Cancer Treatment Challenges and Bruce Cockburn's "Pangs of Love"

What century is this? To transfer my information, this hospital system burned the data on a CD and sent it snail mail. Bigger problems await.

August 5, 2022 By Robin McGee

Many people share with me their outrage over the medical errors described in The Cancer Olympics. What many do not realize is the staggering medical error I have encountered since. Believe it or not, I have even MORE to share today. My middle name is actually "Anne," but I am considering changing it to "Medical Error." It amazes me that anyone survives such a system, full as it is of ignorance and calamity.

My last post shared that chemo is no longer working. Radiation was recommended as an alternative path to controlling the cancer. The radiation oncologist I saw at QEII proposed an extremely aggressive radiation protocol: 40 radiation treatments over 20 days, accompanied by chemotherapy. Worse, this radiation oncologist said he planned to specifically target the area where my repair surgery is, "just in case" there are cancer cells there. My surgeon said he was greatly shocked by this approach and strongly advised me to get a second opinion.

I arranged for an opinion from Sunnybrook, where the repair surgery was done. Two months ago, I requested that the actual images from my most recent MRI to go to Sunnybrook. I had to get Sunnybrook to request it themselves, as patients cannot request records to be sent to specialists. At QEII, the policy is that diagnostic images to be shared outside the hospital must be burned to a CD and then sent by snail mail. After a month, Sunnybrook had still not received it—health records had somehow lost it. Sunnybrook had to ask a second time and even arranged a courier to pick it up. They still did not get it—health records had lost it again—a second time!

I called the NS Health Quality folks to ask for help. Guess what? Health records has no system for tracking the records requests from health professionals. Nothing—not even an Excel file or handwritten log of when the request was made. So, they have no idea how many requests go missing or are unfulfilled. Even though it is 2022, they do not accept or use any electronic file transfers — only fax machines and regular mail. In an age when even the Canada Revenue Agency uses a dropbox for large file communication, our healthcare system has not moved on from the last century. (The quality manager, just new to the job, told me when she heard they used CDs she had to ask them what "CD" stood for.) She said my case has revealed to them the patient safety dangers of such a primitive approach to communication. So once again, I am Patient Zero in a test

case underscoring a major flaw in Nova Scotia healthcare; geez, I sure would like a break from that role.

In the end, the Sunnybrook Radiation Oncologist had to offer an opinion without seeing the MRI images. His view is that aggressive radiation would very likely destroy my bladder repair. Instead, he recommended mild radiation targeting only the tumours causing pain and leaving the repair alone. It would not be a treatment aimed at controlling the cancer but would only be a palliative approach to reduce pain. Nothing is more important to me than protecting the repair that I and my Toronto surgeon worked so hard for, even if it means dying sooner.

So what happens now? The only other option is for me to go back to (ironically) FOLFOX chemotherapy. Last time I was on it I found it physically devastating, and it also left me with considerable permanent neuropathy. It will likely make my current neuropathy much worse. They told me that I would have to choose between being crippled (FOLFOX) or being made 100% permanently incontinent of urine (aggressive rads). I choose being crippled. At least I can aid my mobility with a cane or a walker or a wheelchair. There is nothing anyone can do to rehabilitate a bladder with a hole burned through it.

So next week I start back on FOLFOX. I need to buy myself some time before palliative radiation can be sorted. The plan is for me to go on it for 12 weeks if I can endure it that long. I truly dread it. But something has to happen, as the tumour is growing so large it is starting to impact my ability to walk. All the bungling around records has delayed my treatment by many weeks, and I need it right away.

Today's song "Pangs of Love" is by Canadian virtuoso Bruce Cockburn. A brilliant guitarist as well as a singer-songwriter, Cockburn is referred to by other artists as "a musician's musician" — the highest compliment given in those circles. This song is from his 1988 album Big Circumstance. He wrote it while travelling in Tibet and recovering from broken love affair. It is thoughtful, meditative, and regretful song, interwoven with his evocative and expressive acoustic guitar. I choose it today because I have pangs of love for life, a love of existence that leads to the same kind of apprehensive insomnia, mingled with the melancholy of ongoing sorrow and loss.

Listen to the rain on this mountain town
Listen to the nightbird's lonesome cry
Listen to the scratch of pen on paper
That's the sound of sleep denied

Hear the sleepers toss and turn
Dreaming whatever they're dreaming of
The wind that's clearing the heat from the air
Can't clear my heart of these pangs of love

Pangs of love
That's the price you pay
When you give your love

But don’t give all the way

Pangs of love
Won’t let me go

I came so far around the world
To hear the night say
I told you so

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