



# Jane's story

Person-centered  
thinking with  
people who  
have long term  
conditions

# Jane's story

When I was first diagnosed with ulcerative colitis 9 years ago I had no idea of the impact it was going to have on my life. I thought "Ok, now it has a name... give me the medication that will clear it up and I'll be on my way, thank you very much". But I soon realised it wasn't going to be that easy. I've spent the last 9 years having regular colonoscopies, short/long term hospital stays, constant medication changes and don't even go there in the enema department... think I've tried them all! I was so full of steroids when I got married that I went UP 3 dress sizes!

Back then, I presumed that you get poorly, get a diagnosis, and then get on with it. I honestly thought that if I struggled on each day, did what the consultant/GPs/specialist nurses told me and just got on with things in my own way, then that was a good way of dealing with the colitis that attacked my body far too frequently.

I usually consider myself a confident and outspoken person, but this year I realised that I had lost my voice. I'd somehow let colitis and doctors talk for me and make decisions on my behalf. I don't know where or when it happened, but it was clearly not working for me. Earlier this year, during another painful flare-up that wasn't showing any signs of calming, I had a call from my consultant to say that he felt that all avenues had been exhausted and he wanted to admit me as soon as possible in preparation for

surgery. It was the last thing I wanted to hear! He explained that he wouldn't know what he was going to do until he got me into the theatre and opened me up, the thought horrified me! Avoiding surgery has and still is my main goal. I quickly realised that I needed to get my voice back - and quickly!

That's when a colleague at work, Mandy, introduced me to the person centred thinking tools on the Think About Your Life website. It made me realise for the first time in all these years that I can take the control back that I'd lost from my life and finally let my voice be heard.

Over a cup of tea in the comfy corner of the office, my colleague, Mandy explained the different tools to me that she thought I would find useful in helping me cope better to live with my long term health condition. After only a few sips of tea and a matter of minutes I was telling someone for the first time how I actually felt on a daily basis, and how living with colitis each day is really hard. By the end of our chat Mandy had helped me realise that I wasn't just a colitis sufferer, I was Jane a 37 year old single woman who loves life and happens to get a poorly bowel from time-to-time. So I opened up my laptop and got started working on the Think About Your Life website. As I started using the website and writing, I realised that there were so many things that really upset me about how people treat me and my condition, and the presumptions that people make (on my behalf) but I'd never said anything. My frustration at myself took over and I was soon zipping along. It was such a good feeling (and emotional at times) documenting how

I'd like to be supported and what didn't work for me.

The first person-centred thinking tool that I used was **working/not working**, and just being able to put into words clearly how I felt had a huge impact on me. It enabled me to have a frank and honest discussion with my boss about what my needs were in the workplace around my condition, and we worked out ways that I would be more comfortable in work and to communicate more effectively when I was feeling unwell. I also showed it to my colitis specialist nurse and we worked out how I could feel more in control of my health. I now have a direct line between Rachel my colitis nurse and the consultant so that I can get the answers, support and help that I need during the crucial first stages of a flare up. Letting the healthcare professionals read this is a non-confrontational way of explaining the support I need, to stop my condition spiralling out of control, as it so often had in the past.

Working on my **good days and bad days** showed me that I needed to communicate how I was feeling more effectively with my loved ones and explain how I needed to be supported with my colitis. This information formed the basis of my one page profile.

The hardest tool to work on was **hopes and fears**, well to be more specific it was fears that gave me the most problem. It took quite some time to start being really honest with myself. I had to take a really good look at my life and work out what has happened and what I want from my future. I went through a very amicable divorce

this year, and the realisation that my ex-husband wasn't going to be there as a support around my colitis scared the life out of me. After our split I'd not given this aspect of my life a second thought, as I'd been in remission since then, and had only just started to flare-up again.

I talked to Mandy about them over another brew in the comfy corner of the office and we looked at what I had written, and about what were the next steps I could take. I shared my **one page profile**, what is working and not working for me and my hopes and fears; we giggled about 'is it appropriate to mention enemas by date number 5?', and cried about if I would find someone who would be comfortable and understanding about all of this. We talked about how using the tools can help me work though all of these issues and finds ways to help myself in my day-to-day life. It all seemed so simple and clear now. Simple things like: if I'm going out for dinner with someone new, saying that I'm a vegetarian, which is so much easier than saying I can't eat meat because my bowel can't cope with it; being able to use the toilet on the top floor of the house, so that I don't have to feel anxious about using the toilet in the downstairs office and how to communicate to my colleagues when I'm feeling very unwell and need to head home to bed!

When we looked at my one page profile it made me wish that I'd been able to pull this together when I was first diagnosed so everyone knew where they stood and how I wanted to cope and manage my colitis.

My one page profile is blue. Anyone who knows me understands how important that is to me, and I even like my photo. It was taken on a 'very good day' on a night out. I sent copies to the closest people in my life; parents, brothers, sister-in-law, best friend and ex-husband. I had no idea what they would make of it, as all this was new to them too. I was so amazed and happy that each person took the time to sit with me and talk about what they'd read. Everyone said they were surprised how much impact colitis had on my life on a day-to-day basis, and I had a few telling offs for struggling on for so long on my own... oops! What also became clear was that nobody knew what medication I was taking on a daily basis. It was only my ex-husband who knew all my daily meds and since we'd split up I hadn't taken the time to inform anyone what I was taking. So I quickly created a new section on my profile for current medication.

I've had mixed responses to my one page profile. The best response was from my 12 year old niece Emily; she was really keen to read my one page profile. As she had read it so close to us going on holiday we had a good chat whilst we sat together on the plane journey to New York. We both enjoyed that my profile opened up the opportunity for conversation. It gave Emily the chance to ask all of the questions that had been buzzing around her head over the years while she had seen me at my worst. By the end of our chat, somewhere over the Atlantic, Emily said she felt like she had got to know everything about me and colitis and how she was looking forward to supporting me during our holiday and beyond. I was woken up

each morning on holiday by Emily who had been down to the Starbucks in the lobby and brought me a decaf Earl Grey tea with skinny milk...just how I like it!

My 73 year old mother has always been very supportive and none more so than with me and colitis. She would attend all hospital appointments if I let her, although I did have to make the executive decision many years ago to attend all appointments on my own, after the first one my mum attended she answered all of the consultants questions on my behalf. Her love and concern for me has led her to become an uninformed expert in what is good/bad for me. I had high hopes that after reading my health profile, it would open up the lines of communication regarding not making presumptions on my behalf. I was so pleased that it did, but very quickly my mum reverted back to her old ways and resumed her stance of 'mother knows best'. I have resolved that this is one battle I am never going to win. But it has left me with the ability to be more direct with her, and drop quotes from my one page profile into our conversations. I did have a minor victory with my closest friend and housemate Shell. As best woman at my wedding and the person I turn to most, I thought I wouldn't have had to get a point over. Shell is my best friend, yet since living together she regularly makes assumptions and decisions about me and colitis on my behalf. At times her love and well meaning was making me feel very frustrated and upset, as it is how people verbalise their concerns that makes you feel misunderstood. Comments like: "Should you be eating that?", "Should you be doing that?", and making me feel that I have eating

issues all add up to the stress and anxiety on a condition that is triggered by these things. The first thing Shell said after reading my health profile was regarding 'How best to support me... about food.' She said "Do I make you feel like that?" and somewhere my voice came out, it wasn't loud but I said "Yes, sometimes you do." We talked about how I know what my body can cope with food wise each day, and I do what I need to, to remain as pain and flare-up free as I can. Shell said that reading how I feel and the support I need from the people I love has helped her to really understand what I need. Since reading my health profile and having our chat, I've not felt like she has made any presumptions on my behalf about what I do and don't eat.

In the New Year I am starting a new job. I have the usual concerns like anybody starting a new job. Except I have the added worry that the anxiety of this new start could cause a colitis flare-up. I hope to share my one page profile with everyone once I am settled in, and they have got to know me as a person first, (I don't just want to be Jane, that woman who works on the reception who has an inflammatory bowel disease). I'm just keeping my fingers crossed that my desk isn't too far away from the toilet!

Every 6 weeks I have to go to hospital to have my IV medication. I sit with Rachel the colitis specialist nurse during my infusion; it usually takes a couple of hours. During this time it gives us plenty of time to talk about coping strategies for my condition. After my surgery inducing phone call from my consultant earlier this year,

Rachel received a very emotional voicemail from me. My voice was loud and clear... living with a 'bag' will not work for me! Within 10 minutes she called me back, agreeing with me that surgery at this moment in time was not the best option for me. She spoke to my consultant and between them they agreed to put a hold on putting me in a hospital bed for 2 weeks. I would do anything to avoid surgery, so on Rachel's recommendation I started having intensive acupuncture, the most restrictive diet known to man, cut my working hours almost in half and cut my socialising down to zero! It was drastic, but during those two weeks I went back into full remission and have remained in remission since. I have spoken to Rachel about using the person-centred thinking tools and about developing my health profile and the information it contains, and the impact it has had on my life. I will be taking my one page profile in to show Rachel on my next infusion. Rachel was really enthusiastic about how she could use the information, contained in a health profile, to treat and support the people she helps. We both thought that during our infliximab treatment, would be a good time to get people to talk and work on their own profiles to help them get the control back in their lives. We both felt like this could be even more beneficial for people who are newly diagnosed. I think it would help address many issues brought up by living with colitis/crones that a person wouldn't normally address until it had become a major issues.

Using the person-centred thinking tools and developing my one page profile has dramatically improved how I cope with colitis each day. Just being

able to communicate to people who are close to me how I feel and the support I need has made me look more positively about the next steps ahead. I still get bad days, but now I feel more in control instead of feeling that I have NO control. My wish is that every person who lives with a long term health condition will use the Think About Your Life website, explore and use the tools, and build their own one page profile, enabling them to gain control back in their lives.

**[www.thinkaboutyourlife.org](http://www.thinkaboutyourlife.org)**

# Jane's working/not working

WORKING / NOT WORKING

**working**

Having a direct line to my consultant's office, so it saves time when I need help.

At the moment Infiximab is working (fingers crossed).

Being able to sit with Rachel (colitis specialist nurse) whilst having IV meds and being able to chat about anything that's worrying me.

**not working**

Having to re-learn what my food intolerances are.

Getting tired easily and learning when to 'give-in' and rest.

Having to explain to everyone when I'm having a bad day. It happens so often I feel like people lose interest when I mention it.

The affect that emotional stress has on my gut and bowel...makes me very unwell and then it's hard to get the colitis under control again.

**next steps...**

Explore how I can prevent and manage emotional stress - and still have a life!

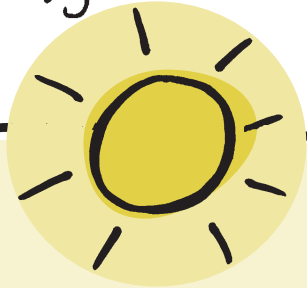
Try books and internet sites first.

Keep a food diary to notice my intolerances.

# Jane's good day/bad day

## GOOD DAYS AND BAD DAYS

*good days*



Waking up after a good night's sleep without any pain.

Only going to the toilet once in the morning with normal functions.

Having a good day at work without colitis affecting my day.

Not having to take any Tramadol (painkillers) as they make me feel pain free but very yucky.

Being able to eat **WHAT I LIKE** not **WHAT I NEED** to eat.

Being able to have a glass of wine with family/friends.

Go for a run.

*bad days*



Having a bad night's sleep and waking up in pain.

Being house/toilet bound all day.

Not being able to eat solid food.

Not having enough energy to go for a run.

Not being able to go to work.

Having to take Tramadol all day.

Feeling alone and isolated.

Write in my one page profile how my housemates can best support me.

Call my consultant and report the change if I've had 7 bad days in a row.

*next steps...*

# Jane's hopes and fears

## HOPES + FEARS

hopes



That I will have a long period of remission.

Be able to go to a camping music festival and not to have to worry about not having toilets facilities for 3 days...to be fine with that.

To be able to eat out and to not have to worry about what I'm eating and how it will affect me over the next 12 hours.

Be able to have a job that I love and not have colitis stop me from doing it to the best of my abilities.

To be able to drink a glass of champagne again without it turning to acid in my tummy!

fears



Feeling like I have to deal with this all on my own and not asking for help when I need it...feeling isolated.

Worrying that colitis and the medication I take will mean that I won't be able to have children.

Having the worry that being single with a long term illness means that I won't find someone who will be understanding and accepting of this, at times, very unpleasant condition.

Worrying that all medication avenues have been exhausted and having to face life living with 'a bag'.

## next steps...

Having a one page profile so people know how best to support me.

Find out age limit for adoption.

# Jane's one page profile

## 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 (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 uplifting.
- Listening to music – I love music (especially Manchester music) going to gigs/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 letting 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 you're 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 IV of steroids, when a flare-up gets to 'that stage' when only IV steroids will do. My GP 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 IV to reduce my suffering and pain.