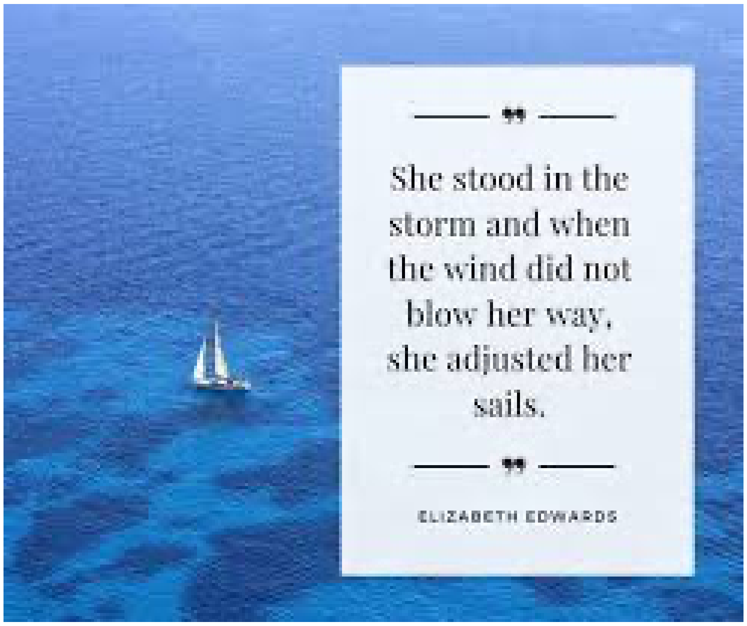
BC Cancer Foundation Speech April 2021



She stood in the storm and when the wind did not blow her way, she adjusted her sails.

ELIZABETH EDWARDS

I think of myself as a lucky person.

But even being a lucky person, nothing prepares you for the words:

You have cancer.

Like most cancer journey’s mine began with a lump, then two and then three.

Thirty five years ago it was next to unheard of for children or teenagers to get cancer. So as a teenager, my doctor didn’t think much of it and put it down to swollen lymph glands in my neck due to the multiple colds I had been experiencing. However, when the lumps didn’t subside my doctor sent me to an oncologist. What was that?

When X-rays showed probable Hodgkin's Lymphoma, which a biopsy confirmed, I was scheduled for a staging laparotomy to remove my spleen and determine the extent of the cancer. Then the rollercoaster of test and procedures began: endless blood tests, bone marrow biopsies, a liver biopsy, ECG's, lymphangiograms, body casting for radiation, mouth guards for fluoride treatment, multiple vaccinations, more X-rays, tattooing for radiation placement, breast exams, pelvic exams and of course, the hours and hours and hours in waiting rooms.

The staging laparotomy scar is still the most impressive of my scar collection. A whopping 10 inches right down the middle of my abdomen. No bikinis for me!

The course of treatment for Hodgkin's Lymphoma in 1987 was five weeks of mantle field radiation…a treatment rarely used anymore due to the toxicity and probability of secondary cancers and other morbidities. People will say I am a cancer survivor but I say I am a radiation survivor.

The experience of this type of radiation was excruciating. I felt an immediate tightness in my chest, heartburn and debilitating fatigue. The nausea and vomiting overtook me and after going from 135 lbs to 107 lbs since my diagnosis it was time for the heavy weight of prescription anti-nausea drugs—marijuana. At $16 a pill it numbed the nausea and allowed me to sleep and eat baby food which was the only thing that could pass over the radiation sores in my mouth. I lost my sense of taste, lost my saliva and I lost my hair. The mind numbing fatigue kept me in bed most of the day unable to read or even watch TV. Even the calming effects of music lost its appeal. The heartburn was unremitting and the radiation burn that covered portions of my upper body was thick and tough.

What made radiation so difficult was that after every treatment I felt worse. So as my friends headed back to university, I headed back to bed.

Cancer is frightening and lonely. Despair is as big a hurdle as malignancies. Loss is an inevitable part of living and cancer has its losses – hair, hope, dignity.

I love quotes and my quote during cancer was by Albert Camus:
In the depths of winter, I found within me an invincible summer.

Because cancer also has its gains. Cancer gave me the reality check that control is an illusion. Life is unpredictable so be adaptable and you really can have the best life appreciating the simple and the ordinary.

Cancer allowed me at a young age to manage my assumptions and expectations about life. People who know me well say I am a person who lives life intentionally. And I can say that cancer gave me that.

However, cancer can also be the gift that keep on giving.

After all my treatment I was told I was in remission. But I was also told that the lifesaving treatment I had would likely have some late effects in my life down the road.

A challenge as big as cancer was the infertility that followed. The difficulty getting pregnant came from some of the rearranging of organs that came with the laparotomy which was ultimately reversed. The multiple miscarriages came from a blood disorder, likely connected to the Hodgkin's Lymphoma which is a blood cancer. With the help of shots of Heparin into my abdomen to thin my blood every 12 hours for 11 months I was able to sustain a pregnancy. All in all I have been pregnant 8 times resulting in 2 of the most amazing kids you would ever want to meet – definitely worth the wait and the heart ache of 6 pregnancy losses.

After Mantle Field Radiation for Hodgkin's Lymphoma the most common late effects are:

Breast Cancer
Heart Disease

Lung Cancer
Leukemia
Thyroid Cancer
Skin Cancer

In the last several years I have experienced many of the predicted late effects.

I have had **20 – 25 Basal and Squamous Cell Carcinomas** removed from the area I was radiated.

I had an **early stage breast cancer** which was removed by having a lumpectomy.

I have had **my thyroid removed** due to a developing goiter predicted to become cancerous.

I have had my **gall bladder removed** due to multiple gall stones which can be common after radiation therapy.

I have had **exploratory kidney surgery** when a spot was discovered on my left kidney close to where my spleen used to be.

I needed a routine **root canal done** but due to the concern of bone necrosis of my radiated jaw I had the tooth pulled by dentists at the BC Cancer Agency.

I have a leaky **mitral valve** in my heart due to radiation which may need to be repaired or replaced someday.

I was recently diagnosed with **Sleep Apnea** most likely due to damage in my throat from the radiation.

And I struggle with **chronic muscle tightness** in my neck and **finger numbness** due to the muscle damage in my neck and torso.

I have **Irritable Bowel Syndrome** due to the damage caused to my stomach and intestines from radiation.

The good news is that Menopause has been a breeze!

It is a lot to ask a GP to be current on the late effects of a treatment no longer given when she does not have the authority to order many of the test I require.

I am a FULL TIME JOB! I spent MANY MANY hours scouring the internet trying to keep current on what new late effect was being discovered and what I should be on the lookout for.

For me I always felt I could handle a new cancer diagnosis but not one I knew I could have prevented. I learned early on that I needed to be very proactive in my health. Needless to say it was VERY stressful trying to read medical articles in The Lancet and keeping my doctor informed of what proactive measures should be taken.

One day I learned that a new clinic called The LEAF Clinic was opening in Vancouver. The BC Cancer Foundation was instrumental in raising funds for the LEAF CLINIC's establishment. LEAF stands for Late Effect, Assessment and Follow-Up. It is available to adults of childhood cancer needing specialized care to manage all the joys of post cancer treatment effects. I have been assigned my own BC Cancer Agency radiology-oncologist, Dr. Karen Goddard. She is the most lovely, caring and thorough doctor. I cannot tell you how grateful I am for her and the LEAF Clinic.

I meet with Dr. Goddard in-person once a year where we review my health in light of my cancer treatment. I am frequently being sent for:

Echo cardiograms
ECG Tests
Cardiac Stress Tests
Carotid Artery Ultrasounds

Breast MRI
Breast Mammograms
Breast Ultrasounds
Colonoscopies
Endoscopes

All of which I have needed. Just this month I had a suspicious area on a mammogram and I was given the royal treatment. In one afternoon I had 9 mammograms, 4 needle biopsies, a breast MRI and a partridge in a pear tree.

One of the most difficult parts of cancer is all the waiting. Waiting for tests, Waiting for results. Waiting in doctor's offices. With what should have been a 5-7 business day wait, Dr. Goddard called me 2 days later to let me know that my test results were clear. She understands how hard waiting can be.

This all sounds very stressful but actually it has brought me such great peace knowing that someone knowledgeable is paying very close attention to my health and I can go about the business of living life, enjoying my family and walking my dog.

My husband once jokingly said that when bodies were being handed out I got a LEMON. I disagree….I got a HUMMER! This old body had been able to tackle everything thrown its way and always in 4 wheel drive! The joke in my family is that I am a living experiment on how many organs a person can live without!

I started today by saying that I think of myself as a lucky person. After hearing my story you may challenge that thought. But I am. I am SO lucky to have been born in a time in history where survival was an easy 80% when only 30 years earlier it was a certain death. I am SO lucky to live in a city with World Class Cancer Research and care. I am SO lucky to have had exceptional doctors and nurses. I am SO lucky to have been able to have 2 of my own children, naturally with only a little blood thinner for help. I am so lucky to actually live in relatively good health, pain free. I am SO lucky to have the LEAF CLINIC for support to I can surf the internet for new TikToks and youtube videos and not spend my time researching cancer. I am lucky to work as a life coach taking all that I have gone through to help others find light in dark places.

And I am lucky that all of you work for an organization that has helped make so much of it possible. I know I speak for the many cancer survivors out there who never get to see your faces and are able to thank you in person. I am LIVING PROOF of the impact you all have. I want to end by sharing my favourite quote by Mother Teresa.

We cannot all do GREAT things but we can all do SMALL things with GREAT LOVE.

The BC Cancer Foundation does GREAT things because all of you come to work every day to do small things with GREAT LOVE.

Thank you.