Sunnybrook

SAVING LIVES, ONE INNOVATION AT A TIME

MINIMALLY INVASIVE APPROACH FOR GYNAECOLOGIC SURGERY GAINS MOMENTUM

HOW SUNNYBROOK TURNS BRIGHT IDEAS INTO MEDICAL INVENTIONS

THE ODETTE CANCER CENTRE LEADS THE WAY IN TREATMENT OF NEUROENDOCRINE TUMOURS

A unique Sunnybrook clinic is making motherhood more accessible

Dalia's story

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Sunnybrook

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PHOTOGRAPHY BY KEVIN VAN PASSEN

We are SUNNYBROOK

Handling with care

Odilia Serodeo is on a mission. "I come to work and try to help people," she says. As a porter in patient transport, Odilia takes pride in getting people to various medical appointments gently, yet efficiently. "I treat patients the way I would like to be treated – with respect and kindness," she says.

Odilia has grown to love her "second family," as she calls them – the doctors, nurses and her fellow porters. But she admits that her first day at Sunnybrook, in 2006, as a part-time porter, was daunting. "I had worked in a hospital in the Azores, where I came from, but it wasn't very big. Sunnybrook is huge and there are so many patients with such different experiences and traumas who needed help."

Two weeks of on-site training gave Odilia the confidence she felt she needed, and a year later, she was hired to work full-time. What she likes best about the job is that no two days are the same. Her pager will ring and a nurse will direct her to pick up a patient, then let her know where the patient needs to be dropped off, which can be for anything from an ultrasound to surgery. Depending on what the patient needs done, Odilia shows up with a gurney or a wheelchair and transports the patient to the next appointment.

The opening of Sunnybrook's Women & Babies program in 2010 was a career highlight for Odilia. She helped move babies from the neonatal intensive care unit at the program's old downtown location to the new facility at Sunnybrook's Bayview campus. "It was so exciting to see all [those babies] here," she recalls. "Everybody was so happy!"

On the job at Sunnybrook for 11 years now, Odilia remains committed and passionate about her role. "Without porters, patients can't go anywhere. There are no words for how good it feels to know I help them."

– Maureen Littlejohn

Responding to the needs of seniors

To Deborah Brown, a good day means spending time with her 19-year-old son or enjoying a motorcycle ride. "It's surprising to me how incredibly calm I am when riding. It clears the mind."

At work she also likes to keep things moving – teaching, conducting research and improving the lives of patients at Sunnybrook.

"A perfect day is when I go to the units and staff talk to me about an aspect of senior-friendly care, or learning that I've made someone's life better," says Deborah, who is a nurse practitioner.

Earlier this year, she received an honourable mention in the Toronto Star 2017 Nightingale Awards, in recognition of her leadership in advancing senior-friendly care.

The definition of "senior-friendly" is clear to Deborah. "[It] means being responsive to the unique needs of the senior population, in our values and beliefs [at Sunnybrook] as an organization, the way we deliver care, conduct research and design our physical spaces. It involves all those things."

Alongside Sunnybrook's senior-friendly team, she leads a program that seeks to recognize, prevent and manage delirium in older people. Delirium, a state of acute confusion experienced by many in hospital, can have serious adverse consequences. She is working to minimize the use of anti-psychotic drugs while helping patients recover from delirium.

Deborah has also brought in new ideas to enhance care for seniors, like a noise-monitoring device to help patients sleep better.

Innovation and commitment are important elements of her work, says Deborah. "If you want to make a difference and significantly impact health care, Sunnybrook is the place for you."

– Nadia Radovini

Patients helping patients

From tragedy comes purpose. Following the suicide of her son, Kit, in 2013, Lesley Skelly and her husband became advocates for mental health, giving a series of media interviews to de-stigmatize schizophrenia, the disease that had taken their son. Immensely grateful for the care Kit had received at Sunnybrook, Lesley also joined the Patient & Family Advisory Council (PFAC) of the Department of Psychiatry "to give back and improve the [patient and family] experience for others."

PFAC consists of patients, family members and staff who provide ideas and recommendations to help ensure that the patient's and family's points of view are integrated into service and quality-improvement projects throughout the Sunnybrook psychiatry program.

The advisory group was instrumental in launching a peer support program, so patients can share their experiences with former patients. Diagnosed in his second year of university at the age of 19, Kit struggled for four years with paranoia, delusions and hearing voices. He was in and out of hospital and on and off his meds, living at home when stable and then on the street and in shelters when not, eventually staying with his older brother. Lesley feels that peer support is an important addition and would have made Kit feel less isolated.

PFAC has also published a brochure about what to expect when patients are admitted. In May, the advisory group organized a community open house with four breakout sessions featuring panel discussions with psychiatrists, support staff and people with lived experience. "It was an amazing night with 200 people in attendance," Lesley remarks.

She is enthusiastic too about the soon-to-be-launched parent support group. "That first time Kit was admitted to Sunnybrook was the scariest thing and we felt totally alone," she says. "For other parents, being able to share, to talk to others in the same boat will be huge."

– Iain Newbigin

Long-distance impact

"It's easy to lose sight of how blessed we are, how well we've been trained as practitioners in Canada, and the integrity we carry with us as Canadians," says Mark Cameron, a paramedic and advanced life support educator at Sunnybrook.

Raised in rural Ontario, Mark says it was the farming community that taught him the essential health-care values of accountability, interdependence and collaboration.

"As a fellow farmer, you're going to need your neighbours at some point and they're going to need you," he says. "You need to be able to trust them at their word because if you can't, you don't survive."

But to Mark, the term "neighbour" has nothing to do with proximity.

For years, he was a critical-care flight paramedic who travelled internationally to bring home injured vacationers. Today, as one of the original advanced-care paramedics trained through Sunnybrook, Mark trains paramedics and other health-care providers from around the world. He is also the co-founder of a growing humanitarian organization that provides medical education and relief for global disaster zones like Syria and Guyana.

He has received two honours from Queen Elizabeth II thus far – a Medal of Bravery and a Meritorious Service Medal. Humbled, Mark says both were simply for answering the call of duty.

"I took an oath. All health-care providers are my colleagues. No matter what country they work in, we are a team. And anyone in need is our patient."

– Katherine Nazimek

PHOTOGRAPHY BY DOUG NICHOLSON

PHOTOGRAPHY BY KEVIN VAN PAASSEN (PEARL ZAKI) . DOUG NICHOLSON (FATIMA BRUNNING)

Learning on the job

University of Waterloo student Pearl Zaki knew she was in for an enriching experience when she joined Dr. Edward Chow's team at Sunnybrook's Odette Cancer Centre for a co-op term.

Over the past decade, every Waterloo co-op student who has worked for Dr. Chow, a radiation oncologist, has gone on to win the university's Co-op Student of the Year Award. Pearl, a health studies undergraduate student in the Faculty of Applied Health Sciences, kept the tradition going: she too received the honour this year.

"Being immersed in a clinical environment was eye-opening and humbling," Pearl says. "There was a steep learning curve, but working with Dr. Chow, his staff and patients in the Rapid Radiotherapy Response Program really extended my health education beyond the classroom."

Pearl spent her co-op term collecting data, coordinating clinical trials and conducting research projects within the program, which provides palliative radiotherapy to relieve symptoms in patients with advanced cancer.

What she didn't anticipate was the profound and lasting impact that working with terminally ill patients would have on her. Some patients came in several times a week and, by the end of her co-op term, Pearl had developed close friendships with five of them.

Within two weeks of her return to school, she received messages that all five of those patients had passed away. "It's a reality you have to accept, but at the same time, you have to maintain your sensitivity. It's one of the biggest challenges of working in medicine," Pearl says, whose ultimate goal is to attend medical school.

– Sybil Millar

Serving war vets

Fatima Brunning, a registered practical nurse (RPN) at Sunnybrook's Veterans Centre, not only cares for elderly war veterans but is also, as a member of the Canadian Forces Reserve, helping to build a committed, responsible young generation through Canada's Cadet Program, which is geared to youth from age 12 to 18.

In 1973, Fatima and her family moved to Canada from Portugal. Several years later, she discovered a love for nursing at Central Technical High School and graduated with a certificate from the Registered Practical Nursing program (back in the '80s and '90s this course was offered at the high-school level).

"What I love about Sunnybrook is that it's a teaching hospital. I'm a preceptor [instructor] and I usually take on at least one student a year," says Fatima. "Not only do they learn during their clinical placement, but I also learn from them and that makes me a better nurse."

Fatima continues to nurture her other interest – being involved with the military. In 2004, she was sworn in as a Reserve Officer with the Cadet Instructors Cadre (CIC). Currently, she is a Supply Officer and her main role is in logistics. Fatima is a First Aid Officer, as well as a marksmanship coach and canoe instructor.

And as for her career at Sunnybrook, Fatima has spent 15 years to date, working at the Veterans Centre – Canada's largest care facility for war veterans – where she helps to take care of Second World War and Korean War veterans. The average age of the residents is 94, and each of them requires advanced nursing skills and expertise in providing reassurance and support.

November 11 is a special day at the Veterans Centre. Fatima will arrive at 6:00 a.m. sharp to wake the residents in her unit and get them ready in their blazers and medals for Remembrance Day. "I'm proud to be able to serve our veterans," says Fatima. "Everyone has a story to tell. [Working here] is both an enriching and a rewarding experience."

– Sally Fur

Q&A WITH DR. ANDREW SMITH

ON SPORTS, LITERATURE AND SURGERY OF THE FUTURE

On July 1, 2017, Sunnybrook welcomed Dr. Andrew (Andy) Smith as the hospital's new President and CEO. Andy most recently served as the hospital's Executive Vice President and Chief Medical Executive. Previously, he held numerous leadership roles within the hospital and at the University of Toronto, including Head of the Division of General Surgery at Sunnybrook, Chair of the Division of General Surgery at the University of Toronto, Chief of the Odette Cancer Program and Regional Vice President for Cancer Care Ontario.

We sat down with Andy to ask him some questions that would reveal the person behind the title of President and CEO.

Which living person do you most admire?
I think there is a lot that can be learned from team sports, so I really admire some of the great Canadian hockey players, like Wayne Gretzky and Sidney Crosby. Although very skilled individually, they exude great pride in the ways they elevate and acknowledge their teams.

Which words or phrases do you most overuse?
Sports metaphors, like "pass the puck" and "health care is a team sport."

What or who is the greatest love of your life?
My family, especially my wife and kids. They provide me with constant and immediate perspective as to why we do what we do in health care. I also love the city of Toronto and all that it has become and the great future ahead of it.

Which talent would you most like to have?
To be able to play the piano.

What do you consider your greatest achievement?
Balancing (at least trying to!) a great career in health care with being a great father and husband.

What is your most treasured possession?
Hard-copy photographs with dates recorded on the back to mark moments and memories. I have a great picture in my office of my wife and me in the operating room. It was taken on the day we met in 1993 by my senior resident at the time.

What is your most distinctive characteristic?
Enthusiasm and optimism!

What do you most value in your friends?
The fact that, even after time apart, we are able to pick up right where we left off. I value exuberance and a buoyant spirit.

Who are your favourite writers?
I read a lot of Charles Dickens's work when I was young – books like *Oliver Twist* and *Great Expectations*. My mother is English and she used to draw connections to some of the characters in those books a fair amount, as I recall.

Who is your favourite fictional hero?
Captain James T. Kirk from Star Trek. He is a really smooth heroic figure – and a great team player!

Which historical figure do you most identify with?
I don't identify [with him] per se, but I read and know a lot about Winston Churchill. I am especially fascinated by the events of the spring of 1940. I am generally interested in historical political leaders, including Abraham Lincoln and Theodore Roosevelt.

What is it that you most dislike?
Wasting time at either work or play. We are only given so many hours in a day and I believe in maximizing those 24 hours.

What is your greatest regret?
Had I got orthotics for my running shoes, it might have spared me the major ankle surgery I had in 2012. It stopped me from running. Nonetheless, I am able to walk a lot and really enjoy that activity.

Thoughts on your new position and what you envision for Sunnybrook's future?
Sunnybrook is in a terrific position for future success. We're building on a solid foundation that we've created over the past few years and we're achieving our vision, which is inventing the future of health care. We're doing this today. It's not science fiction. With the help of our generous community and support from government, our teams are revolutionizing care and it's my job to continue to make that happen.

We are changing how care is delivered. I am a surgeon by training, and in the not-too-distant future, we won't be making incisions in patients anymore. We'll be using ultrasound and other technology to provide cures that were considered impossible not long ago. We have our challenges like any hospital, but we're overcoming them with an incredible team. I'm excited to be in this role and to be at the helm of something great.

What is your motto?
Give it 100 per cent, whatever you do. Be "all in"!

– Laura Bristow

PHOTOGRAPH BY KEVIN VAN PAASSEN

VIDEO zone

Sunnybrook has a growing library of over 1,000 online videos featuring powerful patient stories, innovative medical technology, health tips and more. And the stats show the community is watching!

6.2 million
Number of times Sunnybrook's online videos have been viewed

17 years, 321 days
Total time people have spent watching Sunnybrook's online videos

Top 3 most-watched Sunnybrook videos to date*

Tummy time instructions for your baby
1,147,200 views

Nurses sing Christmas song to preemie baby
406,000 views

Sunnybrook staff sings "Courage" for Gord Downie
384,800 views

*As of May 2017

– Sivan Keren Young

LAUGHING GAS: BEYOND THE DENTAL CHAIR

Nitrous oxide – an inhaled anesthetic known as laughing gas or N_2O, and most commonly associated with a visit to the dentist – may potentially provide relief for bipolar depression.

A clinical trial is underway to compare the immediate effects of laughing gas with those of another anesthetic medication, midazolam, on depression symptoms and on the blood flow in the brain of individuals with treatment-resistant bipolar depression. Researchers hope it will not only ease the depressive symptoms but also offer clues to the role of blood-flow problems in bipolar depression.

Participants 20 to 60 years old with treatment-resistant bipolar depression are randomized to undergo a neuroimaging session that includes either 20 minutes of inhaled N_2O plus an intravenous saline solution or 20 minutes of inhaled room air plus an intravenous of midazolam.

MRI scans will capture the blood-flow changes and brain activity prior to, during and after the administration of the two treatments.

"We predict that N_2O will improve blood flow in the brain, and that this improvement will be associated with temporary improvement of their depressive symptoms," says Dr. Benjamin Goldstein, principal investigator of the trial and director of the Centre for Youth Bipolar Disorder at Sunnybrook.

"If proven effective, N_2O has the potential to become a game-changing treatment for bipolar depression because it's generally well tolerated, safe, low in cost, accessible and easy to administer."

– Nadia Radovini

HANGING UP THE KEYS

Getting a driver's license is a rite of passage on the road to adulthood. For a growing population of older drivers with mild dementia and their families, the question is, When is it time to hang up the keys?

"This is one of the most challenging and emotion-laden decisions with which older drivers with dementia, their family caregivers, health professionals, policy-makers and licensing authorities struggle," says Dr. Mark Rapoport, a geriatric psychiatrist at Sunnybrook.

While driving is clearly a danger for people with moderate or severe dementia, some with mild dementia can continue to drive safely for a period of time. But it's not just about getting from A to B. No longer being able to drive can have significant effects on the health and quality of life of these seniors and their families, including loss of independence and lifestyle, lower activity levels, social isolation, loss of self-esteem, depression and an increased burden on family caregivers.

A team of researchers at Sunnybrook, Baycrest and the University of Toronto are working on developing an intervention program to support older drivers and their caregivers in deciding when it's prudent to give up the driver's seat, and how to manage their emotional and transportation needs afterwards. The researchers reviewed existing findings to identify effective approaches to help older adults, both with and without dementia, on their journey to "driving cessation" and "post-cessation."

The existing research was limited, with only three studies with control groups that described interventions – all delivered in a group setting to support older adults through the transition.

One used a coping group for drivers with dementia who had lost their driving privileges, compared with a traditional dementia support group. A second used an educational approach for the caregivers of drivers with dementia. And the third tried an education and support group for older drivers, not specifically selected for dementia, who had either stopped or were planning to stop driving.

While benefits included reduced symptoms of depression, more trips out of the house, greater likelihood of discussion between the caregiver and the former driver, and better handling of the process, the research team found that specific outcomes and their extent varied across the three studies.

This literature review will help shape the program content and how it's delivered. Pilot tests will then evaluate the intervention. Does it improve the perceived sense of control and satisfaction about deciding when to give up driving, both for older adults with mild dementia and for their caregivers? Does it increase trips out of the house, social participation, mood and quality of life while reducing depressive symptoms for ex-drivers and their caregivers? In other words, is the intervention road-worthy?

– Nadia Radovini

Older drivers are the fastest-growing segment of the driving population and will make up one in four drivers by 2030.

(NHTSA 2012; Turcotte, 2012)

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The number of drivers with dementia is dramatically increasing, with a predicted estimate of close to 100,000 drivers with dementia by 2030 in Ontario alone.

—

Drivers with dementia have a two to three times higher risk of crashes, many of which result in injury or death.

BENEFICIAL BARCODES

Being admitted to hospital goes hand in hand with a lot of testing, such as blood work. Ten per cent of admitted patients may also receive a blood product.

To make this process as safe as possible for patients, Sunnybrook is expanding its use of innovative technologies to make sure those tests and transfusions are done more accurately than ever before.

A new barcode system is being implemented across the hospital. Where the system has already been introduced, patients are issued a barcoded wristband that, when scanned, provides the patient's information and a unique patient identifier. This allows staff to confirm the patient's identity and label at the bedside, track collection in real time and, where applicable, ensure that the correct blood product is transfused.

Two technologies – one for specimen collection and another for blood transfusion – use this barcode system, called electronic Positive Patient Identification (ePPID). The approach makes patient and specimen misidentification almost impossible. To date, over 75,000 samples have already been collected using this new technology, and not a single mislabelled sample has been received in the lab.

Sunnybrook's operating room is the latest department to use the system. The plan is to roll out this new technology to all other areas of the hospital and expand the scope to other treatments in the future, such as medication administration.

– Monica Matys

PHOTOGRAPH BY KEVIN VAN PAASSEN (BARCODES)

NEW TEST FOR PENICILLIN ALLERGIES

One in 10 Canadians report having an allergy to penicillin. But it turns out that the vast majority of people who think they can't tolerate this important class of antibiotics actually can.

"These allergies are often misclassified or go away over time," says Dr. Jerome Leis, Medical Director of Infection Prevention and Control. "Patients who could benefit from a penicillin antibiotic for their infections have better outcomes if they can receive it safely rather than using less effective alternatives that have more side effects. Penicillins are associated with a lower risk of antibiotic resistance compared with broader-spectrum antibiotics."

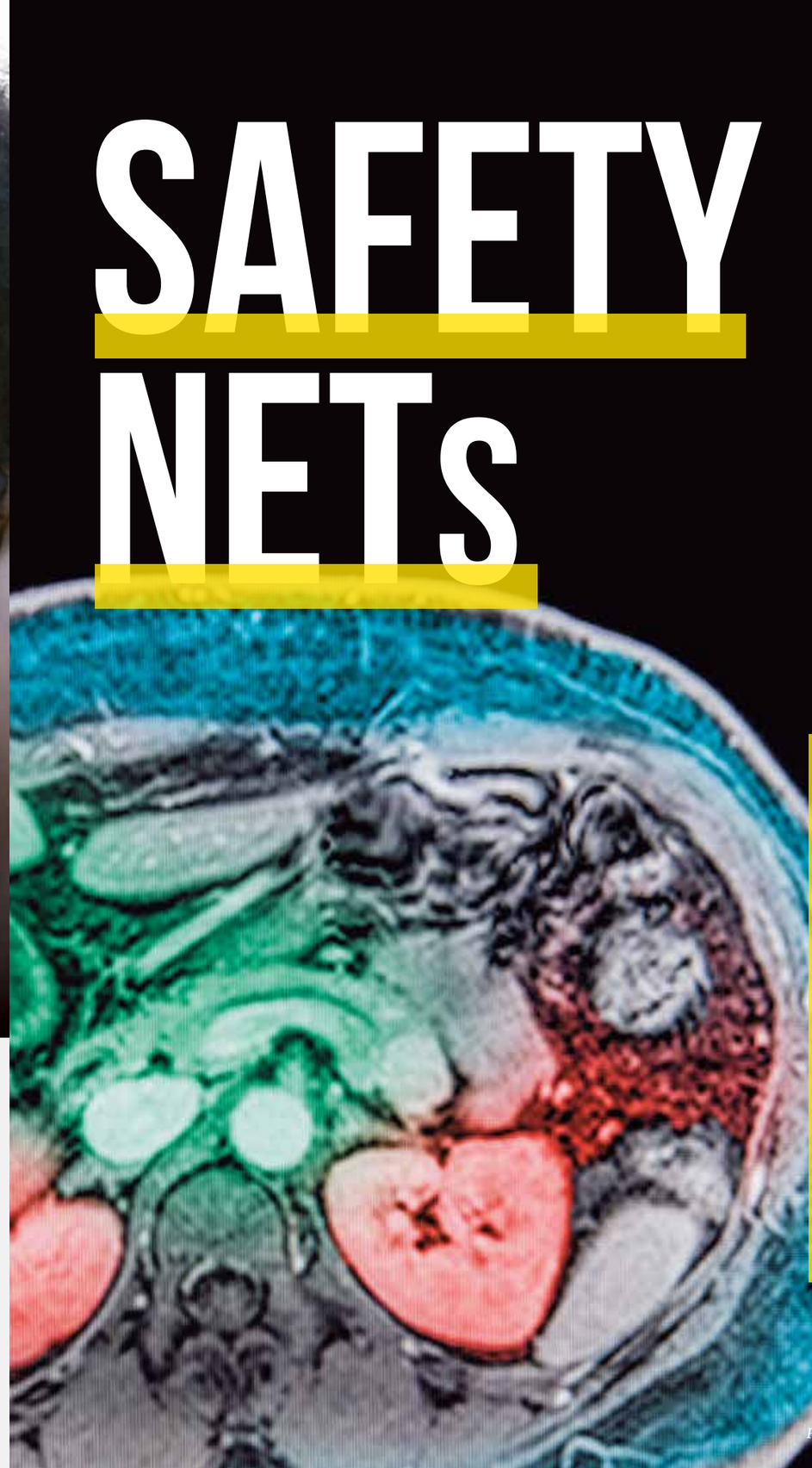
Sunnybrook is leading research on administering penicillin allergy testing at the bedside of hospitalized patients who need it. It involves a skin prick that, if tolerated, is followed by an injection and close observation. Within 30 minutes, the health-care team can determine if there is an actual allergy by watching for signs like swelling.

In a recent study led by Dr. Leis, approximately 80 per cent of patients who thought they were allergic to penicillin were able to receive this medication when they needed it to treat their infection.

"Based on our study, penicillin skin testing is now supported by our hospital to help improve the treatment of patients with reported allergy who would benefit from using this antibiotic to treat their infection," says Dr. Leis. "Many hospitals across North America are looking to implement the same approach that we have used at Sunnybrook."

– Monica Matys

SAFETY NETs



How Sunnybrook's Odette Cancer Centre is inventing future care for neuroendocrine tumours, a cancer that is hard to detect and treat.

by Alexis Dobranowski

Steve Waters knew something wasn't right inside his body. He was exhausted for no reason, and had debilitating diarrhea. His doctor said it was irritable bowel syndrome and that it would come and go throughout this life.

"I just wasn't satisfied with that," recalls Steve, who is 46. "I knew something else was wrong."

After several more tests and visits to specialists, Steve recalls getting a call from his doctor while driving home one rainy night and being told he had two tumours on his liver.

"They were neuroendocrine tumours [NETs], and the hormones secreted from the tumours had already started doing damage to my heart."

NETs are very rare abnormal growths in the neuroendocrine cells. These cancers are usually slow-growing and can affect any organ, but most commonly occur in the lungs, gastrointestinal tract or pancreas.

In Ontario, about 600 people are diagnosed with NETs each year.

"Endocrine cells are present in most of our organs and secrete different types of hormones, most commonly serotonin," says Dr. Julie Hallet, a surgical oncologist at Sunnybrook. "That's why NETs have two unique characteristics: slow cancer growth and hormonal secretions."

If left undiagnosed, the hormones released by the tumours can wreak havoc on the body. For Steve, that meant his right-side heart valves were damaged and having trouble functioning.

He was referred to the Susan Leslie Clinic for Neuroendocrine Tumours at Sunnybrook's Odette Cancer Centre. The clinic, established in June 2009, brings together a multidisciplinary team of experts to simultaneously assess and care for patients like Steve. It's the only clinic of its kind in Canada and sees more than 1,000 new and follow-up patients every year.

After an appointment with medical oncologist and NETs clinic co-founder Dr. Simron Singh, Steve's first major treatment was having his heart valves replaced by Dr. Gideon Cohen in the Schulich Heart Program. For Steve, it was the first of many surgeries.

But Steve counts himself as one of the lucky ones; his journey to diagnosis and treatment took just a few months. For other people suffering the effects of NETs, it takes much, much longer.

Jeanne Yee was an active 37-year-old massage therapist when she began not feeling well in 2000.

"I lost weight, had heart palpitations, was vomiting, sweating and flushing," Jeanne, now 53, recalls. "I had consistent and excruciating abdominal pain, which was made worse with eating, so I ate very little."

For more than a decade, she suffered. She took a leave of absence from work, lost more than 30 pounds from her already slight frame and visited many doctors. She was diagnosed with a variety of ailments, including irritable bowel syndrome, menopause, food allergies and a stomach bug believed to have been picked up on a trip to China.

Finally, an internal specialist in 2014 referred her to Sunnybrook: Jeanne had NETs.

"I had never heard of NETs and I actually thought the specialist was pulling my leg," Jeanne admits. Soon after her referral, she had major life-saving surgery to remove three primary tumours from her small intestine.

According to Dr. Hallet, it's not uncommon for NETs to go undiagnosed for years. "The signs and symptoms are very non-specific. There's often diarrhea or some facial flushing or wheezing, but those things can happen with so many diseases," Dr. Hallet says. "Often, patients will seek out health care for a very long time and get labelled with a bunch of other diagnoses that are not NETs, most commonly asthma or irritable bowel syndrome."

Another reason diagnosis can take so long is that these rare tumours just aren't on the radar.

"Even as health-care providers, we just don't think about NETs. So you can't consider something you don't know about when seeking to diagnose someone," Dr. Hallet explains. "In medical school, we are taught, 'When you hear hoofbeats, think horses,' meaning think straight and consider the obvious diagnosis. But with NETs, it's more like 'When you hear hoofbeats, think zebras.' "

Dr. Hallet and the NETs team at Sunnybrook are currently conducting a long-term research study to help better understand this mysterious

In Ontario, about 600 people are diagnosed with NETs each year.

PHOTOGRAPH BY KEVIN VAN PAASSEN

After numerous tests and visits to specialists, Steve Waters (seated) was diagnosed with NETs. His surgical oncologist at Sunnybrook, Dr. Julie Hallet (right), is conducting a long-term research study of the mysterious disease.

disease. Even though the tumours are rare, the number of people living with NETs is increasing, as patients with these kinds of tumours can, with careful care management, live for a long time.

"We are focusing on finding enablers to more timely diagnoses," Dr. Hallet says. "We are examining the data of 6,000 patients with NETs in Ontario and asking: 'How were they eventually diagnosed? What path led to diagnosis and treatment? Does this vary across regions?' From there, we're hopeful we can identify what works and ways we can improve diagnosis and treatment."

Because this type of tumour is so rare, there's no standard pathway of care, Dr. Hallet points out. Contributing to that variance in treatment is the fact that each tumour is truly unique; the tumours grow at different rates, release different hormones and may or may not be responsive to chemotherapy. Surgery, interventional radiology and anti-hormone injections are all options.

"Treatment really needs to be personalized for each tumour, so that we can control growth and hormonal secretion," she says. "But what is the right treatment at which point in a patient's journey? How do we sequence the treatments? That's really the challenge. This is a marathon, not a sprint."

Dr. Hallet says Sunnybrook's NETs clinic aims to raise awareness of the disease and improve access to care at Sunnybrook and beyond.

"We work with community partners, so patients may come here for initial assessment and treatment recommendations, but then they can undergo that treatment at their home hospital. Eventually, if there are progressions or concerns or questions, we can revisit and reassess."

Steve has attended conferences in the U.S. and made contact with other NETs patients from around the world. He has heard first-hand how challenging it can be to access specialized treatment in some smaller health-care centres.

"I know that having the multidisciplinary care team [at Sunnybrook] really increases my chance of survival. I am so grateful to have expertise in my corner."

Living with this chronic illness is challenging, Steve says, and he can feel his health worsening. But he also has good days and was able to travel to California this year for a vacation. "Cancer is such a generalized term and it's hard to explain to people how I am doing. I can explain it in day-to-day functioning – I am able to make my daughter's lunches and put dinner on the table."

Jeanne retired from her physically demanding job as a massage therapist. She receives monthly anti-hormone injections. Fatigue is an ongoing challenge, as is the knowledge that the cancer will likely progress.

"But for now, the clinic keeps a close watch on me, so I don't worry about the future," she says. "I only care about my quality of life. I savour the time with my family and friends. I still cycle on sunny days, I go for walks and run a little. I pray a little longer, meditate a little longer, breathe deeper, smile more and laugh a lot."

'Treatment needs to be personalized. What is the right treatment at which point in a patient's journey?'

Dr. Julie Hallet
Surgical oncologist

Jeanne Yee is being treated for NETs at the Susan Leslie Clinic for Neuroendocrine Tumours at the Odette Cancer Centre.

PHOTOGRAPH BY KEVIN VAN PAASSEN

‘EVERYONE IS UNIQUE IN TERMS OF NEEDS’

PHOTOGRAPH BY KEVIN VAN PAASSEN

Dalia Abd Almajed, shown with her daughter, Eram, says she put her confidence in the team at Sunnybrook to look after the complexities of her pregnancy.

At Sunnybrook’s new Accessible Care Pregnancy Clinic, women with disabilities are cared for from pre-pregnancy consultation to weaning

by Judith Gerstel

When Dalia Abd Almajed’s smartphone disappeared, she knew her 18-month-old daughter must have taken it and abandoned it somewhere in the house. But where? The ringer was off and Dalia was too busy with her newborn son to hunt for the phone.

Most people would be frustrated, maybe frantic. But for Dalia, it was no biggie, barely registering in a life full of challenges. Dependent on a wheelchair for mobility, the 38-year-old mother has managed two pregnancies and the birth of two healthy babies in the past couple of years.

Coping with the logistics of pregnancy – transportation to medical appointments, transferring from a wheelchair to the examination table, coordinating meetings with specialists – poses a huge challenge for mobility-disabled women like Dalia, who immigrated to Toronto in 2014.

And that’s before labour and delivery and bringing a newborn home. “My medical condition is complicated,” explains Dalia, who practised as a physician in her native Iraq before developing transverse myelitis, a disease affecting her spinal cord. “Pregnancy itself, for everyone, is complicated. So my pregnancy, [because I’m] in a wheelchair, was a very complex case. I needed many referrals, many specialists – respirologist, hemaetologist, neurologist, dietitian, anesthetist.

“I was afraid. I was thinking, How will all this be arranged? Will they be able to care for me?”

Fortunately for Dalia and other women in Ontario of reproductive age with disabilities, the Accessible Care Pregnancy Clinic opened recently at Sunnybrook. North America’s first clinic caring for pregnant women with a wide range of physical mobility disabilities, it was the idea and the passion of Dr. Anne Berndl.

“It’s been my personal project since I started here,” notes Dr. Berndl, a maternal fetal medicine specialist and director of the clinic. “Before I became a doctor, I worked in a home with foster children with disabilities. It gave me a lot of insight. Everyone is unique in terms of needs. There’s no standard approach to people with physical disabilities.”

Dr. Berndl was already caring for pregnant women with disabilities as part of her practice as a high-risk obstetrician at Sunnybrook. She became Dalia’s obstetrician halfway through her first pregnancy. By the time the Accessible Care Pregnancy Clinic officially opened in May, Dalia was well into her second pregnancy.

“For the second pregnancy, I didn’t have many concerns because I knew that they will deal with it very well and they know what I need,” says Dalia. “I felt confidence in the team, in the hospital itself. They were listening to me.”

Just as listening to the heartbeat of the fetus in the womb is the key to caring for the unborn infant, so is listening to the patient, which is at the heart of how obstetrics is practised at the clinic. For several years prior to the clinic’s official opening, pregnant women with disabilities who came to Sunnybrook were invited by Dr. Berndl to take part in exit interviews. They were asked: What do you need? What would you want to see in a clinic tailored for women with disabilities? What should we be doing better at Sunnybrook?

It was from those interviews, notes Dr. Berndl, that Sunnybrook came up with the framework for the Accessible Care Pregnancy Clinic. For example, she made sure there was a scale that can accommodate wheelchairs. Without it, women using wheelchairs tend to not be weighed properly – or even not weighed at all.

There’s also a concerted effort at the clinic to meet the special needs of pregnant women with disabilities. “The ultrasound bed was higher than the wheelchair,” recalls Dalia. “The technician was able take the ultrasound while I was sitting on the chair.”

Allowing extra time for procedures, such as Dalia’s ultrasound, and for getting from one appointment or lab test to the next is built into the clinic’s scheduling.

“Logistics is one of the hardest things we’ve been working on,” says Dr. Berndl. That includes allowing extra time for transfers and positioning the patient; for consolidating care, so appointments are coordinated and especially for the TTC Wheel-Trans schedule. “We’re learning a lot about the challenges of transportation,” she adds ruefully.

Nevertheless, Dr. Berndl is determined that every woman’s needs are considered and properly accommodated.

The first tenet at the Accessible Care Pregnancy Clinic, according to Dr. Berndl, is to respect each woman as an individual. Every member of the health-care team, including ward clerks, is coached to treat every patient with dignity and understanding. “These women deserve respect and encouragement just like any other woman,” says Dr. Berndl.

This attitude is light-years away from how society in the past regarded pregnant women with disabilities and, in some cases, even up to now.

“I sensed that these women were feeling highly discouraged from having pregnancies,”

observes Dr. Berndl. "They'd feel the negativity, the stigma from health-care professionals as well as from others, when they were pregnant."

Because pregnancy may affect the health of women with disabilities, the clinic encourages pre-pregnancy consultations. "They can ask about concerns and about what may happen," says Dr. Berndl, "and then feel good about their decisions."

The connection that begins with the pre-pregnancy consultation doesn't end until the baby is weaned. An advanced practice registered nurse (APRN) calls every patient before the first visit, explains Dr. Berndl.

"We ask: What are your needs? What could we be doing to make it more comfortable for you? How is your mobility? Before [the patient] comes, we're ready," notes Dr. Berndl.

She also points out that at Sunnybrook, there are a number of subspecialists to see women with disabilities and who go out of their way to adjust to the patients' needs. "Two weeks ago, a neurologist asked me, 'Do you mind if I just run upstairs to your office and do the consult there?' There is so much enthusiasm [here at Sunnybrook] for this clinic," says Dr. Berndl.

A lactation consultant is available after the birth. As well, the Accessible Care Pregnancy Clinic connects new mothers with community resources. "[We try] to make those linkages early on," says Dr. Berndl. "These mothers are exhausted and overwhelmed, especially if there is no one out there to support them."

For Dalia, all of these support services have made a huge difference. She has no family in Canada other than her husband, Salam, who worked in Iraq as a biologist and is now training as a lab technician. "The social worker at Sunnybrook arranged for contact with the CHC [Community Health Centre] to provide help with the baby and to give me time to rest or sleep."

While managing the pregnancy and postpartum recovery is routine work at the clinic, the ultimate goal is a comfortable labour and the delivery of a healthy baby, with vaginal delivery whenever it's possible.

Labour and delivery plans are drawn up with input from the entire interdisciplinary team, and every member of the labour and delivery team receives a copy, including the patient herself.

"She is the leader of her own team," emphasizes Dr. Berndl. "Even if she comes to the hospital at 4 a.m. on a Tuesday in a triage situation, she comes with the plan. We're always making sure that everyone knows what is going on. Excellence in communication is another one of the tenets of the clinic."

Being able to communicate is also important for new mothers. That's why Dalia finally went hunting for her phone.

"My daughter plays with it and throws it everywhere," she says. "It was under the bed."

Dalia Abd Almajed had a healthy pregnancy and delivery of son Abbas in May 2017.

PHOTOGRAPH BY DOUG NICHOLSON

Dalia, pictured with Dr. Anne Berndl, founder of the Accessible Care Pregnancy Clinic.

PHOTOGRAPH BY DOUG NICHOLSON

MAKING IT EASY FOR EVERYONE

The Accessible Care Pregnancy Clinic at Sunnybrook is North America's first clinic for pregnant women with physical disabilities, both visible and invisible.

WHOM DOES IT SERVE?

Women who have spinal cord injuries, severe arthritis, spina bifida, a history of trauma such as a car accident or brain surgery, cerebral palsy, multiple sclerosis, a history of amputation, scoliosis, myasthenia gravis and dwarfism. Patients may or may not use mobility devices or aids.

"It's not just for women with obvious disabilities such as those who use a wheelchair," says Dr. Anne Berndl, founder and director of the clinic.

The definition of physical disability, says Dr. Berndl, is a person "requiring a mobility device or having a condition such as chronic pain or muscle weakness that decreases mobility." It's a definition that is still somewhat vague, she says but notes that the clinic is also focused on "conditions that wax and wane, such as myasthenia gravis, a long-term neuromuscular disease that leads to varying degrees of skeletal muscle weakness; and multiple sclerosis, or MS."

In Canada, 6.2 per cent of women of reproductive age are physically disabled, according to Statistics Canada.

HOW ARE PATIENTS REFERRED TO THE ACCESSIBLE CARE PREGNANCY CLINIC?

Referrals are accepted from inside and outside of Sunnybrook, including from family physicians, obstetricians, nurses, social workers, neurologists, physiatrists (physical medicine and rehabilitation physicians) and midwives. Women interested in a pre-pregnancy consultation or for pregnancy care at the clinic should ask a health-care provider to fax a referral.

For more information about the Accessible Care Pregnancy Clinic and referral forms, visit **sunnybrook.ca/pregnancy/accessible** or call **416-480-5367**.

Members of Sunnybrook's gynaecologic surgery team: (from left) Drs. Rose Kung, Patricia Lee, Jamie Kroft and Grace Liu.

PHOTOGRAPH BY KEVIN VAN PAASSEN

KEYHOLE SURGERY A GAME CHANGER FOR COMPLEX CASES

Gynaecologic surgery team treats 'last resort' cases with minimally invasive surgery

by Mary Gooderham

Having suffered from severe endometriosis since the age of 14, Ashley Adams-Jones held out little hope that the pain and fertility problems that plagued her would ever abate.

Numerous consultations with doctors led to various treatments, ranging from the removal of one of her fallopian tubes and an ovary to repeated operations to cauterize or burn some of the endometrial tissue twisted around her reproductive organs.

She even had her gallbladder taken out, with the suggestion that that would make things better. It didn't.

"It was really just a cycle of pain," recalls Ashley, now 30, who had become increasingly frustrated and was even turned away by hospitals unable to deal with the severity of the lifelong condition.

What made the difference, finally, was when she travelled in early 2015 from her home in Parry Sound, Ont., to Sunnybrook and participated in its gynaecologic surgical program. There she underwent a laser procedure – via keyhole surgery, also known as laparoscopy, a type of minimally invasive surgery – in which the problematic endometrial tissue was removed via four tiny incisions in her abdomen under the direction of Dr. Jamie Kroft, one of Sunnybrook's minimally invasive gynaecology surgeons.

"Patients with endometriosis wait an average of nine to 10 years just to be diagnosed; then, it often takes even longer to receive adequate treatment," says Dr. Kroft.

"It was a game changer. I had pain relief almost immediately," says Ashley. Even more important is that the treatment cleared the blockage caused by the disease in her remaining fallopian tube and ovary, allowing her to become pregnant with her third child, which she delivered in the nurturing and comforting environment at Sunnybrook.

"I couldn't say enough about the care I got there. They had every resource that I needed."

Sunnybrook uses minimally invasive surgical techniques for complex gynaecologic problems such as stage 4 endometriosis, difficult hysterectomies, large fibroids, benign uterine masses, severe pelvic organ prolapse and bladder dysfunction.

The hospital's gynaecologic minimally invasive surgery program – one of only two in Canada accredited by the American Association of Gynecologic Laparoscopists – tends to some of the hardest-to-treat cases across the spectrum of reproductive health issues and at every age, ranging from women who are trying to conceive to those in menopause and postmenopause.

"We see a lot of 'last-resort' patients," notes Dr. Patricia Lee, head of Sunnybrook's Division of Gynaecologic Surgery. She is a urogynaecologist, a subspecialty that looks after women with bladder problems (such as urinary incontinence, voiding dysfunction), pelvic organ prolapse (please see sidebar on page 24) and other issues associated with weakness of the pelvic floor muscles.

Such conditions are common as women age and can seriously affect their enjoyment of life, although, Dr. Lee points out, many aren't quick to seek help. "A lot of people don't want to talk about those 'private-area' issues. And they don't know where to turn."

The women's health program at Sunnybrook offers such a place, with its 20-year history of laparoscopic procedures performed by an elite, cohesive team of gynaecologists working alongside experts in related specialty fields such as urology and general surgery.

Patients referred to Sunnybrook often have a lengthy history of previous gynaecologic treatments and additional medical issues. Dr. Grace Liu, a specialist in minimally invasive management of endometriosis and large fibroids, notes that, over the last several years, surgical cases are becoming increasingly difficult as medications improve and patients now opt for surgery only after medical therapy has failed. Previous surgeries can result in even more scarring and those with additional medical conditions, such as diabetes, cardiac conditions and obesity, can make intricate procedures even more complex.

"We are often the place where patients come after having been given multiple opinions that their surgery cannot be performed laparoscopically," says Dr. Liu. The vast majority of such difficult cases are dealt with minimally invasively, with a strong emphasis on organ preservation.

Minimally invasive surgery offers the patient the benefit of a quicker recovery, reducing the pain, scarring and risks of complications compared with traditional open surgical procedures. It also decreases the associated health-care costs of surgery through less time in hospital.

"You're in and out of the hospital on the same day," says Mahjabeen Ali, 60, who, in March, underwent minimally invasive surgery by Dr. Rose Kung, one of Sunnybrook's senior gynaecologic surgeons, to remove a mass from one of her ovaries.

Mahjabeen has a long history of gynaecologic issues. Years ago, she had difficulty conceiving and went through special procedures to have her two sons. This time, she put off seeing a doctor, ignoring months of lethargy that was uncharacteristic for her, as well as the ever-sharper pains in her abdomen.

"It became so excruciating that I threw up. I lived on painkillers for a while," she remembers. Even worse, she worried all the time that she had cancer, but she still couldn't bring herself to seek help. "We women go through so much and are often too scared to find out things."

Eventually, she went to her family physician and then had an ultrasound, which revealed the ovarian mass, as well as a cyst on the other ovary. Then, rather than wait almost two months for further testing at her local hospital, Mahjabeen was referred to Sunnybrook. A week after her first visit there, the keyhole surgery was performed to remove the cyst and the mass, which proved to be benign.

"They dealt with it right away," she says. "It's great to have it out. I feel better, I feel energetic." She recalls too that for patients with what she calls "female problems," the atmosphere at Sunnybrook is warm and personalized.

"They see how scared and sensitive you are, how shy you are about your body and that you want it covered…. The surgery team is fantastic and everything is explained to you," says Mahjabeen.

Dr. Lee has heard this before. Minimally invasive surgical procedures can be "life-changing," providing welcome relief for patients who've had conditions like debilitating pelvic pain or even urinary incontinence. "No one dies of a leaky bladder, but it has a significant impact on quality of life," says Dr. Lee. "To be able to help somebody with that problem is amazing."

For many women, getting help from the gynaecologic surgical program at Sunnybrook also means an end to a long search for answers. "They get bounced around from doctor to doc-

tor," Dr. Kung points out. "But if they happen to land with someone who is knowledgeable, they may actually benefit from treatment."

Also of note is how Sunnybrook is offering ambitious postgraduate programs to teach gynaecologists across Ontario and beyond, including urogynaecology and minimally invasive surgery fellowship training.

Dr. Kung was instrumental in establishing these training programs. In fact, Sunnybrook surgeons often get referrals from other University of Toronto teaching centres for cases that cannot be done there.

"We're teaching the teachers," Dr. Kung says. "There will be more access available to women in terms of minimally invasive surgery for complex gynaecologic problems."

The group of gynaecologists at Sunnybrook are especially committed to minimally invasive surgical techniques, she reports, and they work as a team to allow for more complex and challenging laparoscopic procedures.

Ashley, for one, can't praise enough the "very take-charge" surgical team that took care of her at Sunnybrook and their strong spirit of collaboration. For example, she recalls how, when complications in her urinary tract developed during surgery, a urologist came in right away. "They all really work together."

Her rapid recovery and the significantly reduced pain following the surgery, as well as the fact that the incisions on her abdomen were so small, all made a big positive difference to her well-being. "I can't even see my scars!" she says.

Ashley expects that the effort to control her endometriosis will continue into her menopausal years. Meanwhile, she notices that it really helps to stay fit and eat healthy, which keeps her hormones in check.

And she's relieved after so many years of pain and worry to find there are effective, minimally invasive ways at Sunnybrook to treat her condition. She's also grateful for the knowledge, expertise and sensitivity of the doctors she's met there.

"It's a comforting feeling, knowing you're well taken care of and they know what they're doing in this specialized area," says Ashley.

Mahjabeen Ali, who had a long history of gynaecologic problems, was referred to Sunnybrook and treated for a benign mass and cyst with minimally invasive surgery.

THE 'UNSPOKEN PROBLEM DOWN THERE' FOR WOMEN

It's a condition that affects half of all women who have had children. But while pelvic organ prolapse is common, no one openly talks about it, says urogynaecologist Dr. Patricia Lee.

With pelvic organ prolapse, organs such as the bladder, uterus and rectum "droop," forming a bulge in the vagina and sometimes pushing right out of it.

"Pelvic organ prolapse is common because childbearing is common," says Dr. Lee, noting too that there are surgical and non-surgical procedures to deal with this "unspoken problem," so women with the condition should consult their physician.

The numbers:

- 50% of women who have had children have some prolapse; 10–20% are symptomatic. Even if you have not had children, you could still be at risk.
- 10–20% of women have a lifetime risk for surgery because of pelvic organ prolapse; 30% need repeat surgeries.
- 5–7% of women develop prolapse of the top of the vagina, called the vaginal vault, after having a hysterectomy.

If you a have prolapse, you might notice these symptoms:

- a bulge at the vaginal opening
- a feeling of fullness or heaviness in your pelvic region
- problems with urination or with bowel movements.

Non-surgical treatments:

- A silicone rubber or plastic device, called a pessary, can be inserted in the vagina to support the uterus, bladder and rectum, so they don't drop down.
- Pelvic floor physiotherapy can help in exercising and strengthening the muscles and ligaments of the pelvis. There are also specific techniques to stimulate the pelvic nerves and muscles.

PHOTOGRAPH BY KEVIN VAN PASSEN

PHOTOGRAPH BY ALEKSANDAR ANTONIJEVIC

Pas de deux

How the Family Medicine Obstetrics team at Sunnybrook guides professional dancers and elite athletes through pregnancy

BY JUDITH GERSTEL

Which is more difficult: dancing the lead role in *Swan Lake* with a world-famous ballet company or giving birth?

We asked an expert. "It's close," replied National Ballet principal dancer Heather Ogden after a considered pause. "But maybe giving birth."

Six months after the birth of Leo and still breastfeeding, the preternaturally ethereal ballerina performed the demanding dual roles of the virginal Swan Queen and malevolent Black Swan. The Prince was her longtime dance partner, Guillaume Côté, who also happens to be her husband and Leo's father.

Ogden credits her speedy and triumphant return to the stage in a role that requires superb physical stamina to the pregnancy care she received with Sunnybrook's Family Medicine Obstetrics team, which always accepts new obstetrics patients, and to the guidance of Dr. Karen Fleming.

above: National Ballet principal dancer Heather Ogden (with husband and fellow principal dancer Guillaume Côté) maintained her fitness level goal through her pregnancy to return to the stage as the Swan Queen six months after giving birth to her second child.

"She knew about my fitness goals from the beginning and was always checking in to see how I was, mood-wise," says Heather, 36. "I had the goal of maintaining a better level of fitness for this second pregnancy. (The couple have a two-and-a-half-year-old daughter.) "I felt healthier, I had a much better energy level, and my mood was better. The biggest difference was that I stayed at performance level much longer and kept in top ballet form."

Guiding elite athletes and dancers like Heather through their pregnancies, so they maintain fitness safely and are able to return to peak performance level quickly, is a special interest of Dr. Fleming, division lead of Sunnybrook Family Medicine Obstetrics and interim chief of the Department of Family and Community Medicine.

But helping super-fit women modulate their activity during pregnancy is a small part of Dr. Fleming's practice. For the most part, she's doing the opposite – encouraging pregnant women to move more. Being active reduces rates of gestational diabetes and high blood pressure in pregnancy as well as decreasing rates of operative deliveries like caesarian sections. Exercise is also associated with lower rates of post-partum depression.

"Our challenge with the majority of women is that they're sedentary and tend to reduce exercise during pregnancy, which can contribute to gestational diabetes, excessive weight and high blood pressure in pregnancy," says Dr. Fleming. "One of the preventative goals is exercise, which improves sensitivity to insulin and helps with pushing the baby out."

Childbirth, she notes, is "a physically demanding activity, and exercise during pregnancy is like training for a competition."

It's also crucial for recovery. "Once you go home with the baby, there's a lot of carrying and lifting, a lot of physical demands for being a parent," she emphasizes.

Physical activity is important – whether you're taking on the role of mother or Swan Queen.

New obstetrics patients are always accepted without referral. The Family Medicine Obstetrics team is comprised of 10 family physicians, located at Sunnybrook and in the community across the GTA.

For more information, please visit **sunnybrook.ca/familyob**.

For Mary Lou Nawrocki, it was a great relief to learn she didn't need joint replacement surgery.

Replacement value

Is operating always the best way to treat aging joints? Meet two patients who both have osteoarthritis but followed different treatment paths

BY MARJO JOHNE

They awaken to stiff joints and spend their days fighting pain as they go through the usual motions of living.

An estimated 4.6 million Canadians suffer from osteoarthritis, a degenerative joint disease – and the most common form of arthritis – that starts with the breakdown of the cartilage that protects joints and keeps the bones from rubbing against each other. This chronic disease results in joint pain, stiffness and swelling, often becomes disabling, and is more prevalent among older people.

The implications are troubling for an aging country like Canada, where there are now more people over the age of 65 than there are children and where seniors will account for two out of 10 residents by 2024.

A number of studies in recent years have highlighted the growing prevalence of osteoarthritis among Canadians, and the greater burden this places on the country's health-care system.

One study published in 2011 by the Arthritis Alliance of Canada – in a report entitled "The Impact of Arthritis in Canada: Today and Over the Next 30 Years" – predicts that by 2040, one in four Canadians will have osteoarthritis. With a new diagnosis of osteoarthritis every 60 seconds, almost 30 per cent of Canadian workers will have difficulty working because of the disease, the study's authors wrote.

"Now more than ever, we need to look at how we can best serve the needs of Canadians with osteoarthritis in ways that will also be more optimal for the health-care system," says Dr. John Murnaghan, interim medical director of the Holland Centre, part of Sunnybrook's Holland Musculoskeletal Program.

Sunnybrook is leading the way in this effort. About 12 years ago, the Holland Centre introduced an innovative model of care for hip and knee arthritis. As part of its Hip and Knee Arthritis program, the centre pioneered a Central Intake and Assessment process that today continues to improve access and quality of care. Two patients from the Centre share their stories.

PHOTOGRAPH BY KEVIN VAN PAASSEN

MARY LOU NAWROCKI: NON-SURGICAL TREATMENT

Life changed the day Mary Lou Nawrocki's knees buckled as she was walking about with a friend. Diagnosed shortly after with knee osteoarthritis, the retired elementary-school teacher could no longer take long walks or exercise because of the pain and stiffness in her legs. She became less active and gained weight, which put more pressure on her knees and added to her pain.

"I tried physiotherapy and then a chiropractor, but nothing worked," recalls Mary Lou, who is 67 and lives in Toronto with her husband. "The osteoarthritis would just flare up and my knees would swell."

Her life changed again last year, this time for the better, when her doctor sent her to the Holland Centre. Within the month of getting a referral, Mary Lou walked into the Centre's Assessment Clinic.

A distinctive feature of the Holland Centre Assessment Clinic is that it is led by advanced practice physiotherapists (APPs) and advanced occupational therapists (APP/OTs) – clinicians with extensive credentials that include solid backgrounds in orthopaedics and specialized training from the surgeons.

Instead of immediately putting patients in a long queue to meet with an orthopaedic surgeon, the Holland Centre's intake process connects them first with an APP/OT, who works with them on a treatment strategy and, when needed, refers the patient on to an orthopaedic surgeon.

The process starts with a detailed assessment by an APP/OT that includes a thorough clinical examination and a review of X-rays of the affected joints, as well as functional testing that gives information about a patient's ability to carry out everyday activities. As part of the assessment, they are asked to do a six-minute walk test.

Using this information and a scoring system developed by the Centre's experts, the APP/OT determines if the patient needs to see a surgeon about hip or knee replacement surgery or can carry on with non-surgical strategies such as exercises to strengthen weak muscles, weight loss to reduce joint loads, walking aids or other adaptive devices to help with everyday functions.

"Our APP/OTs give patients the tools, confidence and peace of mind to carry on with their daily activities," says Susan Robarts, an advanced practice physiotherapist and team leader at the Holland Centre. "Many of our patients are pleasantly surprised to learn they don't have to rush into surgery and that there's a lot they can do to maximize their ability to move and function well."

'Those who need surgery get to see a surgeon sooner and those who don't need surgery can learn about their other options for treatment.'

Dr. Albert Yee, Chief, Holland Musculoskeletal Program

According to Dr. Albert Yee, chief of the Holland Musculoskeletal Program, the Central Intake and Assessment model provides a more efficient triage process because it ensures that only patients who need and want surgery are sent to an orthopaedic surgeon.

Today, about 30 per cent of Holland patients do not go on to see a surgeon. "Everyone's immediate needs are addressed within a much shorter period," says Dr. Yee. "Those who need surgery get to see a surgeon sooner and those who don't need surgery can learn about their other options for treatment."

PHOTOGRAPH BY KEVIN VAN PAASSEN

Dr. Albert Yee is the chief of the Holland Musculoskeletal Program.

For Mary Lou, it was a great relief to learn she didn't need joint replacement surgery. Instead, her advanced practice physiotherapist recommended a 12-week education and exercise program, which taught her movements to strengthen her damaged joints and muscles and lessen her pain.

"It's all about strengthening the good muscles you have to support the bad joints," explains Mary Lou, who signed up for physiotherapist-led education sessions at the Holland Centre. "At the end of the 12 weeks, I saw improvement. I could walk without pain, I had more stamina, I could climb stairs without apprehension. I was even doing knee presses on one of the machines at the Centre, and I was able to press a much greater amount of weight than I thought I ever could."

below: Dr. Jeffrey Gollish was instrumental in developing the Central Intake and Assessment Model.

Since it started collecting data in 2007, the Holland Centre has managed 20,000 patient visits using the Central Intake and Assessment model. Today it's widely considered to be the gold standard in hip and knee arthritis care.

"We were the first Centre of Excellence in Ontario for hip and knee replacements," says Dr. Jeffrey Gollish, a former Holland Centre medical director who was instrumental in the development of the Central Intake and Assessment model. "One of our first mandates was to develop a new model of care delivery to improve access to care for patients with hip and knee arthritis, so a group of us went to Glasgow and Edinburgh in Scotland to study what they were doing there, and we incorporated key elements of their model to form the basis for what we have at the Holland today."

Other health-care institutions in Canada have adopted similar models of care. Doctors and health administrators from other countries have also shown interest in the Holland Centre model.

"Our Central Intake and Assessment model functions very well," says Dr. Murnaghan. "Going forward, our hope is to play a key role in working with Ontario's health-system leaders to help other centres adapt it for their own settings, and to extend this model to other areas of musculoskeletal care, for example, for spine and for shoulders."

PATRICIA PETERSEN: SURGICAL TREATMENT

Getting a referral to the Holland Centre also marked the beginning of the end of four years of pain for Patricia Petersen. In 2006, at age 66, she started feeling pain and tightness in her right leg and hip. Two years later, she was finally diagnosed with hip arthritis.

"I've always been very active. I used to hike, cross-country ski, kayak and do a lot of walking, until the pain began to limit my physical activities," says Patricia, a retired University of Toronto professor and former director of the school's Urban Studies Program. "Then in 2010, there was significant deterioration and my doctor looked at my X-rays and said, 'You don't have a hip joint there anymore.' That's when I was sent to Holland [Centre]."

A week after her doctor made the referral, Patricia got a call from the Holland Centre scheduling her for an assessment the following week. Within three weeks, she met with a Holland orthopaedic surgeon.

PHOTOGRAPH BY KEVIN VAN PAASSEN

"I saw the surgeon in mid-May and they had a cancellation in June, but I was scheduled to teach in Germany, so the surgery was scheduled for my return in September. What I found so amazing was that within a month of seeing my own doctor, I had the assessment and was seen by the surgeon and could have had my hip replaced the next month," Patricia recalls.

This optimal pathway from referral to surgery can be attributed directly to the intake process, says Dr. Richard Jenkinson, an orthopaedic surgeon at the Centre.

A study published last March in the international peer-reviewed *BMJ* (formerly the *British Medical Journal*) highlights the importance of joint replacement surgery for those who need it the most.

The study looked at about 4,500 patients in the U.S. between the ages of 45 to 79 and found that patients with severe knee osteoarthritis gained significant quality-of-life benefits from total knee replacement surgery, while those with less severe progression and symptoms of the disease experienced minimal improvement in quality of life after surgery.

"Now we're only seeing patients who stand to benefit the most from surgery," says Dr. Jenkinson. "At the same time, all patients are benefiting from a longer discussion about their options with an APP/OT, which typically takes more time than most orthopaedic surgeons are able to commit to in their clinic."

• • •

Patricia resumed hiking, kayaking and other physical activities after her hip surgery.

Last May, she returned to the Holland Centre, this time with a referral for her left hip. While she's less than thrilled about having a second hip replacement, she's happy her doctor once again sent her to the Centre.

below: Patricia Petersen was able to resume hiking and other activities after receiving hip replacement surgery.

Says Patricia, "Based on my experience with my right hip replacement and on my recent assessment, I know I'm in good hands."

PHOTOGRAPH, COURTESY OF PATRICIA PETERSON

TO OPERATE OR NOT TO OPERATE

Will I need a knee operation right away? Should I stop going to the gym? Patients who are diagnosed with osteoarthritis in the knee are often confused about what it means to have this degenerative joint disease. With so much information available online and through other sources, it can be hard to separate fact from misinformation. Dr. Richard Jenkinson, an orthopaedic surgeon of Sunnybrook's Holland Musculoskeletal Program, discusses some of the most common myths around knee osteoarthritis.

MYTH: My osteoarthritis is bone-on-bone. I need a knee replacement.
FACT: Not necessarily. While the most reliable surgical treatment for bone-on-bone arthritis is a knee replacement, the key issue is the severity of a patient's symptoms. Knee replacement is most beneficial for patients experiencing pain, stiffness and functional limitation that significantly diminish their ability to engage and enjoy their daily lives.

MYTH: Knee surgery is the only option.
FACT: Even if a person has severe knee arthritis, non-operative treatment can alleviate the symptoms. The most effective non-operative strategies to relieve symptoms include strengthening the muscles that support the knee joint and decreasing the forces across the knee through weight loss. A program of low-impact exercises, possibly including formal physiotherapy, can be very helpful. Medications, injections, braces and other treatments can also play a role in improving function.

MYTH: I've been told that I should have knee surgery now when I'm younger, so I can have a better recovery.
FACT: The time to have knee replacement surgery is when the symptoms are severe enough that a person cannot manage a regular lifestyle without severe limitation. Anyone considering a knee replacement should first make sure they've given non-operative strategies a full attempt. Weight loss and exercise can do wonders for knee symptoms. Surgery can be considered for younger patients, but only if their symptoms are severe enough to warrant a significant operation.

MYTH: Knee replacements only last 10 years. My surgeon says I am "too young" for the surgery.
FACT: The vast majority of modern knee replacements can be expected to last longer than 20 years. Surgery should not be rushed into, however, if someone has not fully explored non-operative treatments and is having severe symptoms. On the other hand, they should not be suffering for many years, to the point where their function and mobility become severely limited before getting a knee replacement.

MYTH: If I can't have surgery, I should just take pills for the pain.
FACT: Strengthening the muscles around the knee and adding even light physical activity to one's routine can greatly improve knee arthritis symptoms. Medications such as acetaminophen and ibuprofen, which are over-the-counter drugs, can help manage arthritis symptoms. Stronger narcotic painkillers are not usually recommended to manage arthritic pain due to potential side effects and the risk of addiction. For the minority of those with inflammatory arthritis, like rheumatoid arthritis, medications are very effective and are an important part of the treatment. Injections, braces and other options can also help people manage their symptoms if surgery is not possible. •

Goal, plan, do, check

The CO-OP approach at St. John's Rehab puts stroke patients in the driver's seat

BY WENDY GLAUSER

For years, physiotherapist Anisha Rehmtulla took the conventional approach with her stroke patients. She would set goals for them, assess their mobility and give them exercises to strengthen an arm or help them walk unassisted. She'd direct them through their tasks – "Try to keep your feet apart. Now lift your leg."

She has recently taken a completely different approach with her patients at St. John's Rehab at Sunnybrook. It starts by asking patients what their own goals are. Depending on the patient's particular situation, the goal may be as simple as getting in and out of bed on their own, or as complex as returning to play golf.

An elderly patient, for example, recently mentioned he wanted to get back to woodworking. And there was that young father who said the most important thing to him was to be able to take care of his toddler again. "Okay," Anisha would then say. "So how do you think you can do that?"

Rather than being therapist-driven, that new approach – cognitive orientation to daily occupational performance, or CO-OP for short – "puts the patient in the driver's seat," explains Beth Linkewich, director of the Regional Stroke Centre and North and East GTA Stroke Network at Sunnybrook.

CO-OP was first developed in the late '90s for children with skills learning challenges. A decade ago, Sara McEwen, scientist with a physiotherapy background, began to adapt the approach for stroke patients. After conducting several studies to show that CO-OP works theoretically, Sara and Beth have teamed up to assess how it can be applied in a real-world rehab setting, where time is more limited.

In October 2016, Sara, Beth and their colleagues secured a grant from the Canadian Institutes of Health Research to support training of occupational therapists, physiotherapists, nurses, speech therapists and other therapy assistants at St. John's Rehab in the CO-OP approach. Patients are now being helped with CO-OP, and the goal is to train enough staff to be able to offer it to everyone.

The CO-OP approach uses a problem-solving strategy that has four steps: Goal, Plan, Do, Check. Therapists also use guided discovery, rather than telling patients what to do.

First, stroke patients set goals and are then guided to create their own plans to achieve those goals.

For example, the father who wanted to take care of his toddler recognized that he would need to carry the child, this despite reduced control and weakness on one side of his body. In physiotherapy, he practised carrying a sandbag up stairways. In occupational therapy, he would practise drawing with his finger across an iPad, so he'd be able to play games with his son.

opposite page: Physiotherapist Anisha Rehmtulla (left) and occupational therapist Catherine Chuang (far right) work with a patient.

Since CO-OP was introduced, patients are much more engaged in therapy, as they work together with therapists to better develop the best learning strategies.

With CO-OP, not only do patients define what they want to work on, they're also defining how they want to do it. They have to write down or verbalize the steps in their plan. For patients who want to dress themselves and put a foot into a pant leg, for instance, Catherine Chuang, an occupational therapist at St. John's Rehab, might ask, "What do you think you can do to achieve that?" The patient might suggest bringing her foot to her lap, which will then be added to the plan. It's an approach that's

PHOTOGRAPH BY KEVIN VAN PAASSEN

PHOTOGRAPH BY KEVIN VAN PAASSEN

The multidisciplinary stroke rehabilitation team at St. John's Rehab work together to help patients and their families get back to life after a stroke.

TEAM EFFORT

After a stroke, patients are learning how to move with major weakness or partial paralysis. They may have memory loss and cognitive issues.

During their stay at the rehab centre, patients experience a holistic approach. They will have access to a health-care team that includes:

- an occupational therapist to enable patients to return to their daily tasks such as dressing, bathing and cooking
- a physiotherapist to help patients maximize their physical functions such as getting in and out of bed, walking and climbing stairs
- a speech-language pathologist to address communication changes and swallowing concerns
- nurses available to patients around the clock to help manage all activities, medications and appointments
- a psychiatrist to talk about mental health challenges including feelings of anxiety or depression
- a dietitian to educate patients regarding healthy eating after a stroke
- a social worker to provide support and coordinate the care that patients will need after they leave rehab
- a physiatrist to provide medical support for the patient's rehabilitation and recovery •

analogous to the ancient saying about teaching someone to fish instead of just giving the fish.

When patients leave rehab and go back home, their therapists are not there to coach them through each step. With CO-OP, however, earlier studies conducted by Sara showed that patients tend to continue making gains post-therapy, likely because they have been shown how to solve problems on their own.

"It builds confidence," explains Sara. "If I can't do something, it doesn't mean that I should give up. It means I have to go back to my plan and change something. Maybe I need to put my hand in a different place or maybe I need some adaptive equipment." Eventually, patients start breaking down all tasks with an open-minded, can-do approach.

But that's not to say implementing CO-OP has been easy. "As physiotherapists, we're so used to telling patients what to do," says Anisha. "It's hard for us to stand back and let them try to figure it out for themselves."

Sara remembers feeling trepidation years ago, when she first used the CO-OP approach. Asked what his goals were, her patient, a man in his 40s, talked about helping his wife around the yard, but when he mentioned his personal goal to bike again, his eyes really lit up.

"He wanted to have that sense of speed again," recalls Sara. "I was terrified. Here's someone who was walking at a snail's space, with a cane, wanting to get on a bike."

Incredibly, after five hour-long sessions, she watched as her patient pedalled down the street, turning corners and managing inclines.

"He had to take a leap of faith and I had to take a leap of faith," says Sara. "And the result was amazing."

WHAT DOES IT TAKE

to get back to what matters most?

After an illness or injury, even the simplest of tasks can pose a challenge. Brushing your teeth, buttoning up your shirt and texting a friend – daily tasks you used to do without giving it a second thought now seem like a trek up a mountain. Rehabilitation is about getting you back to the life and activities that matter most to you. Whether it's unscrewing the lid of a water bottle, playing golf again or walking with a loved one, Sunnybrook's rehab team understands what it takes.

– Katherine Nazimek

SENSATION
in your hand to feel the phone

MUSCLE STRENGTH
in your fingers, so you can press the power button

THINKING SKILLS
to know and remember what you want to type

CO-ORDINATION
to make sure you're texting your friend, not your mom

FLEXIBILITY
in your thumbs to reach the letters on the keyboard

ENDURANCE
to hold up the phone while texting

FOCUS
to be able to finish your message

ILLUSTRATIONS BY KATHERINE NAZIMEK

The right treatment for the right patient

An innovative test developed at Sunnybrook helps to determine risk for women with early-stage breast cancer

BY ALEXIS DOBRANOWSKI

When Janice Weintraub was called in for more tests after her first-ever mammogram in 2015, she actually wasn't too worried.

"I have no family history of breast cancer," says Janice. "I just figured they'd do another test and I'd be given the all-clear."

So when the then 50-year-old mother of two heard the words "breast cancer," she was shocked. "I was told there was a suspicion of DCIS," Janice says, "but that stage 1 breast cancer couldn't be ruled out."

DCIS – ductal carcinoma in situ – is early-stage, or stage 0, breast cancer. It's a lesion in the breast that hasn't invaded the surrounding tissue. While women with DCIS have a very low risk of dying of breast cancer, some women with DCIS are at a higher risk of developing invasive breast cancer in the future, notes Dr. Eileen Rakovitch, medical director of the Louise Temerty Breast Cancer Centre, head of Sunnybrook Odette Cancer Centre's Breast Site Group, and the LC Campbell Breast Cancer Research Chair.

"We can't accurately identify which women are indeed at high risk and will get breast cancer, and which women will not," says Dr. Rakovitch. "So right now, we treat everyone."

Breast screening programs mean that DCIS is being spotted in some women who may never otherwise realize they have the disease, have any symptoms or ever develop invasive, life-threatening breast cancer.

"On the other hand, the screening means that for some women, we are so lucky to find it and treat it at this stage before it becomes aggressive," she says.

The challenge is in finding a balance between over-treatment and under-treatment. "We need to move away from a one-size-fits-all approach," she adds. Currently, most women are treated with lumpectomy followed by radiation treatment.

Janice had two surgeries at another hospital to remove the suspicious tissue in her breasts. She then met with a radiation oncologist to plan for radiation treatment.

"To undergo radiation or not was a huge decision for me," Janice says. "The concept of putting my system through the exposure and the side effects was very worrisome. Had it been a higher-stage cancer, I would have done anything to give me hope. But with DCIS, we didn't know how fast or even if these atypical cells would become harmful."

Breast pathologist Dr. Sharon Nofech-Mozes at Sunnybrook does her best to help personalize treatment. She examines a piece of every breast tissue that is removed from patients in order to better understand each individual case and help oncologists determine how best to treat each patient.

Under the microscope, she conducts a thorough examination that includes looking at the size of the tumour, how completely it was removed, and whether it has invaded tissue beyond the milk ducts.

After her investigation, oncologists may recommend additional surgery, radiation or the drug tamoxifen.

"I can look at two cases and they can look awfully similar," Dr. Nofech-Mozes says. "But they might have other features on a genetic level that cannot be found in a regular tissue examination."

Now Dr. Nofech-Mozes and Dr. Rakovitch have something new in their toolbox to help them better understand who is at high risk of invasive cancer and would benefit from radiation, and whose risk is low.

Going beyond what can be viewed under a microscope, the Oncotype DX Breast DCIS Score test looks at 12 genes to see whether they are "turned on or off," Dr. Nofech-Mozes says.

"For example, there are genes involved in cell proliferation – how fast a cell multiplies. The Oncotype DCIS Score looks for genes like these and then uses a formula to calculate a woman's risk of recurrence," she explains. "This is an additional layer of information that is being introduced."

Janice did some digging online and found Sunnybrook's research into the Oncotype DCIS Score. Her radiation oncologist encouraged her to reach out to Dr. Rakovitch, and Janice was accepted into the DUCHESS clinical trial at Sunnybrook, which measures the Oncotype DCIS Score in eligible women with DCIS. When her Oncotype DCIS Score came back low, she decided not to undergo radiation.

"The risk score helped inform the discussions with my partner," she says. "He is a real numbers person and I needed something rational to hang the emotion on. And it really worked both ways. Had the score come back high, I couldn't have stood in the face of science and rejected that radiation treatment. I wouldn't have."

That's the wonderful thing about moving DCIS and breast cancer into the genome era, Dr. Rakovitch says.

"It's individualized, personalized medicine. Instead of using broad estimates, a woman's own DCIS is sampled and the expression of those genes is measured. We get her individual estimate of recurrence with or without radiation treatment.

"For example, let's say her risk of recurrence is 9 per cent. With radiation, the risk might be reduced to 6 per cent. Many women and physicians say, 'That's such a small benefit; it's not worth it.' And so, they more confidently omit radiation treatment. For other women, the score identifies that they will benefit greatly from radiation and lessen their long-term risk."

The DUCHESS trial is also examining whether the Oncotype DCIS Score affected a woman's treatment plan or eased the decision-making process.

For Janice, who now undergoes yearly mammograms, that's a yes. "I don't know how I could have turned to my kids and said, 'I'm not going to do the radiation even though the doctor says to [do it]' if I didn't have something concrete and rational to explain why. The Oncotype DCIS Score looked at my own genetics. That put me in a very different headspace for making decisions."

PHOTOGRAPH BY KEVIN VAN PAASSEN

above: Getting an Oncotype DCIS Score helped Janice Weintraub make a personal decision about treatment for her early-stage breast cancer.

above: Dr. Eileen Rakovitch's research aims to balance the over-treatment of non-aggressive breast cancers and the under-treatment of cancer that could become aggressive.

PHOTOGRAPH BY KEVIN VAN PAASSEN

Critical training

Rural and small-town doctors brush up on their skills in trauma rotations

BY PATRICIA HLUCHY

As a family doctor who works in Northern Ontario communities, Britt Lehmann-Bender is sometimes the only doctor handling what she calls "big and scary" situations: treating victims of snowmobile, ATV or motor vehicle accidents. So the 32-year-old jumped at the chance to take further training to help give her trauma patients the best possible care. Last fall, she took part in Ontario's innovative Supplementary Emergency Medicine Experience choosing as her elective a two-week trauma rotation at Sunnybrook.

The program, which began as a pilot project in 2013 and has been running every spring and fall since September 2015, offers paid fellowships to family physicians practising in smaller or rural communities who want to build up their emergency-medicine skill set.

above: Family physician Britt Lehmann-Bender says the trauma training she received from Sunnybrook has helped her to handle medical emergencies that typically arise in rural practice, such as ATV or snowmobile accidents.

Participants spend three months in Toronto, completing two four-week placements in the emergency departments of Greater Toronto Area hospitals, with one day every week devoted to advancing their skills in classrooms and simulation labs. They get an additional month for clinical study, which they can spend either working in intensive care or in a two-week trauma rotation at either Sunnybook or St. Michael's Hospital, usually complemented by two weeks of anaesthesia training. The program is funded by the University of Toronto's Department of Family and Community Medicine and the Ontario Ministry of Health and Long-Term Care.

For Dr. Lehmann-Bender, who has spent one week a month working in remote Northern Ontario communities – including Neskantanga First Nation on Attawapiskat Lake – the rotation at Sunnybrook's Tory Regional Trauma Centre was invaluable. She got to work with some of the country's top trauma physicians at Ontario's leading centre for the treatment of the province's most critically injured patients. Given that Sunnybrook gets three to four new trauma cases daily, she was able to treat patients in much worse shape than any she'd seen before. She carried out procedures that were new to her, such as putting in an arterial line (for monitoring blood pressure continuously and extracting blood samples).

"It's been easy for me to go back [to my practice] and, when I have to manage traumas, to think of the multitude of experiences with various traumas I had at Sunnybrook," Dr. Lehmann-Bender says. "You're not having a stress response because you've done something a few times and you're comfortable managing similar things. It has helped me be calm."

Dr. Avery Nathens, Sunnybrook's surgeon-in-chief and trauma medical director, says the hospital's trauma elective helps to fill the experience gap for physicians outside of big cities, who might see just a single critically injured patient every year.

In addition to developing their technical expertise, it enhances their confidence.

"If you've never taken care of a patient like this, it's easy to become overwhelmed, and the most important thing is to keep your wits about you, so you can focus on the priorities. And having done this on a rotation five or six times a day, they get pretty confident at being able to focus on the patient's needs and move the care plan forward."

Sunnybrook is an ideal place for learning about treatment of critically injured patients "We have extremely high trauma volumes and are the largest trauma centre in Canada," says Dr. Nathens, who holds the De Souza Chair in trauma research. "We probably see about 1,300 severely injured patients a year. Patients come to us with a variety of different problems. Our location in the city means we encounter victims of high-speed crashes or interpersonal violence, which challenge providers in different ways."

Dr. Homer Tien, a Sunnybrook trauma surgeon who helped to create the trauma rotation for the program, notes that participants work on procedures in a simulation lab but also get a lot of hands-on clinical experience. "They also shadow one of the established trauma team leaders, and they can watch how he or she runs the case and then slowly take over. And there's a comfort level in knowing that you have the backup of someone more experienced to help you in case you run into a difficult situation."

In addition, says Dr. Nathens, there are lessons to be learned from reviewing patient care. "Every morning, we have what we call 'morning report,' where we review each patient in detail and review care plans. It also provides a great opportunity for teaching to build on the experiential learning that takes place in the trauma bay."

PHOTOGRAPH BY TIM FRASER

PHOTOGRAPH BY DOUG NICHOLSON

left: Trauma surgeon Dr. Homer Tien discusses a trauma patient's medical imaging with his team.

COMBAT MEDICINE

Military doctors gain confidence through Sunnybrook's trauma education

Dr. Rob Riddell, a military physician with the rank of Major with Special Operations Forces in the Canadian military, says his trauma rotations at Sunnybrook proved to be tremendously beneficial during a recent deployment overseas.

"I was able to apply all of the skills that I learned at Sunnybrook to severely injured battlefield trauma patients, a significant amount of patients with penetrating injuries, blunt trauma, head injuries and everything in between. I'd say my decision making is much, much more enhanced than it ever would have been had I not gone to Sunnybrook."

Sunnybrook began offering trauma rotations to Canadian Forces physicians in 2012. These sessions – a six-week turn for medical residents and a two-week refresher for physicians about to deploy or in high-readiness units – were launched by Sunnybrook trauma surgeon Dr. Homer Tien, a former senior trauma physician in the Canadian military who spent almost a year in Afghanistan.

"These doctors need to be able to manage major trauma cases and to maintain this clinical readiness throughout their military career," says Dr. Tien, who holds the rank of Colonel. "Sunnybrook's Tory Regional Trauma Centre helps them do this."

For Dr. Riddell – who was among the 17 candidates in contention to become Canadian Space Agency astronauts – his comfort level and confidence in managing severely injured people have "gone up tenfold. It's freed up breathing space, which was sometimes taken up too much by stress and allows me to think a little more clearly."•

Releasing life on their own terms

How patients in Sunnybrook's Palliative Care Unit are able to retain a sense of control and dignity at the end of life

BY DONNA YAWCHING

For Sandra Mitchell, Sunnybrook's Palliative Care Unit (PCU) became her second home in April of this year. She, her two sisters and a close cousin were taking turns keeping constant vigil at the bedside of their 85-year-old mother, Laurie James, who was in congestive heart failure and the final stages of a cancer that had spread from her kidneys to her pancreas and lungs.

above: Laurie James (in wheelchair) spent her last days at Sunnybrook's Palliative Care Unit, bonding with staff and enjoying long family visits.

"I would arrive at 8 p.m., spend the night on a cot next to Mom, help her with breakfast and lunch, then leave at 1 p.m. to pick up my granddaughter from school," says Sandra, recounting her caregiver schedule at Sunnybrook. She would babysit until 6 p.m. and then go home to grab a shower.

Sandra's family isn't alone in their dedication. Given there are 56 beds at the PCU – one of the largest palliative care units in the GTA – the presence of devoted family members is a constant. This is why the extensive renovations taking place at the unit are so critical. "We wanted to have as many amenities as possible for the families that stay overnight," says Sandra De Costa, the unit's patient care manager. "We want to make it as home-like as we can, not so institutionalized."

The first phase of the renovations, which began a year ago, are already bringing comfort and convenience to the unit's families – welcoming open-concept lounges with gas fireplaces, comfy armchairs and flat-screen TVs; a private meeting room overlooking a lovely garden; and two sleek modern kitchens offering patients' families ample space for storing and preparing food, as well as a place for them to gather at tables over coffee or tea.

PHOTOGRAPH BY KEVIN VAN PAASSEN

"The reaction has been very positive, particularly for the kitchens," notes De Costa. "Most families socialize and congregate in the kitchen. Comfort and convenience mean a lot during their time here."

The second phase of renovations will be underway soon. It will see upgrades to the on-site workstations of Sunnybrook's interprofessional health-care teams. The final phase will enhance and upgrade the patient rooms. The renovation work has been largely funded by McDermott House Canada, which has made a commitment of $3.6-million to the project.

When they were caring for Laurie, who passed away in July, Sandra and her family certainly appreciated the new amenities. "We used the kitchen all the time. We brought in our homemade Caribbean food," says Sandra. "It's also great that we were able to do laundry on the unit. And on Mother's Day, we booked some private time in the Garden Room. We brought food, Mom opened her presents, all her grandchildren and great-grandchildren were around her. It meant a lot."

Choosing palliative care at Sunnybrook for their mother – a strong, independent woman from Guyana who fought her first bout with kidney cancer five years ago – was "the best decision ever," according to Sandra. "It maintained her dignity and gave her a greater sense of control."

At Sunnybrook's PCU, Laurie also had numerous activities she could participate in – pet therapy, music therapy and various social events, to name just a few – which Sandra also appreciated. "You're not just lying there on a bed waiting to die," she says. "You can still enjoy life a little. It's not that you're just hooked up to machines fighting for life. It's more that you're releasing life on your own terms, letting go gently."

During her stay, Laurie forged personal bonds with the staff – Ruben Amando a Registered Practical Nurse (RPN), was her favourite. "She used to light up when he'd pass by," says Sandra, laughing. "He could get her to do anything!"

This is precisely the rapport that the Sunnybrook palliative care team aims to build with all their patients.

From physicians and nurses to art, recreation and music therapists, dietitians, a chaplain, a social worker, pharmacist, physiotherapist, occupational therapist and other support services, the unit's interprofessional team does everything possible to ease pain and other distressing symptoms while tending to the emotional, psychosocial and spiritual needs of the patients. Every effort is made to respect cultural differences, rituals and beliefs, to find out what is important to their diverse clientele and incorporate this into their care.

"People think the Palliative Care Unit must be a sad place," says De Costa, herself a registered nurse who worked on the unit for many years before becoming patient care manager. "But our focus is on helping each patient enjoy each day to the fullest. If you were to ask anybody on the team why they do what they do, it's because it's such a rewarding job. It's an honour to help patients at the end of life. You're really making a difference to them and to their family. We're here for the patient and we're here for the family, whomever the patient considers their family to be."

It is this kind and compassionate approach to palliative care that resonates strongly with the family members left behind, once their loved ones are gone. Some return to the unit to train as hospice volunteers, repaying the kindness they received during their own time of sadness.

"I'm certainly going to go back and volunteer," declares Sandra. "We are all diverse, but [in the unit], I see only oneness. We're all there for the same reasons – your loved one is dying and you're just there. It's all about love."

THOUGHTS FROM THE DYING ABOUT LIVING

It's not easy to talk about dying. For many, the subject is almost taboo. But at Sunnybrook, patients in the Palliative Care Unit are being given the opportunity to be heard – that is, if they choose to.

Thoughts from the Dying About Living is a project that aims to open the lines of communication on this difficult topic. Patients volunteer to talk about their lives, their thoughts, their philosophies. Some appear on video, others prefer to share their thoughts in print. Edited for length and uploaded to the hospital's website, these interviews are then made accessible for viewing by their families and the wider community.

The project – unscripted and open-ended – is a way for patients to deal with some of the emotions associated with dying, and to be able to share thoughts and feelings that might be difficult to express in person. Through Thoughts from the Dying About Living, Sunnybrook is helping patients create an emotional legacy for their families, as well as the community at large.

At once poetic and pragmatic, the patients say what's on their minds, as depicted in these excerpts:

Barbara: Don't be sad, it's not worth it. It happens to people and you have to come to terms with it, and I did.
Guy: I'm ready for this. It's okay. I don't like it. Who would?
Wiebke: You just take it as it comes. I'm at peace with myself.
Christl: I'm satisfied with what I had in life. I had 80 wonderful years.
Helmut: The most important thing is the people around you.
Joyce: Life is an adventure. Don't sit back and be afraid to do anything. Go for it! Go do it, I tell my family. Come out and visit me and we'll have this day together.
Judith: When I go out and hear the birds and smell the flowers, that's good!

Visit **Sunnybrook.ca/dying** to watch the videos.

PHOTOGRAPH BY KEVIN VAN PAASSEN

Collective intelligence

Sunnybrook is helping to build Canada's medical technology industry one life-changing device at a time

BY KIRA VERMOND

Last fall, a small group of scientists, clinicians and engineers – complete strangers to one another – spent four months together at Sunnybrook, all to solve a pressing medical problem. First they watched cardiologists perform heart procedures and talked to nurses, interventionists and technicians about the challenges they face in their work. Then they headed to a room down the hall to brainstorm.

above: Cardiologist Dr. Brian Courtney earned a degree in engineering before attending medical school. He is currently also the director of the Medventions program at Sunnybrook.

The team – Ramtin Ardeshiri, Lindsey Di Bartolomeo, Ryan Tennant and Dr. Wael Abuzeid – wanted to address a conundrum that has long plagued cardiologists: how to better image and fix blocked blood vessels. If they could collectively devise a solution to make these life-saving procedures safer and more effective, it would result in improved patient outcomes and perhaps even save hospitals money.

The hard work paid off. Not only did the team build a prototype for a device that can get around hard blockages in blood vessels, they are now in the process of obtaining a patent.

These aspiring medical-technology (medtech) professionals were the first group to take part in the new hospital-based education program called Medventions.

Launched by the Schulich

Heart Program at Sunnybrook, Medventions gives multidisciplinary teams – undergraduate and graduate student interns as well as clinical fellows – the ability to work closely with expert academic and industry advisors who teach them how to create and commercialize innovative life-changing technology that directly answers clinical needs.

Sunnybrook has long been at the forefront of medical innovation and revolutionizing health care. Yet, according to Dr. Brian Courtney, director of Medventions, during this past decade – as health-care funding has been increasingly challenged – more emphasis has been placed on building Canada's medtech industry from within the hospital's own walls.

"We have great research in Canada," says Dr. Courtney, also a cardiologist at Sunnybrook who earned his engineering degree before attending medical school. "We have a lot of people who are very knowledgeable and are world leaders on the scientific front. We have busy physicians who do high procedural volumes and fairly complex cases. And yet, when we go and use devices, they're often sourced from elsewhere, not from [Canada]. Because a good chunk of our future depends on health-care technology, we have to participate more actively in developing and bringing new technologies to the market."

From tongue depressors to hip implants, Canada has long depended on using medical devices from other places. According to Statistics Canada, in 2016 Canada imported $8.6-billion in medical devices while exporting $3.1-billion – a trade gap of $5.5-billion.

Developing more medtech innovations in our own backyard, however, could mean turning Canada into a world market leader in a rapidly growing and lucrative sector, expected to reach an estimated $342.9-billion (U.S.) globally by 2021, according to industry research data.

'It's a marathon, not a sprint. Everybody understands that it takes time to make this all work.'

Dr. Brian Courtney
Director
Medventions

CULTURE SHIFT

Encouraging an entrepreneurial culture at Sunnybrook to become a research and commercialization hub in Canada makes sense. Not only does Sunnybrook serve a large patient population, it also offers access to preclinical and clinical evaluation infrastructure – outstanding scientists, well-equipped labs, medical experts, financial support, patient participants, information systems and regulatory pathways.

On the top floor at Sunnybrook, there's even a laboratory for developing medical devices and a machine shop where researchers can build prototypes in-house.

This vision has attracted donors who share Sunnybrook's ambition to accelerate discovery and commercialization. Their support covers stipends for interns, prototype and equipment costs, networking and educational activities.

"At Sunnybrook, we are working to change the Canadian hospital environment with our vision of 'inventing the future of health care.' We need to move toward a culture with a stronger focus on how we can improve the patient experience and outcomes while making more effective use of finite health-care resources through innovation," explains Graham Wright, research director of the Schulich Heart Research Program.

As a result of the technologies that have been developed at Sunnybrook – ranging from substances that soften plaque buildup in arteries to a world-first helmet-like device that uses focused ultrasound to non-invasively treat areas of the brain that were previously unreachable – more patients could eventually benefit from these kinds of targeted, less invasive treatments.

Dr. Courtney's own research has led to the creation of an ultrasound catheter that takes pictures inside blood vessels and heart chambers – a device now approved in Canada and the U.S.

"What do patients want? They want minimal impact on their lives, ultimately. They want to get out of the hospital as fast as possible and they want to get better," says Dr. Courtney. "So, would you prefer an open heart surgery or would you prefer a thin wire snaked up through your vessel, so you get out the next day, as opposed to seven or eight days later?"

INVENTORS IN TRAINING

Medventions is taking medical innovation even further by developing not just the technology, but also addressing Canada's skills gap by providing the necessary training – a boot camp for inventors. After all, new technologies can't reach the patient's bedside unless there are trained inventors with the skills to bring them to market.

Immersive training is key. Because the program has medtech engineers and students with other skillsets working closely with doctors, nurses and technicians, they're able to get a true sense of the challenges medical professionals face.

For instance, Medventions team members can see with their own eyes the challenges playing out during actual procedures instead of simply visiting the hospital, sitting down with a cardiologist and asking, "What are your challenges?"

"Without that engagement, without that kind of shoulder-to-shoulder way of looking at the problems, discussing and going back and forth, it's really hard to get to the core of the trouble," says Wright.

The program isn't prescriptive either. While team members are given some general suggestions, guidelines and a research area – whether it is in musculoskeletal, orthopaedics, vascular surgery or an area of cardiology – it's ultimately up to them to decide what to focus their problem-solving skills on.

"We don't want the Medventions team to come in and say to them, 'This is what you're going to work on. Here's the project and just implement it,'" says Dr. Courtney. "We want them to identify the need and a number of solutions."

PHOTOGRAPH BY DOUG NICHOLSON

Having students from different professions looking at problems is a boon for the doctors as well.

By working with the Medventions team, health-care professionals, who are typically immersed in their day-to-day work, become more familiar with the innovation and commercialization process. They also begin to see their problem areas through a different lens – challenges that can be solved.

Ultimately, building Canada's medtech industry takes time. Developing an innovative new medical device or technology and bringing it to market – whether it's a new catheter, stent, balloon, pacemaker, heart valve, hip implant or a piece of ultrasound equipment – requires patience and determination.

above: The Medventions program brings together student interns and clinical fellows with academic and industry experts to create innovative medical technology.

The eureka moment is just the beginning, but the Medventions program prepares innovators for the reality.

"It's a marathon, not a sprint," notes Wright. "Everybody understands that it takes time to make this all work. You can't just come in and have an hour's interview and come out with an idea. It's something that takes years overall."

PHOTOGRAPH BY KEVIN VAN PAASSEN

‘Whenever I asked, she took care of me’

To make a big difference, sometimes it’s the little things that count, says patient Sandy Hudson

BY DAVID ISRAELSON

Sandy Hudson says she received terrific care from everyone at Sunnybrook, but it was the woman who took care of the little things who made the biggest difference each day.

Filomena Madeira, patient service partner, was her personal care worker during Sandy’s three-week stay in late 2016.

“She added a third dimension to my stay. She always had a smile. She washed my hair – the personal things that I couldn’t do for myself,” Sandy says.

Filomena made such a big difference that Sandy designated her as one of Sunnybrook’s Champions of Care. The Champions of Care program is a meaningful way for patients to acknowledge exceptional care received from someone special at Sunnybrook – a doctor, nurse, technician, volunteer or any staff member – in the form of a donation.

Launched in 2007, Champions of Care was the first hospital-based employee recognition program of its kind in Toronto. It was set up to let patients recognize the individuals and teams who demonstrate and provide outstanding care and treatment – those who make a difference in someone’s Sunnybrook experience.

Each Champion of Care receives an acknowledgement card and a commemorative pin to wear in recognition of the donor’s generosity. In its first two months alone, more than 100 pins were given to hospital staff members, and to date the program has received more than $1.2-million in donations honouring more than 1,600 caregivers.

Filomena says she wears her pin proudly, and Sandy is still effusive with praise for her caregiver months after returning home from hospital and rehabilitative care. To Sandy, now 71, Filomena was a Champion of Care because she always made an extra effort to ensure she was comfortable during a harrowing time.

It started when Sandy was admitted to Sunnybrook for three weeks after returning from a vacation in Scotland. Feeling unwell, she thought she had a cold at first, but just kept getting worse.

Sunnybrook’s team diagnosed Sandy with an autoimmune disease. Until her trip, she had been healthy; when she was admitted to Sunnybrook, her condition was so severe that she could not walk and could do little for herself.

“The doctors were absolutely fabulous, and so was the nursing staff. When you’re there for a long time, though, the people you see most are your personal care workers. Filomena was just awesome,” Sandy says.

“At the beginning of my stay, I needed a lot of personal help. Whenever I asked, she took care of me.”

Filomena says Sandy was “wonderful,” but she gives all her patients at Sunnybrook the same kind of personal attention.

“When patients come, I introduce myself, tell them my name and let them know that whatever they need, I can help.” says Filomena, who has cared for patients at Sunnybrook for 29 years.

Sandy says after she came home from Sunnybrook, she received a survey in the mail asking whether she was happy with the care she received.

“I said yes to the nth degree for everything. I don’t in any way want to downplay the amazing work that everyone else did for me, but when the survey got to the part asking if I’d like to make a donation and nominate someone to their Champions of Care program, it had to be Filomena,” she says.

Opposite page: Sandy Hudson, right, a recent patient and Sunnybrook donor, received such good care from Filomena Madeira, left, that she nominated the personal care worker as a Champion of Care, a hospital-based employee recognition program.

“She made such a big difference for me. When you can’t do things for yourself, that’s when you really notice.”

Filomena would help Sandy by doing everything from offering her a cup of tea to making sure she was not too warm or too cold. Perhaps her real secret, though, is that “I smile all the time. When I would come in and say good morning to Mrs. Hudson, she’d say, ‘You’re my angel!’ That was it.”

The generosity of donors like Sandy goes a long way to making sure that innovation at Sunnybrook is possible, in part because patients are able to choose which program area they would like their donation to benefit.

For patients, nominating a Champion of Care is a way of personalizing and recognizing the work individuals do at Sunnybrook; for recipients, it’s another reason to be proud of their dedicated service.

Today, Sandy’s condition is vastly improved. After her stay at Sunnybrook, she spent 10 days at St. John’s Rehab before returning home.

Now she is on medication that has stabilized her condition, making it possible for her to drive, sew and make meals in her own kitchen.

“The program I’m on through the rheumatology department appears to be working,” she says.

“I have to be really careful, but I’m feeling big-time better.”

BEHIND THE SCENES

HIGHWAY UNDER THE HOSPITAL

The steady hum of activity and care patients experience at Sunnybrook's Bayview Campus is situated on a solid and bustling foundation. The over-one-kilometre expanse of concrete hallways in the basement serves as a critical roadway for many of the hospital's most necessary daily functions. "It's a busy transportation hub with dozens of staff and services moving through the space," says Daniel Fernando, operations manager. "Think of it as Sunnybrook's version of the 401."

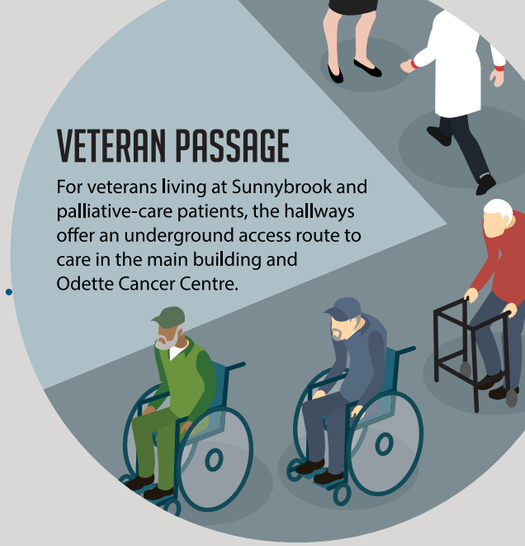
By Monica Matys

MEDICAL RECORDS

This area stores records for many of the 1.2 million patients the hospital cares for each year.

VETERAN PASSAGE

For veterans living at Sunnybrook and palliative-care patients, the hallways offer an underground access route to care in the main building and Odette Cancer Centre.



PRINT SHOP

The Print Shop produces 66% of the specialized handbooks referenced by paramedics in Ontario, and processes hundreds of other in-hospital orders every month.

WASTE

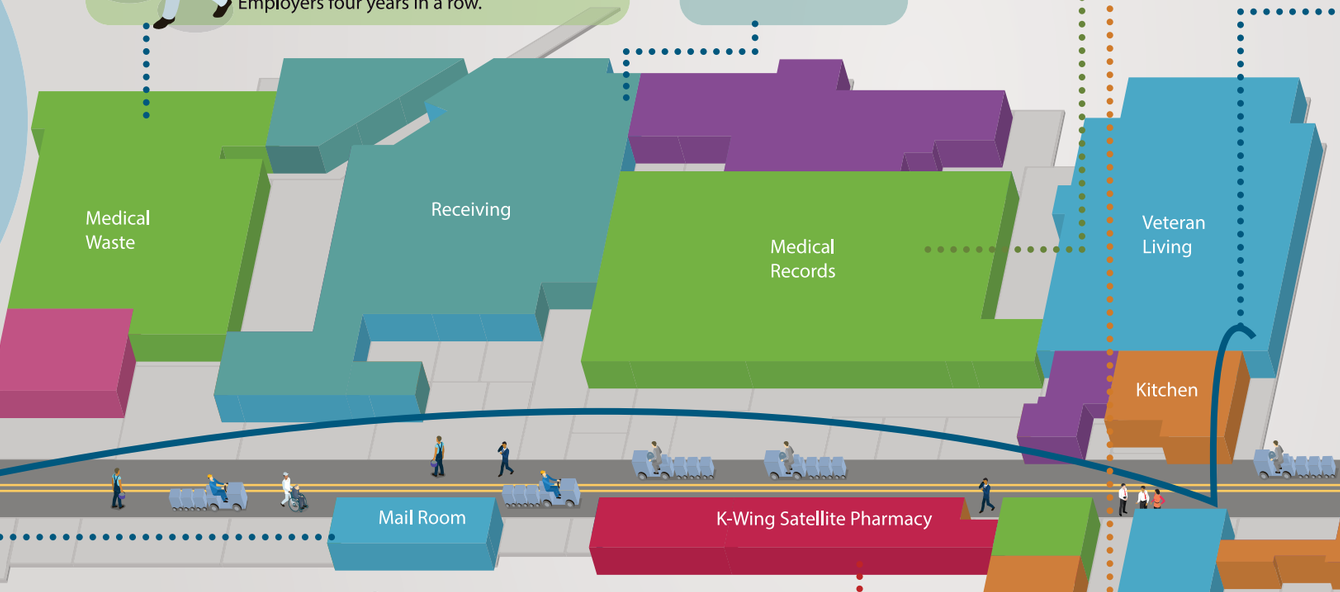
The hospital generates 4,672 metric tonnes of general, recycling and biomedical waste per year but has many green initiatives. It was named one of Canada's Greenest Employers four years in a row.

RECEIVING

The receiving area intakes approximately 500 boxes filled with supplies daily.

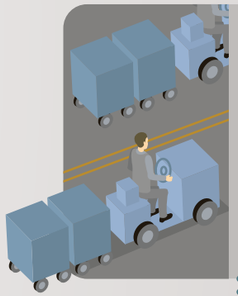
MAIL ROOM

Approximately 3,500-5,000 pieces of external mail and 1,500-2,500 pieces of internal mail across all three campuses are processed daily.



FOOD

Motorized vehicles transport food from the kitchen to designated patient-care areas.



LINEN SPEEDWAY

Over 10,000 kg of linens are moved daily through the basement by motorized vehicles for supplying patient-care needs.

LOCKERS

Approximately 1,600 lockers are available to staff working in the area.

K-WING SATELLITE PHARMACY

The pharmacy provides services to about 500 patient beds within the Department of Psychiatry and the Veterans Centre, and dispenses over 2 million medication doses annually.

PLANT OPERATIONS AND MAINTENANCE

Maintains and repairs approximately 48 km of plumbing pipes within Sunnybrook. The department's call centre processes and assigns 2,890 scheduled and corrective maintenance tasks each month, for a total of 34,680 tasks per year.

SAFETY

Many features have been put in place to protect staff who are required to utilize this area.

Graphic by Kevin Hand

Art and culture

A Sunnybrook lab technologist creates visual art using a palette of distinct colours produced by bacteria

At Linh Ngo's house, almost every night is movie night. Her boys, ages 4 and 7, love watching Disney films.

"I've seen *Finding Nemo* a dozen times," says Linh, "but when we first watched it, I was amazed at the similarities between the coral reef and the bacteria I work with in the lab."

As a laboratory technologist in Sunnybrook's microbiology lab, Linh takes bacteria samples from patients and grows them on plates filled with agar, a jelly-like substance. Those culture plates are used to determine the kind of bacteria causing patients' infections, helping the health-care team select the most appropriate treatment.

The bacteria produce unique colonies and colours on agar plates and can resemble art rather than a lab test.

Using Disney's version of coral reefs as inspiration, Linh combined her skills in the lab with her love for drawing and entered the annual Agar Art Contest held by the American Society for Microbiology.

After finding the bacteria that would produce the colours she wanted, Linh used the tip of a laboratory pipette to "paint" with the bacteria, freehand, on a series of five agar plates.

"I had to be careful not to have any overlap of the different bacteria because if there was, it would alter the image. There was a lot of trial and error," she says.

Her submission, *Finding pneumo* – named after one of the bacteria she used, *Klebsiella pneumonia* – far exceeded her expectations. She won second place in the competition, beating out 264 submissions from 36 countries.

– Sybil Millar

MICROSCOPIC CULTURE SAMPLE VISUALS, COURTESY OF SUNNYBROOK

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