

## Power to the People

### ONE CANCER SURVIVOR'S EXPERIENCE WITH ELECTRONIC HEALTH RECORDS

by DONNA HAMMILL-CHALK

In 2004, at age 41, I was diagnosed with breast cancer. As a bright, positive, resourceful woman—one who had worked in the cancer field with pharmaceutical company Eli Lilly—I thought I would have felt prepared for what was to come. I wasn't. The physical impact, the anxiety and stress all made it difficult for me to absorb what I was being told and follow my course of treatment in an informed way. It's not an uncommon experience—there's even a name for it: “cancer fog”. I felt like a cork in a river, being swept along with little understanding of where I was going, and no control over how I was going to get there.

Don't get me wrong: I received excellent care from top surgeons and physicians, first with surgery at the Markham Stouffville Hospital, and later with more surgery, chemotherapy and radiation at Sunnybrook Hospital in Toronto. But cancer takes away your feeling that you are in control of your body, and your life. Despite my doctors' efforts to keep me informed, I felt like planning for my cancer treatment was just another thing that happened *to* me, rather than *with* me.

Following successful treatment, I agreed to be a patient advisor on a project at Sunnybrook to develop and implement an Electronic Health Record (EHR) for use in cancer care. The resulting system, which has been deployed over the past few years within oncology and other departments at Sunnybrook, is called MyChart.

MyChart's purpose is to provide quick, reliable and portable electronic access to patient information for health-care workers—and, importantly, for patients themselves. Thanks to the efforts of a committed team of developers, medical professionals and patients, the system has been very well received.

It makes sense: my generation is increasingly getting used to having access to their personal information electronically, from banking to education—why should health-care be any different? If we're “getting used” to it, the next generation will *expect* it, and *demand* it.

EHRs aren't a new idea—Canada has just been very slow to adopt them. Similar EHR systems have been used in other countries for years, such as VistA: an open-source system used in hundreds of Veterans Health Administration hospitals in the US.

Their experience has shown that giving patients ready access to their health records makes a tremendous difference in helping them understand and navigate their health care. This is especially true for cancer patients, whose complex courses of diagnosis, treatment and monitoring often take place over months or years, and involve multiple specialists, departments and even facilities. EHRs help the patient manage all of those moving pieces.



Donna Hammill-Chalk

I came to appreciate the benefits of MyChart first-hand recently when it was determined that my breast cancer may have returned.

Surely this time, I thought, I'll be prepared—I'd been through it before, so I knew what to expect. And yet I still found myself experiencing the need to be in control when presented with the news. Coming away from my consult, I wanted to have all the information on my diagnoses and next steps. I needed to feel that *I* was in control, not the cancer.

This time, all I had to do was go to the Sunnybrook website, enter my patient ID and secure password, and there—right at my fingertips—were all my test results, my Doctor's notes on our meeting, my recommended course of treatment and next steps. I had a clear, written record of my cancer care, and it was mine to use—whether to guide my preparations for treatment, or even to obtain a second opinion.

As I prepare for this year, MyChart makes me feel like I'm part of the planning process. I'm still scared, but I also feel informed, involved, engaged: *empowered*. It's given me back a little bit of the control that the word “cancer” took away.

I just wish that I could offer that sense of control to my mother. She was also recently diagnosed with breast cancer, but patients at her hospital in Prince Edward Island do not have access to an Electronic Health Record system. As a result, it has been very hard for me and my siblings, none of whom live in PEI, to get access to information about our mother's care—harder still to help her navigate this challenging process. All of that could be eased with an effective EHR.

I think of all of those other cancer patients who don't have the luxury of having someone in the room to advocate for them at this most frightening of times, and it makes me wonder why patient access to Electronic Health Records isn't already a standard component of care across Canada.

What are we waiting for?

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