

Mary's Journey through Oesophageal Cancer

Mary's words....

I'm delighted to share some words I wrote for the book 'Stronger than yesterday... Living your life beyond adversity' on this website. I do this because, if my story can help anyone facing a diagnosis of oesophageal cancer, I would feel grateful that I gave them hope for the journey that they will travel.

Wednesday 3rd September, 2014

7.25pm

I am sitting out in my back garden that holds so many memories of past family events, the biggest being my daughter's christening; reminiscing on the happy faces of grandparents, brothers, sisters and other close family members, all celebrating the joy of a new arrival to the family. These capsules in time are to be treasured. Living in the present, many years on, is a little late to learn.

Have been working up to this kick-start for weeks now. Just got an urge to put pen to paper, prompted by a beautiful September evening; no wind, virginia creeper turning a rich deep red, aromas emanating from the garden, that Autumnal reminder as a cool evening sets in, despite temperatures of 22 degrees Celsius today! Indian Summer!

Here I am alive, two years on from the official retirement and just beginning to savour it after a rough journey – so much to get out of my clogged up thoughts and experiences since then.

My assignment to write about my journey since my cancer diagnosis fills me with an overwhelming feeling of creativity and purpose, countered with sadness and despair. Selecting it all now and editing it into an essay that is to be submitted for a book is the real challenge. Where do I begin? What do I select? What will resonate with someone who will face the same journey?

Cathy did warn me that a year after surgery might be a bit soon! Having discussed it with family and close friends, I decided to give it a shot! As I've always written a daily journal, my decision to go ahead with the piece, seemed the right thing for me to do.

Thursday 4th September, 2014

6.45pm

Not ready to record! On looking back over details from my diary – too much to process!

Friday 5th September, 2014

5.45pm

Rewind – June 1st 2012

I recorded “what a day and end to my career, with all staff present, giving me a standing ovation. A room filled with laughter at my “Basket & Gown Awards” – really got this one right! Lots of emotions with presents, congrats, hugs and good wishes for my future; the whole scene was overwhelming for me” Just a snippet from my final day at the school where I taught for 34 years, without a career break and only one term’s leave from Christmas to Easter in 1987, to give birth to my daughter. Maternity leave was 14 weeks in those days!

To explain the basket and gown reference, I used an open wicker basket to carry my books and chalk /markers and donned the gown each day to protect me from the dust. As you can imagine, many a stick of chalk was used over the years to impart the joys of teaching calculus, simultaneous equations, theorems, differentiation, algebraic formulae, geometric graphs and diagrams plus the whole spectrum of mathematical delights!

These two items were my signature pieces and I was well known and identified by them. So to mark my retirement, I set up an Award Competition to pass them onto two worthy members of the staff, who would continue the tradition of using them. It created great fun and craic for the end of year activities and my final send off. I might add, two very deserving members of the staff won the said items and continue to proudly use them to this day.

I had crawled to the finish line willing this day would finally come. That last year at work was a struggle for me, as I obviously had a tumour growing on my oesophagus and chose to ignore the symptoms. Perhaps a year or so previous to this, I had noticed my swallow was becoming a problem. By the time I got to my final year, it had got worse. As I was Sixth Year Yearhead, I didn’t want to let them down by going out sick or end the last year of my career on sick leave. I did really feel all was not well, but put off the evil day to get it checked out. When school and career were over, I’d sort it out, I told myself!

With the generous money gift from the staff, I purchased two super racing bikes to mark my cycling off into the sunset. Hubby and I were going to take to the

highways and byways. We cycled the Western Greenway on the day the staff returned to school in August, 2012 to mark the start of my new lease of life. I took up French Conversation Class in September, as we intended spending more time in France. We went there that September for the first time ever, and enjoyed the freedom to do so.

I went to the Retirees Lunches, at last able to join my former colleagues, whom I had envied for years and had longed for the day that I could be a “Lady Who Lunched”!

Now let me see, what excuse/diversion came up next?! In November, we had a joint Retirement/60th Birthday (for Hubby), inviting friends and family. Again I had a sense almost as if it was a farewell party and was uneasy, despite the very successful night.

Travel plans were at our choice and so the big retirement trip was planned for January 2013. South America – Galapagos Islands plus Inca Trail – here we come😊

And then came Christmas!

All the while I knew I was living the dream, but had that awful sense of foreboding. On returning from the big adventure, and knowing that by now my luck had run out, as my symptoms were quite severe – no pain – but swallowing problems with food not going down and serious weight loss. My time had truly come to sort out the problem. I started the inevitable journey by the usual step 1 – going to my GP for a letter of referral for an endoscopy, which I knew I needed!

It was up to the Beacon Hospital for the procedure/Ash Wednesday February 13th! Shortly after the procedure the Consultant gave me a ‘no’ answer to my queries as to whether it was a hiatus hernia or achalasia? He said “some sort of stricture was there and further testing was needed”. So that was the start of the alarm bells going off! I recorded that “I don’t know what lies down the tracks for me”. That was an understatement on reflection now. Just over 24 hours after my scope, a letter arrived requesting me to present to St. Vincent’s Private Hospital. I phoned the Consultant’s Secretary, who couldn’t believe I was seen to so quickly, which further made me suspicious they had found something that needed urgent attention. She mentioned oncology, radio therapy, CT scans, and pulmonary tests and lots more - a whole new lexicon of terms I would soon become familiar with. I knew now I was in the system and there was no going

back. How true this was – it was like jumping into the river and going downstream – no back paddling! It was out of my control now. The rollercoaster of emotions that was set in train was indescribable. My journals contain the whole spectrum of madness that followed. The night before admission for the tests, I wrote “feels like the night before my death sentence.

Cancer of the oesophagus wouldn't surprise me!” How perceptive of me. My daughter texted “Hi Mum, I'm praying for you all day and hoping you will know God's peace tonight”. On admission, I learnt what for many months ahead, in various hospitals, would be procedural questions. My D.O.B. being one. I would get to know the whole myriad of staff that attend to you in a hospital environment in the coming months. Coming from a teaching career and yearhead job for 6 years, I was always interested in people and their stories, so that sustained me. My health issues were bad enough, but everyone has to struggle through this world and we are all on the same path as regards departing this planet at some stage. As they say “we are all just passing through”! Observing and sharing their stories en route, was an enriching experience for me. I approached my 'journey' ahead with this open-mindedness – willing to learn all that I was going to succumb to. While my poor body was going to endure an onslaught, I knew my headspace was in my control and I needed to take and keep ownership of this.

One question everyone asks or wants to know is “How did you find out about your diagnosis”? With a lot of hanging around waiting for tests to be carried out and armed with my medical file, I naturally became curious as to what information it contained about me - needless to say I had a peek inside! To my horror I saw the letter to my GP indicating the presence of an oesophageal tumour, likely to be a squamous cell carcinoma – await biopsy with interest – arranging staging and appropriate management from there. So there I was with this information, not yet confirmed by the Consultant or medical staff. By the time they came to tell me, I knew, and I had all the questions prepared in advance. They hadn't to drop some bombshell on me without warning. I had my list ready.

- 1) What is the diagnosis?
- 2) Is it cancer?
- 3) Do you know the size of the tumour?
- 4) Has it invaded other tissues or organs?
- 5) What are my treatment options?

6) If surgery, who does it?

These questions would not have been possible to formulate, had I not seen the information in my file. I was glad I was composed enough to have some level of ownership of this devastating news. I discovered what the word 'prognosis' meant, i.e. how long do you think I have to live? Should I put my affairs in order? I got all the wrong answers to these questions. At this stage, it was clear I would need to go to a centre of excellence for this type of cancer treatment. I asked for a referral letter from the Consultant and he suggested Prof. Reynolds, an eminent Consultant in St. James'. In the meantime, a pet scan in the Blackrock Clinic was arranged. By the 25th February, 2013, it was confirmed by a call on my mobile from the Consultant, that the tumour was malignant. He wished me luck!

Matters were moving fast and furious now. A visit to my GP was depressing as I clearly picked up he didn't rate my chances too good. He had lit a candle in Clarendon Street Church for me.

On the 27th February, I recorded "Today I met a God on Earth, i.e. Prof. John Reynolds". My chances of remaining alive were in his hands now. No fancy consultant rooms, plain surroundings and plain talking, no plámás or bullshit! This is serious stuff we are dealing with, i.e. life threatening – let's get real without any drama.

The breaking point in these two weeks was on this day when having met Prof. Reynolds, he organized, on my request, to speak to his GI Nurse. She told us some graphic details of the surgery, which sent us reeling. I likened it to my hero, Ellen MacArthur, who sailed in the Vendée Globe Race and wrote a book "Taking on the World", which tells of a young girl who receives a call to adventure and sets out on a compulsive journey and finds mentors, tests, dark caves, despair, a supreme ordeal and triumph. She would be my inspiration for the endurance tests that lay ahead of me. I too was to face a sail into the Southern Ocean!

Human language is woefully inadequate to express our inner feelings. We merely stammer in speaking of them. Words do not present "the real thing" but they hint at it. At crossroads, we discuss the path that seems most promising. The image of swimming, with each stroke, you push a volume of water behind you, as you move towards your objective, but without that water, you would

never get there. When we ponder the twists and turns in every human life, the boundaries which we place around our creativity are burst open.

The rosary beads from my First Holy Communion in the 60's, which I stored in a tattered purse, became my refuge. I prayed that I would be spared and live to see my daughter marry and get to meet and know my grandchildren, hopefully. I knew the heavens were being stormed for me by family and friends.

Breaking the news of my diagnosis to family and friends was a difficult task. As I said, it was all happening so quickly; I just worked on instinct.

I reminded myself that having survived 34 years in a difficult and challenging career, was surely a test of stamina and I was damned if I'd let this "life skill survival kit" go to waste. I wrote to the staff as I was only 6 months into my retirement and had planned to meet up for coffee and tell them of the big South American trip. Coming clean early on was a must for me. Letting them all know directly from me was essential rather than hear it down the line second-hand. I was determined also to let my friends, from the closest to the more casual, hear about my diagnosis from me.

Reactions varied from upfront "you hear these stories just after people retire" and "oh shit, you've just retired".

27th February, 2013

I recorded "I'm facing some serious shit in the coming months and until the PET scan results come back, I don't know if I even have a fighting chance. I told Hubby tonight that if it has spread to any other major organs, i.e. secondary or metastases, I'm not going down the surgery route". In hindsight, this was a bit naïve, as surgery would not have been an option, as I later learnt.

28 February, 2013

Pet scan in Blackrock Clinic: After a drug induced sleep, I was up at 7am. Both Hubby & I met in floods of tears, still reeling after the Nurse's description of the surgery details from the day before. I had to face a whole new world that I was about to be whisked into. Pet scan – radioactive dye injected – 1 hour in dimly lit room – traffic congestion getting there - parking – waiting – the worry of the unknown! All part of our world that would be common place in the year ahead and longer.

1st March, 2013

While playing tennis at noon, I received a call on my mobile from Prof. Reynolds. I took it immediately and have always put the time and place of this call in my memory – there to recall forever. I took the news in the loo of the tennis club! He broke the news in a calm and candid way, answering my question “what stage is the cancer at?” He told me it was a stage 3 and had spread beyond the wall of my oesophagus to nearby lymph nodes. But there were no signs of it spreading to other parts of my body. I was hoping for a 2A or 2B stage, which would mean it was contained within the oesophageal wall, but at least it wasn’t stage 4. So the challenge was on! I had a fighting chance and by God, I’d go for it. We wept and thanked God it wasn’t terminal, but knew the road ahead wasn’t going to be easy. At this stage, my very close family, daughter, sister, brother, were all in the mix and were, needless to say, in a very concerned state for me, but all very supportive. I knew I couldn’t take on their pain as I had to be strong to fight the battle ahead. My elderly mother was kept in the dark at this stage until we knew all the treatment plans were confirmed.

3rd March, 2013

We headed back to Mayo for a much needed break, to get our heads around all the bombshells that had been dropped on us in the past 3 weeks. We bumped into friends of ours by chance, who were staying in the same hotel, so this was the start of having to tell people of my diagnosis and what the coming year entailed. On the way down in the car, I heard an interview on the Marian Finnuane show, with guest, Joan Burton, who described her mother’s death from cancer of the oesophagus, as “harrowing” – timing!!

My first real experience of death in my family that I recall as a child, was my grand uncle on my mother’s side – Fr. Timothy Leahy, who had been a Columban, Maynooth Missionary to China, priest. He wrote about his extraordinary life experiences there. His book had a quote at the beginning – “The Gloom of Night Yields to the Morning Star and Beyond Tomorrow a Brighter World Awakes” – old Eastern saga. Hence, the title of his book – “Beyond Tomorrow”. He had gone to Central China in August, 1930 as a young priest and despite floods, famine, years spent on the run from bandits and Reds, he achieved unprecedented mass conversions of entire villages. The Japanese declared war on China and took possession of Central China in 1938, virtually ending all missionary activity. They remained until the end of World War 2 in 1945. After their defeat and at their departure, they left behind them a void, a land in a state of chaos. Into that void stepped the Chinese Communists, which

left missionary activity proscribed - "External Expulsion from China by the People's Government". This was spread over a period of 10 years from 1938 to 1948. So Uncle Tim endured the efficient machine of the Japanese Army, the invading army leading to a stream of Chinese displaced refugees – 20 million of them on their long sad march to temporary safety of Chung King, over a thousand miles away. Uncle Tim walked with them for several days from Han Yang to Tsandankow about a week before the Japs arrived in force to take possession of Hankow. His adventurous journey and his heroism in those difficult times would be inspiration for me. On his return home to Ireland many years later, he occasionally stayed with us, so I have very fond memories of him. He was a most entertaining and eloquent storyteller and rose to all the challenges life presented him with. I kept his book by my side throughout my hospital stays as a "comfy blanket". His signed copy to me, whom he called "Little Topsy" – April 19th, 1969 – Ever Affectionate – U. Tim – was a rock for me.

5th March, 2013

Climbed Croagh Patrick and made a video on the top, expressing my aspirations to return to this mountain. It was a symbolic climb ahead of the many summits that I knew lay ahead. We got to the top in under 2 hours – a windy, bitterly cold breeze up there! Made a call to my sister, whose immediate reaction was – "Are ya stark, ravin mad"? By chance, I received a call from a friend on the summit and she commented about what a great time I was having due to retirement. If only she knew! This was one of many similar incidents that occurred before I became public about my diagnosis – thus marking that difficult phase of coping with the road ahead, and gradually letting friends from school, tennis, bookclub, neighbours – all people I had planned to meet in the coming weeks, know.

7th March, 2013

Dad's 21st Anniversary – I prayed he was looking after me. I had been to James's and came home in a trance. Today confirmed my treatment options;

1. Radio therapy and chemotherapy before surgery, in approximately 3 months or
2. High doses of radio/chemotherapy only.

I signed up for option 1 as it was a "no-brainer". Either route was devastating, but option 2 meant surgery was ruled out if cancer returned. Met with the lovely Dr. Moya Cunningham on the same day and she (the Consultant Radio

Oncologist) told us that I'd get 18 to 20 hours of chemo each day for a week combined with radiotherapy over a series of weeks. She lost me after that! Just the mere word chemo and the length involved, overwhelmed me. Yet another lexicon of terms to grasp! I was told that a second week of chemo would follow my radiotherapy, so I knew that my poor scrap of a body would have a battle ahead. My fears of surgery after all this bombardment were well routed at this stage and continued until the eventual time of surgery 5 months later. I recorded "I will have to make out a Will soon, as the GI Nurse agreed. Phoned Mum at 7.30pm and just said I'd had more tests and had met with the Dietician". My immediate family were now getting the news and the knock-on effect was devastating for them. They were distraught at the details of what lay ahead. My brother-in-law called with a bouquet of flowers and the dreaded Get Well card. I had written to my staff/colleagues indicating that I didn't want texts or cards yet, until my voyage was complete. My network of friends relayed this to my many contacts and TG respected this request. I recorded "I don't even know if I'll be on this planet in a year's time". As news filtered through to family and friends, offers of "if I can do anything for you", soup left at my doorstep, manuka honey, soft buns, pavlova – so much love and kindness all overwhelmed me. Meanwhile, I was determined to get myself in shape physically by playing my tennis and cycling and, mentally, by staying positive.

12th March, 2013

Went to my dentist as a precautionary visit and ended up with her being overzealous. She extracted a lower left-side molar in what turned out to be a traumatic experience, as the stubborn tooth took gruelling work to extract. A pneumatic sounding drill was used to cut it out – it split in two – and had to be gouged out with great force, requiring stitches and a threat of hospitalization later, if the bleeding didn't stop. Was sorry I went for that check-up! I now have a big gap in my lower jaw and can't lie horizontally for further repair work. Could have done without all this before all the pain that lay ahead.

By the 13th March, I awoke with a jaw that looked like I had an encounter with Mike Tyson after 4 rounds in a boxing ring!

On the same day, I had to attend St. Luke's for a CT scan and get tattoos for my radio treatment. The whole experience of entering St. Luke's marked a new very real step in my journey. Seeing women with no hair and very sick people scared

me. Will I too be like this? The Nurse that met with us kept telling us that the Consultant would explain to me all the questions I had asked her, so I came away feeling frustrated and even more scared now.

When I eventually met with him, he was the fourth Consultant and was the Medical Oncologist.

At this stage, due to numerous hospital appointments, I was cancelling my beloved tennis dates and 18 months on now, it still feels sad that playing tennis on the 8th August, 2013, was the last time I held a racquet. I was meeting up with friends to deliver my bombshell news. My lovely Principal from school was so supportive, letting me know that all the staff were routing for me. The letter I wrote to the staff was to be relayed by a dear colleague on 15th March and later I learned that many staff members wept after it was read out. The phone was on the hop for the next while as news filtered through.

17th March, 2013

This was a very sad day for me as having to tell my poor Mum that her youngest daughter had cancer was news she didn't need to hear. She had experienced a lot of sadness in her earlier life, with both her parents dying young and also two brothers. We had a meal in my brother's house and I couldn't swallow the chicken, further indicating how serious my condition was. A photo taken of my Mum, brother and sister with me, was a reminder that this could be the last one taken of us as a family. Both my brother and sister were a rock for me on this emotional day and I knew they would be with me all the way on my journey ahead. It's called 'circling the wagons' I think! The image of my Mum closing the gates as my sister and I departed for Dublin, will always be etched in my memory. Stuck on a 'Cold Play' disc as we journeyed back.

7.20pm - 19th March, 2013

What's my prognosis? Consultant's answer – 40% chance of survival in the next year. "Great! Well, I'm going to be in that percentile if it kills me!! – And here I am verifying it.

A later study from James's indicated 21% survival after 5 years, so I remain optimistic.

I recorded "the challenge gets tougher with each hospital visit, but heck, I'm up for it. Knowing the odds, I realise it isn't going to be easy. I know what I have to do. Shure life is a battle and I must now take control of this limited word

'cancer'. The word 'choices' keep coming up. They put the skids on a disease that has me thundering down the track like a run-away train. There are no stop signs on this trip or 'journey', as everyone, even the Consultant, called it".

Got up the next morning with a pep in my step, determined to remain positive. Continued to play my tennis! Later a call from St. Luke's said I needed another CT scan as the Radio Oncologist wasn't happy with the original one. Thus triggering off a whole new plethora of stress and uncertainty, in a day that started off full of positivity! The questions arose like "what happens if the permanent tattoos that are the shooting target for the radiotherapy, are in the wrong spot?" "Is the equipment at St. Luke's up to scratch?" and lots more

A friend, who had cancer, phoned me later that day and said how she had cried the day they linked her up to her first chemo treatment and how she hated people telling her to stay 'positive'.

21st March, 2013

Back to St. Luke's! Lack of information on why I was recalled for CT scan; further stress added by a visit to the mould room. This freaked me out, so a Registrar was called to talk and explain to me what was happening. A facial mask was required for my radio treatment to secure the head and prevent it from blocking the area above the tumour, where they also wanted to blast... that worrying enlarged lymph node! It was this that had me scared. Once the mask was moulded, I was ready to proceed to the CT scan room, where I wore it for the first time. I could only breathe through my nose and my whole face was shackled into a muzzle-like frame, just like a dog. I was to have this for all my radio treatment and I hated it from the start. To cope, I thought of David Bowie's space oddity song and visualized myself being in an interplanetary capsule!! That same day, I had to return to the dentist to have my stitches removed.

22nd March, 2013

My letter to the school staff was read out during break time. I was crowned "Queen of Letters" as this was my modus operando; even for my year head assemblies, I always wrote down everything that I was going to say. Ironically, it was Daffodil Day and due to a deluge of rain, proceeds were down considerably (50%). Needless to say, a lot of features in the media focused on cancer that day.

Sunday 24th March, 2013

My sister always called for a chat/walk on Sunday. We started to browse through the information booklets about oesophageal cancer, given to me by the various medical teams. It was all so scary to read about what was facing me. We both cried at the prospects of what lay ahead and felt it all seemed so unreal. Today I also received a text from a former colleague saying “It is such bad luck” – meaning I had just retired and to end up with this was just the pits. She did give good advice though and said “Not to look back or peek into the future”. Messages from friends - “You’re in my thoughts and prayers” unnerved me.

Time was marching on now to treatment kick-start. We decided to escape for a grand finale to the posh Kelly’s Resort Hotel in Rosslare for two nights to pamper ourselves. However, my mind was consumed by the cancer and all its ugliness. Worry about treatment, surgery, and relapse – the whole gambit that was imminent! I booked in for the “Wellness for Life Therapy” as a special cancer- care therapy was on offer in the hotel. I had to fill out a consultation card with all those awful terms unique to cancer on it. I thought – is my world reduced to this? The meal that night was a disaster, with major blockages due to the tumour, causing the familiar exit from the table, to try and regurgitate and release it. Clearly, my quality of life was not good at this point.

The waiting game now kicked in. Texts and calls from many concerned family and friends as to when my treatment plan would start, stressed me as I still hadn’t confirmation of same.

4th April, 2013

The treatment plan arrived. I must now face my destiny!

5th April, 2013

St. Luke’s phoned in the afternoon to confirm admission at noon on the 8th April.

8th April, 2013

3.35pm – Ward D, Room 15

I record “TG I have a private room with an ensuite and it overlooks the leafy suburbs of Rathgar – nice big trees; a pathway and pampas grass are in view also. I had my radio therapy session for about 20 minutes. The dreaded mask was too tight and most uncomfortable, leaving marks on my face. The ward nurse settled me in and took my weight – 49 kilos! Started into my soft diet regime – soup and mashed potato and gravy with water – 100% proof!! This wasn’t going to be The Hilton! An ECG was taken and chest x-ray. At about 4pm

a doctor called to explain the chemotherapy treatment plan. He outlined the awful side-effects – nausea, vomiting, damaged kidneys, numbness and tingling in hands or feet, damage to hearing with tinnitus and loss of hearing high-pitched sounds, diarrhoea, allergic reaction on the skin with rashes and itching, dizziness and headaches. So that was a nice first day intro into what lay ahead! I now just had to wait and see which of these delightful effects would take hold of me! I was to have 16/17 hours of chemo for 5 to 6 days on a particular drug, followed by a 24 hour regime on a second drug. The second chemo cycle was planned for 35 days hence. It was then a series of form filling for another nurse who asked me how much I knew about my illness. I let her know I was fully aware of my prognosis.

9th April, 2013

Exactly 4 months to my surgery date (which I didn't know then), at 16:11 I was wired up to the "chemical warfare machine"! My brother just happened to be visiting me at this time, so I was very glad to have him witness this initial linkup to chemo, which was so feared. "Cytotoxic – handle with care" was written on the bag that now dripped into my poor wee body - 5 Fluoroucil or 5 FU – which was an appropriate abbreviation! Thoughts of the chemo had plagued my head for weeks, so now that I was chained up to it, there was no turning back – a phrase I was to use so often! To add to the stress, my second radio therapy session turned out to be painful, with the mask cutting into my face, as it was far too tight. The mould crew came and adjusted it slightly, but I still found the 20 minute session an ordeal as the routine required that the mask be clamped into position, restricting any movement of the head. Next came the Dietician who wanted to add to my torture regime by having the awful sweet, sickly Forti Juice and Cal Shots added to my diet, as the double dose of chemo and radio therapy would further increase my metabolic rate. The fight now was to keep up a high energy calorie input.

10th April, 2013

The team landed – the RT Consultant, a doctor and ward sister. I was reminded of how serious my cancer was and why the treatment took so long to plan. Again, that lymph area was of concern, as the site was in a delicate area, so hence the mask. Extra time (7 days) had been allocated to RT. The norm would have been 15 days treatment, but mine was increased to 22 days. There was no guarantee the tumour would reduce in size with all this treatment. They would just have to see how I responded to it all. If it worked, it would give a better

chance for surgery. I was reassured that Prof. Reynolds had accepted me for surgery, due to my fitness levels.

And so the days turned into weeks with my stay in St. Luke's, turning out to be 7 weeks, not the 2 planned for. Yes, the sickness came with the chemo and my poor oesophagus got hammered with the RT, causing oesophagitis. I was really sailing in that Southern Ocean now! With so many drugs all fighting for their space, my body was confused with the onslaught – anti-sickness drug painkillers, thick creamy food supplements, steroids, Benylin based pre-meal mouthwash for swallow, procal shots..... to mention a few!

18th April, 2013

The second chemo drug was administered, Cisplatin, with a whole regime before and after taking the drug, to protect the kidneys.

By May 1st, I had a crisis with the oesophagitis, so I was handed over to Prof. Reynold's team in St. James's. With the bank holiday coming up, it was decided I'd have a T.P.N. or N.G. – a tube is inserted down your nose to your stomach, if the oesophagus is not too inflamed. It was the preferred form of feed, as opposed to the PICC Line, where the line is inserted through the arm into a bigger vein up near the collarbone. I met Prof. Reynolds, donned in cap and gown in the prep room before going into theatre. He gave my feet a wee shake to acknowledge me and I knew I was in good hands. This was a trial run ahead of the big op and gave me some insight into what lay ahead. I had an OGD (oesophageal gastro dilation) and an NG (nasal gastric) feed into my jejunum. Unfortunately, the big tube was stitched into my Septum, causing much pain, discomfort and distress. My nose dripped and pulsated and of all the lows in my journey, this had to be one of the most distressing.

Despite all the torture that I endured, I did emerge out of St. Luke's at the end of May with a much clapped out body. The real task now was to build up my strength for the biggest challenge ahead – my surgery! The fear of this overshadowed everything else that happened to me. It would only be in time that all I had gone through in the past months, would be faced. That summer, I was on a mission. I knew the importance of a healthy heart and respiratory functions. Tennis and walking were my daily routine. They helped to keep my head space and I enjoyed them. I caught up with family and friends and decided not to leave the country despite the fact we had a flight to Nice booked. I had a real homing instinct. After my long stay in hospital, the comfort and security of

home was all that I wanted. I was finished with St. Luke's and officially in St. James's team care now.

25th June, 2013

I had another endoscopy and dilation. Joined the rush hour traffic at 08:30 and had over a 3 hour wait before I had the procedure. I was now used to the hospital scene and was calmer, having had these procedures before. I also had another Pet and CT scan. Waiting for the results of these was excruciating, but TG they showed the cancer hadn't spread.

27th June, 2013

Back to James's where I met with Prof. Reynolds. While waiting on the corridor, I overheard the nurse tell a Dietician that I was post treatment and pre-surgery. So "yes", this was like winning the jackpot! I recalled that the staff in St. Luke's had always specified that being offered surgery was a good thing – a chance of survival! Up to this date, it wasn't confirmed, so going from a state of sheer dread of surgery to gratitude that I could actually have it, made me realise how much I had changed my attitude, since my initial diagnosis. I had read the details of the surgery, so was able to ask the surgeon certain questions. He said "shure you don't want to know all the anatomical details", but I said I did! Then he told me that since the tumour was in the middle of the oesophagus, that I had to have 5/6th of it removed. Doing the maths, this meant 25 centimetres off from a 30 centimetre gullet. Also, because of the cancerous lymph node, entry through a third incision in the neck would be necessary. Thus, a major piece of plumbing, with risks to the heart and lungs, because of the awkward position of the oesophagus. Already both had been compromised by the RT, he confirmed. I already knew this from the rotten cough and more breathlessness I was experiencing. He was very pleased to hear I was back on the courts and encouraged this more. He apologised for the delay in seeing him and shook hands when I was leaving – a gentleman as always and a lovely man. I felt safe in his hands. He suggested I take the video "The Patient Journey" which I got from the GI nurse, who admitted, even she hadn't seen it. Few patients did! I decided to pick my time to watch it.

It was all a whirlwind of information once more to absorb and as always, I took the knock full on and processed the consequences of what lay ahead in the weeks to follow. The enormity of what faced me was gargantuan.

15th July, 2013

I had to return to James's for pulmonary function tests, chest x-ray, and 7 vials of blood to check every aspect of my bloods before surgery. I came home with more distressing details about the surgery. The senior GI nurse gave me a pre-op chat and informed me that my right lung would be deflated and a floating rib removed. The so called "back incision" now turned out to be from under my right breast up to my shoulder blade; the other incision down the middle of my abdomen as far as my belly button plus the third incision at the neck, all reiterated the barbarity and butchery of the 7 hour operation. Then the high risks were explained to me – like infection due to leakage from the join from my remaining oesophagus to my "pulled up" stomach. I would never be able to lie down again and would have to sleep propped up. I was asked if that Monday, 22nd July suited me for surgery, but Prof. Reynolds said he'd only do the op when I was mentally ready. So I was let decide my date. I chose the furthest date I could, i.e. 9th August, which was over 3 weeks away. It meant July was still mine and I also avoided a bank holiday weekend, knowing how these work in hospitals. I could also fit in more tennis! Like getting my symptoms seen to, here I was again putting off the evil day! The GI nurse did admit the Gods had a role in all of this, so I knew I was winging it now. I had to face the inevitable, but with a small extension of time, "to sort out my affairs", which the nurse reiterated I should do.

I braved looking at "The Patient Journey" video with my sister about 10 days before surgery and the following was what faced and informed me:

Approximately 200 new cases each year are faced with a diagnosis of oesophageal cancer. An early diagnosis gives a good chance of coming out alive. Out of every 100 patients diagnosed, 50% will be offered chemo, RT and/or surgery. This means the cancer is localised. Key elements of the treatment involve staging, which includes Cat and Pet scans, combined with endoscopic ultrasound. A multidisciplinary team reaches a consensus recommendation for the patient's management. Because the operation is performed in the abdomen as well as the chest and because both compartments are operated within the risk of problems and complications, the risks are greater than for most other operations that are commonly performed.

- 1) The major complication is pneumonia, which occurs in about 20%. In some cases, the patient needs to go back into ICU for ventilatory support.

- 2) Another complication is failure of “things” to heal properly. This occurs in approximately 5%, which can lead to a significantly prolonged stay in hospital.
- 3) Clearly, the most important risk of any major operation, is the risk of dying from the complications of surgery and in St. James’s cases, in their series of over 500 cases, 4% is consistent with the results reported from the best oesophageal centres internationally.

What is the cure rate for oesophageal cancer?

Where it presents confined to the area of the oesophagus, this depends on how early the diagnosis is and can range from an overall cure rate of 40% to much higher if it’s been caught at an earlier stage, or if the chemo and RT that’s given has had a dramatic effect on the cancer.

On reflection now, I wasn’t in the 20% who get pneumonia after surgery. However, I was in the 5% who had “failure of things to heal properly”, but at least I missed the 4% who die. In the video, it was very sad to see Prof. Hollywood speak, as only weeks earlier, he had passed away in St. Luke’s two doors away from me. His untimely death had a profound effect on me and made me more determined to fight my illness, if only for his sake, as his shortened life – aged 53 years – was spent fighting for cancer patients. He became a household name over a decade ago for his role in devising a plan for the roll out of radio therapy services across the State. He was a kind and caring doctor and his patients adored him. Other features of the video kept haunting me. The words “it is viewed as a very major surgery”, “we consider it to be a big operation”, “it’s a very major operation”, were all said by all those speaking on the video - the number of drips and drains – 6 in all – that would be attached to me after surgery.

Note on Post-Operative Care.

In HDU/ICU, there is one nurse to one patient. You are attached to a cardiac monitor to check heart rate, blood pressure, breathing, oxygen level. It is usually 2 to 3 days in this unit. The following drips and drains are:

- 1) Oxygen mask.
- 2) Drain in right side of chest to allow the lung to re-expand.
- 3) Tube in the nose down into the stomach to drain away any excess gastric fluid.

- 4) Tube going into the abdomen that sits into the small intestine to allow you to feed and give you nutrition.
- 5) Line going into a large vein in your neck to give fluids and medications.
- 6) Urine tube – catheter into bladder to drain away urine into a bag.

Pain will be controlled using epidural catheter – small line that sits on the back to give pain relief.

So long as blood pressure and heart rate is stable, you'll be encouraged to sit out of bed after surgery. After the epidural is stopped, a machine called patient controlled analgesia is given to the patient to deliver strong doses of pain relief by pressing a small button, the machine set to release only an allowed maximum dose.

When the last day of July came, I felt that sense of being on that run-away train, with the inevitability of reaching the crash site. The video details played on my mind. I was wrapping up meeting with close family and friends at this stage.

It was August now and the month of the biggest challenge of my life had arrived. We went to a Paul Brady concert in the National Concert Hall on 1st August and sang along to some of my favourite songs – “The Island” and “The Long Goodbye”!!

2nd August, 2013

It was down to “this time next week”, so countdown was ticking loudly now. We took a trip out on the Dublin Bay cruise boat from Dun-Laoghaire to Howth. It was a blustery day with big swells out on the bay, again reminding me of the big swells facing me, as I always had sailing images to compare with what was happening to me right from the start.

3rd August, 2013

I recorded about a very frightening, horrific, suffocating presence leaning on my body that night. I could feel a huge weight on my chest and couldn't move. I could hear myself calling out for help, but to no avail. I awoke scared and in tears. Two neighbours called the following day with homemade buns and a jar of Manuka honey. Texts and cards were pouring in.

5th August, 2013

The Monday of the bank holiday weekend, I went to Glendalough with my husband and daughter and we walked the route along the boardwalk up behind the lakes and back down the other side – spectacular views and perfect day.

7th August, 2013

I record having my “last supper”! On that day, I went over to St. Luke’s and met with Fr. Tom, the Chaplain there, whom I had become very friendly with. He dropped in regularly to have a chat. He always made me laugh and kept my spirits up. The Psychologist was also keen to meet me, as she took great interest in my story from the start. She reaffirmed her faith in my positive attitude and mental fortitude in dealing with all my illness and what faced me, recognising my vulnerability and my acceptance of it. Lots more tears on display that day and the box of tissues was proffered. She had dropped in to me a few times when I was in St. Luke’s, so we had that bond. I also met a close friend for coffee in St. Luke’s that morning, as it was the most convenient location for our final get together for some time.

8th August, 2013

09:00 - I had a final game of tennis with a singles player friend, whom I had played tennis with for about 30 years. I gave her the two boxes of tennis balls I had and put my racquet into the boot of my car, knowing I wouldn’t be using it for some time. (I look forward to that day still, at this present moment in time!) Took a walk down the West Pier in Dun-Laoghaire after that. My final record in the daily diary I kept was “life will never be the same again”. I knew the surgery was going to be radical, but if it saved my life, I’d have a price to pay. Checked in to St. James’s around 4pm.

My phone was on the go all day with family and friends all praying for me and sending their love and support. I sorted out thank you cards and upcoming birthday gifts for my mother and brother, whose birthdays were in August. It was a glorious hot summer’s day and I savoured the last hours of freedom. I had a final shower before going to the hospital and wept thinking of what state my body was going to be in after the surgery. When I was eventually admitted to the ward in the hospital, it was all systems go, with numerous forms to be filled in by nurses and doctors who attended to me. I had my bloods taken and another chest x-ray. Prof. Reynolds landed with the “team” which I found very intimidating, with a large presence of people surrounding my bed. I told him I had played tennis, walked the pier, watched the video of “The Patient Journey”

and hoped he slept well – must have been the nerves with all this outpouring from me! My husband, daughter, mum and sister all called in to see me that evening. It was down to immediate family now and for some time to come! I had to sign a consent form for the surgery later on and all the risks were, again, spelt out. All my questions were answered. One of the doctors who attended to me that evening reiterated all my positives, i.e. small build and fitness levels again came up. I recorded “with just hours to go and the last drops of water down my gullet, I must surrender and let go. Please Jesus keep me calm and trusting”. Months of build-up to this day had tested and pushed me to the limits of my sanity. I wrote “here’s to a new configuration internally that I hope will be the solution to my illness and that they turf out all the cancerous parts”. I brought in a flask of hot water so had my final cuppa with my beloved sister, circa 9.30pm. The hospital tea at 6.30pm was a ham salad, with two slices of brown bread. I record “that’s it for a while now until my body readjusts to a new swallow and PG, the auld stitching of my “pulled-up” stomach to my tiny remaining piece of oesophagus, takes without leaks!” As it happened, this did prove another major challenge on my journey.

11.53pm Over and out!

9th August, 2013

The surgery did go ahead despite a question mark over whether a HDU or ICU bed was going to be available after the operation, which delayed my surgery start time. I don’t want to go into all that happened post-surgery. Suffice to say, just over a year now since I’ve had it, I did survive. The prolonged stay that Prof. Reynolds mentioned in the video, turned out for me to be 8 weeks! He and his team got me through this very challenging time and I owe them my life, making me only too aware of the fragility of life! It is to this end that I am contributing to Cathy’s book. While it has been very difficult to trawl back over the past 20 months, I feel that my story should give hope to anyone faced with the diagnosis of oesophageal cancer. I am living proof that you can survive it despite all the adversities that can arise. Staying positive and having a good attitude are key to survival. Accepting all help and support from family and friends is also important. Learning to let go is another must. Fitness is also an added bonus, both as preparation for the traumatic surgery and to aid recovery. Recovery is slow, so one must be patient and not expect a resumption of normal activities, if ever.

While I'm not back on the tennis court or climbing mountains, I am able to get out for walks and drive again. My body will never be the same again, so rather than bemoan all I cannot do now, I try to focus on all I still can do. I wake up every day and thank the Lord I'm still alive. I want to be alive when I die!!

'Life isn't about surviving the storm but how you dance in the rain'

...ENDS