



PERSONAL HEALTH NAVIGATOR

A patient's guide to Ontario's health care system

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with Ayodele Odutayo, MD

Answers

Advice

healthydebate
unbiased facts. informed opinions.

 **Sunnybrook**
HEALTH SCIENCES CENTRE

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ABOUT HEALTHY DEBATE

ABOUT SUNNYBROOK HEALTH SCIENCES CENTRE

INTRODUCTION

Ontario's health care system can feel like a maze. The system has become so complex that even people who work in it every day often struggle to navigate it. So for members of the public – who often encounter the system at a time of crisis – it can be hopelessly confusing and frustrating.

In response, some hospitals have introduced patient navigators, who act as guides through the labyrinth of health care services. They help connect patients with the right doctors, access available resources and therapies, improve continuity of care and get answers to patients' questions about their diagnoses.

Of course, many patients have the same questions and find themselves facing the same challenges in navigating the system. In response, Lisa Priest, who was manager of community engagement and patient navigation at Sunnybrook Health Sciences Centre, launched the Personal Health Navigator blog, hosted on Healthy Debate, in 2012. Paul Taylor took over the Personal Health Navigator when he joined Sunnybrook in 2013.

Over the past few years, Lisa and Paul have answered nearly 100 patient questions, and their answers have been viewed over 37,000 times.

We believe the Personal Health Navigator is an important resource for Ontarians. In collaboration with Healthy Debate's Citizens' Advisory Council, we have selected 33 articles for this e-book that span a variety of topics, from family doctors to cancer and surgery.

We hope you find this collection interesting and useful. This e-book is provided free of charge, so please feel free to share it with friends, family and co-workers. If you'd like to find out more about Ontario's health care system, please visit www.healthydebate.ca.

If you have questions about your doctor, your hospital or how to navigate the health care system, please send them to AskPaul@Sunnybrook.ca.



FAMILY DOCTORS

WHAT DO I DO IF MY DOCTOR WON'T SEND ME FOR A SECOND OPINION?

Question: I have been experiencing pelvic and abdominal pain radiating to my low back, bloating, bowel irregularities, sudden bleeding, nausea and weight loss. My GP referred me to a gynecologist who said I am fine. The gynecologist was very dismissive when I asked if it could be cancer. I got a copy of my ultrasound report, which recommends a follow-up ultrasound in a few weeks and says, "Endometrial sampling may be indicated to exclude malignancy." But no follow-up testing was ordered.

I asked my GP to send me to another specialist for a second opinion. But he said the gynecologist I saw is "very well regarded" and he "didn't feel it necessary to involve anyone else." My GP said he feels my condition is "hormonal" related and wants to see how things play themselves out over the next four to eight weeks.

It's very distressing. I know I am not well and my symptoms are getting worse. But I can't get someone to listen or do anything further. How do I get another opinion?

Answer: Your symptoms sound debilitating. I must admit I'm surprised your doctor turned down your request for a second opinion without giving you a more detailed medical explanation. At the very least, I would have expected him to do more to address your current symptoms aside from continued observation. The situation you describe makes me wonder if there has been some kind of breakdown in communication between you and your doctor.

In Ontario, the province's Ministry of Health and Long-Term Care doesn't place a limit on the number of second opinions patients can seek for a medical condition. But patients must first get a referral from their family physician or a specialist they have seen in the past year.

This essentially means physicians act as the gatekeepers to other doctors. The Code of Conduct of the Canadian Medical Association instructs doctors to "respect your patient's reasonable request for a second opinion from a physician of the patient's choice."

In order to get an answer to your question, I interviewed David Jensen, a spokesperson for the Ontario Ministry of Health, and Sally Bean, a medical ethicist and policy advisor at Sunnybrook Health Sciences Centre.

Mr. Jensen suggests you should book another appointment with your physician and discuss your concerns. Ms. Bean offers the same advice as a starting-off point.

This may not be an easy conversation and you may want to reflect upon your relationship with him before your appointment. Have you noticed any strains in the past? Has he previously rejected your requests? Does he explain the rationale for his decisions?

Begin the conversation by saying that you feel your request is reasonable and ask him why he thinks a second opinion isn't necessary. Ask him to also explain what was found in your ultrasound test. And ask what can be done to alleviate your current symptoms.

"Have a bit of a dialogue about it," says Ms. Bean.

Your doctor may have good reasons for his actions based on his knowledge of your medical history.

But if you feel no further ahead at the end of the appointment, then you face some difficult decisions. It may mean you need to look for a new doctor. Sometimes certain doctors and patients are not a good fit together. And it sounds like this experience is undermining your trust in his judgment.

"Finding a new family physician isn't easy and takes a lot of time," says Ms. Bean.

So how do you get a second opinion sooner rather than later?

As a last resort, Ms. Bean says you could consider going to a walk-in/after-hours medical clinic or an Urgent Care Centre (UCC) where you can see a physician without a referral. This isn't ideal because the doctor won't have access to your medical records or the benefit of knowing you for a period of time. But you can at least explain your symptoms to a medical professional who can serve as a sounding board. Be sure to bring along your ultrasound results for the doctor to review.

(By the way, a UCC, which can provide assessments and treatments for non-life-threatening injuries and illnesses, is not the same thing as a hospital emergency department. UCC locations in Ontario can be found at www.ontario.ca/locations/health/. Walk-in clinics also can be found online.)

What you do next may depend on what happens at the walk-in clinic or UCC. It may be worthwhile going back to your GP to discuss the physician's comments.

If you conclude that a new doctor is still essential, you may want to tap into a provincial government program, Health Care Connect, which helps Ontarians who are without a health care provider to find a family doctor or nurse practitioner. Find out more at www.health.gov.on.ca/en/ms/healthcareconnect/public. And, of course, ask family and friends if they know of a doctor accepting new patients.

- Paul Taylor

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WHY DOES IT TAKE SO LONG TO GET AN APPOINTMENT WITH MY FAMILY DOCTOR?

Question: Although I like my family doctor, I find it takes a very long time to get an appointment, even when I am not feeling well. A friend of mine has another family doctor and this doesn't seem to be a problem. We both live in Ontario. Why the difference?

Answer: That sounds very frustrating. If it's any consolation, a lot of other patients also have trouble seeing their doctors in a timely fashion.

In recent years, provincial governments and medical associations have introduced various measures to speed up the time it takes for patients to see their primary health care providers. But relatively prompt access is still not available to a majority of Canadians.

Only 41% of Canadians can get an appointment the same day or the next day with their own doctors, according to a report released earlier this year by the Health Council of Canada. When patients can't see their family physicians, they often head to the nearest hospital – and that contributes to longer emergency department wait times. So the issue of access has wide ramifications for the health care system.

The Health Council report is based on data from the Commonwealth Fund, which conducts annual surveys of people who live in 11 affluent nations including the United States, the United Kingdom, Canada, Australia, New Zealand and several European countries.

Canada was at the bottom of the heap in terms of how quickly people can get an appointment with their physician. (Germany came out on top – with 76% of those polled reporting swift access to a primary care provider.)

Still, some Canadians are served better than others. You noted that your friend doesn't have trouble getting an appointment and wondered why you do.

There are several reasons that might account for the difference in response time. But it often hinges on one thing – how well your doctor's office is organized, says Dr. Joshua Tepper, president of Health Quality Ontario, an arm's-length agency of the provincial government.

For a better understanding of the issue, it's worthwhile reviewing a bit of recent health care history in your province. About 15 years ago, Ontario began to encourage physicians to work in groups, rather than in solo practices. "If you have 10 doctors working together, you are just going to have more flexibility during the day and after hours than a one-doctor shop," explains Dr. Tepper.

There are a number of different models including family-health teams, family-health groups and family-health networks. Essentially, if your own doctor is busy or away, you can see another member of the group, including other professionals like nurse practitioners and physician assistants. The team can also take turns providing care after regular business hours.

As part of the move to group practices, Ontario also offered doctors a new way to get paid. Physicians have traditionally worked on a fee-for-service basis, in which the province pays them a set fee for each service they provide to a patient.

Under the alternative arrangement called capitation, doctors receive a lump sum based on the individual patient. The amount is adjusted to take into account the age, gender and medical complexity of a patient.

"You get paid less for a healthy 23-year-old male than you would for an 85-year-old male with several chronic conditions," notes Dr. Tepper. In most models, doctors can also charge the province separately for additional services not considered part of their regular duties, such as home visits.

Overall, physicians' incomes have been on the rise, according to the *Globe and Mail*. "There was a deliberate plan to increase the incomes of family physicians so they didn't lag behind other specialists," says Dr. Rick Glazier, a health services researcher

at the Institute for Clinical Evaluative Sciences at Sunnybrook Health Sciences Centre. The added financial incentive helped to boost the number of physicians entering family medicine – reversing an earlier trend in which new doctors were choosing other specialties.

In theory at least, group practices should be improving the quality of health care and making it faster for patients to see their doctors. But unfortunately the teams don't always produce the intended results.

Although we now have more family doctors in the province than ever before, many are working only part-time – devoting some of their attention to other professional duties or personal matters.

Those other activities “take away from clinical care and make it much harder to fully utilize your resources within the team,” says Dr. Tepper. So a relatively large group practice may have only a limited number of physicians who can take same-day or next-day cases.

Another problem is that it can be hard to coordinate the doctors' schedules so they function effectively in teams that can deal with urgent cases. “Even when you are really committed, it is not entirely clear what is the best way to do it. A few options have been tried,” says Dr. Tepper.

One scheduling approach is called advanced access, in which a doctor leaves open a significant number of appointments each day for those last-minute calls from patients who need immediate attention.

“It's actually very difficult to change your scheduling system,” says Dr. Glazier, who works in a group practice at St. Michael's Hospital in Toronto. “You have to be kind of brave and bite the bullet to leave most of your slots open for a day. What if nobody shows up?”

Some group practices put doctors on a rotation system, in which one of them handles the bulk of urgent cases that need to be seen on a given day.

However, this approach has drawbacks, too, because it doesn't provide for continuity of care. “It works for treating things like coughs and sprains. But if you have diabetes or a chronic problem like hypertension, you want to see your own doctor – not a different doctor,” says Dr. Glazier.

Patients also have had to adjust to the new system. At some clinics, patients were initially told they couldn't book an appointment more than a few weeks in advance. But many patients need extra lead time in order to book off work or arrange child care. The clinics eventually loosened up their schedules to better meet the needs of their patients.

“Every practice handles booking and appointments differently,” says Dr. Glazier. “Some have done well and others have really struggled.”

So what are the options for patients like you who might be in one of the struggling practices?

In an ideal world, the health care system would be patient-driven. You would simply move your business to another group practice that provides services that best meet your needs, says Dr. Tepper. But that's not going to happen any time soon. Also, he points out that “same-day access is only one element of what might draw you to a practice.”

Dr. Glazier suggests you should have a discussion with your doctor about access and availability. Some physicians may be quite open to having patients show up at their clinic, and then they will try to squeeze them in between existing bookings, says Dr. Glazier. If a same-day or next-day appointment isn't possible, there may be other ways to communicate. Some doctors are willing to talk to their patients on the phone or correspond by email.

From my own personal experience, I know that being a patient in a group practice can have its advantages. My doctor is in a well-organized family-health team and I can usually get a same-day or next-day appointment. In fact, I recently had a skin infection that was rapidly getting worse. Because I work at Sunnybrook, I could have popped down to the emergency department and waited my turn to see a doctor. It would have been very convenient. But I realized that was not the right thing to do.

So I called my family-health team at Toronto Western Hospital and was offered an appointment within the hour. When I arrived, I was assessed by a nurse who concluded I needed to be seen by one of the team doctors.

Within a few minutes a physician reviewed my case and wrote a prescription for antibiotics, and I was on my way. And lucky for me, my infection was brought under control without resorting to a potentially lengthy wait in an emergency department.

“One of the things we've done is to focus on the full scope of the practice of the inter-professional team,” says Teri Arany, the acting executive director of my family-health team. “Access to care is integral to our processes.” Nurses, she explains, triage and screen to determine what kind of care the patient needs. “We also have strong receptionists who assist in triage,” making sure urgent cases are seen promptly.

Group practices can work in an extremely efficient manner. Let's hope more doctors learn how to master the system.

- Paul Taylor

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WHY WON'T MY DOCTOR DO AN MRI FOR MY BACK PAIN?

Question: I am 63 years old, have played a lot of sports and have had back pain, on and off, for about 10 years. Unfortunately, it's gotten a lot worse recently. I would like an MRI to find out what is going on. However, my family doctor says that because I don't have any leg weakness or numbness, I don't need an MRI. This bugs me. Is she just trying to save the system money? What if I have a spine tumour?

Answer: Back pain certainly can be debilitating. I'm not surprised you want an MRI to know what's causing the problem. But I doubt your doctor would deliberately deny you access to a test just to save the health care system money. I suspect she thinks there's not much to be gained from an MRI, based on her assessment of your current physical symptoms.

Still, you're not the first person to question a doctor's judgment or motivation. For that reason alone, it's worthwhile checking out a website called Choosing Wisely Canada (www.choosingwiselycanada.org), which provides general guidelines about what tests, treatments and procedures are really necessary for individual patients.

It should give you a better understanding of the criteria for determining when an immediate medical intervention is needed.

The website was set up as part of the Choosing Wisely Canada campaign that officially launched in 2014.

"This campaign is really about trying to increase conversations between doctors and patients about unnecessary tests and treatments and help remind people that more is not always better. In fact, more can be harmful," says Dr. Wendy Levinson, chair of Choosing Wisely Canada and a professor of medicine at the University of Toronto.

For a wide variety of reasons, she notes, we've slipped into a bad habit of doing tests and treatments that aren't always justified. A physician may order tests as a precautionary measure – just to make sure all the bases are covered. At the same time, many patients have expectations they will get some type of treatment when they visit a doctor. Even if the physician feels a test or prescription isn't warranted, it may be easier to do something rather than explain to the patient why no action is required.

In many cases, patients get better without any medical interventions. Time is the great healer. However, unnecessary tests or treatments may actually subject patients to needless risks, says Dr. Levinson. For instance, CT scans and X-rays involve exposure to radiation. Patients can also have allergic reactions to medications.

Furthermore, one test can lead to another. An MRI or CT scan might uncover some "inconsequential abnormality" and the doctor may feel compelled to order an invasive biopsy as a precaution. Going for the biopsy could raise the patient's anxiety level. The

procedure might also cause discomfort or the site could get infected. “So a cascade of things can follow from a test that wasn’t needed in the first place,” she explains.

Choosing Wisely represents the combined efforts of a broad range of medical disciplines. Specialists from various fields got together to identify problem areas. In April 2014, eight national medical bodies – plus the Canadian Medical Association – released a list of 40 tests, treatments and procedures that may be overused and possibly causing needless harm to patients. More items will be added to the list as experts in other medical specialties complete their scientific reviews and find evidence of over-use, waste and potential harm.

Choosing Wisely is modelled after a similar U.S. campaign that made its debut in 2012. It was spearheaded by a foundation of the American Board of Internal Medicine.

Dr. Levinson, who has worked as a physician in both Canada and the United States, was also deeply involved in getting the American campaign off the ground. The U.S. effort involved a partnership with Consumer Reports, which put together explanatory materials that were posted online for patients and their families.

“Consumer Reports is a highly trusted source of information because they are completely independent of any funds from industry,” says Dr. Levinson.

Choosing Wisely Canada is using material developed by the U.S.-based Consumer Reports for its own website. “We’ve modified it, Canadianized it,” she adds. “We also translated everything into French.”

The website is meant to serve two groups – physicians and the public. For doctors, the site provides detailed recommendations from the various medical bodies. And for patients and their families, the site explains in plain language why they might not always need a test or treatment for a variety of common conditions.

So, getting back to your question about diagnosing back pain, this is one of the topics highlighted in the patient materials. “Most people with lower back pain feel better in about a month whether they get an imaging test or not. In fact, those tests can lead to additional procedures that complicate recovery,” says the website.

It goes on to say that an imaging test is needed only when there are certain “red flags” such as:

- a history of cancer
- unexplained weight loss
- fever
- a recent infection
- loss of bowel or bladder control
- abnormal reflexes, or loss of muscle power or feeling in the legs

But is it possible that your pain may be caused by a new, and previously undetected, cancer in the spine? That's unlikely, says Dr. Levinson. "Spinal-cord tumours are extremely rare," she adds.

If a tumour were pressing on the nerve, you would be experiencing clearly identifiable neurological symptoms that would have been apparent when the doctor performed a physical examination. And, as you noted in your question, your family physician found no indication of leg weakness or numbness.

The website also offers some basic advice to aid recovery and help ease the pain, such as applying heat, taking non-prescription medications and remaining physically active. (Inactivity can be counterproductive.)

If the problem persists, or new symptoms emerge, then it's worthwhile seeing the doctor again. At the follow-up appointment, your doctor may think that it's time for an imaging test. The campaign's key message is that a test or therapy should not always be the first response to certain ailments.

"We want people to pause and think," says Dr. Levinson. "Let's reflect on it and make a good decision."

She says some tests can be safely delayed, or avoided entirely, because there is a good understanding of the "natural history" of many common medical conditions.

In medical parlance, natural history simply means what happens to most patients when a condition is left untreated. "If you think someone has a serious illness like leukemia, you don't wait to do the test, you do it immediately, because you know from the natural history of the disease that the patient will get worse without treatment."

Back pain, by contrast, has a very different natural history. It tends to remain the same or get better on its own over a period of time.

Choosing Wisely is reaching out to other organizations to bring them on board. Patients Canada, a group aimed at improving patient care, has endorsed the campaign.

"We think it will help foster a more collaborative relationship between patients, family members and doctors," says Michael Decter, chair of Patients Canada. "There should be a pretty thorough discussion with your doctor before you receive a test or treatment."

Financial assistance and support for Choosing Wisely Canada has come from the Ontario Ministry of Health and Long-Term Care, the University of Toronto, the Canadian Medical Association, the Canadian Institutes of Health Research and the Commonwealth Fund.

Dr. Levinson emphasizes that the main intention of the campaign is to improve patient care, rather than save the health care system money. Even so, the initiative, if successful, should help conserve limited health care dollars. As Mr. Decker puts it: "Inappropriate tests use up a lot of resources."

- **Paul Taylor**

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MY DOCTOR LOOKS THINGS UP ON HIS SMARTPHONE. IS THIS A DISTRACTION OR GOOD MEDICINE?

Question: My son had what seemed to be an infection in his mouth. I took him to a walk-in medical clinic, and the doctor there had a look. The doctor took out his smartphone and started doing something on it, then announced his choice of antibiotic to prescribe. The doctor, by looking it up on his phone, kind of made me lose confidence in him. Was he just Googling? Is there some special site that medical professionals can access? Why didn't he just know what to prescribe? My wife says it's the same thing as if he looked in a book. But the use of the smartphone feels different. I mean, I could have looked at WebMD myself!

Answer: The doctor was likely accessing one of the many new medical resources that are now available online. But you shouldn't be alarmed when your doctor turns to the Internet before writing a prescription. In fact, it's actually a good thing.

"It means the doctor wants to be right as opposed to relying on his memory – memory is fallible," explains Dr. David Juurlink, a staff physician and drug-safety researcher at Sunnybrook Health Sciences Centre.

It's also a positive sign that he looked up the information while you were watching him. That indicates the doctor felt comfortable admitting he doesn't know everything, "and that is a trait every physician should have," says Dr. Juurlink. "The three most powerful words a doctor can say are 'I don't know.'"

Indeed, a cautious approach – and the willingness to double-check – reduces the risk of the doctor making a mistake that could jeopardize your health.

From your question, it's clear that you feel very uncomfortable with the doctor relying on the Internet. It's true there's a lot of junk on the web. However, it's also an invaluable source of data if you know where to look and you have the expertise to discern what's reliable.

"Twenty years ago a doctor would have to pull a book from a shelf – and that book could easily have been out of date," says Dr. Juurlink. "Now, in a matter of seconds, we can access information that is current and accurate. So why not use it?"

It's impossible to say which specific website, or app, the doctor consulted to select an antibiotic for your son.

"There are many good websites that doctors can use as resources – some of them are free, and some of them are not," says Dr. Juurlink. "Every doctor has a list of sites that they are comfortable with, that they know how to navigate and they have found to be useful."

In some cases, physicians are given special access to certain sites through their professional organizations or hospital affiliations.

Dr. Juurlink says one of his favourite online resources, provided by way of Sunnybrook, is called UpToDate, an excellent resource that contains reference materials for physicians. "It is a spectacular resource," he says. "If you can think of a condition, it's in UpToDate."

(If you're curious about other web-based resources that are popular among physicians, you may want to check out an article published November 17, 2013, in the Wall Street Journal, "Health care Apps That Doctors Use.")

As a specialist in drug safety, Dr. Juurlink knows a lot about prescription medications. Yet he is the first to acknowledge: "There are more things I don't know about drugs than I do know." And today's Internet allows him to fill in those knowledge gaps when a specific question arises.

In many respects, the recent expansion of online medical resources can be seen as an encouraging development that has the potential to reduce medical errors.

So don't be annoyed the next time your physician reaches for a smartphone. There is a good chance the doctor is tapping into the latest, most up-to-date medical information that applies to you.

- Paul Taylor

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WHAT CAN I DO TO HAVE SOMEONE TAKE A SKIN LESION SERIOUSLY?

Question: I suspect I have acral melanoma on my foot and I want an excision biopsy done. Most family practitioners are unaware of what it is, and they simply do not know what it is. I waited for a long time and saw a dermatologist who wasn't sure what it is either. He said it's a birthmark, even after I told him that I only had it for one and a half years and it grew over the period of time.

After reading some suggestions from melanoma survivors (who strongly think this

doesn't look good and need to be removed), I am trying to get an excision biopsy from a melanoma specialist, regardless of what it is, for peace of mind.

Answer: Right off the bat, doctors will tell you any new lesion is worrisome – especially one that is growing – and that it definitely needs to be seen. I like that you have reached out to melanoma survivors for advice and it sounds like they have been able to confirm for you that this mark on your foot looks suspicious.

The only part of your question that gives me pause is that two physicians have already seen and dismissed it – your family physician and a dermatologist, the latter of whom would be particularly well placed to spot a suspicious lesion. I do think you are correct to pursue a biopsy as you require a definitive answer; only a biopsy can provide that to you.

Your preference for a total removal of the lesion for “peace of mind” may be extreme, given that the growth is on the foot and if it's large, it could involve a skin graft or a rotational flap to reconstruct the area, according to Dr. Frances Wright, a surgical oncologist at Sunnybrook Health Sciences Centre, who specializes in melanoma.

“He needs to have someone look at it,” Dr. Wright says. “If it needs a biopsy, then it may need to be an incisional biopsy [removing the most suspicious area] rather than an excisional biopsy [removing the whole area] to minimize the morbidity of the reconstruction. Most general surgeons can biopsy the foot.”

There are four major types of melanoma: superficial spreading, which is the most common, making up 70% of all diagnosed cases; and nodular, lentigo maligna and acral lentiginous, the latter of which accounts for about 5% of all diagnosed melanomas. Nodular melanoma accounts for 15% of cases, while lentigo maligna represents 10% of cases.

The type you wrote about – acral lentiginous melanoma – is a common form of melanoma in Asians and those with dark skin. It is sometimes referred to as a “hidden melanoma” because the lesions occur on parts of the body that are typically not easy to examine – or even that one may not necessarily think to examine. These melanomas present on the palms of the hands, the soles of the feet and the mucous membranes, including those that line the mouth, nose, female genitals and anus, and underneath or near the toenails and fingernails.

In your case, the lesion has appeared on the sole of your foot. Typically, melanoma looks like a black spot. Sometimes people mistakenly believe the mark is due to bruising or a recent injury.

Doctors are taught that the classic signs of a melanoma are asymmetric lesion, irregular borders, change in colour or multicoloured, diameter of more than 6 millimetres, or ulceration or bleeding.

“If it looks suspicious, you need to do a biopsy,” says Dr. Wright, associate professor of surgery at University of Toronto. “Something new that is changing can be worrisome. In the end it’s going to be a discussion between the physician and the patient on how worrisome it is.”

Sunnybrook’s Odette Cancer Centre is the only place in Canada that has a pigment-ed skin lesion clinic; it runs every Monday. There, you can have your suspicious lesion looked at by a dermatologist and an oncologist, if need be. You can access it if you are referred by a family physician through our central referral fax number, 416-480-6179, or referral telephone number, 416-480-4205.

“The majority of patients – 70% of melanomas – present with a depth of less than 1 millimetre and have a very good outcome,” according to Dr. Wright. “There are a proportion of melanomas that do present deeper and can be life-threatening.”

Another alternative is that you return to your family physician and ask to be referred to a general or plastic surgeon to do a biopsy and if necessary, remove the lesion. Many dermatologists perform these biopsies as well.

I agree you need to vigorously pursue this, to get a biopsy and a definitive finding. The biopsy alone will likely give you that peace of mind you seek.

- *Lisa Priest*

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LACKING A FAMILY DOCTOR, MY SISTER WENT TO THREE WALK-IN CLINICS, ALL OF WHICH WERE NOT ACCEPTING PATIENTS. SHOULD SHE HAVE GONE TO THE EMERGENCY ROOM?

Question: Late one afternoon, my sister, who is in her 30s, started having bad stomach pains. She decided to wait it out a little. But the pain persisted and at about 5 p.m., she decided to head to the walk-in clinic (newish to the city, she doesn’t have a local family doctor). She didn’t want to go to emergency because she didn’t think her issue was severe enough. I went with her to one walk-in clinic.

While the hours on the door said open until 8 p.m., they were no longer accepting patients. It was packed in there! We went to a second walk-in clinic. They, too, were extremely busy and not accepting any patients. We drove across town to a third clinic only to find it closed entirely (out-of-date website, maybe). So, if patients aren’t supposed to go to emergency unless it’s a real emergency and walk-in clinics are too busy to see people in the evening, what should we do?

Answer: A leading cause of emergency department visits is abdominal pain. At Sunnybrook Health Sciences Centre, it represents about 10% of visits, according to Dr. Jeffrey Tyberg, chief of the Department of Emergency Services. Abdominal pain is a

“perfectly legitimate” reason to go to emergency, and in fact, he is concerned that your sister’s symptoms were such that she went to three walk-in clinics for help – all to no avail.

“Abdominal pain – especially in a woman – can be a serious problem,” Dr. Tyberg says. “You have to decide if it’s worth the wait. She was concerned enough that she went to three walk-in clinics.”

In your sister’s case, her abdominal pain could have been due to medical emergencies that could pose serious threats to her health and potentially threaten her fertility. They include conditions such as ectopic pregnancy, appendicitis, ruptured ovarian cysts and ovarian torsion.

“It can be something benign,” points out Dr. Tyberg. “But it can be something serious. Acute, severe abdominal pain in a young woman is certainly a medical emergency and requires urgent assessment.”

Canadians make close to 16 million visits to emergency departments each year, according to the Canadian Institute for Health Information. With abdominal pain being one of the leading causes – no precise figure is available – it constitutes a challenging component of emergency medicine.

Diagnosis is not easy and typically involves physical examination, internal examinations and an array of diagnostic tests. That’s largely because belly pain can be due to referred pain, as there are many different organs within the peritoneal cavity. Some causes include peptic disease, pancreatic disease, inflammatory bowel disease, gastroenteritis, biliary colic, myocardial infarction and a ruptured spleen.

Tools for examining abdominal pain are far from perfect. Though CT scans can rule out many life-threatening causes of abdominal pain and reduce the need for exploratory surgery, they sometimes don’t lead to a definitive diagnosis. They also expose patients to significant doses of radiation.

Ultrasound, both at the bedside and in the diagnostic imaging department, can help determine or rule out important causes of abdominal pain, says Dr. Tyberg.

Many patients who go to Canadian emergency departments with abdominal pain leave with the comfort of knowing the cause is not life-threatening but without knowing precisely what precipitated it.

While your sister was trying to be a responsible user of health services, if she visited three walk-in clinics, that was probably a sign the pain was severe enough to warrant a visit to emergency.

It would have been best if your sister had a family doctor who could have quickly seen

her. Health Care Connect (www.health.gov.on.ca/en/ms/healthcareconnect/public) helps Ontarians without a family health care provider to find one.

There is another service called Telehealth Ontario (1-866-797-0000 or www.health.gov.on.ca/en/public/programs/telehealth), where patients can obtain free, confidential advice from a registered nurse. It does not replace 911.

Another way to find a family physician is to wait until July, when a new crop of them graduates and they are starting to build their practices and are open to new patients. A university's department of family medicine, the college of physicians and surgeons in your province and, in some cases, the health ministry will have that information.

- Lisa Priest



IN THE HOSPITAL

WHAT CAN I DO TO HELP MY FATHER, WHO HAD DELIRIUM?

Question: My father was recently in a hospital to have a heart operation. During his recovery in the intensive care unit, his behaviour was very strange. He seemed confused and agitated and he was even rude to my mother. My father is usually a kind and gentle man. He wasn't acting like himself. The hospital staff said he was suffering from delirium. What is delirium and how common is it?

Answer: Delirium is very common, especially for patients in a hospital's intensive care unit. Although the ICU provides special one-on-one care for patients in critical condition, the busy nature of these medical environments can sometimes contribute to the development of delirium.

As you likely observed, each patient is watched over by a nurse, usually stationed at the foot of the bed. The patients are hooked up to monitoring equipment and life-support machines that often sound alarms. They also undergo frequent poking and prodding for round-the-clock medical tests.

All this commotion can prevent patients from getting adequate sleep. To further com-

plicate matters, they are usually on heavy-duty pain medications and other sedating drugs that add to their mental fog.

And, most important, they are not well – or they wouldn't be in the ICU in the first place.

These factors, all combined, create a kind of perfect storm that can lead to this distressing mental state.

“Delirium is very frightening for families. Your relative, who previously seemed to be totally normal, is now out of it,” says Dr. Andre Amaral, a critical-care physician at Sunnybrook Health Sciences Centre.

“It happens to about 50% of our patients” in the ICU, he says, adding that the degree of delirium varies greatly from one person to the next.

Some patients experience only mild confusion or become quiet and withdrawn. Others may not be able to recognize their doctor, their nurse or even their own family members and can react in a paranoid fashion.

In the worst cases, they could try to pull out their intravenous (IV) lines, might pose a danger to themselves and may need to be sedated with additional medication.

This state of confusion can fluctuate over the course of a single day. You might have noticed this pattern with your father. He may have seemed fine when you visited him in the morning. By the time you returned in the evening, he may have become very restless and agitated.

Doctors readily acknowledge they still have much to learn about what's actually happening to the brain in these circumstances. But delirium seems to be part of overall organ dysfunction in patients who are very sick.

The chances of developing the condition increase in those who are suffering from multiple medical problems such as heart, lung and kidney failure.

“When you become critically ill, all the organ systems of your body are going through a partial shutdown and the brain does the same thing. Because the brain is so complicated we don't fully understand it,” says Dr. Brian Cuthbertson, chief of Sunnybrook's Department of Critical Care Medicine.

Heart patients like your father may be especially vulnerable to developing delirium. “If you have blood vessel problems around your heart, you probably have similar problems in your brain,” says Dr. Shelly Dev, a Sunnybrook critical-care physician. In other words, restricted blood flow to the brain could further tax mental functions.

Even patients who are less critically ill may experience various forms of delirium. Think back to times when you've had a high fever. You might have felt like you were in some kind of trance.

So it's important to keep in mind that some patients who are actually doing well in their recovery can also become delirious, says Dr. Amaral.

And it is not necessarily a sign your loved one has taken a turn for the worse. In these cases, "I like to say it is a little bump on the way," adds Dr. Amaral.

How much of this experience will patients remember after they've left the ICU?

"It's hard to predict for an individual patient what they are going to remember and how unpleasant those memories are going to be," says Dr. Dominique Piquette, another Sunnybrook critical-care physician.

"Some people recall bits of it, which are not always pleasant memories. And it is all a bit blurred," adds Dr. Piquette. "Others have a complete blackout and don't remember anything ... which can be distressing to have lost a chunk of their lives."

Dr. Amaral says, "Some people have symptoms of anxiety, stress and depression once they come out of the ICU."

However, the good news is that family members can sometimes be extremely helpful in comforting delirious patients, says Dr. Dev.

The ICU can be an alienating place, filled with unfamiliar sights and sounds. So, hearing the voice of a loved one can be reassuring. "I tell the families they are instrumental to healing the patient," she says.

When patients stir to consciousness, they may not be aware they are in a hospital. "There are not many windows in the ICU. There is a lot of noise and a lot of things happening," explains Dr. Dev. "You wake up with a tube in your throat, or someone is suctioning fluid buildup in your lungs. It can be terrifying."

Part of the healing involves "reorienting" the patients so they find their way out of the mental abyss. Dr. Dev provides families with the following tips for aiding the recovery process: "Ask them their name, where do they think they are, do they remember what's happened. And if they get frustrated with all the questions, remind them who you are and why they are in the hospital. "

Don't be afraid to tell your loved one the true nature of their medical condition. Some families are reluctant to do so, preferring to shield the patient from more stress and worry. "It's more frightening not to know what's going on and have everyone say you're fine. You start to think you're crazy because you don't feel fine," says Dr. Dev.

Help them get out of bed and walk around if, of course, they are capable of mobility. “It makes them feel more normal and less confined.”

Bring photographs from home and have other friends and family visit if the patient is in the ICU for a long time.

For patients who normally wear eyeglasses, or require hearing aids, make sure these items are readily available. When they can't see or hear properly, or there is a language barrier, they face a greater risk of feeling lost and confused.

Even having something as simple as a clock nearby enables patients to know the time and improves their grasp on the world around them.

Many things can be done to minimize delirium or shorten its duration – and some of them involve family members playing active roles in helping to reorient the patient.

However, there are times when it's not appropriate for relatives to be at the bedside – such as when hospital staff must perform certain procedures. After all, an extended family can include a wide range of relatives, notes Dr. Cuthbertson. “If you're doing intimate washing and caring, then you don't necessarily want an uncle, or an auntie, or a child being there.”

At Sunnybrook, family members are permitted to visit ICU patients at any time of day, although they may be asked to step outside as medical circumstances dictate.

ICU visiting hours vary from one hospital to the next. If your relative is in a hospital like Sunnybrook, with an open-door policy, try to be there during morning rounds.

This is when the medical team visits all the patients in the ward, assesses them individually and puts together a daily treatment plan. The rounds provide an opportunity for you to see the physicians who have the most up-to-date information about your relative's condition.

Keep in mind the doctors must visit numerous patients during rounds so their time is limited. If you have lots of questions, use this opportunity to make an appointment with the physician who is most responsible for your relative's care. At that later meeting, the doctor should be able to answer your questions, including those dealing with topics like delirium.

As a general rule, the patient's confusion and agitation will lessen as the overall medical condition becomes less critical. “The vast majority of people will improve significantly over a period of a few days or a week as they get better,” says Dr. Cuthbertson.

- Paul Taylor

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CAN INTERNATIONAL PATIENTS BUY CARE AT CANADIAN HOSPITALS?

Question: I would like to know if Canadian hospitals accept international patients and if so, what is the process? My brother needs a full check-up.

Answer: You would think hospitals would see patients like your brother as a way to generate monies to help pay for all the other patients who come through their doors, but that is not the case.

Many hospitals do not currently accept international patients requiring non-urgent care – largely due to capacity issues – but that could change in the future. These hospitals are full, and so treating a paying patient could potentially mean displacing one covered under the Ontario Health Insurance Plan, which funds public health services for the province.

This is not the practice of every hospital. Some do charge a higher international rate to outside patients for procedures, so that they can use that revenue to open more beds. But that approach is taken after careful deliberation, after developing a policy for international patients, and usually for very specialized, lucrative procedures – not for routine check-ups, which by the way are not even funded in British Columbia, unless, of course, the doctor has a reason for doing the examination. Nova Scotia, Newfoundland and New Brunswick also do not cover them in symptomless patients.

No matter what decision a hospital makes on revenue generation, there is one thing that can never take place: allowing a paying patient to oust a Canadian patient who also paid for their health care through their taxes. When that happens, it violates the Canada Health Act, not to mention eroding citizens' confidence in the health care system. It would be a devastating consequence.

Even the sheer act of trying to bring patients to a hospital carries with it significant issues surrounding liability. "If you do anything to bring them here, you have to get private malpractice insurance," according to Sally Bean, ethicist and policy advisor at Sunnybrook Health Sciences Centre. "It gets quite complex pretty quickly."

If your brother came to the hospital with an urgent medical emergency with or without insurance, however, he would be treated because "there is a legal and ethical obligation to provide care," Ms. Bean says.

Dialysis is one example. If a patient requires it and can obtain it in their country of origin only by paying for it, that makes it inaccessible for many patients.

"It's tough because you would be sentencing people to death," says Ms. Bean, noting that in some cases, uninsured dialysis patients have had treatment provided to them.

Other types of patients include those without legal status who came here on a visitor's visa years ago but stayed, those waiting for their 90 days to pass before their provincial insurance kicks in, or tourists who have had a motor vehicle insurance accident but did not buy travel insurance. In the latter case, they would most certainly be treated here, but there would also be efforts to recover the cost afterwards.

"You have to find that reasonable balance, think about what is the fair response; then we have to be resource stewards with our public health care dollars," says Ms. Bean. "We have to ask: Is it justifiable? Are we disadvantaging Ontarians?"

As stewards of public funds, public institutions must be very careful of how they spend monies and must make sure they are doing so responsibly.

In answer to your question, Sunnybrook does not allow patients to come here for check-ups. And I expect many other Canadian hospitals do not as well.

It may be that institutions will look for revenue-generating opportunities in the future, but those will likely involve super-specialized procedures that they are particularly well known for performing.

- *Lisa Priest*

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HOW CAN I MAKE SURE I'M TREATED IN A TIMELY MANNER IN THE EMERGENCY DEPARTMENT?

Question: A friend recently went to a hospital emergency department with abdominal pain. She waited for a long time and eventually began to vomit. At that point, they finally paid attention to her. It turns out her appendix burst. How could something like that happen in a hospital waiting room? Shouldn't she have been seen sooner?

Answer: It's unfortunate that your friend's appendix burst under those circumstances.

The front-line triage nurses try to accurately assess the seriousness of each person's condition to determine the order in which patients are to be seen by a doctor.

As your friend discovered, the system isn't perfect. Many unpredictable factors can affect how promptly patients are treated, including the number of other people seeking medical assistance, and the severity of their injuries and ailments.

All Canadian hospitals follow the same general procedures for processing patients who show up at the emergency department. They are assessed by specially trained triage nurses who rank each patient based on the Canadian Emergency Department Triage and Acuity Scale.

“The triage nurse is trying to identify the patients that if not dealt with immediately, or as soon as possible, there is a risk of death or that their condition could deteriorate quite quickly,” says Ray Howald, a clinical nurse educator for the emergency department at Sunnybrook Health Sciences Centre.

Ideally, patients should talk to a triage nurse within 10 minutes of their arrival. By asking a series of questions and taking some vital signs, the nurse ranks patients on a scale of 1 to 5 – with 1 being the most serious and 5 the least.

“We are basically deciding how long the patient can safely wait to see the emergency department physician,” says Mr. Howald.

Take, for example, the case of a broken leg. Not all breaks require the same response time. “If there is no pulse and the foot is cold, this may indicate injury to the veins or arteries, and this needs to be treated very quickly because the patient could lose their foot,” explains Mr. Howald. “If the patient comes in with a simple broken leg which shows no signs of symptoms of vascular damage – the patient can wiggle the toes, there is a pulse, the foot is warm – then this patient could wait longer than the patient with a similar injury and possible vascular damage.”

Here is a basic breakdown of the triage levels:

Level 1: The patients should be examined immediately by a physician and require aggressive interventions. Patients in this category include those suffering from cardiac arrest, severe respiratory distress or major trauma, or those in a state of shock.

Level 2: The patients should be assessed by a physician within 15 minutes from their arrival. Symptoms may include chest pains, head injury or gastrointestinal bleeding.

Level 3: Patients have a condition that could potentially progress to a more serious problem, such as mild to moderate asthma or shortness of breath. A physician should see these patients within 30 minutes.

Level 4: Patients with less urgent injuries such as minor fractures, abrasions, back pain, abdominal pain, vomiting but no signs of dehydration. Under ideal circumstances, they should be examined within an hour.

Level 5: Patients with non-urgent symptoms such as minor lacerations (not requiring stitches), sprains, sore throat and abdominal pain. They can safely wait up to two hours or more before a physician examines them. In fact, treatment could be delayed or referred to other areas of the hospital or the health care system.

The triage nurse rates each patient in just five to eight minutes. “It is a very rapid assessment because the nurse is trying to get to every patient as quickly as possible,” says Mr. Howald.

Although the ratings are based on well-researched guidelines, the nurses also rely on their intuition of how they think the patient looks.

“These are experienced nurses and they just have a feeling when something is wrong,” he explains. “It is not very scientific by any means, but it is very relevant in the medical profession. You trust your instinct and go with it.”

Once this initial rating process is completed, there is a possibility a patient's condition could change – either for the better or for the worse.

The nurses are required to keep an eye on the patients in the waiting area. But this can sometimes be difficult to do in a thorough manner, especially at those times when there is a constant influx of new cases.

“We always instruct patients, if their condition gets worse, if their pain is worse, or if they feel like they are getting worse, to let us know,” says Mr. Howald.

A family member, or an accompanying friend, could also inform the triage nurses that the patient's condition appears to be deteriorating.

“We can reprioritize who will come in next,” says Mr. Howald.

Still, it can be difficult to always get the order right. And in the case of your friend whose appendix burst, she was clearly not seen soon enough.

But it's important to keep in mind that how quickly patients are treated partly depends on the availability of acute-care beds in the hospital. If there's a shortage of free beds in the wards, then you can get a backlog of cases in the emergency department. “Access block can contribute to the increased length of stay in the waiting room,” explains Mr. Howald.

He also points out that people suffering from appendicitis don't always display the same symptoms, or their cases may have advanced to a higher level of urgency.

“Patient A might have waited two days before deciding to come into the emergency department. Patient B might have come in right away,” he says. “Depending on how long they have had their symptoms, that can dictate what their outcome will be.”

Appendicitis isn't the only diagnostic challenge in the emergency department.

Numerous studies have found that men and women may have different symptoms when they are experiencing a heart attack – and those variations can affect how quickly they are treated in the emergency department. For instance, men usually suffer severe chest pain – a well-recognized sign of a heart attack – and that means they tend to get prompt attention. Some women and also some men, on the other hand, have more

diffuse pain and it may take longer for their problem to be identified.

A study in the Canadian Medical Association Journal found that men suffering a heart attack tended to be treated somewhat faster than women. The researchers looked at a group of about 1,100 cardiac patients between the relatively young ages of 18 and 55. A total of 24 Canadian hospitals, plus one medical centre in Switzerland and one in the United States, took part in the study.

Patients suspected of having a heart attack should receive an electrocardiogram – which measures the heart's electrical activity – within 10 minutes of their arrival at an emergency department. If a heart attack is confirmed, they sometimes require drugs to unblock clogged coronary arteries, and the drugs should be given within 30 minutes of arrival.

The study revealed that the average wait for an electrocardiogram was 15 minutes for men and 21 minutes for women. The men were also administered the clot-busting drugs at a faster rate: an average of 28 minutes versus 36 minutes.

As part of the study, the patients later completed a questionnaire that is used by psychologists to measure masculine and feminine personality traits. The results of this survey provide further insight into why some patients are treated sooner than others, says the study's lead author, Dr. Roxanne Pelletier, a clinical psychologist at McGill University Health Centre in Montreal.

Indeed, both women and men with higher “femininity” scores waited longer for care. But more “masculine” traits increased the likelihood of getting quicker treatment.

This suggests that sex alone – being either male or female – isn't the sole factor that's determining promptness of care. Instead, certain personality characteristics – like being more or less assertive – play a role, too.

Dr. Pelletier believes her study provides valuable lessons for patients who end up in the emergency department. “People need to know that when they come to the emergency room they need to be precise, concise and assertive,” she says.

Dr. Pelletier points out that the triage nurse has a relatively brief period of time to question each newly arrived patient. So patients who aren't concise in their answers may end up delaying their own care.

“If they feel chest pain, this must be the first symptom they report and they must put the emphasis on this symptom to expedite their treatment.”

This discussion of heart attack patients may seem like a digression from your original question about a burst appendix. But I hope it illustrates that patients can do things to increase their chances of getting timely and effective medical care.

And, in particular, it's critical to be clear and concise about your symptoms.

Once you've been assessed, it's extremely important to notify the triage nurses if there's a change in how you're feeling. They need to know if you have taken a turn for the worse.

There are other things that you can also do to speed up your initial processing. For instance, Mr. Howald says be sure to come prepared with the following:

- your health card
- your family doctor's name
- a list of your current medications
- a list of any allergies and diagnosed medical conditions

Having these items on hand can help make your time with the triage nurse more efficient.

- Paul Taylor



SENIORS

MY ELDERLY MOTHER SEEMS READY FOR DISCHARGE AT THE HOSPITAL, BUT WE DON'T THINK SHE'S READY TO GO HOME. WHAT SHOULD WE DO?

Question: My mother is in hospital. We feel she is not well enough to go home as she cannot get up to go to the bathroom or walk, but they seem ready to discharge her. She walks with the help of a rollator and is medically stable. Our family wants her to stay in hospital because we are nervous about what happens when she goes home. What should we do?

Answer: This question came through our Office of Patient Experience and it is one that doctors hear frequently. There are a couple of things to note right off the bat: doctors only send patients home who are medically stable, and once that decision is made, the hospital often ceases to be the best place to convalesce.

“One problem is that because you are in hospital, you may wind up staying in bed more than you would in your own home,” says Dr. Steven Shumak, former head, Division of General Internal Medicine at Sunnybrook Health Sciences Centre. “Not only does that weaken or decondition you, it also sets you up for complications in your lungs as you

are less likely to take deep breaths when in bed. In fact, every moment you spend in hospital increases the chance of a complication or infection.”

In hospital, patients tend to become less active and they quickly lose their muscle. That deconditioning causes them to stay in bed longer, creating this vicious cycle that can be difficult to break.

This is a significant concern for many hospitals, including Sunnybrook, where the average age of patients cared for by internists like Dr. Shumak is 80 and the length of stay for them is around six or seven days.

Patients admitted to medical beds are acutely ill, coming through the emergency department. Common diagnoses include pneumonia, stroke, difficulty breathing, heart attack or internal bleeding. They are some of the sickest and most complex patients doctors will treat and they are growing in numbers.

Seniors are the fastest-growing segment of the population; currently about 4.8 million Canadians are aged 65 and older. That figure is expected to more than double to 10.4 million by 2036, and by 2051, one in four will be older than 65.

Oftentimes, living a long life means living with several chronic medical conditions that require skilled clinicians to manage, especially when it comes to different medications.

For some patients who are older, the mere act of being admitted to hospital, with the changing faces of health providers, unfamiliar routine, bright lights and sleep disturbances, can be enough to precipitate delirium, a medically significant event characterized by sudden, severe confusion. Delirium doubles the length of a patient's hospital stay for any given diagnosis.

“When it starts, delirium will typically begin at night, perhaps because people no longer have the visual cues they depend on,” says Dr. Shumak, an internist who has practised medicine for more than a quarter century. “It's very serious but beyond that, delirium can be persistent. It can be like a hangover you don't get over.”

So I do share your concern about what happens when a patient goes home – and seemingly is out of the hospital system. “No matter which way you slice it,” says Dr. Shumak, “most patients are better off at home than they are in hospital.”

- Lisa Priest

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SHOULD WE SELL MY MOTHER'S HOUSE WHILE SEARCHING FOR A NURSING HOME?

Question: My mother is searching for a long-term care home for my father and be-

cause of the expense involved, she will probably end up selling her house and looking for a new place for herself to rent. I can't imagine that this is the best way to go – it just seems like we are extending my father's hospital stay somewhere else at our expense and now my mother is going to be out of her home. At least at the hospital, my parents are not draining their resources paying for my father's care.

Answer: It can be daunting to search for a long-term care facility at the last minute when returning home is no longer possible for your father. You also face the sad reality that your parents, after being together for years, may not be able to live together any longer.

Though it seems like a nursing home is costly compared with the hospital, the monthly payment is only for the “living portion” – room and board – of the facility, as the medical care is still funded by the provincial health plan.

The fees for these homes – there are about 630 in Ontario – include, among other things, meals, bed linens, having medication administered and assistance with the essential activities of daily living. There are additional costs for cable television and hairdressing.

According to Donna Rubin, chief executive officer of the Ontario Association of Non-Profit Homes and Services for Seniors, a spouse will not be forced out of their home to afford long-term care.

“There is certainly no need to sell a house,” Ms. Rubin says. “If you can't afford it, the government steps in and provides the long-term care home with a subsidy on your behalf, so there really is no need to sell the family home. In fact, if the spouse is still living at home, a ‘special circumstances’ application may be made to reduce the resident accommodation charges even further.”

The fees for nursing homes are regulated, costing in Ontario per month \$1,674.14 for a basic room, \$1,947.89 for a semi-private room and \$2,274.86 for a private room. The short-stay or temporary stay at a home costs \$1,083.75 per month, according to 2012 figures from the health ministry, the latest available.

Retirement homes – where about 40,000 Ontario seniors reside – can also be an option, though their residents generally tend to be healthier. The cost of these homes ranges from \$1,200 a month to \$6,000 a month.

In some cases, it can be worth exploring the cost of hiring help inside the home, such as a personal support worker – especially if it will keep the couple together for longer, according to Betty Matheson, patient care manager at Sunnybrook Health Sciences Centre, who manages specialized geriatric services.

“The costs do vary for care at home, depending on the services you require,” says Ms.

Matheson. “The family should weigh the affordability of care in the home, compared with the costs of a nursing home. That way, your parents can spend their days happily in their own setting.”

That hired help would almost always be in addition to any funded help you may receive, such as assistance through the Community Care Access Centre.

“I would really explore all those options and see what’s the best for you and your family,” says Ms. Matheson.

However, she points out that not all people are candidates for staying at home with hired help.

“If Dad is in such a state that behaviourally he is not safe at home – he wanders or becomes aggressive – sometimes there is no option except a nursing home for the safety of everybody involved,” she says.

Ms. Rubin, whose provincial association represents not-for-profit long-term care homes, seniors’ housing and community service agencies, offers several tips on what to look for. She suggests you ask about the ratio of staff to residents and how many residents are under one personal support worker – the ratio for the latter typically ranges between 1 to 10 and 1 to 13.

She recommends that you go to one of the homes you are interested in and spend time observing staff. Is it a welcoming atmosphere? Do staff members know the names of the residents? Is the facility clean and in good repair? Is the call bell within easy reach? Does the food look appetizing?

What kind of volunteer support does it have for any number of activities, including feeding? She also suggests that you try to determine how committed the home is to maintaining the independence of its residents: incontinence programs and other programs to regain function – such as eating and walking – would be ones to seek out.

- Lisa Priest

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HOW CAN I GET MY MOTHER THE HOME CARE SUPPORT SHE NEEDS TO LIVE INDEPENDENTLY?

Question: I’m getting really worried that my mom cannot cope at home. She is 85 years old and has severe shortness of breath from bad heart failure, but she has still been able to live independently. Unfortunately, she fell while walking up the stairs three days ago and now has trouble standing because of soreness in her knee.

We took her to the hospital and there was no fracture found on her X-ray. The doctor

referred us to a physiotherapy clinic but my mom has so much difficulty getting to and from her car that she cancelled her physiotherapy appointment. At home, she is also having trouble dressing herself, showering and cooking. We have asked her about home care help and maybe even a move to a long-term care home but she refuses to hear of it. What should we do?

Answer: When illness requires people to accept support from caregivers, this realization can be difficult and troubling. Although people may deny their need for support, simple tasks such as maintaining personal hygiene and caring for themselves can easily become challenging without help from others.

In Ontario, Community Care Access Centres (CCACs) are the coordinators of home care and community care for those in need of extra help. The costs of CCAC services are completely covered by the government, and anyone, including doctors, patients and family members, can contact their local CCAC. There are 14 CCACs in Ontario and you can locate your mother's CCAC by entering her postal code on the website at www.healthcareathome.ca or by calling 310-CCAC (2222).

When you contact the CCAC, a care coordinator will discuss your concerns with you and arrange a time to meet with your mother and review the supports she needs. CCAC care coordinators are registered health professionals (nurses, social workers, rehab therapists) whose job is to help people find their way through the health system. CCACs use standardized tools to assess each person's needs, including their personal values and goals, health concerns, decision-making abilities, memory, mood, non-financial resources and social supports.

The CCAC care coordinator would help your mother develop a care plan that could include services provided by the CCAC or involve arranging other services in the community. Services in the community – such as meals programs, homemaking help, transportation to medical appointments – are provided by community support agencies and may require a financial assessment and a co-payment.

If your mother needs services from the CCAC, there are different programs to help her. Since your mother is recovering from a fall, the CCAC could provide physiotherapy to help her with exercises to improve her walking, or personal support to help her with personal care such as showering and getting dressed.

Other types of services, depending on your mother's health needs, might include nursing care; occupational therapy to identify medical equipment aids and improve home safety; social work to provide support for social and mental health issues; and nutritional counselling. CCACs also have very specialized care for people with more complex health issues, such as nurse practitioners, pharmacists and telehome care support, which provides a nurse to monitor vital signs for people with serious health conditions.

If your mother's health condition deteriorates and she is no longer able to live at home, the CCAC will also help her apply for long-term care. CCACs are responsible for the application process, determining eligibility and managing the wait lists for long-term care home beds in Ontario.

Although many services are available through the CCAC, there are a few important limits to take note of. With respect to nursing and personal support workers, there are limits on the amount of care your mother can receive from the CCAC. CCACs do not provide 24-hour care except for very short periods of time and in limited circumstances.

Levels of support provided to an individual will depend on their initial assessment and care place. For people who need the highest levels of care – such as people with multiple conditions who are completely unable to care for themselves – the maximum level of nursing service from a CCAC is 28 visits or 43 hours of care within a one-week period.

For personal support services, the maximum amount of care a CCAC can provide is 80 hours of service in the first 30 days and 60 hours for the next 30-day period. You can review the specific limitations on CCAC care at www.health.gov.on.ca/english/providers/pub/manuals/ccac/cspm_sec_7/7-2.html. People who require higher levels of care may be more appropriately cared for in hospitals or in long-term care homes.

You should also note that every region of the province is served by a CCAC, and where you live determines which CCAC you can receive care from (find your CCAC at www.healthcareathome.ca). Each CCAC offers different types of services and different levels of care to its community. As well, some CCACs have had wait lists or longer wait times for services, depending on historical differences in how the CCACs were funded.

The government has recently increased funding to home care and is looking at a new and more fair model for funding CCACs. Whether this will address the wait lists or improve the quality of care within the CCACs is not clear. You can keep track of the quality of care in CCACs through Health Quality Ontario's web-based public reports (www.hqontario.ca/public-reporting/home-care). CCACs also produce an annual quality report that identifies their current performance and where they are improving quality of care.

As the family member of a potential CCAC client, it is essential for you to be an advocate for your mother and to provide feedback to the CCAC, either to give positive comments or to raise concerns about the quality of the service. Your care coordinator at the CCAC is a key point of contact, and you can learn more about providing feedback to the CCAC here.

If you're hesitant to contact your local CCAC or are unhappy with the outcome of the feedback you already provided, you can contact the long-term care action line, where

you will be referred to an independent complaints facilitator. This individual is meant to serve as a neutral mediator between you and the CCAC. If the facilitator does not resolve concerns, an appeal of CCAC decisions can be sent to the Health Services Appeal and Review Board of Ontario (www.hsarb.on.ca).

Some individuals may prefer an alternative to the CCAC or may wish to supplement the services received. If this is true for you, home care can also be arranged through out-of-pocket payments to a health care agency or through the Live-in Caregiver Program coordinated by the Canadian government.

Whichever way, there are many options for obtaining support for your mother. If she ultimately agrees to receive home care, she should be able to continue living at home safely and maintain a relative amount of independence. You and your mother should consider contacting your local CCAC or speaking with a health care agency to begin the process of arranging home care.

- Ayodele Odutayo

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DO I NEED A LIVING WILL?

Question: I have been following the news about the Supreme Court of Canada's ruling involving Hassan Rasouli, the patient who has been on life support for three years. The case has made me think that I should create some instructions about my medical treatment if I am ever in a situation in which I am unconscious. I've heard of living wills. Is this my best option?

Answer: A living will is basically a written document outlining your wishes for your medical care if you are unable to speak on your own behalf.

For instance, if you're living with an incurable illness — or even if you're perfectly healthy but want to be prepared for the unexpected — you might state you don't want to be put on feeding tubes or mechanical breathing that could prolong your life.

While it can be helpful to write down your wishes, medical professionals who specialize in end-of-life care say it's far more important to select someone who can make decisions on your behalf if you cannot, and to have conversations with this person about what is important to you. This process is called advance care planning. It also involves communicating with other key loved ones and your health care providers.

Why, you might wonder, do you need to engage in these conversations if you have a living will?

A major reason is that you can't possibly anticipate all the various things that might happen to you, explains Dr. Jeff Myers, head of the Palliative Care Consult Team at the

Odette Cancer Centre of Sunnybrook Health Sciences Centre.

As a result, a living will may be either too vague or too rigid to provide meaningful direction for an evolving medical condition. And this is true of any written document expressing wishes or preferences for future care.

It's also important to know that the legislation governing these documents, sometimes called advance directives, varies from province to province. Depending upon where you live in Canada, your caregivers may not be legally bound by your written instructions.

However, if your loved ones and health care professionals know your values and wishes, they can make difficult decisions accordingly.

Advance care planning “gets people to think about the things that bring meaning to their life,” explains Dr. Myers. “What do you believe in? What do you value? What do you worry about? This exchange begins to shape a person's goals for medical care.”

Dr. Myers points out that various studies have found people aren't very good at guessing what others may want – even when it involves a very close relative.

One person may want to live long enough to see a grandchild graduate from university. Someone else may value physical independence above all else. And yet another may have a strong desire to die at home.

Dr. Myers adds that a person's wishes for their medical care can change or evolve. “As an example, a young individual may consider dialysis to be a worthwhile life-extending treatment, whereas an older person with a number of medical conditions may consider dialysis to be overwhelming and something not worth pursuing,” he explains.

“That's why it is a conversation that needs to take place over a period of time.”

The Canadian Hospice Palliative Care Association has launched Speak Up, a national campaign to increase public awareness about end-of-life advance care planning.

You may want to check out the campaign's website, www.advancecareplanning.ca. It contains resources and a workbook to help frame your discussions.

The legal process for selecting a surrogate, or substitute decision-maker, varies across Canada. The website includes an overview of these jurisdictional differences.

Of course, it's critically important to pick a surrogate whom you can trust to abide by your wishes, says Louise Hanvey, a nurse and project manager for Advance Care Planning in Canada. “They have to understand that these are your wishes, even though they may not fully agree with them.”

Going through advance care planning eases the emotional burden on families at those times when a loved one can't communicate. It eliminates second-guessing, and the potential tensions that can arise within a family faced with such decisions.

"The research shows that when people have had these conversations, they have a better quality of death, their families are less stressed, and the grief process is usually better following death for the family members," says Ms. Harvey.

With this background in mind, let's return to your question about living wills. You may still feel a need to write down your wishes. But Dr. Shelly Dev, a Sunnybrook critical-care physician who has witnessed many families in the throes of making decisions for an incapacitated relative, says having a conversation beforehand is what matters the most.

"They need to hear it from you," says Dr. Dev. "A piece of paper is very abstract."
- Paul Taylor



SURGERY

DOES BEING PUT ON A CANCELLATION LIST FAST TRACK SURGERY?

Question: My right knee is worn out and I am waiting for an operation to have it replaced by a highly respected Toronto surgeon. I've been waiting months and my pain is getting worse. A friend told me I might be able to get an operation sooner if I got put on the doctor's cancellation list. How does that work?

Answer: It's true some surgeons have cancellation lists. If a patient doesn't proceed with a scheduled surgery – for whatever reason – someone on the cancellation list will get offered the spot.

The cancellation list seems like a good solution, but it's not as easy as it sounds, cautions Dr. Jeffrey Gollish, medical director of the Holland Orthopaedic & Arthritic Centre of Sunnybrook Health Sciences Centre.

For starters, you are not going to get much advance notice. You might receive a phone call from the doctor's office only a week to 10 days before the surgery, and very few people can drop everything else so quickly in order to move forward with the surgery.

“When my secretary calls them up, they will often say they already have a commitment

that week,” explains Dr. Gollish. “It is a very small percentage of people who will actually do it.”

And it's not just the day of surgery that you need to consider. It will take many weeks to recover from the operation. During that time, you won't be very mobile, you will be on heavy-duty pain medications, and you will need to devote yourself to physiotherapy.

So don't book a major overseas vacation if you are hoping to take advantage of a possible cancellation. If you have a job, you may want to let your employer know that you may need to take time off work without much advance warning.

“It's a huge challenge for people, and that's why the cancellation list is a limited option,” says Dr. Gollish. “People really aren't as available as they think they are.”

However, there are other ways you may be able to shorten how long you have to wait for knee surgery.

You mentioned that you are currently booked to have your operation with a “highly respected” Toronto surgeon. You can safely assume that a high-profile doctor is going to have a longer than average wait list. If you are willing to have the surgery performed by someone else, then you might be able to get a new knee in less time.

For instance, your surgeon may be able to recommend someone else with a shorter wait list. Or you could go through a centralized referral service run by the Local Health Integrated Network, or LHIN.

Back in 2006, the Ontario government set up a total of 14 LHINs across the province. Each one of these non-profit corporations works with health care providers and community members to determine local health-service priorities.

And, where you live, the Toronto Central LHIN has created a method of coordinating surgical services for certain high-demand procedures, such as total knee and hip replacements.

Your family physician can make a referral for you through a single fax number (1-877-411-4577) and may request the first available appointment with an orthopaedic surgeon within the Toronto Central LHIN, the first available appointment with an orthopaedic surgeon at a specific hospital or an appointment with a specific orthopaedic surgeon.

At some of the hospitals – including Sunnybrook's Holland Centre, Mount Sinai Hospital and St. Michael's Hospital – the patient is seen first by a specially trained advanced practice physiotherapist, who performs a comprehensive assessment and provides education about the condition. If the physiotherapist and the patient conclude a joint replacement is needed, an expedited appointment would then be arranged with an

orthopaedic surgeon.

(In other parts of Ontario, some – but not all – of the LHINs run similar referral services. “Others have used different approaches to wait times or aren’t facing the same challenges,” says Megan Primeau, a spokesperson for the Toronto Central LHIN.)

You also have one more option that may speed up your surgery date – and it depends on the condition of your knee. You noted in your question that your pain is getting worse. If your knee has seriously deteriorated from when you first saw your surgeon, he or she could move you up on the wait list.

You would need to book an appointment for a reassessment. “The surgeon will have to examine you and feel it’s justified to move you ahead of others, based on an objective assessment of the severity of your arthritis and functional impairment,” says Dr. Gollish.

Keep in mind that pain alone wouldn’t be a reason for changing your position in the queue.

“Most people are in the same basket,” he says. “They have got pain. They have limited range of motion. They can’t do the things they would like to do. And they would like to have the surgery.”

Provided you can be flexible and organize your life around the demands of the surgery, you might be able to take advantage of one of the shortcuts to the operating room. But if none of these options work, you should still talk to your family doctor about what can be done for your pain. Even the use of non-prescription medications can bring some relief as you wait for your surgery.

- Paul Taylor

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WILL I BE OPERATED ON BY A STUDENT AT A TEACHING HOSPITAL?

Question: I was recently in hospital to have some fibroids removed. It seemed there were a million people checking me out at each appointment! Who were all these people? I was told that it had to do with the fact that I was at a teaching hospital. What is a teaching hospital; does it mean a student might operate on me instead of the “real surgeon”?

Answer: You’re not the first person to ask this question. Many people feel uneasy about the thought of a novice involved in their care and treatment.

But studies show that patients at teaching hospitals receive care that’s just as good as the care at other medical centres, and possibly better.

Of course, it is true you may be asked the same questions by a lot of different people while you are at one of these hospitals. They're the next generation of health care professionals at various stages of their training, and they include:

- Medical students who are studying to be doctors. Most of those you see in the hospital will be in their final two years of medical school training.
- Residents who have graduated from medical school and are now acquiring expertise to practise in their chosen fields such as family medicine, surgery or oncology. Residency training can last from two to five years, depending on the field.
- Fellows who have completed residency training and are undergoing additional study in a subspecialty of their discipline. For instance, a surgeon may decide to focus on the heart.

In addition to medical students and doctors-in-training, you will likely encounter students from other health-related professions such as nursing, physiotherapy, pharmacy and social work.

All trainees learn through an incremental process in which they are closely supervised at each step of the way. After they have demonstrated competency in a particular task, they are then permitted to do it on their own, says Dr. Mary Anne Cooper, a gastroenterologist who is director of undergraduate medical education at Sunnybrook Health Sciences Centre.

Medical students start off by learning basic skills, such as listening to a patient's heart-beat with a stethoscope or taking a blood pressure reading. They don't play a significant role in surgery until they have graduated from medical school and have begun working on their residency requirements.

"An undergraduate student is never participating in surgery alone without extensive oversight and supervision, and their role would be to assist, not to conduct the actual surgery," says Dr. Ari Zaretsky, psychiatrist-in-chief and vice-president of education at Sunnybrook.

"I remember when I was a medical student, I had to stand for hours scrubbed up and observing" in the operating room, he recalls. The most responsibility he was given at that time involved holding a retractor – a tool used to pull back skin in order for the surgeon to gain access to underlying tissues and organs.

Surgery residents start their hands-on training by doing a small component of a much larger operation. As they master each skill, they are given more to do. By the time they have completed their residency – which takes five or more years – they are capable of performing an entire procedure without staff supervision.

It's also important to keep in mind that surgery is a team effort and there are lots of experienced people in the operating room.

You may also be relieved to learn that doctors-in-training often practise on dummies and artificial body parts before cutting into a live human being.

Huge advances have been made in operating-room simulations in recent years. The artificial hearts and parts often look like the real thing. These training exercises are similar to the learning processes for commercial jet pilots who practise takeoffs and landings on flight simulators.

Throughout their training, the residents, fellows and medical students work under the watchful eyes of staff clinicians, who remain ultimately responsible for the patients.

“Obviously, they have their reputation and everything else on the line,” says Dr. Zaretsky. “They are not going to download responsibility without thinking. They are going to be very cautious.”

As they gain more experience, the residents assume a larger role in caring for patients admitted to hospital or recovering from surgery. It is the residents whom you will often see working the gruelling overnight shifts.

With the residents involved in daily patient care, staff clinicians can devote more of their time to research, says Dr. Cooper, who is an associate professor of medicine at the University of Toronto.

In fact, one of the benefits of going to a teaching hospital is that the staff physicians are often at the forefront of medical innovation. They also tend to be the doctors who are willing to take on patients with complex conditions.

Over the years, researchers have done numerous studies that compared teaching hospitals with community medical centres. These studies are difficult to do properly because the patient populations are not always comparable. In particular, the teaching hospitals tend to be magnets for difficult medical cases.

“Despite the fact that teaching hospitals consistently take care of sicker patients, outcomes – including satisfaction outcomes – are typically as good as or better in teaching hospitals than in community ones,” says Dr. Kevin Imrie, Sunnybrook’s physician-in-chief.

So, in general, you should expect to receive top-notch care at a teaching hospital. But there is a catch: it may take a little longer to get through each procedure because there are additional people involved. Every patient examination is viewed as another learning opportunity for the group.

For instance, you likely saw a whole gang of trainees gathered around your bedside during morning rounds when the physician in charge of your care assessed your condition and drew up a treatment plan for the day.

Or you have been questioned by a resident, and shortly thereafter quizzed by a staff physician about the very same issues.

Some patients may find this repetition a bit annoying. But it is part of the teaching process and, to some extent, it is one of the safeguards to make sure nothing is missed.

In my time at Sunnybrook, I have had an opportunity to follow some doctors on their morning rounds, and the experience has bolstered my confidence in how the teaching system works. The trainees are eager to do their best. And, I think, senior staff benefit from the stimulating discussions with the students, residents and fellows. When they are reviewing a patient's case, all the care options are carefully weighed and considered. It's fascinating to watch.

I hope this explanation of a teaching hospital puts your concerns to rest. You may still feel tempted to ask the senior staff physician to perform your entire surgery – and not let the trainees touch you.

However, if you make such a request at a teaching hospital, don't be surprised to encounter some resistance. "Teaching is part of the mandate of our hospital," says Dr. Cooper. "This is what we do here."

- Paul Taylor

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WHAT ARE THE OPTIONS AFTER A FAILED SHOULDER SURGERY?

Question: My wife had arthroscopic surgery for a rotator cuff injury more than two years ago. Unfortunately, the surgery did not help because my wife is still experiencing severe pain intermittently. She did physiotherapy and lately she did shock wave therapy. Basically, we did everything. We want to get another opinion. Please help us on how to start.

Answer: I sense you are exasperated and justifiably so – it is difficult to know where to turn, especially when you feel you have gone through every available avenue to address your wife's medical issue. According to Dr. Robin Richards, Sunnybrook's surgeon-in-chief emeritus, in about 15 to 20% of cases, symptoms persist after rotator cuff surgery. "Nothing we do is 100% successful," notes Dr. Richards, an orthopaedic surgeon who specializes in shoulders. "There is a significant percentage who don't get better."

The rotator cuff is a thick tendon that surrounds the upper end of your arm bone, medically referred to as the humerus. Its job is to initiate movements of the shoulder and to hold the ball in the socket of your shoulder, allowing you to use the big muscles in your arms. It can be damaged through repetitive use, age-related changes and, in rare cases, trauma. When it's damaged, patients feel pain from the swollen, inflamed tendon,

which can be particularly intense at night or when lifting overhead.

The most common need for surgery is to decompress painful chronic rotator cuff tendinopathy, a wear-and-tear process, or to repair a tear of the cuff. “The tendon can become thin and develop a tear,” says Dr. Richards. “When a patient doesn’t get better after surgery, you have to ask: ‘Did the repair fall apart?’”

When surgery is unsuccessful, the surgeon will look first for complications such as infection and then try to determine if the surgery was done for the correct diagnosis, if the decompression of the cuff was adequate and if the cuff repair healed. The surgeon will do a physical examination, take a medical history and order investigational procedures such as an MRI and X-rays. From there, the surgeon will form a diagnosis and determine whether a revision surgery is likely to work.

“If the MRI shows a re-tear, the repair has failed – then we would think about surgery again,” according to Richard Holtby, an orthopaedic and shoulder surgeon at Sunnybrook’s Holland Orthopaedic & Arthritic Centre. “Usually the MRI accurately diagnoses a re-tear but it is not perfect, and sometimes the only way to know if a repair failed is to look at it again surgically.”

Typically, surgeons will do a revision if it is medically indicated.

“If it was a small rotator cuff tear, and the surgeon felt he had a good repair and expected a good result but the patient did not get a good result, we would think about doing another surgery,” says Dr. Holtby.

If it’s a big tear, however, and the surgeon knew it was never going to be perfect but did the best job possible given the the limited amount of tissue, a second surgery is unlikely to be more successful, says Dr. Holtby.

Something to be mindful of: in revision surgery for rotator cuff problems, 70 to 75% of patients will rate the operation as good or excellent, compared with 80 to 85% who undergo a primary rotator cuff decompression and/or repair. Complication rates also increase with revisions, with 5% of patients experiencing at least one, such as an infection, bleeding, nerve damage or stiffness. That compares with the 2% of cases that typically experience one of those complications the first time around.

The good news is that the rotator cuff doesn’t have to be perfect to have a good result. It’s rare that surgeons can’t find a way to fix it. If the repair didn’t work the first time, the surgeon might reinforce the cuff with other biological material, transfer a muscle from nearby to replace the damaged cuff muscle or replace the shoulder.

Dr. Holtby suggests you ask for a second opinion. “No one should hesitate to ask their surgeon for a second opinion,” says Dr. Holtby.

If your wife is still experiencing pain, she should go to the surgeon. She might want to say that she knows the doctor did her or his best and she knows that shoulder surgery is complicated. She could also say that she's not sure why she's having the symptoms but would like to find out. She should then ask if she could get a second opinion or if there is someone else she could talk to. She should thank the surgeon for the care.

Once you have that appointment, she needs to get all the reports together, preferably on a CD. She needs MRI scans, X-rays, copies of the operation record and consultation reports. She should physically carry these with her to the appointment with the new surgeon – she should not rely on her surgeon to send these reports because they may not get there in time.

“Whenever there is failed surgery,” says Dr. Holtby, “it is probably reasonable to get a second opinion.”

- *Lisa Priest*

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WHAT SHOULD I EXPECT WITH PAIN MEDICATION AFTER SURGERY – AND HOW DO I WEAN MYSELF OFF OF IT?

Question: After hip replacement surgery, I was placed on tramadol for pain. It worked moderately well, although in retrospect, I would probably have done better with something stronger. The worst part is that I wasn't told how to wean myself off of it, only to switch to over-the-counter pain medicine when I felt I didn't need the prescription pills anymore. As a result I suffered withdrawal symptoms. As a patient, I had to figure this all out for myself. Whose job is it to tell me this information?

Answer: This question was posted by Emily Nicholas, who is a Patients' Association of Canada board member and one of the experts providing advice on how to navigate the health care system for pain management. As a patient, she knows this story because she lived it: she had a hip replacement in July 2010 at age 28 and was prescribed tramadol – similar to a narcotic – by an orthopaedic resident.

It didn't work very well and by hour 3, the next pill couldn't come soon enough. She was also placed on morphine for breakthrough pain, which made her so nauseous she had to take Gravol to help alleviate it. Ms. Nicholas was told to switch to ibuprofen when she felt ready, but no one told her what ready felt like, leaving her to figure this out on her own.

“They can only give you a rough estimate of the length of time you will need the medication,” she says. “The amount of pain and suffering that came after was more intense and persisted for longer than I had expected.”

She points to information sheets from the pharmacy that she was given. For six typed

pages, in words that few would describe as patient-friendly, the drug's uses and precautions were explained.

"The patient often has a lot of insight into their condition, but is kept out of the loop," says Ms. Nicholas, who has an interest in patient engagement and health policy design. "Just putting information out there doesn't mean you are communicating it."

While the information sheets do note that tramadol can cause withdrawal reactions, especially when used regularly for a long time or in high doses, they suggest patients see a doctor to reduce the dose gradually. Now that Ms. Nicholas was no longer seeing the orthopaedic resident, what doctor was going to help her get off of the medication, a month after taking it?

Ms. Nicholas went cold turkey in late August 2010, dropping the tramadol. Within days, she felt like she had the flu and had an odd sensation of a shock-like pain in the back of her neck. She didn't make the connection straight away that she might be experiencing withdrawal symptoms.

"I thought I was getting the flu," says Ms. Nicholas. "I was anxious and shaky, with the feeling of shocks up my head."

Realizing she might be experiencing withdrawal, she went back on the pills, reducing their dose, until she was able to get off of them for good.

Ms. Nicholas wishes she had been given a plan for pain relief and weaning from the pain drugs. She also wished she was provided alternatives, including the bean bags, body pillows and deep breathing exercises she later discovered on her own.

Anesthesiologist Chris Idestrup, director of the Acute Pain Service at Sunnybrook, says patients are typically provided a bundled approach to pain management in a hospital setting consisting of a combination of acetaminophen and anti-inflammatory medication, plus nerve blocks and possibly opioids.

When patients are ready to leave hospital, they typically go to one drug – be it tramadol or another drug that is a combination of oxycodone and acetaminophen. He describes the medication Ms. Nicholas was on as "middle of the road," in regard to its strength, and one that is prescribed if patients "are not able to tolerate a stronger opioid."

He indicates that post-surgical patients are typically started on stronger medicine, such as morphine, which would be reduced to a weaker opioid if it is too strong. He recommends patients ask their doctor if there are other medications they can take in addition: by throwing an anti-inflammatory into the mix, that would help reduce the need for other pain medication and decrease the side effects of one drug.

“Realistically, after surgery, patients might need to use opioids to control pain for two or three weeks. Some require it for longer,” Dr. Idestrup says.

Oftentimes, he says, patients can wean themselves off the drug by tapering it by about 20% per day. Sometimes it is as simple as dropping one tablet each day so that by day 12, the patient is not taking any medication.

“Instead of taking two in the morning, take one in the morning,” he says. “Drop a pill each day and see how you deal with that.”

He recommends patients see their family physician a week or two after being home, with their pain medication in hand. If they are still on the maximum dose, discuss whether they should be set up with a “weaning protocol” to get off of the medication.

“I wish I had known that it was okay to try to get your physician on the phone,” Ms. Nicholas adds, “and to ask for what you need and tell them what you want.”

- Lisa Priest



CANCER

WHAT DOES AN EARLY-STAGE BREAST CANCER DIAGNOSIS MEAN?

Question: I was just diagnosed with breast cancer. My doctor said I have DCIS with micro invasion on the right breast. What does that mean? I am very scared – and I’m especially worried about the possibility of needing radiation therapy after surgery. I’ve heard that treatment can be very difficult.

Answer: It’s totally understandable that you feel scared. No one welcomes a diagnosis of cancer. However, it sounds like you are in a very early stage of the disease and you should have an extremely good chance of being cured.

DCIS stands for ductal carcinoma in-situ, which means cancerous cells have started to grow within one of the milk ducts of your breast. If the cells were still confined to the milk duct, you would be classified as having a Stage 0 breast cancer. But your doctor has indicated that some cancer cells have spread into the surrounding breast tissue – hence the term “micro” invasion.

You basically have Stage 1 breast cancer, and that suggests you have an excellent chance of a successful outcome, says Dr. Frances Wright, a breast cancer surgeon at Sunnybrook Health Sciences Centre.

“A Stage 1 breast cancer causes tremendous anxiety among patients,” she says. “There is a lot of fear – which I understand – because who wants cancer?”

But, she adds, major treatment advances have been made in recent years and patients' prospects are much more promising than they used to be.

In fact, the five-year survival rate for women diagnosed with Stage 1 breast cancer is 99%, says Dr. Prithwish De, an epidemiologist with the Canadian Cancer Society.

“The five-year mark is usually used as the measure of a cure,” he explains, and the cancer is considered to be gone from the body. If a patient receives a cancer diagnosis after that period of time has passed, it is usually thought to be a brand new cancer, unrelated to the first bout of the disease.

Of course, this is the average survival rate for women in the population. Some individuals may have certain risk factors – such as genetic mutations – that make them especially vulnerable to cancer reoccurrence, or they may be prone to aggressive forms of the disease. A woman's age, response to treatment and previous medical history can also affect her prognosis.

In general, though, women diagnosed with Stage 1 – in which the tumour is 2 centimetres or smaller and the cancer has not spread outside the breast – can be fairly optimistic they will beat the disease.

The odds are also very good for Stage 2, in which the cancer has reached the lymph nodes. The five-year survival rate for this group is about 86%.

Doctors divide cancer into four distinct stages – although you will sometimes see it broken down into subcategories such as Stages 1A and 1B.

As you might expect, the chances of survival decrease as the disease becomes more advanced.

For Stage 3 – in which the cancer has spread to nearby tissue outside the breast, such as the chest wall – the survival rate drops to 57%.

And for Stage 4 – in which the cancer has metastasized, spreading to distant parts of the body – the five-year survival is about 20%.

The encouraging news is that the vast majority of breast cancer cases in Canada – about 80% – are diagnosed when they are still in the early stages, either 1 or 2.

By drawing attention to these rosy statistics, I don't mean to minimize the seriousness of the disease or to downplay the huge upheaval it causes in the lives of individual women and their families. About 24,000 women are diagnosed with breast cancer in Canada each year, and it's responsible for about 5,000 deaths annually.

But it's clear that significant progress is being made in the fight against breast cancer.

Back in the 1960s, the combined five-year survival rate for all four stages of breast cancer was 58% in Canada. By the mid-1980s, that figure had climbed to 73%. Today it's up to 80%.

Part of those gains can be attributed to the introduction throughout Canada during the late 1980s and early 1990s of population-wide mammogram-screening programs that have led to an improvement in early detection of the disease in many women.

Experts also point to a much wider array of effective treatments that tend to be less onerous than past therapies.

"For early-stage breast cancer, a patient can usually get a lumpectomy rather than a mastectomy, which used to be the standard practice several decades ago. So treatments are less radical than they used to be – but no less effective," says Dr. De. "There is less pain, fewer side effects and a faster recovery," he adds.

(In a lumpectomy, only the tumour and a small margin of surrounding normal tissue are removed, along with a few lymph nodes for testing. A mastectomy involves the surgical removal of the entire breast and all the lymph nodes in the armpit.)

When it comes to drug treatments, or chemotherapy, some of the newer medications are tailored to deal with very specific aspects of the patient's cancer.

For instance, many women have a form of breast cancer that's fuelled by hormones, such as estrogen circulating in the body. After the initial surgery, tumour samples are examined in the lab for the presence of estrogen receptors. The results of these tests will determine if a woman would be a good candidate for a drug like tamoxifen, which binds to the hormone receptors – and prevents the real estrogen from acting on the tumour. Tamoxifen can slow or stop the growth of cancer cells and is considered highly effective in lowering the risk of breast cancer recurrence.

(For post-menopausal women with hormone-sensitive tumours, doctors may prescribe a class of drugs known as aromatase inhibitors, instead of tamoxifen. They work differently than tamoxifen but generally achieve the same result; they lower estrogen levels.)

Herceptin is another drug that can help put the brakes on uncontrolled cancer growth. It is used in women who have a gene that leads to an excessive number of HER2 receptors on the surface of the cancer cells. These receptors pick up growth signals

and spur on the tumour. By blocking HER2 receptors, Herceptin can slow or stop the growth of the breast cancer.

“The drugs today are much more targeted, and treatments are selected based on the woman’s genetic makeup,” says Dr. De.

In other words, cancer therapy is moving toward a personalized approach. And the newer, more specialized medicines tend to have fewer side effects than the earlier forms of broad-acting chemotherapy.

There have also been significant changes in post-operative radiation therapy – which you raised as one of your chief worries.

Typically the radiation is focused on a smaller area, using a higher dose for a shorter period of time, says Dr. De. This approach helps to reduce side effects and limits the damage done to surrounding healthy tissue. “Usually radiation is tolerated very well by patients. The main side effects are fatigue, and 1 in 10 women will get a ‘sunburn’ from the radiation,” says Dr. Wright.

Aside from the cancer treatments, we now know that adopting certain lifestyles can affect a woman’s chances of keeping cancer at bay. Two large clinical trials have shown that a low-fat diet and regular exercise can reduce the risk of recurrence and lower the chance of death in women with early-stage cancer.

“This type of information wasn’t available in the past, but these are things that we can now recommend to women as they are going through their cancer journey,” says Dr. De.

It should also be noted that not smoking tobacco increases the likelihood that your cancer treatment will work.

I hope this overview of improved survival rates and increased treatment options alleviates some of your fears.

As Dr. De puts it: “The arsenal of tools available for treatment has grown tremendously over the past several decades. And women with breast cancer today are certainly benefiting from those advances.”

- Paul Taylor

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HOW LONG DOES IT TAKE TO GET RESULTS AFTER A LUMPECTOMY?

Question: I had a breast lumpectomy at an Ontario hospital on March 7. My follow-up appointment was on March 25. At that appointment, the surgeon told me I have two

breast tumours and one is invasive. I took the pathology report home and noticed that it was written on March 13. If it only took six days to analyze the lump and write the report, diagnosing cancer, why did it take another 12 days after that for him to inform me?

I feel I have been robbed of the opportunity to get a second opinion. (Surgery is scheduled for April 9 to deal with the second tumour).

Furthermore, the last few weeks have been tremendously anxious ones for me. I was almost incapacitated by anxiety last weekend before the diagnosis; I have a five-year-old daughter and I really feel that I should have been allowed to meet my surgeon and hear the news of my cancer much sooner after it was discovered.

I really hope to hear your unbiased opinion of how this went.

Answer: A diagnosis of breast cancer is always unnerving. Like many patients, you want to move forward with treatment as soon as possible. But you also want to be sure it's the right therapy.

I think there are two components to your question:

1. How long do patients typically wait to learn the results of their cancer surgeries?
2. Have you been given adequate time to seek a second opinion?

For an answer to your question, I talked to Dr. Frances Wright, who is head of breast and melanoma surgery at the Louise Temerty Breast Cancer Centre of Sunnybrook Health Sciences Centre.

Dr. Wright says it can sometimes take between two and three weeks to have the full pathology report completed. The report contains a detailed description of the tumour and it's based on a variety of tests and observations. Cells from the tumour, and some of the surrounding tissue removed in the surgery, are examined under a microscope.

This work can help determine its size and the potential aggressiveness of the cancer. The tumour is also studied for a variety of hormone receptors. The growth of some tumours can be fuelled by hormones such as estrogen. Doctors will often prescribe certain drugs – for example, tamoxifen – that can block these hormone receptors.

So the results of the pathology report are very important for determining what additional surgeries and therapies may aid in your cancer treatment.

Some of these findings take longer to complete than others. Dr. Wright says it's usually best to book the patient for an appointment when there is a strong likelihood that all the results will be ready.

“It’s upsetting for the patients if we bring them back too early and the pathology report is not there, because then they have to make a second trip and they are anxious again,” says Dr. Wright, who is also an associate professor of surgery at the University of Toronto.

Based on the dates you provided, your follow-up appointment was 18 days after your surgery. So that would be within the normal range of time for meeting with your surgeon. The fact that your pathology report was completed 12 days prior to your appointment means that certain results came back sooner than expected. And that’s not a bad thing.

Still, you’re obviously thinking those 12 days amount to a lost opportunity and that time could have been spent seeking a second opinion.

However, you likely have more time to consider your options than you think, says Dr. Wright. “In general, cancers spread in months – like six, seven, eight or nine months – not in days to weeks,” she explains. “It doesn’t move that quickly.”

You mention that your surgeon has already booked you for another operation to deal with the second tumour.

“It sounds like the surgeon saved operating time for the patient when he thought the patient would need a second operation, and that, to me, is good patient care because the surgeon is moving things along,” says Dr. Wright.

But, she adds, an “operating room date is never cast in stone, especially if the patient is not comfortable with it or needs more information.”

Make sure you have a full discussion with your surgeon. He may be able to ease your concerns.

If you still feel you want a second opinion, then ask for one. Your surgeon may be able to refer you to one of his colleagues. Or your family physician can possibly set up an appointment with another cancer specialist.

“It doesn’t happen that often, but when patients ask us for a second opinion, usually we are more than happy to facilitate it because we want the patient to have the right information,” says Dr. Wright.

It will likely take several weeks to arrange for a second opinion. So you should be aware that getting a second opinion will cause a delay in your treatment. “But from a cancer outcome point of view, waiting a couple of extra weeks won’t make any difference,” says Dr. Wright. “And if it gives her more peace of mind, and she feels that it helps her make a decision, then she should do it.”

Postscript: The patient has since had additional conversations with her surgeon. She says her concerns have been addressed and she's decided to proceed with the operation without first seeking a second opinion. "I was doubting the care I was receiving, but I'm now aware it's in line with the norm," she says.

- Paul Taylor

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WHAT SHOULD I DO IF MY FATHER'S CANCER TREATMENT DOESN'T WORK?

Question: My father has been diagnosed with lymphoma and has begun treatment with one round of chemotherapy so far and several medications. I was wondering, if early results are not favourable, how can I get better care rather than what he is receiving now?

Answer: There are more than 40 different types of lymphoma, a cancer of the lymphatic system, that are typically divided into two main types: Hodgkin's lymphoma and non-Hodgkin's lymphoma. Since the medical protocols for treating these forms of cancer are standard, most can be easily managed in community and teaching hospitals, according to Dr. Eugenia Piliotis, a hematologist who specializes in lymphoma at Sunnybrook.

"In the majority of cases there is no need to be sent to a teaching hospital for treatment," said Dr. Piliotis, who is also an associate professor in the University of Toronto's Department of Medicine. "An exception to that would be if there is a potential for a clinical trial you may be eligible for, and you and your physician think you would be a good fit."

The other exception is if you have a rare type of cancer, such as cutaneous T-cell lymphoma, high-grade lymphomas or other rare, aggressive types of lymphoma that require super-specialized treatment by clinicians as well as pharmacists and nurses most familiar with them.

What I am wondering, though, is if this is a treatment issue or one where you are lacking confidence or are having trouble trusting the oncologist. When a patient has been diagnosed with cancer, it is almost always the worst thing that has ever happened to them. It's not a surprise, then, if you are wondering whether the treatment your father is obtaining represents the best possible care.

If your father does not have a favourable response, that may be due to a cancer that is not responding to treatment and requires another protocol, rather than a clinician who is not providing the best care.

Having said all that, it is reasonable to ask for a second opinion if you are having

doubts or you want to confirm the diagnosis and treatment plan. However, to obtain that second opinion, it is best to ask the treating oncologist to arrange it – not your family physician. Just having this conversation with the oncologist may help dissolve some of your concerns.

If you want a second opinion and you are concerned about offending the oncologist, don't be. So long as you word it politely, it should not be an issue – oncologists are used to being asked for second opinions.

You may want to word your question along these lines: "I have faith in you but I'm anxious. This is a big diagnosis and I want to make sure I'm doing the right thing for my father. Is it possible to get a second opinion?"

That oncologist is the best person to facilitate the second opinion as she or he can tell the other cancer specialist what treatments, tests and scans your father has had.

"Most often patients get here and we tell them the exact same thing that their primary oncologist has already explained, so usually we are just reassuring," said Dr. Piliotis. "Everyone deserves a second opinion if they have concerns."

- **Lisa Priest**

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AS A CANCER PATIENT, HOW DO I JOIN A CLINICAL TRIAL?

Question: I have run out of conventional medical treatments for my cancer, which has metastasized. How do I join a clinical trial? How do I increase my chances of receiving the drug rather than taking a sugar pill?

Answer: For this question – a common one here at Sunnybrook's Odette Cancer Centre – I went to Dr. Scott Berry, who in addition to being a medical oncologist is also a bioethicist.

"As oncologists, we have made great advances in improving outcomes for people with cancer but we need to do better. The best way of doing this is to study new treatments so we put a high priority on offering our patients the chance to take part in a clinical trial," Dr. Berry says. We spoke at the cancer centre, the second largest in Canada.

Currently there are more than 650 clinical trials taking place across Canada for all different forms of cancers. Trials aren't always for patients who have run out of conventional treatments. And most are not placebo controlled, so the worries over a sugar pill are few. Most trials today compare a new treatment with a current one.

More broadly, a trial is an intervention that can be a drug, surgery, device, radiation, diet or even an exercise program. The results can be compared with a new medical

approach, a standard one already available or a placebo. It can even be compared with nothing at all. The purpose is medical knowledge.

For some patients who have exhausted other conventional therapies, a clinical trial can be seen as a lifesaver. Doctors always try to give patients the full picture: that as much as this may lengthen their lives or reduce their symptoms, it doesn't work in every patient every time.

"We have to balance this hope and encourage people. But we have to remind them that although we hope that people getting the new treatment will do better, in some cases, they could do worse," says Dr. Berry. "And unless we do this type of study we will never know for sure."

Indeed, a dozen years ago, there was little oncologists could provide to patients whose colorectal cancer had spread. Back then patients faced an average life expectancy of one year. Now, there are five new drugs available and many patients live twice as long.

Clinical trials can last months or years as researchers try to determine the safety of a given intervention and whether it helps, harms or is no different than what is currently provided. Certain outcomes are measured in patients.

A significant issue for patients and clinicians is informed consent, says Dr. Berry. "We tell them why we are doing the trial, the background information, but we do not promise too much," he says. "I think the thing is we hope things will be better but we really don't know that."

Some patients want to sign up right away after hearing details and going over the risks with the oncologists or nurses, but Dr. Berry always tells them to sleep on it. Most come back, wanting to discuss options. "Some are uncomfortable with the randomness of it," says Dr. Berry.

There are four phases to clinical trials, with phase 1 being the earliest and smallest – recruiting up to about 30 patients; these are often referred to as dosing or safety trials.

Phase 2 trials try to find out what types of cancer the drugs work for and to get a better idea of side effects.

If a drug works well, it goes on to Phase 3 trials, which are large trials (hundreds or thousands of patients recruited at many centres) that compare a new treatment with the standard one, or with different doses or ways of giving a standard treatment.

These trials are randomized, which means that patients are put into two groups: one to get the new treatment and the other to get the standard, or placebo (a sugar pill) if there is no standard treatment. That type of study is the gold standard for establishing new treatments.

“We are very clear about the treatment goals,” Dr. Berry says. “There are enthusiastic people who want something done, but they have to be willing to understand what the goals are.”

Even if a clinical trial is not available at your hospital, it could be elsewhere, such as other teaching or community hospitals.

- *Lisa Priest*

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HOW CAN I GET FINANCIAL AID FOR CANCER DRUGS?

Question: My wife was recently diagnosed with breast cancer. We are both self-employed. So we don't have drug insurance coverage through a workplace. We're worried about how much we may have to pay for cancer medications. I hear they can be really expensive. What are our options?

Answer: I can tell from your question that you are already well informed about one of the major shortcomings of the Canadian health care system: medicare will pay for doctor visits and medically necessary treatments received inside a hospital, but it doesn't necessarily cover the cost of medications administered outside a hospital, like a cancer pill you pop in your mouth at home.

Many people are “shocked and upset” to discover they may have to pay out of pocket for their cancer medications that can cost thousands of dollars, says Manisha Gandhi, manager of the patient and family support program at Sunnybrook Health Sciences Centre.

She notes that physicians, nurses and other specialists are extremely mindful of the fact that the cost of treatment can impose a financial hardship on some patients and their families.

Your wife will likely be asked if she has private insurance. And I expect a member of her cancer-treatment team will point you in the direction of where your family might be able to get financial aid.

A growing number of cancer centres – including Sunnybrook – now have specialized staff to help patients deal with drug reimbursement issues. “Since we know that patients and their families are going through a lot, we try to smooth out the process as best we can,” says Ms. Gandhi.

But even without such a specialist, your cancer team should be able to put you in touch with a pharmacist, pharmacy technician or social worker who can provide some guidance.

It's important to know that most Canadian provinces and territories have some form of assistance for patients facing huge drug costs, although the level of aid varies considerably across the country.

(Seniors and those on social assistance get automatic drug coverage, but not all medications are included on a province's formulary, or list, of approved drugs. So a senior could still be facing a big bill for a relatively new and pricey cancer medication.)

In Ontario, people who have high prescription drug costs relative to their household income can apply to the Trillium Drug Program. Once you qualify, and if the drug is listed on the provincial formulary, you will still be expected to pay a portion of the drug costs. For most people, it equals about 4% of their household's total net income.

"You will have a deductible based on your income, which means you are buying drugs up to a certain dollar amount, and after that the costs will be covered," explains Alison Chambers, a drug reimbursement specialist at Sunnybrook.

She points out that many people with private insurance are also required to pay a deductible or make a co-payment and there may be a cap on the total payout.

By contrast, some provinces – such as British Columbia, Alberta and Saskatchewan – will pick up 100% of the cost of the cancer drugs listed on their formularies – regardless of whether the medications are administered intravenously in a hospital or taken in pill form at home.

In a few special circumstances, pharmaceutical companies will offer price breaks to those in need. A hospital pharmacy team member or a drug reimbursement specialist may be able to help you apply for these programs.

Overall, how much people end up paying for essential cancer drugs depends on where they live, the terms of their private insurance (if they have any) and the specific medications they are prescribed.

"When it comes to reimbursement, it varies case by case," says Ms. Chambers. And, unfortunately, some people face onerous costs.

Leading medical organizations and patient groups, including the Canadian Cancer Society, have called for a uniform national catastrophic drug plan that would kick in when medication costs exceed a certain level of a patient's household income.

Many provincial and federal politicians have voiced support for such a program, although there's no agreement about who would pay for it. In the meantime, some patients and their families are forced to make difficult choices.

Be sure to reach out to your wife's health care team for financial advice and any other

issues that arise in the course of her treatment. People may not realize the range of services available to them.

If you want to know which cancer drugs are covered under the various provincial programs you can check out Cancer Drug Access (www.cancerdrugaccess.ca), a website developed by Dr. Kong Khoo, vice-chair of the Cancer Advocacy Coalition of Canada.

- Paul Taylor



MEDICATION

IS IT SAFE TO TAKE ACETAMINOPHEN DAILY FOR ARTHRITIS PAIN?

Question: I suffer from osteoarthritis. My doctor says I should keep exercising even though my joints hurt. He says it's okay for me to take a pain medication like Tylenol in order to remain active. But I've read that Tylenol can damage my liver. What am I to do?

Answer: You are right to be concerned about medication safety. But your doctor's also right that you need to be physically active. So how do you balance these seemingly competing objectives?

I posed your question to two specialists at Sunnybrook Health Sciences Centre: one is a surgeon who performs joint replacement operations and the other is an expert in drug safety.

Let's start with the surgeon. Dr. Jeffrey Gollish, medical director of Sunnybrook's Holland Orthopaedic and Arthritic Centre, says he sees lots of people who feel the same way you do.

Many patients, he says, fear that exercise will lead to additional damage of their joints. The fact that it hurts when they move is taken as a sign that they are doing harm to themselves. And they worry medications that mask their pain will simply allow them to do even more harm.

“The issues of exercise and medication are two areas where the public has misconceptions,” says Dr. Gollish. “They think both are harmful. In fact, both are beneficial.”

Exercise, in general, is good and won't harm the joints. “The only thing we tell people to stop doing is running – and avoiding any impact activity.”

Patients who are waiting for knee or hip replacement surgery need to keep up their strength and remain flexible, he adds. Patients in better shape tend to have smoother recoveries than those who are out of condition.

“If people exercise before surgery, and maintain their flexibility, the likelihood is that their post-operative range of motion will also be better.” And, likewise, “the worse they are pre-op, the harder it is for them to get better post-op.”

At Sunnybrook's Holland Centre, the assessment process for knee and hip surgery includes patient education about exercise. Indeed, even before patients are referred to a surgeon, they see a specially trained advance practice physiotherapist.

“The therapist spends time with them, assessing their problem and educating them on what they can do to help themselves from the standpoint of exercise, activity modification and over-the-counter non-prescription medications,” he explains.

“Our experience is that people are coming into the hospital much better prepared for surgery than they were before we adopted this approach a decade ago.”

And, he says, if medication can relieve pain and enable patients to exercise, that is a good thing.

So let's now address the safety issue of using drugs in this fashion. Acetaminophen, commonly known by the brand name Tylenol, tends to be the most recommended pain reliever for patients like you who have osteoarthritis. There is ample justification for choosing it, according to Dr. David Juurlink, head of clinical pharmacology and toxicology at Sunnybrook.

“It is an exquisitely safe drug so long as you don't take too much of it,” says Dr. Juurlink, who is also a researcher at the Institute for Clinical Evaluative Sciences.

“There is a reason why it's been on the market for decades and is available in so many over-the-counter products.”

He says most patients can safely consume 3 or even 4 grams of acetaminophen day after day for long periods. "It is when you get to 6, 7 or 8 grams a day that you get into trouble."

An extra-strength tablet contains 500 milligrams.

"If you take two extra-strength tablets, three times a day, you are consuming a total of 3 grams a day," he notes. "You can't get liver damage from that amount."

Furthermore, Dr. Juurlink says acetaminophen tends to result in fewer negative reactions than the alternative non-prescription pain relievers. For instance, regular use of non-steroidal anti-inflammatory drugs (NSAIDs) – such as ibuprofen (Advil), naproxen (Aleve) and acetylsalicylic acid (Aspirin) – can damage the lining of the stomach, cause gastrointestinal bleeding and lead to kidney problems.

(It's important to mention that acetaminophen is a good pain and fever reliever, but it doesn't have anti-inflammatory properties. If a patient has an inflammatory condition, such as rheumatoid arthritis, then acetaminophen won't be their drug of choice.)

"The NSAIDs have more toxicities at recommended doses than acetaminophen," he adds. "Put another way, if everyone who was taking acetaminophen became concerned about its safety and switched to an anti-inflammatory drug such as ibuprofen, we'd see a major increase in drug-related problems."

Dr. Juurlink says, "People shouldn't be afraid to take acetaminophen, provided they are mindful of the dose."

That is a very important caveat. He warns that it's fairly easy for people to unknowingly take too much acetaminophen in part because it is an extremely common ingredient in numerous over-the-counter products including many of the best-selling cold and flu remedies.

For patients who are already consuming 3 or 4 grams daily for pain control, they can quickly move into the danger zone simply by self-medicating for a cold or flu.

"The message for people who are taking acetaminophen regularly is check the ingredients on the other products they are using to make sure they don't include more of it," he advises.

So, to recap, the message from our Sunnybrook specialists is twofold: exercise is good for patients with osteoarthritis. And you can safely take acetaminophen so long as you're mindful of the dose.

If you are still reluctant to take the pain reliever, that's fine too, says Dr. Juurlink. "There are no rules that say people with pain have to take a drug for it. Some people choose

to live with discomfort rather than risk taking medication. That is a personal choice, and I respect that.”

Just don't let the pain be a reason to forgo physical activity.

- *Paul Taylor*

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DO PEOPLE WITH ARTIFICIAL JOINTS NEED ANTIBIOTICS BEFORE A DENTAL VISIT?

Question: I had a knee replacement two months ago at a hospital in Ontario and was provided with literature about what to expect and what to do after the surgery. Included in it was a caution to request an antibiotic prescription from my dentist for any dental procedures – including getting my teeth cleaned – for the rest of my life. The hospital literature said that without antibiotics, my new joint could become infected. But when I recently visited my dentist, he said antibiotics weren't necessary for people with knee or hip implants. Who is right?

Answer: Your dentist is correct, according to the best available scientific evidence. But patients have good reason to be confused because of conflicting messages from different medical and dental associations in recent years.

It's true our mouths are teeming with bacteria. So there has long been a concern bacteria might enter the bloodstream during a dental procedure; simply cleaning the teeth can cause the gums to bleed.

It was feared bacteria could travel in the blood to the site of a prosthetic device – such as a knee or hip implant – and lead to an infection. If the infection eroded the bone around the implant, the patient might need another joint replacement operation.

The risk, however, is considered hypothetical, says Dr. Susan Sutherland, chief of dentistry at Sunnybrook Health Sciences Centre. There is no evidence directly linking dental procedures to implant infections.

Even so, many medical experts felt some precautions were needed.

Unfortunately, those good intentions led to a string of public health recommendations that were not grounded in good science.

It's worthwhile reviewing the history of the various guidelines to see how they may have contributed to public confusion.

Back in 2003, the American Dental Association (ADA) and the American Academy of Orthopaedic Surgeons (AAOS) issued a joint statement, saying patients should take

one dose of antibiotics an hour before dental procedures for the first two years after they received a knee or hip replacement. In Canada, the dental and orthopaedic associations adopted an identical approach.

Then in 2009, the AAOS, without the agreement of ADA, called for even stricter measures, saying joint-implant recipients should use antibiotics before every dental procedure for their rest of their lives.

Yet, at that same period of time, other medical professionals were openly critical of antibiotic prophylaxis – the practice of giving healthy people antibiotics to prevent a potential infection. In fact, the critics warned the overuse of antibiotics was contributing to the emergence of worrisome antibiotic-resistant strains of bacteria – a major public health threat.

So the American dentists and orthopaedic surgeons decided, once again, to join forces to review the scientific literature. The reviewers found no direct evidence that dental procedures can lead to implant infections. But their final recommendations, published in 2012, were vaguely worded. They seemed to be neither for nor against antibiotic prophylaxis. Surgeons and dentists essentially had to decide for themselves what to recommend to their patients.

“The guidelines were ambiguous and really not helpful,” says Dr. Sutherland, who is the chair the Canadian Dental Association (CDA) committee on clinical and scientific affairs.

Indeed, the rather nebulous recommendations from the American groups led Canadian health professionals to chart their own course.

The CDA released last year a position statement that said: “Routine antibiotic prophylaxis is not indicated for dental patients with total joint replacements, nor for patients with orthopedic pins, plates and screws.”

The Canadian Orthopaedic Association (COA) is still in the process of reviewing the scientific literature and coming up with its own guidelines. “I think it is going to take us another year,” says Dennis Jeanes, the COA’s manager of communication and advocacy. But he indicates the COA reviewers will likely produce recommendations that are very similar to those already adopted by their dentistry counterparts.

Let’s recap where we currently stand. Canadian dentists now have clear guidelines from their national organization – and antibiotic prophylaxis is out. Orthopaedic surgeons are still waiting for their recommendations, although they are probably headed in the same direction as the dentists.

I hope this helps explain why you received different advice from your dentist and the hospital where you got your new knee.

In the meantime, the scientific case against antibiotic prophylaxis continues to get stronger. One piece of evidence is particularly convincing: the bacteria in the mouth tend to be different than those associated with infections around implants.

“The organisms that are most responsible for early and late stage [prosthetic joint infection] are *Staphylococcus aureus* and coagulase-negative staphylococci, both uncommonly found in the oral cavity or outside their usual skin habitat,” according to a paper published in the *Journal of Canadian Dental Association* by Dr. Andrew Morris and Dr. Sandra Howie [now Dr. Sandra Nelson], who are researchers at Mount Sinai Hospital in Toronto.

The paper also contains a sobering statistic. Up to a million patients each year receive total joint replacements in the United States alone. (There are more than 93,000 knee and hip replacement operations performed in Canada annually.)

That’s a big number of additional people who would be taking antibiotics unnecessarily every time they had a dental appointment. It actually amounts to 2 tonnes of antibiotics every 6 to 12 months, further fuelling the growth of resistant bacteria – without any proven benefit to patients.

“We use so many antibiotics that are absolutely unnecessary,” says Dr. Morris. “It is almost implausible that the benefits can outweigh the costs. Prosthetic joint infections are extremely uncommon while side effects and complications from antibiotics are rather common.”

So you would be well advised to follow the recommendation of your dentist and forgo the antibiotics.

“The routine use of antibiotics for prevention of infection in healthy patients is not indicated by the evidence,” says Dr. Sutherland.

- Paul Taylor

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WHAT ARE THE RISKS OF TAKING A NEWER DRUG?

Question: I have diabetes and my doctor has prescribed a relatively new drug to treat my condition. I trust my doctor, but I’m still worried about taking a new medication. I remember all those news reports about Avandia – another diabetes drug that turned out to have serious side effects. Should I be worried?

Answer: I wouldn’t want you to lose sleep from worry, but your concerns do have some merit. The full effects of a drug – the benefits and potential harms – become known only when it has been used for an extended period by many patients.

“The way in which a drug is used in the real world is often very different from how it is used in a clinical trial,” says Dr. David Juurlink, a physician and drug-safety researcher at Sunnybrook Health Sciences Centre.

Before a new drug ends up on the market, a pharmaceutical company must conduct a series of studies as part of the government approval process. Usually these tests are carried out on a few thousand patients under near-ideal circumstances. “The manufacturer purposefully selects people who they think might benefit from their drug, and they exclude people who are particularly likely to be harmed,” explains Dr. Juurlink. The patients are then closely monitored for results, including potential side effects of treatment.

This pre-market research provides a best-case scenario of a drug’s safety and effectiveness picture, because “real world” patients are often very different from those in the clinical trials. Once a drug enters the market, it may end up being used by millions of patients worldwide.

Rare side effects that weren’t apparent in pre-market studies may then come to light. Furthermore, “because patients in clinical practice may be on more medications and less closely monitored, the risk of drug interactions is higher,” he adds.

As a general rule, physicians are trying to act in the best interest of patients when they prescribe a new drug, says Dr. Juurlink. “Doctors want patients to feel better or live longer because of our treatments.”

A new drug may be promoted as having some novel mechanism that works differently than older medications, suggesting it may be particularly helpful for certain patients.

“There is a tendency to believe that new and approved is new and improved. But that is not always the case,” he says. And physicians, like everyone else, can succumb to the pharmaceutical sales pitch.

It’s clear from your question you have some confidence in your doctor’s judgment. But how can your doctor protect you from what’s currently unknown – such as side effects that could emerge over time?

Dr. Juurlink says it’s important to keep your physician informed about how you feel while taking the medication. “If you don’t feel better, the doctor needs to know because that might warrant reconsideration of the drug or the dose prescribed.”

Still, some side effects may not be obvious. In other words, you might not feel them. They may be revealed only through a blood test or another medical procedure.

Dr. Juurlink says patients may be able to help themselves by paying attention to any reports that suggest there could be a problem with their medication.

For instance, you could set up a Google alert to automatically notify you of news about the drug you've been prescribed. "The Internet is actually a useful resource for patients," he says. Of course "you have got to be careful because there is all kinds of misinformation on the Internet, particularly from people with axes to grind."

If the news comes from a credible source, such as a medical journal, the U.S. Food and Drug Administration or Health Canada, you should mention it to your physician. In fact, with an alert system, you may learn of a potential problem sooner than your doctor does. But your doctor will be well positioned to help interpret that information.

Taking a new drug "is not necessarily a bad thing; it might turn out to be a good thing in the long run," says Dr. Juurlink. "We often just don't know up front."

But playing an active role in your health – paying attention to how you feel and being alert to news about your medication – should give you a greater sense of control.

- **Paul Taylor**

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SHOULD I BE WORRIED ABOUT MEDIA REPORTS LINKING FLU VACCINE TO NARCOLEPSY?

Question: I read a news story that said the vaccine used a few years ago to protect against the H1N1 flu virus could have caused narcolepsy in children. Should I be worried about having my children vaccinated this year? Is the flu shot safe?

Answer: It's true researchers are investigating the possibility that the H1N1 flu shot, or the virus itself, may be linked to an apparent spike in cases of the sleep disorder.

However, you can rest assured that the 2013/14 flu season vaccine is very different from the one used to guard against H1N1 in 2009. H1N1 was a very special case – it was not the regular flu vaccine," says Dr. Brian Murray, a sleep specialist at Sunnybrook Health Sciences Centre.

At the time, you may recall, influenza experts were concerned the H1N1 virus – commonly known as the swine flu – could lead to an extremely deadly global pandemic. Pharmaceutical companies rushed special vaccines into production to deal with the potential threat.

Like regular seasonal flu shots, the H1N1 vaccines contained antigens, or proteins, that trigger the immune system to produce antibodies to fight the virus. But some of the H1N1 vaccines also included an adjuvant – or booster – to increase the body's immune response. Using an adjuvant meant the vaccine could be made with fewer antigens. This helped speed up production of the pandemic flu shots, which were in great demand from governments around the world.

About a year later, doctors in Finland were among the first to report an unusual blip in narcolepsy cases, especially among children and teens. Only one type of H1N1 vaccine had been used in Finland – Pandemrix, which contained an adjuvant. In other countries where adjuvants were used – notably in Europe and China – doctors began to make similar observations.

Still, the actual number of cases remains relatively small compared with the millions of people who received the vaccine worldwide. According to a report from the National Institute for Health and Welfare of Finland, the increased risk corresponds to about six extra cases of narcolepsy per 100,000 children vaccinated and one extra case per 100,000 adults who got the shot.

Narcolepsy is a rather uncommon neurodegenerative condition. It normally occurs among 25 to 50 out of every 100,000 people in the general population and rarely affects children.

Patients suffer from profound daytime drowsiness, says Dr. Murray, who is also an associate professor at the University of Toronto.

They can also experience a related problem called cataplexy – the sudden loss of muscle tone, particularly with an emotional trigger. “If you tell them a joke, they can fall down,” says Dr. Murray. “It sounds very bizarre, but there are pathways in the brain that suggest why that happens.”

Narcolepsy results from the loss of a brain chemical called orexin (also known as hypocretin) that plays a key role in regulating sleep-wake cycles.

Dr. Murray points out that the human mind typically exists in three different states – awake, REM sleep and slow-wave sleep.

“Orexin is a kind of psychic glue that holds you in one state or another, and it is when you start to drift in between states that there is a problem,” he explains. “You start to fall asleep while you are awake. Or you lose muscle tone, which is a normal feature of REM sleep, but it is abnormal for the waking state.”

Dr. Murray says it's possible a component of the H1N1 vaccine leads the immune system to destroy orexin-producing cells in some people who are genetically predisposed to the disorder. But he cautioned a lot more work is needed to confirm such a theory.

The Brighton Collaboration, a vaccine-safety group sponsored by the World Health Organization and the U.S. Centers for Disease Control, is providing seed money to researchers who are investigating the matter.

With some of that funding, Dr. Murray and Dr. Jeff Kwong, an epidemiologist with the Institute of Clinical Evaluative Sciences at Sunnybrook, are conducting a study to see

if the vaccine is linked to a rise of narcolepsy cases in Ontario.

“It’s a gargantuan task,” says Dr. Murray. “We are trying to identify every patient who developed narcolepsy in Ontario, and then go through all the paper records of immunization status to figure out whether they got the vaccine or not.”

In Canada, the H1N1 vaccine was called Arepanrix. It was similar to the Pandemrix used in Europe and included an adjuvant. (Some batches of non-adjuvanted vaccine were produced for pregnant women.)

The findings from the Ontario research, and other studies, could have important implications for the future use of adjuvants, says Dr. Murray.

For normal flu seasons, though, adjuvants are not an issue. The vaccine doesn’t contain them. “Don’t let this prevent you from getting the regular flu vaccine,” says Dr. Murray. “This is not the same kind of scenario.”

- **Paul Taylor**

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HOW CAN YOU PREVENT DANGEROUS DRUG INTERACTIONS?

Question: My mother is on six different medications from different pharmacies under the care of three specialists. How do I avoid a dangerous drug interaction?

Answer: This is the kind of question doctors hear all the time and highlights some of the dangers of being on multiple drugs, particularly from multiple doctors and especially multiple pharmacists. There is no guarantee any of these health professionals are talking to each other, and the risk of a dangerous drug interaction – when one drug changes the response to another medication – is high.

“There are literally thousands of drug interactions out there,” says Dr. David Juurlink, head of the division of clinical pharmacology and toxicology at Sunnybrook Health Sciences Centre. “If I have a patient in the emergency department on 8, 10 drugs, there’s a very good chance we will find at least one, and possibly several, potentially dangerous interactions.”

According to Dr. Juurlink, “Drug interactions are largely predictable and, as a result, largely avoidable.”

Some drugs are particularly prone to interactions. They include common cholesterol drugs (statins), antibiotics, anticoagulants and lithium – all of which, when taken with other medications, can cause potentially dangerous reactions.

Though it is rather well known, it is worth repeating that taking grapefruit juice can

amplify the effect of certain drugs because more drug is absorbed from the gut. This is particularly true with statins – lovastatin, simvastatin and atorvastatin – used for the treatment of high cholesterol. Grapefruit juice taken with those drugs will cause too much of the active ingredient to enter the bloodstream, resulting in side effects such as muscle damage.

Anticoagulants, which are typically taken by patients with atrial fibrillation, deep vein thrombosis or pulmonary embolism – abnormal blood clots that develop in a leg vein or travel to the lung – can lead to potentially catastrophic bleeding in the stomach and brain. Antibiotics and anti-fungal agents are two drugs that often don't mix with them.

Since lithium – a drug that works in the brain to treat bipolar disorder – is eliminated from the body by the kidneys, patients should be careful when starting non-steroidal anti-inflammatory drugs, diuretics or ACE inhibitors. That's because they can increase lithium blood levels and therefore should be treated with the utmost of caution and close medical supervision.

Dr. Juurlink has suggestions on how to avoid interactions. They include:

- Have your mother's prescriptions filled at the same pharmacy.
- Make sure her doctor and pharmacist know what medications she is taking – including non-prescription drugs such as Aspirin, ibuprofen and herbal medications.
- Be vigilant about monitoring symptoms in the first five to seven days when starting a new drug – the time when drug interactions are most likely to appear.

“When a patient comes to hospital, they should bring all of their pills in their bottles,” says Dr. Juurlink, “or at least have an up-to-date list at hand.”

You can also try the online tools below to see if your drugs interact with each other:

- MedScape Reference's Drug Interactions Checker (www.reference.medscape.com/drug-interactionchecker)
- Drugs.com's Drug Interactions Checker (www.drugs.com/drug_interactions)

- **Lisa Priest**



MENTAL HEALTH

WHAT TREATMENT OPTIONS ARE THERE FOR DEPRESSION WHEN MEDICATION AND THERAPY DON'T WORK?

Question: My wife suffers from depression. She has tried the usual treatments like psychotherapy, cognitive-behaviour therapy and lots of different antidepressant medications. But nothing seems to help much. Now the doctors are suggesting she should try electroconvulsive therapy. But she is not interested in subjecting herself to electroshock – and I don't blame her. Is there anything else that might lift her out of the blues?

Answer: Your wife is certainly not alone. About one-third of patients don't get lasting relief from the standard therapies. But there is a relatively new treatment that may benefit your wife and other patients like her.

It's called Repetitive Transcranial Magnetic Stimulation, or rTMS, and it's essentially a treatment that uses magnetic-field pulses to reset the circuits of the brain that control emotions. It hasn't yet received much public attention, partly because it takes a lot of treatments to work and only two provinces – Quebec and Saskatchewan – currently pay for the therapy.

But you could soon be hearing a lot more about rTMS.

Two more provinces – Ontario and Alberta – are now considering adding rTMS to the list of treatments covered by their health insurance plans.

Even more important, researchers have been fine-tuning rTMS to make it accessible and effective for more patients.

Dr. Jonathan Downar, a psychiatrist and neuroscientist at Toronto Western Hospital, is one of the researchers leading the way. “I am hoping we will be able to deliver effective and affordable rTMS treatment to everyone who needs it,” he says.

To understand depression, he says, it helps to think of brain activity as traffic patterns in a big city.

“The brain is composed of billions of neurons that are organized into regions like neighbourhoods in a city,” he explains. Each of these regions performs a different function, and they are all connected through networks that act like roads. Activity is supposed to ebb and flow between the various regions as the brain performs different functions.

In the case of depression, however, some areas involved in regulating emotions, thoughts and behaviours are overactive. This means some circuits, or roadways, in the brain get stuck in certain activity patterns, preventing others from operating normally.

“Imagine if rush-hour traffic wasn’t just one or two hours, but lasted all day. The city would be gridlocked,” says Dr. Downar. “And what depression looks like on a brain scan is gridlock that doesn’t go away,” he said referring to areas of the brain that are unusually overactive.

The patients basically become preoccupied with negative thoughts and feelings and can’t get those ideas out of their heads.

Talk therapy can help some people break out of their mental gridlock. Others benefit from antidepressant medications that can alter brain activity.

But for those who don’t respond to either talk therapy or medication, rTMS may bring relief, says Dr. Downar, the director of the MRI-guided rTMS clinic at Toronto Western Hospital.

“It’s an electromagnet that can deliver finely focused magnetic-field pulses to anywhere in the brain to a depth of 2 to 3 centimetres,” he says. “We can use an MRI to guide it. And by applying repeated pulses over time, we can strengthen or weaken circuits that are overactive or underactive,” he explains.

“This is not a fridge magnet – this is a pretty powerful tool,” he adds. Earlier studies

have shown that 50% of depressed patients experience an improvement in their symptoms, and a third said they were no longer depressed after completing the therapy. To put those figures into context, all of the patients who received rTMS had failed to respond to conventional therapies.

An added bonus is that rTMS is relatively free of long-term adverse effects. It doesn't affect memory or attention – a common complaint of electroconvulsive therapy. There is a 1-in-10,000 chance of a seizure, but that's about the same or less than the level of risk associated with antidepressant medications.

“All the effects are short term,” says Dr. Downar, and most patients can tolerate them. The magnetic pulses from the device “feel like an elastic band being snapped against your forehead,” he says. “You can get a headache afterwards for an hour or two – that usually goes away after the first week of treatment.”

Without question, rTMS sounds very promising. But there is a catch. It takes a lot of treatment sessions to get the desired results. With the standard course of treatment, patients require 20 to 30 separate sessions of treatment – each lasting 38 minutes.

Dr. Downar and his research team – with funding from the Ontario Brain Institute – have been searching for ways to shorten the overall treatment time. After reviewing findings from earlier studies, the researchers decided to adjust the stimulation so that it mimics theta rhythms – signals the brain naturally uses to alter its own activity patterns.

“Based on the data we have so far, it looks like 3 minutes is equivalent to 38 minutes using this approach,” he says. Patients still need 20 to 30 separate sessions. But, at just 3 minutes a treatment – instead of 38 – it may be possible to schedule several in a single day, shortening the time to recovery.

“We don't want this to be taking four to six weeks with the person schlepping into the hospital every day for treatment,” he says. “We need to get this down to one or two weeks.”

Speedier therapy is good for patients, but it also makes the treatment much more cost-effective for the health care system – and that means more patients could potentially receive the therapy.

In another refinement of the treatment, Dr. Downar's team changed the spot in the brain that's stimulated with rTMS. Most of the earlier research focused the pulses on the dorsolateral prefrontal cortex – an area on the side of the frontal lobes.

Instead, Dr. Downar stimulates an area called the dorsomedial prefrontal cortex, tucked away between the two hemispheres of the brain. This seems to boost the number of patients who experience full remission, rather than just feeling partially better.

“Not everybody responds to rTMS treatment, but with this new brain area, you get fewer partial responses. So if you do improve, you are more likely to get all the way to remission.”

Dr. Downar is very cautious not to call this treatment a cure. Some patients lapse back into depression after an average of about 10 months following the initial therapy. But “booster” treatments with rTMS can restore their mental well-being.

Once the depression lifts, the patients need to work on the life stressors that tend to push them over the edge, says Dr. Downar.

By breaking patients out of their mental gridlock, “we strengthen people’s ability for self-control,” explains Dr. Downar. “We are not pushing a happy button. We are improving their own ability to regulate their thoughts.”

If a job or a bad relationship is repeatedly sending a person into depression, then rTMS provides a window of opportunity to fix it. “What we are trying to do is get you to the point where you can climb the stairs yourself – this is not an escalator ride up.”

Dr. Downar is trying to develop a screening test to determine, in advance, which patients are most likely to benefit from rTMS – so depressed individuals won’t have to waste time on multiple treatments before realizing it’s not going to work for them.

He would also like to increase the treatment’s success rate above 50%.

Some people might not benefit from rTMS because the source of their mental gridlock may be located deep in the brain – and out of reach of the electromagnetic pulses.

Dr. Downar points out that neurosurgeons are already helping some severely depressed individuals by implanting electrodes that provide a steady stream of electric current to a region deep inside the brain – a therapy aptly named deep-brain stimulation.

He also notes that several companies are currently working on new and improved rTMS equipment designed to send electromagnetic signals deeper into the brain than is currently possible. If they succeed, patients may be able to benefit from deep-brain stimulation without undergoing invasive and costly brain surgery, says Dr. Downar.

Other mental health professionals also look upon rTMS as a potentially promising therapy.

“We wish we had one treatment that everyone responded to. We know that is certainly not the case. And so the broader the menu of options that we have, the better it is for our patients,” says Dr. Ayal Schaffer, head of the mood and anxiety disorders program at Sunnybrook Health Sciences Centre.

In addition to depression, rTMS may be useful for treating other conditions, such as anorexia nervosa, bulimia, obsessive-compulsive disorders and post-traumatic stress disorder, says Dr. Downar. Each of these conditions shares a common trait with depression. The brain is caught in a kind of endless loop and the patients can't break out of it on their own.

Right now, in Ontario and most other provinces, rTMS is available only to a limited number of patients involved in studies funded by grants and donations.

If more provinces decide to fund rTMS, it would open up this treatment option to more and more patients – including possibly your wife.

- *Paul Taylor*

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HOW CAN I HELP MY TEEN GET HELP FOR HER ANXIETY AND DEPRESSION?

Question: My daughter is avoiding school and has a lot of anxiety and seems to be depressed. She has been acting out, too, cutting herself and stealing things. I'm worried she is also getting involved in drugs. We got her to talk to our family doctor and he referred her to a specialist, but there is a very long wait for an appointment.

I'm worried about what's going to happen to my daughter in the meantime. We live in Toronto. A friend saw an article in a newspaper that said Sunnybrook has a new program to help families with adolescents who have mental health problems. Can you help us?

Answer: I would say there's a very good chance that the Family Navigation Project (www.sunnybrook.ca/content/?page=family-navigation-project) can help. It was set up to assist parents of youth between the ages of 13 and 26 who are dealing with mental health issues, addictions or both.

In fact, the impetus for the project came from parents who struggled to find the right treatments for their kids. Parents might wait months to get their child into a particular program, only to learn that it's the wrong type of service or program or treatment.

They didn't want other parents to experience the same frustrations. So a group of them approached Dr. Anthony Levitt, a staff psychiatrist at Sunnybrook Health Sciences Centre, with the idea of putting together a program that would guide families through the confusing maze.

After several years in the making, the Family Navigation Project got up and running in June 2014. Its aim is to serve families who live in the Toronto area. All you need to do is phone 1-800-380-9367, and you can expect to get a response back within one busi-

ness day. (You can also send an email to familynavigation@sunnybrook.ca.)

“It takes a lot of courage for parents to pick up the phone and make that call. So we really want to connect with them as soon as we can,” says Jillian Polson, one of the navigators.

Your navigator will ask you a series of questions about your daughter and may later reach out to others involved in her care such as your family physician. But before contacting other health care professionals with knowledge of her case, the navigator must first obtain your daughter's permission in order to respect her patient confidentiality rights, which are protected under the Mental Health Act.

“We navigate best when we have information, and we often request consent from the youth to allow access to assessments and consultations that have been done in the past,” says Dr. Levitt, who is the medical director of the Family Navigation Project.

Once all this information is collected, the team of navigators, and Dr. Levitt, will review your daughter's case. Much thought is given to the most appropriate treatment options specifically matched to your daughter and your family's needs.

“We brainstorm and share ideas to come up with a care plan,” says Dr. Levitt.

Ms. Polson says families are usually offered a few options so they can pick the one they intuitively feel is best. Equally important, the navigator will then provide ongoing support.

“When a family contacts us, we don't just say, ‘Call this number, good luck with everything,’” explains Ms. Polson. “We follow up to see how the treatment is going.”

If something doesn't work out, the navigator is there to back up the family with an alternative plan. And should additional assistance be needed following treatment, the navigator will help make those arrangements as well.

As Dr. Levitt puts it: “We stay in the boat with you throughout your journey.”

It is this ongoing assistance – combined with clinical expertise – that makes the Family Navigation Project fairly unique in the world of mental health.

Dr. Levitt says, “We have tremendous resources in our health care system and some remarkable facilities.” The problem is that many families have a hard time finding the appropriate treatment program for their loved one, and often wait times are unacceptably long.

For instance, some programs deal solely with youth who have mental health issues,

while others focus exclusively on substance abuse.

Yet many youth need a program that addresses both problems simultaneously. Without the right match to resources, they can get lost in the system, leading to a delay in the start of treatment, and for youth in crisis, this can lead to unnecessary suffering and even dangerous consequences.

“Families are left with no sense of what they are supposed to be doing and where they are supposed to be going in the system,” says Dr. Levitt. “A lot of time can be wasted, which results in a lot of unnecessary pain and suffering. The role of the Family Navigation Project is to find the right treatment as soon as possible.”

And even if a youth ends up having to wait to get into a program, the fact that the family has a plan in place sometimes goes a long way to easing the family's anxieties, says Dr. Levitt.

“We have a view from inside the system so we are able to identify the right pathways to the right resources,” he says. The navigators actually spend about a day each week visiting various treatment facilities and getting to know the staff. “We really get a feel for what a program offers,” says Ms. Polson.

The cost of treatment is an issue that will likely need to be discussed with your navigator. Not all programs are covered by the public health care system. For an outpatient, a therapy session with a clinical psychologist can cost up to \$250 an hour.

A course of treatment in a residential facility – where the youth stays overnight for a prolonged period – can be very costly. One advantage of the private clinics is that wait times can often be significantly shorter than for publicly funded programs, but the issue for many families that contact the Family Navigation Project is, of course, the cost.

Some families are able and willing to pay for that care, including specialized treatment facilities inside and outside of Ontario. But others can't afford the additional expense. Your navigator will take your financial situation into account when looking for programs.

“We find resources regardless of the financial capacity of the people who call. We are connected to service providers in both the public and private health care systems, and we work with the family according to their wishes, capacity and need,” says Dr. Levitt.

Most of this care-planning work with the families is done over the phone or through emails, which can be more convenient than face-to-face meetings.

“These families are in crisis,” says Dr. Levitt. “To try to book an appointment, leave home when the child is unwell, and come speak to us is very difficult for many families.” By communicating on the phone “we can offer times that work for people – there

is a lot more flexibility this way.” And with follow-up emails “we can keep up to date with many families on a daily basis by just a few words back and forth,” adds Ms. Polson.

Families who have already been through the mental health system with a troubled youth continue to play a supportive role for those just starting the process. “Our parents do peer support for families who need to know that someone else has been there and got through it,” says Dr. Levitt.

By June of 2014, the navigators have handled about 180 cases since the project had its unofficial start in the fall of 2013. With four navigators, a program manager, an intake worker/administrative assistant and three doctors pitching in, as well as several parent volunteers, the team is already operating beyond its original projections.

“We thought we would serve about 125 in the first year. We are finding that the need is greater than that. In fact, we projecting close to 400 families will contact us and find help in this first year,” says Dr. Levitt.

For now, the team’s focus is confined to youth in the Greater Toronto Area. But Dr. Levitt thinks the project could serve as a model for other regions and age groups. “Our goal is to have a network of navigators across the province ... patients could move across the system to get the most appropriate care.”

He notes there are several other organizations helping families find their way through the mental health system in other parts of Canada, such as the Parents LifeLine of Eastern Ontario (PLEO, www.pleo.on.ca) and The FORCE Society for Kids’ Mental Health (www.forcesociety.com), which operates in British Columbia. These groups were started by parent volunteers and “they do a remarkable job in their communities,” says Dr. Levitt.

The Family Navigation Project also operates under the guidance of a volunteer parent advisory council. “These parents are passionate about the project and spend countless hours helping at every level,” he adds.

The Family Navigation Project differs from FORCE and PLEO in that the navigation is led by clinical staff who work closely with parent volunteers. “The system knowledge of the clinical staff is particularly helpful in matching patients to the right treatment programs,” says Dr. Levitt.

So, hopefully, the Family Navigation Project can also help you and match your daughter up with the most appropriate care, as quickly as possible.

- Paul Taylor

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COULD MY EMOTIONAL PROBLEMS BE CAUSING PHYSICAL SYMPTOMS?

Question: I am looking for a geriatric psychiatrist. I am 77 years old and I have newly surfaced emotional problems. It started with physical symptoms, which were treated in the emergency department. However, none of the symptoms disappeared, and by now I am convinced that they are the manifestation of my emotional state. I am also a child of a Holocaust survivor. Thank you for your attention and looking forward to receiving some direction.

Answer: You are correct to want to seek a geriatric psychiatrist, but typically they are in short supply and are most likely found in large Canadian cities. There is a very good chance, however, that a general psychiatrist may also do a perfectly good job of treating your symptoms, so you may want to consider being open to that possibility, particularly if the wait to see a geriatric psychiatrist is long.

“It sounds like the right thing was done,” says Dr. Nathan Herrmann, head of the Division of Geriatric Psychiatry at Sunnybrook. “She has seen her physician and had a good medical checkup to rule out any obvious medical problem.” He suggested a geriatric psychiatrist would be ideal, though most psychiatrists would be able to treat your symptoms.

You also raise a very important issue that has been studied since the dawn of psychiatry: Do physical symptoms cause psychiatric disturbances or is it the other way around?

It turns out it's a bit of both. There are psychiatric disorders that can cause physical symptoms and medical illnesses that can cause psychiatric symptoms.

Patients who have suffered a stroke, for example, run a “high risk of developing clinical depression that can be due to biological reasons as well as psychological and social reasons,” Dr. Hermann says.

Psychiatric disorders, in turn, can cause physical symptoms, often amplifying aches and pains that many may live with but not feel as intensely. There are also medications to treat a physical symptom that cause depression and mania.

“There is a whole category of somatic illnesses that are actually psychiatric disturbances that present with medical complaints,” he says.

Sometimes, the psychiatric label is placed on patients when doctors cannot determine the cause of their symptoms.

“Patients with multiple sclerosis are notorious for presenting with vague physical com-

plaints that are never diagnosed and thought to be psychiatric in nature,” says Dr. Herrmann.

There is one other group that has both – psychiatric and medical illnesses that have a tendency to accentuate the negative. “People who have coronary artery disease and depression are more likely to drop out of their cardiac rehabilitation,” says Dr. Herrmann, who is also a professor in the Department of Psychiatry at the University of Toronto.

Typically, most patients go to their primary care physician with symptoms of palpitations, dizziness, fainting, nausea, weakness or vague pains. Some have premature ventricular beats that are within normal limits, but because of an underlying psychiatric condition, they are hyper-focused on them.

And then there is aging itself, when many life changes occur: children are leaving home – or coming back when their parents are living on a fixed income. Friends are dying; chronic medical illnesses – diabetes and heart disease, for example – are more common.

You mentioned that you are the child of a Holocaust survivor. There is a huge amount of literature on this very issue and “whether they are truly different is not clear,” says Dr. Herrmann, noting that the parents sometimes have post-traumatic stress disorder.

“The children of Holocaust survivors are a different story,” he says. “They can be burdened by their parents’ guilt and emotional problems. The emotional distance can affect their psychological development.”

However, it would be incorrect to assume, he said, that there is a specific symptom or cluster of symptoms that is associated with being a child of a Holocaust survivor.

“What a psychiatrist would do is include that knowledge in her information and how it might relate,” says Dr. Herrmann.

I suggest you return to your family physician and request a consultation with a geriatric psychiatrist, or if that is not possible, with a general psychiatrist who can treat your problem.

- Lisa Priest



PRIVACY & COVERAGE

DO AMERICAN BORDER GUARDS HAVE ACCESS TO CANADIANS' PERSONAL HEALTH INFORMATION?

Question: News reports have suggested that U.S. border security agents have access to medical records of Canadians. This is beyond outrageous and nullifies the entire basis of trust in a doctor-patient relationship. Effectively a government spy is in every examining room!

Why would I even go to a hospital or doctor in Ontario if the result is going to be public disclosure of my medical records to any government agency (Canadian or foreign), or insurance company, or employer, or police force? I now have no medical care, not without tremendous risk of disclosure of my highly personal medical information.

Answer: There are many troubling issues that have been raised by the media reports. But new details are emerging and the situation may be different than you were originally led to believe.

For the benefit of those who didn't follow the story, I will briefly recap what's happened.

On November 25, 2013, Ellen Richardson went to Toronto Pearson International Airport

to board a plane for New York, the starting point of a 10-day cruise to the Caribbean. A U.S. Customs and Border Protection agent turned her away, apparently citing the fact she had been hospitalized in June 2012 for “a mental health episode.” Ms. Richardson was told that if she wanted to enter the United States at some future date, she would need a “medical clearance” from a U.S.-approved doctor.

The incident seemed to suggest border agents, working for the U.S. Department of Homeland Security, are able to access personal medical files on their computer screens at the airport.

Ontario's information and privacy commissioner launched a probe into the matter. However, a spokesperson for the provincial health minister said border officials don't have access to the medical or health records of Ontario residents.

Several legal experts have speculated that the information about Ms. Richardson's hospitalization likely came through Canadian police – not the Ministry of Health.

Even Ms. Richardson's lawyer, David McGhee, came to think police were the likely source.

Ms. Richardson suffered from depression in 2012, following the breakup of a relationship. She made what she reportedly described as a “half-hearted” suicide attempt by consuming some pills. Her mother called 911 and an ambulance took her to hospital.

“When people have a problem, they call 911. They don't know that 911 is operated by the Toronto Police Department,” says Barry Swadron, a prominent Toronto lawyer.

He explains that the police routinely make notes of these events, including suicide attempts and mental health episodes. Some of this information is then added to the RCMP-operated Police Information Centre database, which is accessible to the U.S. Federal Bureau of Investigation and other American agencies such as the Department of Homeland Security.

Mr. McGhee confirms that “police did attend” when the 911 call was made at the time of Ms. Richardson's attempted suicide. “The local police relay the information to the RCMP, and the RCMP then shovel it over to U.S. authorities. That appears to be the way it works,” he says.

Mr. McGhee is still seeking additional information to verify that this was what happened to his client.

But even if the Ministry of Health was not involved, that's cold comfort to mental health advocates who are worried about the type of non-criminal data that are often collected by the police and shared with foreign governments.

“It’s discriminatory,” says Abby Deshman, a lawyer and program director with the Canadian Civil Liberties Association.

“The minute you put mental health information into police databases, you run the risk of people making decisions based on that information,” she adds.

“There is frequently a wrong association made between mental health and violence, ... and that can lead to direct discrimination against an individual.”

In Ms. Richardson’s case, an apparent police record of her hospitalization for depression was enough to bar her from the United States, and she ended up missing the departure of her cruise ship.

Under the U.S. Immigration and Nationality Act, border agents can reject travellers who are considered to have a physical or mental disorder that could pose a threat to property, safety or welfare of themselves or others.

Ms. Richardson has sought treatment for her depression and her condition is stable, according to media reports. (Ms. Richardson is paralyzed below the waist as a result of a failed suicide attempt in 2001 when she jumped off a bridge.)

This was not the first time U.S. border agents turned back Canadians because of mental health information contained in police files. In 2011, the CBC reported that more than a dozen Canadians had told the Psychiatric Patient Advocate Office in Toronto they were kept out of the U.S. in circumstances that resemble what happened to Ms. Richardson.

So when it comes to border crossings, the key issue seems to be what’s in the police files.

But it’s still worthwhile reviewing the measures that are meant to keep your medical records confidential, because that is the main focus of your question.

The first thing to know is that the Ontario Ministry of Health doesn’t actually have a complete copy of your medical records – those files are retained by your doctors and the hospitals you visit.

At Sunnybrook Health Sciences Centre, for example, patients can see their own medical records through a secure online service called MyChart (www.sunnybrook.ca/content/?page=mychartlogin-learnmore). The patients themselves have the ability to grant access to third parties such as other doctors and family members.

Other hospitals and physicians’ offices have adopted, or are in the process of creating, other electronic medical records. That essentially means there is not a single and complete record system for the entire province. However, all health care providers must

abide by the Personal Health Information Protection Act, which contains rules for ensuring the privacy of the medical records under their control.

What the province does collect is billing information. So if you're treated by a psychiatrist, the Ontario Health Insurance Plan will have a record of the date of your visit and your diagnosis, but not the substance of your conversation.

Still, much can be learned about the state of your health by a list of your medical appointments. The treatments you receive, if they are covered by OHIP or the provincial drug benefit plan, would also be on file. So the province has adopted various security precautions to protect that information.

I asked David Jensen, a ministry spokesperson, to paint a picture of those safeguards. In an email, he replied: "The Ministry of Health and Long-Term Care has a number of databases that contain different types of information about the health services received by individuals. Each database is organized differently.

"Most databases, however, do not contain the names of individuals, and are organized by Health Card number. The Ministry protects the privacy of individuals by not including the name and Health Card number together. If a person inadvertently or improperly accessed an individual's record from a database containing Health Card numbers and a description of health services, the individual's identity would not be revealed.

"A separate Ministry database that specifically links Health Card number with name and date of birth – and has separate and independent security processes – would also have to be accessed by the person in order for them to identify the individual who received the services described in the other database."

This explanation helps show why it's highly unlikely U.S. border agents tapped into Ministry of Health records to learn about Ms. Richardson's medical history.

I hope this overview will ease your concerns about your own medical records – at least as they pertain to the files kept by your health care providers and the health ministry.

The police are another matter. "It would be extremely troubling if people felt they couldn't phone the police or an ambulance because they were worried about the implications down the road of having it on record," says Ms. Deshman.

- Paul Taylor

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IS MY HEALTH CARE STILL COVERED WHEN I MOVE TO ANOTHER PROVINCE?

Question: I am planning to move to Ontario from British Columbia. I looked at the web-

site for the health branch of the Ontario government and discovered I will have to wait about three months before I am eligible to receive health coverage from Ontario. Why is that? I am a Canadian citizen. Shouldn't I be entitled to immediate medical benefits in my new home province?

Answer: You are correct – there is a three-month delay before your Ontario health coverage takes effect. But that doesn't mean you will be without public health insurance. British Columbia will continue to pay your basic medical bills during the transition period.

If you need to visit a hospital emergency department during your first few months in Ontario, you won't have to pay out of pocket. The hospital will ask you to sign some paperwork, stating that you are now an Ontario resident. In turn, the Ontario Ministry of Health will use this documentation to seek reimbursement for your medical expenses from B.C.

A similar arrangement exists between all the provinces and territories. In 1991, the provincial and territorial governments agreed to a common policy to deal with migration within Canada.

When Canadians move from one part of the country to another, they have to wait roughly three months before they can get a health card in their new home province. In the meantime, their former province is largely responsible for their medical bills.

This agreement provides for continuity of care. "No matter what province you are in, you are entitled to health insurance," said Maggie Epp, manager of patient accounts at Sunnybrook Health Sciences Centre. "I have never seen a situation where someone falls between the cracks and isn't covered anywhere."

Even so, it won't be a seamless move in terms of your coverage. While basic medical care is covered, some of the "extras" may disappear once you're outward bound. British Columbia won't pick up the tab for an out-of-province ambulance ride. The B.C. Ministry of Health website even advises people leaving the province to "buy additional private health insurance to supplement your basic coverage."

There are a few exceptions to the three-month wait. Among them, most provinces waive this policy for families of Canadian Armed Forces members.

But, you might wonder, why is there a lag for the rest of us? As you asked in your question, why doesn't your new home province start paying your medical bills immediately?

The truth of the matter is that not all provinces pay for the same list of medical services and health-related benefits. For instance, B.C. has a fairly comprehensive drug benefit program that covers the cost of cancer medications – regardless of whether the patient gets the drug intravenously in a hospital or pops a pill at home. In contrast, Ontario

covers only the cancer drugs administered in a hospital medical clinic.

If a waiting period did not exist, Canadians could theoretically visit another province that offered more generous health benefits when they needed them, and then head back home – which would essentially be a form of “medical tourism.”

The provinces have a vested interest in making sure newcomers plan to stay before they are permitted to make use of the local health services.

But some health policy analysts and media commentators see it differently. For them, the waiting period highlights certain disparities within Canadian health care. “We should be drawing attention to variations in care at every opportunity, and demanding they be fixed,” André Picard, the Globe and Mail’s public health reporter, wrote in October 2013.

So now, let’s get back to your question. You can rest assured that your basic medical coverage will continue without interruption when you move to Ontario. But bear in mind that you will be leaving behind a generous drug benefit plan in British Columbia.
- Paul Taylor

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HOW DO I ACCESS THE MEDICAL RECORDS OF A DECEASED RELATIVE?

Question: I live in Ontario and my father recently died of cancer. I was his medical advocate and I’m now the executor of his will. I feel my father’s treatment was compromised because of poor communications between the medical staff involved in his care. I would like to obtain my dad’s medical records. How do I get access to them?

Answer: The information contained in the medical records belongs to the patient. When the patient dies, the person who is responsible for administering the estate – such as the executor – becomes the “substitute decision maker.”

That means, as the executor of your father’s will, you have the legal authority to access his medical documents.

But keep in mind that the physical records are the property of the doctors or hospitals that created them – and they have a legal responsibility to maintain them for a certain period of time. You won’t get the originals. Instead, you will be given copies and charged an administrative fee.

The amount of this fee has been an occasional source of controversy. A few years ago, a patient in Ontario was asked to pay over \$2,500 and complained to the province’s

information and privacy commissioner. In response, the commissioner set a guideline of \$30 for the first 20 pages, plus 25 cents for each additional page. (Many other provinces, or the local medical regulatory bodies, have created similar rules to keep fees in a reasonable range.)

Based on your question, it sounds like you have some concerns about your father's medical treatment. However, there are many reasons why the medical records of a deceased person can be of great interest to the living relatives. The factors that contributed to the death could have a bearing on their own health – think genetics. And the records may be needed for dealing with legal and financial issues related to the estate.

An example might be when the spouse of a deceased individual requires confirmation of death in order to be entitled to the individual's pension or insurance benefits.

So it's fairly common for people to seek the medical records of a deceased next of kin, says Sarina Cheng, director of the Health Records Department & eHealth Strategies at Sunnybrook Health Sciences Centre.

To obtain your father's records, you will need to contact the health records department of the hospital where he was treated. For a complete picture, you will likely have to contact the offices of the physicians who cared for him outside the hospital.

You will have to show documents that prove you have the authority to act on behalf of your father, says Ms. Cheng.

I don't expect you will run into any problems. But what happens when someone dies without a will – which is a frequent occurrence.

The law in Ontario does allow for some flexibility in these situations. Very close kin – the spouse, partner, sibling or child – can get the records without being the dead person's legally designated substitute decision maker. However, the law also states that the release of the documents is “discretionary, not mandatory” on the part of those who hold them.

If the relatives are denied access, they can appeal to the information and privacy commissioner of Ontario.

The privacy office has produced an online fact sheet (www.ipc.on.ca/images/Resources/fact-15-e.pdf) with frequently asked questions about obtaining the medical records of deceased relatives.

Some may find parts of the fact sheet are written in an overly legalistic fashion and lack clarity. But it does include links to the request forms – and that makes it a useful resource.

- Paul Taylor

THE AUTHORS

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Paul Taylor is a patient navigation advisor at Sunnybrook Health Sciences Centre (www.sunnybrook.ca) in Toronto. Previously, he played a key role in the Globe and Mail's health coverage for more two decades, first as a medical reporter and later as the paper's health editor. He was responsible for launching the Globe's first weekly health section in 1998. While editing the page, he continued to write, including a weekly column called "Small Doses" that highlighted significant studies and medical trends. Taylor has received numerous journalism awards, including the Connaught Medal for Excellence in Health Research Journalism and two awards sponsored by the Canadian Science Writers' Association; he received an honourable mention for the Roland F. Michener Award for Public Service in Journalism. He is also a co-winner of an award from the Centre for Investigative Journalism. From 2000 to 2007, he was a member of the Ontario Press Council, a body that adjudicates public complaints about news coverage in Ontario newspapers. Follow Paul on Twitter @epaultaylor

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ABOUT HEALTHY DEBATE

Our health and the health of our loved ones are more important to us than almost anything else. We all have stories about how our health care system has provided excellent care, and how it has let us down. Despite the personal and societal importance of health care, we believe many Canadians are less informed about our health care system than they would like.

Healthy Debate attempts to fill this gap by making every effort to provide unbiased information that will lead to thoughtful deliberation and informed opinions. We publish articles, opinion pieces and a podcast on www.healthydebate.ca, providing accessible information about a wide variety of issues in health care. We aim to offer information that is interesting and useful to both the general public and health care workers, and hope that by creating a forum where patients and professionals can deliberate about the future of the system, we can work together to make it better.

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Our **vision** is to invent the future of health care.

Our **values** are: excellence, collaboration, accountability, respect and engagement.

From our beginnings as a hospital for Canadian veterans, Sunnybrook has flourished into a fully affiliated teaching hospital of the University of Toronto, evolving to meet the needs of our growing community. Today, with 1.2 million patient visits each year, Sunnybrook has established itself as the largest single-site hospital in Canada, with four strategic areas of focus: Heart and stroke; cancer; trauma, emergency and critical care; and women and babies.

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