

What happens when you outlive your diagnosis of death?

A night of Shakespearean proportion looms

On June 2, 2015 a number of us have arranged with TIFF Bell Lightbox to show a film about the life of mental health consumer activist Linda Chamberlain. It is Chamberlain's tribute to Diana Capponi and a fundraiser for a scholarship fund that bears Diana's name.

In the closing scene of the film, Diana Capponi holds the very first (proof) copy of Not Anytime Soon, a scrapbook that chronicles Linda's life of ups and downs culminating in accolades for Linda's activism. The film is called Linda! Not Anytime Soon: It is a complement to the book as it shows Linda's daily life as a consumer survivor.



Photo courtesy of The Toronto Star: Catherine Porter

The titles are prescient because Linda had told her world that she was dying of bone and liver cancer with a secondary diagnosis of Crohn's disease. Although her diagnoses left her little time, her infectious optimism was captured by the titles of both film and scrapbook.

With her mortality at hand, I rushed Linda's scrapbook into print while Norman Lofts doubled his efforts to complete his film before Linda's expected demise.

And Diana Capponi amped up her efforts to create and dedicate the plaque honouring Linda that now hangs on a wall inside the Irma Brydson Youth Inpatient Unit within the new Intergenerational Wellness Centre at CAMH.

In what was to be a fitting climax, the last scene in the film shows Diana leading a tribute to Linda early in 2013 to ensure that Linda would receive this honour during her lifetime. That's how things were supposed to end; the hat trick; the trifecta; tribute, book and film all in one place and then Linda would exit stage left.

But that's not what happened.

On September 21, 2014, 536 days after the tribute to Linda Chamberlain, Diana Capponi died of cancer. She was 61.

And Linda Chamberlain has long outlived her diagnosis of two forms of (untreated) cancer that precipitated the early completion of the three tributes to her.

In an ironic twist of fate, Linda's newest medical odyssey shows serious disease but it does not include cancer. Linda's life is not threatened at this time.

In other words, the woman who masterminded the first of three tributes to Linda died of a form of the disease that was supposed to take Linda.

There is much to explain in this mystery but what remains central to the plot is that Linda believed that she was dying of cancer. If I didn't believe Linda, it would make little sense to help organize the June 2 event.

But I knew that I could not be part of showing a film where Linda claims illnesses that would make it medically improbable for her to attend the tribute. The reality is that June 2, 2015 marks 780 days since Diana's tribute to Linda. With no treatment of any kind in the interim, most people legitimately wondered what was happening to Linda.

We could not allow her film to be shown without an explanation.

So we arranged for a new Doctor who started out anew. Linda had a number of tests. Some of the tests were invasive and the biopsies painful. After months of visits, no completely clear picture has emerged.

But we have enough that Linda has issued the following statement which we will also read at the June 2 tribute to Diana Capponi. It illustrates (among other things) the problems associated with 'Google-osis', the act of diagnosing yourself. This is Linda's statement:

“My name is Linda Chamberlain and I am a consumer survivor living in poverty. I have ‘lived experience’ of mental health issues, addiction and sickness. I am now a senior living in subsidized housing.

About 10 years ago, I weighed about 220 pounds. I came off a drug and lost a lot of weight and started to look better. But I kept losing weight. I couldn’t keep any food down. I was sick all the time.

I went to a doctor in Montreal at one point and he said I could have cancer. I visited my sister and her son died of bone cancer so I thought I had that.

My stomach started to swell out like what happens with liver cancer so I thought I had that too. And when I still couldn’t keep anything down, I thought I had Crohn’s disease.

I should have gone further into it right there but I didn’t. When you live, as far too many of us do, from crisis to crisis, your mind immediately goes to the worst possible outcome.

I lost more weight but I didn’t die. So I went to the doctors again and started to get tested. I stayed with it and I found out that what I believed for so long was not going on.

I don’t have liver or bone cancer and I don’t have Crohn’s disease.

I have Hepatitis C and I was surprised to learn that I have Hepatitis B. I also had a thyroid cancer scare because I have a cyst on my thyroid. I have high cholesterol and I have a muscular bowel disorder that is serious.

The fact I can’t keep anything down is not Crohn’s but the combination of my bowel disorder, my habits, my diet and my age.

I apologize to all the people who supported me because they thought I was dying of cancer. I believe I have let them down.

I don't know what my final diagnosis will be, I have a good doctor and everything is being tested and checked, including my lungs, and I don't know if I will live or die or when. What I do know is that all those who reached out and gave me comfort and who allowed me to speak for them should know that I will be speaking directly to each of you, and I hope you will continue to be there for me.

*Sincerely,
Linda Chamberlain – May 25, 2015 (revised)*

As Pat Capponi says, “Diana loved Linda, and would be pleased that she is still on this earth, being Linda. If you loved and respected Diana, then treasure Linda in her name, both women have done so much for our communities.”

We hope to see all of you at the gala tribute at TIFF Bell Lightbox on June 2, 2015. The link is here to read more and buy tickets: [Diana Capponi](#)

If you cannot attend, please contact Veronica Jo Snooks at 416-768-2738 to make a pledge so that someone with lived experience of poverty and mental illness can attend in your place.

John Stapleton, May 25, 2015