Improving Care for Seniors in Windsor/Essex: Understanding Alternate Level of Care Designations

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Prepared by MASS LBP

A partnership among:

Ontario
Erie St. Clair Local Health Integration Network
Réseau local d'intégration des services de santé d'Érié St. Clair

LEAMINGTON DISTRICT MEMORIAL HOSPITAL

WINDSOR REGIONAL HOSPITAL

Erie St. Clair CCAC Community Care Access Centre / CASC Centre d'accès aux soins communautaires d'Érié St-Clair

Hotel Dieu Grace Hospital

Executive Summary

Alternate Level of Care (ALC) is the designation given to patients who occupy hospital beds but do not require acute care. It is a symptom of the health care system failing to provide predominantly elderly patients with the medical, psychological, or emotional supports required for them to transition out of the acute care setting. ALC is a phenomenon experienced in hospitals across Ontario, but is a particular concern in the Windsor/Essex area.

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) initiated a project to better understand the circumstances that lead to patients remaining in hospital under ALC designation. The ESC LHIN partnered with Leamington District Memorial Hospital, Hôtel-Dieu Grace Hospital, Windsor Regional Hospital, and the Erie St. Clair Community Care Access Centre (CCAC) to collectively engage patients, family members, and front-line staff to gain insight into the ALC pressures in Windsor/Essex. 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 August 15 and 30, 2011, ESC LHIN staff conducted private interviews with ten ALC patients and sixteen family members. The ESC LHIN also hosted five 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 for the growing number of seniors 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. **Roles and responsibilities** – Increase the integration, collaboration, and transparency among health care providers. Clarify and standardize the responsibilities of providers across the continuum of care at all hospital sites. Encourage and promote partnerships among care providers to help patients and their families with preplanning and transitions.

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2. **In-hospital treatment of ALC patients** – ALC designation should act as a trigger to transition patient care away from the medical model. Enhance communication, ambulation, and allied health care supports to reflect the needs of ALC patients.

3. **Decision-making supports** – Develop a comprehensive and standardized package to promote long-term care homes to patients. Expand the use of evaluation tools and decision-making resources for patients and family members to determine their needs and evaluate their care options.

4. **Communication** – Increase emotional support to both patients and family members who should be considering long-term care. Look for opportunities to expand hands-on, compassionate navigation support to both patients and family members. 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.

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Introduction

Alternate Level of Care (ALC) is the designation given to patients who occupy hospital beds but do not require acute care. Patients are designated ALC when their needs would be better served at home or in long-term care but the patient cannot acquire the medical, psychological, or emotional supports required to leave hospital.

The consequences of ALC designations are disruptive for hospitals. A backlog of ALC patients interrupts patient flow within the health system and manifests in bottlenecks, notably in emergency departments. Patients who need to be admitted to hospital must wait because of a lack of available beds. Patients who do not require acute care command resources and staff attention. This increases the pressure on already-taxed front-line staff within hospitals. It also strains tight budgets because patients receive expensive and unnecessary care.

Moreover, remaining in hospital is hazardous for patients, the vast majority of which are the frail elderly. The uncertainty of ALC designation can be confusing and stressful for patients and their family members. The risk of infection is ever present. As patients linger in hospital, they de-condition due to lack of physical exercise, intellectual stimuli, and social interaction. They risk decline and depression. Most importantly, ALC complicates the task of providing optimal care to a vulnerable patient population.

While the symptoms of ALC are apparent, its causes 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) initiated a project to reach out directly to ALC patients, their loved ones, and the front-line staff who have the most contact with them. The ESC LHIN partnered with Leamington District Memorial Hospital, Hôtel-Dieu Grace Hospital, Windsor Regional Hospital, and the Erie St. Clair Community Care Access Centre (CCAC) to better understand the circumstances that lead to patients remaining in hospital under ALC designation.

Goals

The project aimed to capture the perspectives of patients and their loved ones through conversations with patients, family members, and front-line staff. Specifically, we set out to:

- Learn what patients and their loved ones understand about patient conditions 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 a long-term care setting.

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- 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

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. 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 August 15 and 30, 2011, ESC LHIN staff conducted private interviews with ten ALC patients and sixteen family members. The ESC LHIN also hosted five workshops for the front-line staff at each of the partnering organizations to discuss their understanding and perceptions of ALC patients and their families.

Interviews averaged approximately forty-five minutes each. Patients were interviewed individually, unless the patient requested a family member 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. Two ESC LHIN staff were present for each interview. Staff met in groups of ten to twenty for one-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 interviewed had two kinds of profile. The first, and by far the most common, are elderly people with complex chronic conditions. These patients range in age from seventy to ninety-four. With few exceptions, they suffer from at least two conditions. Patients identified cardiovascular ailments and arthritis most often.

The second profile of ALC patient is much younger and suffers from a debilitating chronic condition. This segment of the ALC population is much smaller, in this case represented by one middle-aged patient.

For the majority, this was not their first admission. Patients indicated that previous admissions had occurred at least one year and often many years prior. The current admission ranged from one day to more than one year.

Most lived at home, either alone or with a spouse or child. The majority of home care was left up to family members, though many also received regular care from the CCAC and community care providers. Patients listed meal delivery, bathing, and nurse visits as services they had received at home.

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Patients had difficulty identifying additional services they could have received at home that might have prevented their hospital admission. A few singled out overnight care and additional mobility assistance. Most seemed confident that their admission could not have been avoided.

Perception of condition and hospital care

None of the respondents could answer how long they might have to remain hospitalized. Some attributed this to lack of communication from staff or long wait times for long-term care homes, although many seemed uninterested in the possibility of discharge. None could specify a goal or target for improvement.

Patients expressed satisfaction with the care they receive in hospital. Quality of food, nursing staff, and physiotherapy were most commonly identified as positive aspects of hospital care. Some patients noted comfort and familiarity with the staff, or fear that, should they leave hospital, they would be transferred to long-term care away from home. A few patients mentioned affordability as an important factor making hospital the best option for them, citing medications or specialty equipment such as an electric lift as resources they would not be able to afford if discharged.

Patients were unconcerned about the risks of staying in hospital. Most seemed unaware of the risks. Some noted growing more comfortable in the hospital setting over time.

Patients voiced confidence in the care they receive in hospital, and many expressed a desire to remain. There was no difference between the responses of patients on waiting lists and those who were not.

Perception of long-term care

Patients admitted to having very little knowledge about long-term care before their most recent admission to hospital, but did not demonstrate that their knowledge had increased appreciably while in acute care.

Half of the patient respondents claimed to be on the waiting list for long-term care. Only a quarter could identify how many homes they were on a waiting list for, and fewer still could name the homes they had selected.

Perceptions of long-term care varied. Many patients expressed they did not want to go to long-term care. Some were defensive when asked what they thought of long-term care, responding they would prefer to go home. Patient descriptions of long-term care included:

- “Substandard care”
- “Expensive”
- “Restrictive”
- “Don’t know”
- “No anxiety”
- “A place you go to die”
- “It’s all what you make of it”

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- "A place to live with people in your own age group"

Patients often described long-term care in terms of resignation: "If I've got to go, I've got to go." Their concerns about long-term care centred on cost, staffing, quality of care, quality of the physical condition of the home, and isolation. Many patients noted that they would want a long-term care facility located near their current home.

Four factors emerged as clear priorities for patients selecting long-term care homes:

Location – Patients were extremely concerned about the proximity of any long-term care home to their home, friends, and family. They voiced trepidation that they might be transferred to a home where their support network could not easily visit them. Also, unease over leaving familiar neighbourhoods was common. Patients valued being able to maintain consistency in the landmarks and community attractions around them.

Quality of care – Patients expressed misgivings about the quality of care available in long-term care. The frequency of care and chronic understaffing in long-term care homes was a major concern. Many doubted their care needs could be met within the scope of practice of the staff on site in long-term care homes. Patients also highlighted the friendliness of staff and bedside manner as important factors in determining their attitude toward a long-term care home.

Cost – Anxiety over the cost of long-term care was considerable for a few patients. The cost of mobility aids and assistance, the affordability of medications outside of the hospital setting, and the affordability of moving into a long-term care or nursing home with a spouse were cited as huge obstacles. However, though the cost of long-term care was a substantial issue for a few, it was not mentioned by a majority of patients.

A feeling of home – Patients prize a facility that allows them to maintain a sense of home. Privacy, being able to live with a spouse, retaining the autonomy to participate in community events and freedom of movement – "not being cooped up" – were mentioned by patients as priorities. As one patient stated, "I want to go where I can be happy."

Communication and communicators

The responses to questions about how and from whom patients receive information generated inconsistent responses. Patients receive information from a range of sources, including family members, the CCAC, doctors and nurses, discharge planners, and social workers. Few patients referenced multiple sources of information; this indicates that the responsibility for informing patients is not shared well and that the team of care providers does not reinforce information.

Patient responses revealed a number of weaknesses in the established methods

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of communication. Patients remarked on the complexity of paperwork and how many required help from loved ones or staff. Multiple patients felt that their decisions had been made for them, asserting that they had been presented with a list of their choices for long-term care as a *fait accompli*.

The long-term care homes themselves did not play a constructive role in helping people make the transition to long-term care. Patients learned about long-term care through the CCAC or their families, although the level of patient comprehension remained shallow. In some cases, family members, friends, or the CCAC had arranged for visits to local care homes. Some patients complained about the difficulty or hassle their representative encountered in arranging these visits. The visits did not seem to have a positive influence on the patients' perception of long-term care. This implies that the visits themselves are uncoordinated, uninformative, unwelcoming, or all of the above.

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 a quarter were the spouse of the patient. Most of these family members had no other family in the area. The majority had Power of Attorney over the patient. Those who had not arranged for Power of Attorney seemed not to understand the role and importance of the function.

On the whole, caring for a loved one is very difficult on the families. Family members voiced stress, frustration, and exhaustion. Many were juggling work schedules with caregiving. Those with family support noted the importance of an extended support network. One family had established a schedule so they could take shifts feeding and ambulating their loved one, a solution that left them all "stressed, and always running." Those with less support expressed feeling overwhelmed and alone. As one wife put it, "This girl is tired."

Family members were uniformly reactive in their approach to patient care. They tended not to seek help until they were extended beyond their capacity. Even then, they often did not know where to go for help and remained poorly informed. One family member noted that before her loved one's admission she had been paying out of pocket or taking time off work to care for her loved one at home, unaware that compensation and assistance were available.

Some remarked that even with community support the family was not always relieved. A few family members observed that their loved ones were uncomfortable with strangers in their homes, or did not want to be left alone with unfamiliar people. In these cases, even though service providers were visiting to provide care, the family members still had to be at home with their loved one. The discomfort with strangers also made some patients reticent to agree to home care, and more prone to discontinue services.

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None of the families had established a plan for their loved one to aid the transition as the loved one required more care. Many seemed to view seeking help as an admission of failure. Family members, especially spouses, struggled with feeling that they are betraying or abandoning their loved one by placing them in long-term care. As one spouse put it, “I promised I’d never do that.”

Perception of patient condition

On the whole, family members were more specific in their descriptions of the patient’s condition than the patients themselves. The family members gave detailed descriptions of the patient’s condition and history. Patients were suffering predominantly from stroke and dementia. Diabetes and cancer were also common. Family members mentioned depression and wandering regularly. While patients had multiple chronic conditions, in the majority of cases a fall was the event that precipitated hospitalization.

Most had seen their loved one admitted to hospital before. The current admission ranged from a few days to thirty weeks.

Prior to the current admission, the majority of patients lived at home, either alone or with a spouse. A minority lived either with grown children or in retirement facilities.

Almost all of the patients had been receiving some form of assistance at home. Home care, CCAC services, house cleaning and bathing assistance, physiotherapy and occupational therapy, and assistance from family members were the most common types of assistance listed in the responses.

A slim majority of family members felt as though their loved one’s admission to hospital was unavoidable. Service maximums were noted to be a major barrier to keeping loved ones at home. Some noted that fall prevention, overnight care to help with wandering or continence, or other supports might have prevented the hospital stay. A few speculated that with additional input and communication from care providers – “If we had known more help was available” – hospitalization would have been avoided.

Perception of hospital care

Few family members could identify a timeline for their loved ones leaving hospital. Many attributed this to the long wait times for their preferred long-term care home, lack of improvement in the patient’s condition, or lack of communication from staff. Many family members also cited the condition of their or the patient’s home as an obstacle to discharge. The work involved to retrofit the home (e.g., installing a lift to navigate stairs, removing carpeting, renovating kitchens, or installing ramps) to make it safe and accessible for the patient seemed insurmountable to many family members.

Though the majority held a positive opinion, family members were more critical of the care provided in hospital than the patients were. Many family members

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expressed relief to have their loved ones in a controlled environment and felt that the patient was safer receiving round-the-clock supervision. One noted that with the steady schedule of the hospital and other people around, the patient's sleeping and stress level had improved.

Others were more concerned with infection and de-conditioning associated with hospital stays. Family members were complimentary of nursing staff, but often described staffing shortages resulting in both harried nurses working beyond scope and challenges receiving timely toileting assistance. Toileting and continence issues weighed heavily with family members. Some observed that as patients became incontinent in hospital, there was also a marked decline in cognitive capacity and health.

Many family members discussed the need for more recreation and social activities and worried that lack of stimulus and socialization would contribute to their loved one's decline. Family members often mentioned the need for improved access to rehabilitation services to improve the patient's health or prevent de-conditioning. Family members made no distinction between physiotherapy and ambulation maintenance (e.g., support walking in order to improve or maintain strength and stability).

Perception of long-term care

Half of the family members interviewed had considered long-term care before the current admission, a marked increase compared with the patient group. Perceptions of long-term care varied considerably, even within the same family. One family member considering long-term care for his father described long-term care as "a death house," whereas another person in the same family considered long-term care "a good place" that "provides more care." Feelings and words family members associated with long-term care included:

- "24/7 care"
- "Safe for her"
- "Bedridden"
- "Have to be fed"
- "Long waits"
- "Scared"
- "Not a good place"
- "Resort style"
- "The last stop"
- "Expensive"
- "Institutional – fluorescent lights"

Family members portrayed the standard of care in long-term care homes as at best unexceptional and at worst substandard. Despite that, most understood that it is in many cases the safest option for the patient. All viewed long-term care as a final step and a last resort.

Family members selecting long-term care homes shared the same priorities as patients, though often provided greater detail about specific long-term care homes. Like patients, family members stressed the importance of the following:

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Location – Family members wanted their loved ones close by. Family members also valued keeping their loved ones in familiar surroundings, but it was more important to them to be able to maintain a frequent visitation schedule with the patient. Family members also noted that they are often required to supplement the care received in both hospital and long-term care settings. Family members need to be in close proximity to their loved ones in order to assist with feeding, socialization, and ambulation.

Quality of care – The frequency of care regarding toileting or changing incontinence pads was a major concern, as was chronic understaffing in long-term care homes. Family members often cited the ratio of nurses to patients as a significant consideration. Many doubted their loved one's care needs could be met within the scope of practice of the staff on site in long-term care homes and factored their own time supplementing their loved one's care into their decision. Family members wanted to be comfortable in the knowledge that their loved one would be treated kindly and respectfully by staff.

Cost – Anxiety over the cost of long-term care was significantly more common among family members than among patients. Affordability of mobility aids and assistance, of medications outside of the hospital setting, and of supporting a loved one in a long-term care or nursing home were major concerns for most family members. One family member cited cost as the major factor making a prolonged hospital stay the best choice for their loved one.

A feeling of home – Family members with loved ones on the waiting list for one or multiple long-term care homes were preoccupied with the task of easing their loved one through the transition from hospital to long-term care. They emphasized the importance of putting the patient's possessions in their new room and having time to introduce them slowly to their new surroundings and to the staff at their new home. Family members stressed the disruption that change poses for patients and highlighted the importance of continuity – especially of staff – for making patients feel secure.

Family members had an additional priority when considering long-term care for their loved ones that was not mentioned by the patient group:

Safety – Family members prized round-the-clock security and protection from wandering, hazards due to confusion, and falls as the main benefits of long-term care. Loved ones particularly valued overnight assistance, including continence care.

Family members also shared their perceptions of specific long-term care facilities in the area. The long-term care homes most preferred by families are listed below, with an indication of the number of times they were listed as either first or second choice.

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- Huron Lodge (5) – “location,” “staff,” “insurance coverage,” “room arrangements, privacy,” “perfect”
- Aspen Lake (3) – “private room,” “location,” “staff,” “close to family,” “nice,”
- Sun Parlour (5) – “familiarity,” “proximity,” “knows people there”
- Leamington United Mennonite Home (5) – “language,” “food,” “culture,” “knows people there,” “good reputation”

The long-term care facilities least preferred by families are listed below, with an indication of the number of times they were singled out as a place where families would specifically not want their loved one to be placed.

- Franklin Gardens (3) – “run down, staff not nice,” “institutionalized atmosphere,” “condition of home,” “not welcoming,” “no air conditioning”
- Regency Park (3) – “health unit complaints,” “high death rates,” “outbreaks,” “no parking,” “not good care”
- Roseville Garden Villa (3) – “health unit complaints,” “high death rates,” “outbreaks,” “elevators too small,” “physio room not used,” “lack of help”

Family members are deeply uncomfortable with the idea of accepting temporary long-term care placements for their loved ones. They are equally apprehensive about their loved one being placed at a home lower on their list of preferences as they are about a placement at a home not of their choosing at all. Many reported that patients need consistency and familiarity. Moves – be they intra- or inter-hospital or into long-term care – are profoundly disruptive and often very confusing and frightening for the patient. Some family members reported a noticeable decline in the cognition or conditioning of their loved ones after a sudden change in routine, particularly after being moved to a new bed within the hospital.

Communication and communicators

Though it was clear that family members try to make the patient an active participant in the decision-making process when their cognitive capacity allows, the choice of long-term care home rests heavily with the family members. The interviews revealed that, while family members feel this responsibility keenly, they often struggle with navigating the health system and getting the best support for their loved one.

The majority of family members consulted the CCAC regarding their loved one’s care options. Social workers were the next most popular advisor, followed by doctors and nurses. No one had consulted a long-term care facility when deciding their loved one’s next steps.

Family members’ assessment of the communication they had received was mixed. Some noted that communication has been very good, while others required better consistency, thoroughness, and empathy. Some expressed feeling unsupported as they decided their loved one’s future. Others felt that

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their decisions had been made for them, a sentiment also espoused by many of the patients.

Despite being content with the communication they had received, most family members demonstrated a consistent lack of knowledge about the care options available. Many were unaware of the care options available in the community even after multiple incidents with a loved one. Their stories of their struggle to provide care for their loved ones revealed that many were unaware of community providers as part of the continuum of caring for elderly people at home.

Family members often came upon information in a haphazard fashion, either from friends or from social contacts. Many did not know they were able to arrange tours of long-term care homes. Those who had arranged for tours of various long-term care homes commonly expressed frustration with the customer service received from homes in scheduling and conducting tours.

Many acknowledged they did not know what was important to consider when selecting a long-term care home and suggested printed materials and a trusted, standardized resource would help families compare long-term care homes.

What we learned from front-line staff

Front-line staff met in one-hour workshops. Working in small groups and plenary, participating staff were asked to complete three 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 rank their responses, identifying the reasons they hear most frequently and those that present the most challenging obstacles to overcome. Finally, they were asked for 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 share 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. The following appeared multiple times in every staff workshop:

- Comfort and familiarity with hospital setting and staff.
- First choice long-term care home is unavailable.
- Patient refuses to go to long-term care/Family member promised never to send loved one to long-term care.
- Hospital is the only affordable place for patients and families.
- Lack of access to support at home.
- Patient's perceived health needs require hospitalization.
- Quality of care is better at hospital.

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From the aggregate list of obstacles facing ALC patients, front-line staff identified the two they hear most frequently and the two they believe to be the most challenging. Below is the complete list of their top-ranked responses. The bracketed numbers indicate responses that occurred in multiple staff sessions.

Challenging:

- Patient refuses to go to long-term care (4)
- Physician misinforms patient about care needs/options
- The hospital is the only affordable place
- Patient's perceived health needs require hospitalization
- Patient believes s/he needs daily observation from a physician
- Family members lack confidence they can look after their loved one at home
- Families cannot adequately support loved ones during farming season
- First choice long-term care home is unavailable
- Older homes are not as desirable

Frequent:

- Care substandard at nursing homes
- The hospital is the only affordable place (2)
- Not psychologically prepared
- Patient refuses to go to long-term care
- Comfort and familiarity with hospital setting and staff (2)
- Quality of care is better at hospital (2)
- Available beds are too far away for family members to visit
- Patients don't want to be a burden on family members
- Cultural needs cannot be met in long-term care
- First choice long-term care home is unavailable

Discussions with staff revealed a profile of patients who trust the care received in hospital and are either ill-informed or misinformed about their care needs and options. They are often unable to access either the family or community provider support necessary to return home, but are not psychologically prepared to move away from home and family. Further, while they trust their immediate care team, they do not trust the system to look after them, as seen in their refusal to accept a temporary placement. Because of fear or a sense of entitlement, these patients are slow to decide and quick to refuse anything that is not their first choice.

Staff added that this situation is also often compounded by cognitive impairments, especially early dementia, which are not always known or recognized by family members. Family members are stressed by service maximums that do not meet the level of support they require to care for their loved ones. As one staff member said, "the CCAC provides a lifeline" for people at home, but that "lifeline is too expensive." Further, staff noted that nursing homes "only want the perfect patient," resulting in hospital admissions as well as stress and uncertainty for patients with behavioural issues or patients requiring higher levels of care.

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Collaboration among care providers

Front-line staff indicated a strong imperative to improve coordination and collaboration between service providers. As one staff member put it, “flow and collaboration – good process, where is that at?” This was noted within the hospital setting, but especially between hospital staff and the CCAC.

Each hospital employs a different model in regards to how the CCAC is engaged with the hospital care team. At Leamington District Memorial Hospital, the CCAC is fully integrated within hospital operations, and there were fewer instances of complaint regarding this arrangement. At Hôtel-Dieu Grace Hospital, the CCAC is integrated within the Assess and Restore program to provide resettlement case management to other hospital units. At Windsor Regional Hospital, the CCAC operates at a distance from hospital operations.

At both hospitals where the CCAC was not fully integrated into the on-site care team, there were more instances of concern regarding how hospital social workers and CCAC case managers work together to support ALC patients. Hospital social workers feel ill-informed about CCAC services and are unclear on the qualification criteria. Hôtel-Dieu Grace Hospital social workers reported being most familiar with Resettlement, a program for which few patients qualify, and noted that the standard service maximum for home care is the only knowledge they can impart to patients. Windsor Regional Hospital staff lamented that CCAC involvement is administrative in nature. Some staff described patients having no engagement with the CCAC until two days prior to discharge to long-term care, when patients are given an offer and have forty-eight hours to either accept or reject the bed.

More broadly, some hospital staff voiced concern over patient access to CCAC services, noting that the criteria to qualify for some services are confusing and opaque. Many expressed the need for greater CCAC involvement with patients and family members during hospitalization. This would better inform patients and family members about options beyond the service maximum of standard home care and about when patients may return home, and would support families through the transition to long-term care.

Within the hospital setting, staff pointed to policies that could be adjusted to better serve patients with ALC designation. Staff at Leamington District Memorial Hospital observed that they conduct regular checks of the vital signs of ALC patients, even though they are medically stable and cleared for discharge. The time spent could be diverted to other patient care activities, and may also reinforce the perception among patients that they require constant observation.

Both sites of the Windsor Regional Hospital reported being understaffed with respect to physiotherapists. The bottleneck created by patients waiting for assessments results in delays for rehab and ambulation services and for transfers, and in logjams, especially in occupational therapy and the Emergency Department. Improving the physio assessment and referral process to expand and speed up access to ambulation team care is essential to combating de-

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conditioning and de-compensating.

Front-line staff at the hospitals and the CCAC commented that Resident Assessment Instrument (RAI) assessments favour long-term care placement, and they stressed the need for greater latitude for the care team to apply professional discretion. Hospital social workers also noted that poor coordination between hospital staff and CCAC hospital case managers often results in redundant and/or out-of-date RAI assessments.

Finally, 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 informed a patient that the patient was unable to return home but failed to inform that patient that he or she needed long-term care. In the absence of physician instructions, the patient could not be convinced he or she was well enough to leave hospital. Other staff noted cases in which a physician gave the family a false sense of the prospect of a patient's recovery, also leading to the patient remaining in hospital waiting to improve sufficiently to return home. These examples imply that the care team is often working inefficiently, or even at cross-purposes. Ultimately, a coordinated care team is not supporting the patient.

Suggestions for improvement

Front-line staff had many suggestions to address the challenge posed by ALC. Some of their ideas include:

- Break down silos between hospitals and community care.
- Establish an official "patient navigator" to be the sole point of contact for patients and their family members.
- Create roaming medical units for treatments, especially dialysis, that can travel to provide care at long-term care homes.
- Change the incentive structure to make it more affordable for patients to leave hospital (e.g., cover difference in cost between semi-private and basic long-term care beds).
- Create population-specific long-term care units to respond to patient needs, such as wandering, dialysis, or language.
- Reinstitute home visits from physicians and nurses.
- Redefine the physical space of hospital rooms and communications for patients designated ALC in order to transition and reinforce the change in their status and care needs.

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.

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Observations

For ALC patients and their families, the decision to leave hospital is fraught and can be traumatic. Patients and family members are acutely aware of the permanence of their decision. In this regard, even prolonged hospital stays maintain the illusion that the patient may be able to return home.

Both patients and family members are reluctant to take a proactive role in patient care, yet both groups are extremely sensitive to feeling pressured or forced into decisions by providers. This creates a challenging situation for providers struggling to be sensitive to the wishes of the patient while securing the most appropriate care. Transparency, providing patients and families with the knowledge required to be full participants in care, and empathetic and proactive communication will help ALC patients and their families find acceptance of their care needs and better understand and evaluate their options.

The interviews revealed that there is no consistent implementation of communication protocols to inform patients and families of their care options. The roles and responsibilities of CCAC case managers, hospital social workers, and other staff varied from site to site. At all sites, hospital social workers and CCAC case managers view their role as one of supporting clients in decisions regarding long-term care. In practice, patients and family members reported receiving information from a range of actors, including physicians and acquaintances, and sometimes from no one at all.

There were many instances of either redundant duplication of assessments or disconnects between hospital discharge planners and CCAC case managers. Some staff spoke of disagreement or lack of clarity among the care team regarding the care path for a patient. Greater integration among the care team, as well as integration and coordination between CCAC case managers across in-patient and community settings would improve the flow of information among care providers.

Patients and their family members were often unaware of or did not understand the various care options available. Specifically, they were uninformed about the differences between home care, acute care, rehab, complex continuing care, and long-term care, and about the scope of care provided within each setting.

Though patients and family members demonstrated a consistent and significant lack of knowledge about their care needs and options, they generally believed their communication had been adequate. This indicates that although the individuals providing the information provide a good client experience, they are not as effective as they could be. Further, the manner in which care providers within the hospital consult family members also varied greatly between sites. It is clear that some patients have fallen through the cracks.

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The psychological impact of change on elderly patients cannot be understated. Comfort, stability, and familiarity were foremost priorities for patients and their family members. Even moves within the hospital, for example within complex continuing care or from rehab to complex continuing care, were disruptive and traumatic for patients. Patients, families, and front-line staff stressed the impact of routine on a patient's perception of their care needs and abilities, and the tendency toward de-conditioning in hospital. Conversely, the patient's routine can be designed to encourage the transition from hospital to the home or long-term care setting. The model of service for patients with ALC designation can signal their evolving care needs and help prepare the patient for their next steps.

The transition to long-term care is difficult for patients and their families even in the best of circumstances. Patients and their families desire the safety and amenities of long-term care, but are understandably reluctant to forgo the comfort of home. Currently, the quality and convenience offered by long-term care homes is not easing the burden of this transition. Inconsistencies in both the physical conditions and the quality of the services between long-term care homes present a major obstacle. Reputation and word of mouth play an outsized role in determining patient and family perceptions. Ultimately, any improvements will remain incomplete unless the long-term care homes are integrated into the solution.

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.

Roles and responsibilities

1. Clarify the roles and responsibilities of CCAC and hospital staff at all sites.

2. Enhance and standardize the CCAC's role across all hospital sites as patient navigator and care connector for community care and long-term care.

3. 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.

4. Enhance the role of hospital social workers as advocates providing emotional support for patients and families to understand their health needs, the decisions they will be making, and other considerations.

5. 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.

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6. Investigate staffing methods and provider partnerships to limit change among care providers. Allow the same service providers to provide care in and out of hospital. Wherever possible, keep the same staff assigned to patients to preserve continuity and familiarity.

7. 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.

8. Integrate long-term care homes into the education process. Encourage long-term care homes to provide brochures, pictures, and information to CCAC.

9. ESC LHIN should work with the long-term care homes identified as non-preferred to review the issues raised by participants and create action plans to improve the conditions, quality of care, communications, and customer service experience.

10. 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.

11. All social workers and CCAC case managers should receive yearly tours of all long-term care homes.

In-hospital treatment of ALC patients

12. Establish ALC designation as a trigger to transition hospital care away from the medical model. Cease daily checks on vitals and redeploy staff time to support the daily living tasks of patients.

13. Expand ambulation supports in the hospital to ALC patients and remove barriers with respect to program referrals.

14. Increase allied health care supports to hospitals, such as physiotherapists, kinesiologists, occupational therapists, and related assistance.

15. Adopt Assess and Restore philosophy to motivate patients (e.g., dressing in their own clothes, conducting regular ambulation, congregate dining).

16. Review options to create hospital units or refit existing rooms to better reflect the needs of ALC patients and enhance communication.

Decision-making supports

17. Develop decision-making resources for patients and family members to determine their needs and evaluate their care options.

18. Expand the use of evaluation tools to assess and compare long-term care

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homes. Consider such factors as the site's physical condition, services offered, staff ratios, recreation and social activities, specialty programs for dementia. Produce online and printed versions.

19. ESC LHIN, long-term care homes, and the CCAC should partner to develop a comprehensive and standardized marketing 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.

Communication

20. Increase emotional support to both patients and family members who should be considering long-term care. Shift the care model for ALC patients away from the medical paradigm to address de-motivation and de-conditioning.

21. 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.

22. Look for opportunities to expand hands-on, compassionate navigation support to both patients and family members. Families feel more confident in their decisions when a provider they know and trust supports them.

23. Explore methods to provide precise information on wait times for long-term care.

24. 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.

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Appendix A

Interviews – Patients

Gender

Response	Chart	Percentage	Count
Male		50%	5
Female		50%	5
	Total Responses		**10**

Question 1 - Do you have family in the area?

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

Question 2 - Why were you brought to the hospital?

#	Response
1.	Broken arm and shoulder
2.	COPD attack
3.	Bad stomach
4.	Can't walk, kept falling
5.	Diabetes
6.	Cellulitis
7.	Hard time breathing

Question 3 - What are your current health conditions?

Response	Chart	Percentage	Count
Stroke		20%	2
COPD		20%	2
Hip fracture		0%	0
Pneumonia		10%	1

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Cardiovascular		50%	5
Arthritis		30%	3
Cancer		0%	0
Diabetes		10%	1
Other, please specify:		70%	7
	Total Responses		**10**

Other responses:

#	Response
1.	Broken arm and leg
2.	Dental, memory issues
3.	Catheter
4.	Prostate cancer
5.	Two heart attacks, diabetes
6.	Cerebral palsy
7.	Weight, blood clots, failed bariatric surgery

Question 4 - Is this your first admission?

Response	Chart	Percentage	Count
Yes		33%	3
No		67%	6
	Total Responses		**9**

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

#	Response
1.	1 week
2.	14 weeks
3.	4 months
4.	1 day
5.	9 weeks
6.	9 months
7.	1 year
8.	7 months

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9.	11 months

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

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

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

Response	Chart	Percentage	Count
Yes		12%	1
No		88%	7
	Total Responses		**8**

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

Response	Chart	Percentage	Count
Food		44%	4
Nursing care		44%	4
Doctors		33%	3
Comfortable surroundings		22%	2
Therapy options		33%	3
Other, please specify:		33%	3
	Total Responses		**9**

Other responses:

#	Response
1.	24-hour care
2.	Good overall care
3.	Lift in her room, nutrition counselling

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

Response	Chart	Percentage	Count
Home alone		50%	5
Home with spouse		10%	1
With children		10%	1

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Assisted living		10%	1
Retirement home		10%	1
Long-term care home		0%	0
Other, please specify:		10%	1
	Total Responses		**10**

Other responses:

#	Response
1.	Seniors building

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		44%	4
Transport		0%	0
In-home nursing		11%	1
Day programs		0%	0
Meals on wheels		11%	1
Neighbours		0%	0
Family		56%	5
Volunteer visits		0%	0
Other, please specify:		78%	7
	Total Responses		**9**

Other responses:

#	Response
1.	Beeper system
2.	Red Cross bathing 3 hours/day
3.	Scooter
4.	Friend
5.	CCAC came 2x/week
6.	Medication help, drop in centre
7.	CCAC complementing

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

Response	Chart	Percentage	Count
Yes		44%	4
No		56%	5
	Total Responses		**9**

Question 12 - Which age bracket do you fall into?

Response	Chart	Percentage	Count
40-54		10%	1
55-64		0%	0
65-74		30%	3
75-84		30%	3
85-94		30%	3
95-104		0%	0
	Total Responses		**10**

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

#	Response
1.	Prefers RA over NH
2.	Nothing
3.	Knew nothing
4.	CCAC didn't really share options available to her

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

#	Response
1.	CCAC - home visits and previous hospital stay.
2.	Aspen lodge
3.	CCAC
4.	Doctor (vein specialist) and family doctor
5.	Social worker named options only

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6.	Didn't/haven't

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		29%	2
Assisted living		14%	1
Financially unable to go home		14%	1
Health will not permit it		14%	1
Other, please specify:		57%	4
	Total Responses		**7**

Other responses:

#	Response
1.	Meals on wheels
2.	LTC
3.	Volunteer visits
4.	Renovations on condo, additional care and support

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

Response	Chart	Percentage	Count
No options		22%	2
LTC Facility		56%	5
Other, please specify:		44%	4
	Total Responses		**9**

Other responses:

#	Response
1.	Return home - LTC too costly
2.	Cost is issue
3.	Prefer to go home
4.	Going to home, but needs more info on assisted living

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

Response	Chart	Percentage	Count
Yes		78%	7
No		22%	2
	Total Responses		**9**

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

Response	Chart	Percentage	Count
Social worker		25%	2
Family		25%	2
No, feeling forced		0%	0
CCAC		38%	3
Other, please specify:		38%	3
	Total Responses		**8**

Other responses:

#	Response
1.	Nurse communicates options
2.	Daughter
3.	Friend in building picks options - has POA

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

#	Response
1.	"I am going home"
2.	Cost still a limiting factor
3.	He knows he is going to LTCH
4.	She is unsure
5.	Resistant to change
6.	Yes, he is happy here, but if he has to go, he has to go
7.	LTC
8.	Yes
9.	No, needs more info from social worker regarding assisted living
10.	Yes, she prefers to go home

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

Response	Chart	Percentage	Count
Yes		22%	2
No		78%	7
	Total Responses		**9**

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

#	Response
1.	Too much restriction, not enough care, too costly
2.	Important to know some residents where he ends up
3.	People are in your age group. It's what you make of it
4.	Ready for you to die
5.	Substandard care, don't know other patients, some in city aren't good, hospital has better care
6.	Can be isolating, depends on people
7.	Prefers assisted living
8.	No anxiety, wants to be close to home

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

#	Response
1.	No
2.	More accepting of his future in LTCH
3.	She now knows she needs help
4.	No
5.	Haven't thought much about it
6.	Became interested in assisted living
7.	No change - still wants to go home

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

Response	Chart	Percentage	Count
Yes		71%	5
No		14%	1
Unsure		14%	1
	Total Responses		**7**

Question 24 - How many have you chosen?

Response	Chart	Percentage	Count
1		33%	1
2		0%	0
3		33%	1
4		33%	1
5		0%	0
	Total Responses		**3**

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

#	Response
1.	Doesn't know if he's on a list
2.	1 year
3.	5 months

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

#	Response
1.	The presence of friends is very important. Positive view of homes he has visited
2.	Riverside – 24-hour care, close to daughter, gave lots of info
3.	Huron Lodge. Leamington - only half full, what's wrong with it? Woodside - out of town is a concern
4.	Aspen Lake - only option. Huron Lodge can't take her
5.	There are too many far from home.

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Question 27 - Are there certain homes that you do would never put on your list? Why/why not?

#	Response
1.	Proximity to family is important.
2.	Homes out of town
3.	Roseville - depressing. Chateau Park - getting in and out
4.	Yes – will only select those with a smoking option
5.	Those far from home

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

#	Response
1.	Yes
2.	No
3.	No
4.	Yes, by CCAC - Leamington and Woodside, but he had bad experience and they are out of town.
5.	No, most can't care for needs
6.	No
7.	Yes - declined because she is wheelchair-bound (according to Banwell Gardens)

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

#	Response
1.	Plans to go home once able
2.	Friends
3.	Wants to be happy and safe. A good place with good care
4.	He wants to be confident in the level of care
5.	Care
6.	Can I smoke, and do they take cats
7.	Mobility

Question 30 - What is your biggest concern?

#	Response
1.	Cost of LTCH
2.	Fear of unknown, worried about falling

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3.	Would like to be kept busy, family is concerned about him falling
4.	Death, feels useless, food is important
5.	The feeling of being "warehoused." Not being taken seriously
6.	Smoking options
7.	Mobility - cost of special wheelchair

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

#	Response
1.	More staffing, more independence while at LTC facility
2.	Don't lump LTC and ALC together. Talk to patients - deal with the problem. LTC tours lack excitement
3.	Give patients time to make adjustments in transition - also better advice for patients
4.	Flexibility to move around e.g., shower, electric lifts

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.	Very appreciative of the level of care in hospital
2.	Worried about miscommunication between staff shifts
3.	Social worker has been very good but is busy
4.	Why no TV in room?

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

#	Response
1.	Not scared. The information the system has provided has been "satisfactory"
2.	I want out of here

Interviewer observations and comments:

#	Response
1.	Some dementia
2.	Speech is difficult, confused at times
3.	This patient may have had dementia
4.	Patient was confused but content
5.	Family helped him answer questions. Clear lack of info about LTC homes and general transition process. Has been discharged but nowhere to go

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6.	Money is a barrier, nurses have become family - does not want to leave them
7.	Not very social, but honest, wants to go to YMCA

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Appendix B
Interviews – Family Members

Question 1 - What is your relationship with the patient?

Response	Chart	Percentage	Count
Mother/Father		53%	9
Mother-/Father-in-law		18%	3
Aunt/Uncle		0%	0
Grandparent		6%	1
Friend		0%	0
Spouse		24%	4
Sibling		6%	1
Other, please specify:		0%	0
	Total Responses		**17**

Question 2 – Do you or anyone else have Power of Attorney for the patient?

Response	Chart	Percentage	Count
I do		64%	9
Aunt/Uncle		0%	0
Friend		0%	0
Spouse		7%	1
A patient's child		21%	3
Other, please specify:		14%	2
	Total Responses		**14**

Other responses:

#	Response
1.	No POA
2.	Brother-in-law

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

Response	Chart	Percentage	Count
Yes		25%	4
No		75%	12
	Total Responses		**16**

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

#	Response
1.	Fall - broken hip
2.	Fall - head injury
3.	Difficulty eating and breathing
4.	Ulcer from medications
5.	Loss of bowel control, dehydration/confusion
6.	Fractured ankle, delirious, possibly a stroke
7.	High BP - lead to stroke
8.	Fall - total hip replacement
9.	Ongoing breathing issues, fall in April
10.	Not getting out of bed, eating, or taking meds
11.	Seizure
12.	Dementia/wandering
13.	Congestive heart failure
14.	Fall - broken hip
15.	Stroke
16.	Fall risk - found on floor dazed
17.	Seizures
18.	Rehab

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

Response	Chart	Percentage	Count
Stroke		39%	7
COPD		11%	2
Hip fracture		11%	2
Pneumonia		6%	1

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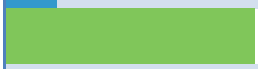
Cardiovascular		17%	3
Arthritis/mobility		11%	2
Alzheimer's/dementia		44%	8
Diabetes/dialysis		22%	4
High blood pressure		17%	3
Cancer		22%	4
Other, please specify:		78%	14
	Total Responses		**18**

Other responses:

#	Response
1.	Alzheimer's
2.	Ulcer
3.	Fistula, regular bladder infections
4.	Angina, fractured ankle
5.	Depression, risk of wandering
6.	No appetite
7.	Wandering
8.	Sight loss, mobility, weakness
9.	Wandering
10.	CHF
11.	Depression
12.	Auto immune, syndrome similar to Parkinson's
13.	Paralysis on 1 side
14.	MS, cranial hemorrhage

Question 6 - Was this his/her first admission?

Response	Chart	Percentage	Count
Yes		18%	3
No		82%	14
	Total Responses		**17**

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

Response	Chart	Percentage	Count
Under 2 weeks		12%	2
2-4 weeks		24%	4
4-6 weeks		12%	2
6-8 weeks		6%	1
8-10 weeks		12%	2
10-12 weeks		6%	1
12-14 weeks		0%	0
14-16 weeks		0%	0
Over 16 weeks		29%	5
	Total Responses		**17**

Responses over 16 weeks:

#	Response
1.	23 weeks
2.	32 weeks
3.	32 weeks
4.	20 weeks
5.	30 weeks

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

Response	Chart	Percentage	Count
Yes		18%	3
No		82%	14
	Total Responses		**17**

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

Response	Chart	Percentage	Count
Yes		62%	10
No		38%	6
	Total Responses		**16**

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

Response	Chart	Percentage	Count
Food		0%	0
Nursing care		43%	6
Doctors		14%	2
Comfortable surroundings		21%	3
Therapy options		7%	1
Other, please specify:		79%	11
	Total Responses		**14**

If other, please specify:

#	Response
1.	Quality of care, affordability
2.	More hands-on care because of small hospital setting
3.	Family access, receiving great overall care
4.	Medication, and social aspect
5.	24/7 care
6.	Music entertainment
7.	Good communication
8.	None
9.	Fewer falls, more peaceful with people around
10.	Level of care relative to LTCH
11.	Progression - they push her harder

Question 11 - How is your family coping?

#	Response
1.	Daughter has severe anxiety, sad and frustrated - family has no life right now, they don't know who to talk to
2.	Issue with money, unsure of next steps
3.	Difficult due to conflict with work schedule
4.	Patient is coping better than son
5.	Good family support network
6.	Caregiver role overwhelming, developed family schedule for care - good family support
7.	POA in denial, schedule is in place for feeding

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8.	Time consuming
9.	OK
10.	Feeling of helplessness
11.	Alone - relying on friends
12.	Stressful, feels hospital is not supporting her desire to go home, LTCH is hard decision
13.	Son and daughter-in-law taking turns required for daily tasks
14.	Nothing we can't handle
15.	Frustrated, process is depressing
16.	Stressed, always running, patient was the centre of family
17.	Not much support, not doing well
18.	Dealing with it, have support

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

Response	Chart	Percentage	Count
Home alone		33%	6
Home with spouse		33%	6
With children		11%	2
Assisted living		0%	0
Retirement home		11%	2
Other, please specify:		11%	2
	Total Responses		**18**

Other responses:

#	Response
1.	Rest home
2.	Parkwood Hospital - London

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

Response	Chart	Percentage	Count
Home care		43%	6
Transport		0%	0
In-home nursing		14%	2
Day programs		0%	0

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Meals on wheels		7%	1
Neighbours		0%	0
Family		21%	3
Volunteer visits		7%	1
Other, please specify:		57%	8
	Total Responses		**14**

Other responses:

#	Response
1.	Physio, OT
2.	Full care at retirement home
3.	All services provided at rest home
4.	Cleaning help – Veterans Affairs
5.	CCAC – physio, OT, home oxygen. Bayshore - nursing. Red Cross - personal care
6.	Some CCAC
7.	CCAC (comcare), all else provided by retirement home
8.	CCAC shower twice a week

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

#	Response
1.	No
2.	Yes, help with fall risks
3.	More involvement of doctor and supports staff to avoid "logjam" in drug and pharmacy process
4.	Yes
5.	No
6.	Physically no, conflict in family over types of medication
7.	No
8.	Husband has limited mobility
9.	Spouse resistant to help
10.	Maybe - but communication has been lacking
11.	No - health deteriorating, money is an issue
12.	No - very independent
13.	No

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14.	Some falls could have been prevented if someone was there
15.	No

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.	Just what they already had through CCAC
2.	Knowledge of Windsor/Essex services through grandson
3.	Scared, and understood it was difficult to get into LTCH
4.	Word of mouth, experience with other family member in home care
5.	Bayshore, Red Cross, CCAC
6.	Harrowwood RH informed of additional services
7.	Veterans Affairs
8.	Respite after stroke

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

Response	Chart	Percentage	Count
Veterans		6%	1
N/A (no help/options unknown)		19%	3
Social worker		12%	2
Hospital		6%	1
CCAC		56%	9
Nurse		12%	2
Word of mouth		19%	3
Retirement home		6%	1
Doctor		12%	2
Other, please specify:		31%	5
	Total Responses		**16**

Other responses:

#	Response
1.	Hospitalist, advertisements - CCAC did not have video
2.	Through tour process, advertisements
3.	No need – didn't need

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4.	Toured local LTCH

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

#	Response
1.	24/7 care, locked unit so that she doesn't get hurt
2.	Not an option
3.	Snow removal, lawn cutting
4.	Mobility assistance (grab bars)
5.	24/7 care, assessment of home, mobility assistance
6.	Can't return - level of care needed too high
7.	24/7 care
8.	24/7 care
9.	24/7 care - home not option
10.	More CCAC services - 3 hours every other day
11.	Health level won't allow it
12.	Bathing
13.	Not option - needs 24/7 care
14.	24/7 care
15.	Cannot return home
16.	Said home assessment would need to be done
17.	Depends on progression

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

#	Response
1.	Options limited by poor health of patient. They have no support.
2.	ODSP - in the form of income support for LTC
3.	Hope to return to retirement home
4.	LTCH
5.	LTCH
6.	LTC - due to care needs
7.	LTC
8.	LTCH
9.	LTC – can't go home now

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10.	LTC
11.	Leamington court LTCH
12.	Forced to accept LTCH because RH will no longer be able to meet care needs
13.	LTC
14.	LTC
15.	With support, may be able to go home
16.	LTC

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

#	Response
1.	Better care, safe for her
2.	Not a good place, language a barrier
3.	Provides 24/7 care
4.	Bed-ridden, have to be fed
5.	Institutional - fluorescent lights, newer - resort style
6.	Scared, long wait list for LTCH, unable to accommodate needs at home
7.	Positive - they are nice and provide care
8.	Positive - tours of homes, people seem happy, friends - socialization
9.	Not sure if LTCH can accommodate complex needs
10.	When you can't care for yourself
11.	Care, cannot look after him at home
12.	Death house, the last stop, more care place
13.	Positive
14.	Lack of quality care
15.	Not enough staff, money issues, holding tank, shove in front of TV and leave
16.	Depends on home, not impressed with Aspen. But some would be comfortable
17.	Huron- good facility, staff, and resources

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

#	Response
1.	She understands it is necessary
2.	Sometimes OK, sometimes not, doesn't quite understand
3.	Parents are worried about being separated

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4.	As long as care is good he is accepting
5.	She is resistant. Had a preference of Southgate in Kingsville
6.	He can't communicate, but he was happy at rest home
7.	Does not realize she is going to LTC
8.	Understands
9.	Unsure about accommodation of pain pump (ability to monitor)
10.	Father promised wife not to send her to LTC
11.	Understands it's time
12.	Fine as long as it is local
13.	She understands
14.	He is comfortable
15.	Reluctant but understanding
16.	Not happy

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

Response	Chart	Percentage	Count
Yes		53%	8
No		47%	7
	Total Responses		**15**

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		41%	7
Medication management		6%	1
Care level		41%	7
Location relative to family		12%	2
Social aspect (patient knows others in the facility)		12%	2
Feedback regarding facility		6%	1
Waiting list considerations		0%	0
Forced decision		12%	2
Other, please specify:		29%	5
	Total Responses		**17**

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Other responses:

#	Response
1.	Peaceful place, safe in locked unit
2.	Increased care level
3.	Limited support
4.	Children convinced mother
5.	Condition of facility

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

#	Response
1.	Terrible to be here - needs to get out of here
2.	May need more care than retirement home can provide
3.	We know now that she needs 24/7 care, want close LTCH placement
4.	Realization that she cannot return to rest home
5.	Realization the LTCH is required
6.	No change - new experience
7.	More realistic view on needs
8.	She feels hospital has made her condition worse
9.	They have been made aware that she is on wait list. Feel forced into choosing LTC as option
10.	Change in abilities
11.	Father's experience scares daughter
12.	Views have been changed due to experience
13.	Not all the same

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

Response	Chart	Percentage	Count
CCAC		76%	13
HDGC		6%	1
Advertisements		6%	1
Doctor		24%	4
Social worker		29%	5
Family		6%	1

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Hospital staff (incl. nurses)		24%	4
LTC facility		0%	0
Other, please specify:		6%	1
	Total Responses		**17**

Other responses:

#	Response
1.	Psychiatrist

Question 25 - How could we improve communication?

#	Response
1.	Increase role of physician - never sees a physician!
2.	Good communication thus far
3.	Hospital CCAC had good LTC communication, but not a lot of help for retirement home info
4.	Flyers, brochures
5.	More integration with doctor, communication is "lacking"
6.	More proactive approach to advertising - get families aware before they need service
7.	CCAC is doing a good job
8.	Letters - 3 months
9.	Communication has been very good
10.	More information earlier about dementia
11.	Provide info (brochures, etc.) about LTCH. She feels hospital CCAC is not listening to her
12.	CCAC should have told family she was on wait list. Brochures would help. Need better communication between RH and CCAC
13.	Consistency in communication
14.	More empathy, walk through each step and not just giving us papers
15.	Has had a hard time communicating with social worker and CCAC – no one understands
16.	Would have appreciated more guidance

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

Response	Chart	Percentage	Count
Yes		89%	16
No		11%	2
	Total Responses		**18**

Question 27 - How many has s/he chosen?

Response	Chart	Percentage	Count
1		19%	3
2		19%	3
3		38%	6
4		19%	3
5		6%	1
	Total Responses		**16**

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

Response	Chart	Percentage	Count
Huron Lodge		28%	5
Southwood Lakes		11%	2
Aspen Lake		17%	3
Heron Terrace		11%	2
Riverside		6%	1
Extendicare		6%	1
Kingsville		11%	2
Essex		6%	1
Sun Parlor		28%	5
Leamington Court		6%	1
Royal Oak		6%	1
Franklin		11%	2
Leamington Mennonite		28%	5
Tecumseh Extendicare		6%	1
Iler Lodge		6%	1

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Regency		6%	1
Windsor Place		6%	1
Chateau Park		6%	1
	Total Responses		**22**

Question 29 - What factors influenced his/her choices?

Response	Chart	Percentage	Count
Language preferences		17%	3
Location relative to family		44%	8
Familiarity		17%	3
Accessibility issues (e.g., elevators)		6%	1
Positive word of mouth		22%	4
Presence of friends		17%	3
Accommodations		22%	4
Needs		11%	2
Insurance coverage		6%	1
Private room options		11%	2
Staff		6%	1
No choice		6%	1
Other:		17%	2
	Total Responses		**17**

Other responses:

#	Response
1.	Food, culture
2.	Food, social dinning room

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

Response	Chart	Percentage	Count
Yes		56%	9
No		6%	1
N/A family made decision		38%	6

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Total Responses		**16**

Question 31 - What influenced your choices?

Response	Chart	Percentage	Count
Language preferences		6%	1
Location relative to family		62%	10
Familiarity		12%	2
Accessibility issues (e.g., elevators)		6%	1
Positive word of mouth		25%	4
Presence of friends		12%	2
Accommodations		19%	3
Needs		6%	1
Cost/financing		12%	2
Staff		6%	1
Other, please specify:		19%	3
	Total Responses		**16**

Other responses:

#	Response
1.	Tours
2.	Food, social dinning room, privacy
3.	Privacy

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

Response	Chart	Percentage	Count
Yes		56%	9
No		6%	1
N/A family made decision independent of patient		38%	6
	Total Responses		**16**

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

#	Response
1.	Those not close to home
2.	Those not affordable
3.	Leamington Court - cannot accommodate wanderers (locked units?)
4.	No
5.	Aspen Lake - rooms are not homey and cold atmosphere, Banwell Gardens - very aged
6.	Those not local
7.	Franklin - run down, staff not nice
8.	Regency Park and Rosedale Gardens - health unit complaints, high death rates, and complaints
9.	Not really
10.	Franklin - condition of home, atmosphere (institutionalized)
11.	Henry St. - did not like room set up
12.	Franklin - not welcoming
13.	Those not local
14.	Regency Park, Roseville, Chateau Park - death rate and outbreaks
15.	Those too far from home
16.	Huron Terrace - not professional
17.	Riverview 3-4 people in a room
18.	Roseville - elevators too small, lack of help. Physio room not used. Regency - no parking, not good care

Question 34 - Do you agree with that decision?

Response	Chart	Percentage	Count
Yes		78%	7
No		11%	1
N/A		11%	1
	Total Responses		**9**

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

Response	Chart	Percentage	Count

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Under 2 weeks		8%	1
2-4 weeks		15%	2
4-6 weeks		8%	1
6-8 weeks		15%	2
8-10 weeks		46%	6
10-12 weeks		8%	1
12-14 weeks		0%	0
14-16 weeks		0%	0
Other, please specify:		0%	0
	Total Responses		**13**

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

Response	Chart	Percentage	Count
Yes		46%	6
No		54%	7
	Total Responses		**13**

If so, where?

#	Response
1.	Roseville Garden
2.	Roseville Garden
3.	Leamington Court
4.	Regency Park

Question 37 - Why was the offer declined?

#	Response
1.	Too far from home - not a nice place
2.	Cost
3.	Not on her list
4.	Declined at the time because she was OK at home, but now she is starting again on the waiting list
5.	Did not have choice to decline

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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		15%	2
Affordability		23%	3
Safety		15%	2
Language barrier		8%	1
Open channels of communication		23%	3
Location relative to family		15%	2
Comfortable accommodations		8%	1
Help to understanding the LTC options available (services and cost)		31%	4
Consensus within family regarding decision		8%	1
Other, please specify:		38%	5
	Total Responses		**13**

Other responses:

#	Response
1.	Immigration sponsorship issue
2.	Staff, comfort
3.	Transportation for visits
4.	Getting in - then adjusting
5.	Insurance
6.	Access to resources

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		47%	8
Affordability/financing		12%	2
Safety		29%	5
Language/cultural barrier		12%	2

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Open channels of communication		6%	1
Location of facility		24%	4
Comfortable accommodations		12%	2
Help to understanding the LTC options available (services and cost)		0%	0
Consensus within family regarding decision		0%	0
Level of staff professionalism		6%	1
Mobility		6%	1
No concerns		6%	1
Other, please specify:		59%	10
	Total Responses		**17**

Other responses:

#	Response
1.	Possibility of multiple moves, social aspect
2.	Staff comfort
3.	Multiple moves, and what to bring from home to assist her transition
4.	Cultural needs are met
5.	Wandering, boredom
6.	Staff turnover
7.	Pain management
8.	Lockdown as dementia increases, kept active
9.	Physio needs
10.	Compassion, resources - responsiveness

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

#	Response
1.	Something like maternity leave for people caring for elderly and better care for Alzheimer's patients outside of NH and hospital
2.	Sponsorship exceptions, increased financial assistance
3.	There is little help/funding for couples that have different needs (e.g., LTC and retirement home)
4.	Pharmacy needs to be more involved to avoid "logjam" in needs
5.	CCAC service has been positive and timely

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6.	Work on "stigma" of LTC - more promotional work
7.	More therapy/activities, LTC beds, more socialization opportunities
8.	Has had excellent care and communication
9.	More access to information (online resources), improved standards for PSW's – should be weeding out bad ones already in workforce
10.	Need for more planning, more empowerment of health promotion (preventative health)
11.	Hospital understaffed
12.	More sensitivity, give family more time to make transition (get patient's belongings to the LTCH), familiarity is essential
13.	More therapy, more LTC beds, more activities
14.	More open communication, more time with patient
15.	Having a central place to get information on the facilities on the MOH site. Make violations public. Have rating system for facilities

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

#	Response
1.	They are worn out. Money is an issue if they have to pay to get her in a better bed
2.	Multiple moves causes anxiety
3.	Ensuring confidentiality - only immediate family getting patient info
4.	Family support is strong
5.	Keep trying to inform families about options, educate families on what to expect on tours
6.	More RNs
7.	Better compassion required
8.	Better communication, 3-month law for LTCH wait list needs to be improved, better communication between community services and retirement home, CCAC needs to be more interactive with retirement homes
9.	Nurses are short-staffed - increased wait time for assistance
10.	More communication would be good
11.	Needs to be more education on how to involve families more. Consider person, not bed or money

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

#	Response
1.	Worried about sponsorship application - if it fails they can't afford care
2.	Leamington faces demographic problem, less and less young people. Elderly have no support and do not know what services are available
3.	Like the idea of easing father into LTCH

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4.	Need for more LTCH, "governed" homes are more affordable, more continued care at home
5.	Concern for transportation for cancer treatment
6.	Families need to be proactive and not reactive - it's a lot of work
7.	Frustrated - does not understand why can't go home
8.	Living at home would be better for patient, lack of communication between CCAC, RH, and hospital is creating a lot of stress
9.	Moving from surgery back to care was difficult
10.	This is only the second time someone has talked with the family about the patient in question
11.	Want a place I know she is safe when I am not there

Interviewer observations and comments

#	Response
1.	They are frustrated that she is blocking a bed. CCAC needs to better educate families in the system
2.	Wife having difficulty accepting husband's need for LTC, some contradictions - wanting to be home yet needing more care
3.	"Hospital tried to force everyone to Windsor Place"
4.	More transparent standard evaluations would make decisions easier. More guidance/support needed. Staff turnover. Media finds out things first – no transparency

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Appendix C
Staff Sessions

Hôtel-Dieu Grace Hospital

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

- Can't afford transportation
- Family not agreeing on home
- Convenience for family
- Dialysis and services
- I don't want to go to LTC
- Doc doesn't explain about LTC
- Want specific criteria for homes
- Cheaper to be here
- Care substandard at nursing home
- Need more time to plan and decide
- Too complex for CC
- No one home to care
- My entitlement
- Location of nursing homes
- Not safe to go home
- Designated ALC as they come in door (about 10% of population)
- Family or Serv. Agencies don't know what to do with patient - hospital is safety net
- Staff going back to the physician and make resp. to communicate with patient
- Patient level of care different than their (the patient's) expectation

Most Challenging

1. I don't want to go to LTC
2. Doc doesn't explain about LTC

Most Frequent

1. Want specific criteria for homes
2. Cheaper to be here
3. Care substandard at NH

Further Observations

- Patient's perception of hospital care
- Physician siding with patient when "they want to go home." Then they discharge home
- "Here for a rest" - not appreciating this is acute care
- Dealing with multiple family calls
- CSS – fractured services
    - Staff are preplanning patient readmission due to ongoing problems – they know they will return
- Find CSS sending patients to hospital (not deeming incapable and moving to appropriate care directly!)
- Gap between CCAC managers and hospitals
- Gems not doing discharge planning

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- Hospital workers note if they don't connect with home care they don't hear from them
- RAI – "we are not working as a system"
- RAI not being updated
- Why do we have RAI?
- Why can't social workers do RAI?
    - They know the patients!
    - Feel it is useless – everyone seems to land up qualifying

Convincing solutions

1. Educate all parties: on challenges at hospital
2. Negative attitudes of patients: What is MOH doing to change reflection of LTC?
3. MOH dealing with regulations and enforce at LTC homes (bad home no one wants to go to, that needs to change!)
4. "Silos" between hospital and community sector
5. Acts need to be the same (LTC/Hosp.)
6. Cover transportation Saturday dialysis in LTC, care/dialysis home
    a. Start conversations sooner on next steps/placement
    b. More training at LTC and outreach program to increase level of care there
    c. Incentives/disincentives to stay or go
7. Population-specific care at LTC home, i.e., dialysis patients (specialized unit)
8. Compensate family to take patient home, care options and support
9. Increase CSS at home
10. Give hospital more control to say "need to go"
11. Go back to doctor/nurse home visits
12. Add more personal
13. More cost support for equipment
14. Increase caregiver relief
15. Some LTC homes don't want to take problem patients (behaviour issues)
    a. Need special homes to deal with these patients
16. Nursing homes want the "perfect patient"
17. Need more assistance with head injury or dementia patients at hospital
18. Suggest patient "navigator," involved in planning and scheduling so families know what to expect
19. Be clear on expectations of staff on admission, empower families
20. Need care partners (family members)

Erie St. Clair Community Care Access Centre

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

- I don't want to pick a home I don't like and there is a long wait list on preferred homes
- Money
- Perception that LTC company is more than ALC company
- CCC beds become a "mini nursery" home and don't want to move
- Like it here, especially monitoring
- Docs and nurses always around
- Access to docs
- Perception of certain LTC homes

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- Can't change their minds
- Lots of negativity in media
- Afraid to go home in resettlement program if they have been in hospital so long
- Secure with staff at hospital
- Location – home too far away
- Empowered – I don't have to take a bed anywhere
- Haven't realized they have been discharged and are not acute anymore
- Right to stay there
- Talk among patients
- Believe they have more access to therapy and will deteriorate in LTC
- Haven't recognized that they can't return home
- Staying in hospital means they don't have to make that big decision
- Issues in timing of agricultural season
- Families reluctant to make decisions because of promises to keep them home and would never put member in certain home (maybe cultural)
- Should not be an option to make LTC choice from hospital. Must be made from home
- Concerned about making multiple moves
- Grandkids moved back home with mom and dad who support them – kids are dependent on mom and dad income and home (Windsor)

Most Challenging

1. Older homes not as desirable (because of amenities and structure – not as nice)
2. Rights, "I don't have to take a bed"
3. Only want to get their first choice
4. Cost

Most Frequent

1. Don't like that home (based on rumours about care and aesthetics)
2. Not ready (family, logistics, mentality, physical condition)
3. Cost

Convincing solutions

1. More education and preplanning
    a. Systems (LTC vs. retirement home, etc.)
    b. More info about the homes
    c. Formal doc for all homes
2. Find place for people to stay (not in acute care) while making a decision
3. Change expectations of "older" generation as to what hosp. care is
4. Make home care 24/7 and free
5. Subsidize retirement homes
6. More CCAC in retirement homes
7. "Get real" with the patients about not being sick
8. Physician-driven tough conversations and input
9. Use real numbers – 1 day in bed = 3 days in physio
10. Physician education about system realities
11. Conv. care beds should be run by CCAC
12. Increased allied health in hospital – they could get involved earlier
13. OT, PT, SW has been cut
14. May not need rehab if OT and PT hours are increased
15. Quicker OT, PT assessment timing by increased staff hours

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16. Patients get overwhelmed by info in 1 hr – not enough time to work with family to make life-changing decisions
17. Reduce unnecessary care protocols such as vitals in patients who are medically stable
18. What to expect from your care
19. Public expectation levelling campaign
20. Stronger role of physician in moving into next point of care
21. Model after birth model education campaign
22. Improve time and money waste in system
23. Docs need to discharge, not label ALC
24. Improve access and restore administration time – i.e., later than 1 p.m.
25. Improve retention/LTC admission timing
26. Improve respite admission times
27. Increase rehab assessment time
28. Make POA and families responsible
29. ALC should not be accepted destination, esp. when acute rehab is done
30. ED needs 25 OT and 50 PT dedicated to ED
31. More PT and OT to reduce LOS and get ambulation services activated

Windsor Regional Hospital – MET Campus

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

- Cheaper
- Better care
- Nowhere to go
- Ugly, too old – won't go
- No doctor there
- No bus route
- Location
- Bath 1 time a week
- Nurse to patient ratio
- Vitals and nursing care
- Safety
- Like history/therapy
- Routine
- Reputation of some LTC
- No one to treat them
- Nowhere to go – no beds available
- I like it here
- Sense of entitlement
- Family can't care for them
- Family docs sending to ED for placement
- Unwilling to accept care in home until too late
- Cost – if it were free they would go

Convincing solutions

1. Some people need a transitional bed for short stay to get them reconditioned and back home
2. Eligibility criteria for confirmation disqualifies them for rehab
3. Assess and restore (LDMH) really works – it may take 2 to 3 times longer, but it really works
4. Resettlement program works well, espescially with family

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5. Some may need resettlement longer than the 60 days
    a. 6 months might be ideal
    b. More support in home
    c. More family support
    d. 2-hour blocks may be too long – more frequent shorter blocks may be better
6. Way too late patients are identified they are not able to go home
7. Start discharge from admission – inform the nurses
8. Get physio involved sooner so people don't de-condition
9. Physio assessment needs to be sooner so ambulation teams can get involved
10. Faster access to physio assessment
11. Review flow, institute collaborative projects for learnings
12. Send PSW to set up home and let patient have a trial with commitment to return back if it doesn't work out
13. Create a homeward-bound program
14. Continuity of cope managers between resettlement and reg. service
15. More could go home in resettlement program, but many are afraid
16. Supportive housing is part of the solution
17. People seem more receptive to touring shorter wait list homes because they aren't forced to choose
18. Gap between resettlement 60-day program and first choice coming available
19. Be creative with using advanced care at retirement homes vs. resettlement
20. Use retirement homes more
    a. Short-term respite
21. Avoid the admission to begin with
22. Open a transitional care program like at Central Park Lodge
23. Videos of LTC – tablets at bedside
    a. People really like them
    b. Tablets with videos
    c. Room photos
    d. Use computers during meetings at CCAC
    e. Caravan of LTC homes
24. LTC info sessions held at hospital every 2 weeks with LTC reps.
25. LTC brochures at nursing stations
26. Focus on the community so people don't have to be admitted
27. CCAC needs to be 24/7 and more time in-house
28. Crisis management and charging
    a. No leverage to coax pt./family to accept beds
    b. Aware that they will get bed of choice and force issue (stay)
    c. It is OK to come and stay indefinitely
    d. Co-pay – cheaper in hospital. Rehab no charge at all
29. Waiting in hospital for other hospital bed – could have gone home but refused
30. Family vacations
31. Gaming the system
32. Lack of education
    a. Pre-planning for trans. to LTC
    b. General health system literacy
33. Finality of decision - LTC placement

Windsor Regional Hospital – Western Campus

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

- Family not good enough (well) for a LTC
- Paid our taxes to stay here
- I'm not going to WP
- I'm happy here - convenient for my family
- Can't afford rest/retirement home
- Unrealistic goals set by family/patient
- Not ready
- Family requesting more time to keep patient in hospital
- More therapy
- More nursing care
- Never going to LTC
- Not enough family support
- Financing

Convincing solutions

1. Brochures from each LTC about their services, especially therapy
2. Accessibility of LTC for wheelchairs, etc.; elevators are an issue
3. Financial help for assisted living and retirement homes
4. More education regarding CCAC services and distribution of care options
    a. Better advocacy
5. CCAC service sessions
6. Educate public regarding what it means to stay in hospital
7. More support for front line from MOH so front line don't equal bad guys
8. Increase education about if they have to go to LTC
9. Alter motivation to wait for 1st home choice – send home with increased CCAC services
10. CCAC too discretionary
11. RAI doesn't help answer who can go home
12. Tax credits for people who purchase services from CCAC
13. Cross comparison of similarly functional people for going home vs. CCAC
14. Subsidy for rest/retirement home
15. More LTC/retirement home combos
16. Hospital assessment vs. CCAC. LTC assessment (quality) differences. Qualify don't always equal need or best choice
17. Decrease list for supportive housing with 24/7 care for 60 and younger
18. Relax CCAC criteria for services
19. Change culture of thinking at LTC so that it isn't the decided place to be
20. People do not plan for LTC and come to us in distress
21. CCAC met patient the day before discharge. Organize social worker's support ahead of time
22. People who agree to go to certain LTCH get increased priority for their first choice
23. Timing of CCAC meeting with patient is not as important as knowing basket of services and having to make choices quickly
24. Status of patient at end recommended services aren't always available or agreed to by CCAC
25. CCAC services on weekend
26. Difference in CCAC assessments and consistency
27. Need 12 a.m. to 8 a.m. services
28. Lifeline provided through CCAC
29. Lifeline too expensive
30. Advance planning for LTC

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31. Don’t look elsewhere
32. Elderly don’t want to spend money on themselves but leave to their kids
33. LTC is fine for “big three”
34. Can’t qualify for resettlement services
35. Great partnerships with APPD
36. Early stage Alzheimer’s patients should go home with services
37. Many families don’t look at names
38. Need support to get people out of rehab beds
39. Incentives to go to less desirable homes
40. Fire escape worries for people on top floor
41. Parking is significant cost

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Leamington District Memorial Hospital

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

- Get a lot more attention at hospital
- Nursing home = death
- Hosp. is safe haven
- Hope they will get better while at hosp.
- Staffing at hospital vs. home
- Spouse/family feels that if they put their loved one in LTCH they will be a bad person
    - "I promised I would never do that"
- Cost
- Choice is due to appearance and what they hear in community about them
- Not wanting to move more than once
- Fear of change
- Physician access
- Loss of freedom
- Family scheduling (not available to move their loved one)
- Not sure if they can handle the level of care
- No supports for working caregiver
- Cost to accommodate home
- Having confidence to become caregiver
- Bathroom – mobility issues
- Trust they will get care at the right time
- OT assessment timing
- Become comfortable in the hospital
- Safer to be in hospital than at home during farming season whereas family not avail. 24/7 to provide care
- Dementia is an issue
    - Repeat visits
    - Cognition
- Sometimes family members do not know patient has dementia
- Heard it's like a hotel – all needs are taken care of

Most Challenging

1. To convince them that they don't need to see a doctor daily and that they will be OK
2. Family support/trust/confidence in care

Most Frequent

1. Comfort
2. Safety
3. More attention
4. Security
5. Don't want to burden family
6. Cultural issues

Convincing solutions

1. Sippy cups for patients
2. PSW follows patient from hospital to home
    a. Provides familiar face

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    b. Ensures patient initial needs are met
3. If patient can meet some of the health providers from the home prior to going – may relieve some hesitation
    a. Reassurance of care
    b. Familiar face when arriving
4. Follow-up care for hospital regarding how they are doing if meds are being given. etc.
5. Provide a picture of their room to give them an idea of what to expect
6. Provide a tour to the patient to help them make their choice easier
7. Tele medication/Skype to keep communication going
8. Tablet for communication
9. Have family pick their own home care worker
10. Home care to provide service to meet their needs
11. Multi-skilled worker to keep companionship/caregiver consistency
12. Keep the same home care worker rather than rotating different workers
    a. Constancy=familiar=comfort
13. Improvement of timeliness of care
14. Funding to provide this timely service
15. Mobile teams for home visits/follow-up
16. Transitional teams – looking toward the hospice model
17. Weaned off – hospital care is pulled back for non-essential as the patient gets closer to discharge
18. Give families more control of the patient care

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