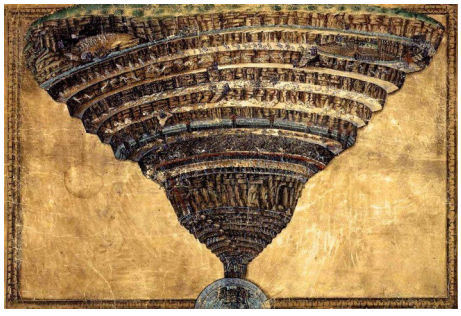
The Devil Inside

The Last Days of Summer



The Devil

I first met him on 30 May 2022. My wife had been unwell for a while and 2 weeks earlier her GP had sent her to hospital for an urgent assessment which included a chest CT scan which I was now looking at. And there he was, a pale blob in her right lung. He was the devil and he had brought his little demons along just for good measure and they were sitting in the lymph nodes in her neck and around her trachea. My beautiful wife had lung cancer. It was her 65th birthday and our lives would never be the same again.



The Road To Hell

We will never know when he first decided to pay her a visit but it was probably around the end of 2019. In

March 2020 we were in Nepal and my wife started to get increasingly short of breath while walking uphill. Our trip was cut short by the first COVID lockdown and we returned to the UK. The little outside exercise allowed was not unduly taxing and her symptoms settled. However, as restrictions were lifted and we were able to get out and about more it was clear that the breathlessness had not gone away.

My wife had had some mild chest pain and intermittent shortness of breath a few years earlier but extensive investigations including CT scans failed to find a cause. The CT scans at the time certainly did not show any devils inside her right lung so we have a pretty good idea when he came to call. At the time her doctors suggested that it might be asthma and prescribed inhalers but with little effect.

As 2021 gave way to 2022 the shortness of breath going uphill became quite an issue but she had no problems walking miles on the flat. Then the cough started. Just a dry, tickling cough that was more a nuisance than a problem. Things came to a head on 25 May 2022 which was our 16th wedding anniversary. My wife had severe chest pain and shortness of breath at rest. A phone call to her GP prompted an urgent referral to the local hospital for assessment. I thought that she had had a pulmonary embolus or possibly COVID. She wasn't kept in hospital and her chest pain subsided. She was made a follow-up appointment with a consultant chest physician for 30 May. Our alarm bells started to ring when on Googling the consultant we learned that one of his specialty interests was Lung Cancer. They were further agitated when we were shown into the consulting room by a MacMillan nurse.

The consultant explained the CT findings and showed us the scan images. He declined to give a firm diagnosis without histology but it was clear to all what we were likely looking at. I am a retired consultant surgeon and I knew exactly what we were looking at.

My wife had an ultrasound guided biopsy of the lymph nodes on the right side of her neck on 6 June and we met up with the consultant for the results on 13 June. Unfortunately, they confirmed our worst fears. It was indeed metastatic lung cancer. To be precise T3N3M0 stage 3B non small cell adenocarcinoma. Stage 3B lung cancer is incurable. It would be later upstaged to stage 4.

My wife had never smoked (unless you count a couple of Balkan Sobranie as a student), swam 100 lengths twice a week and shunned all processed foods. In short she was fit and healthy and not what one would call a typical lung cancer patient. This diagnosis was a complete surprise to us and her GP. Further molecular marker studies on the biopsies showed that she had a particular mutation EGFR+. The EGFR+ mutation is found in around 10-15% of lung cancers and is more common in people who have never smoked or only smoked a little. It is also more common in younger women.

While we remained calm and professional throughout the consultations and information giving when we got home we simply dissolved. Statistically, stage 3 lung cancer has a 15% 5-year survival rate. Only 58% of people live longer than 12 months after diagnosis. And while these are generalised population statistics and every patient is different my wife's outlook was very bleak and I can say with confidence that 13 June 2022 was the day our lives changed forever and all the plans for our future lives together fell apart.



The Journey

Midway upon the journey of our life I found myself within a forest dark, For the straightforward pathway had been lost

Dante - Inferno

My wife was made an appointment with a clinical oncologist for 24 June 2022. Before the appointment we researched everything we could about the devil and how to kill or at least contain him. Much to our surprise and relief the oncologist said that there was a new drug just out of clinical trials that specifically targeted the EGFR mutations in the cancer cells. Moreover, this was a tablet taken once a day, not intravenous chemotherapy. This was the first bit of positive news we had been given. My wife had resigned herself to intravenous chemotherapy and all that entailed. To be able to take a single tablet at home was a huge relief.

She was started on Osimertinib (Tagrisso) on 5 July 2022.

It is worth emphasising at this point the truly excellent service that we received from the NHS. From the point of initial referral with symptoms to starting treatment after a full workup with imaging and histology was only 41 days. I think this is extraordinarily impressive given the huge pressures the NHS was facing at the time. All the staff involved with my wife's treatment and care were hugely professional and kind.

My wife is a very private person. She was adamant that she was not going to be defined or labelled by her disease and was equally adamant that she wanted nobody outside the household to know. We told our eldest son as he was living at home and my brother but that was it. The MacMillan nurse and GP were pushing her to "open up" and tell family and close friends but my wife refused. I have deliberately omitted peoples names, especially hers from this account to honour her wishes for privacy and anonymity.

Osimertinib

A once daily tablet rather than intravenous chemotherapy with a mild side-effect profile sounded too good to be true but that's what Osimertinib offered. And for several months it was a silver bullet. There were side effects to be sure. Hair loss, bleeding gums and digestive problems but by and large these were minor. My wife's dentist was superb in helping her maintain excellent oral health and with an intensive oral hygiene regime she reversed the early gum disease. The hair loss caused her much emotional distress, she had beautiful hair but it was partial and set against the chemotherapy side effects it was minor.

More importantly, the Osimertinib was working. She felt well and her breathing was much easier. She was still able to swim 100 lengths twice a week. A chest X-ray in August and CT scan in September showed a 50% reduction in the size of the primary tumour and lymph nodes. The devil and his demons were retreating. We actually started to feel positive, not complacent as the knowledge that the cancer was incurable never ever went away but we were able to go on a few trips to Spain and relax a little. Things might just be OK.

We were walking along the waterfront in Bilbao on a wet Sunday morning in November when my heart sank. For the first time in months my wife was short of breath! Neither of us commented on it but I think she knew what I was thinking. We put it down to the bad weather, it really was raining hard, but a bit of the light had gone out.

We met with the oncologist on 16 December 2022. Sure enough, December's CT scan revealed that while the primary tumour and neck nodes remained unchanged, the nodes around the trachea (mediastinal and carinal) had enlarged. This was dreadful news. It suggested that the Osimertinib had stopped working after only 6 months and conventional chemotherapy would be the only option remaining. It was during this meeting that the suggestion of seeking a second opinion was first raised. We had no complaints about the treatment received, quite the opposite but wanted to ensure that we had explored all options. A suitable expert was suggested who worked at a regional cancer centre not far from us. I will simply refer to him as Prof C. A couple of emails later and my wife had an appointment to see him on 10 January 2023.

Shortly afterwards the whole house went down with the dreadful Flu which was going around at the time. My wife was unable to get out of bed for 4 days and lost over 10Kg. This was exactly what was not required. Sure enough, her December blood test results were off and her oncologist took her off the Osimertinib. This was the second low point in our

journey. My wife felt crap, she felt she looked crap, she'd been taken off her silver bullets and her metastatic nodes had enlarged. We had a grim Christmas but made the effort all the same. The trees and decorations went up, Christmas dinner was cooked of which my wife ate hardly any. Our traditional boxing day with our daughter and her partner was enjoyed with them in ignorance of the true situation. My wife went back to bed.

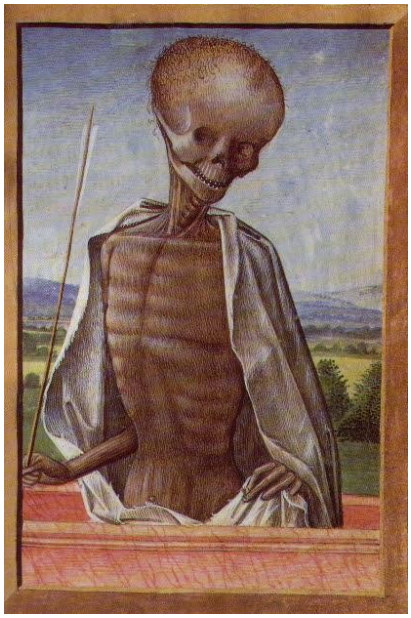
It was with much effort and cajoling that I was able to take her for her blood tests on 3 January which thankfully showed a marked improvement and her oncologist felt able to recommence the Osimertinib. The Flu symptoms improved although they had not completely gone but she looked and felt better and was actually gaining a little weight. This was good news.

Not Happy

We had a further consultation with the Oncologist on 6 January. For the first time I felt that perhaps we were not being told the whole story. From our point of view the situation did not make sense. The primary tumour and neck nodes were still being held in check so the Osimertinib must still be having an effect yet the mediastinal and carinal nodes had enlarged. Why? I expressed surprise and the oncologist opined that they were also surprised and did not know why. My wife had a biopsy of these nodes on 20 December. Histology confirmed the same pattern of adenocarcinoma as before although they were sent off for molecular marker studies to see if anything had changed. To our way of thinking there might be a role for radiotherapy, particularly proton beam therapy to the mediastinal and carinal nodes. Surely, we said, selectively targeting these areas which had escaped Osimertinib control made sense? The oncologist was having none of it. Indeed, he actually tried to scare us by saying radiotherapy could end up with my wife needing a feeding tube! I felt that this was unprofessional and unkind.

A few weeks previously one of the national newspapers had exposed that the NHS was restricting access to radiotherapy on cost and capacity issues. Apparently only 27% of patients deemed suitable for radiotherapy were being offered it. As the meeting progressed it became clear that the option of radiotherapy had not even been discussed by the MDT (Multidisciplinary Team). So here we had a situation where my wife's oncologist who openly declared he had no specialist knowledge of radiotherapy had unilaterally decided that radiotherapy was not an option. He knew I knew this was all about funding. I was polite but firm. I wanted radiotherapy discussed with the radiotherapist at the next MDT meeting. If radiotherapy was not an option I wanted the radiotherapist to tell us why not. Pointedly, the

oncologist then offered to increase the frequency of review appointments from 3 months to 1 month with a further CT scan in 3 months. The MacMillan nurse was very keen to know the outcome of my wife's consultation with Prof C. I got the distinct impression they were worried about what Prof C might say which is a pity because up until this meeting we had no complaints at all about the treatment and care received.



The Evil Spirit

The evil spirit is the devil's helper. It sucks all the joy and happiness from our lives. The evil spirit is inside her every waking hour. It is there when she goes to sleep, it is there the moment she wakes and it is there any time her mind is not engaged on something else. And of course it affects me the same way. But I am not the one dying here. She is constantly aware that she is living on borrowed time and that treatment options are limited or non-existent.

It is the inevitability of the course her disease will take and the knowledge that there is absolutely nothing she can do to change it that is so corrosive. I am helpless. My heart is broken.

I have already made mention of my wife's desire for privacy and her determination not to be labelled or defined by her cancer. She shunned all offers and suggestions of what I might call traditional support mechanisms. The health care professionals that she came into contact with may have misdiagnosed this as denial. They would be in error to do so. My wife is a supreme pragmatist. So borrowing a line from Mark Rylance in "Bridge Of Spies" we would both ask of any suggested therapy/support "would it help"? The answer was invariably no it would not.

We don't have the same relationship as we did before he came. It's not worse but it is different. We can never truly relax and be at peace. We don't make love any more. We occasionally cry together and hug but we only talk about the practical things we can do to make things better or easier. In a bizarre way I think it has made me a better, more tolerant person. Less quick to judge and criticise. When she has a bad night and can't sleep I am thankful she is still with me. I'll get up and make us a cup of tea and we will chat for a while. Back in the day I would have been Mr Angry for having my sleep disturbed. What problems could I possibly have in comparison to hers? Sure I am sad but I am not the one dying and

she does not complain.

Seriously, I think in the whole time she has actually said "I am going to die" only twice. Would it help to dwell and ruminate on the situation? No it would not. Would it help to talk about our feelings and problems to total strangers? No it would not. How could it?

In the early days I disagreed with her decision not to tell people. I wanted to tell our children, family and friends. But when I thought deeply about why, the answer was because I am selfish and was looking for sympathy for myself. How shallow and pathetic is that? My wife is dying and I'm looking for sympathy.

Some days we are strangers. Keeping our own demons at bay. Looking for the strength to face a new day. I think it's a bad cliche to say we should live each day as if it's our last. It was probably written by someone who has never actually been in this situation. It is simply not possible. There are too many household chores to do for that but we take the pleasures where we find them. Booking foreign travel trips is important to us. Having the dates in the diary. We never mention the elephant in the room. What good would that do? Just getting on with life as normal is important. Cooking, shopping, watching movies, listening to music. All the things we enjoyed doing together before he came. Being able to entertain or just talk to friends and family who don't know the situation means the conversation flows naturally. There are no pregnant pauses. No films or books that can't be discussed or music listened to because they might be too sensitive. Above all no sympathy, false or otherwise.

My wife and I are not religious but I find the words of the serenity prayer often come into my mind:

God grant me the serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference.



A Second Opinion

We met Prof C on 10 January. Our aims for the meeting were to allow him to review my wife’s diagnosis and treatment to date and to ask if he felt any other treatment options were available to her, including targeted radiotherapy. Being

attached to a regional cancer centre we felt he would have knowledge of, and access to any appropriate clinical trials.

My wife was very apprehensive about this meeting even though it's for a second opinion she was terrified Prof C would opine there are no other treatment options available for her.

In the event the meeting was extremely positive. Prof C felt that the carinal and tracheal node enlargement may be inflammatory and a reaction to the bad chest infection and not necessarily due to cancer progression. It was too early to say whether the Osimertinib had stopped working. He also said that if it was due to cancer then targeted radiotherapy may well be an option. This was wonderful news. More investigations were going to be needed and he would take her on as a patient. My wife was so happy to hear positive news for a change. The only negative news was that he said 1:4 patients with stage 3 lung cancer have brain metastases! This had never been mentioned before. Certainly her oncologist had never discussed it. Prof C told us it was important to check as if they were present he would need to modify treatment. He also warned my wife that if a brain scan did show metastases she would have to stop driving. My wife agreed to have all the investigations he suggested. We can work around her not driving if she is alive and well.

The difference between Prof C's approach and what he could offer my wife compared to what we had experienced to date was huge. My wife said that one of the nurses had told her "if we take you on as a patient we will never give up on you". Wow!

We felt my wife now had access to the best possible opinion and treatments available. A little light had been turned back on.

The Journey Continues

The light has just faded.

We met up again with Prof C on the last day of January. The good news was that there were no signs of brain metastases so no need for my wife to stop driving which was a huge relief. The bad news was that the PET scan had shown that the hilar and carinal nodes had continued to enlarge as had the primary tumour and there was now evidence of a pericardial effusion (fluid around the heart). This meant that radiotherapy/proton beam therapy was no longer an option. Prof C told us my wife now had a life expectancy of only 18 months. Nonetheless, he offered her the option of going onto a clinical trial which she instantly accepted. This meant she might be offered the current best available treatment or one of

two new treatments. It would entail regular visits to the Regional Centre for treatment and scans and mean we would need to cancel the two upcoming foreign trips we had booked to cheer ourselves up but we both felt being in a clinical trial would give the best chance of improving her quality of life for as long as possible. Moreover, we were confident that the diagnosis, prognosis and treatment options were the best available and put our faith in Prof C to do his best for her.

The only way to deal with this is by being positive. We had been given a window to organise our lives and in particular to get my wife's financial and personal affairs in order. While our hearts were breaking we both knew it would be madness to waste the time she had left. We try to find joy where we can but it is so hard. There was no cheating the devil inside but he would have to wait a little longer.



The Black Dog

The black dog comes to me in the small hours of the night, every night. I know he visits my wife too. Anxiety, worry, sadness. Night after night. It is so corrosive.

A new day the same as yesterday. But I must push these feelings aside. My role is to support her anyway I can. To listen. Always positive. I love her so much. I cry by myself. I am crying now as I write this but it is my comfort and release. I have to be strong. I will be strong. I am strong.

We both long for the simple pleasure of a restful night's sleep in our own comfortable bed. Just holding hands until we drift off. I think this is what I will miss the most when he finally takes her away from me.



Mariposa 2 Clinical Trial

Mariposa (butterfly in Spanish) was the name of the clinical trial that my wife was hoping to be recruited into. On 8 February 2023 and after being sent a 34 page patient information pack she had a face to face meeting with a research nurse to get her informed consent. This was followed by an extensive series of investigations over the next two weeks to ascertain if she was suitable to enter the trial proper. It was a very anxious time waiting to see if she would be accepted or not.

On 16 February we heard that she had successfully passed all the pre-trial investigations and had been provisionally accepted. Unfortunately, there was some confusion and miscommunication from the trial team which resulted in a delay in my wife actually starting the new treatment. This delay only added to our stress and worry. We were starting to wonder whether she would have been better off accepting the 4-drug chemotherapy regime advocated by her local oncologist. Time she did not have was passing and the devil inside her was getting bigger and stronger.

However, things got back on track and she was finally accepted onto the Mariposa 2 trial. She was randomised to the standard chemotherapy (carboplatin plus pemetrexed) arm of the trial and received her first cycle on 1 March. All we can do now is hope this new treatment is effective.

The sun will rise again tomorrow, who knows what the tide will bring in?

Tom Hanks - Cast Away

Despite some tiredness on the days after the chemotherapy my wife managed very well. We even managed to get away for a week in the sun even though it meant she had to fly home a day ahead of me for the obligatory blood tests followed by the second cycle of chemotherapy the following day. The break was a life saver and allowed us to reset. The trial team was amazed how much exercise my wife was able to do and all her blood tests remained good. This was how we wanted things to continue for as long as possible. There would be no point in going through with the trial if it did not confer a positive benefit to her quality of life and our time together.

Towards the end of April 2023 we got some really good news. The latest CT scans demonstrated that there had been around a 45% reduction in the size of the primary tumour and metastases. Prof C's team told us that this was pretty unusual as more often the chemo just halted disease progression or did not work at all. All the blood test results remained in the normal range so Prof C decided to add an additional treatment cycle.

As usual the weather in the UK was miserable so we decided to escape to the sun again. We flew out the day after the fourth cycle of chemotherapy and flew back the day before the fifth.

Spring slipped into summer and our lives got back to some sort of normality. We had a lovely break in Portugal in July. August was wet and miserable. Autumn was in the air.

My wife had completed 8 cycles of chemotherapy and was complaining of pain and swelling in her right neck. All her blood test results were fine, in fact as a result of an intensive vitamin and supplement regime they were actually better than they had been for months. On 16 August she had her pre-cycle 9 investigations and to our horror the MRI showed that she had developed brain metastases! This was totally unexpected and devastating news. Prof C came to see her personally in the clinic and was hugely supportive and discussed options but left us in no doubt that we were now in the final stages of the disease and her life. She could not continue on the Mariposa 2 trial now that she had brain metastases and so did not have her 9th chemotherapy cycle. One of the options was a different chemotherapy but the side effects were dreadful and even if it worked it would only buy her a few more months of poor quality life. My wife declined the treatment even though this meant she would not be eligible for radiotherapy to the brain metastases.

Mariposa 2 had been a beautiful, but short-lived butterfly.

The Last Days of Summer



My wife looking across to her favourite beach and the lighthouse at Cape Trafalgar - September 2022

We pushed Prof C for other options and he offered to investigate the possibility of palliative radiotherapy to her neck to control the increasing pain. We went back to our hotel room numb and distraught but went out to dinner as planned and actually had a nice evening. It's amazing how the brain shuts down at times of overwhelming stress.

A couple of days later a radiotherapy colleague of Prof C's conducted a telephone consultation with my wife and agreed to take her on for a course of palliative radiotherapy. He was totally professional and supportive and while we all knew this was no cure at least we felt something was being done. The radiotherapy could not come too soon as my wife was experiencing increasing pain in her neck especially at night which kept her awake and robbed her of any energy the following day.

A few weeks before we got the dreadful news about the brain metastases we had booked a short trip to Iceland. We were trying to pack in as much travel and quality time together as we could before the inevitable happened. With luck the radiotherapy should be completed a

few days before we were due to fly and we were hoping that she would be well enough to travel.

The appointment came through for a planning CT scan for 30th August 2023 to be followed by 5 doses of radiotherapy. The days leading up to the radiotherapy were particularly stressful. My wife was continuing to get pain in her neck which was now visibly swollen. She was terrified that something would burst and cause a massive bleed. It was also a time when she began the process of putting her financial affairs in order. We were both depressed, anxious and scared.

We met up with the GP on 5 September who was very kind and supportive. She put lots of things in place that we could access when needed. My wife told her that she did not want to be admitted to hospital under any circumstances and wanted to die at home. I asked the GP what I should do and who I should call when my wife died. It was the hardest question I have ever asked. I just cried.

My wife completed her palliative radiotherapy the following day. It had been tough going for her not least as we had to get up at 4:30 every morning to drive to the Regional Centre but it did ease her pain and although she was fatigued and had to sleep during the day she was able to sleep a little better at night. That day was also when she completed her trial exit questionnaire and had her final blood tests. It was a very emotional scene at the hospital. Many of the staff had become friends during her treatment and were very upset for her. There were hugs and tears. It was like leaving a job after a long and happy time but unlike that scenario my wife would not be going onto new pastures.

Amazingly, a few days after completing radiotherapy the neck swelling started to go down and the pain virtually disappeared. Although my wife had a really sore throat we were able to fly to Iceland as planned and had a wonderful happy time together.

She had follow-up CT and MRI scans in the last week of September. Unfortunately, by 28 September she began to feel very unwell with a persistent cough and breathlessness. Her GP felt it was a bad respiratory infection, possibly COVID. She was so unwell we were unable to travel to the Regional Centre for a planned follow-up with Prof C. We were desperate to know the results of the scans and as always hoping for the best but expecting the worst. Prof C telephoned my wife at home when he was told she was too unwell to travel. The news was even worse than we feared. All the tumour sites had grown and there were more brain metastases which were now producing some brain swelling. Prof C told my wife (because she asked) that she probably only had 2 or 3 months left to live. We were utterly devastated. My wife might be dead by Christmas!

Her condition then deteriorated rapidly. Her cough worsened. She had constant pain in her chest and limbs that no drugs could ease. She had nausea and vomiting that no antiemetics would prevent. She was unable to lie down and sleep and became increasingly breathless. By 4 October she was in a really bad place and just wanted to die, but at home not in hospital. The following 24 hours were harrowing as she continued to decline and I was powerless to help other than holding her close - which now hurt her. By midnight she could take no more and asked me to phone the Goldline emergency contact number. Not to be admitted but for someone to give her enough painkillers to ease her passing. Paramedics arrived very promptly but were unable to relieve her pain or breathlessness.

She passed away in our own bed at home while I held her hand in the early hours of 5 October 2023. She was 66 years old.

He had waited 16 months but the devil had finally taken her from me and had broken my heart.

The moving finger writes; and, having writ, moves on: nor all thy piety nor wit shall lure it back to cancel half a line, nor all thy tears wash out a word of it.

Omar Khayyam

Epilogue - Satori

In accordance with her wishes my wife was cremated and her ashes were scattered in the surf along her favourite beach at Cape Trafalgar.



Me scattering my wife's ashes at Cape Trafalgar on March 10th 2024 - Mother's Day

And the individual atoms, cycled through her body and then cycled through wind and water and soil, cycled through generations and generations of living creatures and minds, will repeat and connect and make a whole out of parts. Although without memory, they make a memory. Although impermanent, they make a permanence. Although scattered, they make a totality.

Mr G. Alan Lightman

I started writing this account on 30th May 2022. This was my wife's 65th birthday and the day we received her diagnosis. I wrote it to help me with my pain and sadness and as a permanent record of our last days together. Much of it was written as a diary, on the days the events occurred or shortly after. I wanted my raw emotions and thoughts to be recorded as I felt them at the time and not viewed through the perspective glass of imperfect memory.

I showed my wife an early draft when she had just started chemotherapy. After reading it she said she knew that I loved her.

The Return Of The Light



It is 3 years since I last wrote anything here. Much has changed. I am not the man I was. I am whole again, but I am not the same. When I first read the words of Elizabeth Kubler-Ross I did not believe healing was possible for me, my grief was all consuming. But I have healed and I have found peace and happiness. At the very least I am not suffering.

I had a grief counsellor. I have a daily mindfulness practice. I believed healing was possible. I joined an online grief group. There I met my “grief buddy” who became “my person” for unconditional companioning. I have started to travel again. I volunteer at a local hospice. In short, I said “yes” to opening up to new experiences and healing. As I walked on my way my way appeared.

I wrote The Devil Inside as a way of helping me navigate the earliest days. It suddenly came to me last night that my story is incomplete and that somehow it is important to tell the rest of it. To show to anyone who reads it that my journey did not end with scattering her ashes. Indeed, it was really only the beginning. Healing is possible for every griever. But we have to want to heal. It takes hard work, courage and commitment but the light is waiting for all of us who seek to find it.