

A Mum's Story

In 2012 our son Phil who was then 28 years old was enjoying living and working in Wellington New Zealand. In June he began to have niggling abdominal pain which was thought to be appendicitis.

He was admitted to hospital for routine surgery which proved more complex than planned. Following the surgery we received a phone call our family will never forget at 1am with the devastating news that they had found cancer in the appendix and Phil was being rushed back to surgery to have part of his bowel removed. This was the beginning of a very challenging and difficult five and half year journey.

Six weeks after the surgery Phil returned to the UK to face a course of chemotherapy which was brutal and Phil was very ill due to the awful side effects. Less than 3 months later Phil began to get abdominal pain which became increasingly worse. By September 2013 Phil was seriously ill and a Scan showed there was a possibility that Phil's abdominal cavity wall could also be cancerous. We were all terrified, it was an incredibly anxious time. Thankfully the surgeon was able to remove the cancer which was in 3 places in his abdomen. However, when Phil's tests came back we were told that in one of the places they hadn't removed all of the cancer. This was devastating news and once again, Phil went through a course of chemotherapy. We continued to hope it would be the end of this horrific disease in Phil's body.

In October 2014 Phil began to get discomfort in his left side, following a Scan and laparoscopy in January 2015 more cancer was discovered. Eventually he had very complex surgery in Basingstoke to remove part of the lining of his abdomen along with part of his liver, diaphragm and bowel. He then went through another course of chemo. At the end of Summer 2016 further Scans showed tumours in Phil's lungs. This came as a huge emotional shock for Phil and us. Surgeons in the North deemed it inoperable and he was offered no curative treatment. It was really hard to hear that Phil was being deemed terminal for the first time.

In December 2016 following a second medical opinion, Phil had more major surgery at The Royal Brompton Hospital in London, but soon after another Scan showed that his cancer had returned to both lungs. This time Phil decided he didn't want any more chemotherapy. He had been through so much and felt he couldn't face it again. At the end of August 2017 Phil's surgical team decided they could no longer offer any surgery and offered Phil a room in the palliative care unit at North Tyneside. Phil was in palliative care for 7 weeks and it was during this time that I first contacted HospiceCare.

We desperately wanted him home too though we were very daunted by it. So we took the scary step to bring Phil home in mid-November 2017 knowing that we couldn't manage without a lot of help. Nina, one of the HospiceCare nurses, came to visit to see how they could help. From day one HospiceCare provided night sitters as it was the nights that we found most difficult, as the years of stress were taking their toll and we were exhausted. This was a huge support to us all. The pain Phil was having was very difficult to control due to the complexity of his condition and sadly he deteriorated quite quickly. By December Phil was being nursed in bed, so HospiceCare stepped in to take care of his personal care each morning, with one of the nurses, Sue, Debbie or Nina and a carer coming in every day. Absolutely nothing was too much trouble for them, they were so kind, gentle, caring, supportive, thoughtful, professional and patient. They respected Phil's dignity and were in no hurry to leave until they were satisfied they had done everything Phil needed. The nurses could give Phil extra pain medication, antinausea drugs and sedation by injection to help him relax, and often stayed with us until they knew his pain had settled. Phil himself said on many occasions that the HospiceCare nurses were amazing. He felt very safe and well cared for. They were also a huge support to us as a family, especially me, as I was carrying the most responsibility administering so many controlled drugs and trying to keep on top of the awful pain Phil suffered. It's difficult to put into words the extent of the stress on a journey like this but the HospiceCare team really were a huge part of the scaffolding that held us together with their support at an extremely difficult time.

Through all of the five and a half years that Phil battled cancer he was incredible. So many people would tell him and us that he was such an inspiration. He, along with ourselves, was a committed Christian and his faith and the faith and prayers of so many others carried us through. Phil never let cancer defeat him, he had such resilience to bounce back after each set back, devastating news or major surgery. He was kind, caring, thoughtful, fun loving, joyful and had a wonderful smile. He was always very thankful for everything others did for him and even in his most difficult times had time for others to ask how they were. He has inspired, encouraged and prayed for so many others through his own difficult journey. Phil was a precious son, we are heartbroken, we miss him terribly and always will but we're thankful for the close time we have had with him through these years, thankful that we were able to have Phil at home with his family around him for those last weeks and so thankful that he is no longer suffering.

We're also extremely grateful to HospiceCare for the wonderful work that they do and the incredible support they gave us and are still giving us through bereavement support. We really missed them when they weren't coming into our home after so many weeks of seeing some of them each day. We really can't praise them enough and hope that the support they receive from our community and beyond will increase in the years to come so that they can continue to offer this amazing service and be there for families like ours when they need it. *Margaret Logan, Phil's Mum.*