

Our story

I have called this our story as it really was something that we went through as a family and an event that we are all still living with – any shock event has repercussions for the whole family, some during an event for the patient who has to recover and some in the case of my children much later as they are growing up they realise the seriousness of what happened and in the case of my husband quite a few years later as at the time he had to cope with everything and then deal with his trauma at a later date.

My name is Emma, and I live in Shalbourne, Wiltshire, with my husband, Graham and my 2 children, who at the time of being ill were Phoebe, 7 and Molly, 10.

It all started with an ingrown hair – something so simple. I had come back from a run – 6 miles - my furthest ever!! I had showered and noticed a spot on my right had side on my bikini line and I popped it and put a plaster on and thought no more. As normal I did the school run and picked up 5 x 6 years old to come back for a birthday sleepover. All went well. I didn't feel like a glass of wine that night – maybe that should have been the warning sign.

3AM I then woke in the night at 3am feeling sick – I rushed to the loo and was violently sick and had dreadful diarrhoea. I sat on the bathroom floor with my head draped over the loo for the rest of the night. I presumed it was just very bad food poisoning. I did feel a bit giddy.

7AM I crawled back to bed at 7am. That is when I heard all the children wake up – I didn't have enough energy to get out of bed which is unheard of for me. I woke up Graham, he also presumed it was food poisoning.

8.30AM One hour later he said I looked very pale and went 3 doors away to where our GP, Angela Padden of Great Bedwyn Surgery lives. She came around, and did normal medical checks, she gave me some antibiotics and an anti-sickness injection. She then left and said if you feel worse, then to call straight away.

9.30AM She came back 40 minutes later of her own accord – I am hazy on the detail of this and details have been filled in by my husband. Angela had left her exercise class early as she was worried. It was only when she came a second time did I mention that I had a dull ache in my groin area. The 'spot' was a little red and very slightly raised. My blood pressure was very low, and she told Graham I needed to go to hospital to be monitored. I was protesting asking if it was necessary. Angela gave Graham a letter and sent us to the Linnet Ward – at GW Hospital - this meant that we bypassed passed A & E. Graham phoned my sister who came and looked after our kids and he then phoned all the sleepover kids relevant parents.

10.30AM By the time my sister arrived I couldn't really stand or get myself dressed. They helped me into the car. That was the longest journey I have ever had – I wanted to get out of the window – I was just so hot – I had my feet out of the car window. I was apparently very pale and talking a bit of nonsense.

11.30AM We arrived at GWH. Graham pulled up outside and I said I would try and walk in, I got out of the car and couldn't really stand. I just felt like I wanted to die. I can't describe the feeling - almost like poisoning I imagine, hot and muddled thoughts. Graham left the car on the side of the road somewhere and helped me walk into the reception. I remember being in the lift and taking my top off to put my body against the metal of the lift – I just wanted the cold against my skin. I don't know how I made it, but we eventually arrived at the Linnet Ward and I collapsed on the floor and started being sick and diarrhoea all over again but even worse than in the night.

I was put into a room but spent the next hour sitting on a loo and being sick - that is where I had my blood pressure taken and bloods taken – I was in floods of tears. I had been through all my clothes that had been packed – they had been thrown away – I wanted a shower but couldn't stand - my memory of this is very hazy. I do remember saying that my groin hurt. I was so grateful to have Graham he just sorted me out - no one seemed to understand how awful I felt.

12.30AM I was taken for an x-ray – I had no idea why. Everyone I saw at the Linnet Ward had no idea what was wrong, I suppose the symptoms were much the same as food poisoning, although Angela's letter had mentioned infection. Graham had to really fight for me to be seen quickly. My blood pressure etc was falling very low and so it was decided I should be moved to ICU.

2PM Arrived in ICU. Given Saline and put on lots of drips / machines etc. A few people examined me, but one brilliant registrar called Vulcan, examined me and then quickly went off to find a consultant. He had spotted necrotising fasciitis (NF). Graham was told that I needed to get into theatre quickly as I was gravely ill.

2.30PM – first operation – I remember Graham telling me to have a good sleep. I remember a lot of medical staff around my bed

5PM – Graham was told that I had NF and it was very unlikely I would make it and to be prepared for a difficult night. My organs started to shut down and I was desperately trying to fight the infection.

During the following 7 days, I was kept in an induced coma. I had 4 long operations, was ventilated, on dialysis etc. The amazing team of microbiologists were trying to work out which antibiotics to give me. After the fourth operation Graham was told that I had 1 to 2 hours to live and it was systemic – they said there was no hope. Then very surprisingly a few hours later my blood pressure started to hold and the situation inexplicably turned around. It was a very traumatic 7 days.

Medically – GWH were amazing and their care and dedication was unbelievable - I won't list all the medical facts - they all helped me to fight. ICU provided a diary (I have it here today) for the nurses and my family to write in - I found this very useful when coming to terms with what had happened, I also believe my sisters and my family found it very useful to write in.

Spiritually - Graham did not leave my side and was constantly talking to me and never gave up hope - he never allowed that to be a thought in his mind or in anyone else's mind. His strength was my strength - I know that because he was in my sub-conscious. The part I still find hard to understand is the hallucinations – over and over again – lots of them always culminating in a fight of some description but all of them had Graham's influence in them, sometimes very subtly, that extra push up the mountain or that extra strength to claw my way out. I know he gave me the power to live and I will be forever grateful. To this day I still have real trouble believing that the hallucinations were in my mind, they still feel more real today than real life. I often still struggle with this. I still believe there is a floor in the hospital that has gold and silver people living in it and that you have to go to a swamp area that is all cool to be turned over. I still believe there is ivy growing up the back of the hospital that I used to escape from after being attacked. So real, that I even walked round the hospital when I was there last year.

Graham was always there for me and if there is one learning it is that it is possible to give people strength through presence. I am lucky, and it wasn't my time. I won't go into the finer details, but I will say that I know that dying is not scary.

I came off the ventilator and I think that was a very difficult night - I felt I was fighting for every breath and I was very thirsty. That first night off the ventilator I was also slightly mad and extremely paranoid – I thought I was in Thailand and made Graham write down an equation as I thought I had cracked the

code of light! I was swearing a lot and I very rarely swear, I thought everyone was having a party I wasn't invited to.

A large part of my side was cut away - almost like a shark bite. I was told I would lose 6 of my 10 toes and maybe the tip of a finger. I was on a vac system draining the extremely large wound.

After 10 days of being in ICU I was moved to Ampney Ward. I was really scared about this, losing the security of ICU and the constant nursing.

The first night on Ampney was very difficult, I had no control of my bodily functions – I could not feel below my waist. I didn't know the extent of the wound. My alarm button fell on the floor – that is the night I just lay awake all night and cried – with exhaustion / relief / fear / frustration... we underestimate how one's dignity is just taken for granted and take it away and what have we left.

From then it was a wonderful uphill journey. I was in hospital for another 5 weeks. With the help every day from the physio team I started to eventually take a few steps. which was hard work, excruciating painful and brilliant all at the same time. With the help of the tissue viability nurse I started to accept my wound. The first step was they showed me the wound on a digital camera, so I could imagine it was on someone else - that really helped. A big huge thank you to all the amazing staff at GWH – the guys that put the pic line in to the porters, the x-ray staff to the microbiologists and of course the consultants to the nurses to name a few.

The antibiotics I was given meant that I couldn't eat a lot of food available –for the majority of meals I couldn't eat most things on the menu – luckily my family made food I was allowed.

I was told I would need plastic surgery and so I had a consultation with my consultant and a plastics consultant from Oxford. After a long meeting they agreed to take the skin from my thighs to patch up my side. That was the plan.

I was discharged in a wheelchair from GWH. At home I had a community nurse who visited every day. The main nurse in charge had worked in a burns unit and she did say that with diet occasionally people can heal themselves even though the wound is very large. We decided to try this. Graham was amazing with researching the correct diet and being very very strict. Graham together with the help of the nurses who visited me every day for 10 months meant that I didn't need those skin grafts for which I am now very grateful when on the beach in shorts! Then there was coming off the meds – cold turkey – night sweats, twitching muscles, headaches, hair loss, etc.

I was also lucky enough to only have lost the tip of one toe not the 6 toes and fingertip as predicted– I put this down to a friend, who massaged my feet every day for 6 months to keep the circulation going - amazingly kind woman for which I will be eternally grateful.

In terms of timing, it was 10 hours between feeling a little sick and having my first op and then another 2 hours after Graham was told I probably wouldn't make it so time was very precious

Learnings

- Spotting the signs when arriving at hospital
- Ensuring that relatives are encouraged to sit by patient's bed side and talk to them – never giving up hope
- Giving as much support to people on first night out of ICU onto a ward
- Making sure that there is a hook so that 'call' button does not fall on the floor
- Writing a diary for ICU patients if time was very beneficial
- Taking photographs of large wounds before showing the real wound to patients
- Making sure that all nurses have adequate Vac Pac training and that there is a supply of cannisters on the ward
- It is important for people to talk about their experiences – survivors forums are very helpful