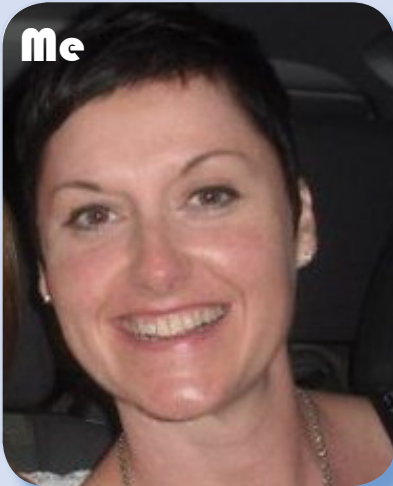


# Jane's profile



## My health history

My Ulcerative Colitis was diagnosed 8 years ago as right-sided distal colitis (on the right side of the 1st section of my bowel) but in summer of '09 colitis spread to my entire colon.

## What's important to me...

- Being with honest, supportive and trustworthy people who can make me smile even when I don't feel like I can.
- Spending time with my family and friends. Spending good quality girly time with Shell, Claire and...my sister-in-law Jo.
- I like to try and see my family once a week.
- Being an ex-chef I'm passionate about food, so I love to eat-out as often as I can. I like to eat in Town Bar once a week, and treat myself to eating out in a nice restaurant in Manchester once a month (but always like to try somewhere new).
- Cups of tea throughout the day - builders brew strength with milk.
- I'm a huge Manchester city supporter and (watch matches on TV, see live matches when I can afford it).
- Wearing converse (I would live in a pair of converse every day of my life if I could; there actually is a pair for every occasion).
- Running 3 times a week, especially listening to the Arctic Monkeys on my iPod.
- Travelling - seeing new places and experiencing new cultures is up-lifting.
- Listening to music - I love music, (especially Manchester music) going to gig's/concerts.

## How best to support me...

- **About food** I am the expert about me, my colitis and my diet, so please don't try and advise me on what I should or shouldn't be eating. I know what my system can/cannot cope with each day, it's not me being fussy or watching my weight. Please trust my own judgement on this subject and know that I'm doing what is best for me on that day for my body, and ideally avoid taking Tramadol which you all know I hate.
- **Talking about Ulcerative Colitis** Don't confuse IBS with Ulcerative Colitis - I find it frustrating when people tell me they have IBS from time-to-time, they are NOT the same condition.
- **About stress and tiredness** I refuse to 'opt' out of life as a whole so don't tell me that I should avoid certain emotional stresses, I am working on finding ways of coping with it not avoiding it.  

Don't worry if I lie in bed all day watching movies and sleeping, it's me recognising I've done too much and could really do with the randr. When my body gets run down that's when a flare-up can take over.
- **About cups of tea** At home and at work, the answer to "Would you like a brew Jane?" is always yes! If I say 'I think it's a peppermint tea day today' (no milk and leave the bag in the cup please) it means that I am having a bad day, and that is the easiest way of me let you know.
- **When I am ill or in hospital** Don't feel you always have to visit me at home when I'm poorly, a text with a kiss on it will always put a smile on my face and just to know your thinking of me is enough. If I get admitted into hospital, please take time to visit (even if it's for a few minutes) I hate being in hospital and feel very alone and isolated, so knowing I will get visitors means the world to me, but don't bring me anything...it's thoughtful but not necessary.  

At hospital I really hate using enemas, they don't always help and usually aggravate an already sensitive area, so if there is an alternative please offer it.

Always cc me into consultant appointment review letters, treatment letters and hospital admission letters, when you are in the situation it's very easy to forget some of the information that's being discussed about you.

Always trust me when I know my body needs i.v of steroids, when a flare-up gets to 'that stage' when only i.v steroids will do. My G.P is understanding of this, and it would be really helpful during a severe flare-up if crucial days are not wasted trying to decide if I need a bed, when I should just be brought in and put straight on a steroid i.v to reduce my suffering and pain.

Always contact me asap when there is a problem with my blood levels, especially if I need medication to help with low iron levels, it's when I get tired and run down when my body can have a flare-up. When I'm in hospital, just because I appear to be less poorly than other patients, please don't put a patient in the next bed to me that needs extra care and attention, just because I am an independent patient does not mean that I need to look after that person, I'm in hospital for treatment for my condition not to look after other patients, the stress of this just makes my hospital stay more stressful. This has happened EVERYTIME I have had a stay on a hospital ward.

When I have a colonoscopy please don't mention if I am having a little cry when I walk into endoscopy room, no matter how many I have they don't get any easier, but my eyes leaking is just my way of not bottling up the stress and worry of what's about to come.

- **At work** Please don't comment when I disappear to the top floor toilet and take a book with me....I'm not on a skive, but some things can't be rushed if you understand??

When you ask me how I am in the morning and I tell you I've had tramadol then you know I'm feeling poorly that day, and if I tell you later in the day that I'm about take another Tramadol, then I'd like you to tell me to put my coat on, go home, go to bed where I can stay close to my en-suite. I do have a habit of struggling on when things are really bad and making myself worse in the long run.

Please be patient with me when I've taken Tramadol, if I've resorted to it then it means I'm having a very bad day, but I will be a little 'spaced-out', it might be best to give me lots of little jobs that I can work quietly and happily away on without having to talk too much.

Please give me the option of working from home when I am poorly, it's my bum that doesn't work, not my brain so it's good to have a focus even when I'm poorly as it takes my mind off worrying about how bad this flare-up will get.