



Spring 2015

Graeme's Story – In His Own Words



At the Ottawa Evening of Hope, we had the pleasure of meeting Graeme Godet, a person living, truly living as you will see from his story, with stage IV lung cancer. He was enthusing about the opportunity he had to speak to a group of medical students. He kindly shared his talk with us. Our original intention was to edit it into one article. However, his voice and spirit comes through best in his own words so we decided to share it as he told it. Over the next two newsletters, you will be hearing Graeme's story, complete, unabridged – in his own words.

And now Graeme...

It is important to me that I can tell you about my journey. It is unique, but I hope informative. I structured my talk around some questions I thought you might be interested in.

1. What was my diagnosis?
2. Chemo or not – the first big decision?
3. What was chemo like?
4. How did I move on with my life?
5. Dr Paul and the Village. (Next issue)
6. Have you tried alternative therapies? (Next issue)
7. What do you worry about most? (Next issue)

What was my diagnosis? In the spring of 2010, I went to Anganguero, Mexico with my wife and five other friends to see where the Monarch butterflies spend the winter. It is at a higher altitude and I had some shortness of breath as we climbed up to see the butterflies' habitat.

When I returned home I started running in ball hockey again, but still found my breath to be short. I had pneumonia before so I went to my doctor and she ordered a chest x-ray. She called me the next day to tell me that she had arranged a number of tests for me, including a biopsy. She had seen a mark on my right lung that hadn't been there two years ago.

The diagnosis was non-small cell lung cancer, stage IV. The radiologist who gave me my diagnosis explained that it was at the last stage of cancer because it had metastasized and was in my lymph system. He explained metastasis by saying "my cancer was just looking for a new home". The receptionist wished me good luck as I left the office completely stunned.

That was the worst weekend of my life. I thought I was going to die right away. I was afraid. I am an extrovert and glass half full guy but I was floundering; I had no idea how to deal with what felt like a death sentence.

Chemo or not? First big decision. When I was first diagnosed, Dr Paul Wheatley-Price and I fully discussed treatment options. Without chemo, the average life expectancy for my kind of cancer is 12 months and an average of 12 to 18 months with chemo. One option, since my cancer is slow growing, was to "watch and wait". I was not keen on chemotherapy given the short life expectancy, and believing the cure might be worse than the cause, I decided not to take any chemo to avoid suffering the side effects.

Several days later I met with a friend of mine who is a doctor and he asked me quite pointedly, "What are you waiting for?". There was only one answer of course. I was waiting for the cancer to progress or metastasis before taking treatment. My friend pointed out that progression was inevitable and depending on how it progressed, it might be too late to start any kind of treatment. This hit me very hard and I phoned my oncologist the next day and started chemo several weeks later. That was 4.5 years ago.

What was chemo like? I would just like to share my experience with chemotherapies and their side effects. I have had six different chemotherapy treatments (carboplatin, taxol, cediranib, pemetrexed, tarceva and the current PD-L1 clinical trial).

Every one came with a list of awful possible side effects as long as my arm and included everything but a plague of locusts. This is done, of course, in the interests of full disclosure to the patient just in case. The side effects with all of my treatments have generally been mild and my quality of life has not been greatly affected; the ones that have been with me the longest are tiredness and mild nausea (which is greatly relieved by other medications). I had hair loss with only one treatment.

I have a pleurex catheter in my abdomen to drain my acites; I have a home care nurse who comes three days a week to do this although I drained myself in Ireland. I have a nephrostomy tube in my right kidney due to a tumour pressing on my right urethra.

How did I move on? I went and saw my wife's aunt who is a six year pancreatic cancer survivor. She gave me the best advice I ever got and still follow to this day. She said, "Ask as many questions as you want, find out as much as you can, understand your cancer and your treatments, then push it all aside and live your life."

"Don't let cancer become you", was the message. It is just another very important thing to take into consideration in your life but it is not the only consideration.

Another thing I learned quickly was "Don't look or act sick". The only clue people have who are just as scared as you are is to react to how you are and behave. I made it a point not to "give up or give in"; I make a big effort to continue to do all of the things that I have always done, including golf and playing goalie in ball hockey.

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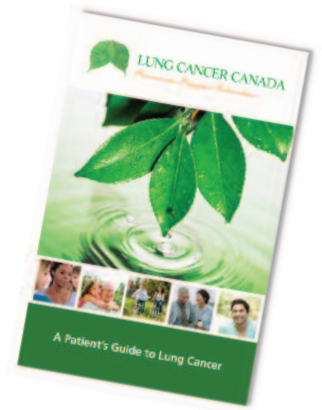
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Patient Resources

A Patient's Guide to Lung Cancer is a Lung Cancer Canada publication designed to meet the educational needs of lung cancer patients and their families.

Available in English and French.



Lung Cancer Canada Info Sheets

Available in English and French.

- Questions to Ask Your Oncologist When You've Been Diagnosed with Lung Cancer
- Lung Cancer and the Use of Oxygen Therapy
- How to Prepare for Lung Cancer Surgery When You Smoke
- Nutrition and Lung Cancer
- For Patients and Caregivers: Coping and Emotional Support
- Thoracic Surgery for Symptom Control
- Managing Daily Activities: Energy Conservation and Work Efficiency

Managing Shortness of Breath

Produced by Lorraine Martelli, MN, RN(EC),
Nurse Practitioner Lung DST,
Juravinski Cancer Program

The CD consists of a five part series:

1. Introduction/Learning Abdominal Breathing
2. Managing an Acute Episode of Shortness of Breath
3. Sitting to Standing
4. Climbing Stairs
5. Respiratory Muscle Exercises

Check out the video series link on our homepage.

Call or email Lung Cancer Canada to order material.

Materials and resources are free
for individual patients and caregivers.

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Connect with us    from our home page:

www.lungcancercanada.ca

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Lung Cancer Canada wishes to acknowledge
our community partners:





Celebrating Hope

In presenting the first newsletter of 2015, Lung Cancer Canada is full of gratitude and thankfulness for all the support that has been given to us over the past year. We would like to express our deepest appreciation to all those who helped to further our mission of lung cancer awareness, support, education, and importantly, hope. Join us for a quick trip down memory lane as we review some of the events that happened in the second half of 2014.

Convoy for Hope

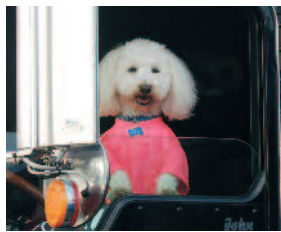
On September 6, 2014 the Convoy for Hope Atlantic travelled more than 80 km from Salisbury, NB to Aulac, NB, and raised \$5,000 for the fight against lung cancer.



Thank you to the Convoy for Hope team!

Founded in 2008, Convoy for Hope works to raise money to help fight lung, breast, prostate, and colon cancers. The Convoy of Hope 2015 is scheduled for Saturday, September 19, 2015. Plans are well underway, and a raffle for a \$13,000 custom Jeramand Cottage has already been opened. Tickets are \$20 and can be obtained by calling 506-853-5238.

Lung Cancer Canada would like to express a sincere thank you to all of the donors and organizers for helping to raise funds for lung cancer.



Is this one of the drivers?

Scotiabank Toronto Waterfront Marathon



*Runners and LCC supporters
Bret & Yolande Northrup*

On October 19, 2014 Lung Cancer Canada once again participated in the Scotiabank Toronto Waterfront Marathon. There were over 180 official charities in the Charity Challenge, and we were happy to once again be a part of such a great group. We are excited to announce that runners raised over \$36,000 in support of Lung Cancer Canada!

Lung Cancer Canada is a small organization but the large hearts of friends and supporters like you make us stronger and have increased our profile. It is because of you that Lung Cancer Canada is able to participate in such events – raising awareness and much needed funds in our fight against lung cancer. Lung Cancer Canada would

like to thank all of our supporters – runners, walkers, water station volunteers and pledge seekers. Everybody braved a very early start, cold temperatures, gusty winds and a lot of Gatorade cups, all for a great cause and we very much appreciate it.

Evening of Hope

On November 13, 2014, the lung cancer community gathered for An Evening of Hope at the Toronto Reference Library. This night celebrated hope, survivorship, and scientific progress in the fight against Canada's most common cancer.

The evening's program highlighted the many faces of lung cancer. Jonathon Brodsky, ever supportive son to Roz Brodsky provided background piano music during the cocktail hour. Lung cancer survivor Casey Cosgrove emceed the event and used humour to remind us of the impact of lung cancer on families. Anne Marie Cerato and Joe Gonçalves also took turns sharing their stories, praising the great new advances in lung cancer treatment as the reason they are able to continue living full and exciting lives. Joseph Neale's musical performance reminded us that lung cancer does not discriminate, but with heart and determination it is possible to sing, even with one lung.

The return of the popular Wall of Wine and Silent Auction helped raise funds for Lung Cancer Canada initiatives. It was an evening dedicated to increasing lung cancer awareness. Even the CN Tower and Niagara Falls were lit green to help raise awareness.



Volunteers made this night possible! Volunteers Tom Tian and Mike Sung running the LCC info booth.

Our thanks go out to everyone who attended, our donors, all of our speakers and performers, and all of the volunteers who helped put the event together. We are so fortunate to be part of such a supportive and engaged community! Mark your calendars for the 2015 Toronto Evening of Hope, which is scheduled for Thursday, November 12, 2015.

The activities then moved up to the nation's capital. Ottawa's Evening of Hope was held on Thursday, November 20, 2014. Over 350 guests attended the cocktail reception, held at the beautiful Shaw Centre. In addition to enjoying great food, drinks and entertainment, guests had the opportunity to take home some amazing prizes with both a Silent Auction and a Tree of Hope Raffle.

An Evening of Hope Ottawa would like to thank the generous supporters who donated prizes, the talented musicians and the volunteers, as well the guests for their generosity and support. A shout-out as well to the MC, Matt Skube of CTV News, and all of the speakers. A special thank you to Chris Draft, former NFL linebacker and lung cancer activist, and Mark Deschamps, a lung cancer patient, and his wife Natalie for sharing their stories. A big thank you to the sponsors: All Seniors Care Living Centres; Medigas Praxair Canada Inc.; Systemscope; Cattail Creek Family Estate Winery; Beau's All Natural Brewing Company; Perth Brewery; and Turtle Island Brewing Company.

The inaugural event was held November 2013 in support of Philip Clarke's advocacy work. Louise Bowles, a friend and former colleague of Philip, is the driving force behind the event fulfilling a promise she made to him to continue to raise funds for and awareness of lung cancer. Plans are already underway for the third annual event which will be held on Thursday, November 19, 2015. 🌿



Remembering a Lung Cancer Champion

Social Attitudes Are Resilient and Change Will Take Patience

Marla Rotenberg, with the help of Emily, Lowell, Anne, Warren and Harrison



Jaye Kornblum-Rea's passing in January 2015 marked a great loss for so many: mother, wife, sister, friend, mentor and last, but certainly not least, lung cancer advocate. Her reflection on her Bronchioloalveolar cancer (BAC) diagnosis in 2005 revealed the challenge of such a life changing moment, "It was a day of disbelief, fear, tears and friendship. Love poured out all around me." She rose to the challenge, determined to learn everything she could. Having spent decades in Public Relations, she quickly recognized the misconceptions surrounding lung cancer, the importance of combatting stigma and critical need for funding. This became Jaye's mission.

Writing "social attitudes are resilient and change will take patience," Jaye did her best to build momentum to Lung Cancer Canada's mission of increasing awareness, education and support. In conversations with friends, colleagues and clients, she didn't hesitate to bring lung cancer into the discussion with grace and humour.

Jaye was blessed and thankful to have the love and support of many good friends and family. Sister-in-law Emily writes, "Along with her family, friends and a caring network of medical professionals, with fierce determination, Jaye took on her cancer."


Still a little boy in 2005, Jaye's son Harrison was her pride and joy. Focusing on his happiness fueled Jaye to stay positive and forward thinking. Now flourishing in second year university, Harrison is, as Jaye

said herself, "growing up to be one amazing young man." His caring demeanor at her bedside and composure since her passing have revealed one remarkably mature individual.

Jaye, a cancer survivor for many years had surgeries in 2005, 2009 and 2014. She felt "privileged to have two successful operations performed by Dr Gail Darling" and "extremely lucky to have Dr Natasha Leighl" as her oncologist. Jaye would want to thank them again for all they did for her and their work with the Lung Cancer Canada community.

From diagnosis until just shortly before passing, Jaye continued to work in PR with a talent for corralling a team, capitalizing on assets and strengthening weaknesses. Jaye's brother Warren noted at her funeral that so many whose careers were touched by Jaye had expressed gratitude for the confidence she displayed in them. When it was time to slow down, Jaye volunteered and discovered how much she loved to teach.

Jaye's last year was one of renewal and forgiveness. She traveled to Canyon Ranch just before surgery to get ready mentally and emotionally. She took trips to Montreal to visit Harrison. Following several chemotherapy treatments, two arterial blood clots were found in her leg and amputation was not an option. Jaye understood this life-changing event, gathering family and the closest of friends to say her goodbyes and I love you's before her passing in January.

Jaye was an optimist, a fighter, a smart and wonderful woman. A loving, generous and loyal friend, she is missed by many, every day. Jaye's friends and family will carry on with her mission to educate and inform on behalf of Lung Cancer Canada. 

Talking About Your Cancer

Excerpted from Lung Cancer Canada's "A Patient's Guide to Lung Cancer"

Being a new patient and getting introduced to the many healthcare providers who may make up your team can be overwhelming. Feelings of fear and anxiety may make it hard to remember and understand what the doctor or nurse says during appointments. Open honest two-way communication with your healthcare team is very important. Sharing and letting your team know about relevant matters in your life will help them understand the unique way in which lung cancer affects you. That information will allow them to suggest ways to help you manage your lung cancer.

Here are some tips to help you establish open communication with your healthcare team.

Keep a list – Keep a list of the members of your cancer care team, who they are and their contact information

Speak up – If you do not understand something your care provider tells you, say so. Try to be specific about what you need, such as a more detailed explanation or less medical jargon. Check to make sure you have understood correctly, for example: "What I hear is that this type of cancer usually responds better to surgery than chemotherapy or radiation. Am I understanding this correctly?"

Put it on paper – Jot down the questions you want to ask at your next appointment and take the list with you. Take notes to help you remember what the doctor or nurse said. Bring along a friend or family member who can make notes and also interpret what you were told.



Record it – Some people find it useful to tape record their conversations with healthcare providers. They replay the tape later so they are clear about the topics discussed. If you choose to do this, always inform the provider before starting to record.

Share – Share with your healthcare team who the important people are in your life and to whom they may or may not communicate. Tell them if you want to share detailed information on all aspects of your medical situation, or if you prefer general information only.





There Is No Single Face of Lung Cancer – It is a Disease That Impacts Everyone

Lung Cancer Canada Launches a Report that Spotlights the #1 Killer in Canada

Lung Cancer Realities

- More Canadian women die from lung cancer than any other cancer.¹
- While lung cancer incidence and mortality rates have been declining for Canadian men over the past 30 years, they have steadily risen in Canadian women during the same time period.²
- A national screening program could save 1,200 lives each year, according to experts.³
- The survival rate for patients with lung cancer is low, but can be even lower depending on where you live.⁴
- Lung cancer only receives 7 percent of cancer-specific government research funding, despite accounting for 27 per cent of cancer deaths.⁵



Natalie Deschamps and her family. Natalie's husband Mark is living with lung cancer.

the patient community. The key priorities cover the importance of screening, stigma, the incredible toll on the Canadian population, the status of current research, and access to diagnosis and treatment.

"Lung cancer screening will save lives and save money - we predict 1,200 Canadian lives can be saved every year," says Dr Natasha Leighl, medical oncologist and Lung Cancer Canada President. "Treating people when the cancer has advanced to an incurable stage costs us all more. Not only is it better for the patient to detect and cure lung cancer early, it ultimately saves the Canadian taxpayer about \$10,000 per case."⁶

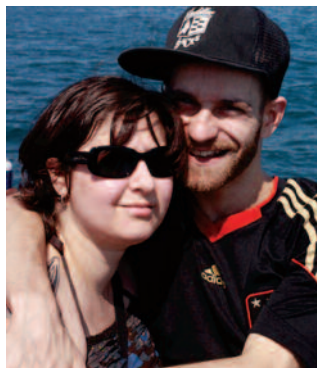
Comprehensive screening programs that detect the disease early and improve the chances of survival are lacking across the country. The increased survival rates seen in breast and colon cancers are from national screening programs. By contrast, almost half (48 percent) of lung cancer diagnoses are made when the cancer is at its most advanced and incurable stage, dramatically reducing the chance for survival.⁷

There are some shocking statistics that put the impact of the disease into context. Lung cancer remains the number one cause of cancer death in the country and is responsible for one out of every four cancer deaths.⁸ Equally disturbing is that every twenty-seven minutes, a Canadian dies from lung cancer. Numbers and data can create the scope, but they simply cannot define the human impact of the disease.

According to a Lung Cancer Canada survey, more than one in five Canadians feels less sympathy for people with lung cancer than those with other cancers because of its link to smoking. The reality is that for those diagnosed with lung cancer, more than 15 percent are lifelong non-smokers and over 35 per cent are ex-smokers, who in many cases quit years before being diagnosed.

"I still find that I have to justify my husband's disease to others. He was healthy, athletic and never smoked. He was still running regularly when he went to the doctor for a spot at the back of his eye. It turned out to be a secondary tumour from his lung cancer. That was three years ago. He was 40 and our girls were 5 and 7," says Natalie Deschamps.

Research also shows that non-smoking women are significantly more likely to be diagnosed with lung cancer than non-smoking men.⁹ In 2014 alone, 9,700 Canadian women will die from lung cancer. This is more than the 8,050 who will die of all other women's cancers combined (breast, ovary, uterus and cervix). While Canadians are very aware of breast cancer, they don't realize that almost double the number of women die from lung cancer in Canada every year.¹⁰



Anne Marie Cerato, fiancée, daughter and sister who is fighting lung cancer (diagnosed at age 30), Toronto, Ontario

drugs or modern surgical and radiotherapy technologies. The reality that there are such stark differences across different provinces should be alarming to Canadians – this is simply unacceptable and something we need to change."

"We're very lucky with the overall healthcare system that we have. The problem, however, is that not everyone has as prompt or complete access as they should to the services and treatments they need. I had to advocate strongly for myself to ensure I got what I needed. Not everyone is able to do that, so they miss out. That's not fair," says Jessica Miller a 77 year-old lung cancer patient from Montreal.



Ruth Wasylenko, priest who is fighting lung cancer, Edmonton, Alberta

The report also notes that there are provincial differences in access to diagnosis, treatment, and survival outcomes. One-year survival rates vary across the country. Some of these differences may be related to access and resources.

Dr Paul Wheatley-Price, medical oncologist and Chair of Lung Cancer Canada's Medical Advisory Committee comments, "Every Canadian should have access to the same level of care, no matter where you live. This means the same access to gold standard therapies, including life-saving



You Can Help Make A Difference

Graeme's Story ...Continued from page 1

For example, there was a bit of a story that I gather went around the cancer clinic about a guy that went out and shot 18 holes of golf the same day after his four hour IV treatment of carboplatin, taxol, and a clinical trial drug called cediranib. I found this out from a friend who also has cancer. He told me he had heard about this guy. I laughed and said "Danny, that was me".

Fortunately I have always had good health throughout my cancer which has made "don't act sick / look sick" a lot easier. Dr Wheatley-Price told me before my first chemo that I was the healthiest person he had ever given chemo to; I also believe that I have a strong immune system which has kept me away from colds, the flu and other illnesses.

So cancer for me is like writing a book. I know the beginning and I know how the story will end... my job is to write the chapters in

between and make it the longest book I possibly can. I once told Paul that given there is a date out there in the future when I will die, I realized that the longer I live, the less time I have to live.


And that is how I learned to live with cancer. Keep my life as normal as possible; keep on doing the same day-to-day things, keep on living the life the way we had built it over 30 years together. Why change it now?

Distractions are also important. I volunteer at Vintage Wings, and I am always planning a couple of trips for the next six months; it keeps me positive and distracts me from thinking about cancer... right now it is Disney World with my daughter and grandkids, Puerto Vallarta in January, Punta Cana in February, Palm Springs in March and Florida in April. A month ago I got back from an 11 day golf trip to Ireland.

See the next issue to hear more of Graeme's story. 

There is No Single Face of Lung Cancer ...Continued from page 5

Every day, the medical community gains new perspectives on this devastating disease and progress continues to be made as understanding of the disease increases and new tests and treatments are developed. However, despite the terrible toll on life from lung cancer, it receives much less attention than other cancers when it comes to research funding. Less than one percent of private cancer donations goes to lung cancer. Ultimately it is research that will improve outcomes and yield more choices for patients at all stages of diagnosis and treatment.

The lung cancer community will continue to create an environment that will see improvements in all five areas included in the report - the national patient voice for the disease strongly encourages all Canadians to do their part to help. The report is available in both English and French. To view the full report, please www.lungcancercanada.ca. Copies can be requested by emailing info@lungcancercanada.ca. 

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8. Canadian Cancer Statistics, 2014
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