often do not seek help until they are in a crisis situation.

The second ALC patient profile comprised elderly patients with a diagnosed progressive illness, often Alzheimer's or dementia. Due to the progression of the disease, they are no longer capable of living independently or their care needs have advanced beyond their loved one's capacity to care for them. Patients either cannot deny their increasing care needs or are no longer aware of their surroundings. Having had time to process their loved one's condition, family members accept that long-term care is the best option for the patient.

The third ALC patient profile comprised younger individuals suffering from complex chronic diseases. These patients are eager to leave hospital but feel there is no appropriate environment available to them. They are adamant not to go to long-term care, which they feel restricts their independence and limits their opportunities for a

MASS LBP
392A King St. East
Toronto, ON M5A 1K9
416 841-4433
800 369-7136

social life among people their own age. Further, long-term care facilities are poorly equipped to accommodate their care needs, especially those of bariatric patients.

The vast majority of patients in the Windsor/Essex consultations belonged to the first patient profile, who could be served either in the community or in long-term care but lack the support required to make the transition. The second and third ALC patient profiles were prevalent in the interviews in Sarnia/Lambton and Chatham-Kent. These patients want to leave hospital, but procedural delays or lack of available options often results in extended hospital stays. These patients are also more likely to be denied a placement by a long-term care facility, further diminishing their options.

It is likely that all three ALC patient profiles are present throughout the region. The ESC LHIN's demographic data will confirm the degree to which the sample we spoke to is representative of the populations in each community.

Navigating the system

Despite their varied situations, all patients shared certain qualities or experiences. All of the patients and families struggled with service maximums, and many shared the view that more comprehensive home care would allow them to remain in the community. Difficulty navigating community care and reluctance to seek help before a crisis situation was common throughout the region. Likewise, the need for greater caregiver education, transportation assistance, and preplanning supports was emphasized across the LHIN.

Patients' approach to wait lists for long-term care facilities has strong implications for the development of long-term care within communities as well as the wait-list procedure. Location was the greatest factor determining a family's preference of long-term care home. Many patients flatly refused to consider any home that was not in their home community. Given that strong preference, careful coordination with long-term care facilities is required to anticipate demand in a community and encourage the development or expansion necessary to match the facilities and available beds in a community with client need. It also indicates that creating a central facility equipped to handle specific client needs, such as creating a single long-term care facility directed toward younger bariatric patients, might not be a successful approach.

The wait-list procedure for long-term care encourages patients to select up to five homes. To increase the likelihood of placement, staff encourage patients to select all applicable options. Patients, however, are disinclined to select more than one or two options, and are loath to accept any placement that is less than their first choice. The pressure to select multiple homes distorts wait lists, as patients are waiting for homes to which they have no intention of going. It also creates unnecessary conflict between staff and patients. Patients resent feeling pressured to select homes to which they do not want to go. Staff are frustrated as patients refuse placements.

Comparing staff perspectives

The consistency of staff responses among the six partnering organizations indicate there is a strong appetite for initiatives that help care providers clarify their roles and responsibilities and streamline the process of transitioning ALC patients into the appropriate care setting.

Staff across all sites are most concerned with improving the coordination between the hospitals and the CCAC. Each hospital has adopted its own model in regards to how the CCAC is engaged with the hospital care team. Comparisons across sites reveal that staff satisfaction with the inter-organizational relationship is greater when the CCAC is more fully integrated into the hospital care team.

Both the hospital and CCAC staff noted a more effective relationship at Leamington District Memorial Hospital and Chatham–Kent Health Alliance. Hôtel-Dieu Grace Hospital, Bluewater Health, and Windsor Regional Hospital had more instances of staff noting confusion or ignorance over roles and procedures, or hospital staff expressing frustration at the CCAC, largely based on the former’s assumptions about the responsibilities of the latter.

The role of the CCAC requires greater clarification. There are mixed perspectives, even among CCAC staff, as to whether the CCAC is primarily administrative – ensuring that patients are thoroughly assessed and accurately matched to the appropriate services – or whether the CCAC’s primary function is to fill the role of patient navigator – helping the patient understand their needs and options and guiding them to the appropriate services. As CCAC staff feel pressed for time and stretched to capacity, they focus more on the administrative role.

It is clear that the penetration of the CCAC does not extend as far into the community as it could. Many patients are unaware of the CCAC until an adverse incident brings them to hospital. Greater coordination with family doctors and emphasis on public outreach and education may help more families learn about the CCAC and access its services before an adverse incident.

Staff across all hospital sites also emphasized the need for greater collaboration and communication among the care team. Lack of clarity or ignorance about the placement process results in confusion and frustration among staff. Further, it increases the likelihood of sending mixed messages or misinforming the patient. Staff noted that patients are extremely sensitive to the instructions they receive from their care team, especially physicians. Staff education about the placement process and increased collaboration among the care team will help them reinforce information and set realistic expectations for ALC patients.

The role of long-term care facilities

Long-term care facilities can play a greater role in enabling patients to leave hospital and helping them through the transition. Patients and families have an outdated perception of long-term care, and misconceptions about the range and quality of services persist. Recent improvements in long-term care are not well known or understood by the public. Long-term care homes have a great deal of work to do to improve their reputation.

Long-term care homes had little interaction with patients and families considering placement. None of the families interviewed identified long-term care homes as a source of information or decision-making assistance. Families in Chatham–Kent and Sarnia/Lambton were more likely to tour the long-term care homes they were considering. Families in Windsor were far less likely to reach out to long-term care homes for information, and those who had visited long-term care homes on tours often cited a negative experience.

Among patients and families, the general perception of long-term care was at best unexceptional and at worst substandard. For the most part, word of mouth and reputation had an outsized influence on this perception. Newer facilities are more attractive to prospective clients. Families in Chatham–Kent and Sarnia/Lambton were far less likely to single out a particular home as a facility to which they would refuse to place their loved one. The quality of specific long-term care facilities was more of a concern in Windsor/Essex, where many patients and family members deemed certain homes unacceptable based on their reputations.

Finally, patients, family members, and staff noted the opportunities for long-term care facilities to expand their range of services to serve additional client populations. There was great support to see long-term care homes develop designated floors or units for younger clients and expand services for clients with behavioural issues or other individuals requiring higher levels of care. Respondents were keen to see long-term care homes take a greater role coordinating with the LHIN and the CCAC to standardize the quality and reputation of long-term care and to enhance their services to address population need.

Recommendations

The recommendations that follow are based directly on the input we received from ALC patients, their family members, and front-line staff. They represent their interests and perspective and are not intended to be comprehensive or conclusive. Instead, they are recommendations that should be weighed against the medical expertise of the health institutions that commissioned this report.

These recommendations are organized into four themes.

Streamlining the process

1. Enhance and standardize the CCAC’s role across all hospital sites as patient navigator and care connector for community care and long-term care.
2. Involve CCAC case managers from the early stages of hospital admission to review options for care in the home and community and to work with hospital staff, patients, and families to connect patients to services.
3. Review patient assessments performed by hospital and CCAC staff to reduce redundancy, standardize frequency, and clarify what events merit

- updates. Look for opportunities to collaborate in the completion of assessments and share the results.
4. Explore methods to provide precise information on wait times for long-term care.
 5. Increase emotional support to both patients and family members as they consider their care options, especially those who should be considering long-term care.
 6. The Ministry of Health and Long-term Care can review the incentive structure inherent in the placement process with a focus on encouraging patient transition.

Collaboration among care providers

7. Clarify the roles and responsibilities of CCAC and hospital staff at all sites.
8. Improve communication among the care team in the hospital to ensure patients and family members receive consistent messages from all care providers, including physicians, nurses, and allied health professionals.
9. Develop avenues for hospital and CCAC staff to exchange knowledge and approaches regarding ALC patient care.
10. Establish a system to provide patients and their families with regularly scheduled updates of the patient's position on long-term care wait lists.
11. Strongly encourage long-term care homes to review the ratio of private and semi-private to basic beds. The review should be included in the long-term care redevelopment strategy in order to advance access to appropriate beds based on community need.

Education and prevention

12. ESC LHIN should coordinate with community service providers and the CCAC to begin the process of educating and preparing patients and their families before an adverse incident.
13. Review the process by which hospital patients at the emergency department or at discharge are transitioned from the in-patient unit to the community falls prevention program to improve access for high-risk seniors.

14. ESC LHIN, long-term care homes, and the CCAC should partner to develop a comprehensive and standardized educational package to promote long-term care homes. Include video tours of each home, a brochure/guide, photography, and testimonials from residents and their family members.
15. Establish an education program for hospital staff, including physicians, to orient them to the referral process.
16. The CCAC should develop and conduct ongoing classes to educate the family members and caregivers of seniors. General health system literacy to help with navigation, tips on what to look for and consider when contemplating long-term care, and how to know when your loved one needs long-term care are all areas of CCAC expertise that can be shared with the public.
17. Develop decision-making resources for patients and family members to determine their needs and evaluate their care options.

Special needs cases

18. Consider creating a sub-category within ALC to distinguish frail, elderly patients waiting for long-term care placements from younger patients with debilitating chronic conditions. Using sub-categories in initiatives such as the patient “snapshot” will achieve a greater degree of standardization and granularity when measuring ALC patient populations.
19. Create a specific unit within long-term care homes to bring together and care for patients with behavioural issues.
20. Expand training for front-line staff in hospitals and long-term care to deal with dementia patients as well as patients with other challenging behaviours.
21. Research the group home model for younger patients with complex needs, such as bariatric, atherothrombotic brain infarction (ABI), or other young patients requiring assisted living. If possible, develop options for these patients that are outside the traditional long-term care model.

Appendix A
Interviews - Patients

Gender

Response	Chart	Percentage	Count
Male		70%	7
Female		30%	3
Total Responses			10

Question 1 - Do you have family in the area?

Response	Chart	Percentage	Count
Yes		100%	10
No		0%	0
Total Responses			10

Question 2 - Why were you brought to the hospital?

The 10 response(s) to this question can be found in the appendix.

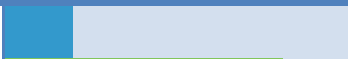

Question 3 - What are your current health conditions?

Response	Chart	Percentage	Count
Stroke		0%	0
COPD		11%	1
Hip fracture		11%	1
Pneumonia		0%	0
Cardiovascular		11%	1
Arthritis		11%	1
Cancer		11%	1
Diabetes		33%	3
Other, please specify:		89%	8
Total Responses			9

Question 3 - What are your current health conditions? (Other, please specify:)

#	Response
1.	Knee issues
2.	Huntington's disease, gout
3.	Infection due to catheter
4.	Broken ankle, bariatric; physical and emotional exhaustion
5.	Lupus, leg wounds, ulser
6.	Many operations
7.	MS
8.	Huntington's disease, gout

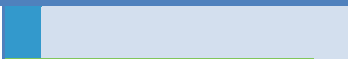

Question 4 - Is this your first admission?

Response	Chart	Percentage	Count
Yes		20%	2
No		80%	8
Total Responses			10

Question 5 - How long have you been in the hospital?

The 9 response(s) to this question can be found in the appendix.

Question 6 - Do you know how long you might have to stay?

Response	Chart	Percentage	Count
Yes		11%	1
No		89%	8
Total Responses			9

Question 6 - Comment:

The 8 response(s) to this question can be found in the appendix.

Question 7 - Are you worried about staying in the hospital?







Response	Chart	Percentage	Count
Yes		22%	2

No		78%	7
Total Responses			9

Question 7 - Comment:

The 8 response(s) to this question can be found in the appendix.








Question 8 - What services make staying here a good option?

Response	Chart	Percentage	Count
Food		0%	0
Nursing care		25%	2
Doctors		0%	0
Comfortable surroundings		0%	0
Therapy options		12%	1
Other, please specify:		62%	5
Total Responses			8

Question 8 - What services make staying here a good option? (Other, please specify:)










#	Response
1.	People around.
2.	"You should eat the food". Some staff are nice, others aren't nice; sleeps poorly.
3.	Nothing really
4.	daily health examinations
5.	everything good - except food

Question 9 - Where were you living before you came to hospital?

Response	Chart	Percentage	Count
Home alone		67%	6
Home with spouse		33%	3
With children		0%	0
Assisted living		0%	0
Retirement home		0%	0
Long-term care home		0%	0
Other, please specify:		0%	0

Total Responses	9
------------------------	----------



Question 10 - When you were at home did you receive any help, either with medical needs or just with day-to-day things?

Response	Chart	Percentage	Count
Home care		56%	5
Transport		11%	1
In-home nursing		33%	3
Day programs		0%	0
Meals on wheels		11%	1
Neighbours		11%	1
Family		44%	4
Volunteer visits		0%	0
Other, please specify:		67%	6
Total Responses			9

Question 10 - When you were at home did you receive any help, either with medical needs or just with day-to-day things? (Other, please specify:)

#	Response
1.	House cleaner 1X per week.
2.	CCAC - health care nurse
3.	CCAC, Red Cross - home making and personal care
4.	PSW, M.O.D.
5.	Red Cross arranged through CCAC - daily living, meal prep, 2x a week bed bath
6.	Red Cross - PSW








Question 11 - Would extra help at home have helped you avoid being admitted to the hospital?

Response	Chart	Percentage	Count
Yes		75%	6
No		25%	2
Total Responses			8

Question 11 - Comment:

The 6 response(s) to this question can be found in the appendix.

Question 12 - Which age bracket do you fall into?

Response	Chart	Percentage	Count
40-54		0%	0
55-64		33%	3
65-74		22%	2
75-84		22%	2
85-94		11%	1
95-104		0%	0
Other, please specify		11%	1
Total Responses			9

Question 12 - Which age bracket do you fall into? (Other, please specify)

#	Response
1.	35 years old






Question 13 - What did you know about the care options available to you in your community before you came to the hospital?

The 9 response(s) to this question can be found in the appendix.

Question 14 - How did you learn about the availability of different kinds of services?

The 6 response(s) to this question can be found in the appendix.




Question 15 - What kind of help or services do you think you will need in order to return home safely?

Response	Chart	Percentage	Count
Wheelchair		11%	1
Assisted living		11%	1
Financially unable to go home		0%	0
Health will not permit it		0%	0
Other, please specify:		100%	9
Total Responses			9

Question 15 - What kind of help or services do you think you will need in order to return home safely? (Other, please specify:)

#	Response
1.	Dressing. More than an hour per day.
2.	Hospital bed, supports for getting out of bed/chair
3.	Husband will need to be on board. "I scared him a bit, so I've been laying low for a while"
4.	Not sure
5.	CCAC nursing and daily care
6.	wheelchair adjustments to home
7.	toileting, help to get out of bed
8.	Red Cross - and more time for health to improve
9.	Waiting on M.O.D



Question 16 - What options do you feel you have right now?

Response	Chart	Percentage	Count
No options		0%	0
LTC Facility		56%	5
Other, please specify:		100%	9
Total Responses			9






Question 16 - What options do you feel you have right now? (Other, please specify:)

#	Response
1.	"I want to go home".
2.	Want to go home
3.	Home.
4.	I'd rather be at home... not sure what would help.
5.	Would like to go home with CCAC support, then transition to LTC when space becomes available.
6.	Would have to take a look at the options and prioritize
7.	MOD/assisted living
8.	Working towards an apartment. "They make us pick an LTC facility"
9.	MOD

Question 17 - Is anyone helping you to understand your care options?

Response	Chart	Percentage	Count
Yes		62%	5
No		38%	3
Total Responses			8

Question 18 - If so, who and how are they helping?

Response	Chart	Percentage	Count
Social worker		25%	2
Family		12%	1
No, feeling forced		0%	0
CCAC		25%	2
Other, please specify:		62%	5
Total Responses			8


Question 18 - If so, who and how are they helping? (Other, please specify:)

#	Response
1.	Don't remember. Maybe a pamphlet?
2.	I don't like talking to people
3.	Communication has been a problem.
4.	hospital
5.	Physio

Question 19 - Do you feel ready to decide your next steps?

The 9 response(s) to this question can be found in the appendix.

Question 20 - Had you considered long term care before you came to the hospital?

Response	Chart	Percentage	Count
Yes		0%	0
No		100%	8
Total Responses			8




Question 21 - What are some words or feelings you associate with long-term care?

The 9 response(s) to this question can be found in the appendix.






Question 22 - How have your views changed since you've been in hospital?

The 7 response(s) to this question can be found in the appendix.

Question 23 - Are you on the waiting list for any long-term care homes?

Response	Chart	Percentage	Count
Yes		62%	5
No		38%	3
Unsure		0%	0
Total Responses			8

Question 24 - How many have you chosen?

Response	Chart	Percentage	Count
1		14%	1
2		71%	5
3		14%	1
4		0%	0
5		0%	0
Total Responses			7

Question 24 - How many have you chosen? Comment

The 8 response(s) to this question can be found in the appendix.

Question 25 - How long have you been on the waiting list?

The 4 response(s) to this question can be found in the appendix.

Question 26 - Can you tell me more about the homes you chose?

The 6 response(s) to this question can be found in the appendix.

Question 27 - Are there certain homes that you do would never put on your list? Why/whynot?

The 6 response(s) to this question can be found in the appendix.

Question 28 - Have you ever been offered a place in long term care? If you declined the offer, why?

The 7 response(s) to this question can be found in the appendix.

Question 29 - When you think about your next steps, what would you say is most important to you in making your decision?

The 8 response(s) to this question can be found in the appendix.

Question 30 - What is your biggest concern?

The 8 response(s) to this question can be found in the appendix.

Question 31 - What suggestions do you have to improve the design of the healthcare system?

The 7 response(s) to this question can be found in the appendix.

Question 32 - Is there anything important that we haven't talked about? Is there anything else you can tell me to help us better understand patients in your position?

The 5 response(s) to this question can be found in the appendix.

Question 33 - Is there anything else you would like to share?

The 5 response(s) to this question can be found in the appendix.

Question 34 - Observations and comments

The 2 response(s) to this question can be found in the appendix.

Appendix

Question 2 - Why were you brought to the hospital?

#	Response
1.	Heart attack
2.	"Sickness. I don't know anything"
3.	Cancer - medication made her hallucinate
4.	ran away from home - wandering is an issue
5.	Infection due to catheter operation.
6.	fall - became bed bound, inactive and bariatric.
7.	Insulin shock due to diabetes, kidney infections
8.	Congestive Heart Failure
9.	No support at home
10.	Running away from home

Question 5 - How long have you been in the hospital?

#	Response
1.	12 weeks
2.	Approx. 1 year (confused)
3.	"A while". Said she was at Chatham before.
4.	32 weeks
5.	20 months
6.	8 years
7.	13 months
8.	1.5 years
9.	8 months

Question 6 - Do you know how long you might have to stay?

#	Response
1.	"They say until I can go home and take care of myself".
2.	Don't know. "Haven't told me anything. Haven't told me if I can go home. " "Don't think I need to be here. I should be at home."
3.	No indication.

4.	Will depend if I can look after myself at home. Have to make sure the infection doesn't return.
5.	Don't know. "There's no independent environment for me to go". "I don't really know what my condition is."
6.	Maybe February? Wants M.O.D. - they have free units coming up.
7.	No. Needs to learn to walk again. Hopes to get out and get an apartment.
8.	2-3 months; waiting on placement

Question 7 - Are you worried about staying the hospital?

#	Response
1.	"I think everybody worries about it."
2.	"I don't like it"
3.	Not really. I can do most things for myself.
4.	No, but I don't want to stay. I don't like anything about it.
5.	Freedom of movement is lacking.
6.	Gave up worrying - too much stress. Lack of integrity with medical staff and their answers
7.	All the positives are outweighed by the negatives. The nurses are really good, but they're always short-staffed, so they can't answer the bell with regularity.
8.	Not really a worry, but I don't like the lack of freedom. You have to be back by 10:00 pm and in bed by 11:00pm

Question 11 - Would extra help at home have helped you avoid being admitted to the hospital?

#	Response
1.	House is well laid out, "I can get around pretty easily". More support with cooking, laundry and clearing would have helped.
2.	Hospital bed, wheelchair; supports for getting in/out of bed.
3.	Mentioned pills contributing to "silliness" (hallucinations). "Don't need help from nurses to keep clean or anything.
4.	Tried to arrange reconfiguration of doorways for wheelchair, but was unable to; bigger bathroom
5.	Probably not because of diabetes. Didn't know what was going on.
6.	It's hard to get extra services. They get watered down every minute (try to cut time every few months - definitely contributed to being hospitalized)

Question 13 - What did you know about the care options available to you in your community before you came to the hospital?

#	Response
1.	"Nothing much outside of Bayshore"
2.	"I don't know anything"
3.	Pamphlet from Chatham Hospital

4. No
5. CCAC
6. vague idea about facilities, dont know who to ask for help. I wasn't really looking - I expected nothing from health-care system
7. Knew a lot - courses in college, friends are nurses,
8. they don't tell you anything, or what you are entitled to
9. CCAC - provided all info - confident in CCAC

Question 14 - How did you learn about the availability of different kinds of services?

#	Response
1.	Pamphlets - can't remember
2.	CCAC referrals, word of mouth and specialists
3.	things in the paper - called for information. Didn't have any hope.
4.	On committees is community
5.	relying on friends who are also recieving services, CCAC - could do more
6.	CCAC

Question 19 - Do you feel ready to decide your next steps?

#	Response
1.	"I don't want to go."
2.	Doesn't know what the care options are.
3.	Yes - "just need to talk with husband to see how he feels".
4.	Not sure... don't want LTC, but don't want to remain in the hospital.
5.	Just about. Has looked at three homes, not on a wait-list though.
6.	no
7.	yes
8.	no - a ways away (6 months at least)
9.	yes - I want to leave

Question 21 - What are some words or feelings you associate with long-term care?

#	Response
1.	"I don't want to go". Lack of privacy; has a dog she'd like to go home and take care of (neighbour and nephew are looking after dog).
2.	"I've never been there. I don't know". Going home is preferred. Fairfield would be ideal because it's closest to the family.
3.	"There is no place like home, but if I have to go then I have to go"

4.	Not sure
5.	massive change, day to day living, social life - may know a few folks
6.	warehousing people, no privacy, stuck in little rooms, go to die. Death is preferable to LTC. Nursing homes "suck".
7.	Loss - give up apartment and possessions, Loss of autonomy, someone else takes over your life,
8.	I know I am going to get it - i worry if it will meet my needs; can't afford the things I need (\$10,000 bed, new wheelchair, new lazy-boy)
9.	Old. I won't consider it.

Question 22 - How have your views changed since you've been in hospital?

#	Response
1.	No.
2.	No
3.	looking more as an option
4.	no
5.	gone up and down emotionally - angry with some, but I see the good and how they help. It's difficult to assert yourself.
6.	no
7.	If age specific floors - may be an option

Question 24 - How many have you chosen? Comment

#	Response
1.	Fairfield; thinks she's on the list for one in Chatham.
2.	Riverview, Meadow Park
3.	Riverview Sanders
4.	1 in Sarnia, 1 in Kitchner, 1 in Alberta
5.	Would rather die
6.	Afton, Marshall Gowland Manor
7.	Afton, Marshall Gowland Manor
8.	Afton, Marshall Gowland Manor (LTCs with longest wait-list)

Question 25 - How long have you been on the waiting list?

#	Response
1.	"Couple of years"
2.	5 months
3.	maybe 4 months

4. 4-5 months

Question 26 - Can you tell me more about the homes you chose?

#	Response
1.	"They wouldn't have time to visit me if I were anywhere else" (niece and nephew)
2.	nice looking - bright, high ceiling. Coffee available; spacious; safety door. "Open cafeteria"; free to walk and go where they want. Smelled clean. Able to see outside, but it's old. Got to stay in Chatham - family visits are important.
3.	location, cleanliness, affordability
4.	new, friends there, activities, location is central
5.	Location is important - proximity to family, Home needs to be wheelchair accessible
6.	Location, age, new, accessibility - auto doors, transit options; happiness of residents; I chose the places with the longest wait-lists

Question 27 - Are there certain homes that you do would never put on your list? Why/whynot?

#	Response
1.	Any that are far away.
2.	Don't really know all of them
3.	All of them
4.	Sumac - at one point but I have heard some good this too.
5.	Petrolia - location, Vision; Any home that doesn't have elevators
6.	Sumac, Trillium - old location, Fiddicks - heard bad things

Question 28 - Have you ever been offered a place in long term care? If you declined the offer, why?

#	Response
1.	Yes - Fairfield, "but I was doing well at home at the time. They phoned on a Tuesday and wanted em to be there on Wednesday. I needed time to get there" (to think; to prepare)
2.	No
3.	I've been told it'll be a 1.5 year wait.
4.	yes - but will never go. The concept "makes my blood boil".
5.	no
6.	Yes, Fiddicks - but too far
7.	no

Question 29 - When you think about your next steps, what would you say is most important to you in making your decision?

#	Response
---	----------

1.	"I don't know" (looks sad).
2.	Family being able to visit
3.	"Don't want to mess up opportunity to go to Meadowpark" - concerned that if she goes home, she'll lose her placement.
4.	I want to make the correct choice. Wants time to make a decision and not be forced. Would be happy in familiar surroundings. "I'm weighing out the options", home-care isn't out of the picture, but "I have to consider a lot of things".
5.	Priorities change with passage of time. Used to have no expectations in a bureaucratic, corrupt system.
6.	Financing - get ODSP back - gives me independence
7.	Accommodations - main floor
8.	Proximity to family, freedom, availability of help

Question 30 - What is your biggest concern?

#	Response
1.	"I like to help other people. I like to take care of myself"
2.	"That I will be forgotten."
3.	"I know I'm going to get worse - I worry about where they will put me"
4.	The future.
5.	"piss poor communication", lack of trust. "I'm a cynic"
6.	Financing - would like to be independent
7.	Heart health and medical conditions; don't see doctor very much
8.	None really- just want out of the hospital

Question 31 - What suggestions do you have to improve the design of the healthcare system?

#	Response
1.	"Everyone has been very kind to me, but just need to listen once in a while to the patients". Especially in regards to physiotherapy - take patient's injuries into account when asking me to do things. A bit more empathy, too: "We're all old. Staff are all young. They don't know what it's like"
2.	The food is bad.
3.	Information is hard to find - LTC has lots to offer but they don't advertise enough. Spread the word about the different options available for people.
4.	Has to be more communication, lack of integrity - deal with patients in a straight forward manner
5.	listen to people, good to make it homly, more for 50s and 60s - care accessible housing, should not have 20s and 80s together
6.	Staffing issues, More services at hoome, more variety of food
7.	Consult people in wheelchairs when designing hospitals. Clutter in Halls makes mobility difficult

Question 32 - Is there anything important that we haven't talked about? Is there anything else you can tell me to help us better understand patients in your position?

#	Response
1.	"I know they'd rather me go someplace, but I want to go home."
2.	Communication is an issue in healthcare. Bariatric patients have different health concerns.
3.	accessibility/vans a need in S/L
4.	Nobody uses bedpan between 5 and 6 pm - just gross - trying to eat. Food is gross to begin with
5.	Need more adiquate housing for people in wheelchairs

Question 33 - Is there anything else you would like to share?

#	Response
1.	Sometimes it is unfair that certain patients get more attention. Behavioural issues negatively impact the ability for others to get good care.
2.	Enjoyed touring the homes - new experience. If offered a preferred bed tomorrow, he'd look at the financial piece and weigh the options.
3.	"I have an attitude". Not enough independence in the environment with healthcare - like MOD
4.	was very upset when I had to leave home, but looking as a new chapter, new adventure. I would be ok at LTC but want freedom to get better on own. Emotional care is also needed.
5.	Staff are not trusting - I am not comfortable

Question 34 - Observations and comments

#	Response
1.	Seemed unsure about LTC options
2.	Seemed confused as to why she was there. She couldn't give a clear picture as to why she was admitted. Confusion or lack of knowledge? Doesn't really think this is a hospital?

Appendix B
Interviews - Families

Question 1 - What is your relation to the patient?

Response	Chart	Percentage	Count
Mother/Father		82%	9
Mother/Father in law		0%	0
Aunt/Uncle		0%	0
Grandparent		9%	1
Friend		0%	0
Spouse		27%	3
Sibling		0%	0
Other, please specify:		0%	0
Total Responses			11

Question 1 - What is your relation to the patient? (Other, please specify:)

#	Response
---	----------

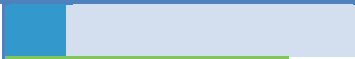

Question 2 - Who has PoA

Response	Chart	Percentage	Count
I do		36%	4
Aunt/Uncle		0%	0
Friend		0%	0
Spouse		36%	4
A patient's child		45%	5
Other, please specify:		9%	1
Total Responses			11

Question 2 - Who has PoA (Other, please specify:)

#	Response
1.	Listed name

Question 3 - Are you the only family member in the area?

Response	Chart	Percentage	Count
Yes		18%	2
No		82%	9
Total Responses			11












Question 3B - If no, who else is in the area? (NI = Not Involved, I = Involved and SI = Somewhat Involved) - (e.g. Brother NI)

Variable	Response
Relative 1	The 6 response(s) to this question can be found in the appendix.
Relative 2	The 3 response(s) to this question can be found in the appendix.
Relative 3	The 1 response(s) to this question can be found in the appendix.
Relative 4	There are no responses to this question.

Question 4 - Why was s/he brought into the hospital?

The 11 response(s) to this question can be found in the appendix.


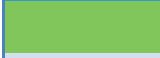
Question 5 - What are his/her current health conditions?

Response	Chart	Percentage	Count
Stroke		9%	1
COPD		0%	0
Hip Fracture		0%	0
Pneumonia		0%	0
Cardiovascular		0%	0
Arthritis/Mobility		27%	3
Alzheimers/Dementia		36%	4
Diabetes/Dialysis		0%	0
High Blood pressure		0%	0
Cancer		0%	0
Other, please specify:		73%	8
Total Responses			11










Question 5 - What are his/her current health conditions? (Other, please specify:)

#	Response
1.	Ostomy, pace maker and depression
2.	Kidney infection
3.	Not sure - awaiting results of EEG
4.	Not eating - issues with swallowing
5.	Bed sores, aspiration, Down's Syndrome, seizures, and blood clots
6.	Physical frailty (7 falls in two years), anxiety, bad knee,
7.	Broken vertebrae
8.	No specific health conditions, just getting older. Deconditioning due to infection

Question 6 - Was this his/her first admission?

Response	Chart	Percentage	Count
Yes		55%	6
No		45%	5
Total Responses			11

Question 7 - How long has s/he been in hospital?

Response	Chart	Percentage	Count
under 2 weeks		0%	0
Between 2-4 weeks		0%	0
Between 4-6 weeks		9%	1
Between 6-8 weeks		9%	1
Between 8-10 weeks		0%	0
Between 10-12 weeks		18%	2
Between 12-14 weeks		0%	0
Between 14-16 weeks		0%	0
Other, please specify:		64%	7
Total Responses			11

Question 7 - How long has s/he been in hospital? (Other, please specify:)

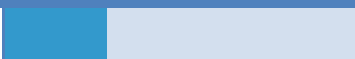
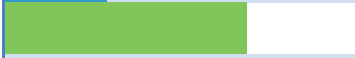
#	Response
---	----------

1. almost one year
2. 32 weeks (April 2011)
3. 36 weeks
4. 9.5 months
5. 1.5 years
6. five months
7. 5 months

Question 7 - Comment:

The 1 response(s) to this question can be found in the appendix.



Question 8 - Do you know how long s/he might have to stay?

Response	Chart	Percentage	Count
Yes		30%	3
No		70%	7
Total Responses			10

Question 8 - Comment:

The 8 response(s) to this question can be found in the appendix.

Question 9 - Are you concerned about your loved one remaining in the hospital?

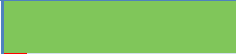




Response	Chart	Percentage	Count
Yes		64%	7
No		36%	4
Total Responses			11

Question 9 - Comment:

The 10 response(s) to this question can be found in the appendix.

Question 10 - What services make staying here a good option for him/her?

Response	Chart	Percentage	Count
Food		0%	0

Nursing care		64%	7
Doctors		9%	1
Comfortable surroundings		27%	3
Therapy options		0%	0
Other, please specify:		82%	9
Total Responses			11







Question 10 - What services make staying here a good option for him/her? (Other, please specify:)

#	Response
1.	Supervision
2.	Proximity to family
3.	Comfort knowing that he can't run away.
4.	Seizures are better."He has been treated great. They love him. He's happy." Staff are in tune to the needs of the family.
5.	He wants to leave.
6.	Proximity to granddaughter
7.	Safety; medication restraints
8.	"He copes well with it". There are less people and the environment is smaller.
9.	Social services were warm, welcoming and listened; "open door"

Question 11 - How is your family coping?

The 10 response(s) to this question can be found in the appendix.

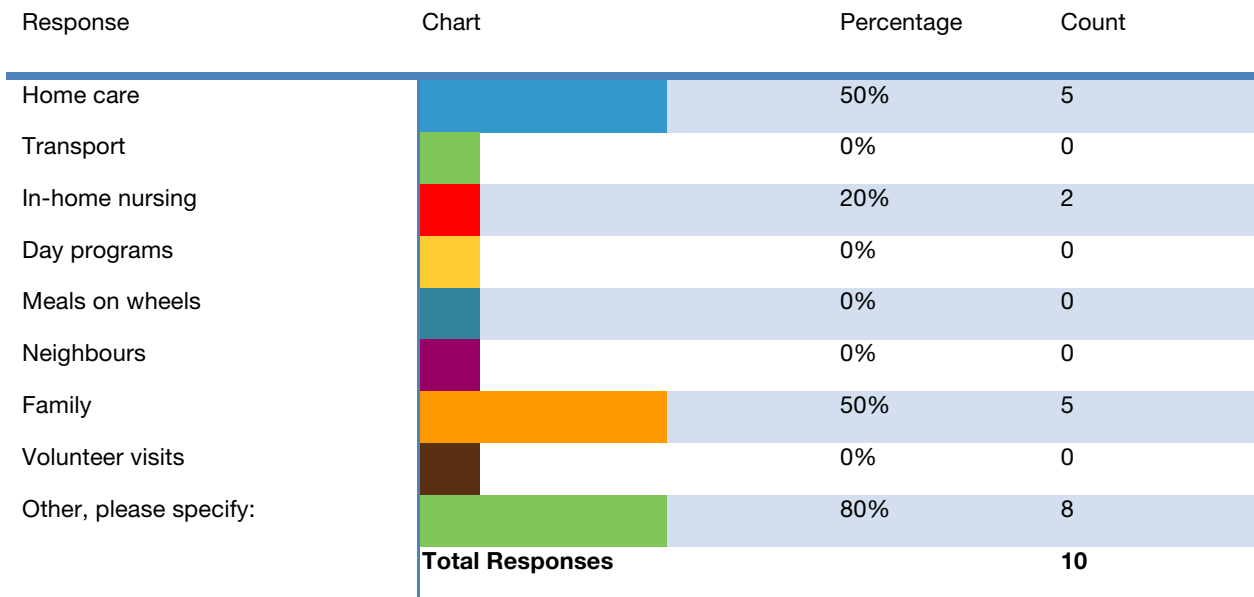
Question 12 - Where was s/he staying before s/he came to the hospital?

Response	Chart	Percentage	Count
Home alone		18%	2
Home with spouse		45%	5
With children		36%	4
Assisted living		9%	1
Retirement home		0%	0
Other, please specify:		9%	1
Total Responses			11

Question 12 - Where was s/he staying before s/he came to the hospital? (Other, please specify:)

#	Response
1.	Rotating between family members

Question 13 - When s/he was at home, which organizations or individuals, if any, provided medical help, housekeeping or other day-to-day things?



Question 13 - When s/he was at home, which organizations or individuals, if any, provided medical help, housekeeping or other day-to-day things? (Other, please specify:)

#	Response
1.	"All they did was bathing, they never walked him - I had to do that." "Didn't get the care we thought we were going to get. Workers seemed more interested in talking to me than to him".
2.	VON
3.	Private (not through CCAC)
4.	therapy
5.	Activities of Daily Living (ADL), bathing
6.	Family took care of the everyday functions: all transportation, house hold chores, shopping.
7.	Housekeeper

Question 14 - Would extra help at home have helped him/her avoid being admitted to hospital? If so, what?

The 11 response(s) to this question can be found in the appendix.

Question 15 - What did you know about the care options available to him/her in your community before s/he came to the hospital?

The 11 response(s) to this question can be found in the appendix.

Question 16 - How did you find out about what help was available?

Response	Chart	Percentage	Count
Veterans		0%	0
N/A (no help/Options unknown)		0%	0
Social worker		22%	2
Hospital		11%	1
CCAC		22%	2
Nurse		0%	0
Word of mouth		33%	3
Retirement home		0%	0
Doctor		0%	0
Other, please specify:		56%	5
Total Responses			9

Question 16 - How did you find out about what help was available? (Other, please specify:)

#	Response
1.	Daughter in-law (PSW)
2.	support group (no longer functioning)
3.	Lamberton Elderly Outreach. Always sought additional services, but was ineligible because of grandmother's relative physical health.
4.	Alzheimers society provided pamphlets
5.	Did research as a family.

Question 17 - What services would your loved one need in order to safely return home?

The 10 response(s) to this question can be found in the appendix.

Question 18 - What care options do you feel your family has right now?

The 10 response(s) to this question can be found in the appendix.



Question 19 - What are some words or feelings you associate with long-term care?

The 11 response(s) to this question can be found in the appendix.

Question 20 - How does your loved one feel about long-term care?

The 11 response(s) to this question can be found in the appendix.










Question 21 - Had your family considered a long-term care placement before s/he was hospitalized?

Response	Chart	Percentage	Count
Yes		45%	5
No		55%	6
Total Responses			11

Question 21 - Comment:

The 8 response(s) to this question can be found in the appendix.

Question 22 - What were the deciding factors for your family and your loved one in choosing long-term care as the next step?

Response	Chart	Percentage	Count
Patient's condition		45%	5
Medication Management		0%	0
Care level		64%	7
Location relative to family		0%	0
Social aspect (patient knows others in the facility)		0%	0
Feedback regarding facility		0%	0
Waiting list considerations		0%	0
Forced decision		0%	0
Other, please specify:		45%	5
Total Responses			11










Question 22 - What were the deciding factors for your family and your loved one in choosing long-term care as the next step? (Other, please specify:)

#	Response
1.	Need for locked ward
2.	Want transition to be as easy as possible
3.	"Didn't know how to take the next step without guidance".
4.	No other option that we know of.
5.	Stairs are an issue at his home.

Question 23 - How have your views changed since s/he has been in hospital?

The 11 response(s) to this question can be found in the appendix.

Question 24 - Who have you spoken to or consulted regarding your loved ones's care options?

Response	Chart	Percentage	Count
CCAC		64%	7
HDGC		0%	0
Advertisements		0%	0
Doctor		9%	1
Social worker		18%	2
Family		18%	2
Hospital staff (incl. nurses)		36%	4
LTC facility		18%	2
Other, please specify:		36%	4
Total Responses			11

Question 24 - Who have you spoken to or consulted regarding your loved ones's care options?



(Other, please specify:)

#	Response
1.	Discharge planner
2.	Discharge planner - very good.
3.	Specialists
4.	Placement worker (unsure if they're from hospital or CCAC).






Question 25 - How could we improve communication?

The 10 response(s) to this question can be found in the appendix.



















Question 26 - Is s/he on the waiting list for any long-term care residences?

Response	Chart	Percentage	Count
Yes		100%	11
No		0%	0
Total Responses			11

Question 27 - How many has s/he chosen?

Response	Chart	Percentage	Count
1		64%	7
2		27%	3
3		9%	1
4		0%	0
5		0%	0
Total Responses			11

Question 28 - What are his/her first choice and second choices for long-term care homes?

Response	Chart	Percentage	Count
Blenheim Community Village		0%	0
Copper Terrace		0%	0
Fairfield Park		27%	3
Meadow Park Nursing Home		0%	0
Riverview Gardens		27%	3
Tilbury Manor Nursing Home		0%	0
The Village, Ridgetown		0%	0
Afton Park Place		27%	3
Fiddick's Nursing Home		0%	0
Lambton Meadowview Villa		9%	1
Marshall Gowland Manor		18%	2
North Lambton Lodge		0%	0
Sumac Lodge		0%	0
Forest		9%	1
Vision Nursing Home		18%	2
Watford Quality Care Centre		0%	0
Trillium Villa		0%	0
N/A		0%	0
Other, please specify:		0%	0
Total Responses			11

Question 28 - What are his/her first choice and second choices for long-term care homes? (Other, please specify:)

#	Response
---	----------

Question 29 - What factors influenced his/her choices?

Response	Chart	Percentage	Count
Language preferences		0%	0
Location relative to family		22%	2
Familiarity		11%	1
Accessibility issues (e.g. elevators)		0%	0
Positive word of mouth		0%	0
Presence of friends		0%	0
Accommodations		22%	2
Needs		0%	0
Insurance coverage		0%	0
Private room options		0%	0
Staff		11%	1
No choice		0%	0
N/A		78%	7
Other, please specify:		33%	3
Total Responses			9

Question 29 - What factors influenced his/her choices? (Other, please specify:)

#	Response
1.	The kind of programming available.
2.	"Bright, cheery and active. The Alzheimer ward was very different, though"

Question 30 - Do you agree with his/her selections?

Response	Chart	Percentage	Count
Yes		27%	3
No		0%	0
N/A Family made decision		73%	8
Total Responses			11

Question 31 - What influenced your choices?

Response	Chart	Percentage	Count
Language preferences		0%	0
Location relative to family		89%	8
Familiarity		0%	0
Accessibility issues (e.g. elevators)		11%	1
Positive word of mouth		22%	2
Presence of friends		22%	2
Accommodations		11%	1
Needs		0%	0
Cost/Financing		22%	2
Staff		0%	0
Other, please specify:		44%	4
Total Responses			9

Question 31 - What influenced your choices? (Other, please specify:)

#	Response
1.	Demographics: want to make sure there are some young people there.
2.	"Homey", it's like a hotel: pub, hairdresser. "There aren't people sitting there all drooped over".
3.	"Looks like a cruise ship" (not a "nursing home")
4.	Accessible by transit

Question 32 - Have you had any input or influenced his/her choices?

Response	Chart	Percentage	Count
Yes		10%	1
No		10%	1
N/A Family made decision independent of patient		80%	8
Total Responses			10

Question 33 - Is there a long-term care facility that they would prefer not to select as an option?

Why, why not?

The 10 response(s) to this question can be found in the appendix.

Question 34 - Do you agree with that decision?

Response	Chart	Percentage	Count
Yes		17%	1
No		0%	0
N/A		83%	5
Total Responses			6

Question 35 - How long has s/he been waiting for a placement to long-term care?

Response	Chart	Percentage	Count
Under 2 weeks		0%	0
Between 2-4 weeks		0%	0
Between 4-6 weeks		11%	1
Between 6-8 weeks		22%	2
Between 8-10 weeks		11%	1
Between 10-12 weeks		11%	1
Between 12-14 weeks		0%	0
Between 14-16 weeks		0%	0
Other, please specify:		44%	4
Total Responses			9

Question 35 - How long has s/he been waiting for a placement to long-term care? (Other, please specify:)

#	Response
1.	36 weeks (march 2011)
2.	Might be waiting up to 2 years.
3.	10 months
4.	1 year (currently at the top of list)

Question 36 - Has s/he ever been offered a place in long-term care?

Response	Chart	Percentage	Count
Yes		56%	5
No		44%	4

Total Responses

9










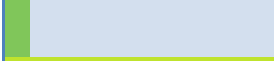
Question 36B - If so, where?

The 5 response(s) to this question can be found in the appendix.

Question 37 - Why was the offer declined?

The 5 response(s) to this question can be found in the appendix.

Question 38 - When you think about his/her next steps, what would you say is the most important to you in helping him/her make that decision?














Response	Chart	Percentage	Count
Confidence in care		45%	5
Affordability		0%	0
Safety		18%	2
Language barrier		0%	0
Open channels of communication		9%	1
Location relative to family		18%	2
Comfortable accommodations		55%	6
Help to understanding the LTC options available (services and cost)		9%	1
Consensus within family regarding decision		0%	0
Other, please specify:		91%	10
Total Responses			11

Question 38 - When you think about his/her next steps, what would you say is the most important to you in helping him/her make that decision? (Other, please specify:)

#	Response
1.	Need programming available; need him to be encouraged.
2.	Respect
3.	Able to retain dignity and shown respect
4.	Familiar belongings are important; own t.v., pictures.
5.	Food, things from home
6.	Not sure. Care at Afton is good. Still adjusting
7.	Wish LTCs were smaller. Homes are too big; trouble finding rooms.

- | |
|---|
| 8. His comfort with the whole idea. Him accepting the idea. |
| 9. Maintaining independence; maintaining his right to choose. |

Question 39 - When you think about the next steps in securing appropriate care for your loved one, what are your greatest concerns?

Response	Chart	Percentage	Count
Confidence in care		11%	1
Affordability/Financing		22%	2
Safety		0%	0
Language/cultural barrier		0%	0
Open channels of communication		0%	0
Location of facility		22%	2
Comfortable accommodations		22%	2
Help to understanding the LTC options available (services and cost)		11%	1
Consensus within family regarding decision		0%	0
Level of staff professionalism		0%	0
Mobility		0%	0
No concerns		0%	0
Other, please specify:		100%	9
Total Responses			9

Question 39 - When you think about the next steps in securing appropriate care for your loved one, what are your greatest concerns? (Other, please specify:)

#	Response
1.	Wait time for room, rotation of patients in hospital is difficult, "Why am I still stuck here?"
2.	Understands that mom will degenerate. Wants her to be comfortable.
3.	"I've heard horror stories, but we're not too worried. We'll be there everyday."
4.	Deterioration leading to death
5.	The right wheel chair, I want him to meet people and "be part of it", ease of transition (important for family too), wants to be part of the decision making process.
6.	Hopes help will be there during the night
7.	Wait time for appropriate facility; no quality of life in the meantime.

8. Want the same care as he has here (in hospital). Very happy with it here.
9. Important to speak to the individual. What do they want? How do THEY feel?

Question 40 - What suggestions would you make to improve the design of the health care system?

The 11 response(s) to this question can be found in the appendix.

Question 41 - Is there anything else you can tell me to help us better understand your family's position?

The 10 response(s) to this question can be found in the appendix.

Question 42 - Is there anything else you would like to share?

The 8 response(s) to this question can be found in the appendix.

Observations and Comments

The 2 response(s) to this question can be found in the appendix.

Question 3B - If no, who else is in the area?

#	Response
1.	wife
2.	son NI
3.	Sister SI
4.	son
5.	Mom I
6.	Sister I

Question 3B - If no, who else is in the area?

#	Response
1.	son
2.	son
3.	Brother 1

Question 3B - If no, who else is in the area?

#	Response
1.	daughter

Question 4 - Why was s/he brought into the hospital?

#	Response
---	----------

1. Ostomy, fell at home
2. Kidney infection
3. Started getting "twitches" that would last a long time. Brought to hospital, received treatment, discharged, brought back to hospital when twitches returned, then admitted.
4. Running away/behaviour issues
5. Sepsis, dehydration
6. stroke
7. Toileting issues, falls
8. Couldn't take care at home; too long to wait (for LTC?)
9. Fell and broke a vertebrae. Brought in after pain and dementia set in. Doctor didn't act quickly enough.
10. Had massive prostate cancer, issues with pulling catheter out which resulted in massive infection.
11. Massive infection after surgery; indwelling catheter

Question 7 - Comment:

#	Response
1.	She's bounced around various centres until sent here for extended care.

Question 8 - Comment:

#	Response
1.	No idea. Waiting for LTC.
2.	Staff say approximately 1 year, could be 2.
3.	Waiting until we find out what the diagnosis is; until a LTC bed becomes available
4.	Depends on wait list for LTC. We need a place on the 5th floor.
5.	A few months. On LTC wait list.
6.	3 weeks
7.	Left on Monday for private room at North Lambton Lodge, waiting for a semi-private. This process is confusing.
8.	Think he's at the top of the wait list.

Question 9 - Comment:

#	Response
1.	He has deconditioned significantly. Depression has increased. "He's become so quiet and withdrawn". Won't watch television, doesn't like the food. "Not homey here".
2.	Lack of consistent care, "lack of attention from some nurses". Described food and medications sitting in front of her face (can't eat by herself or administer her own medication). She's bought "accessible" clothes for her mother, but staff aren't dressing her in them. "Sometimes it seems that computer work is more important than the patients".

3.	"They've been great"; "they're fabulous".
4.	The treatment hasn't been good: confined to his room due to behaviours, threatened with restraints and transfers (situation with a needle to scare him); lack of compassion; nursing staff show their frustration; lack of education about Huntington's; alleged physical abuse by hospital staff; money has gone missing; costs a lot to stay in hospital.
5.	He's deconditioned - not walking, has to be fed now.
6.	"It's depressing here". Meals aren't good; lack of comfort and utilities (television, radio, music). Husband wants to get out. "He gets good care, but a hospital's a hospital."
7.	She's been ALC since day 5. The hospital isn't the place when she isn't sick. Risks for infection are high; difficult for people to visit her (hospital is in neighbouring town). She's very private and independent; doesn't like being "manhandled".
8.	Safer here where he's properly medicated than at home.
9.	Would rather have him stay here
10.	Not used to this type of environment, lack of privacy; very apprehensive.

Question 11 - How is your family coping?

#	Response
1.	Not too bad, kids try to get out, but both work. Son does most visiting
2.	Better now with assistance from VON.
3.	Good - "We're very close". For the most part they agree on care issues.
4.	not well - struggling with "treatment"
5.	difficult - faith is helping
6.	Stressed, but family agrees on course of care (LTC)
7.	Taking turns, checking in
8.	Fine
9.	So far, okay. "It's a job, but he's my dad."
10.	Better now that he is in long term care. Another death in the family right after took a big toll on the family. Having sister there helped with coping.

Question 14 - Would extra help at home have helped him/her avoid being admitted to hospital? If so, what?

#	Response
1.	No, care need too high
2.	No - Alzheimer's made care needs to great
3.	No. "We were getting concerned. Getting to the point where she needed someone around all the time".
4.	24 hour RN care - constant supervision
5.	No, care need too high

6.	no
7.	Yes. Additional respite (only eligible for 12 hrs per moth) would have helped decrease risk of falls, but only "care" required was bathing. Would pay for additional time if needed. Don't know if this would have changed the outcome.
8.	Don't think so. The disease just progressed.
9.	it was inevitable (his fall). He fell in the kitchen (not sure how).
10.	No. Her father wouldn't have been honest about his health issues. Wouldn't admit it if there was a problem. If someone was at home maybe we could have blown the whistle earlier
11.	Possibly, but he's the type of man who won't tell you something is wrong. Had a friend come down who suggested he go to hospital.

Question 15 - What did you know about the care options available to him/her in your community before s/he came to the hospital?

#	Response
1.	Nothing.
2.	Nothing - alzheimers society was of little help
3.	Yes - learned from brother-in-law's experience. Knows people in LTC.
4.	CCAC - looked at options for in-home RN care, assisted living and LTC options. Spouce - DSW - well aware of options
5.	CCAC, OSDP, Community living
6.	no
7.	Not much. Had to do our own research
8.	Alzheimers society was just getting involved when patient turned aggressive
9.	Not really. "You never think it will happen to you". We've talked to other people, but still don't know it all; don't know where to go for info.
10.	Didn't know. Discovered as they went.
11.	Not much until provided with pamphlets

Question 17 - What services would your loved one need in order to safely return home?

#	Response
1.	Not realistic
2.	Nothing right now - care needs too high
3.	24 hour RN care - something to stop him from running away
4.	Can't.
5.	need nursing care daily - risk for falling is high (limited to 3 hours a week for nursing assistance)
6.	Impossible. Can't manage physically or emotionally

7.	None.
8.	Won't be able to. Needs 24 hour care and home isn't set up properly.
9.	Risk of falling demands 24hr care
10.	None. Needs 24/7 care

Question 18 - What care options do you feel your family has right now?

#	Response
1.	LTC
2.	LTC
3.	Only LTC - frustrated with the situation
4.	LTC only option
5.	LTC
6.	LTC. (Should have applied 2 years ago and waited at home. May have improved everyone's quality of life)
7.	LTC is the only option
8.	LTC is the only option
9.	N/A
10.	Retirement home/LTC

Question 19 - What are some words or feelings you associate with long-term care?

#	Response
1.	"What's best for him"; where he will be well taken care of.
2.	Realization that she can't function for herself. Daughter will advocate on behalf of her mom and address any issues of neglect as soon as they're seen.
3.	"A little nervous about it" - changing routines may be an issue. "Hear all the good stuff" - family friend had very positive experience. Unfamiliarity, "but we'll be there" to help her get used to new routine.
4.	Where he needs to be safe and secure. Make it home-like environment.
5.	"Scared", "too young", "want him cared for"
6.	likes it
7.	"Seniors maximize living potential in a setting that is built around their needs." It's necessary for those in need.
8.	"T'ill you're dead"
9.	Not sure. Only been there. Don't like it, but know there is no other option. Glad services are available
10.	Didn't feel one way or the other.
11.	"Good for people who don't have another option"

Question 20 - How does your loved one feel about long-term care?

#	Response
1.	Would prefer to go home, but accepting of it
2.	Don't think she's aware. Family can't use the word "home" or she gets upset.
3.	Not really aware: "goes in one ear, out the other"
4.	Does not like or support the options
5.	Doesn't know (moves scare him)
6.	He doesn't really know. "He didn't realize he was that sick". When learning that a neighbour had had a stroke and was transferred to LTC, he'd said "I'd sooner die than go into a nursing home".
7.	Before: "no way" would "rather go to cemetery". Now: "new apartment" (doesn't "look like" LTC so doesn't realize that it is)
8.	Never wanted to go but now doesn't know.
9.	Doesn't know.
10.	"Scary" "Hen house" Very opposed, "Why move into LTC when he has a perfectly good home paid for" (his perspective)
11.	Was hesitant at first, now settled and feels okay. Doesn't have to worry about laundry and meals, so he's more relaxed.

Question 21 - Comment:

#	Response
1.	Started considering it earlier in the year. Tried to get assessments done, but it was difficult to schedule.
2.	"We were a bit split that way". Some family members supported the idea, others were very reluctant
3.	Prior to cognitive decline. Got POA so that decisions could be made when needed.
4.	No. Would still be at my mom's if they hadn't admitted her. We needed someone else to make that decision. "Mom and dad were at the end of their string".
5.	Had applied and told it was over a two year wait.
6.	There didn't seem to be a need.
7.	Yes, but not seriously. They knew the day was coming.
8.	Took him to visit three homes.

Question 23 - How have your views changed since s/he has been in hospital?

#	Response
1.	Not really
2.	Unchanged
3.	Care here is wonderful
4.	Didn't anticipate the staff being the way they are - not compassionate

5.	"I'll be there"
6.	Not really
7.	"Happy where she is at", have recognized the stress they were under.
8.	Hospital has taken good care of him. Medication helped. Care at home was just as good but couldn't change meds when needed. Couldn't get to doctor's due to increasing aggression.
9.	Grateful to the nurses and services. Glad that we have services available.
10.	Changed twice. Worst experience she's ever been through. Initially it felt like a bad car deal. Misinformed. Now, they are starting to feel like they're on their side.
11.	Yes. See that they do have a place.

Question 25 - How could we improve communication?

#	Response
1.	Only get to visit at night after work and often feels left out of the loop in terms of how her day went.
2.	Communication has been good
3.	Staff need better training for dealing with Huntingtons Disease. Notes on chart on what to expect in behaviour.
4.	"I have no options".
5.	"It didn't feel like we had a choice". The long wait list for LTC and the application process to get there is frustrating. "I thought the minute we came here that he was on a wait list. This is wrong. As soon as the person knows there's no chance, get them on the wait list".
6.	"If there is such a pressure to get them out, why does it take so long to get the ball rolling?" After paperwork was signed, there was no communication for 4 weeks. Check-ins would have been beneficial and bed offers should never be a surprise. There is a short window of opportunity when admitted and deemed ALC. Too much time between ALC and application completed - "could be dead by the time the papers are all signed".
7.	Knew what our choices were. No problems.
8.	Information: Where can we get it? Should make care options and care options available.
9.	Schedule of events, explaining what the process is. Knowing what to expect when it was happening. A manual of some sorts. Video tour or photos would have been helpful.
10.	Case consultations could improve. Now they're very infrequent. They should be held more often and on a regular basis

Question 33 - Is there a long-term care facility that they would prefer not to select as an option?

Why, why not?

#	Response
1.	Tillbury, Blenheim, Ridgetown - due to location
2.	Yes, but can't specify. "Can tell when you walk in that it's bad".
3.	Don't know them well enough.
4.	Anything aside from Riverview isn't an option. Need young people there and lifts.

5.	Copper Terrace - "too institutional. It's like you're just waiting to die there".
6.	Sumac. Heard it has a horrible reputation, but didn't visit.
7.	Nothing out of the city
8.	Not that I know of. Have seen 3 locations. "Non-profit" (Cost?) is the only influence/deciding factor
9.	No. We ignored the chatter about certain places. Wanted to make our own decision.
10.	Sumac. Very crowded; no privacy

Question 36B - If so, where?

#	Response
1.	Fairfield
2.	Sumac
3.	Afton
4.	Afton.
5.	Afton.

Question 37 - Why was the offer declined?

#	Response
1.	Still don't know the diagnosis. Waiting to hear from doctor: "Is this Mom at 91, or something else?"
2.	Location. Forest is the only option
3.	Wasn't. Just got in.
4.	It wasn't. Patient is currently there.
5.	Wasn't. Her father is currently there.

Question 40 - What suggestions would you make to improve the design of the health care system?

#	Response
1.	Reduce wait times, improve physical facilities, more family doctors. The environment makes a big difference.
2.	Need more staff and qualified people. "Patients crave attention. Make sure they know that they're the priority." Small gestures show that you care.
3.	Physio: language wasn't really respectful. Waiting on neurologist report is an issue (recognizes that she's bust, but... "is it just because she's 91? That bothers me".
4.	More locked units in LTC (currently only one). More education for RNs; more compassion for patients and families
5.	Need people who care.
6.	"Shouldn't have to wait so long for LTC."
7.	If we are going to try and manage seniors at home the system needs to be prepared to support those who need more. What about transitional beds (not available in Sarnia, yet) Sick people shouldn't be in hospital;

	dignity.
8.	"If it was me, I would have put him on a list sooner" but Mom has PoA, had to wait for her decision.
9.	More information. Communicate services available. Smaller LTCs.
10.	Patient focused, make it patient centred. More "people" focused. Too often treated her father (the patient) like he wasn't there. Need to be more personable in the hospitals; more sensitive to those going through health issues and the families going through it.
11.	Disclose where the bed is (on the Alzheimer's ward, example). Make the complaint process clearly outlined for patient.

Question 41 - Is there anything else you can tell me to help us better understand your family's position?

#	Response
1.	So many closed doors here. Needs programming to get him active, " he can't lie in bed from morning 'till night". Hospital can't just depend on family, "they need at least something here".
2.	need more people on a 1 on 1 basis - staff are overworked. Need increase in communication in re. to care plane (meds, side-effects, who'll be coming, who to talk to)
3.	"I know our family is the exception. Most can't do what we do". Advice for other families: "Try to do your best, let the rest go. Take it one day at a time".
4.	Not enough information for families - it's very easy to get lost. Need more engagement with healthcare providers to solve issues.
5.	Money can be a concern. Being involved and engaged is very important.
6.	Telling someone that they can't go home is "almost the same as when someone goes to the doctor for a bad diagnosis: significant. My mother had this conversation on her own and should have had support. We underestimate how important these steps are." Communication is lacking: "Need reassurance that we haven't been forgotten."
7.	"Every patient is different even when they have the same disease." It's hard on families, eventually families can't handle it. LTC becomes the next step.
8.	"If we had someone at the beginning to walk through the process and provide information it would have been easier". Are there any options other than LTC homes? i.e. home care, home improvements to bring someone home again (grants available?). Switched preferences on LTC because they wanted 2 bed basic, not 3 bed. We felt forced to switch. We can't actually afford a semi. We don't want him moved again if he takes the 2nd choice. "We still don't know all the options".
9.	Come up with a manual to help families; get information to families earlier to help them be more prepared.
10.	It's very emotional. A trying time for the patient, but more so for the family. Happy, proper care is needed. Feel they are "dumping" him.

Question 42 - Is there anything else you would like to share?

#	Response
1.	Concerned about future of healthcare, need long term visionary planning to ensure future generations have care. No reason for the discrepancy between LTC homes and bed numbers, and the number of elderly people in the area: "they know the percentage of us who are elderly".
2.	Greater collaboration needs to happen between nurses, doctors, physio, social workers, etc... Care team needs to know what's happening and how medication changes will impact other areas of care. Family needs more information about medication side-effects and how they 'mix' with other meds.

3.	System as a whole is busy - a bit overwhelming sometimes. "Need to advocate for yourself". "There is so much good I see happening".
4.	Make food better, keep food simple (hotdogs and hamburgers).
5.	Wonders how many patients would be ALC if we did the right "job" in the first place - appropriate care and supports. How many things do people have to face before we can get them support? Prevention as opposed to responsive.
6.	Consistency is key for patients in this environment. Everyday things: nursing staff - may do things differently, patient may become agitated. Know nurses can't be here 7 days a week, but would make a difference. The process of choosing homes wasn't clear.
7.	Social worker (provided name) was the one person they felt was on their side
8.	should be a 24/48 hour period to go into LTC setting. It's wrong to have to wait so long. They should all be able to go back to a waiting bed. In our situation there was no way to back out.

Observations and Comments

#	Response
1.	Appeared resigned to be dissatisfied with care; resigned to the fact that she'll have to advocate for good care.
2.	Seemed unsure about role of CCAC. Discribed lots of "red flags" RE: health of husband - could this have been prevented?

Appendix C – Staff sessions

Chatham-Kent Health Alliance

Thank you, but I'd rather stay here...

- Cost: patients think the government will take all their money
- People ask around - can hear the compliments and complaints of each home
- Poor transportation to/from home
- Confusion about how 'far' away facilities really are
 - Concerned that people won't drive so far
- People from Sarnia don't want to leave Sarnia
- Doctor issues:
 - Doctors in Petrolia tell patients they can stay there forever.
- Lack of tours for patients
- Perception that LTC homes are "places you go to die" - they don't realize the perks!
- Sumac has no private rooms
- Reluctant to take 2nd or 3rd choice in case their first choice comes up – once patients go to second choice, they usually don't move
- Lack of clarity in terms of what people can expect in LTC homes
 - They're shown the newer, bigger rooms, but offered a small, dingy one when the time comes
- People don't understand PoA
- Referrals are inappropriately timed (i.e. one day before surgery)
- CCAC's working relationship with hospital is great, though the flow and process is sometimes problematic
- Hospital is too quick to identify patients as ALC
 - Referral should go to homecare first. If it fails, then LTC
- Bariatrics, patients with aggressive behaviours are very difficult to place there's no good place for them to go:
 - Fiddicks will try anyone, but if they refuse...then what?
- "I could just stay here. This is almost like a LTC"
- The process by which available beds find new occupants isn't always done right:
 - There are internal and external waits for 1 bed basics.
 - It's supposed to be that every 2nd bed is supposed to be offered to someone on the public waiting list. Sometimes the people waiting internally jump the queue

Convincing Solutions

1. Provide promotional packages to help show homes
 - a. Clarify expectations: need to be honest and show the older parts, too.
2. Public Education on fees/process
3. Every hospital needs a discharge planner
4. Incorporate the physician's involvement
 - a. Encourage patient that hospital isn't the right place to be

Erie St. Clair Community Care Access Centre

Thank you, but I'd rather stay here because...

- Too much misunderstanding surrounding processes between hospital staff, between hospital staff and CCAC, physicians and staff, discharge planners, etc...
- Waits for assessments from the CCAC; hospitals not familiar with ESC programs
- Flow/process needs to be refined (CCAC can't do an assessment until they receive a referral)
- CCAC informs hospital/floor of assessment date and plans but the rest of staff don't understand what this process will really look like.
- Clarify expectations: 5 days versus 7 days for a referral:

- Clarify these timelines
- Homes can hold up admission process, too
- "Basic" isn't the same across LTCs
- Many patients are denied due to their behaviours - we don't have a Home ready to deal with behaviours
- Existing LTCs can't handle the needs of aggressive patients
- Lack of tours to LTCs
- Transportation is a barrier
- Patients don't want to be moved again
- Hospital staff don't understand the process or regulations unless they are a discharge planner
- CCAC only sit in rounds if patient is going home
- Expectations of LTCs aren't clear:
- When you go on a tour you see a room people leave thinking that's the room they will get - not true.
- Need to be honest - show good and bad; new and old;
- Videos of LTCs could be made available
- Long-distance calls cost money (long distance phone calls are a barrier for seniors)
- Need more basic 2-bed rooms in LTCs - many patients can't afford more.

Convincing Solutions

1. Education about process is crucial
2. CCAC and hospitals could tour LTCs more often so they could provide more accurate information to patients and families
3. Training for front line staff working with aggressive behaviours or patients with dementia
4. Hire more staff for LTC assessments

Bluewater Health

Thank you, but I'd rather stay here because...

- Historically, "nursing home" has a negative connotation - it's more acceptable to stay in hospital.
- Home is preferred, but hospital is preferable to LTC.
- They don't think they have to pay if they stay in hospital.
- Co-pay is always an issue, though the financial piece is usually worked out by the time they reach CCAC (find it helpful when patient/family is prepared for the co-pay discussion).
- Since 2005, social workers have had to play the role of both "social worker" and "discharge planner".
- CCAC is only engaged once patient is deemed ALC, but if patient declines LTC, CCAC closes the case.
- When this happens it's up to hospital staff to get the process going again (depending on the floor - there's inconsistency here, too).
- Wait times are frustrating.
- We wait too long between ALC designation and getting paperwork end done from the CCAC.
- CCAC is understaffed, but do a lot here.
- They call out, do phone calls, make bed offers themselves as opposed to waiting for office staff to do it (good!).
- Some patients "play the game" - there's beds available in Watford/Petrolia, but they refuse to be put on list (even if that's where they live). We don't get it. Why do they like it her so much?
- They think they need to be here and fear their condition will worsen at LTC.
- Often the more family they have, the more unrealistic ideas there are (always think extra therapy will help when it won't and get angry when denied more rehab).
- There's a lack of affordable retirement homes (if it was more affordable, the spouse could go, too).
- People on basic OAS can't afford retirement homes.
- Younger bariatric patients have become a real problem (Tim Horton's hasn't helped).
- There's no place for bariatrics to go, and they're often younger, so they refuse LTC.

- Since "1st available bed" was taken away it has had a negative impact: "This is the new nursing home".
- Patients are choosing LTCs with the longest wait times.
- Home First won't work with certain patients (i.e. dementia); lack of therapists (only 1 for whole 5th floor).
- Staffing is tough - have priorities to fill, if have vacation or illness occurs certain floors go understaffed.
- More active interventions would help.
- There has been an increase in beds, but not staff.
- Cognitively complex patients are hard to find LTC placements for - they won't even do a referral if they've been restrained once in a one month period, then when an LTC said it WILL take the patient, we can't get an assessment.
- We need to think outside the box to get people placed if LTC is willing to take them.
- Fiddicks will look at trachs., but others won't.
- We have some homes that are more willing to work with us around the behaviour piece - has really helped.
- Need incentives for LTCs to take bariatrics.
- Older generations are in the poor house. European approach: take care of family in home; "take care of our own" here: drive by emergency and drop them off.
- "I'm too young for LTC". There is no LTC for younger people. Younger people don't need hospital, but LTC isn't right.
- In regards to ODSP, if patient doesn't report it, hospital can't on their behalf. Also, they can't get it (ODSP) once they go to LTC.
- Younger ones use ODSP to stay in hospital to accrue the money without paying room and board.
- Sense of entitlement with patients to be waited on hand and foot.
- There's a lack of transitional care units.
- Unable to retrofit older homes.

Convincing Solutions

1. ODSP could revise its policy – make it more of an incentive to leave hospital
2. Need specialized youth/younger person wards/units in LTC
3. Consider resources for bariatric patients
4. Incentives to retrofit older homes
5. There are a lot of re-admissions because they can't cope at home and can't afford private services - CCAC isn't enough
6. Re-instill "1st Available Bed" policy
7. Revise the restraint system/policy
8. Need more clinics - COPD, chronic disease, education on medication (i.e. puffers)
9. More health education in community