

Step by Step Guide

to **Navigating**

your way

through

Canada's

Healthcare

System

and

Minimizing

Your Wait Time



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Author's Note

The case examples in this book are based on true experiences of individuals who came to Medical Confidence for assistance. In order to protect confidentiality, individuals' names and details have been changed. Any resemblance to actual individuals is purely coincidental.

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Introduction

Alice prided herself on how well she took care of herself. At fifty, she went to yoga twice a week, swam at the local pool and worked out in the gym regularly. She limited her alcohol to two or three glasses of wine per week, and made eating organic food a priority. She felt she was one of the healthiest people she knew, and an inspiration to her family and friends.

A week after her annual medical checkup, which included a physical examination, blood work and a mammogram, she received a call from her doctor asking her to come in to discuss the results. Alice always liked to meet and review all test results so she could compare the new findings with last year's results and discuss any changes she should consider making in her lifestyle. Alice was not expecting these results to be unlike any from the past.

As soon as she saw her doctor, Alice knew something was not right. Her mammogram came

back classified as a Category VI – possibly breast cancer. Alice went numb. She could no longer hear her doctor explain that it may not be breast cancer. The radiologist had recommended a biopsy.

Unfortunately, the biopsy did confirm she had stage IIB breast cancer. Alice had to wait two long, stressful months to see the oncologist she was referred to by her family doctor. Alice read everything she could find on stage IIB breast cancer, including her treatment options. She still felt uncomfortable as she knew nothing of the oncologist's expertise or background. Plus, she had to wait two months without treatment, increasing her level of risk. Alice waited dutifully since she did not know what else she could do and felt she had no other choice. She followed the oncologist's recommendation of a lumpectomy with treatments of radiation.

Four months later, and just before the oncologist was leaving on vacation, he told her that the cancer had advanced to stage IV. Shortly after that, Alice started experiencing intense pain – pain

and swelling in her arm. She could not consult her oncologist as he had left for his vacation. The pain and swelling scared her so much that she went to the hospital Emergency Room (ER) not once, but twice. Both times she was told that they could not treat her and that she would have to wait for her oncologist's return.

Her oncologist returned two weeks later and an appointment was scheduled. He prescribed morphine to help Alice cope with the pain while she waited for the appointment date. When she finally saw the oncologist, he informed her that the swelling and pain in her arm were symptoms a thrombus (a blood clot).

How did this happen? Alice prided herself on being an intelligent and tenacious woman. Yet, in the course of six months, her chances of survival had plummeted from 74% down to only 22%. She felt trapped, alone and helpless in the healthcare system, and saw no alternatives. She asked the same questions you might be asking: What if she had received treatment immediately

after first being diagnosed? Did the oncologist recommend the right treatment plan? How could her oncologist go on vacation and not have backup arrangements for patients requiring immediate attention? How could a hospital ER turn her away twice when she had a blood clot? She was sick. Wasn't the system supposed to help her when she needed it most? What could she have done instead?

Studies show patient engagement is essential to improving health outcomes.

Studies show that patient engagement is essential to improving health outcomes, and the lack of it is a major contributor to preventable deaths²⁸. The legal and medical costs of misdiagnosis are one thing, but the emotional and physical costs to patients and their families can be devastating. Compensation never makes up for the stress and frustration when one is caught up in the situation that could have possibly been prevented. Those involved in unnecessary procedures, due to

medical under-diagnosis, misdiagnosis or incorrect treatment plans, often suffer physical and psychological trauma. It is no surprise that patients are frustrated, stressed and unsure of where to turn when they hear conflicting treatment options and/or do not see an improvement in their condition. On top of that, the length of time it takes to see another doctor can make it prohibitive to get another opinion.

51% of us reported fundamental changes are needed in our healthcare system.

While most Canadians are thankful for our healthcare system, 51% reported to the Commonwealth Fund that fundamental changes are needed². Our system is failing to provide Canadian healthcare consumers with reasonable access to essential medical services regardless of employment, income or health. When it comes down to who is treating us, we often have very little choice, and only a few of us have contacts to

help us find and access a qualified specialist within a reasonable amount of time. Like Alice, many individuals feel alone, helpless and scared when dealing with a healthcare challenge.

After years of helping individuals understand and work within the Canadian healthcare system, I want to share valuable lessons that I have learned. By becoming actively involved in your own healthcare, you can get the care you need when you need it, even if you are weakened by your medical condition.

Individuals who participate in their own healthcare learn how to manage important pieces of health information, such as copies of their medical records. These important records can help medical practitioners to efficiently and effectively identify a diagnosis and optimal treatment recommendations.

Fully engaged healthcare consumers can also decrease the misuse of precious and limited healthcare resources, which reduces overall

healthcare costs and wait times.

The tips in this book are intended to help consumers of the Canadian healthcare system become their own best advocates and effective partners with their treating team of healthcare professionals. This partnership is necessary for healthcare consumers to get the answers they need so they can make informed decisions and achieve the best possible outcome given the situation at hand.

Before we get to these tips, I want to share some of the challenges that you may encounter while navigating the system itself. I have used actual cases to help you understand these challenges, as they will greatly improve your chances of getting the treatment you need, when you need it.

Waiting Too Long

Jeanette was working as an executive assistant. At sixty-two years of age, she spent most of her day sitting down. This was because she had great

difficulty walking or standing due to problems with her toes.

Ten years earlier, an orthopedic surgeon had suggested to her that the best way to stop one toe from crossing over the neighbouring toe was to sew the two toes together. The doctor believed that the normal toe would help hold the disfigured toe in place. Jeanette did not question the doctor about the procedure, as she did not want it to seem like she was challenging his expertise. Feeling intimidated and fearing he would not help her if she refused, she opted to proceed with the surgery on his recommendation.

The procedure was unsuccessful. Over the next few years, the two toes completely crossed over each other. Finding shoes that fit her foot was extremely difficult. Walking was next to impossible. Jeanette resorted to walking on the side of her foot.

Consequently, she stopped walking unless she had to. Shopping, running errands and going out with friends were tasks that became too difficult for her. She needed to conserve her energy to get to and

from work.

When Jeanette could no longer tolerate her condition, she asked her family doctor to refer her to another orthopedic surgeon. Her doctor agreed she needed a solution, however the wait time to see an orthopedic surgeon who specialized in foot surgery in Montreal was up to five years. After further investigation, it turned out that the particular orthopedic surgeon they were considering only treated ankles, and would not have been able to deal with toes.

Jeanette took things into her own hands and called every orthopedic surgeon in Montreal. There was only one who could help her and he could perform the surgery in four months. The only problem was that his was a private practice and the surgery would cost \$8,000. How was this possible? Wasn't this considered an essential procedure and therefore paid for by the system?

If you have ever required treatment from a specialist, you can likely relate to Jeanette's story.

Much time is often spent either waiting for an appointment, or for a procedure. Either way, you are waiting, and you are not alone. According to the Organization for Economic Co-operation and Development, Canadians are waiting longer to see a specialist than patients in any other developed country in the world.

Canadians wait longer than patients in any other developed country.

The Commonwealth Fund's 2014 International Health Policy Survey of Older Adults confirms this, stating Canada's wait times for access to a specialist are longer than any of the 11 other Commonwealth countries surveyed.

Both the provincial and federal governments have acknowledged this problem and have worked to correct it. In fact, over the past ten years they have allocated substantial resources with the intent of improving wait times. The central focus of this investment was to budget for more doctors, yet wait times have not decreased.

Canadian provinces spent \$134 billion more on healthcare between 2004 and 2012. Despite this infusion of funds, national wait times are actually slightly longer today than they were in 2004, and almost twice as long as they were in 1993.

A 2013 study by the Fraser Institute revealed that specialists average 18.2 weeks from referral from the primary care practitioner when an elective procedure has been requested. Specialties such as orthopedic surgery have wait times as long as 39.6 weeks.

Wait times are 95% longer than in 1993.

Today, wait times are 95% longer than in 1993 and studies also show that median wait times are at higher than levels deemed ‘clinically reasonable’ in every category⁴.

As a patient in the system, you may be asking, “What can I do? I am only one person!” While you cannot fix the system, you can take measures to get the best care available when you need it. After

waiting to see a specialist, it is vital that you go into your appointment fully prepared.

This book can help you do just that. I believe you should be as prepared for an appointment with a medical practitioner as you would be for a job interview. However, before you start preparing for your appointment, you will need to know about some flaws in our healthcare system, particularly those that complicate things for you when you need to see a specialist.

A Broken Referral Process: Doctors Working in the Dark

Jim, a software developer, was frustrated after spending two years trying to find someone to help him with his shoulder pain. He had fallen and had fractured his shoulder in multiple places. Once healed, he fell a second time. Neither injury required surgery (this is actually quite common).

One year after his second fall, the pain became unbearable. He could no longer work or even

perform the most basic of tasks. His family doctor suggested cortisone injections, which provided little relief. His doctor referred him to an orthopedic surgeon. Jim waited four painful months for the appointment, but remained hopeful this surgeon could help him, and perhaps even help get him back to work.

Shortly after arriving at the office, the surgeon's receptionist called Jim's name and escorted him to the examining room. Ten minutes later the doctor joined him, and said, "So what brings you in today?" Jim presented his story, starting at the beginning with his first fall two years earlier. The doctor was respectful and let him finish his story. Jim could not believe what he heard next. "I am sorry to hear about your shoulder problem, but I do not treat shoulders. My practice is dedicated to hips and knees. You will need to see another orthopedic surgeon. I would be happy to refer you to my colleague, and if he prescribes surgery, I believe his wait time is approximately 2 years."

Exasperated, Jim left with the referral to the

surgeon's colleague. "Four months for nothing. How could my doctor not know this surgeon only treats hips and knees?"

Good question, Jim. Today, terms such as orthopedic surgeon or oncologist are simply not descriptive enough to reveal necessary details about a specialist's practice. A 2011 Canadian Medical Association survey showed that only 43% of primary care practitioners surveyed found the referral system to be efficient. The main reason for their discontent was the inability to find an available specialist practising in the area required. There are many reasons why this is happening.

Primary care practitioners' #1 complaint is finding an available specialist in the area of need.

First, there is an increasing level of sophistication within medical specialties, which is bringing far more complexity to the system. Each day, medical research is discovering new diseases and conditions, new drugs, new procedures, new

therapies and new surgical equipment. There is simply too much knowledge for any one person to reasonably master. The system responds by specialists narrowing their focus of expertise which ensures an individual can achieve an expert level of knowledge.

When Canada's Royal College of Physicians and Surgeons was established in 1929 there were only two specialties: Medicine and Surgery. The College is the governing body which evaluates and facilitates initiatives in medical education and establishes their guidelines. Since its inception, there has been a continuous increase in the number of medical specialties and subspecialties. Today there are 67 specialties, subspecialties and special programs recognized by the Royal College.

Without a detailed directory of physician specialists, no one knows who is treating which conditions. Making a referral becomes a guessing game.

Regrettably, this does not reflect the full extent of subspecialization and sub-subspecialization. Today, subspecializations and sub-subspecializations are in practice at the universities and hospitals long before the College formally recognizes them.

Continuing with the orthopedic example, there are no recognized orthopedic subspecialties within the College, but there are 10 orthopedic fellowships (a specialty training program which allows a doctor to practice without direct supervision by other physicians when it is completed) offered by Canadian medical faculties.

At the time this book was published, these fellowships included:

- Arthroplasty & Lower Extremity Reconstruction
- Sport Medicine & Arthroscopy
- Foot & Ankle
- Hand & Upper Extremity
- Lower Extremity/Trauma
- Musculoskeletal Oncology

- Pediatrics
- Spine
- Upper Extremity/Trauma
- General

With such exacting specializations and a governing body that cannot keep up with the rate of change, it is no wonder no one knows who does what anymore. Alex's case is a perfect example of how an individual can get caught up in the complexities of medical specialization.

Alex, an athletic 55-year-old man suffering from pain in his hips, loved tennis and soccer, but it became impossible for him to play without painkillers. His family doctor referred him to an orthopedic surgeon, who told him that a hip replacement was his only option, but he was far too young for the surgery. His only option was to keep taking painkillers and to come back when he was older.

Alex consulted Medical Confidence and learned of a relatively new procedure called hip resurfacing (which first emerged in Canadian medical practice in 2006). This procedure maintains the integrity of the hip and allows a fuller range of motion, whereas a hip replacement results in a limited range of motion. Hip resurfacing also ensures a faster recovery. Alex and his family doctor met with a hip resurfacing specialist, and six months later Alex had his surgery. He was swimming after two weeks and playing tennis again in only six weeks.

This time, the problem with the healthcare system was that Alex's primary care practitioner did not have access to tools she needed in order to find an orthopedic surgeon who had the expertise Alex required. While each Canadian province does maintain a directory of physician specialists, this directory does not provide sufficient detail for each specialist and often leaves out important data points including specialists' particular area of practice and availability. This makes the task

of referring a patient to the proper specialist challenging, and at times, impossible.

Unfortunately, Alex's and Jim's experiences are not unusual. Seeing multiple specialists before finding the right fit is happening all too often. Since individuals must access physician specialists through their primary care practitioners, they often end up losing valuable time seeing multiple specialists before ultimately finding one who has the skills they actually need. As a result, more individuals are seeking treatment outside of Canada or through private clinics. A comprehensive list of specialists could minimize these delays and improve the overall patient experience.

Even though officials are aware that the system is flawed in this way, little has been done to rectify it. Medical Confidence has devoted considerable time and effort creating and maintaining a comprehensive database of leading physician specialists across Canada. We assist individuals and primary care practitioners in finding available

and highly skilled specialists in the individual's area of need based on each specialist's availability. Our database not only identifies specialists' main areas of specialization, but also their subspecialty, and sub-subspecialty areas. Furthermore, the rigorous assessment process performed by our team includes surveying over 10,000 physician specialists and asking them to identify the leaders within their area of practice across more than 800 subspecialties.

We carefully review the credentials of every physician specialist being considered for our database, and examine many data points including:

- Education
- Certification
- Fellowships
- Training
- Hospital appointments
- Administrative posts

- Professional achievements
- Speaking engagements
- Academic posts
- Patient reviews
- Malpractice and disciplinary history

Another reason individuals do not always get to see the ideal specialist results from many specialists spending too much time with individuals like Jim and Alex – individuals who shouldn't have been referred to them in the first place. For every individual who is directed to the wrong specialist, there is another individual who cannot be seen. Having to see patients who do not map to a specialist's area of expertise puts increased demands on specialists' schedules. As a result, wait times increase and physicians must take on more patients to handle the increased case load.

To further complicate things, specialists are often not given enough patient medical history from

the referring primary care practitioner. When first meeting with patients they often must start from scratch to find out why a patient was referred. In Jim's case, if his primary care practitioner had included the word "shoulder" in the referral documentation, the specialist's office would have refused the referral. This would have saved Jim delay in his treatment and would have freed up an appointment slot for the specialist to see another patient.

Specialists' #1 issue is lack of supporting documentation.

Besides the lack of a specialized directory and missing patient medical history, many primary care practitioners do not know which tests an individual must undergo prior to seeing a specialist. In a 2011 Canadian Medical Association study, specialists stated that they were not being provided with sufficient supporting information (e.g., test results, diagnostic images, etc.). Far too often patients find themselves being told in

the first consultation that laboratory tests such as blood work, MRI, CT-scan or x-rays are needed before the specialist can properly assess, provide a diagnosis or discuss recommended treatment options. No wonder patients are frustrated after months of waiting when they are told they need to go for tests and then wait for another opening in the specialist's busy schedule. Of course, the patient would have gladly had the tests completed prior to the appointment if they had only known they were needed.

Canada ranked 9th out of 11 countries for its use of electronic medical records.

In other cases, the patient may have already completed the required tests, but the tests were not sent to the specialist before the appointment. In 2013, the Health Council of Canada reported Canada was rated ninth out of eleven countries in the use of electronic medical records. Considering Canada's size and number of citizens living in remote areas, this is a serious concern.

Fear not! Though our healthcare system is an ever-evolving work in progress, there are things you can do to effectively access care when you need it. In the following chapters you will find valuable tips to help you work with the system and find the right physician(s) who can meet your unique needs. Remember – no one physician can treat every patient!

Doctors Are Not All The Same

As you can see, there are many reasons why finding a proper specialist is difficult. Medicine has become extremely specific and the general term for a specialist is not enough to differentiate between specialists. New technologies are constantly being discovered and it's impossible to expect any one individual to keep up to date on all of them. Yet, when a physician provides us with her/his opinion, we often treat it as fact as opposed to what it is – an opinion! I learned this important lesson in 2003 when I had the following experience:

My menstrual cycle had become very painful and I was having intense contractions. After being admitted into the hospital, I learned I had uterine fibroids ranging in size from less than a centimeter to over 2 centimeters. Once the contractions passed and my fluids were replenished with an intravenous of electrolytes, I felt fine. I did not want to end up in the hospital every month so I asked to see a gynecologist. My family doctor referred me to one, and after some tests, he recommended a “permanent solution” – a hysterectomy. I went numb. All I could think of was “permanent solution” – this was too permanent for me! It never occurred to me that another gynecologist might give me a different opinion.

I consulted the Internet and learned that blood flow increases the size of fibroids, and that decreased blood flow could shrink them. I talked to my family doctor about putting me on contraceptive pills, since they virtually stopped my cycle in the past. In the beginning it worked, but progressively over the years my cycle became

heavier and lasted longer. It reached a point where I could not leave the house for more than 30 minutes over four days each month.

I asked my family doctor about alternatives such as Depo-Provera (a contraceptive shot administered every 3 months which had a common side effect of no bleeding at all). She warned that some patients experience the opposite (increased bleeding). I decided to try it. Turns out I was one of the rare cases. The bleeding became extremely heavy and constant. My hemoglobin was 4 gm/dL (normal is 12 to 16 gm/dL), red blood cell count was 2.1 million/uL (normal is 4.2 to 5.4 million/uL) and my iron was 2 (normal is 35 to 180). I was given iron injections every week for 3 months. This helped, but we were only treating the anemia symptoms, not its cause.

By this time I had helped many others find an appropriate doctor for their medical needs and it was time to focus on my own health. Modern technology and medicine offers minimally invasive alternatives to traditional hysterectomies. These

methods require fewer incisions, carry lower risks for organ perforation and abdominal wall infections, reduce blood loss, shorten your hospital stay and allow you to return to normal activities quicker. Surprisingly, however, the rate of traditional hysterectomies in Canada is still one of the highest in the world. Approximately 50,000 Canadian women undergo a hysterectomy each year, and approximately 90% of those are done for non-cancerous reasons, such as fibroids or genital prolapse.

I scoured the Medical Confidence network looking for gynecologists with expertise in complex cases and who were skilled in minimally invasive techniques. I found three who had the skills and access to a facility with the necessary equipment to handle my case. Why so few? A minimally invasive laparoscopic hysterectomy takes approximately 3-4 hours, while an abdominal hysterectomy takes between 1-2 hours. Hospital operating rooms are always in demand, and minimally invasive procedures often take more

time – time some hospitals simply do not have. Furthermore, not all hospitals have the resources to invest in the required equipment or have physicians on staff who are sufficiently skilled to perform laparoscopic procedures. As a result, these procedures are available in fewer hospitals. Finally, provincial healthcare insurance fee schedules do not differentiate between the two methods in their fee structures. Healthcare providers receive the same compensation for both procedures, even though one takes longer and requires more equipment and expertise to perform.

I was fortunate. My gynecologist focused on complex cases, and my case had become very complex since my uterus had grown to more than 3 times the normal size. I now had more than a dozen fibroids, 5 of them between 4 and 6 centimeters each. Rather than resorting to an abdominal hysterectomy (which would have been my only option even with most of the minimally invasive trained gynecologists), the gynecologist who treated me used a technique

to shrink the fibroids instead thus allowing him to proceed with the minimally invasive surgery. To accomplish this, he temporarily induced me into menopause through the use of a drug called Lupron. 8 months later I returned for my surgery. I felt amazing! I had no pain, I had so much energy and my stomach was significantly smaller. Another ultrasound was taken the day before the surgery. My uterus had shrunk to less than half of its earlier size. I achieved a remarkably successful outcome all because I found the right specialist to treat my condition.

Communication Gaps in the Healthcare Team

So far we've talked about the importance of finding the right specialist, but what about when you have to go to the hospital Emergency Room (ER)? When you are in an ER, typically you do not get to choose the physician who sees you. Sonia's case highlights some additional challenges you need to be aware of.

Sonia, a 75 year old grandmother, was feeling extremely exhausted and suffering from intense headaches and fever. Her doctor diagnosed her as having the flu, and since she hadn't received a flu shot that year, this diagnosis made sense to her. Sonia's condition worsened over the next several weeks, and she was eventually taken to the ER.

The ER triage nurse took Sonia's vitals while Sonia described how her symptoms of fatigue, pain and severe headaches had worsened over the previous four weeks. Sonia said, "I don't ever remember having a case of the flu like this." Her son shared with the nurse that he had also noticed some memory loss. The nurse noted everything in Sonia's file, including an irregularly slow heartbeat, diabetes and osteoporosis. The ER team ordered an x-ray of her chest, urinalysis, blood work and an echocardiogram.

To rule out lupus and rheumatoid arthritis, a rheumatologist was called in to see Sonia. More blood work was done to test her erythrocyte sedimentation rate and the protein and red blood

cell levels in her urine. The results of these tests indicated Sonia had neither lupus nor rheumatoid arthritis.

Forty-eight hours later Sonia still had no idea what was causing her symptoms, and no one seemed to have any answers for her.

The next morning a neurologist came to see Sonia. She repeated her symptoms to him while he scanned her chart. He asked her about diabetes, osteoporosis and whether she suffered from urinary incontinence. She said, "Of course! I've had 4 children and I'm 75 years old!"

Sonia and her son did not know that the neurologist's working diagnoses were cystic fibrosis and multiple sclerosis. Diagnosing cystic fibrosis after the age of 30 years is unusual, and even more unusual after the age of 60, but the neurologist had just read a case study about a woman in her mid-sixties who had been diagnosed with cystic fibrosis. He ordered a sweat test and an MRI to be sure. Thankfully, the sweat test came

back negative, ruling out cystic fibrosis. However, the MRI was not sufficient to rule out multiple sclerosis. The neurologist recommended a spinal tap. Sonia's son questioned why a spinal tap was necessary and the neurologist assured them it was a very common procedure with minimal risk. Both Sonia and her son were apprehensive, but neither wanted to challenge the physician, who was clearly working hard to help. Sonia did not want to upset the doctor, or show any disrespect.

The spinal tap results revealed her white blood cells, glucose and protein levels were all normal, and there were no signs of bacteria, fungus or cell irregularities – all of which meant Sonia did not have multiple sclerosis. She was diagnosed with chronic fatigue syndrome and was subsequently discharged from the hospital.

Sonia continued to feel ill. She tried alternative treatments including massage, acupuncture and herbal remedies but saw no improvement. The more she and her family read about chronic

fatigue syndrome, the more they questioned her diagnosis.

Sonia connected with Medical Confidence and shared her medical history with a consultant (a Registered Nurse). The consultant asked Sonia what she missed the most since she got sick. Sonia said, “Walks at the cottage with my grandchildren.” This turned out to be the missing information needed to diagnose her condition.

Her case was further reviewed by a panel of Medical Confidence specialists, and additional testing revealed a diagnosis of Lyme disease. Sonia had been bitten by a tick while hiking in the woods in the Niagara Region.

What went wrong at the hospital and why hadn't Lyme disease been ruled out when Sonia was being diagnosed? The team working on Sonia's case had experienced a communication breakdown. Not only did Sonia not realize her hikes in a high-risk tick-infested region put her at risk for Lyme disease, but none of the team

members (triage nurses, interns, rheumatologists, neurologists, etc.) took the time to find out about her activities and consequently uncover the clue necessary to get to the right diagnosis. Neither Sonia nor her son actively engaged with the doctors to understand the testing and the possible diagnoses the doctors were considering. If they had, the diagnosis may have come much sooner.

Users of the Canadian healthcare system traditionally take a passive role in their care. They assume healthcare practitioners have all the answers and that they (the patients) should have little or no involvement in the process. The patient, however, is a key part of the team! A team can be defined as a group of people with a full set of complementary skills required to complete a task, job or project. On a healthcare team, the patient is the most important player since she/he often holds the clues to solving any mysteries. Can you imagine solving a mystery with only a few clues, or having the clues without knowing what mystery you were trying to solve? When you're a

patient, the situation really IS all about you! You've got to get in the game!

This is why it is so important to prepare for a medical appointment. Since a typical appointment with a physician lasts 15 minutes or less, it can be very difficult to remember everything we want to say in such a short period of time. This is even more difficult when we are sick and not at our best. How often have you found yourself remembering something you wanted say shortly after the doctor has left the room? In Sonia's case, her lack of awareness of Lyme disease in the Niagara area meant that she had no idea that she was at risk.

Doctors also need to work faster and faster to see all of the patients they need to attend to within their day. In order to do this, doctors look for ways to save time and limiting the time dedicated to taking a patient's history is common practice. By asking a list of yes/no or short answer questions, they can save time.

Process of elimination medicine leads to excessive and unnecessary testing.

Patients often fail to communicate clues that could help their doctor figure out what could be wrong with them. How often does a doctor ask questions like: Do you have a headache? Is your stomach upset? When did the cough start? Patients sometimes need to be coached to provide the information that doctors need. Based on the patient's response, the doctor then selects a pathway diagnosis that maps to the symptom(s) uncovered in their answers. Pathway diagnosis involves a series of tests and instructions that confirm or rule out potential diagnoses. Unfortunately, this process of elimination may also lead to excessive and unnecessary testing.

On the other hand, differential diagnosis starts with a complete list of possible medical causes behind the patient's symptoms (complaints) and signs (physical findings). The medical possibilities that could explain the complaints and findings are listed from the simplest and least problematic

to the most severe and life-threatening based on their probability. Probability is determined through an interview and an examination. The doctor then selects the most likely diagnosis as the working diagnosis, and relies on pathway diagnosis to confirm the working diagnosis.

If Sonia understood the importance of being aware of the health risks in her area of the woods, or a member of her medical team had taken more time to perform an in-depth patient history, Lyme disease would likely have been diagnosed much sooner.

An earlier diagnosis for Sonia would have avoided the over-testing, delay and frustration of remaining undiagnosed. Furthermore, the system would have been saved the expense of unnecessary tests, doctors' time and Sonia's hospital stay. Far too often patients become frustrated by the process and give up, leaving their condition untreated. In the event of a serious ailment, this could lead to complications, additional hardships and even death.

Only 48% of us feel engaged in our healthcare.

According to a 2011 Health Council of Canada report, only 48% of Canadians who see a primary care practitioner on a regular basis feel engaged in their healthcare. Engaged patients are more involved in decision-making, feel they have enough time with their primary care practitioner and freely share their preferences and priorities. Sadly, this number is not high enough to be the norm in the Canadian healthcare system.

Healthcare studies have shown that engaged patients better understand and know more about their care, which leads to better use of healthcare services and resources. Today, the majority of patients feel disengaged when it comes to their health, and for good reason – the current system has little room for input from patients. Consequently, patients may not fully understand how their behaviour can impact their long term health. In Canada, half of patients do not adhere

to their treatment regime once they have been diagnosed.

Half of Canadian patients do not adhere to the treatment recommended by their healthcare practitioners.

The same study by Healthcare Canada found that patients who discuss issues with their healthcare practitioner, explore treatment options and share in decision-making are happier with their care and feel better about their health. According to the report, both patient and practitioner benefit from this type of engagement, which tends to contribute to better care and outcomes.

The good news is the trend is changing. Healthcare practitioners now recognize that discussing issues with patients and involving them in the decision-making process is an effective way to deliver care. The Canadian Foundation for Healthcare Improvement is working on patient engagement support activities and encouraging patients to

help in the design, delivery and evaluation of healthcare services. While change rarely happens overnight, there are things healthcare consumers can start to do right away in order to avoid the pitfalls in the system and receive the best possible care.

14 Tips to Becoming a More Empowered Healthcare Consumer

You are now equipped to spot some challenging pitfalls in our healthcare system. You also know, as healthcare consumers, that we can no longer afford to be passive with our healthcare and let the system make all decisions for us. If we think of an appointment with a physician as being as important as a job interview, we will accomplish far more during each appointment.

Preparation and engagement are crucial to overcoming healthcare hurdles and to obtaining the care you need. Now it's time to provide you

with the tips that will help you to become a more valuable and empowered member of your healthcare team.



Tip 1 - Do Your Due Diligence

You now know that specialists have subspecialties and even sub-subspecialties. Furthermore, just because a specialist practices in the field of medicine you may require, this does not mean she/he is the right specialist for you to see.

You also know that your primary care practitioner may have limited insight into a specialist's area of expertise, practice and credentials. This means you might, if you are not proactive, be referred to a specialist that is simply not suitable for you.

Physicians are professionals, but this does not mean that you cannot ask them questions. If your primary care practitioner wishes to refer you to a specialist, it is important that you understand why

she/he feels that particular specialist is the right one for you. The days of patients simply agreeing to any referral must come to an end. Ask your primary care practitioner why she/he wishes to refer you to this particular specialist. Perhaps she/he knows the specialist personally and that she/he has the required skills and expertise. Perhaps other patients or peers have recommended the specialist and can vouch for her/his credentials and abilities. If your primary care practitioner cannot give you a specific reason for referring you to this particular specialist, ask her/him to consult with the specialist to ensure the referral is appropriate. Reconnect with your primary care practitioner once this consultation has been completed. Don't be afraid to ask questions and express concerns about anything that does not seem right to you. It is your body and you have the right to seek and receive appropriate care.

At the same time, be sure to do your homework. Use the Internet to acquire information about the specialist you are being referred to. Look for

details about her/his credentials and area(s) of practice. Some Websites even include patient testimonials, which can provide further insight into the specialist's abilities.



Tip 2 - Keep Your Medical Records On Hand

Canada ranks as one of the worst countries for sharing information between primary care providers and specialists. You may recall that specialists reported they do not receive enough supporting information (e.g., history, diagnostic tests, images, etc.). All too often referral documentation consists of nothing more than a few lines scribbled on a page. As a result, specialists must start from scratch in their analysis of a patient's condition. This may mean sending the patient for some or all of the same tests the primary care practitioner did if the patient did not provide the specialist with a copy of all results from tests already completed.

Being an engaged and empowered healthcare consumer means you need to effectively manage your medical records. If you have completed tests, be sure to keep all results (including images) on hand for the specialist to review. Your primary care practitioner will receive a copy of test results but not the actual images (e.g., x-rays, etc.) – you will need to get these yourself from the lab or hospital where the test was administered. If you cannot go yourself, you can provide written consent allowing someone to collect these items on your behalf.

Gather as much information as you can prior to your appointment with the specialist. If you are not thorough in your efforts, you may experience further delays. If you give the specialist all the data you can, she/he will reward you with efficiency and effectiveness.



Tip 3 - Call Ahead to Confirm Your Appointment

There is nothing more frustrating than waiting for months to see a specialist only to find out that your appointment is on a different date, the office moved or there were tests you should have completed ahead of time. Call the specialist's office to confirm your appointment and location. In the past, the doctor's office called patients to confirm appointments, but high caseloads have made this impossible in most specialist's offices. Do not expect to be reminded about your appointment. Do your absolute best to be there at the time you were given, but if you need to reschedule make sure that you give ample notice. There are many others waiting for that appointment slot.

Once the appointment is confirmed, make sure to ask if there are any preparations that need to be made or testing that needs to be done prior to the appointment. This is an area where information

is often overlooked when patients are referred by their primary care practitioner. Patients may be unaware of things like needing to book an appointment for a test, needing to fast before a test, and so on. They also may not know that testing needs to be completed at least one week prior to the appointment with their specialist in order to ensure results are available in time. In addition to calling the specialist's office, call the lab to confirm you understand all pre-testing instructions (e.g., fasting, etc.). Be diligent and thorough! If you overlook a single detail there's a good chance that detail will result in delays.

One final word of advice about calling ahead – try to make a genuine connection with the specialist's receptionist. Personal relationships run the world. Building rapport with the specialist's receptionist will make your experience go smoother. Address her/him by name and try to exchange pleasantries (e.g., ask her/him how the day is going, etc.). This tactic will help her/him to focus and connect with you.



Tip 4 – Have a Goal and Write It Down

How often have you left an appointment with a physician and suddenly recalled something you wished you had mentioned or asked? There is a lot to cover in a short period of time and it is important to be clear about what your objective is for the appointment. Stay focused and ensure your objective is achieved!

Write everything down. Your story could be long, with plenty of twists and turns and you will not be able to remember it all. Use the following template to be sure you don't forget important things.

Symptoms:

- How and when did your symptoms start?
- What do your symptoms feel like? Have you had them before?
- What are you doing when they occur?

- Have your symptoms changed, and if so over what period of time?
- How have your symptoms affected your life?
- Why are you seeking the specialist's care now?
- What lessens your symptoms? What makes them worse?

Medical History:

- Have you had any changes occur in your life? Any new stressors?
- Which medications (prescribed or over-the-counter) and/or supplements are you taking? What is the dosage? What are the side effects you are experiencing?
- Do you have any allergies? If so, to what?
- Do you have any family members who have a history of any similar symptoms or major illnesses?

Differential Diagnosis:

- To what do you attribute your symptoms, and why?

- What are you most concerned about?
- Is there anything you are sure you can rule out from a list of potential diagnoses?

Don't forget to bring your notes to your appointment as you will want to refer to them during your conversation with the specialist. Write down any questions you want to ask. It's easy to forget key details when you have a lot of information to go through.



Tip 5 - Bring a Buddy

It can feel daunting going to a specialist on your own. Having someone at your side to get the most out of your appointment can be very helpful.

Whether it is a family member, a friend or a patient advocate, having someone with you can provide crucial moral support and help you stay relaxed and focused. This person can help ensure the physician listens to you and responds to your

questions. She/he can also take notes that you can refer to later.

If you have problems explaining your issues because of a language barrier or an impediment, be sure to bring someone who can help you (e.g., translator, etc.). Be sure the person who accompanies you fully understands your problem and that you are totally comfortable allowing this person to discuss your condition with the specialist.

Try to avoid bringing someone with you who is short-tempered or impatient. Your buddy needs to be diplomatic and polite, but also assertive. Discuss her/his role in advance – rehearsing the appointment ahead of time is always a good idea.



Tip 6 - Dress for the Occasion

Wear comfortable clothing that is easily removed for a physical examination. Avoid complicated

clasps, buttons or multiple layers. The area of your body in question may need to be exposed. If you are provided with a gown, undress and put it on. Your willingness to undress signifies your receptiveness to the examination and desire to be engaged in the diagnosis process.



Tip 7 - Bring Everything You Need

Make sure to bring your health card and that it is current. This may seem obvious, but many people forget their card or have an expired card when they arrive for their appointment. Patients must present their card to each new healthcare practitioner who is involved in their care.

Make sure to bring your notes (have I said this enough?), and your test results (including images).



Tip 8 - Have an Agenda

A typical appointment with a physician lasts 15 minutes or less, meaning there may be a lot to cover in a short period of time. Make good use of your notes. Try to keep to the following agenda so you don't run out of time: 5 minutes to tell your story, 5 minutes to answer the specialist's questions and for a physical examination to be conducted, and 5 minutes to discuss treatment options. Keep your own dialogue to the point and succinct.

Tell your story. This is when you relay data and share key details. Use your notes so you don't leave out any important pieces of information.

Questions and examination. Remain focused as you answer questions the specialist may have based on what you have already told her/him.

Now begins the differential diagnosis – the process by which the specialist will list and rate the likelihood of each potential cause of your condition. She/he is looking for clues to explain your symptoms. Physicians are trained to recognize specific triggers that can affect your health that you may not have even considered. Increased stress levels, radical changes in diet and personal problems can all have adverse effects on our health, even when we feel we have these issues under control.

Diagnosis and treatment options. If the specialist believes she/he has diagnosed your problem, the final minutes of the appointment should be used to discuss how your health condition can best be treated. There are often multiple approaches that are dependent on your personal preference, the urgency of the matter and/or the physician's recommendations. Go through each option slowly and ask questions until you understand.

If the specialist is unable to diagnose you with one appointment, you may need to undergo additional

tests. Ask questions. What will the tests tell us? What do the tests involve? Are there any dangers or side effects? How will I find out the results? How long will it take to get the results?

When test results are ready, make sure the physician shares them with you and explains what they mean. Don't forget to get a copy of all test results and images for your records.



Tip 9 – Create Rapport

Studies have shown that effective physician-patient communication is an important contributing factor to achieving optimal outcomes. Just as you would in a job interview, try to create rapport with the physician – rapport that will set the stage for an effective and engaging discussion. If your physical or mental condition prohibits you from being able to do this, rely on your buddy to do this on your behalf.

When the specialist comes into the room, stand up (if you are able) and initiate a handshake. Greet her/him with a smile, make eye contact and state that you have been looking forward to your appointment. Next, invite her/him to take a seat. Studies have shown that physicians who sit down (rather than stand) during patient appointments may achieve improved patient outcomes. Be yourself! Tell the specialist a bit about yourself, and let her/him get to know you. All of these actions signal your desire to partner with her/him and be an engaged participant in your own healthcare. Don't be aggressive or threatening. This is not the time to start asking about the specialist's credentials (see Tip #1).

It is also a good idea to continue to develop rapport with the specialist's receptionist, since typically you will need to see the specialist more than once. Always refer to the receptionist by name and let her/him know how much you appreciate her/his assistance.



Tip 10 - Tell Your Story

Now it's time to tell your story – don't be shy! Each of us is unique and no one knows a body better than its owner. It can be difficult to know what is and what is not important. Don't omit details because you think they don't matter – let the physician(s) make that determination.

Keep these additional tips in mind:

Use your own words. There is no need to use medical terminology when you discuss your symptoms. Speak as though you are talking to a family member or friend.

Describe events in order. Start by stating when your symptoms first occurred and then move forward through time to discuss the changes you have observed.

Identify patterns and changes. Talk about the frequency of your symptoms and when they occur.

Note whether they have increased or decreased in severity and whether patterns have changed over time. Share any observations you have made about the impact your actions have had on your symptoms. If something unusual has happened, let the specialist know.

Describe how your symptoms have impacted your life. Has your employment, personal life or financial situation changed? Are you experiencing changes in levels of energy, stress, fear or anxiety? If something is concerning you, be sure to share it.

Don't self-diagnose. Your job is to tell your story in the most succinct and efficient way you can. While you can be an active participant in the process, you must also call upon the physician's expertise. Let her/him work through the diagnosis process.

Discuss current treatments. If you have taken accurate notes you have likely documented all of your current medications and naturopathic treatments including the dosages of each. Also remember that everyday medicines taken for

colds, flu or aches and pains can affect your body during a diagnostic testing or a physical examination. If a physician suspects a certain condition but a telltale symptom is not present, she/he may incorrectly eliminate that condition from the differential diagnosis. For example, the presence of a viral infection may be accompanied by a high fever. If you have taken a cold and flu tablet your temperature may be lower than it would be had you not taken the medication.

Speak up! Too often patients complain that their physician isn't listening to what they have to say. This is not surprising when studies have shown it usually takes only 23 seconds for a physician to interrupt a patient. Use your voice, be assertive (yet polite) and make sure to tell your story.

Explore all options. Don't allow the specialist to focus solely on your chief complaint. Remember – the art of diagnosis involves having all clues before making a diagnosis. You need to describe all of your symptoms before a diagnosis is decided upon.

If you feel that you are not being heard it is important that you remain polite, courteous and respectful. If you are interrupted, steer the conversation back to your point and make sure your thoughts are heard in their entirety. If you find this does not work, politely ask the physician to listen to your entire list of symptoms or to let you ask your entire question. Sometimes a simple gesture such as gently holding up your hand will signal your physician to stop and listen to you.

Always attempt to answer questions in detail. “YES” and “NO” responses do not provide enough information to serve any real purpose. For example, if your physician asks you if it is your knee that hurts, don’t simply respond by saying “Yes.” Describe where your knee hurts, when it hurts and the level of pain intensity on a scale of 1 to 10.



Tip 11 - Ask Questions

Don't be embarrassed if a physician's use of medical terminology confuses you. You are not alone. Studies report nearly half of patients cannot understand the terminology used by their physician. The stress of dealing with a health challenge can make it even more difficult to follow complex conversations and grasp what is being said. It is perfectly OK to ask your physician to use simple, plain language or even analogies to help you understand. Make sure your buddy speaks up as well if she/he doesn't understand something. Being an empowered healthcare consumer means taking responsibility for your own healthcare and overcoming barriers such as feeling awkward or embarrassed.

Your physician may want to order tests before discussing potential diagnoses with you. This is a common step when following a pathway diagnosis – eliminating or confirming a particular

condition. This is a good time to ask questions. If your physician has not yet told you what she/he is thinking – ask! Neither of you is a mind reader. If your first question doesn't work, ask another one. What are you hoping the test will reveal? What do you think could be causing my symptoms? Which diagnosis or diagnoses are you leaning towards at this point? What else do you think it might be? Which diagnosis or diagnoses have you eliminated, and why? These are all great questions that can help deepen the discussion and your understanding of the situation.

If you are worried about offending your physician, don't be. You are not telling her/him how to do her/his job. You are simply asking questions and highlighting your concerns. It is essential for you to partner with your physician to make sure no clues are missed – clues that may be necessary for an accurate diagnosis.

If you've already completed all the tests required to diagnose your condition and you understand your diagnosis, treatment is next on the discussion

agenda. Don't let medical jargon or pressure from the physician cut the appointment short and/or get in the way of you understanding your treatment options. Again, it's time to ask questions.

- How common is this procedure or treatment?
- Is this a tried and true procedure, or is it something new that has been developed for this specific condition?
- What is the success rate?
- How many times have you performed this treatment or procedure?
- How long is the recovery period?

These are all great questions that will deepen your understanding.

Many treatments and procedures nowadays are same-day procedures, while others can involve weeks or months of recovery time. If you need to

function in the world for work, family and/or other obligations, recovery time is an important factor for consideration.

You will also want to know what the long term effects and impacts on your quality of life will be. Many medical treatments may force you to stop, or at least reduce, particular activities in your life. These changes can not only affect your physical world, but your emotional and/or spiritual worlds as well. It is important that you are aware of the ramifications of a treatment, especially if that treatment is something you will have to live with for the rest of your life.

Many treatments for life-threatening diseases have serious side effects. Treatments such as radiation, hormone therapy and chemotherapy can cause symptoms including nausea, hair loss, bone marrow suppression and organ damage. These treatments rarely come with guarantees, so patients must always carefully measure risk(s) against possible outcome(s).

It is also worth exploring any new treatment methods being developed in Canada or elsewhere. There may be new treatment programs in clinical trials that should be considered. If you do become involved in a clinical trial, make sure your physician takes the time to explain the various phases of clinical trials and how randomization could impact your chance of actually receiving the treatment under investigation.



Tip 12 - Take Time to Think

At the end of your appointment you should feel as though you have all the information you need to make an informed decision. This doesn't mean that you have to make a decision on the spot.

Don't feel pressured to respond immediately. Take the time you need to process all of the information you have received and to ponder the path that your specialist is recommending.

Take time to speak with and learn from others. There are many Online medical forums where you can connect with others who have already been through a similar situation and/or treatment. Share your anxieties and reservations with them and find out what others experienced to lessen your fears and overcome your anxieties.



Tip 13 - Talk Things Over with Your Primary Care Practitioner

Once you have seen the specialist and you have a diagnosis, reconnect with your primary care practitioner. This is not something that is done automatically – you must take the initiative. Your primary care practitioner is a key member of your healthcare team and an important contributor to the decision-making process. She/he should never be left out of the loop.

Discuss your appointment and provide feedback on the specialist. This is important information that will help your primary care practitioner to

know if she/he should continue to refer patients to that specialist. If your primary care practitioner has questions or concerns, have her/him contact the specialist directly to clarify any issues. Your primary care practitioner may be aware of something in your medical history that could influence the specialist's decision. The patient, primary care practitioner and specialist must communicate and work as a team to maximize the potential of achieving the best possible outcome.



Tip 14 - Trust Your Instincts

Rely on your instincts and common sense. If something does not seem right to you, speak up! If you do not feel comfortable or failed to ask important questions, ask to speak with the specialist again. There is a lot to take in. It is perfectly OK to consult your team when you would like to have something clarified.

If you're still not comfortable, there is always the option of getting another opinion. Discuss your reservations with your primary care practitioner and ask for another referral. Yes, you must go through the process again, but it is well worth the effort if you are concerned.

In the end, it is always your decision. Try your best to be analytical, not emotional. If all of your options seem undesirable, you may have to go for the best one among them. Decisions can be difficult to make. Look for a path that will lead to long term health benefits with the least amount of risk. There are no guarantees, but there may be treatments that have a better chance of helping you. Educate yourself and be proactive.

Conclusion

Thank you for reading this book and joining me to challenge the conventional approach to healthcare in Canada. It's time to take bold steps and for individuals to become empowered healthcare consumers.

Remember – if and when the time comes for you to see a specialist, don't expect your first appointment to be flawless. It takes practice for all of this to become more comfortable. I hope you will discuss this book and these tips with friends, family members and of course your healthcare practitioners. Encourage your physician to practise a patient-centered approach with you and all of her/his patients.

If you are struggling with a healthcare situation and you don't know where to turn, please reach out to us at Medical Confidence. Our mission is to empower consumers of the Canadian healthcare system so they get the care they need in a timely manner. We can help individuals and their primary

care practitioners find the most appropriate specialists, obtain second opinions and treatment options within Canada, and clarify details so individuals can be confident their decisions are as informed as they can be.

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Angela Johnson

A first of its kind, this revealing book provides valuable tips and tools for individuals navigating the Canadian healthcare system. As medical knowledge grows and our system adapts to keep pace with change, individuals must become empowered healthcare consumers in order to minimize wait times and effectively collaborate with their treating team of medical practitioners.

Angela Johnson (President and founder of Medical Confidence Inc.) realized, while supporting her sister who struggled to deal with a rare neurological disorder, the Canadian healthcare system can be difficult to navigate when someone is in need of

care. Since creating Medical Confidence, Angela and her team have helped many individuals (along with their primary care practitioners) access Canada's leading physician specialists in an efficient way, which has minimized their wait times and increased their chances of a positive outcome.

Using real case examples, this book equips the reader with an understanding of the factors that may cause delays and user-friendly strategies to help overcome them.

A must read for any patient.

"There is a huge problem with wait times, and I agree that patients need to be directed to the right specialist. This is a good book for any individual in need of healthcare."

Dr. Hagen, Medical Director, Humber River Hospital

"As a family doctor, I sometimes feel lost in a maze when I have to refer a patient for a less common condition. I have a difficult time finding the right specialist."

Family Physician, Greater Toronto Area

"Very Pertinent tips. If a patient arrives with all their information intact, the specialist can be efficient and effective."

Orthopedic Surgeon, Scarborough Hospital