A patient's experience of perioperative anaphylaxis

When you know you're going to have an operation you are naturally apprehensive but trusting, not implicitly, but faithfully.

The one person I tend to put most of my faith in is the anaesthetist. To that end I was ready to meet my anaesthetist to discuss my medical history, my medication and my known allergies. As he was leaving I quipped, as I always do, with any anaesthetist "Now, you won't lose me will you?" The young man looked at me slightly uncomprehendingly, as my daughter chipped in "Oh mum!"... as in our family we pay due deference to highly trained experts, especially over-worked NHS staff and she thought this was a bit forward.

I was all set except that I had to remind someone to put on my red allergy alert bracelets on.

After the operation, the next thing I remember was vaguely hearing my name and opening my eyes to what can only be described as a waking nightmare! I was uncontrollably shaking, very nauseated and feeling as if I'd been run over by a bus! There was, what seemed to be a large number of people standing around me, chattering and looking down at me. I felt like I was in an advert about 'Injury Lawyers For You.' Shot in monochrome, this features many people including a (very scary) clown, scrabbling to get to you. It felt like I was being spoken to by everybody, and all at once. Not true of course, but that was the sensation.

I had uncontrollable shaking and was feeling very scared and peculiar. I began to recognise a sort of panicky, concern and relief on the faces above me. Something was definitely wrong!

I was spoken to by a senior anaesthetist who introduced himself as the mentor for the poor young anaesthetist whom I had met earlier and whom I did spot lurking in the background. He explained that my blood pressure had dropped, my heart had "blipped" and it became clear that I was in anaphylactic shock. He told me that I'd "reacted to something" during or at the end of the operation, possibly fentanyl... "and given us a scare... You're looking much better now." He reassured me. Then a cardiologist reiterated everything the anaesthetist had said and after both reassured me that follow up appointments for allergy and cardiac clinics would be made, they disappeared! That's when I stopped blaming myself for being a nuisance to these nice people and attempted to gain some composure and take it all in.

Sometime later my consultant gynaecologist came to say the operation had been successful, what she'd found, what she'd removed and she also confirmed that I'd "given them a fright... glad that you're looking much better". Then she too disappeared.

Being left alone, trying to keep calm and take anything in was difficult. A nurse was beside me all this while and she was just the best. She was calm and kept talking to me in a more down to earth way "You are much better... you did give us a scare but you're doing fine... just let me know if I can do anything... Is there someone waiting for you?" I rallied, but then she told me I was supposed to go ICU. We patients are not as daft as you think we are and ICU is not what we want to hear after a routine operation!

With the nurse talking to me about ordinary things, the shakes began to abate and because my vital signs were so much better, I was returned to the ward and avoided the need to go to ICU.

All this time my daughter had not been given any useful information and having waited for four hours asked one more time about me and was told to go home. She then had to relay – well, 'nothing' – back to the family who of course became worried and ended up ringing and bothering busy ward staff by trying to gain more information.

I spent a restless, sleepless night on the ward eventually vomiting for some while. The next morning brought back a parade of juniors from the various teams all reassuring me that appointments for follow-up clinics had been made and that I would be hearing soon about those. I was doing so well by then that I was able to go home. Well it was polling day and I needed to vote!

However, I went home without a completely clear picture of what had happened or what drug might have caused the reaction other than "Fentanyl is the most likely drug" and "you might want to mention this if you have an emergency event before seeing an allergist." I bought myself an 'allergy alert card' and stickers for my purse and handbag.

Then the appointment system failed. I was sent an allergy clinic appointment but for the wrong doctor and clinic. It took me two months to find anyone who could explain who had made the original appointments and sort it out.

My drug allergy clinic appointment came after a couple of months. My GP had to intervene with the cardiology clinic as well in order for me to be seen and this took the same time. At the cardiology appointment I was told that I would have the results within a fortnight and be called back to talk to the consultant about them. This didn't happen and again my GP intervened to find that the results had been sent electronically, that there were no problems and it would not be necessary for another visit. Good news but, to this day, I have never seen or been sent a copy of those results! After leaving hospital and while I was in no great pain, it was clear that I needed to recover. Being forced to rest is not 'my thing'. Inevitably reflection took over and my mood was affected. I had faced my mortality head on and my brain took a while to process this fact. It was a struggle. It took a while, but after some reflection I'm glad that firstly, I'm still here, secondly, I wouldn't be if I'd been born in the 19th century and finally I'm damn glad you lot were around to help.

Finally I got to the allergy clinic, and I cannot thank my allergy clinic doctor enough for being the amazing person she is. She is now known as 'Dame F' in our house. She asked me about previous operations and procedures and when I said I had a similar experience after an operation in 1979, she chased up and found my records from that operation to reveal similarities which were, I believe useful to her sleuthing! I am so grateful for her extraordinary skills and ability in finally finding the cause of my allergy but also the diligence and lengths she will go to in making her patients' well-being her prime concern in her consultations.

She gave me a letter detailing her investigations and recommended that I keep a copy of her letter in my handbag. The letter gave for a full account of the operation including the drugs used and timings of administration etc. I have now purchased an 'alert bracelet' and registered my allergies and medical history. My final plea to 'you all' is to have patience with your patients. The majority of us try not to take you or your phenomenal skills and expert work for granted. We don't mean to be rude or difficult: it's just that feeling ill and the resulting fear put us in a difficult place. Putting our faith in you is what we end up doing, and we want to be a testament to the extraordinary skills you have used in making us well again. Please let us work with you. You can explain the mysteries away but you can also listen to what we have to say because sometimes it is worthwhile.

Thank you to the NAP6 team for giving me this opportunity to tell my story and thank for your continued and amazing work for this project.

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