



Manitoba Lung Cancer Voice

Summer 2021

Contents:

I'm more than just cancer p. 1

Helpful recipe p.2

Resources p.2

Lung cancer news p.3

Patient story p. 3

I'm more than just cancer

By Alyson Hairt

What do many people think when they hear that a person has stage 4 cancer? What do they think that person living with stage 4 cancer can do? Probably not a lot, well, I'm here to dispel a few myths.

I may not be as active as I used to be, but I still walk outside (could always walk more often), I work in the garden, weeding and mowing the lawn. I'm learning a new language, started learning to paint and Zentangle as well as travel.... pre COVID.

I am originally from England; my partner is from France and one of my son's lives in Australia with his wife and their two young sons. So, plenty of places, family and friends to visit. Since being diagnosed stage 3 lung cancer in 2014 I have flown to Australia several times including following my stage 4 diagnosis. One time I travelled by myself to Brisbane and spent 5 days exploring, before meeting up with my son to fly to Darwin. My trips to Europe have been great, catching up with family and old friends in England, Scotland, France, and Spain, we even spent a weekend in Dublin where my youngest son and his girlfriend joined us as they were living in London at the time. I've always had medical insurance, which was important to me; thankfully, I never had to use it. I mentioned learning a language, so I'm studying French (yet again), and you could say "but you live with a Frenchman, doesn't that make it easier?" and my response to that is "is it a good idea to have your spouse teach you to drive?"

Becoming a painter has been a tremendous gift that lung cancer gave me.....the time not spent working to pursue my new passion. I've taken lessons in Watercolour and Acrylics, in person and via Zoom. From my local instructor and Zoom classes from England and Berlin. Many of you may not know what Zentangle is, it's a way to relax and use repetitive pen strokes to create unique designs. I started lessons though the leisure guide in 2015 and then started meeting with a group of ladies for Tea and Tangle monthly, we still meet monthly via Zoom.

I also volunteer at Cancer Care being part of the Patient Advisory group, and had had the opportunity to participate in person and online as well as contribute to the Lung Cancer Support Group. I've also done local advocacy work, with an article in the Winnipeg Free Press and an interview with CBC radio week end show, both timed to bring awareness to Lung Cancer Month which is in November.

What do I see for my future? Lots of hope that I remain as well as I am for as long as possible and continue with everything that makes my life meaningful.



Resources for Patients and Families living with lung cancer:

CancerCare Manitoba Patient and Family Resource Center:

Rm ON1016—675 McDermot Ave
Kathleen Helgason 204-787-4367

Psychosocial Oncology Department:

204-787-2109

Psychosocial Oncology Clinician (Counsellor/Social Worker):

Mike Edwards 204-787-1325

CCMB Patient Representative (Patient advocacy):

Heather Purvis 204-787-2065

CancerCare Nutrition Services:

204-787-2109

Lung Cancer Canada:

<https://www.lungcancercanada.ca/>

CancerChat Canada (Canadian Online Support Groups):

<https://cancerchat.desouzainstitute.com/>

Facebook:

Canadian Lung Cancer Advocacy - Breathe Hope
https://m.facebook.com/groups/520424908293279/?ref=group_browse

Palliative Care Program Info Phone Line:

204-237-2400



High Calorie Smoothie

by Jennifer Levins

1 cup of whole milk

1 scoop of protein powder*

1 tbsp of almond flour

1 tbsp of avocado oil or any vegetable oil

1 tbsp of honey or maple syrup

¼ cup of strawberries (optional or fruit of your choice)

1 cup of ice cubes (optional)

In a blender, combine all ingredients

Blend until smooth

*Protein powder comes in vanilla, chocolate and strawberry flavours. Choose your flavour and a complementary fruit for a variety of smoothies

Nutritional breakdown:

Total Calories 496

Net Carbs 31g; Protein 33g; Fat 26g

News & Events

Manitoba

Lung Cancer Support Group, Facilitated by Psychosocial Oncology Clinician Mike Edwards; Occurs the 4th Tuesday of every month, 10:30-12:00, no registration required; During COVID meetings take place over ZOOM, please email Mike if you wish to attend (medwards6@cancarecare.mb.ca), or enter ZOOM Meeting ID: 819 0992 0588 Passcode: 647705

Challenge for Life Fundraiser for CancerCare Manitoba, August 5-17 learn more at: <https://www.cancercare.mb.ca/home/>

Canada

“What’s New from ASCO 2021”, Moderated by: Dr. Paul Wheatley-rice, Featuring: Dr David R Gandara and Dr. Stephanie Snow, at 2:00 PM – 3:00 PM EDT, Thursday July 8, 2021. Register Now! <https://www.lungcancercanada.ca/Get-Involved/Events/What-s-New-From-American-Society-for-Clinical-Onc.aspx>

“Lung Cancer Canada Name New President”, <https://www.lungcancercanada.ca/News/News-Updates/Lung-Cancer-Canada-Names-New-President.aspx>

International

IASLC 2021 World Conferences on Lung Cancer, September 8-14, 2021, Worldwide Virtual Event, register required, <https://wclc2021.iaslc.org/>

III Annual Congress Liquid Biopsy, Virtual Conference, October 22, 2021, Register required, <https://www.islbcongress.org/>

“Stronger Together”, ALK Summit 2021, July 31-August 1, 2021, Registration required <https://www.alkpositive.org/>

My lung cancer story

by Don Levins

Let me start by saying this is not a cancer survivor story. When you are diagnosed with a terminal illness, you don't come out of it alive. You still have hopes and dreams but it's more about learning how to live while you are dying.

At 59 yrs. of age, my world was shaken when I went from being an active, healthy, non- smoker (had not smoked in over 25yrs) to a diagnosis of stage 4-lung cancer. I had gone to my GP for a routine exam. After getting a clean bill of health, I casually mentioned a nagging cough. After listening to my chest he sent me for a chest x-ray. After two courses of antibiotics for pneumonia and still having a cough a second chest x-ray was ordered. The x-ray showed what looked to be a mass in my left lung. A CT scan confirmed I had a large nodule in my left lung, along with metastasis to my lymph nodes and my right pelvis. I was referred to a thoracic surgeon for a biopsy and my fight for survival began.

Oct 1st, 2018 was the first time my wife and I walked into CancerCare Manitoba. Having never been exposed to cancer before, we had no idea what to expect. With eyes wide open, we saw people of all shapes and sizes, young and old. Seeing young children there was so gut wrenching, what did they do to deserve this? Understanding that cancer had no boundaries did not make it any easier. After nervously waiting to meet my oncologist, we were immediately put at ease when he walked in. He was casually dressed, unshaven and knew how to cut to the chase. Despite the news he delivered, we liked him immediately and knew we had an ally. He confirmed the diagnosis of stage 4-lung cancer, but explained further that I had small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC). Trying my best to keep it light, my wife and I joked that I was an over achiever. Not only did I have lung cancer but my biopsy revealed I had two types of lung cancer. The initial prognosis given was 6 months to live if I did not do any treatment but 1 year with treatment.

During the initial few months of being shell shocked, I knew that I had to get my mind under control. I had to remain positive, keep a brave face for my wife, daughter and grandkids. I was preparing for the fight of my life. I vowed from day one that I would put my life in the hands of the incredible doctors at Health Science Centre (HSC) and CancerCare Manitoba and not to second guess them or rely on 'Dr. Google' for answers. I put my priorities in order, I wanted to spend as much time with my family and not just dwell that this would be the last birthday or holiday that we would spend together. There were certain documents that I had to ensure were complete and updated: wills; power of attorney; and medical directive along with meetings with insurance companies and financial advisors. My wife and I had many difficult conversations but I had to ensure all the I's were dotted and T's were crossed.

My treatment plan began with chemo (Cisplatin and Etoposide) to attack the most aggressive cancer first - the SCLC. After 4 rounds there was only a minimal result. In early 2019, I was transitioned to immunotherapy (Pembrolizumab) to determine if it was the NSCLC being persistent. Let me add that I did lose my hair with chemo; in fact I looked like I had a body wax. Much to my wife's chagrin, my nose and ear hair remained intact. When the immunotherapy did not show a response, my oncologist determined a second biopsy was necessary. Complications from this biopsy resulted in a 10-day hospital stay for a pneumothorax and collapsed lung. While waiting for the biopsy results, I began a third line of treatment. After one round of a new chemo (Pemetrexed), the biopsy results revealed the tumour cells had tested positive for an EGFR mutation. This meant my new treatment plan was to be one pill a day for as long as it worked. This new "find" would give me an additional year. We felt like we had won the lottery.

Throughout the rest of 2019, managing the side effect was challenging as my treatment changed from Afatinib to Getfitnib and eventually settled on Osimertinib. We continued to keep life as normal as possible, spending summer weekends at our boat and having Sunday dinners with our daughter and her family. We found ourselves living in 3-month intervals- the time between CT and MRI scans. Things appeared stable and in the fall of 2019, my wife and I enjoyed a bucket list trip to the Maritimes.

Perfectly timed with the arrival of COVID and lockdowns in 2020, things were starting to change. Coincidentally the symptoms of lung cancer mimic the symptoms of COVID. Each time I had a new symptom, a COVID test became a mandatory part of the treatment protocol.

I saw my cancer support team grow from just having my Oncologist, 'the Chemo Guy' but to now include a Bone Guy, a Brain Guy, a Breathing Guy and a Heart Guy. Each of these specialists worked closely with my oncologist. I have since received Gamma Knife surgery for brain mets and 3 shots of radiation for different bone mets. The year 2020 also brought challenges with several hospital stays for blood clots, radiation pneumonitis, pleural effusions and pericardial effusions, all side effects of either the cancer itself or my treatments. A third biopsy revealed that only NSCLC was now visible.

As of the fall of 2020, I transitioned to full time oxygen therapy. Scan results in December showed additional progression whereby a new line of chemo (Carboplatin and Pemetrexed) was ordered; this was now my 7th line of treatment. After completing 4 rounds, I lost my Dad after his own short battle with cancer. This took a huge emotional toll. I endured 1 more round of just Pemetrexed before I decided I had enough. With bad days exceeding my good days, on May 4 of this year, my 62nd birthday, I decided to stop my chemotherapy and decided to fight for better days.

Throughout this journey, our circle of family and friends has played a large role in my ability to enjoy every new day. I have learned that everyone accepts the news of terminal cancer differently; some friends are curious and ask questions while others seem to fade into the background and appear to be afraid to talk about it. I have one friend with a similar diagnosis but a different cancer. She has been a source of strength through my journey as I attempt to mimic her courage.

I am truly fortunate to have my wife Jennifer supporting me through this process. This is not a journey you want to venture on your own. She is my record keeper, my scheduler, my hands and feet and truly my best advocate. We still refer to pill time as “nag o’clock’ but I can’t thank her enough.

We feel extremely fortunate to have met some remarkable lung cancer patients in our monthly lung cancer support calls. I never thought I was the kind of person to rely on a support group, but we look forward to our monthly zoom calls. This is an amazing group of individuals sharing this crazy journey. The calls are always enjoyable and usually good for a few laughs. I know how odd that sounds.

Today, I am part of the palliative care team for comfort care. I have nurses that visit my home regularly, a bed in my living room and an electric wheelchair for mobility and portable oxygen. I take a plethora of opioids that help manage my pain and assist my breathing. I continue to take life one day at a time even though some days are more challenging than others. I get to decide how to spend my precious time. Whether it is time with our daughter, son-in-law and two grandkids or with my wife and our friends on weekends at our boat or simply coffee in the backyard. I get to call the shots. As I stated at the beginning of this story, I will not be the survivor in this cancer story, my wife and daughter will be.

Don passed away on July 2 with his wife and daughter by his side

