

In a Rowboat of My Own

A SURVIVOR'S STORY

DEBORAH MASKENS

At the age of 14, my outlook on life was forever warped by a diagnosis of cancer, not a usual cancer, but a cancer typical of older, heavier men with a history of smoking. From that moment, I have been in uncharted waters in what seems to have been a rowboat of my own. Through some 34 years of cancer survivorship, I have learned a lot—much of it by sheer accident.

Lifelong Follow up is Essential

I have learned most importantly that the smiling surgeon who says “I got it all” really means to say “I got everything that I could see, but that you will still need to be followed up for the rest of your life.” Five years after my initial treatment (a radical nephrectomy, or removal of the kidney), I was discharged from my urologist's office and told to “go and live your life. You're cured.”

From that point, while I mentioned often enough “I had kidney cancer you know,” I was never scanned for recurrence—not every year, every five years—never. Of course, 22 years later when the silent recurrence finally made itself known, it was huge and life-threatening. A tumour in the renal bed was so large that it had abscessed, necrotized, and required extensive emergency surgery and a week in the ICU.

Since then, I have heard of other kidney cancer patients whose cancer has metastasized after 14, 17, 19 years. Some of these patients are lucky enough to have a scan for some other reason. Others are as blissfully unaware (as I was) of their life-long risks or the signs of recurrence.



Deborah Maskens with Tony Clark, Chair of Kidney Cancer Canada

Delayed Complications of Successful Treatment

Patients know well enough that treatments have side effects and long term consequences. In my case, I would like to have known how to protect my now solo kidney from damage. I have since learned that smoking, diabetes, hypertension, and some NSAIDs are all damaging to kidney function. At the time of initial treatment, the only advice I was given as a teenager was not to play touch football. I had no idea whether I could have children (I have), live a normal life (I have) or how the cancer diagnosis would affect the rest of my life.

You Might Get Another Cancer

At a routine physical, my family

physician casually mentioned that I have a higher risk of getting another cancer. This was news. What should I do to reduce the risk of acquiring a second cancer? How much screening is too much screening? How much radiation from CT scans can I be exposed to? Since 1996, I have already had more than 45 CT scans. Who is counting? Who is looking at the long-term picture of those of us living today with cancer as a chronic disease?

You Can Improve Your Odds of Recurrence

Again by accident, I have come across research that points to the favourable effects of diet and exercise in reducing the risk of recurrence. There is convincing research about the role of diet,

about lifestyle, about vitamin supplements, but none of this comes to me from my cancer centre. We discuss the latest CT scan and schedule the next one, but in the meantime, what should I do? “Live your life. Follow Canada’s Healthy Eating Guide. All things in moderation.” I would stand on my head if it would reduce the risk of recurrence.

There are Resources Out There

In my 34 years of cancer survivorship, I have never once met with a dietician, a social worker, or a psychologist as part of my care plan. I have since learned that these specialists are tucked away in the corners of my cancer centre, but I have never known they were there or how they might be able to help. In 10 years of being treated at a large cancer centre, I have never known a primary care nurse. I come in for an eight-minute clinic appointment and I leave. Sometimes I have news to celebrate. Sometimes I cry in the parking lot.

Patients Need to Connect With One Another

For over 30 years, I was the only person I had ever known with kidney cancer. Meeting (by accident) another patient with papillary renal cell carcinoma was a life-changing experience. Since then, we two patients have formed a national patient organization so that no one with this disease will ever feel so utterly alone. We’ve discovered first-hand how a survivor support system can make a profound difference for patients and caregivers. As fellow survivors, we educate, inform, and help to fill in the gaps between those eight-minute clinic appointments. We have built a national support system that informs and enriches our individual personal journeys of survivorship. Each story is unique, but none of us is alone.

Deborah Maskens is a cancer patient on the Board of CACC and Vice Chair, Kidney Cancer Canada. Deb is currently undergoing treatment in the United States for a rare form of kidney cancer that still has no publicly funded treatment options in Ontario.

© 2009, Deborah Maskens.

Used with the kind permission of the author.

Navigating the Cancer System with a Rare Cancer

Patients who are diagnosed with rare cancers face additional challenges in finding the expertise, treatment options, and support systems that will help them navigate towards their goal of long-term survival. Patients often feel isolated and disadvantaged simply because they had the misfortune to be diagnosed with something not-so-common. In many cases, patients with rare diseases need to take their care plan into their own hands:

Step 1: Seek an Expert Opinion

Many kidney cancer patients are still uncomfortable asking their urologist or oncologist about getting a second opinion. Some are afraid of hurting their doctor’s feelings and damaging the local doctor-patient relationship for the long-term.

For kidney cancer patients, that second opinion should be with an expert who sees many cases of kidney cancer per year. Depending upon where patients live, they might expect to travel into a major cancer centre. In my experience speaking with hundreds of fellow patients across Canada, no patient has ever reported that they regretted seeking a referral — only that they wished they had done so sooner.

Step 2: Build Your Own Multi-Disciplinary Healthcare Team

Cancer centres are excellent places to treat tumours, but they often fall short of treating the patient as a whole human being. Back in the community setting, the patient’s family doctor can play a huge role as the gateway to a multi-disciplinary team of resources including pharmacists, physiotherapists, dieticians, and counselors.

Step 3: Learn What You Can From Others in the Same Boat

Patients with rare cancers often feel that they are entirely alone. Generalized cancer support groups often aren’t always helpful for someone with a non-traditional form of cancer. Specific cancer groups such as Kidney Cancer Canada play a huge role in helping patients navigate the cancer system and learn from one another through online discussions, patient education meetings, and peer support.

Step 4: Help us Build a Bigger Boat

Sadly, treatments for rare cancers are often overlooked in public funding decisions. The first two drugs to be approved by Health Canada in over a decade were denied by the Common Drug Review. More recently, the Joint Oncology Drug review recommended against funding a third drug. Patients and families need to raise their voices to help governments understand that it wasn’t our choice to have an unpopular cancer. The choice we make today is to advocate for our own survival.

The Many Surprises of Life and Cancer

ROMAN GAWUR

We all know and expect that life is full of surprises, unexpected twists turns, joys disappointment, ups and downs. We even say, "That's Life!"

As a Canadian baby-boomer, I have grown up with an expectation and belief that if life zinged me or my family with a truly life threatening situation the "Social Safety Net" would be there to for us. After all, I have paid taxes for over 40 years as well as premiums for private supplementary health insurance. I was fortunate to never require any kind of help from any level of government and I never filed a major claim with the private health insurers. So in my mind I should be more than adequately covered for life's gotcha.

Surprise! I wasn't.

At the age of 56, I was diagnosed with colon cancer in October 2006. Surprise!

A successful colon resection was performed in November 2006. In January of 2007 it was discovered that I had lesions on my liver that were considered inoperable. Surprise!

Along with my chemotherapy the oncologist recommended a drug called Avastin to be injected at a private clinic, if I had the means to pay for it. Since Avastin was already approved by Health Canada and covered by British Columbia and several other provinces, I asked why I must pay for it.

I was told the Government of Ontario had decided not to cover Avastin. Surprise!

There appeared to be holes in the Safety Net. Ah, but all was not lost because I had supplementary

health insurance which covers drugs. Because the Avastin was going to cost in excess of \$30,000, I wrote the insurance company to inform them of the anticipated expense. The insurance company promptly informed me that Avastin was not covered because it's supposed to be a hospital administered drug. Surprise!

So, the provincial health plan will not pay for Avastin. The hospital would not administer cancer drugs that the province would not pay for, forcing the use of a private clinic. The supplementary health insurance company will not pay for the drug because it's supposed to be covered by the province. This is Alice In Wonderland!! From what I thought were two Safety Nets to no Safety Net. I was in free fall.

This was Canada after all, and I shouldn't be forced to sell the "family farm" to pay for life saving treatment. That's only supposed to happen in the big bad USA. Right ?

I started my chemo without the Avastin and looked for help in finding a private clinic and arranging for the Avastin. If the farm had to go it had to go! The hospital social worker pointed me in the direction of the Avastin Help Line. It turned out that the pharmaceutical company that provides Avastin was funding a compassionate program that not only helped defray part of the drug cost but also coordinated the private clinic where I could be treated. Surprise!

Baby-boomers just don't know how to take NO for an answer. We have a long history of challenging authority going back to the 60's. So it was natural for me to challenge



the decisions of my supplementary health insurance company and the government.

I discovered that the insurance company had a process for appeals and exceptions. I filed the required documentation and promptly received approval for 75 per cent of the cost for a year of Avastin treatments. Surprise!

I had some great results with my chemo and Avastin. After five cycles the surgeon observed significant improvement and decided I was a candidate for surgery. Upon completing 13 cycles of chemo (nine with Avastin) I had a successful liver resection in August 2007.

Subsequent to the surgery, even though there was No Evidence of Disease, I had another eight cycles of chemo to eradicate any microscopic seeds. I am currently NED for CRC. Surprise!

As for the fight with the Ontario Government over Avastin funding, that is a whole other story. Suffice it to say that the Government of Ontario approved funding for Avastin as a first line cancer treatment drug in July of 2008. Not a surprise!

Roman Gawur is a business executive and colon cancer patient, currently with no evidence of disease, living in Toronto.

© 2009, Roman Gawur. Used with the kind permission of the author.