Caroline's story:

Medical Misadventure compounded by System Failures. Post-op complications, but doctors and nurses are not listening to me. Year's before admission of liability.

Background

In 2005, Caroline (a 39 year-old-nurse) was diagnosed with an ovarian cyst – 8cm in maximum diameter. Caroline was otherwise in relatively good health. She did have a long-standing history of endometriosis, for which she had received treatment and laparoscopic surgeries over the years whilst living in England. She had also previously had an appendectomy (by open surgery) when aged 18 years.

Caroline is married with one daughter who was aged 5 years at the time. She and her husband were both working full time. Her daughter was in her first year of national school. Everything seemed to be going well for Caroline and her family – life was good with no major worries or concerns.

Part 1: The incident and its impacts

Admission for routine surgery to remove ovarian cyst

Caroline was scheduled for admission to hospital in March 2005 for surgical removal of the cyst. The surgery was expected to be conducted laparoscopically, with a view to open surgery if any complications arose. It is usually a fairly routine procedure and it was expected that Caroline's hospital stay would be no longer than 5 or 6 days at the most. Caroline was admitted to hospital on Thursday, March 3 2005. The surgery was scheduled for the following morning.

But major post-operative problems

Caroline went for surgery as planned on the Friday morning. It was in the recovery room afterwards that the pain hit her *'...it was horrific, absolutely horrific...I screamed with the pain, and the nurse couldn't understand...said it might be because I had the open surgery...'* The consultant and anaesthetist were asked to review Caroline in the recovery area. After review, more analgesia and sedation were administered before Caroline was transferred back to the ward (private room) around 14.00hrs.

Throughout the afternoon Caroline continued to have severe pain. She was very distressed and crying with the pain when visited by her mum later that afternoon. The analgesia did not seem to be working. The anaesthetist came up and set her up on patient-controlled analgesia around 16.00hrs. She continued to have pain when her husband and daughter visited in the early evening. Apart from the pain, her observations and vital signs appeared to be ok at that time. The consultant came around and explained to Caroline and her husband that the operation had gone well, but it had to be converted to open surgery and that this was most likely the cause of the pain. He was confident that Caroline would be feeling much better soon. He was then off duty for the weekend. Caroline is not sure if her care was handed over to another consultant or not.

Caroline continued to have pain. She also reported having difficulty passing urine post operatively, and she was catheterised in the early hours of Saturday morning. Despite the catheter draining 800mls immediately, she continued to complain of severe pain (but her medical notes documented that she was "feeling better"). As her cannula had 'tissued' (fluid flows into tissue around the site), her intravenous fluids had been discontinued. Staff were trying to get her to drink fluids and take food orally. She was having difficulty eating and drinking, the pain continued to be severe and she felt she could not have a bowel movement. She could not understand why she had this pain so severely in comparison to previous laparoscopic & open surgeries, and said this to her visitors who called in at lunchtime.

From there on she says *'...it just went downhill...I remember up until, say, midday Saturday...by the Saturday afternoon I had spiking temperatures - went up to 38 degrees centigrade - and my pulse was 140....the doctor was asked to review me. He thought maybe I had a urinary tract infection ...*' A urine specimen was tested and, although nothing abnormal was detected, the doctor started her on oral antibiotics for a urinary tract infection.

Nobody seemed to be listening to her

Her condition continued to deteriorate, her abdomen was noted to be distended and she continued to have severe pain *'...Saturday night people were coming and going, but I really don't remember...I actually phoned a friend from my mobile and apparently I was crying down the phone because I didn't understand what was wrong with me...I felt really sick, the degree of pain was abnormal yet nobody seemed to be listening to me'.* She was very unsettled all night Saturday; she felt herself that there was something seriously wrong although the nursing staff thought she was just anxious. *'...Sunday morning the doctor came to see me, and again wrote on the chart "feeling better"(god!), but I wasn't feeling better...*

My abdomen at this stage was swelling to the point that I looked like I was going to give birth (as per visitors). Visitors noticed how unwell I looked but the nursing staff did not seem concerned at all - nobody seemed to be really noticing at all...' When her mother visited that afternoon, Caroline was in the bed *'...and she said I couldn't even bear anyone to touch me... that's how bad the pain was...the sweat was pouring off me, my mother didn't think she would see me alive again, but still the staff seemed to think there was not anything wrong with me...'*

She says *'...it was like nobody listened, no matter what...I had even got to the point where, I phoned friends of mine that I used to work with in another hospital from my mobile – (I don't have any memory of this), telling them how sick I was in this hospital and that nobody would listen to me'.*

Very slow to get medical attention

Sunday evening Caroline continued to get worse and eventually had to ask to see a doctor. A doctor came up that night (early hours of Monday morning) to see her and examined her. The doctor wasn't 100% sure what was going on (although Caroline only has vague recollections of this, she thinks that this doctor was on the right track), so she spoke to her Registrar and requested a second opinion. He came down to see Caroline and said he would have to get in touch with the medical team, as he suspected it could be a pulmonary embolism. Nobody informed the consultant on call that Caroline was ill and needed to be seen.

When the medical team were contacted (this was the early hours of Monday morning), they advised to do bloods, get a chest x-ray and get Caroline reviewed by the medics the following morning. This consultation was done over the phone and the medical team didn't actually visit. A portable x-ray was taken during the night. The patient-controlled analgesia was discontinued as the cannula had tissued. Caroline received more pain relief by injection... but this did not touch the pain she was experiencing, and her temperature was still high. She continued to complain of feeling constipated (she was given prescribed suppositories with no effect), had only passed a small amount of urine since the catheter was removed. A catheter was reinserted and drained a small amount of concentrated urine.

Caroline recalls wondering what she would do next as her condition continued to deteriorate. She says '*I feel I would have been better off discharging myself from the hospital and going down to casualty, and coming in through casualty, because perhaps I would have been picked up sooner...they just thought they were handling it ok, they never even considered the differential diagnosis of a perforated bowel, despite the symptoms - this did not enter their heads...'*

Uncaring treatment by nurse

On Monday morning, Caroline's husband had come in early to see her because he was really worried. While he was there, she received some very uncaring treatment from a nurse. Caroline recalls *'...one of the nurses came into the room and clapped her hands and said ''out of bed, up out of bed''...and I said no, I wasn't moving, the pain was that bad…She said "up out of bed"(again) but I said "I'm not getting out of bed, leave me alone..."...She went out, came back in with a colleague, and they proceeded to drag me out of the bed, to sit me in the chair to actually make the bed...now I screamed the place down with the pain...when the bed was made, she told me I could get back into it...This was very distressing and upsetting – I will remember that nurse and that incident forever, mentally – it has left me with a permanent scar'.*

Delay in getting ultrasound done

During this, while Caroline was sitting in the chair (this was about 9.30 or 10 in the morning), the consultant who had conducted the surgery arrived. He reassured Caroline and her husband that she didn't need to see the medics, but that an ultrasound needed to be done to see what was going on...advised not to worry, everything will be fine.

The consultant left and went down to the x-ray department with the form, to arrange getting the scan done. As the day went on, Caroline's condition was continually deteriorating. She was again reviewed by the Registrar and Senior House Doctor, at the request of nursing staff. Bowel sounds were noted to be present, abdomen was soft but tender and swollen, temperature remained high, pulse was increased and oxygen levels were decreased. Further pain relief was given and oxygen therapy started. It was 3.30 that afternoon before Caroline was brought down for the ultrasound. She was very ill at this stage and in severe pain *'...even to get onto the scan table, the pain was unbearable, words could not describe how I was feeling - it was pain like I had never experienced before...'*

Eventually found to have a perforated bowel, and was critically ill

The consultant radiologist came down and decided he wanted to do another x-ray. After about 2 hours Caroline was brought back to the ward where, as she says, *'…there seemed to be doctors coming out of the woodwork, I was surrounded – at last they were noticing…trying to find veins in my arms, putting cannulaes in, intravenous fluids, pain relief, various doses of IV antibiotics...told me then that I had a perforated bowel and needed to go for surgery..'*

Caroline hasn't much recollection from that time or over the next few days. She went for an emergency operation which found a perforation of the sigmoid colon with associated peritonitis. She developed septicemia. From theatre she went straight to intensive care, where she remained on life support. When her husband came in Caroline says she *'...had tubes everywhere – tubes from my mouth, neck, nose, drains, down to my feet...I can only imagine how horrendous it was for my husband and family to see...'* Her husband was told she had a 50:50 chance of survival, if she made it through the first night, but she was getting progressively worse and her chances went down to 30:70 at one stage.

Thankfully Caroline survived, but seriously ill and remained in hospital for weeks

Thankfully Caroline survived and came off the ventilator after about 10 days. But she remained seriously ill *'...developed everything you could possibly...multi-organ failure, acute respiratory distress syndrome...had to have a colostomy...had problems with my blood clotting mechanism, required several blood transfusions, ...sinus tachycardia...absolutely everything you could possibly think of...'* During all the process she had also got some sort of a fungus in her blood, and needed a lot of intravenous anti-fungal treatment as well. She developed a deep rooted wound infection, this was compounded by the fact that she developed MRSA, *'...had that everywhere as well...'*

Eventually she was moved from ICU to the ward and stayed in hospital for another good few weeks '*...battling along, trying to get rid of infections...the whole wound just opened...immune system was so low, not resistant to anything...I had big gaping gaps in my abdomen, a sinus developed …it was not a pretty sight. Having the wound dressing replaced was incredibly painful to endure... I also had the colostomy to deal with...and my bloods weren't right...had more transfusions...'*

To add insult to injury, Caroline had taken her jewellery off and put it in her purse when in hospital, but the purse was stolen and found empty a few days later in a bin near the theatre.

Struggle to recover everyday functioning

All this took its toll and Caroline had a struggle to get back to some reasonable level of functioning. *'...when I came off the ventilator, breathing was shocking, couldn't get out of bed, couldn't do anything myself ...couldn't hold a cup, couldn't stand unaided...'* She says she didn't start to get better until her daughter visited (hadn't been allowed for a long time because Caroline had MRSA, tubes and pipes coming out from everywhere ...eventually the infection control nurse organised that she could visit). *'I was sitting out in the chair beside the bed...when my daughter walked in ….I remember thinking she looked so tall, so different... yet she looked at me like as if I was a stranger...beside me was a Zimmer frame and I had a beaker...took her a little while to cotton on that this was Mammy...She asked me why I was using the Zimmer frame...and why using that cup?...this was the turning point for me...I said that its time to get yourself well and get out of here...' My husband told me that she later asked him "is my mammy 100 …is she going to die"...*

...first thing I did was ask for a proper cup...needed the beaker initially but because was being given it all the time, never actually questioned this...could hold the cup...asked for walking stick instead of the Zimmer frame...started making a little progress every day...'

Eventually discharged, but treatment continued

Around the end of April Caroline was given the go ahead to go home, but she had to continue with expensive 'vac' treatment for the wound at home (a vacuum system for helping wounds to heal). To cover the costs of this, she had to apply for an emergency medical card before leaving the hospital. So Caroline went home *'...with the vac therapy unit, in a wheelchair...'* She needed a lot of care at home and was very weak *'...nurse would visit on a daily basis, would have to get the dressings done, colostomy bags sorted out, all of this...'*

Over time, Caroline was getting better in some ways, but she then developed a large incisional hernia, and the colostomy was still there and giving a lot of problems. Around October she went back to hospital for surgery to have the colostomy reversal and the incisional hernia repaired. This was complex surgery and required a large piece of mesh to be inserted in her abdomen, which remains in place permanently.

Couldn't go back to work for a long time, major financial impacts for household

Because of Caroline's medical problems, the household went from two people working full time to a much lower income situation. Her husband had to take time out of work to look after their daughter, and ended up working part-time. Caroline herself was off work for a full year after leaving hospital, and even then it was at a stretch that she actually went back to work. Financially, Caroline recalls it was a difficult time…this added to the stress of the whole situation.

She started back to work May 2006 but could only manage on a part-time basis. Because of the mesh, her abdomen kept swelling and she had a lot of 'scleroma' formation, and she had to constantly go in and get it drained. She also had chronic pain and was getting a lot of acute intestinal obstruction, and ended up in hospital many times over that period.

As a result, she wasn't really able for the job she was doing and had to stop work. She was then off sick for the best part of four years, during which she was in and out of hospital regularly (and still is). She had a lot of sub-acute small bowel obstructions and then had to have her gall bladder removed. This wasn't easy surgery - everything was stuck together, she had to have open surgery. Eventually she got a redeployed post at work, on part-time hours, and this is where she is now, although she is not doing her nursing in the way she would like to.

...An awful time, but not all bad

Even though she went through an awful time, Caroline can also point to some positives. Some of the care she received was very good '*...but throughout all of this, I can't say that everything was bad...I got excellent care in the hospital as well, I really did, you can't paint everywhere black, because there are a lot of very good people who worked in that hospital, and I wouldn't be here today if it wasn't for them...'*

For herself, the fact that she nearly died prompted some reflection '*...it made me reflect on my own life as well...happened to me when I was 39...was thinking 'I nearly died and I can't swim...I'm going to learn'...made me start thinking of things I'd never done (like camping)...so I did try to make positive experiences from all that happened…I had a horrific time, horrific experience, horrific battle...but in the end I came out pretty ok, I think, I'm not too bad...I'm struggling, I get by...I do not like having to be hospitalized but then not many people do.'*

Part 2: The search for the truth

When she was recovering Caroline started to wonder how something could go so awfully wrong, when she went in for a relatively simple procedure. How, how, how – it was a question that needed an answer!

'I decided I would have to look into it...after all I was the sickest person in the hospital for a number of weeks. I felt that people were trying to avoid coming to me. I did develop a very good relationship with the general surgeon who took over my care...but the original consultant obstetrician/gynaecologist... although he was asking about me he did not offer me any apology or explanation of what/why this had happened. We all make mistakes, errors do happen. There really is no shame in that, but it is shameful not to be open regards errors or failings in an honest and timely manner...it's about standing up, acknowledging failings, reflecting and learning from the experience, preventing reoccurrence'.

Complaint to HSE, formal review acknowledges care management issue

Caroline lodged an official complaint to the HSE. The HSE decided that the case required a full root cause analysis by their healthcare Risk Management service. The final HSE report was issued in April 2008 after a few earlier drafts. The report acknowledged that there was a care management issue in that there was a delay in the diagnosis of Caroline's presenting clinical condition, and recommended a care management review to see how this would be preventable in the future.

One element of Caroline's complaint was that, when she got a copy of her records from the hospital, she found information about her emergency surgery that had not been given to her before. During the emergency surgery for the perforated bowel it was discovered that she had another cyst (on the same ovary), but nobody had ever mentioned this to her before. The surgical team had not been aware of this and it was inadvertently perforated during the surgery. The HSE review report recommended that full disclosure and explanation of events (including unplanned events) should be part of the post operative consultation with the patient.

But no admission of error and Caroline left without answers

There was no admission of error in the report and Caroline was left without answers, particularly about whether or not she actually had an underlying bowel condition prior to the surgery for cyst removal.

'...was never going to be an admission of any error on his [the consultant's] behalf...they said that I had a weak bowel - but I had never had a problem with my bowel prior to that...

...was what brought me to Patients for Patient Safety Ireland - because people do make mistakes, and there's no problem to say that you've made a mistake...but to actually be able to do that, to do it and maybe to learn from it...and then going forwards, that things can actually change, wouldn't happen to other people the same way...I was being told very differently, it was almost like that it was something that I had done...that there was something wrong with MY bowel...whereas really I was left with a lot of questions, like, do I have an underlying bowel condition or not?' I needed to know!'

Had to go the litigation route

So Caroline had to resort to litigation in order to try to get to the truth. This was a long, expensive and stressful process, for both Caroline (plaintiff) and her family and the HSE and staff (defendants).

'*This process took years, these cases cost huge money…from solicitors, barristers, medical expert reports, court fees…it's not a route you choose lightly…as you may not recover your costs. In my case, the initial cost to me was approximately 6,000 euro…to provide an indication as to whether or not I would have a case.*

After this, you start down the long and windy road to seek justice, the battle of the legal teams and costs continue to mount (on both sides). All of the time you are being told 'you could lose your home, you could be bankrupted'...there's a constant barrage of pressure to make you say 'hang on, should I withdraw from this process'...but I just felt so strongly that I was wronged, I needed an admission of liability.

Caroline's case was lodged with the court system in March 2007 and was eventually set to go to trial in January 2013 *'...all of those years of a battle, on top of being sick and everything else...'* In the end the case never actually went to the High Court - it was settled at a meeting in December 2012, with an admission of liability by the HSE. And Caroline says *'...that's all I ever wanted...for somebody to say, we did wrong.*'

'... [but] I had to go the whole litigation route to actually seek justice, but even then I didn't really get the answers...to the day I die, I think, I won't find out exactly what went wrong...but there was an admission of liability in that, I was left for three days with a perforated bowel and nobody took any bit of notice...
I had almost reached the point of no return'.

Even without ever going to court, there were 200,000 euro costs just from Caroline's side...if it went to court they would have had costs of witnesses coming over from England, going in front of the judge...and the legal team's costs. Then there were the HSE's costs, which are likely to have been high as they use well known and expensive firms.

As Caroline says, '*...the legal teams make plenty of money from medical negligence cases…this is money that could be much better spent on improving patient care. I really feel that has to be part of my story, because it was a battle, an expensive battle to actually get to the day that liability was admitted. There's got to be an easier way for people to get redress. The State Claims Agency and the HSE now openly encourage 'open disclosure' and I would advocate for this. This is a big step in the right direction if taken on board by the staff involved in adverse events. It's important not to be putting up a full defense for something that's really indefensible, you know...That was all I ever wanted - somebody to say, yes we did wrong here, we caused you harm. I had carried a lot of guilt, for years, that it was my fault my family went through this horrendous experience'.*

Lessons that could be learned

The HSE's risk management review report on Caroline's case presented a series of recommendations. These focused on improvements needed in care management arising from Caroline's post-operative experience and the missed diagnosis. Caroline herself also thinks that there are other important lessons to be learned.

Listen to the patient and observe

Caroline emphasises the need to listen to the patient and observe, not to rely only on machines.

'*Number one, if you listen to the patient, a patient knows their body...if you actually listen to what the patient is saying you might have an answer...**LISTEN** (has to be underlined many times)...I wouldn't have asked for a doctor to come to me if I didn't feel I needed it....*

...also observe...you are listening but you are also looking...don't rely on machines...very good now at relying on machines, but machines are not always right...if someone is in bed, profusely sweating and they look hot, flushed and delirious, and you put a thermometer in their ear and it comes out at 36, why don't you go back to feeling the patient...machine will tell you someone's pulse, but not whether fast, thready or regular...you need to go back to basics, open your eyes and see if the machine is reflecting what you are actually seeing...'

More attention to patient consent

Aspects of the experience also prompted Caroline to reflect about patient consent whilst in hospital *'...the nurse who actually clapped her hands to get me out of the bed did come down to see me, when I was back on the ward...asked me did I remember her?...it stuck with me, having been a nurse all my life I couldn't believe that care like that could be dished out... got me thinking about consent as well...if someone says they don't want to do something, they have every right to say that, so we need to be listening to people...again it goes back to listening...that was a simple thing...said I didn't want to get out of bed...and then to be dragged out against my will...'*

How to ensure it will not happen again, without having to resort to professional body

'...I suppose I could have lodged complaints with the professional bodies, An Bord Altranais and The Medical Council... I could have put complaints in against specific people and had them called up in relation to their practice...but I chose not to. I recognize the fact that we are all human and we all make mistakes...I do feel people deserve a second chance...which may not be given at misconduct/malpractice hearings. If you have a person who has made a mistake and comes back and repeats it again, it is the responsibility of the HSE/employer to report to the professional body of that person...let there be leeway...but if after disciplinary proceedings, re-training etc etc, it does happen again, the HSE/employer has to question whether the person is professionally competent to be doing the job they are doing...'

Would be great to capture both sides of the story

Another suggestion from Caroline concerns the benefits of capturing both sides of the story, for herself and the consultant to work together on the story and the lessons that can be taken from it.

'...Stories are so powerful, there are two sides to every story...my doctor didn't get up to go into work that day planning to perforate a bowel or anything like it... I'm sure he may have had sleepless nights (well I'd like to think he had a few anyway)...wouldn't it be lovely if you could work together...hear that side of the story... for other staff to hear the impact of a litigation case from a staff perspective could also have a positive impact on embracing the Open Disclosure process when dealing with adverse events. The money saved can actually go back into healthcare... I think there could be great learning from both sides all round...'

Preventing another occurrence

In making a complaint in relation to her care, Caroline wanted to ensure that procedures would be put in place to reduce the risk of this happening to another patient. She says '...*the final report made a total of 18 recommendations which (when in place) would reduce the risk of reoccurrence of my case. I am unsure if these recommendations were ever put in to practice. So feedback would be nice'.*

Supporting the patient during the review process

Caroline would encourage patients to ask questions, participate in care and work in partnership with health professionals. She also feels that patients should be better supported during the review process, which can often take a long time. '*The carrying out of the review into my case fell way outside the timeframe as specified in the terms of reference. The final report was issued to me in April 2008. At times I found this very frustrating, as no one communicated with me on a regular basis. This is a gap which could be successfully filled by a Patient Liaison Officer…who would be there throughout the process for the patient and family, providing continuity of care'.*

Final words

To conclude her story, Caroline says '*I have said from day one and have written it in my initial complaint - I wouldn't be where I am today if it wasn't for the people who worked in the very same hospital that I almost lost my life in. I would like to think that each person (myself included) involved in my adverse event learned from it in one way or another, and that perhaps this has had a positive rippling effect on others'.*