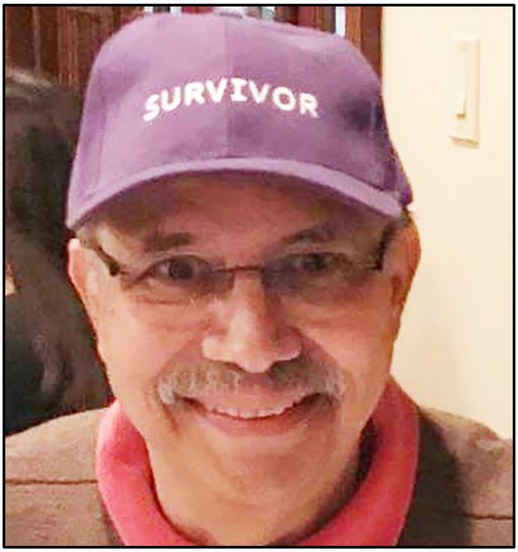
Special Lustgarten Foundation Edition

Surviving Cancer and Embracing Life

My Personal Journey

by Joel R. Evans



Note: This is a special Lustgarten Foundation edition of the book, updated and with new chapters.

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Thanks for your cooperation.

Foreword from the Lustgarten Foundation

I initially met Joel, a five-year pancreatic cancer survivor, at the Lustgarten Foundation's annual Long Island Pancreatic Cancer Research Walk.

As the world's largest private funder of pancreatic cancer research, the Lustgarten Foundation is committed to finding a cure for this disease, and Lustgarten-sponsored events like the walk bring together patients, survivors, loved ones, and others impacted by pancreatic cancer for an inspiring day of hope.

Each year, patients, survivors, and their loved ones gather at our survivor tent, where they have an opportunity to share their experiences with each other, browse through the latest material on our research, and participate in our ribbon-cutting ceremony. Joel has been an enthusiastic, committed supporter of our walk since 2016, when he and his family started "Team Joel" to raise funds for the Foundation's research program.

In 2015, early detection likely saved Joel's life. Prior to his pancreatic cancer diagnosis, Joel was enjoying a rewarding career as a professor at Hofstra University's Zarb School of Business and spending time with his family—his wife Linda, daughters Jennifer and Stacey, and sons-in-law Phil and Adam. During a routine office visit with his endocrinologist for his diabetes, his bloodwork showed a high score on a bilirubin test as well as other blood tests, indicating the possibility he was suffering from a serious illness.

His diagnosis of early stage pancreatic cancer was confirmed by undergoing additional testing. After processing the initial shock, he was determined to do whatever was necessary to get through treatment. As

his cancer was diagnosed early—which is often not the case with this disease— he was able to undergo a Whipple procedure, a surgery offering the best chance for long-term survival. That was followed by chemotherapy. Now, Joel is grateful to be a survivor and believes it is his responsibility to give back by sharing his story and providing advice, based on his personal experience, to others dealing with pancreatic cancer.

Joel's experience exemplifies why early detection is so important and why the Lustgarten Foundation is currently supporting many early detection initiatives, including an early detection blood test; a study focusing on pancreatic cancer prevention in families; a test to determine if pancreatic cysts, which can be common within the general population, can develop into pancreatic cancer or remain as benign cysts; and research using artificial intelligence to discover pancreatic cancer earlier, when it may be missed by a diagnostician, so diagnosis and subsequent treatment can be initiated sooner.

Joel gives readers an open, honest perspective on the challenges he faced following his new life after surgery, both mentally and physically, and a glimpse into what his life is like now as a survivor. And in the most heartwarming passage, Joel describes the thrill of that surreal moment when he walked his daughter Stacey down the aisle on her wedding day and then danced with her—he didn't know if he would even be alive to experience this once-in-a-lifetime milestone.

On behalf of the Lustgarten Foundation, we thank Joel for sharing his pancreatic cancer journey and for inspiring the pancreatic cancer community. For more information about the Lustgarten Foundation, visit www.lustgarten.org.

Kerri Kaplan,
President, Lustgarten Foundation

Dedication

This book is dedicated to:

My wife Linda for your phenomenal—and enduring—support and love. You will always be the LOML (love of my life) and best friend.

My daughters Jennifer and Stacey and my sons-in-law Phil and Adam for always being there for me.

My medical teams and other health care (body and soul) professionals, who helped save my life and who always showed caring and compassion to me—and still do.

My friends, who provided me with so much kindness and comfort. And a special shout out to my friends also dealing with cancer; you really inspire me.

All cancer victims—and others suffering with major illnesses—and their families as you go through your own personal journeys. I wish the best for you. You hold a special place in my heart.

The Lustgarten Foundation, which has helped enable me to give back to others who are afflicted with pancreatic cancer and their families

Live Life EVERY DAY!!

JRE

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Introduction

Before getting to the true introduction of *Surviving Cancer and Embracing Life* in the next paragraph, let me note the following: I am writing this book to inspire hope. Despite the subject matter at hand, I want to try to be uplifting—and even inspiring.

There is a light at the end of the tunnel, even if that light is not as bright as before. And sometimes, we have to fight to see that light. I am NOT a medical professional. And I am not alone in my battle with cancer. This is one person's journey, both the ups and downs—with the strong determination to have the best life possible for as long as possible.

I am a pancreatic cancer survivor. I underwent an 8-½ hour Whipple surgery to remove the cancer. I had a lot of problems during chemo. As a diabetic, I passed out from low blood sugar a few days after finishing chemo. As a result, I fell and had to miss my daughter's bridal shower. And I had to have cement pumped into my back. I have a lot of other stuff going on. But enough of that. I am NOT complaining. I just want you to see where I have been—and where I still am going.

With this book, I want to share my personal cancer journey with you. I want to offer hope and support to those dealing with any terrible disease and their families. Why? To quote the late NY Yankee star Lou Gehrig when he was honored at Yankee Stadium while dying from ALS: "Today I consider myself the luckiest man on the face of the earth."

In, fact, I consider myself the luckiest man on the earth EVERY DAY. **I have felt this way each day since February 12, 2015. That was the date of my Whipple surgery. Why am I the luckiest man alive?**

- **I have a great family that has been with me every step of the way.**
- **Because of my endocrinologist, Dr. Joseph Terrana, I was diagnosed very, very early and thus I was able to have surgery because the cancer had not spread to my lymph nodes.**
- **Through the prodigious skill of Dr. Gene Coppa and his team from Northwell Health, my Whipple surgery was a great success.**
- **Due to my excellent oncology team headed by Dr. Jeffrey Vacirca and his right-hand person Diana Youngs, my chemotherapy was done with both compassion and caring—even when the treatments were toughest.**
- **My friends and fellow cancer survivors continue to be there for me.**
- **Despite the dire prognosis for those with pancreatic cancer, I was able to dance with my daughter and give a toast at her wedding.**
- **Until I retired in March 2019, I was able to continue working full-time and doing what I love.**
- **I can exercise and keep in the best possible shape. (I even went to the gym while undergoing chemo. Now, I walk 3 miles every other day).**
- **And my wife Linda and I have traveled since my surgery, including a "restful" vacation in Puerto Vallarta, Mexico; a cruise from Amsterdam down to St. Petersburg, Russia; a visit to Curacao; a family vacation in Eastern Mexico; and more.**
- **We have made it through the COVID-19 pandemic.**

Accordingly, I want (need) to give back. That is the driving force behind this book, and my participation with the Lustgarten Foundation and my other volunteer work. It is also the reason why I am making the original version of the book available for free at my blog. And giving back is the impetus behind the blog I started in summer 2018: *Living Well While Surviving Cancer*. Please visit that blog and join us: https://survivingcancerembracinglife.com. There are already 300 posts (as of September 2020.

> ***Surviving Cancer and Embracing Life* includes the honest reflections of my own personal journey—including the tough times and the great times. There are many intense discussions, lightened up with some humor. And thankfulness for the more than five-and-a-half years since my Whipple surgery.**
>
> **I have NEVER asked "Why me?" Rather, I always ask "How am I so lucky?" My personal credo revolves around living life every day and recognizing that happiness is a choice. Being upbeat is a great gift.**

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Let us all live as long as we can –
and as well we can!

My Life Before Cancer

To put my personal cancer journey into the proper context, here is a brief synopsis about me before I got cancer.

As a kid growing up, we moved around a lot. I was the first one in my immediate family to go to college. Then, while working, I attended graduate school as a part-time MBA student. At that point, I switched to full-time status and went on to get my Ph.D. And I became a professor.

I met my wife—and best friend Linda -- when we were both teenagers at Queens College in NY. We got married after graduating. Linda earned two master's degrees, one an MBA, while working at a bank. Linda is truly the LOML (love of my life).

Our two grown daughters Jennifer and Stacey, and our sons-in-law Phil and Adam, are our treasures. We are fortunate to have them within driving distance of our home. In one case, within walking distance.

Because we moved around when I was a kid and I had virtually no friends, I set and have attained three main life goals: to marry one woman as my forever partner, to work for one organization for my career, and to live in one house so my own children never were uprooted. Linda will not let me say how long we are married. 😊
I finished 44 years full-time at Hofstra University's Zarb School of Business [where I still teach part-time as an emeritus professor] until retiring in 2019. And we have lived in our house in Commack, NY since 1977. I have truly hit the trifecta.

We have a number of great friends, some going back to our school days and others gained as married adults. We used to spend time together mostly talking about our families and careers. Now, we always start with the question: How are you feeling? [LOL]

I was quite fortunate to have had a great career. I reached distinguished professor status at Hofstra University's Zarb School of Business, won a teaching award, co-authored two textbooks that used around the world, won a best article commendation, and became a very active blogger. Several of my former students have also become my long-time friends.

I always enjoyed participating in sports, especially jogging, tennis, and gym activities. I actually started lifting weights for the first time in my 50s! Currently, I participate in walking as my main activity.

But not everything has come up roses. It's how we deal with adversity that matters. When I was sixteen, I broke my collarbone for the third time. As a result, I've had an eight-and-a-half-inch screw in my shoulder ever since then. I blew out both of my knees from years of jogging on cement. And shortly before my cancer diagnosis, I ended up with rotator cuff surgery from falling down stairs in my own house.

In 1995, I learned that I had Type 2 diabetes. This led to a significant change in my diet and to my taking regular oral medications. After a few years, insulin was added to my regimen. At first, having diabetes was a downer—until I accepted it, learned that some things are beyond our control, and that the power of positive thinking makes a huge difference in one's physical AND mental well-being.

Amazingly, I now credit having gotten diabetes as one of my greatest blessings. Because of it, I have gotten a full blood work up (not just A1C) every three months. In January 2015, my regular blood work showed a high score on a Bilirubin test and other blood tests. My endocrinologist immediately set into process all of the steps that have given me an extended life. Most people with pancreatic cancer are diagnosed too late to have surgery and usually face an impossible prognosis. That’s why I am lucky EVERY day.

The personal journey from cancer diagnosis to my life today follows next. I pull no punches and unveil some of my most personal recollections. Why? Because if you are afflicted with a serious illness, I am you. And this is how I got through everything. One new chapter updates my journey—and encompasses life in the time of the COVID-19 pandemic. A second new chapter deals with my growing involvement with the Lustgarten Foundation for Pancreatic Cancer Research.

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Discovering I Had Cancer

In January 2015 at about 7:30 in the morning, my wife Linda and I were having breakfast. At that time, I got a call from my endocrinologist, Dr. Joseph Terrana. To say that we were startled and nervous would be a tremendous understatement. Wouldn't you be very concerned if a doctor called you at 7:30 AM?

[Interestingly, without referring to my MRI scan results, I don't remember the exact date as January 15, 2015, only that it was a Thursday. I do remember other key dates so well. But I draw I blank on that one. I think that's because I must have been in a daze. I guess that's one reason why they make calendars.]

Some background: As a Type 2 diabetic for two decades, I got a battery of blood tests every three months through Dr. Terrana, besides the A1C test to monitor my blood sugar. One of the tests that Dr. Terrana regularly ordered—that I did not even know anything about since the results were one in a long list—was a Bilirubin test.

When Dr. Terrana called, he said my Bilirubin test result and a couple of other blood tests were elevated. And this might mean a tumor. Because he is an amazing doctor and person, by the time he called me, he had already scheduled a MRI scan for me for later that same day.

Linda and I went together when I did the MRI. And then we waited to get the CD of the scan and the radiologist's report. This was the number one impression of the radiologist:

> *Marked atrophic changes within the body and tail of the pancreas associated with dilatation of the main pancreatic duct and ductal side branches within the pancreatic body and tail to the level of the pancreatic head where an approximately 3.0 cm heterogeneously enhancing pancreatic mass is present. Residual soft tissue in the region of the inferior aspect of the head and uncinate process of the pancreas may represent residual pancreatic parenchyma, but, the possibility of additional mass cannot be ruled out.*

As a layperson, I had to read this at least three or four times to make any sense of that impression. When I had some grasp, these are the words that stood out to me: pancreas, pancreatic mass, and possibility of additional mass cannot be ruled out. I was pretty sure that "mass" meant tumor.

Linda and I immediately drove over to Dr. Terrana's office about twenty minutes away to discuss the test results with him. We arrived at roughly 5:00 PM with no appointment and a waiting room full of patients. As soon as Dr. Terrana heard that we were there, he ushered us into his office. We were there for over an hour. [To this day, I'm still sorry for causing the other patients to wait for so long.]

Dr. Terrana calmly discussed the possibilities with us. And he suggested the steps that should be taken next. Previously, neither Linda nor I knew anything about pancreatic cancer nor the dire consequences often associated with it. But we were fearful of the possibility of cancer.

As the next step, Dr. Terrana wanted me to have an endoscopy with ultrasound. He would not let us leave the office until he arranged the endoscopy with a highly-rated gastroenterologist. He made calls to contact that doctor and to get an early appointment. This was a Thursday night, the following Monday was Martin Luther King Day, and Dr. Terrana secured an appointment for Tuesday morning. Wow!!

Since our family is close, Linda and I decided we would tell our daughters about the early prognosis on the day of my first scan. As we drove to see Jennifer, who lives two blocks from us, I got a call from Dr. Terrana on my cell phone noting that I forgot to take the CD of the scan with me after seeing him. Again, this is where he is an amazing human being.

When I said I would stop by his office the next day, he immediately replied that we had enough to worry about; and he insisted on dropping the disc in my mailbox. We live on his way home. Yes, our doctors can be extremely compassionate.

Jennifer is not usually outwardly emotional. But clearly she was shocked when Linda and I stopped by her house and told her. Thankfully, Phil was there to give her moral support.

Then, we drove over to see Stacey—who's about 30 minutes away. Stacey is the emotional one. And I tried to reassure her that everything would be OK. She instantly said that she wanted to cancel her October wedding. My response: I intended to be there, to dance with her, and to make a toast. Thankfully, soon-to-be hubby Adam was there to support her.

The endoscopy revealed that “there is a 3 cm lesion that is hypoechoic and heterogeneous with loss of interface of SMV.” After that? We set up a consult with the best surgeon recommended to me: Dr. Gene Coppa, the Chair of Surgery at the LIJ Medical Center (part of Northwell Health) and the Chair and Professor of the Surgery Department at the Zucker School of Medicine at Hofstra/Northwell.

In an interesting twist of fate, my initial consult with Dr. Coppa was postponed for one week due to a severe snowstorm. Waiting another week to see him was not a fun time, as we were all so nervous.

Based on my various test results, Dr. Coppa recommended that I get Whipple surgery ASAP. He explained what this entailed; and it sounded pretty scary. He said that pancreatic cancer could spread very quickly and that we needed to act fast. OK, onward.

Dr. Coppa was also amazing. Obviously, he had a very full surgery schedule. What was especially complicated in trying to squeeze me in was that the Whipple surgery itself was going to be 8-½ hours, besides Dr. Coppa’s own prep time. Nonetheless, he cleared the decks to operate the week after I saw him.

What a miracle. It was exactly 4 weeks (including the snow storm) from my first CT-scan until my Whipple surgery.

While all this pre-surgery stuff was going on, I was remarkably calm. I truly surprised myself with this. But, Linda, the LOML, was a nervous wreck as events unfolded. That was when I really saw how tough a serious illness is on the whole family, not just the person who is ill.

A few final points for this chapter:

- **From the date of my first scan in January 2015, I let both my department chairperson and the dean of the Zarb School of Business at Hofstra University know what was going on with me. And I started getting information from the human resources department so as to prepare the required forms for my anticipated sick leave.**
- **At Hofstra University, our spring semester typically starts at the end of January. So, I began teaching my undergraduate and graduate classes without knowing when I would have my surgery and how long I would be out.**
- **I contacted a couple of colleagues who graciously agreed to cover my classes at the time that I needed them. Yet, I did not tell my students that I would miss significant time that semester until the Monday before my surgery. I did not want them to be uncertain about what they faced that semester. My colleagues Andy and Donna did a fabulous job with the classes. Bravo to them.**
- **By far the worst thing that I did during the lead up to my Whipple surgery was to go online to read too much about it. It was frightening enough to learn what I could regarding pancreatic cancer and its far-reaching consequences. But looking at a gruesome (to me) online video on YouTube about the Whipple surgery could have been THE single dumbest thing that I have ever done in my entire life. Why would I look at a video that was so gory in detail as to what I would go through? Yes, sometimes, ignorance is bliss!!! [As I update and expandt the book in summer 2020, I still cannot believe that I did this.]**