

TAMING UNCERTAINTY: Facing Cancer In The COVID Era
A talk for the IPOS-2022 World Congress, Toronto, Sept.1, 2022.

[01] INTRO

Delegates, staff, ladies and gentlemen, it is an honour to be with you today.

It was a difficult decision to cancel my travel plans to the conference last week when I found myself in hospital dealing with complications of cancer – though it did inspire an update to this story.

It's a special thing to address people in the world of psycho-social oncology, a sub-discipline I wasn't aware of before I was asked to speak. To cap your experience of these talks I hope to add some insights on the patient experience.

In truth, it is a pleasure *just* to be here, anywhere, and perhaps it's appropriate that I am coming to you in a slightly cinematic form.

Two years ago this upcoming long weekend I was led to believe my remaining time on the planet was seriously limited. One warm summer Edmonton evening I checked into emergency at the University Of Alberta Hospital (hereafter, the hospital), following a long day of nausea and vomiting unlike anything I had ever known. A bad case of food poisoning I assumed – but no such luck.

After I was officially admitted around 11 p.m. I had a tube inserted down my nose that drew black goop from my stomach for several days, I got an IV inserted into my arm, I got a CT scan, an ECG, more tests, and I got bored enough to figure out that there were seven different shades of green in the private room where I was isolated. Bonus: green is my favourite colour.

Then, some 18 hours after checking into the ER, a surgeon walked into my room interrupting another doctor's interview which was already in progress.

With the barest introduction Dr. B. told me...

“I'm sorry, there's nothing we can do but send you to palliative care. There are some large masses and many smaller growths, too many to operate,” he said, waving at my abdomen. “It's probably melanoma and it's too advanced.”

He was there for *maybe* 90 seconds to tell me that time was limited, and then he left as abruptly as he came. Laying there a bit stunned, trying to process it all, I was at the start of a new experience, reconciling the immediacy of life and death, facing that great uncertainty factor, cancer.

On a whole extra level which I'll explain later, I was also in my own movie.

A shout out to that surgeon, Dr.B, and his visit. Surprise! I'm still here. While a little part of me wants to say so with a note of “so there”, Dr.B. initiated one of the great learning curves of my life. I try not to begrudge anyone for their bedside manner – or lack thereof.

By the end of those 12 days in hospital I was given four different diagnosis, none of them totally correct.

Today I marvel at the many contradictions in my journey to this moment.

Briefly, I was born in 1960 in the scenic northern Alberta town of Peace River, I'm the youngest of six siblings. My mother was a life-long visual artist who painted in a high realist style, and later, a teacher. My father was the first lawyer to be appointed Queen's Council in Northern Alberta and later, the district judge. His choice to hang a velvet seascape over the fireplace in our homestead only hints at the many reasons which led my parents to separate when I was five years old. I have lived in the culturally vibrant city of Edmonton since my adolescence.

Aptitude testing indicated my bookish, introverted character was suited to a career as a writer though it happened more by accident. I have been working at the game of word-craft professionally for nearly 40 years now. Being an arts aficionado has driven much of this, especially since the life-changing event of my first live jazz experience, around age 18, when I came to understand that music was the universal language.

By age 60 my business card read, “check one: ~ actor, painter, writer, voice.”

The voice part is chiefly connected to my 25-plus years in public/community-based radio. Some of the greatest fun I've ever had came from working wildly eclectic, late-night shifts on the airwaves. I also put in two years of university, majoring in English and History before dropping out to join the media.

Radio led to work in print media, writing about jazz, blues, roots and global sounds, hundreds of film reviews, and stories on dance, theatre and more for the Edmonton Journal, stories often rerun in the paper's sister publications.

More recently I was nominated for a National Newspaper Award for two extended features tied to my diagnosis and treatment for cancer which ran in the National Post in late 2020.

I got good at painting homes, a welcome Zen balance to more intellectual work.

And finally, my small but vital career as an actor.

In the spring of 2016 I was on a shopping errand in a downtown Edmonton mall when I witnessed the suicide of a young woman who jumped and hit the hard marble floor a few meters in front of me. During the dark weeks afterwards a friend pointed me towards the work of Standardized Patients, actors who portray specific, detailed roles as medical patients in the interests of training and testing student doctors, nurses and techs. It has become one of the more profound, challenging facets of my life.

[For those unfamiliar with SPs, I believe they are called S-Clients elsewhere.]

It took me a couple of years to decide whether SP work was *really* acting. It covers a wide expanse from simple, unscripted “warm body” roles to teaching students, for instance, the chain of cranial nerves, to playing extended characters, scripted or improvised. For myself, well over 50 roles now.

I knew it was acting the day I put on a fat suit and taught myself to cry on call for a series of simulations as a former football player talking to multi-disciplinary teams of students. My proudest moment came after I made student psych nurses cry during a day-long set of half-hour improv simulations, portraying a lawyer who had tried to commit suicide. Think about it, drawing empathy for a lawyer.

I take pride in having played a part to train hundreds of medical professionals.

As the German film director Werner Herzog put it:

“We live our lives in a fabricated theatre, all of us – we live through performances. Which is okay, it makes life bearable and it is very human. Our memories are shaped voluntarily or involuntarily according to our needs.”

This work as an SP included rehearsals for my real-life movie as a cancer patient. I've often wondered if I might have had a nervous breakdown over those first 12 days in hospital had I not been so familiar with the setting.

Between media work and SP encounters I have considerable expertise in the art of the interview. I believe it's an essential skill for medical professionals.

One last note to this backstory. 22 years ago my girlfriend used to read the National Enquirer for laughs. One fateful issue had a pictorial on how to spot skin cancer and my skin caught her eye. Weeks later I got a call from my doctor. The discoloured spot on my right arm which had just been biopsied turned out to be malignant melanoma. Not the first time I would learn, at home, alone, that I had cancer. That spot of melanoma never spread, but the chunk of flesh that was removed around it, my first invasive surgery, gave me a sense of how cancer can lead to an emotional, irrational frame of mind, something I'm still getting used to.

So, most of my careers were on hold that night I checked into the hospital ER two years ago. That world-changing factor COVID-19 had put them on hold months before. My freelance writing work for Postmedia News was suspended the previous spring when suddenly, there was no arts scene to write about.

COVID was effecting medicine big time. While the hospital wasn't as stressed in Sept. 2020 as it has often been since, the sense of distress was palpable, the need for precautions serious. I was moved to an isolated room in the surgery ward one day in and watched everyone don gowns, gloves and visors, even to deliver a glass of ice chips for that first week. It took a week to get a negative COVID test result. The government's lab had managed to misplace my first swab.

Today I puzzle over the odd path that has led me to speaking to a convention of medical experts. But that collective experience leaves me with an enhanced appreciation of the more holistic approach of psycho-social oncology. If you're at this convention I probably don't need to say so, but I have to ask...

How could there be any other approach to such a life-encircling disease?

[02] DIAGNOSIS: UNCERTAINTY

Hearing about “large masses” that first day in hospital left me understandably worried, at least until several days later when one of the city's top ultrasound experts examined me and asked, “*what large masses?*”.

I learned that different types of imaging can give vastly different results. Eventually the only course was to do a laparoscopy or surgical biopsy, to send a camera inside my abdomen and snip a bit of tissue for analysis.

Between the hospital's role as the key trauma centre for Northern Alberta, long surgical waiting lists, and the staffing pressures of the developing pandemic, just a fraction of its operating rooms were available and it took most of a second week of lying in the ward, waiting to get into one of them. In the end a surgical team worked overtime late one night to make it happen. Thank you *team*.

I'll never forget being wheeled into the amazing, glowing-white surroundings of the OR. wing, the staff's bubbly sense of humour, and the collective state of heightened consciousness. All that before any drugs.

As I lay there in a prep bay, the chief surgeon, Dr. M strolled over to say hello.

“It will involve several small incisions,” he explained, “but if I see something I can fix then I might open things up wider to take a look. Sometimes you have to get your hands in there to see what’s going on,” he added, grasping the air over my torso as if he was mixing up a bowl of meatloaf.

Then they wheeled me into a room with a huge flatscreen monitor, rows of instruments and utensils, industrial lighting, and a modular table that I was transferred to. After getting me to spell out my name a few more times someone put a mask over my nose and I was out – for about 70 minutes.

Once I drifted out of the fog, around 10:30 p.m., the assistant surgeon Dr.C walked up to my rolling bed with a serious expression on her face.

“I’m sorry to tell you that it’s not good news,” she began. My insides were dotted with numerous nodules. “Likely melanoma” she told me, enough to make further surgery pointless. Any treatment at this point would involve sending me to palliative care. I asked her to please hold my hand for a moment, sputtered out a few words, and apologized for not making sense.

By 11 p.m. I was back in the regular ward, hooked up to more tubes and wires than I could comprehend. After phoning an old friend to debate Buddhist notions of reality, life and death, I lay back and started considering the music I would like to be featured at my wake. I'm not sure that I actually slept that night at all.

Then it was 6:30 a.m. and my friendly ward doctor came by on his rounds, sounding surprisingly upbeat about my condition.

When I repeated what I had been told the night before he insisted the final outcome was still up in the air, adding, “you are absolutely *not* going to die.”

Mental conniptions ensued.

He told me I would meet with the chief surgeon to get my biopsy results some two weeks later. Trying to make sense of it all, I was unaware that I had encountered a case of medical tunnel-vision. Because they knew that I had had

melanoma – even one small spot 22 years earlier – most of them assumed I must have melanoma again – one of the fastest growing, most dangerous cancers.

Every day I was in hospital I made a point of learning my nurse's name, making acquaintances despite our masks. Their names were different every day too, given the staffing issues. But I let everyone know I appreciated their work. As I was leaving the ward manager told me “we're all rooting for you.”

Of course, I didn't have to wait so long for the final diagnosis.

Over a decade ago Alberta Health Services initiated an online network to make patient information available, even to the patient, so we could actually see the test results our tax dollars pay for. What a concept! Despite its slow implementation the system got a push as COVID testing began. By consequence I may have been one of the first individuals to find out the details of a terminal diagnosis via email notice, a week later. Taking a deep breath, I opened the report. After an hour of research online I made myself a nice dinner, watched a good Norwegian movie, and went to bed.

Understand. I was relieved to find out and able to handle the news but I'm not sure anyone knew it would happen that way. The month after I wrote about all this in the newspaper the Alberta government's Health Services sent out a generic warning notice that such important results could show up unannounced in your email – possibly to cover their ass?

So, what was that final diagnosis?

Strangely, there was no obvious point of origin. I had nodules of one of the most common cancers, adenocarcinoma, dotted across the lining of my peritoneum (the sack holding your organs in place). More nodules on several organs, including the outside of my colon.

So it was Stage 4. My patient status: palliative.

I had been to the Cross Cancer Institute (hereafter, the Cross) years before to keep my girlfriend company when she had her first meeting for breast cancer treatment. It was quite another experience to be there one afternoon in October, 2020 for my own orientation. “No guests”, this time, because of COVID.

I likened it to enrolling in college again, starting with an I.D. Card, a stack of reading material, plus a film on cancer treatments and the technology I would use. There was a long appointment with my team, a nurse, a pharmacist, a dietitian, and my oncologist, a memorable character named Dr.S.

“Technically, I am required to tell you that you’re at risk of dying in six months,” he told me, “but I'll be damned if that happens on my watch. It is treatable and I would typically use colon cancer drugs in this setting.”

He explained that some patients stuck around for as long as 18 months or two years with the course of chemotherapy he was suggesting. I would come in to be connected up for chemo cycles every two weeks and take home a pump that would convey the toxic chemistry into my body over a period of 48 hours in the comfort

and convenience of home. Then I would disconnect the pump myself.

To facilitate all this I had what's called a “power port” surgically implanted in my chest, identifiable by a triangle of three little bumps under the skin. The needle from the pump goes between those bumps, to a catheter, into an artery to my heart. It was installed by a surgeon at the Cross, working on the other side of a curtain that kept me from seeing anything while an '80s pop hit, Neil Young's Heart Of Gold streamed on in the background.

My chemotherapy program started about a week later in early November, 2020.

[03] REACTIONS 1

As family and friends gradually got the news one phrase I heard was “I can't believe you're taking this so calmly”. It was still sinking in that life was no longer something to take for granted and I still have my share of dark moments. But I had to wonder, 'how am I supposed to feel, how am I supposed to react'?

A few of the emotions that have inhabited my recurring brain loop include guilt, anger, confusion, and fear.

Guilt – over what I have done or not done to my body over the past few decades that may have contributed to cancer. I've had lectures about not blaming myself, but Catholic youth guilt syndrome is a powerful thing. I thought about all those sandwiches I had consumed with nitrate-ridden deli meat, about my sweet tooth – sugar feeds cancer, I was told. Then there's all that exercise I've set aside since I became chained to a computer.

Anger – because I always knew in the back of my mind that I was increasing my chances of stumbling into health problems. Especially after my scare from melanoma. Why hadn't I acted on good advice?

Confusion – did my denial of a healthier way to live stem from some childhood psycho-social damage, or a self-destructive impulse? In some strange way, was I expecting cancer? How had the combined stresses of my psycho-social environment contributed?

And fear – not so much of death itself, but that it would come for me, leaving too much unfinished. Or that it might be painful, or messy. My oncologist tells me that death from colon cancer usually “isn't pretty”.

One aspect I could have skipped from the start was anxiety. In an insidious sense, it's been worse than all the physical symptoms along the way.

By fate, during my first minutes in the chemo ward I came across a friend who recognized my voice behind the mask. He had already been getting treatments for a few months and offered up a tidbit of wisdom that, “cancer brings clarity”. It's true. You come to see certain elements in your life, maybe even certain people, as a waste of time. You want to spend time in a way that matters.

My appreciation of family and friends over these past two years has never been greater, and I hope, the same for their appreciation of me. Yes, it's sad that it takes

cancer to bring this out but I have never felt closer to those around me. I found out it wasn't too late to get to know the next generation and it has given me greater hope for the future to befriend my nieces and nephews.

Unexpectedly, friends, family and work associates were incredibly kind to offer me various forms of support. After writing about my experiences in the newspaper a nomination for the National Newspaper awards was a total surprise. I didn't win but getting that nod as finalist boosted my spirits.

From that first night in emergency I felt a compulsion to take notes and this strange real-life echo paralleled the patient simulations I had played out.

It is pretty engrossing when you're watching your own movie.

My editors at the Edmonton Journal plumbed the drama of the story of course. The headlines quoted doctors telling me “you're going to die from this” and the paper sent a photographer around for a photo-video shoot to fill out the story. My photo ran on the front page and I started to get a flood of communications. For months afterwards I sat down at my desk each morning to check emails, tears running down my face from so many meaningful messages.

Thanks to generous friends, before long I had the most well-stocked bar and collection of cannabis products that I have ever had in my life. I have never consumed less mind altering agents than I do now, but it's good to know I'm prepared for the end should I feel the need for good cognac or scotch or something stronger. Is stress *another* contributor to cancer? I have never been more aware of the need to relax, so, I'm working on that.

Getting a terminal diagnosis leads you to strange, idiotic thoughts. That first Christmas I found myself walking the aisles of my favourite gourmet grocery pondering, is it time to try out that variety of exotic imported mustard or that flavour of gelato that I've always wondered about? Will I have another chance?

Know that, mango and raspberry gelato are still my faves.

As I gradually sank into the physical and mental routine of chemotherapy over that first winter, baring my experiences exerted a side-effect unto itself. I am a private person and that lengthy confessional made me feel like crawling into a corner some days. I completely understand the psyche of those cancer patients, scared with what the world dishes out, who want to shut the world out. But that's not the wisest approach to staying in the picture.

Simply put, *you* are your own ultimate advocate for staying alive.

[04] MY NEW ADVENTURE IN MODERN MEDICINE

There was a positive side to all this, something calming about the fact that I was doing what I was supposed to do to fight cancer, and educating myself in an intriguing first hand encounter with so many informative medical professionals.

At times I joked that it was my new adventure in modern medicine.

At other times it has felt like a part-time job, staying on top of medications, my

appointment schedule, paperwork, diet and exercise.

A nurse took me through the drill on chemotherapy and disconnecting power ports before my first chemo appointment, three times, eventually in front of a large mirror, but I was still very nervous the first few times I did it alone at home in front of my bathroom mirror. There are well over a dozen steps, some of them performed with one hand, all in a particular order, from setting up your clean workspace to rolling up everything in a bio-hazard disposal bag at the end.

It never gets easy waiting for the nurse to put a needle in my chest, and I always take a deep breath before it comes to pulling that needle out. If the chemo chemicals ever leak, I have my amateur hazmat kit handy. Now, 33 chemo cycles later, I have established a ritual of sorts, starting with ambient music in the background. What first took about half an hour now takes less than 15 minutes.

I still ponder how it is that these toxic chemicals which demand such careful precautions go dripping into my body. On the other hand, I am so lucky to live in Canada and close to a world-class facility like the Cross. In most parts of Africa for instance, it would be difficult to get chemotherapy at all, let alone the technology like a power port to deliver it.

I have always tried to be as cheerful as possible hitting the chemo wards at the Cross and often come away feeling lucky compared to the other patients. I'm conversational, friendly and try to humour the nurses when I can but I never push myself on other patients and have only communicated with a few on rare occasions. How much of that reflects the ace masks we wear for protection?

Each time I'm there to start a chemo cycle I'm sitting for around three hours, usually one of a few dozen people or so stationed in matching blue-gray recliners, or some on beds. If I'm lucky I can get a nap in while I'm connected.

The only shocking thing about going for chemo treatments came on the first visit when I got up to leave. I turned around and realized that the outpatient ward I had been sitting in, the hall of recliners, was actually one of three such rooms which ran on into the distance, and that this was one of three large chemo wards.

Sometimes I'm booked into "the Penthouse", that chemo ward on the fourth floor with huge windows that look out over the treetops of Windsor Park.

Either way, the scale of cancer can be rather humbling.

[Cross Cancer Institute stats]

For the past two years I've had a whole extra reason to mask up and I continue to do so in public places. Having a compromised immune system is just one more reason to fear breathing. When I exert myself I'm often out of breath from low hemoglobin levels. After eight COVID tests and four vaccine shots, I have still apparently avoided the virus. My sickest incident, an awful week-long cold in April, 2021, left me wondering if I was going to die.

I won't voice much on this but, the politics and protests of the anti-mask-anti-

vax brigade feel so trivial when you've got cancer. Just trivial.

The degree to which the pandemic has altered the medical system, and my own experience is impossible to gauge. I can only offer my quiet admiration for the many overworked nurses and doctors I have met. Staff at the Cross are simply stellar for the patience, devotion and compassion they bring into play.

I don't own a car and the pandemic led me to avoid public transportation. That meant developing a fleet of chauffeurs, supportive friends who drive me to and from appointments. Their friendship means more than I can express.

[05] MY NEW PART TIME JOB(S)

Facing the uncertainty of cancer is never easy, under the reality of a stressed-out medical system and pandemic it's worse. Time is a resource as never before.

Over the years I have felt more than once that a doctor or nurse was addressing me as the patient on the page, as a collection of statistics. Cancer tends to add an extra note of import to interviews but interviews are *so* important. You learn this quickly when you do a patient simulation five, or ten, or maybe 40 times in one day. Every doctor and patient is different than the last. Doctors think they're in charge of the interview, but if they aren't listening or asking the right questions they're not conducting things properly. If they are not *seeing* the whole patient, the patient isn't fully involved. Important things go missing.

I'm hardly a perfect patient advocate but I do try to give and get all the details. You can get a few surprises. I've even had a tip on how to kill myself, though to be fair, it was probably to underline the importance of taking blood thinner daily.

I have been relatively lucky with the side effects of chemo – minor nausea and disturbances to my G.I. tract but not much else. Other side effects developed cumulatively over time. My sinuses dried out severely and it took a toll on my mouth and gums. Six months in it was getting painful just to bite down on a piece of toast and brushing my teeth brought on inevitable bleeding gums.

Then there was that gradual change in taste. Not a disappearance of taste, but the feeling that everything I ate had a weird layer of something else. I couldn't name it and then one day a nurse said, “oh, that metallic thing” and I realized, everything was starting to taste like I was chewing on a fork. Two of my favourite high protein foods, peanut butter and humus had no appeal and there was no point in spending money on good wine.

It was decided that things were going well enough to give me a slight reduction in the main chemo drug (Fluorouracil, Bevacizumab), and that helped.

Quarterly CT scans were very positive. *Everything was shrinking.*

By mid-July, 2020, the cancerous nodules left were barely measurable and my oncologist gave me a pause in chemo which wound up lasting six months.

He underlined the cancer wasn't gone, but explained a break was a good thing.

The longer cancer cells were exposed to chemo there was a greater chance that they might learn how to subvert the toxic medicine and to start growing again.

I will never forget that Sunday morning in July when Dr.S. called me up to pass on the good news, off regular hours because he was way over-booked at the office. I could hardly talk about it for days after. There was a note of surprise in his voice and I realized anew that even with educated, expert guesses absolutely nothing is certain. Uncertainty would return sooner or later.

The battleground in my abdomen would rest but there were plot twists coming.

Along the way I enrolled in two separate 12-week research studies at the UofA, geared to diet and exercise, specifically designed for cancer patients.

The first study, called PRIME, targeted muscle and bone mass in chemo patients with nutrition and high protein foods. I was asked to monitor my diet in detail and got measured a lot.

The strangest part? Two 24-hour stays in Canada's only million-dollar WBCU. That's the Whole Body Calorimetry Unit. I was sealed in a 10-foot square room with grey metal walls, a bed, a recliner, bathroom facilities, an air-lock for delivering food and of course, a television. Sophisticated systems measure the exact rate of your oxygen and carbon dioxide exchange. All that gets indexed to changes in your muscle and bone mass.

I found out how chemo can suppress your fitness level when I enrolled in a study tied to the University of Alberta's Dept. Of Rehabilitation Medicine.

ACE, or Alberta Cancer Exercise, involves a carefully designed, supervised, twice-weekly workout program with physical assessments at the beginning and end of the study. It was a major boost to my physical and mental strength, and working with friendly, encouraging trainers to guide you was a pleasure.

My pause in chemo treatments in July, 2020 coincided with an invitation to return to writing for the Edmonton Journal arts section. As our beloved premier declared Alberta "open for summer" arts and entertainment began to come back from the pandemic and there was something to write about. I had to be careful not to take on more assignments than I could handle. Still, it was good to be back in journalism, and, new encounters took my mind off cancer.

As a film fanatic I also found the answer to a question I had had for years, 'how do cancer patients feel, watching movies about cancer patients?'. Purely by chance, I wound up seeing four cancer movies in one month ranging from the stupid and sentimental to a couple that moved me. Inevitably, you wind up picturing possible scenarios of how your own end might happen.

How might my face look in that final scene as I drift into a morphine haze?

[06] REACTIONS 2

Months into that first pause in chemo in autumn, 2021 I felt as if I was

becoming an irritable, stressed-out crank. The few story deadlines I met each month were nothing compared to what I used to face 10 or 20 years ago, but either from age, pandemic fallout, cancer stresses or all of the above even one deadline can now gnaw away at my brain.

Surprise, anxiety is a common side-effect of going *off* chemo. When you're on chemo you get a sense of routine, you're doing what you're supposed to do. Going off chemo opens up that door to the uncertainty factor all over again.

I learned this in another side benefit as an outpatient at the Cross. For over a year now, at six-week instalments, I've had Zoom chats with psychologists provided to patients. Dr.J has been so helpful in explaining this sometimes irrational trip. Lifting my spirits when being a patient just sucked.

More recently, speaking with a new psychologist-slash film fan further honed my thoughts to cinematic angles. Even so I was perplexed to hear that astronaut Alex Bowman's trip into the monolith at the end of 2001: A Space Odyssey – one of my favourite movies – was an allegory to my cancer journey.

Now..., two friends I have known since high school days became successful doctors. I had been sending them copies of my scan reports for second opinions. Then, on a Saturday morning in Oct.2020, I was shocked to find one of them listed in the obituary column. It seems that she had been in total denial to the end, but it was incomprehensible that she hadn't considered telling anyone about her cancer for the final three months between her diagnosis and death. By the end of that weekend I was reduced to watching kitten videos on YouTube.

Around the same time last fall I went back to in-person standardized patient work at the University Of Alberta. It was great to meet up with colleagues after the work break that COVID had imposed, but it was also harder, especially one exam weekend where a diagnoses of cancer was delivered to me over 20 times.

Thanks in large part to the then-recent development of COVID-Omicron variants, the holiday season last winter was a new low as isolation goes. I created my own jazz cooking variation for an Xmas eve dinner and had a long Zoom call with an old friend. My nieces visited on New Year's Day, but my experience of the pandemic has been easier than it has for many. After living and working at home alone for the majority of my adult life isolation is nothing new.

Shortly before last Christmas, the last CT Scan of 2021 indicated that nodules in my abdomen were growing again, not alarmingly so, but they were growing.

I returned to a new course of chemotherapy at the start of January, but not without a little boost in confidence beforehand, after finding out that my level of COVID antibodies was substantially higher than I had ever guessed.

At several points doctors had suggested I might want to look into that. There's a real dearth of information on whether chemotherapy compromises the efficacy of a vaccine. No one seemed to know how or where I could get a meaningful antibody

test. I spent hours on the internet and the telephone with Alberta Health Services to find out and when I eventually did, nurses on the AHS Health Line thanked me for leaving them better informed.

What's wrong with *that* picture?

It turns out that the single, small, now-closed for-profit service offering detailed antibody tests in Edmonton would send your blood to the Mayo Clinic in the United States by Fed-Ex. Apparently it's not important enough for AHS to set this up in Alberta for patients like myself who want to know where they stood.

Yes, I will grant you, COVID presents an ever-changing set of threats that can alter protection factors from week to week. But is there too little information, or a problem of information overload? Anyone out there who has to read research reports knows what it's like to stay up-to-date on a facet of medical treatment.

Anyway, my antibody test results gave me an excuse to return to nearly empty afternoon movie matinees at my downtown multiplex, wearing a mask of course.

Chemo was easier and harder the second time around.

Easier because I knew what to expect from side-effects, how to manage my gastrointestinal tract, all that fun stuff.

Harder because, by this past spring, I had hit a point of “patient burn-out,” as my therapist put it.

I was tired of all the needles and pills, *and tired of feeling tired*. At one point the staff at the Cross told me they would consider giving me a blood transfusion if my hemoglobin levels went any lower. Luckily it didn't come to that but just making my bed in the morning could leave me out of breath.

The shadow of death is insidious. There have been weeks when the news of acquaintances facing cancer just kept coming. As I speak, a relative has just been admitted to hospice with cancer. Professionally, obligations to write obituaries on musician friends for the newspaper hasn't been getting any easier.

Over the past couple of years I have conducted an informal survey of health workers I've met including staff at the Cross. How did they choose to work in oncology I wondered? It often comes out that professionals like yourselves entered this specialty after a family member died of cancer. They have my great admiration for facing oncology every day on the job.

[07] PATIENT BURNOUT

Reconciling all this is an evolving, sometimes bizarre movie.

My new therapist at the Cross helps me to plumb the existential context. He argues that the sanest way to go – at least for cynical, jaded agnostics like myself – is to embrace the absurdity of everything what's going on.

Over the past year my oncologist has told me that I'm doing extremely well, and that my palliative status has shifted to (quote,) “indefinite.”

If that's not absurd, what is?

On medical English: I've found myself referring to matters of stool shapes and farts. "Are they mouse farts or horse farts? - one doc asked me. Early on in my journey I apologized to a tall, lanky young doctor for my references to stools. To put me at ease he replied forlornly, "I talk about stools *all day long*." In truth, SP work helped me end embarrassments years ago.

I often recall that night nearly two years ago when I was wheeled back from my laparoscopy at the hospital to lie in bed contemplating the end. That same day I had taken in a TV news report about how scientists had discovered that there was more plastic in the ocean than anyone had previously imagined, but pollution is only one way that our existence on the planet may come to an end.

In this day and time, to stay sane, to shape your awareness of the wider world, you have to carefully consider how much news you peruse. Between the next "great extinction", the current international war, revived threats of nuclear annihilation, the rise of nationalism or fascism in states around the world, and climate change, well... Need I go on? There are lots of ways to go.

My point here? I'm not sorry to say goodbye to all that when my time comes.

Personal note: I don't run my life by astrological beliefs but I do subscribe to the personality disorder-slash-character model that comes with being a Gemini.

As Miles Davis said, "Gemini – it's a curse".

So, I am of two minds over the global and personal issues that death touches.

Or as the famous French existentialist Albert Camus put it,

"There is no love of life – without despair of life."

Despite the many ways we can go, I take a few moments everyday to enjoy life's simple pleasures. I have never been financially well-off as a freelance writer but I have tapped life's riches.

I have heard the siren songs and insights from many artistic giants of my time. A good friend suggested that the real often unrecognized giants are the ones who don't find it necessary to tell you so. At last count I have interviewed and written about musicians from over 60 nations, and I have danced to some of the most dangerous dance bands from most continents. Deadly stuff.

In writing reviews or meeting up with artists over the years my most enthusiastic compliment to a performance has been to dub it "killer".

I guess that's about the death of thought, a nod to that experience beyond words that leaves you in ecstasy, feeling one with the flow.

Thanks to journalistic access and simple pleasures, I'm a wealthy man.

Amidst the burnout I was starting to feel this past spring I came to reconcile cancer on a new level, despite my oncologist telling me...

"You've still got cancer. We just can't seem to find any evidence of it."

I'm not expecting to become cancer free. Whether I'm around for another six months, or six years or whatever, I know that death will still be shadowing me in the background. I like to think he's in a classic trenchcoat, fedora and shades.

So death stalks, and music talks.

Belgian film director Jaco Van Dormael sees it this way...

"Not knowing the date of one's death means that we have a tendency to forget about it, giving the feeling of immortality. Until that is, the shadow of death revives our taste for life... Some change everything. Others don't want to know."

When you think about it, that's the way it is for all of us, cancer bound or not. Anyone can still be hit by that proverbial bus tomorrow, or possibly face the next great extinction the day after. You're just not expecting it.

The zen master of jazz Wayne Shorter once told me, waving his hand in an arc, "Everybody's just moving through life."

Knowing that, facing that – through cancer – is to try and tame uncertainty.

[08] EXTRO

Let's talk about vigilance in the face of uncertainty.

To other cancer patients, I can only encourage you to be your best advocate, with the acknowledgement that some days are easier than others. You will only be prepared to handle this disease based on the best information you are given so demand the best, demand details. It's your responsibility to demand what the medical system offers, recognizing that *you will* encounter cracks in the system.

To doctors, I can only implore you to see beyond the masks we're all wearing, beyond the stats on the page, to see the patient as completely as you can, to seek out and treat every part of the person, known or unknown.

To nurses, I can only encourage you to perfect your Zen techniques, like those perfect, painless needle pricks – I've had a few – and to strive for compassion and empathy, to nurture the fragile but resilient seat of consciousness in patients as well as their physical fount of life.

You are all *so* important.

As recently as this past May I found myself back in medical simulations taking on the notorious "breaking bad news" role. In front of small teams of second year med students and their preceptor, my guy is told that he probably has terminal cancer. Symptoms not so similar to my real-life case, but close enough.

The delicate part, the art of the interview, is *finessing* the way he's told.

Over eight 45-minute simulations on two successive afternoons I sat through interviews that ranged for the most part from good to very good. One interviewer on day one was so bad that I found myself thinking, (a), how did you make it to second year, and (b), please quit and go into research or some other area.

But on day two I came across another young student doctor who took my case study at the last minute and apologized for being ill-prepared. Ironic, as it turned

out: she wasn't ill prepared as a human being. As the simulated patient *I* was the first one to mention the word “cancer”. She knew that the second she said the “c” word my guy's brain might drift off into another personal space altogether.

In my feedback to the student I let her know that she was exemplary, and I told the team of students, briefly, how I had been lying in a bed in the emergency ward just down the street on that holiday Monday afternoon in Sept. 2020 when I was told – in my real-life movie – that I had months to live.

'That's why what you're doing here is so hugely important' I explained. 'Your interaction is setting a course for the patient's psyche, maybe for their future.'

When I got up she asked to shake my hand and I realized that without trying, I had left an impression that she might remember the rest of her career. It was a beautiful, cathartic moment that made me feel good about the future of medicine.

I had to cancel my plan to be there in person today because, just over a week ago I found myself checking into the emergency ward at the University of Alberta Hospital again, this time about 10 a.m., on a Sunday morning, after two days and nights of gastrointestinal distress.

I left it that long to visit ER because I was hoping that the symptoms would abate as they usually have over some seven or eight previous similar attacks. And because I've heard enough recently on the horrors of waiting in ER rooms. At least this time there was no need to search for a diagnosis and I was lucky enough to get admitted in half an hour. After several quick interviews I was fitted with another hose down my nose to vacuum my stomach, and another IV drip.

Deja vu. The healing began again.

Over that first 12 hours lying in a busy, distracting ER I was interviewed at least another four or five times, and every time it was a little different. It was mostly, about sorting out who had the bed space upstairs to take me, but speaking with doctors from several departments I felt as if I was meeting with sales reps, as someone behind the scenes decided where and when I would shift settings.

In the end I was sent to the surgery ward as I was two years ago, installed in an isolated room again where the relative silence was deafening, and the ceiling conjured up a lovely Kandinsky painting. Part of this talk was written there.

Once more, I had that disconcerting realization that I was passing on not only my case history, but key elements of my treatment, meds I had been given, procedures to come, etc. I had the latest rewrite of the hospital script before all of my fellow performers got it. I was a key conduit of information.

I learned the name of every nurse and doctor who served me, graduating from ice chips to liquid meals to solid foods over several days, finishing the *New Yorker* Summer Reading issue, and babbling away on a cell phone. Once energy permitted, leaning on my I.V., tower, I took an exercising stroll around the inner atrium that makes the hospital an architectural marvel.

Precautions and masks remain, but I noticed a subtle relaxation of adherence to

pandemic rules this time, more humanity seeping out from behind the masks.

After facing cancer two years, shooting my little movie, I'm just getting started. I want to leave with an encounter from my recent time in the hospital ER.

With no sound isolation I couldn't help overhearing the guy next door through the curtain, on the phone to a loved one, joking about getting a hole in the side of his head thanks to a brain tumour. I mentioned this to a friend on my own phone call and pondered how lucky I was.

'If only we could talk to each other,' I thought, but I didn't have the courage to bother someone in such an intensely public-private circumstance.

A while later, brain tumour guy was able to leave, having sailed through whatever attacks you get when you have a brain tumour. The curtains shook as his feet hit the floor and as our nurse Nina showed him past the crack in the curtains, for a split second I saw a young guy, *maybe* 40, missing hair on one side of his head. Then he was just a set of sandal-clad feet walking away under the edge of the gray curtains that surrounded me. As I watched those feet go I had an overwhelming psychic pang: a chance at meaningful exchange was lost in time.

And then, after a few steps his feet stopped, I heard mumbling and Nina showed him back to my sickbay. He poked his head in and said,..

“I heard you too.”

We exchanged notes and commiserated for a couple of minutes before he had to go to meet his ride home. I was invited to meet with his coffee group of fellow glioblastoma patients. He passed on a note with his name and number and we had a celebratory fist-bump.

For that moment of contact in the face of uncertainty, I am a lucky man.

For all my diatribes over cancer, it has made me a better human.

I implore all of you, never forget that psychic connection beyond the flicker of facts and figures. It may be the greatest defence in facing this killing force.

Let me close with my favourite haiku, from around the span of the 18th and 19th centuries, courtesy of the Japanese poet Issa.

“Never forget: we walk on hell, gazing at flowers.”

Thank you.

© Copyright 2022 Roger Levesque.

-30-