

Prologue

"You see," Professor B explained calmly, "what has happened here, Paul, is that your cancer has spread into your liver."

We could hear normal life going on outside on the corridor at Saint Luke's Hospital in Dublin. But there was total silence in the small consultation room where my husband Paul and I sat with Professor B to discuss Paul's latest CT and bone scan.

"There are multiple metastases in the liver," Professor B read aloud from the CT scan report on the table in front of him. "Half of the liver tissue has already been replaced by the cancer." With this our worst fears were confirmed. This diagnosis explained Paul's rapid weight loss, his constant feeling of being full, his lack of appetite, his ever-increasing nausea and frequent vomiting, his growing weakness and the frequent stabbing pain on the right side of his body under the rib cage we had observed for some months now.

"What do you suggest as the next step?" I asked with a trembling voice. I needed him to say that there was something we could do. I needed him to say that there was a good chance that we could treat the liver secondaries and get the cancer in the liver under control. I needed him to say that everything would be okay again.

"Well," he said thoughtfully, there is the option of chemotherapy of course if you are so inclined." He hesitated for a moment, then added, "But I would be saying to you: Is chemotherapy even going to work?"

"Right," Paul said, "I understand. It is really serious then."

"Yes, Paul," Professor B replied calmly. "This is really bad now."

"Are there any alternatives to chemotherapy?" I asked. "Maybe something that would be less aggressive?"

"No," Professor B said, "this situation is really bad now. The cancer has become very aggressive and I would imagine it is growing very quickly. As Paul is already symptomatic, we need to use an aggressive treatment. Chemotherapy is the most aggressive treatment we have. And we should start treatment as soon as possible. Time is of the essence here."

We looked at each other. We had always avoided chemotherapy because we had thought it to be too harmful for Paul's body. But it seemed like we had no choice but to go for chemotherapy now if we wanted Paul to stay alive.

"When do you think I can start treatment?" Paul eventually asked.

"I will ring my nurse Anita on the Day Ward now," the Professor said and reached for his phone, "and we will get you an appointment for early next week."

The consultation was over. We got up, thanked Professor B for his time and advice and left the hospital.

It was a warm and sunny day in mid-July 2017. But we did not notice the balmy breeze and the warm sun shining from a cloudless sky. Nor did we hear the laughter of the children who were playing on the nearby playground. For us, our world had just begun to fall apart.

Chapter 1

When Paul was first diagnosed with prostate cancer at Saint Luke's Hospital in July 2003, exactly 14 years earlier, the cancer had already spread from the prostate to his left hip and into some lymph nodes. In the first number of months after diagnosis, Paul received radiation treatment and took part in a trial for a new prostate cancer drug. When the trial ended in 2005, Paul started hormone treatment the purpose of which is to improve quality of life and slow the progress of prostate cancer although it is not a cure. When the first line hormone treatment showed biochemical failure about two years later in 2007, Paul was moved onto second line hormone treatment. When the second line hormone treatment showed biochemical failure in 2009, he was moved onto third line hormone treatment.

Whether the treatments Paul was receiving were working was determined by monthly PSA tests. PSA (Prostate-specific Antigen) is a protein produced exclusively by the prostate gland. Even though the PSA level can be elevated in a man's blood for many different reasons, once a man has been diagnosed with prostate cancer and is undergoing treatment the PSA test can give indications as to whether the cancer is growing and is therefore widely seen as a tumour marker and used to monitor the progression of the disease.

Paul and I met when he had just started third line hormone treatment in June of 2009. I was 27 and living in the small town of Marburg in my native Germany and was doing a course to

become a bilingual secretary. Paul was 59 and living and working in Dublin. We both came to the Shambhala Buddhist centre in Marburg in summer 2009 to participate in a seminar on loving-kindness. Most of the participants on the course were from Germany but there were a few people from France and two people from Ireland as well. The language the course material was presented in was English. But on the second day, some of the course material was presented in German. I was aware that one of the people from Ireland was sitting right behind me and so I turned around and asked whether he would like a translation into English. The man, tall and slim with a kind face, dark brown eyes and thick black curls said yes immediately and pushed his chair closer to mine. Later we would often talk about the instant when I had turned around to him to offer him a translation as a really special moment. To both of us it had felt like a moment of intense recognition.

We became inseparable for the days we had in Marburg. During the course we sat side by side in the meditation hall. During the breaks we would take our cups of tea or our plates with food that had been prepared by other members of the community for us outside and sit on the grass. In the evenings I showed Paul my town and we spent wonderful hours sitting in the evening sunshine at Marburg Castle or by the river Lahn and, once the sun had gone down, we would go for dinner in one of Marburg's many bars and restaurants all the while telling each other about our respective lives and having a lot of fun.

When Paul went back to Dublin, we knew that something incredibly significant had begun between us. We were both confused about what was happening to us because neither of us had expected to meet somebody special and to fall in love. But exactly that had happened to us. We found it painful to be apart, even though we had only just met. We were in touch every single day on email and sometimes with a long phone call at night. And even though we had only just met and were only just beginning to get to know each other, it also felt as if we had known each other forever and we missed each other terribly.

A couple of weeks later, Paul surprised me with an invitation to Ireland and of course I accepted his request immediately. I could not wait to see him again. We had a wonderful week together and it felt so amazing to be physically close to him once more. We spent some of the time in Dublin at his family home where he lived with his mum - and which we had all to ourselves because she had gone on holiday to Italy for two weeks - and the rest of the time in Doolin in the west of Ireland and then for one night on Inishmore, one of the islands off the west coast of Ireland. When I had to leave, I knew that not only had I fallen even more deeply in love with Paul but also with Ireland.

As part of my secretarial course I had to do work experience either in Germany or abroad for two months in autumn of that year. When I told Paul about this, he arranged for me to come to Ireland and work with him at his community employment scheme. So only six weeks after my first visit to Ireland I was back again, and this time I would stay for two whole months. As Paul's mum did not want us to live with her for the two months, we rented an apartment together. It was a beautiful apartment, small but with everything we needed, and we soon felt at home there and began to call it "our love nest".

Living and working together was wonderful and we got to know each other so much better. When I had to return to Germany at the end of the two months, we knew that we wanted a future together and that I would move to Ireland the following summer.

Paul told me about his prostate cancer early on in our relationship.

"It is important that you know about my cancer," he said, "before you make a decision on how you would like our relationship to go forward. You have to understand that not only am I a lot older than you, but I am also not a well man. And we can never have children." He proceeded to tell me about the treatments he had already received and the third line hormone treatment he was currently on.

I listened to him quietly, smiled and then said, "I love you. I want my life to be with you. I will never leave you. And I don't want to have children anyway. So everything is perfect." And it was.

Over the next couple of months, we flew back and forth regularly between Germany and Ireland for long weekends or during holidays. When we were not together, we wrote emails or text messages and spoke on the phone at least once every day.

Our respective families were a little sceptical of our relationship because of our age difference, because of Paul's illness and mainly because everything was happening so quickly between us. We were surprised ourselves of course at the speed with which we had made our plans. But we also knew and, more importantly, felt that what we were doing was absolutely right for us.

Our relationship was truly something extraordinary and different from a lot of relationships I know. When Paul and I met, it felt for both of us as if we had been waiting for each other our entire lives. It was like we were finally renewing an ancient connection again, one that we had been waiting to re-establish for many, many years. We were finally being re-united with our other half or another part of ourselves without which we had never been whole. I think this explains our longing to be together right from the start and our enthusiasm and passion to make it happen. We just could not be stopped by any obstacles - not by the fact that I had to move my whole life to Ireland and leave my home country, my family and my friends behind to step into a completely new life nor by the fact that he had to leave the family home that he had been sharing with his mum all his life. The relationship was perhaps a little unusual because Paul was 33 years older than me, something that never bothered us in the slightest, and because we came from different countries and cultural backgrounds, something which was a little challenging at first but that we both embraced with happiness and excitement. When I visited Paul in Ireland over the Easter holidays in April of 2010, he introduced me to his mum and his two sisters. Paul's dad had died years ago from a rare heart condition. Paul's relationship with his mum and his sisters had always been complicated but had become even more difficult since he had met me and had decided to move out of the family home and build a life with me. For reasons that would be too complex to describe in this book and are unnecessary to explain for the purpose of telling our story, suffice to say that, even though Paul's family and I met and would even have some good times in the years to come, we would lose touch with Paul's mum and sisters in later years.

During Paul's next visit to Germany in May of 2010, I arranged for Paul and my parents to meet. We travelled by train from Marburg to Braunschweig, the city in Germany where my parents lived, and met my parents in a café. It was a lovely afternoon. Despite the obvious language barrier, the three of them got on really well right from the start. I felt it was important that my parents met the man with whom I was so madly in love and with whom I would spend the rest of my life in Ireland. Of course my parents had wanted to meet him too. And Paul, even though a little nervous, was delighted to meet them as well.

In June of 2010, after graduating top of the class from my bilingual secretarial course, I packed up all my things – the ones from my apartment in Marburg and the items that were still at my parents' apartment in the north of Germany – and left for Ireland with three suitcases. The rest of my belongings I had packed into removal boxes that my parents would send on to me once Paul and I were settled. We were so looking forward to moving into the beautiful two-bedroom apartment Paul had found for us in Rathgar, a beautiful part of Dublin's inner city, during the spring.

The summer of 2010 was truly magical. Paul was able to get a lot of time off work and I decided to postpone my job search to the autumn and so we had plenty of opportunity to enjoy the summer. We had fun getting settled into our apartment and with the unpacking of my 17 removal boxes when they arrived from Germany. The weather was beautiful almost every day and we did our yoga and meditation in our large back garden every morning. Paul brought me to all the places he loved in Dublin and it was wonderful for me to see where he had grown up, where he had played with his friends as a small boy, where he had played rugby and other sports as a teenager and where he had gone for long evening walks along the Dodder River in his adult life. We also went on a few day trips into the Dublin Mountains and into the Wicklow Mountains or to the Powerscourt gardens on particularly warm days to go for long walks and have picnics. But one of our favourite places to go was the playground in the park closest to our home where we could spend hours messing around on the swings and in the little wooden playhouse in the evenings when the kids had long gone home. It is that playfulness, that light-heartedness, that childlike happiness and joy that I remember most about that summer. We felt so free and were just so happy together.

In autumn of 2010, when Paul was back at work full time, I started to look for a job as bilingual secretary. But Ireland was in the middle of a recession and getting work as a bilingual secretary in a multinational company seemed impossible. I eventually found voluntary work as a receptionist but left the firm after a couple of months when my request to change my post from a voluntary one into a paid one was declined. I spent day in and day out applying for one job after another, occasionally going for job interviews, and always being unsuccessful. I loved my life with Paul, but I felt frustrated about my work situation.

In summer of 2011, we moved to Killiney in South County Dublin into a small two-bedroom house and even though we were only renting, it felt great to have our own house and so near the coast. We were sure that we would buy our own home one day.

Once we were settled in our new home, I decided to give up on finding a job as bilingual secretary and to concentrate instead on the complementary therapies I had learned years ago in Germany: Reiki Healing, a form of Aromatherapy and Mindfulness Meditation. I felt that there was a need for such therapies within the Irish community and that the Irish were very open to complementary treatments as an addition to their medical care. I sought help from Paul's niece who worked as a graphic designer and website builder and soon I had a business name, a website, a place to work from and my first clients. My complementary therapy practice Healing Well was established and soon flourishing.

Those were happy times. We both had good jobs. We had a lovely house in a beautiful part of south county Dublin. I had begun to feel really at home in Ireland. And Paul was in good health; the only signs that he had cancer were the monthly blood tests and the three-monthly consultations with his oncologist at Saint Luke's Hospital.

We went on a two-week long holiday to Crete that summer. We enjoyed sunbathing on the beautiful beaches and swimming in the warm sea or in the pool that belonged to our hotel. We explored many of the ancient sites with great interest. And we loved the good food and excellent wine.

Of course the cancer was always at the back of our minds. But we were hoping and praying that things would continue really well for us for a long, long time. We felt that we had reason to be hopeful as, after all, Paul's hormone treatments had been working for quite a long time and we felt that he was in really good hands with the doctors and nurses at Saint Luke's Hospital and we still believed that our love and happiness would help him to stay well.

Therefore, it was a shock when we learned in spring of 2014, after yet another blood test, that Paul's third line hormone treatment was failing. The blood tests showed that the PSA level had gone up way beyond the normal range suggesting that the cancer had become very active in Paul's bones again. It was then that chemotherapy was suggested to us for the first time. We did not know much about chemotherapy but the thought of such an aggressive form of treatment frightened us because we felt it might be too hard on Paul's body. Just as we thought we would have no other choice but to go for chemo anyway as Paul's cancer had begun to spread rapidly in his bones and we had been told that chemotherapy was the only remaining option, a new drug named Abiraterone was introduced into the Irish healthcare system. This drug, taken in combination with the third line hormone treatment Paul was already on, was showing great results in men with advanced prostate cancer. Paul's oncologist referred us to Professor B, the leading consultant for this new drug in Ireland from the university hospital who also had occasional clinics at Saint Luke's Hospital, and Abiraterone was added to Paul's treatments soon after. According to research, this drug was going to be effective for two to three years. We were sure that by the time Abiraterone was no longer useful, there would be another, even better drug available to us. For now, we were happy to have been referred to Professor B and to have been given access to this new drug. We had to move house during that time. Our landlord had written to us earlier in the year to inform us that he would have to increase our rent. But we would not be able to pay more than we already did. We were sorry to have to leave our house in Killiney but, thankfully, we found a beautiful one-bedroom apartment not far away in the village of Shankill.

"Love, how does it make you feel that our time together is limited?" Paul asked me one evening when we had just come back from a long walk in Shanganagh Park. On evenings like these, we used to turn our living-room couch around so that it would face the window, switch on Classic FM radio, pour a glass of nice red wine each and enjoy the view of Howth Lighthouse in the dusk. And this is where we were sitting now.

"It makes me sad that we won't be able to grow old together," I said beginning to feel very melancholic. "But I love being with you so much that being with you for a relatively short time is better than not having been with you at all and definitely worth the pain of loss that will come inevitably when I will have to let you go. I love you and our togetherness so much that being together with you even for only a day would be so much better than not having been with you at all."

Paul looked at me with tears in his eyes.

"I never thought that I would be this important to anyone," he said in a low voice. "It is hard to believe sometimes that anyone would ever feel this way about me."

"I love you so much, Paul," I said and hugged him close. "And, who knows, maybe we will have a lot more time than you think?"

In the first few months on Abiraterone, Paul's tumour markers dropped from 150 to 50. We were so hopeful. Then I remember the day in September when, after yet another appointment

with Saint Luke's Hospital to discuss his latest blood test results to which I had not been able to accompany him, Paul picked me up from my work.

"You won't believe this," he said and planted a kiss on my forehead, "my PSA levels have dropped from 50 to 0.2!" I could sense such relief in his voice. We did not care where we were or who could see us or what people might think of us. "Yes, yes, yes," I shouted out and Paul took me in his arms and whirled me around in the middle of the busy street. We were so overjoyed and relieved the treatment was working.

We celebrated the success of the treatment with a trip to the west of Ireland two weeks later. And there, on a mild but rainy day on the cliffs outside the village of Doolin, at a place we had found during our very first trip to the west in the summer of 2009, Paul asked me to marry him. Of course I said yes. I felt he had made me the happiest woman in the whole world and I was so proud to be his fiancée.

The next one and a half years were so exciting. There were all the wedding plans to be made. There was our wedding in July of 2015 at the registry office in Dublin with only a few of our closest friends present followed by a reception at one of the wine bars in the centre of Dublin with friends and colleagues followed by Paul's wedding surprise for me – a night at one of the best and most expensive hotels in Dublin – and then, one week later, the wonderful party that my parents organised for us in Germany and where the whole family from near and far came together to celebrate with us! 2015 was also the year of Paul's retirement. He had loved his job at the community employment scheme but was also happy that his working days were now over and that he would have more time for our small family and our new home that we were looking to buy. In February of 2016, after months of unsuccessful searching, we eventually found and bought our dream home, a small two-bedroom house, in a quiet estate in Bray. It took a couple of months and some of our savings to pay for the work of some competent and reliable decorators before we were finally able to move into our new home in early June of 2016.

It felt like we had it all: we had each other. Paul's illness seemed to be under control once more thanks to the Aberaterone and he was feeling well and strong. Paul really enjoyed his retirement while I was very happy to be working at my therapy clinic and to be the bread winner for us. And we were both so grateful that my job, even though it was very busy with clients all the time and sometimes very long working hours, gave me enough flexibility to spend a lot of time with Paul in our new home. Everything was perfect.

But then the cancer raised its ugly head again. In the autumn of 2016, Paul's blood test showed that the PSA level started to go up suggesting increased cancer activity and therefore that the Aberaterone was beginning to lose effect. Of course we had known that this would happen one day, but we had hoped that somehow we would have more time before we would have to look for a new drug yet again.

During the autumn of 2016, I read everything I could get my hands on about prostate cancer, prostate cancer research, prostate cancer treatments, trials with prostate cancer patients and complementary prostate cancer treatments. I ordered essential oil complexes from an essential oil firm from the United States that promised to slow down cancer growth and support healthy cell growth and made Paul take them every single day. I gave Paul regular Reiki healing as well as treatments with essential oils that were supposed to strengthen the immune system. Paul himself did not seem so interested in looking for alternative treatments and, when I asked him why not, he said that he trusted Professor B and the other oncologists at Saint Luke's Hospital and that he felt confident that they would inform him about any new treatment options.

One day in early January of 2017, I came across a podcast on a German radio station where some doctors from a hospital in Munich spoke about LU177, a new form of radiation treatment that was primarily used on prostate cancer patients with bone metastases in private hospitals in Munich and Heidelberg in Germany. Of course I rang the hospitals to find out whether Paul would qualify for the treatment. I was eventually able to speak to one of the professors in charge in Munich who asked me to send him Paul's file from Saint Luke's Hospital. And, having studied Paul's case, the German professor told us that Paul would qualify and that we should try the treatment. Professor B was willing to support us with the German treatment but advised us to wait a little to see what was happening to Paul's cancer activity first. So, we were waiting nervously from blood test result to blood test result hoping that the PSA level would go down again.

And it did. Paul's PSA, which had gone up from 0.2 to 2, to 3, to 5, to 7, to 10 and to 11 for months suddenly dropped back to 7 in April of 2017. Was it possible, I asked myself, that our

closeness, that unique bond that we shared, had helped Paul to live a much longer life and somehow the cancer had stopped growing once more? And were the essential oils perhaps really working and shrinking the cancer?

But even though the blood test results looked promising, we noticed that Paul had become weaker over the winter and spring and that sometimes he felt overcome by nausea.

Something just was not right and we both knew it.

"Should we not go for another CT and bone scan just to make sure that everything is okay?" I asked the oncologist at one of our visits in April when everyone marvelled at the improving blood test results.

"There is no need to do scans on a patient whose tumour markers are so low," the oncologist said.

"But what about the weakness and nausea?" I asked, "What if the cancer is growing somewhere unnoticed?"

"The weakness and nausea could be the side-effects of the slowly failing Abiraterone," the oncologist replied. "The tumour markers are low and Paul doesn't have symptoms. There is no need for another set of scans right now." So we left it at that and let him convince us that probably everything was all right and that the best thing we could do in this situation was to wait and observe Paul closely.

Over the next month, Paul started to lose weight, even though he was still eating the same as before. He lost his appetite and interest in food. He started retching and occasionally vomiting. He felt also weak and shaky and had a pain on the right side of his body, under the rib cage, right where the liver was.

We had booked a two-week long trip to Morocco for May of that year. And, since Paul said that he felt well enough to go, we did one last blood test of which we would receive the result upon our return to Ireland and went to Morocco.

We had a fabulous time. We spent the first week in a small village by the coast and the second week in Marrakesh. Everything about this country was so different: the food, the climate, the culture, the sounds, the smells. But even though we were really enjoying ourselves, we could not help but notice that Paul was not well. He needed a lot of time for rest and was often sick in the morning after breakfast. He had also begun to have night sweats.

We knew that we would have to go to the hospital immediately once we were back home.

When we returned to Ireland, we both realised that we had missed calls and voice messages from Saint Luke's Hospital on our phones that somehow we had not been able to receive while out of the country that told us that Paul's last blood test, done right before we had left the country, had shown a significant rise in his PSA level to 27.

"Don't you think we should do scans now?" I asked our oncologist when we met with him one day after we had come back from our holiday. "The PSA is higher and Paul wasn't feeling well while we were away."

"Let's do one more blood test," the oncologist advised, "and if the PSA is still this much raised, we will do the scans."

When the next blood test result showed a PSA of 89, that together with the symptoms we had been describing for some months was finally enough for the hospital to decide to do a CT and bone scan. And the results of those scans were the scans that we were discussing with Professor B on that warm and sunny July afternoon and because of which Paul was now given his first appointment for chemotherapy.

Reflections from the Author

The importance of scans

In my opinion, scans for patients with any form of advanced cancer must be performed every four to six months. It is not prudent only to perform scans when the patient has developed symptoms or when specific tumour markers have gone beyond the normal range. Many tumours would be discovered a lot sooner, and in many instances they would be much more treatable, and maybe even lives could be saved, if our health service introduced this practice. Paul was not feeling right all through the spring of 2017. This is why, when we had the appointment with the oncologist in April who told us that Paul's PSA was down to 7 again, and two months later again when we had just come back from our holiday, we made our wish known to have another set of scans performed just to be sure but the oncologist did not want to send Paul for scans on each occasion saying, "When the PSA level is low in the patient there is no need for a scan." In our experience, that is simply not true. And when Paul eventually had a CT and bone scan because now the PSA levels were so high that even the hospital got worried, he had extensive liver metastases. While in Paul's case it would not

have made a difference whether the liver metastases were found in April or in June because his cancer was very progressed at that point, for other patients the difference of two months might be life saving.

It should be noted as well that in prostate cancer, the PSA level is only one indicator for tumour activity. There is really no reason to think that just because the PSA level is low the patient's cancer is not growing. In addition, in people with advanced prostate cancer, the cancer sometimes changes into forms where it no longer shows PSA. This is especially the case when the cancer spreads into an organ such as the liver or the lungs. So it is possible that, while the patient's PSA level is low and it is therefore assumed that there is little or no cancer activity, the cancer is growing elsewhere in the body and this can only be detected with the help of frequent scans.

Furthermore, I think that as patients or relatives of patients we must become stronger in saying what we feel we want to get from the oncologists. If we feel a scan should be performed, or if we are unhappy with what they are telling us, or if we do not fully understand what they are saying to us and why, we have to ask. It is our life we are talking about, the life of a loved one, it is our body or the body of our loved ones who are sick and we have to have as much understanding and knowledge of the situation as we can.

https://www.amazon.co.uk/When-Love-Means-Let-Go/dp/B088N91JX6/ref=tmm_pap_swatch_0?_encoding=UTF8&qid=1624273322&sr=1-1