

Having a Baby After Stoma Surgery: One Woman's Experience

BY RICHARD BIDDLE

It was around this time last year that one of our volunteers, a young woman, said to me that more needed to be done for women with stomas who were pregnant or wanted children.

Afterwards, when I checked what was available in terms of support, advice and encouragement, I rapidly came to the conclusion she was right. The existing patient literature is far from comprehensive. Similarly, when I searched 'pregnancy and stoma' on Facebook it yielded plenty of support groups, but none in the first 60 (I gave up looking after that) made any reference to stomas whatsoever. Of course, this doesn't mean that such groups don't exist. But if nothing else it illustrates how difficult it is for women with stomas to get ostomate-to-ostomate peer support while they are trying to conceive, during their pregnancy or afterwards as new mothers.

This article makes a start at addressing the paucity of information out there. It is about a woman called Jessica and her two pregnancies: the first before stoma surgery, the second after. What follows focuses primarily on Jessica's experience of being pregnant as an ostomate, rather than on the illness that led to her needing stoma surgery.

Jessica lives in Buckinghamshire with her partner Karl, children Lucas and Evelyn, and the family's two dogs. Jessica was diagnosed with Crohn's disease when she was 19. This followed four years of feeling unwell, undergoing lots of tests, and watching puzzled doctors scratch their heads.



It took some time to get Jessica's Crohn's under control. She went through all the known medications and had intestine resection surgery all to no avail, before going on a trial for a new experimental drug, which worked. Jessica became pregnant with Lucas towards the end of 2017 when she was 26 years old.

When a woman with Inflammatory Bowel Disease (IBD: Ulcerative Colitis and Crohn's disease) becomes pregnant many medical considerations come into play. In simple terms, the pregnancy can affect IBD and IBD can affect the pregnancy. For women with the disease in remission at the time of conception the risk of a flare-up remains similar to non-pregnant women. Conversely where the disease is active at the time of conception, persistent flare-ups can accompany the pregnancy. Each woman is to an extent a unique case, requiring complex decisions to be made about important issues such as whether to continue with existing IBD medications, find alternatives or perhaps even stop medication altogether.

Jessica had a difficult first pregnancy. As the impact of the experimental drugs on her unborn baby were not fully understood, she was initially taken off of them. Very soon afterwards she had the first of many terrible flare-ups. Six weeks later she was put back on the drugs, as this was considered the lesser of risks and preferable to her losing the baby. Even back on the medication it proved impossible to control Jessica's Crohn's. 19 weeks into her pregnancy she was put on bed rest, where she stayed for the remaining four months. It was a period characterised by sickness, pain and flare-ups and frequent visits to hospital. This was because each time something happened, it needed to be established whether what she was experiencing related to her baby or to her Crohn's. In the end she was admitted to the Women's Centre at the John Radcliffe Hospital, which is a regional referral unit for high-risk pregnancies.

All in all, it was a stressful nine months, which ended happily in August 2018 with delivery by C-section of a healthy baby boy. After Lucas was born (and before her stoma surgery) Jessica was advised not to have any more children, given how her Crohn's had interacted with her carrying. Around a year after Lucas arrived, Jessica had stoma surgery. The need for this was not connected with her pregnancy. Jessica had known for some time that she would probably need a stoma. Her healthcare team were just unable to be specific about when this would be necessary.

Once she had recovered from the surgery and started to adapt to life with a stoma, Jessica and her partner began to think about having another child.

They were buoyed by hearing from Jessica's Crohn's doctors that now she had a stoma, it should be possible to keep her condition in check, should she fall pregnant again. Even so, the decision wasn't one that the couple took lightly. Jessica believes that, ultimately, the difficult experience of her first pregnancy gave her and Karl the confidence they needed to try for another baby. As a consequence of being able to mentally prepare, Jessica developed a positive mindset,



thinking along the lines of: "It's only nine months, I coped last time, I can cope again. If it's better than last time round, then that's a bonus." By the middle of 2022 Jessica was expecting again.



Jessica enjoyed a much easier second pregnancy. There was no forced bed rest or unplanned hospital visits. She stayed on her Crohn's medication throughout and had no flare-ups. Evelyn was born safe and well in February this year. From the point of view of being pregnant when you have a stoma though, it was not an entirely uneventful nine months.

Although Jessica received little in the way of specific antenatal stoma advice, she was informed that stoma function could be affected. Jessica was told to keep an eye out for possible blockages which could occur if the baby was lying in a particular way. She was advised that if she had no function for a day and a half then she was to call her doctor or go to A&E, so that the issue could be resolved (perhaps by moving the baby). In the event, Jessica did not have any blockages, but the consistency of her output did alter. Almost as soon as she became pregnant, she started to experience constipation.

The next thing of note to happen was that the size and shape of Jessica's stoma changed. It developed a mushroom shaped head. This was not something Jessica was prepared for, and initially found a bit scary. Calls to her doctor and stoma care nurse did little to alleviate her unease. She sensed that neither really knew the cause. They speculated that it was connected with the baby getting bigger, but couldn't be sure, which Jessica found frustrating. As her stoma wasn't hurting, a plan of 'wait and see' was adopted. It was only after Jessica posted what was happening on the Colostomy UK Private Facebook Group, that she started to feel happier: someone responded to say that the exact same thing had happened to their stoma when they were pregnant.

Finally, during the last month of her pregnancy, the edge of Jessica's stoma began to bleed, and she started to feel what she describes as 'pressure' pain. She again sought medical advice and was told that both the bleeding and the pain were likely due to the fact that the baby was getting bigger. Again, this wasn't the definitive answer that Jessica had hoped for. It left her feeling like being pregnant and having a stoma was something that was a little out of the ordinary. She was told to take normal painkillers and that the issue should resolve itself after her baby was born (which it did). On a humorous note (but also something that would-be ostomate mums need to be aware of) Jessica says to look out for the baby kicking.



During the third trimester she swears that Evelyn was using her stoma as a target!

Jessica testifies to having felt very daunted by the prospect of being pregnant as an ostomate. But as her story shows, it is possible to have children after stoma surgery. Of course, not every pregnancy is planned, but where feasible it is sensible to discuss matters with your doctor and stoma care team as soon as you can. Their advice (on everything from potential issues with conception, to the pregnancy, and then birth) will take into consideration your particular circumstances, including the reason(s) why you had stoma surgery in the first place. Jessica's experience also highlights some of the difficulties expectant mums with stomas can face getting definitive answers when odd things happen and the problems of connecting with other women in similar situations. As you will have noted, this was where members of our Private Facebook Group came to the rescue. Although they couldn't give the answers Jessica craved, they were able to reassure her from their own experiences. On a final note, since speaking to Jessica, we have begun the research and work needed to put together a Colostomy UK advice/information booklet. The volunteer I mentioned at the start of this article is helping with this and has already managed to recruit a senior stoma care nurse to the team!

