Transfer of Care - A Patient Perspective.

Ladies and gentlemen, good afternoon. As you have heard I am Nigel Westwood and I was diagnosed with Inflammatory Bowel Disease a number of years ago. This has had a substantial impact on my life and has given me considerable experience in a wide range of treatments, surgery and medicines use.

Over the next few minutes I would like to talk to you about the patient perspective of Transfer of Care.

In addition to being a patient of long standing, I have worked with NICE and a couple of hospital trusts over a number of years. I am a member of a NICE Technology Appraisal Committee and have been a lay member on a number of Guideline Development Committees. I have also been in a number of steering groups with the Royal Pharmaceutical Society and I am also a former board member and Vice Chairman of the patient support group Crohn’s and Colitis UK and a former UK representative to and Vice Chairman of the European Federation of Crohn's and Colitis Associations.

To start I would like to tell you a bit about me which will hopefully explain why I have a view on transfer of care. When I was diagnosed with IBD I was a well thought of commander in the Royal Navy. I had been in command of a ship at sea for over 2 years and was soon to start work in a pressure job in the Ministry of Defence in London working on future equipment requirements.

One morning I woke up with an extraordinary sense of urgency and deposited a substantial quantity of blood and slime in the toilet. After what I now know to be a not uncommon route of “it’s-haemorrhoids” and “it’s-food-poisoning” followed by “we’re-not-certain-what-it-is-but-we’ll-do-something-unpleasant-with-a-camera-and-then-tell-you” I was diagnosed as having Ulcerative Colitis and embarked on a course of treatment involving steroids, Mesalazine and a couple of foam enemas, Azathioprine was added at a later date.
Thus started a two-and-a-half year battle to control the condition, a battle that I was determined to win. However, it was not to be. I was eventually forced to admit defeat when it became clear that I was steroid dependent and that I had developed Pyoderma Gangrenosum; an extra-intestinal manifestation that elevated me into the unusual class where I found myself the centre of attention as a teaching piece for student doctors.

I was a little surprised when I was being treated for the pyoderma to find that there appeared to be no link between my gastroenterologist and my dermatologist. I accept fully that there was an urgent need to treat this extra-intestinal condition but it really was treated as a totally standalone condition with my dermatologist apparently having no knowledge of my underlying condition. Similarly it was me that had to tell my gastroenterologist which drugs my dermatologist had put me on.

Ultimately I had no option but to accept that I had to have my colon removed and I underwent a pan proctocolectomy and became a permanent ileostomist. I left the Royal Navy shortly after this when it was made clear to me that I could not go back to sea nor serve abroad and that I would not be further promoted.

I was discharged from hospital on a substantial number of medicines to not only deal with a high output stoma but also type 2 diabetes which started at about this time and was thought to have been steroid induced. Over the following months I took the decision to walk back my Loperamide and the codeine as they did not seem to be having any impact on reducing my stoma output. I discussed this with my GP who agreed my decision and was pleased that I was driven to remove the potentially addictive codeine. Despite agreeing this with my GP the information never made it to my gastroenterologist until I told him.

I have had additional problems since my initial pan-proctocolectomy with a strangulated parastomal hernia and a ruptured Meckel's diverticulum resulting in my ileostomy being moved to my left side and the loss of a further 80 centimetres or so of small intestine.
A week after the operation to deal with the hernia and rupture I had more surgery to deal with a major post-operative infection which resulted in a large wound about 20 centimetres up and down, 12 to 14 centimetres wide and around 3 centimetres deep left open to heal by secondary intention. This took well over 2 years to heal and resulted in my rectus abdominis being either destroyed by the infection or removed to counter the infection… that'll be no 6 pack for me!

As you can imagine, this gave me still more first-hand experience of a number of medicines and transfer of care processes. I am now facing further major surgery to remove a large area of scar tissue and to rebuild my abdominal wall.

In broad terms my experience of transfer of care has been pretty good. It would be fair to say that there have been occasions when changes to my drugs regimen has not been communicated between primary and secondary care which has caused confusion with repeat prescriptions for example.

That said, I am not sure that I am a typical patient, I am very interested in my treatment and am fully engaged with my medical team at all levels. I am well able to deal with any perceived loss of information during a transfer of care.

As a balance to my story which in overall terms was not too bad, I would like to talk a little about my wife's experience of a short stay in hospital.

She was admitted to one of our local hospitals for surgery resulting in a 6 day stay. Like me she is diabetic, although not injecting, and she was told to bring her prescription medications with her on admittance. She was also told to stop her Metformin and Gliclazide as the hospital would set up a sliding scale to control her diabetes while she was nil-by-mouth.

Her surgery was not minor, she had part of a kidney removed, but at no point were her prescription drugs checked or integrated into her hospital drugs routine. Her blood glucose levels were only checked at her insistence and no sliding scale was set up despite being nil-by-mouth for well over 24 hours.
The post surgery period did not improve. Her epidural ran out and there was no more on the ward, the sliding scale was never set up and her Metformin and Gliclazide was not restarted, her blood sugars were still only tested when she asked and changes to her pain medication were not implemented by the off-going shift and not briefed to the on-coming shift so they only occurred when she asked what was going on several hours later.

Her discharge from hospital was also tedious. We experienced the normal delay in actually being able to leave while waiting for her medicines to go home with. In the event I returned to the hospital that evening to collect them.

Post my wife's discharge she did not have any form of medicines reconciliation with her GP or community pharmacist and there was no pharmacy involvement with her as the patient at any stage in the entire hospitalisation process.

The patient's perspective? Transfer of Care is potentially a game of 2 halves. Many have a good experience and many a bad one. It worries me that the more vulnerable of less aware members of society may not appreciate where it's going wrong. It is imperative that we get transfer of care right.

Ladies and Gentlemen, Thank you for your attention. If you have any questions I will do my best to answer them. I should probably say that we have recently moved to Wiltshire so please don't think that you may have identified the hospitals where this all happened!