Keeping care and family close to home

Telemedicine has made a huge difference for Malcolm Kienapple.
Brian Heaney was diagnosed with amyotrophic lateral sclerosis six years ago when he was just 41. Read about his life, research participation and care at LHSC.

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Who We Are

One of Canada’s largest acute care teaching hospitals, London Health Sciences Centre (LHSC) cares for the most critically ill patients in the region. Located in London, Ontario, Canada, LHSC encompasses:

• University Hospital
• Victoria Hospital
• Children’s Hospital
• Byron Family Medical Centre
• Victoria Family Medical Centre
• Kidney Care Centre (at Westmount Shopping Centre)

LHSC is the home of:

• CTSTAR (Canadian Surgical Technologies and Advanced Robotics)
• Fowler Kennedy Sport Medicine Clinic
• London Regional Cancer Program
• Children’s Health Research Institute
• Lawson Health Research Institute
• Children’s Health Foundation
• London Health Sciences Foundation

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PATIENT EXPERIENCES

Living with ALS

It began with his fingers, a gradual weakening in his hands. He noticed he had some difficulties handling his car keys.

A ctive and athletic, Brian Heaney thought he may have a pinched nerve. “I made an appointment for a physical,” says the Waterloo resident. “They ran a number of tests over a one month period, X-rays, MRI ectcets. Then I was sent to a neurologist.”

The neurologist ordered an electromyography (EMG) to check nerve pulses and determined that Brian may have amyotrophic lateral sclerosis (commonly known as ALS). That was in 2009 before the ice bucket challenge raised the public’s awareness about ALS, and Brian had no idea of the gravity of the diagnosis.

“My wife and I were completely in the dark and we didn’t really know what was happening,” says Brian. “There is unfortunately no specific test for ALS. As a consequence, when symptoms begin they can be quite mild and may be initially dismissed by the patient, or even the family doctor. When the symptoms evolve to be more noticeable, the initial symptoms may not be specific. For ALS and several potential diagnoses need to be considered,” says neuropathologist Dr. Christopher Shoemaker, Medical Director of the MND Clinic.

“Since I didn’t know how bad it was, I went back to work, looked it up there and I said an ALS patient has about two to three years to live. It was quite a shock. I told my wife that night after the kids were asleep. It was a hard day,” says Brian. “Sanners and I were devastated.”

Brian was then referred to the Motor Neuron Disease (MND) Clinic at London Health Sciences Centre. The official diagnosis was made after further testing and a nine-month monitoring period to watch his progression to determine the defensive diagnosis. Brian was 41 years old.

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skater Kurt Browning’s Ice Bucket Challenge at LHSC operating room scrubs as he accepted figure Canadian broadcaster Ron MacLean who sported (MND) Clinic. See video footage of the MND Clinic medical director of LHSC’s Motor Neuron Disease Sciences. Those who had the honour of dumping I station would not be accessible. It left them scrambling and says Tammie. get anywhere, go places and see people. You need to think a new fully accessible home. It has made a difference for them. says Tammie. running of errands, and when Brian stopped driving it had a saw the changes, such as doing less on the home front. What they hadn’t counted on was that the Yorkdale subway a trip to a Blue Jays game in Toronto in August seemed like "One of the biggest adjustments is the time it takes to speak, go places and see people. You need to think a new fully accessible home. It has made a difference for them. says Tammie. The family has daily help in the home. “For one or two hours a day I have a Personal Support Worker, because there is too much that I cannot do by myself,” says Brian. The family has daily help in the home. “For one or two hours a day I have a Personal Support Worker, because there is too much that I cannot do by myself,” says Brian.

LHSC’s MND team is one of the largest adult multi-disciplinary health-care teams in the country and the clinic has become an international referral centre, seeing Canadian patients from Manitoba to Newfoundland and others from as far as Europe and Asia. The team provides consultation, diagnosis, support and care advice to patients with a motor neuron disease, including amyotrophic lateral sclerosis (commonly known as ALS), primary lateral scleroses (PLS), spinal muscular atrophy (SMA) as well as other motor neuropathies. The MND Clinic was started in the 100% by Dr. Arthur Hadjistavrou and saw the first adult multi-disciplinary MND health-care team in Canada.

What is ALS and how is it diagnosed?

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. Gradual onset, progressive, muscle weakness is the most common initial symptom in ALS. Other early symptoms vary but can include tripping, dropping things, abnormal fatigue of the arms or legs, slurred speech, muscle cramps and twitches, and uncontrollable periods of laughing or crying. ALS is a difficult disease to diagnose. There is no one test or procedure to ultimately diagnose ALS. It is through a clinical examination and series of diagnostic tests, often ruling out other diseases that mimic ALS, that a diagnosis can be established. A comprehensive diagnostic workup includes some of the following procedures:

• A thorough neurological examination by a neurologist with expertise in ALS
• Blood and urine tests
• Spinal tap (lumbar puncture)
• Magnetic resonance imaging (MRI)

Although there is no cure or treatment for ALS, early identification and treatment can improve the patient’s quality of life. The MND Clinic was started in the 100% by Dr. Arthur Hadjistavrou and saw the first adult multi-disciplinary MND health-care team in Canada.

For anyone who has just been diagnosed with ALS, I would recommend living life to the fullest, especially in the first year or so when you still have muscles. You start losing abilities and what you can still do decreases with time.” – Brian Heaney

“The ALS clinic helps patients be as functional as they can be with their disease. The team advises the patients of potential modifications that may improve their safety, function, or quality of life.” – Dr. Christen Shoesmith

ONLINE EXCLUSIVE

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Motor Neuron Disease Clinic

Brian Heaney created the Heaney’s Heroes team and invites family and friends to join him at the Walk for ALS to raise money for support services and research. This year Brian and his wife Tammy had over 100 people, their largest team ever. Heaney’s Heroes has raised between $20,000-$50,000 in each of the past five years. Brian Heaney created the Heaney’s Heroes team and invites family and friends to join him at the Walk for ALS to raise money for support services and research. This year Brian and his wife Tammy had over 100 people, their largest team ever. Heaney’s Heroes has raised between $20,000-$50,000 in each of the past five years.

Brian Heaney

In the early years of his diagnosis Brian was still going in to work every day. Then, as his reliance on a walker and then a wheelchair increased, he cut back his time at the office and now works from home as a computer analyst. The impact of ALS is personal, private and stands to every member of the family when a loved one is diagnosed with the disease. And this is certainly true for Brian, husband of Tammy and father of Mollie, 16, Emma, 14, and Megan, 12. The Heaneys told their daughter about ALS when Brian was first diagnosed, but says it didn’t really sink in until they saw the changes, such as doing less on the home front. “We could no longer split the household chores and the running of errands, and when Brian stopped driving it had a big impact because we have three active daughters in sports,” says Tammy. About those ages when main became increasingly difficult, the family moved from their mid-rise condo into a new fully accessible home. It has made a difference for them. “One of the biggest adjustments is the time it takes to speak, go places and see people. You need to think a new fully accessible home. It has made a difference for them. says Tammie. Brain and Tammy come to Canada every four to six months, and Brian has a five-hour period of appointments at the ALS clinic. “The MND team says that my ALS journey has been longer than most allowing me to have had the chance to enjoy my family,” says Brian. Brian created the Heaney’s Heroes team and invites family and friends to join him at the Walk for ALS to raise money for support services and research. The team advises the patients of potential modifications that may improve their safety, function, or quality of life.” – Dr. Christen Shoesmith

Brian Heaney and occupational therapist Lewia lost modified scissors which can make eating easier as the patient’s range of motion in the hands or fingers changes.
Keeping care and family close to home

Eleven hours, 1,086 km and hundreds of dollars. That is how much the Kienapple family saves each time they participate in a telemedicine appointment with Dr. Guido Filler, paediatric nephrologist and Chief of Paediatrics at London Health Sciences Centre.

Robert and Dominique Kienapple and their children Malcolm, Bronte and Parker live in Sturgeon Falls, located between North Bay and Sudbury in Northern Ontario. Their son Malcolm, 7, was diagnosed with nephrotic syndrome at 20 months.

Nephrotic syndrome is a kidney disorder that causes the body to excrete too much protein in the urine, while the protein is in the blood. It typically presents itself through unusual swelling in the feet and ankles. Dominique noticed Malcolm had swollen weight gain, beyond what would be considered typical for a healthy growth spurt.

“We had bought a pair of shoes for Malcolm and found two days later he could no longer fit into them,” says Dominique. Nephrotic syndrome is caused by changes to the filters in the kidneys that normally prevent proteins from the blood to enter the urine. Often this condition causes a serious form that requires stronger and possibly life-long treatment.

“However, the thought of not having to travel to London three or four times a year would bring for the family an average of savings over 1,000 km with young children, childcare for Malcolm’s siblings, the concern about road safety especially in the winter months, and the overall impact of being away from home,” says Robert.

That is not to say all of Malcolm’s appointments are through telemedicine. The Kienapple family has made three trips to London since the initial visit in 2010, however they also have the benefit of three to four OTN appointments a year.

“We have found very few disadvantages to telemedicine. The main one is the pre-determined duration of the appointment. Although we were advised that the appointment was 30 minutes, we saw a little longer during our first visit when the call cut out while we were in mid-sentence,” says Robert.

What is telemedicine and how does it work?

Telemedicine is the use of technology to electronically exchange medical information and provide medical services to patients at a distance, a location. It is conducted through videoconferencing between the patient and the health-care provider. For example, once or twice a month Dr. Filler holds a half-day telemedicine clinic in Windsor with up to seven patients.

The patients are booked back-to-back with a preparation for their time with the specialist.

For example, once or twice a month Dr. Filler holds a first telemedicine appointment with Dr. Filler was held at an appointed hand at the start of the telemedicine appointment. Dominique admits they were a bit uncertain about how telemedicine would work and whether the level of care would be comparable to seeing the doctor in person.

“However, the thought of not having to travel to London again for a little while was welcoming since we were expecting our second child in less than a month,” she says.

The first telemedicine appointment with Dr. Filler was held at his appointment’s office in Sudbury.

“We were immediately very pleased with the quality of the picture, sound and ease at which we could communicate, and our suspicions quickly turned to relief as we realized the benefit that this technology would bring to our family,” says Robert.

Most telemedicine stations also have a small portable camera to check for fine hair growth, which is a side effect of one of the medications.

“Sometimes these tools allow for a more detailed assessment when comparing to the tools in a clinic,” says Dr. Filler.

What does this mean for the Kienapple family?

For Malcolm, this reduces the number of hospital visits and he is able to spend more time enjoying just being a seven year old.” – Robert Kienapple

Keeping care and family close to home

As a parent, the comfort of knowing that we can have regular visits and our son can get excellent care right where we live eliminates a great deal of our worry and stress about his well-being. For Malcolm, this number the reduce of hospital visits and he is able to spend more time enjoying just being a seven year old.” – Robert Kienapple

The first few years after diagnosis, the family would drive to Sudbury for the telemedicine appointments, and Malcolm’s nephrotic syndrome would into.

“The paediatrician would be in the room and could speak with Dr. Filler if she had any questions,” says Robert. “It was a huge benefit for all of us, there is a definite advantage with everyone on the same page.”

Malcolm Kienapple, right, with his dad Robert, mom Dominique, and siblings Bronte and Parker, enjoys a sunny autumn day at home on the porch in Sturgeon Falls. Telemedicine clinics with LHSC paediatric nephrologist Dr. Guido Filler save the family significant travel, costs and time off work.

New Malcolm’s clinic visits are held at the Local Health Integration Network (LHIN) facility, which is two blocks from home and two blocks from work, so everyone in the family can attend the appointments. Indeed, Sturgeon Falls now has three OTN clinics.

“The trip to London is a challenge for us for several reasons – the loss of work time, the reality of driving over 3,000 km with young children, childcare for Malcolm’s younger siblings, the concern about road safety especially in the winter months, and the overall impact of being away from home,” says Robert.

To keep Malcolm’s clinic visits held at the LHSC, the family would have to travel to London three or four times a year. This would bring for the family an average of savings over 1,000 km with young children, childcare for Malcolm’s siblings, the concern about road safety especially in the winter months, and the overall impact of being away from home,” says Robert.

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Keep care and family close to home

For Malcolm’s appointments, a nurse in Sturgeon Falls first completes point-of-care testing such as blood pressure, weight and physical as necessary, and has this information at hand at the start of the telemedicine appointment. Dominique admits they were a bit uncertain about how telemedicine would work and whether the level of care would be comparable to seeing the doctor in person.

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Booming demographic: Caring for the growing population of older adults

Interviews with three health-care professionals

Like many countries around the globe, Canada has an aging population with more Canadians living longer. The first wave of baby boomers turned 65 in 2011, representing about 15 per cent of the population. When the last of the baby boomers reach 65 by 2031 they’ll make up close to 25 per cent of Canadians. Putting that into numbers, Canada has an aging population with more than 5 million older adults in 2011, representing about 15 per cent of the population. When the last of the baby boomers reach 65 by 2031 they’ll make up close to 25 per cent of Canadians. Putting that into numbers, Canada has an aging population with more than 5 million to more than 10 million.

One of the most pressing imperatives of our time is the growing health-care needs of Canada’s older adults. With the rising demographic of older adults there is an ever-increasing need for care both in the community and in health-care facilities. The demand for home care and for long-term care will increase. Seniors need access to coordinated, integrated, and affordable care. So what does this mean to acute care hospitals such as London Health Sciences Centre? How are hospitals preparing for the aging of Canada’s older adults? The rising demographic of older adults is an important component of hospital care. One of the key challenges facing acute care hospitals such as LHSC is the inability to discharge patients who no longer need acute care in a timely manner. Often this is because the required next level of care is not available at that time. So the impact to patients who need an alternative level of care is significant. For hospitals this also impacts our ability to admit patients in need of acute care.

What are the challenges facing hospitals with the growing demographic of seniors?

A The reality for older patients who no longer need acute care is that while they are more often served outside the hospital setting, the longer older adults stay in hospital, the more vulnerable they become to hospital acquired infections due to a weakened immune system, to depression and delirium, and to issues related to reduced mobility such as falls while in hospital.

One of the biggest challenges facing acute care hospitals such as LHSC is the inability to discharge patients who no longer need acute care in a timely manner. Often this is because the required next level of care is not available at that time. So the impact to patients who need an alternative level of care is significant. For hospitals this also impacts our ability to admit patients in need of acute care.

What systems issues are emerging?

A In addition to what I’ve mentioned above, there are gaps in a community-based care such as long-term care for example, which also impact hospitals. Such is the case for older adults with dementia who have severe behavioral issues. Long-term care homes do not always have the appropriate level of staffing to care for these adults and so they are referred to hospital where they will experience long waits until an appropriate level of care is available in the community.

While the patients do not have acute care needs, there is not enough capacity in the current health system to care for them. Whereas the patient, despite behavioral issues, would benefit from the long-term care environment because of the recreational and social aspects of the care provided.

In acute care we want to ensure that patients are safe and are receiving the right care, in the right setting. This means that LHSC works proactively to identify patients at risk for falls, or those who may need alternative levels of care. LHSC has a number of programs in the emergency department for these patients and works with community providers such as home care to prevent an admission to the hospital. This does not occur with every patient and more could be done from a systems perspective to ensure that patients receive the best care in the right setting, at the right time.

What challenges are emerging in acute care hospitals as the populations of seniors change?

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There are a number of challenges to providing care to older adults. Aging adults don’t necessarily bounce back quickly after treatment of acute illness and take longer to recover. The hospital environment is meant for managing acute illness, and is ill-equipped to manage the longer recovery phase of an illness.

Older people are very sensitive to the adverse effects of being in bed. They may have poor mobility to start with and losing it for any extended period of time can cause even more detrimental to their health. Other disabilities are also present that can make the hospital environment challenging. For example, communication can be difficult because of hearing impairment, and visual impairment can result in disorientation and an inability to manoeuvre within the environment.

Cognitive problems become increasingly prevalent with aging, and this can make the hospital environment particularly difficult.

Even without these factors, older people may have certain routines that are different from expectations in hospital. For example, the hospital environment may tax the patient’s autonomy while they walk in order to prevent a fall. However, the patient has traditionally been comfortable walking in their own home and does place as much importance on having autonomy for walking. Alternatively, for a patient who has already struggled with walking and perhaps has fallen at home, the fear of falling may result in a reluctance to walk.

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With more people living longer, are you seeing any changes in how patients are aging?

As I provide care in an acute care hospital, the patients I see are very ill; as such, I may have a biased view of seniors. People are living longer and this is accompanied by increasing co-morbidity, which is another way of saying that there are more likely to have more than one disease at the same time. This is evident in the hospital environment, where multiple illnesses are more often the norm. In addition, geriatric syndromes such as immobility, confusion, pressure sores and functional decline, are becoming increasingly prevalent as people live longer.

What are the greatest changes in the care requirements for older patients in an acute care setting?

Older adults may have certain routines which can help guide them when they are in their home setting. The acute care setting disrupts these routines. Whether a visually-impaired older adult or one with cognitive impairment can adapt to their own familiar home environment, this becomes increasingly difficult in the acute care setting. The acute care setting in many ways becomes more overwhelming to others.

Patients who struggle in their own home come to depend on the extra assistance provided in hospital. In addition, older patients do have an increased risk of losing their functional abilities — for example, walking or falling difficulties leading to potential injury. In fact, hospitalization is one of the biggest risk factors for losing functional abilities in seniors who live in their own homes.

What is the single most important change we can make?

Thinking about the functional and psychological needs from the moment patients are admitted, and thinking about how to optimize those aspects of health from the beginning may be beneficial. Long after the acute medical condition is round, the hospitalized senior may still not be able to return home, and this may reflect the non-medical aspects of care. Therefore there should be greater focus on those aspects of health.

What are some of the best programs/initiatives for older patients here at LHSC?

There are several. I will mention a few of them. The MOVE-ON initiative, being done on several inpatient units, is about keeping elderly patients moving in order to maintain their mobility so that they can be as independent as possible at discharge. Initiatives for delirium are in place on several inpatient units to optimize assessment and management of delirium.

A Geriatric Emergency Medicine (GEM) nurse in the Emergency Department (ED) follows up on those older people identified as high risk for admission to hospital, admission to nursing home, or re-admission to the ED.

The Geriatric Consult-Liaison team (geriatricians, psychiatrists, nurses, psychologists and medical students) make recommendations on geriatric medical and psychiatric issues of inpatients when requested by the attending physician.

The Geriatric Mental Health Program has two teams for the elderly— the Mental Health Team provides care in a clinic or at home for people with mental health issues and the Behavioural Response Team provides crisis intervention to families and long-term care facilities to manage behavioural problems. Two programs are being designed to help with family issues and helping older patients to recover.

What can we do to prepare for the increasing number of older adults in an acute care hospital setting?

From my perspective, we need to build on all the excellent elderly care initiatives that are already occurring at LHSC to create and implement an interprofessional, educationally, comprehensive and sustainable corporate strategic plan to ensure that LHSC is an elderly-friendly hospital for elderly patients, caregivers, their families and visitors.

I believe that the creation of an interprofessional team of people with geriatric expertise at LHSC is important to develop and implement sustainable programs to consistently enhance elderly care with a focus on both prevention and intervention strategies for common geriatric issues.

Hospital and community health-care providers need to encourage older adults and their significant others to discuss their wishes about future health and personal care choices (Advance Care Planning). These discussions will greatly help prepare for and guide decision-making when the older person is not able to make decisions about health or personal care.
There is a popular misconception that eating gluten-free is the latest diet. However, for people with celiac disease, eating gluten-free is not an option—it’s a necessity to live normal, healthy lives.

When Theresa Misek was diagnosed with celiac disease in April 2014, she was surprised. She describes it as an incidental diagnosis. Her son Luke had been diagnosed two months earlier. Luke, who was four-and-a-half at the time, had shown the classic symptoms of celiac disease: losing weight, lack of energy, diarrhoea, and not thriving. After blood tests showed the possibility of celiac disease, Luke’s family physician referred him to LHSC paediatric gastroenterologist Dr. Kevin Bax for further testing. Following Luke’s diagnosis, the entire family was tested because celiac disease can run in families, and that is when Theresa learned she had it as well. She then referred to LHSC gastroenterologist Dr. James Gregor.

“While Luke had all the classic symptoms, I didn’t notice that there was anything wrong with me,” says Theresa. “Dr. Gregor explained, ‘We need to look for it in patients with chronic diarrhoea, but we also need to look for unexplained anaemia, osteoporosis, particularly in younger women, and autoimmune diseases such as Type 1 diabetes.’”

Celiac disease can be triggered by stresses such as pregnancy, stress, or trauma, and Theresa was pregnant when she was diagnosed. While the disease is not that common—the overall prevalence is 1%—some can also occur in other diseases more common than celiac disease.
Research uncovers molecule pivotal in making ovarian cancer cells so lethal

Thousands of women are living with ovarian cancer across North America. It is estimated that this year alone, 2,800 Canadian women will be newly diagnosed with the disease. And even though ovarian cancer continues to be one of the most serious women’s cancers, there is a lack of reliable early detection tests and few treatment options.

Lawson Health Research Institute’s Dr. Trevor Shepherd is a research scientist at the Cancer Research Laboratory at LHSC. He has spent the last few years hoping for improved treatments.

The silent killer
Ovarian cancer, often called “The Silent Killer”, is one of the most deadly cancers in women. According to the Canadian Cancer Society, only 20-30 per cent of women diagnosed with late-stage ovarian cancer are alive five years later. Think of it this way: if there are 10 women with ovarian cancer in a room, only two or three of them will be alive in five years.

Why? There are no good routine screening tests for early or late detection of ovarian cancer. Furthermore, it is usually found at a very advanced stage because there are few symptoms that draw a woman’s attention to the fact that something is wrong. By the time the diagnosis is made, the majority of women already have extensive spread of the disease which makes it difficult to treat by surgery or chemotherapy. According to Dr. Shepherd, what is even more concerning is that ovarian cancer shows little survival and may not be detectable with chemotherapy.

“T o get to metastatic cancer – cancer that has spread from one location to another – cells go through a lot of changes,” says Dr. Shepherd. “They can change as the disease progresses from its early to late stages.”

Recently, Dr. Shepherd’s lab discovered that the spheroids that are created on a surface could change their metabolism, promote tumour cell proliferation and form metastatic tumours.

“The only way to detect cancer cells is if they form spheroids,” says Dr. Shepherd. “What we have here is a huge opportunity to develop a therapeutic treatment that targets LKB1,” says Dr. Shepherd.

“Blocking these molecules could potentially kill ovarian cancer cells.”

By relating the previous studies, Dr. Shepherd has uncovered a new target for future therapy.

What’s next?
Currently, Dr. Shepherd’s team is focused on further understanding the role of LKB1 in ovarian cancer. The team is also forming a collaboration with the Lawson Tissue Centre, Research Institute at Mount Sinai Hospital in Toronto that will speed identification of chemicals that effectively target LKB1.

“We need to move on this quickly,” Dr. Shepherd says. His hope is to find a targeted therapeutic that can be utilized in conjunction with chemotherapy to form a multipronged approach for improved treatment of ovarian cancer.

Lawson Health Research Institute is the research arm of London Health Sciences Centre and St. Joseph’s Health Care London, and one of 10 Pan-Canadian Cancer Research Institutes in Canada.

His latest findings bring new hope for improved treatments. His hope is to find a targeted therapeutic that can be utilized in conjunction with chemotherapy to form a multipronged approach for improved treatment of ovarian cancer.

Lawson Health Research Institute is the research arm of London Health Sciences Centre and St. Joseph’s Health Care London, and one of 10 Pan-Canadian Cancer Research Institutes in Canada.
I have an appointment in Zone E at Victoria Hospital and have trouble walking. What is the easiest way to get to the main entrance of Zone E at Victoria Hospital?

Zone E at Victoria Hospital is home to many of our outpatient clinics. A common sight in Zone E is a patient and family member having difficulties making their way from the visitor parking lot over to one of the Zone E entrances. It can be quite a trek, especially if you have problems walking, are using a wheelchair or assistive device, or are facing the snow in winter.

We encourage anyone who has trouble walking to use the drop off circle at the main entrance of Zone E where visitors can stop for a few minutes and take advantage of the easy and quick access to the main entrance. Inside the doors of the main entrance there are wheelchairs, as well as an information desk with a volunteer who can help you find your way. There is also a place for your loved one to wait for you while you park your car.

Clip out this map and keep it handy next time you visit Zone E at Victoria Hospital.

How to read your room number
Victoria Hospital and University Hospital room numbers are in the following format:

Zone Floor Room
E 2-503