

**TRANSFER FROM HOSPITAL
TO LONG-TERM CARE:
REFRAMING THE ETHICAL DEBATE
FROM THE
PATIENT'S PERSPECTIVE***

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ADVOCACY CENTRE FOR THE ELDERLY

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1. **Introduction to the Advocacy Centre for the Elderly**

The Advocacy Centre for the Elderly ("ACE") is a specialty community legal clinic that was established to provide a range of legal services to low income seniors in the Province of Ontario. The legal services include individual and group client advice and representation, public legal education, community development, and law reform activities. ACE has been operating since 1984 and is the only legal clinic in Canada with a specific mandate and expertise in legal issues of the older population.

ACE currently employs five lawyers and three support staff. Since its opening in 1984, legal issues of residents in long term care homes and in other health settings have been a primary focus of work. Annually, ACE receives over 2500 new client contacts. Of these, approximately a third can be identified as directly involving issues in long-term care and other health facility settings.

In response to this demand and need for expertise in long term care and health facility legal issues, ACE created the position of "Institutional Advocate" in 1988. The Institutional Advocate, who is a lawyer, is responsible for providing legal services to clients who need advice or assistance with legal issues in long-term care homes, hospitals, psychiatric facilities, and other institutional settings. Other staff also provide advice and representation to these clients because of the high volume of cases in this area.

In the last several years, calls about discharge from hospital have been a growing part of practice at ACE. In the past three years we have had approximately 450 calls of this type. An increased percentage of these have occurred in the last year. We have done extensive research on the legal issues related to these problems, looking for practical remedies to assist our clients. We have done many workshops at conferences for both lawyers as well as health providers on these issues. We are very aware of the pressures in the health system and the challenges of finding effective solutions to the problems.

1.1 **ACE's Role as Instructed Advocates**

ACE provides legal advice to clients. As lawyers, it is our obligation to advise clients of all their legal options and to act on those instructions, unless the instructions are something we cannot ethically do as lawyers. As we explain to our clients, it is not the role of an advocate to impose the advocate's own values and goals on the person being assisted. However, it is appropriate within the lawyer-client relationship to express concerns with the client's position, and even to try to gently persuade the person of an appropriate course of action. Once instructions are received, however, it is the lawyer's duty:

to raise fearlessly every issue, advance every argument, and ask every question, however distasteful, which the lawyer thinks will help the client's case and to endeavour to obtain for the client the benefit of every remedy and defence authorized by law.¹

1.2 Purpose of this Paper

In this paper, it is our goal to describe the law regarding admission to long-term care and the realities of what is taking place in Ontario hospitals and long-term care homes from our clients' perspective.

2. The Law of Admission to Long-Term Care and Discharge from Hospitals

Placement in a long-term care home in Ontario is regulated by three pieces of legislation: the *Homes for the Aged and Rest Homes Act*,² the *Nursing Homes Act*,³ and the *Charitable Institutions Act*,⁴ and specifically by their regulations. All three pieces of legislation are identical with respect to placement and for the purpose of this paper, we will reference only the *Nursing Homes Act (NHA)*. In addition, the *Health Care Consent Act (HCCA)*⁵ regulates the consent portion of the admission process.

The placement role is statutorily delegated in the *NHA* to the placement co-ordinator from the Community Care Access Centre (CCAC); therefore all legal obligations regarding placement in the *NHA* are that of the placement co-ordinator.⁶ While hospital employees, such as discharge planners, may be the primary contact, it is the legal obligation of the placement coordinator to ensure that all statutory and policy requirements have been met with regards to applications for long-term care.

The application process commences with an application by a person for a determination that the person is eligible for admission to a long-term care home.⁷ Once the person is found by the placement co-ordinator to be eligible, the person must then apply for authorization for admission to a long-term care home.⁸ The request must be in writing and provided to the placement co-ordinator.⁹ When a person chooses a long-term care home, the placement co-ordinator is required to

¹ *Rules of Professional Conduct*, Law Society of Upper Canada, Adopted by Convocation on June 22, 2000

² R.S.O. 1990, H.13, as am.

³ R.S.O. 1990, N.7, as am.

⁴ R.S.O. 1990, C.9, as am.

⁵ S.O. 1996, c. 2, Schedule A, as am.

⁶ For the placement co-ordinators' statutory duties, see R.R.O. 1990, Reg. 832, s. 128.1-157.

⁷ O.Reg. 832, s. 129-134

⁸ O.Reg. s. 135.

⁹ O.Reg. s. 136.

give the relevant information to the long-term care home in order for them to determine whether they will approve or withhold approval for admission.¹⁰

A person may choose up to, but no more than three long-term care homes, unless they have been designated a “Category 1A” as a person who requires immediate admission as a result of a crisis arising from the person’s condition or circumstances.¹¹

When choosing which long-term care homes to apply to, the person is legally allowed to choose any home they wish. Consent to admission to a long-term care home is regulated by the *HCCA*.¹² Part III of the *HCCA* defines long-term care homes as follows:

“care facility” means,

- (a) an approved charitable home for the aged, as defined in the *Charitable Institutions Act*,
- (b) a home or joint home, as defined in the *Homes for the Aged and Rest Homes Act*,
- (c) a nursing home, as defined in the *Nursing Homes Act*, or
- (d) a facility prescribed by the regulations as a care facility.¹³

Valid consent is required for the person to apply for the application to be sent to the home and for admission to that home. The *HCCA* codifies the common-law definition of consent. There is no specific section regarding consent to admission to a care facility, so one must look to the section regarding “treatment” and modify it for placement. The section, modified for placement, is as follows:

Elements of consent

11. (1) The following are the elements required for consent to [placement]:

1. The consent must relate to the [placement].
2. The consent must be informed.
3. The consent must be given voluntarily.
4. The consent must not be obtained through misrepresentation or fraud.

¹⁰ O.Reg. s. 137.

¹¹ O.Reg. 832, s. 141, as am. The regulation is clear that the designation relates to the person, not the facility. The regulations do not allow persons to be placed in the crisis category due to hospital overcrowding.

¹² *Health Care Consent Act, 1996*, S.O. 1996, C. 2, Schedule A.

¹³ *HCCA* s. 2(1). As of yet, there are no facilities prescribed in the regulations.

Informed consent

- (2) A consent to [placement] is informed if, before giving it,
- (a) the person received the information about the matters set out in subsection (3) that a reasonable person in the same circumstances would require in order to make a decision about the [placement]; and
 - (b) the person received responses to his or her requests for additional information about those matters

Same

- (3) The matters referred to in subsection (2) are:
1. The nature of the [placement].
 2. The expected benefits of the [placement].
 3. The material risks of the [placement].
 4. [not applicable to placement].
 5. Alternative courses of action.
 6. The likely consequences of not [being placed].

Express or implied

- (4) Consent to [placement] may be express or implied.¹⁴

When choosing a long-term care home, therefore, one has the freedom to choose whatever one believes to be appropriate for that person. They are entitled to look at all options, have all information requested provided to them, and then freely choose whichever option they like.

The legislation was drafted specifically in this fashion, to allow persons to choose where they wish to live. It has been recognized that a long-term care home will be the person's home, likely for the rest of their life, and therefore it is important that the person be comfortable in their surroundings, and that the surroundings be appropriate to the person. Regulators have decided that just because a person must live in an institutional setting, it does not mean that they lose all choice. They have therefore very deliberately included choice in the law, recognizing its value and importance in the successful placement of the person. Other issues that must be addressed when looking for a long-term care home are the persons' abilities and disabilities, their family structure, past history, likes, dislikes, etc. There are no "one-size-fits-all" homes: what one person likes may not be to another's taste. It is up to the person or their substitute decision-maker to determine what would be in the best interest of the person. This cannot, and should not, be done by a third party based on issues unrelated to the person. While it is recognized that in some situations a person will agree to go to a place which would not be of their first choice, they must still be able to weigh the pros

¹⁴ HCCA, s. 11.

and cons of this admission to ensure that it suits their particular needs. Other issues must also be recognized. For example, those suffering from dementia or other diseases often find change of surroundings extremely difficult to deal with, and the recognition that the person may suffer from Relocation Stress Syndrome (also known as “transfer trauma”) must be included in the equation by the person making the placement decision.

As part of the process, if there is a reason to believe that a person is mentally incapable of making a placement decision¹⁵ then a substitute decision-maker must make the decision.¹⁶ The incapable person cannot legally make decisions and any consent from that person would be invalid.

Mr. M is semi-conscious, non-verbal, and clearly incapable of making personal care decisions. While his SDM is investigating whether any long-term care home would even accept his application, the hospital discharge staff repeatedly approach Mr. M to try to get him to sign a paper consenting to be discharged to long-term care. Any admission based upon this purported consent would be illegal.

The substitute decision-maker must abide by very specific rules set out in the *HCCA* when making their decision. Those rules are as follows:

42. (1) A person who gives or refuses consent on an incapable person’s behalf to his or her admission to a care facility shall do so in accordance with the following principles:
 1. If the person knows of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, the person shall give or refuse consent in accordance with the wish.
 2. If the person does not know of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, or if it is impossible to comply with the wish, the person shall act in the incapable person’s best interests.

Best interests

- (2) In deciding what the incapable person’s best interests are, the person who gives or refuses consent on his or her behalf shall take into consideration,

¹⁵ *HCCA* s. 4(1) A person is capable with respect to a ... admission to a care facility... if a person is able to understand the information that is relevant to making a decision about the ... admission... and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.

¹⁶ See *HCCA* s. 20 for the rules regarding who can consent on the incapable person’s behalf.

- (a) the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable;
- (b) any wishes expressed by the incapable person with respect to admission to a care facility that are not required to be followed under paragraph 1 of subsection (1); and
- (c) the following factors:
 - 1. Whether admission to the care facility is likely to,
 - i. improve the quality of the incapable person's life,
 - ii. prevent the quality of the incapable person's life from deteriorating, or
 - iii. reduce the extent to which, or the rate at which, the quality of the incapable person's life is likely to deteriorate.
 - 2. Whether the quality of the incapable person's life is likely to improve, remain the same or deteriorate without admission to the care facility.
 - 3. Whether the benefit the incapable person is expected to obtain from admission to the care facility outweighs the risk of negative consequences to him or her.
 - 4. Whether a course of action that is less restrictive than admission to the care facility is available and is appropriate in the circumstances.¹⁷

The duty of the substitute decision-maker is quite restrictive and they can only make the decision within these parameters. The substitute decision-maker has a legal obligation to make a decision based on the person's particular needs and requirements: they cannot take into consideration their own needs or that of some third party except as it relates to the person being placed.

Nowhere in either the *NHA*, its regulations, nor the *HCCA*, is there any requirement that the choice is to include anything other than the **person's** own choice, or what is in their **best interest**. Nowhere does hospital policy, the requirements of the acute care system, or any other such thing make its way into the equation. Therefore, based upon the legislation, the person is free to choose whatever long-term care homes they like.

The placement co-ordinator owes a fiduciary duty to the person being placed to follow the law and ensure the best appropriate placement. He or she may be held liable if they fail to comply with their legislation, both in a civil action as well as pursuant to their College professional responsibilities, as they apply. It must

¹⁷ *HCCA*, s. 42.

be remembered that the placement co-ordinator is not an employee of the hospital and owes no duty to the hospital nor is it in a position to enforce any policies. The placement co-ordinator's duty is to the person being placed.

Hospital representatives often state that they are required by law to discharge a person 24 hours after the person no longer requires acute care. The regulation to the *Public Hospitals Act* regarding discharge are as follows:

16. (1) If a patient is no longer in need of treatment in the hospital, one of the following persons shall make an order that the patient be discharged and communicate the order to the patient:

1. The attending physician or midwife or, if the attending dentist is an oral and maxillofacial surgeon, the attending dentist.
2. A member of the medical, dental or midwifery staff designated by a person referred to in paragraph 1.

(2) Where an order has been made with respect to the discharge of a patient, the hospital shall discharge the patient and the patient shall leave the hospital on the date set out in the discharge order.

(3) Despite subsection (2), the administrator may grant permission for a patient to remain in the hospital for a period of up to twenty-four hours after the date set out in the discharge order.¹⁸

Based upon this, it would appear that as soon as a patient no longer required treatment, they must be discharged from hospital, the only exception being a 24 hour grace period. On its face, this would appear to mean that the hospital has to discharge everyone 24 hours after treatment is no longer required, regardless of whether or not a bed is available in long-term care. We argue that this is not, in fact, the case.

Hospitals are already picking and choosing when to rely on this regulation: when it suits them they enforce it, when it doesn't, they don't, based upon the person's compliance with individual hospital "policy".

It is clear that the hospital owes a legal duty to the person being discharged, meaning that they cannot discharge the person to the community knowing that it is unsafe and that they will likely come to harm. This is the same reason that a hospital cannot force a person to go to a retirement home: people cannot be forced to "wait" for placement in the community if they require and are entitled to publicly funded health care. Retirement homes are tenancies and are not part of

¹⁸ R.R.O. 1990, Reg. 695, s. 16.

the public health system. Retirement homes are not regulated in the same ways as long-term care: there are no requirements or standards for the care provided therein. When a person has been found to be eligible for long-term care, they are entitled to public health care, as the retirement home industry is user-pay and the level of care cannot be guaranteed, no one can be forced to go to one.

How can the hospital both discharge someone within 24 hours and at the same time meet the duty of care owed to the sub-acute patient? When one reviews the law, one can argue that when it comes to those awaiting placement in a long-term care home, hospitals are not required to comply with the 24 hour rule.

In 2002, prior to the opening of the new long-term care beds, issues similar to today's arose regarding placement into long-term care homes. At that time, applicants for long-term care could choose as many facilities as they liked, and those in hospital were often forced to "choose" many facilities, sometimes **every** facility in their geographical area or even further.¹⁹ Those applying from hospital were a "category 3", a category which included all those applying from the community.

To deal with the problem of discharge from hospital, the government amended the regulations, making those applicants awaiting placement from hospital a "category 2", but restricting the number of facilities which could be chosen to a maximum of three.

In 1996, amendments were made to the regulations to the *Health Insurance Act*, in response to complaints that people were refusing to apply to or accept long-term care placements from hospital because they did not have to pay for the bed in the hospital. These regulations specified that patients in hospital who, in the opinion of the physician, were more or less permanent residents of a hospital or other institution, could be charged the "chronic care co-payment".²⁰ The physician would designate a patient as being "alternative level of care" or "ALC", allowing them to stay in hospital to await admission to a chronic care hospital or long-term care home, while charging them the same rate as they would pay in one of those institutions.²¹

This regulation recognized the right of the person awaiting placement in long-term care to wait in hospital, and set a maximum amount that the person could be charged while waiting. This amount generally corresponds to the rate the person would pay for basic accommodation in a long-term care home.

Hospitals often state that they have passed a policy relating to the discharge of persons into long-term care, often requiring patients to choose specific homes,

¹⁹ It should be made clear, however, that this was contrary the law in place at that time.

²⁰ R.R.O. 1990, Reg. 552 as am., s. 10.

²¹ *Chronic Care Copayment 2004*, Ministry of Health and Long-Term Care, available at: <http://www.health.gov.on.ca/english/public/pub/chronic/pdf/chronic.pdf>

accept “available” beds, etc. It is our opinion that this is outside of the purview of the hospital’s authority. The *Public Hospitals Act* and its regulations do not convey this type of authority on the hospital. The *Public Hospitals Act* contains a regulation making provision, stating that the Minister may make regulations regarding the “the admission, treatment, care, conduct, control and discharge of patients or any class of patients.”²² Hospitals often use this section as the basis for their making and enforcing policies requiring people to accept the first available bed, choose specific long-term care homes, etc.. However, this is not the case. Hospitals have no authority to make policy regarding the application process for long-term care.

In fact, the *NHA* clearly states that it is up to the Minister to make regulations regarding discharge.²³ The Minister has done that. Further, a hospital cannot make rules or policies which contravene other pieces of legislation. The placement process, including how one is to make decisions, has already been clearly set out in detailed legislation, as outlined above. Therefore these hospital policies are of no force and effect as they are attempting to regulate what is clearly in the sole purview of the government.

3. **Ethics of Transfers from Hospital to Long-Term Care**

In our own practice, within the last 12-month period, our office has received more than 110 calls for advice and representation when a person was facing a forced discharge to a long-term care home not of their choice. We receive yet more calls from families who have been forced to accept beds in long-term care homes they did not want, complaining that the care is substandard.

We have advised families across Ontario on an individual basis, and presented at numerous seminars and conferences regarding the issue of ALC Placement. In 2007 contacted every hospital in Ontario to request copies of discharge planning policies, and have completed a study on the impact of these policies on decision-making.

In studying the “ethics” of transfer from hospital to long-term care, one must look at the people, the law and the situations involved. For example, one cannot be “ethical” by ignoring or skirting the law: the legal framework is at the core of what is meant by ethical. One also has to look at how the law and actions are being used by the “authorities”, and what the impact is on those who are most affected by them: that is, the person being admitted to long-term care.

²² *Public Hospitals Act*, R.S.O. 1990, P.40 as am., s. 32(1).

²³ R.S.O. 1990, P.40, as am., par. 32(1)(j).

3.1 People, Not Numbers

Our office deals with the real individual decisions each family faces. We learn each of their stories: the difficult health and personal circumstances of every senior faced with the transfer to long-term care from hospital. The people involved represent every income bracket, ethnicity, and background.

The ethical framework surrounding this issue must be grounded in the personal stories of the individuals involved. These patients are not mere numbers in a bed-flow process; they are people. They have the right to control their own bodies and make their own decisions concerning their lives. If they are no longer capable of doing so, they have the right to have those decisions made by their substitute decision-maker pursuant to their competent wishes or their best interest, in accordance with the *HCCA*.

4. A Systems Problem, Not a Discharge Problem

The problem of moving patients from hospital to long-term care is a health systems problem that manifests itself most acutely at the discharge planning stage. There seems little doubt that hospital discharge planners are constrained in finding creative options for hospital patients because of systemic resource shortages.

However, it is misplaced to blame bed shortages on seniors awaiting long-term care placement. In a report by an expert panel on alternative level of care, the Ministry's own statistics show that admission to long-term care represents one quarter of the ALC designations. The Ministry statistics showed the following breakdown of those waiting in hospital for alternate level of care:

1.	Home (excluding home care)	14.1%
2.	Home-care	13.0%
3.	Long-term care home	23.9%
4.	Complex continuing care	23.7%
5.	Rehabilitation	20.2%
6.	Other	5.1% ²⁴

The statistics did show that the percentage of ALC days for those awaiting placement in long-term care was higher, at 39%; however, this means that 61% of the days were spent awaiting another type of care. While it may be convenient to point at a specific group of patients as being the main problem, it is in fact, a systemic issue.

²⁴ "Appropriate level of care: a patient flow, system integration and capacity solution". Report by the expert panel on alternate level of care for the Ministry of Health and Long-Term Care, December 2006.

Moreover, in certain parts of Ontario and particularly at certain times of year, there are simply no long-term care beds available in the area to be offered to hospital patients. Our clients are told that currently there are no open beds in communities such as Burlington, Belleville and Ottawa. During flu season, many homes are closed for days or weeks at a time due to outbreak, resulting in a complete halt to admissions to the affected homes.

What is required is a systems solution to a systems problem. A systems solution would see a combination of improvements, including the following:

4.1 Increase Availability of Home Care

- Broader services for assistance with IADLs (vacuuming, cleaning, shoveling snow, etc.²⁵) would mean people can stay in their own home longer.
- Earlier availability of services would help people avoid crisis situations.
- Increased funding for respite services would alleviate pressure on caregivers, so that both the caregiver and the senior can avert a crisis. This would include reduced or waived rates for those who cannot afford it.
- Increased and stable funding across all home care services would ensure that a person's access to services does not depend on the time of the fiscal year in which they experience need.
- Increased funding to home care would aid with recruitment, retention, and proper remuneration of home care providers.

4.2 Increase Availability of Complex Continuing Care and Rehabilitation Beds

- Greater availability of complex continuing care beds would allow physicians more options once a patient has finished the acute stage of their treatment, and would lessen the pressure on physicians to discharge to long-term care before the patient is ready for discharge.
- Greater availability of complex continuing care beds for those who actually need it. The trend has been to move patients out of

²⁵*When Home is Community: Community Support Services and the Well-Being of Seniors in Supportive and Social Housing*, Janet M. Lum, Simonne Ruff, and A. Paul Williams, Research Initiative of Ryerson University, Neighbourhood Link/Senior Link and the University of Toronto Funded by United Way of Greater Toronto, April 2005

these facilities into long-term care; however, this has led to inappropriate placements of those who require higher levels of care than can realistically be accommodated in long-term care homes.

- Greater availability of rehab beds would mean that patients can receive the assistance they need to return to independence.
- Increased availability of long-stay rehab beds would allow for the realistic timelines some people require to rehabilitate after traumatic health incidents or to account for the impact of new medications.

4.3 Create Specialty Facilities and Units for those with Behavioural Issues

- Beds and/or facilities be developed for the care of demented or cognitively impaired residents exhibiting aggressive behaviour as an alternative to LTC facilities, with appropriate funding and staffing levels. Many residents in long-term care are presently inappropriately placed, or cannot find a place, as there are no facilities that presently offer this specialized type of care.

4.4 Increase Supportive Housing and Group Homes

- While admission to long-term care is universal for those over 18, with OHIP coverage and who meet the care requirements, many residents of long-term care homes ethically should not be there. This includes young residents, those with psychiatric disorders only, and those with specific types of disabilities which would be better suited to another type of housing solution. Unfortunately, because these types of housing are in short supply as well, these residents get placed in long-term care as it is the “easiest” way to house them.

4.5 Make Long-Term Care Homes Places People Would Choose

- Ensuring compliance with Ministry regulations and policies. Often, the long-term care homes that hospitals push patients to accept are those with the worst records.²⁶ Cleaning up, or, in the most egregious cases, closing the homes with disastrous compliance records would mean that no person is faced with the

²⁶ It is not unusual to find 25 or 30 unmet standards and criteria, plus a number of citations under the legislation as well as verified complaints when one checks the Ministry website Reports on Long-term care – www.health.gov.on.ca

prospect of living in a long-term care home that does not meet basic provincial standards.

- Upgrading older long-term care homes would mean that patients no longer have to choose homes with four-bed ward rooms or other unattractive features. In the alternative, other strategies could be utilized such as giving a “price break” which may induce patients to apply to them.
- Determining where beds are required now and forecasting where they will be needed in the future, and building beds in those communities would reduce the impact of people being forced to leave their community to enter long-term care.

5. **The Ethics of Treatment: Deciding Who Gets Hospital Care**

In media reports about hospital bed-flow pressures, one frequently sees the situation described as a question of access to acute care services. Seniors are portrayed as “bed blockers” who are less deserving of health care services than non-seniors waiting for a hospital bed. This approach is a value judgment on the worthiness of people to receive equal access to health care. The common denominator in these stories is that the “bed blockers” are seniors.

While the failure of the system to meet the needs of those waiting for the bed in the emergency room is recognized, the failure of the system to meet the needs of the senior is not.

It is assumed that the person in the ER is more deserving of the bed than that of the person awaiting long-term care. The assumption is that the “bed blocker” should be happy to go to any long-term care home available: “that one-size fits all”, and that all long-term care homes are created equal. It is not recognized that an inappropriate placement can result in the further illness, return to hospital, or even death of the senior.²⁷

²⁷ This issue was highlighted in the 2006 British Columbia case of Al and Fanny Albo. The couple were in hospital and the hospital forced Mrs. Albo to be transferred an hour away from her husband. She died two days later. An investigation and report about the case was prepared by Deputy Minister of Health Dr. Penny Ballem.

Mr. M requires dialysis six times per week for two hours each time. He cannot move from his hospital bed so the dialysis machine is brought to his bedside. The hospital indicates that Mr. M is ready for discharge to long-term care. The hospital promises that the long-term care home will get Mr. M ready for daily trips to the hospital and will provide transportation. Despite these promises, the family does not believe that the long-term care home has the resources to devote this much time each day to one resident. As a compromise, Mr. M's physician changes Mr. M's dialysis schedule to four hours three times per week to alleviate the pressure on the long-term care home, despite the trauma this would cause to Mr. M's body. Mr. M's family refuses, despite ongoing threats to charge them \$750 per day. Mr. M dies shortly thereafter.

Reframing the ethical question may help us think about this problem in a different way. Why is our value judgment not focused on the people seeking care in the emergency room? For example, why is it unethical to restrict care to persons who engage in self-injurious or risky behaviour that they know or ought to know will cost the health care system²⁸ but fine to force people into unsuitable and inappropriate care institutions?

It is unfair and, at base, discriminatory to place blame for scarce hospital resources on a single group of people, the elderly, who have little or no control over their health status. Many of our clients report that they have had little or no contact with the health care system throughout their lives. They feel that they should not be looked down on when they eventually need to call upon the system that they helped to build.

Mr. K has extremely complicated care needs and rapidly progressing dementia. There is money available to pay for a private room in any of his three chosen long-term care home. The hospital says Mr. K cannot wait for the very short waiting lists to move. The hospital says he can either pay \$800 per day to stay in hospital, or the hospital will discharge him to the care of his wife, a retired nurse. Mr. K's wife tells ACE: "We went through the war in Holland where we were hidden from the soldiers. This experience is worse. We trusted the hospital and we trusted the doctors. We are taxpayers. They are treating us as though we are criminals."

5.1 The Problem with Warehousing in Transitional Units

Some hospitals in Ontario have created "transitional units" for ALC patients awaiting long-term care placements. These transitional units may be located in hospital or they may be in alternate settings such as in a wing or floor of a long-term care home. Patients in these units are still hospital patients, but the intent

²⁸ This debate has recently taken place in the United Kingdom:
<http://www.telegraph.co.uk/news/main.jhtml?xml=/news/2008/01/27/nhs127.xml>

is for the care and staffing to approximate that available in a long-term care home.

Transitional units may solve some short-term problems, but are not the final solution to bed-flow problems. If these are to be used, they should be more than a warehouse for the patients: they should provide appropriate care and services geared to those awaiting placement.

The more difficult issue lies with the use of “off-site” transitional units. Because they are classed as “intra-hospital” transfers, the patients are told they have no choice in the move. However, despite requests, we have been unable to confirm that these units are actually part of the admitting facility.

Further, these transitional units simply shift the discharge process one step further, and in effect double the number of patients for whom the discharge team is responsible. Once the hospital beds are full and the transition units are full, the bed-flow problem is compounded. While these units seem like a good short-term solution, they will only add to the challenges.

Such units can be dangerous to patients and care providers because there is no mechanism for placing violent patients separately from those who pose no danger. For example, one transitional unit houses a mix of patients that has proven to be volatile. Patients who would require a secure unit in a long-term care home are housed next to those who are capable, frail, and non-mobile. Clients in those units have reported fearing for their own safety.²⁹

It is also unclear who has ultimate responsibility for these transitional units. The running of the unit may, in fact, be contracted to an outside company. Complaints to the hospital about care or other matters on the units are referred to the contracted care provider; and complaints to the care providers are referred back to the hospitals contracting out these beds. Patients on these units are falling through the cracks.

The very nature of a transitional unit risks compromising patient care. For example, medical records have not been transmitted from hospital to the transitional unit in a timely way, such that our clients report that medication allergies or specific care needs are not indicated on their charts. Being moved from location to location increases the potential of the person suffering from Relocation Stress Syndrome.

Similarly, there is little continuity of care in the move to transitional units. Hospital patients already report that they are unable to establish relationships with nurses or personal support workers because these caregivers change so frequently. This problem is exacerbated in transitional units, where caregivers have little opportunity to get to know patients and their important care needs.

²⁹ “What Happened is a Nightmare” by Lisa Priest, *Globe and Mail*, January 5, 2008.

Mr. C is sent from hospital to a “transitional unit” located in a wing of a closed-down long-term care home. He is still technically a hospital patient awaiting placement in a long-term care home, and hears himself referred to as a “bed blocker” by the staff. At the transitional unit, he is housed on a wing with patients who are acting out due to dementia or psychiatric illness, and he fears for his safety. He regularly blocks his door from the inside so the violent residents cannot get in. He reports that he feels like a character in “One Flew Over the Cuckoo’s Nest”. Due to poor care at the transitional unit, he needs to be sent back to the emergency room at the hospital. He is told there is no bed for him. He remarks that he is both a “bed blocker” and “blocked from a bed” despite his official designation as a patient of that hospital.

6. The Ethics of Treating: Compromising Clinical Judgment

In our view, policy development in this area must take into consideration that the registered health professionals involved may face professional and ethical conflicts. In several cases, we have identified situations of professional misconduct in the actions of the nurses, social workers or physicians involved in the discharge process. If reported, these complaints could be the basis for discipline by their governing College.

Those working in the hospital setting have dual responsibilities: they owe a duty to both the hospital as well as the patient. Unfortunately, these roles may conflict. Hospitals may put pressure on staff to such an extent as to compromise their clinical judgment. For example, we have had physicians advise that their clinical judgment is that the patient is not ready for discharge, but they are being pressured to discharge the person as quickly as possible. One physician reported to ACE that as soon as he walks onto the ward, discharge staff aggressively approach him to demand that he sign off on patients’ stability for transfer or discharge. This erosion of clinical decision-making power risks compromising patient health, but it also puts the physician at risk for complaints to the College of Physicians and Surgeons.

Mr. L is deemed to be ready for discharge from hospital to long-term care, despite his uncontrollable diarrhea, pain, and rapid weight loss. His family repeatedly requests he be categorized as requiring chronic or palliative care. The hospital refuses and the family is forced to agree to long-term care. Mr. L dies within three weeks of discharge. The Coroner tells Mr. L’s wife that Mr. L should have been a palliative patient and never should have left hospital.

While some discharge planners are ethical and provide client-centered care, others are less so. It is unfortunate that we have had to deal with discharge planners who have had to compromise their professional judgment to comply

with the hospital-mandated discharge policy. Discharge planners have downplayed or questioned medical diagnoses to make them eligible for specific long-term care homes. Patients may not be provided with the full spectrum of options, or with correct information about what kinds of services are available in long-term care homes.³⁰ Attitudes towards patients and families who are not “complying” with hospital policies have been inappropriate and bordering on harassing at times. In the most egregious of cases, discharge planners have simply blocked applications for long-term care, refusing to give the application to the CCAC unless the person or their substitute decision-maker complies with hospital policy.

Mr. H requires dialysis three times per week. He has Stage IV ulcers and must be on a special air mattress. He has to have dialysis in his hospital room as he is in too much pain to be taken downstairs to the dialysis unit. The hospital says his wife must “agree” to his admission to a long-term care home two hours away from his dialysis site, which will require him to be transported three times per week, several hours each trip, to receive dialysis treatment. The hospital advises his wife that if she does not consent to the admission, she will have to pay \$800.00 per day. Mr. H is aware of what is happening. He refuses dialysis and dies shortly thereafter.

It is our opinion that the entire placement issue should be dealt with by the CCAC, as set out in law. The original reason for the implementation of the placement co-ordination services system, the precursor to the CCAC, was to ensure fair and equitable placement in long-term care in accordance with the law. This goal has not changed. The CCAC should be fulfilling its legally mandated role in the placement process, removing it from the hands of the hospital staff. This would not only ensure fair and equitable placement of the patients, it would also remove the hospital staff from the compromising position in which they presently find themselves.

7. The Ethics of Decision-Making: Patients and SDMs

It is the substitute decision-maker’s legal responsibility to make decisions in accordance with the incapable person’s known wish or their best interests. While patients or substitute decision-makers are in the process of making their choices, they are often confronted by faulty assumptions on the part of discharge staff surrounding the process of choosing long-term care homes to which applications will be made. Staff are often not familiar with what is available in the long-term care home that they are “recommending”, do not understand the law under which long-term care operates, etc. Many of these faulty assumptions contribute to the sometimes confrontational nature of the relationship between discharge staff and

³⁰ Similar problems about what is available from home care has also been observed.

the patient or substitute decision-maker making the application on an incapable person's behalf.

7.1 **Faulty Assumption: One Size Fits All, So All Homes Are "Appropriate"**

Not every long-term care home is appropriate for every potential resident. Hospitals with policies that seek to place residents in "appropriate" or "suitable" beds rarely recognize that all homes are not alike, and every patient is not an appropriate candidate for every long-term care home. Usually, the hospital receives a list of "available" beds, which state the sex, the level of accommodation (basic, semi, private), and the level of care provided (light, medium, heavy, locked unit). If a person is a "female, basic, medium" and this bed becomes available, it is assumed that the bed is appropriate. This is patently untrue.

Factors such as the patient's age and type of illness are important considerations in deciding whether to apply to a particular long-term care home. For example, many homes may simply be unsuitable for younger persons with Multiple Sclerosis or Acquired Brain Injury.

Ms. X is forty years old and has Multiple Sclerosis. There are no suitable places for her to live, as she needs constant care. She is told that she must take a bed in a long-term care home more than two hours away from her home. Not only is this woman faced with living in long-term care at such a young age – taking this bed means she must leave her 18 year old daughter, her only family member.

Similarly, secure units are inappropriate for those who do not require them: yet patients may be told that they must accept a bed in a secure unit in a home to which they have applied to. Besides the obvious liberty issues, placement of a capable person in a setting where most of their fellow residents are incapable, demented, and often exhibiting potentially dangerous dementia-related behaviours can affect the person negatively.

In a province as diverse as Ontario, it is another faulty assumption to think that persons of different socio-cultural, religious or linguistic backgrounds can be appropriately placed in just any long-term care home. For example, patients who only speak a language other than English or French, and who rely on family members for translating even the most basic information, cannot simply be sent to long-term care homes where they will be separated from their interpreters. To do so would be to cut them off from all meaningful communication with those around them, and could even be dangerous where care needs are involved.

Long-term care homes are required by law to provide for residents' needs, including cultural, religious, dietary, safety, and spiritual needs. Residents are entitled to expect such provision under the legislatively-enshrined Residents' Bills of Rights. It is not realistic to expect each long-term care home to meet all the needs of such a broad scope of residents. One size does not fit all, and all long-term care homes cannot accommodate all types of patients transferring from hospital.

At the most basic level, the goal is that all long-term care homes should be able to house and feed residents and provide basic care. However, it is a fallacy to believe that even if this were true, an open bed at a particular home can automatically or necessarily be assumed to be able to meet every patients' needs.

When an available bed is in a community far away from their home, family may not be able to provide the support and, indeed, the hands-on care, that their loved one requires. It is the reality in long-term care that family members are frequently called upon to assist a resident with care, such as exercising, feeding, or behaviour management. When families are separated from their loved one because the bed that is available "that can meet the person's needs" is too far away, the person will not have their needs met, and will deteriorate because of the separation. Such deterioration is a factor that the substitute decision-maker is lawfully required to take into consideration when choosing long-term care homes to which to make an application.

Mr. B has advanced Alzheimer's disease and exhibits aggressive dementia-related behaviours. When his wife is present, he is calm and requires no restraints. Mrs. B has been her husband's primary caregiver for many years but he now requires long-term care. The hospital wants to send him to a long-term care home two hours away from Mrs. B, who is low-income and does not have a driver's license nor any relatives who could provide transportation. She would not be able to afford to travel to see her husband, his behaviour would escalate, his condition would rapidly deteriorate, and their 60-year marriage would end with them being separated.

7.2 **Faulty Assumption: Decisions Can and Must be Made Immediately**

It is understandable that hospitals want to ensure that decisions are made promptly so that bed offers can be made and patients can be discharged. However, it is a faulty assumption to think that every patient's family members and substitute decision-makers are in a position to drop everything in order to facilitate the application process. Often, family members have already lost work time in caring for their relative, and cannot drop everything to attend various meetings at the hospital. Further, while it is strongly recommended that you never apply to a long-term care home that you have not seen or had someone seen on your behalf, this is easier said than done. One cannot simply "drop in"

on most homes to take a tour: these must be booked in advance. Many homes have tours only during the day, or infrequently, making it difficult for family to attend. The person or their substitute decision-makers has the right under the law to the information that is necessary for them to make their decision, which would include such visits. It is often unreasonable to ask that three facilities be chosen in a short time frame, and it can take some time to gather the required information.

The system should be modified to ensure that substitute decision makers and families involved in their relative's care be able to attend meetings or visit long-term care homes while recognizing that they also must work. Similarly, we have cases where hospital discharge staff claim not to be able to get in touch with substitute decision-makers who work during the day and cannot be reached by phone during the discharge staff's working hours. Family members and substitute decision-makers have been harassed because of their inability to attend during regular hours and have been made to feel that they are not caring properly for their loved one, despite visiting regularly in the evenings and/or on weekends.

Mrs. S is in hospital. Her SDM is a teacher, who has already taken off time prior to Mrs. S's admission to hospital. The SDM visits every evening and on weekends, but cannot attend during the day and is difficult to reach during school hours. The SDM is trying to see as many long-term care homes as possible, but it is difficult as most homes do not offer tours in the evenings and on weekends. The SDM is told that if they do not make themselves available during "business" hours, the Public Guardian and Trustee will make the placement decision for them.

In many cases, the substitute decision-maker has other care giving responsibilities, either for young children or for other older adults. A growing number of substitute decision-makers we deal with in our practice are members of the "sandwich generation": people caring for both parents in their eighties and nineties, as well as children and grandchildren. In order to make themselves available for long-term care home tours or care meetings, child care or respite arrangements must be made.

7.3 Faulty Assumption: Patients are all waiting for their "Preferred Facility"

The hospital discharge policies ACE has reviewed typically ask patients to apply to temporary homes until their "preferred home" has a bed available. In our experience, it is false to think that bed-flow problems are due to patients' intransigence in refusing to accept any bed other than their "preferred home".

Our clients understand that they cannot spend three years waiting in hospital until a bed comes available at their first choice home. In fact, most do not want to stay in the hospital. Our clients are always told that they must be realistic in

their choices, and that a hospital is not a good place for anyone to stay for a long time. However, they are also not willing to be admitted to a facility where their care needs cannot be met.

8. CONCLUSION

The ethics of transferring patients from hospital to long-term care is complex. The legal framework must be adhered to as part of the ethical dynamics. It must be recognized that the individuals who will be most affected are some of the most vulnerable in society. It is their rights which will be affected by any change in law or policy regarding placement.

We cannot allow a system in which hospitals have authority over placement of persons into long-term care. We must instead look for solutions which can meet the needs of all those concerned. To do otherwise is to ignore the value and worth of this vulnerable population.