



My experiences of supporting breastfeeding women with inflammatory bowel disease (IBD) via social media

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'Scientific, evidence-led information which is very up to date and relevant, and ... better informed than some doctors'

Member of 'Breastfeeding with IBD' Facebook group

For the last 40 years, I have had a passion for breastfeeding, and as a pharmacist, I first began looking more closely at the safety of drugs in breastmilk 25 years ago. I began writing about the topic in 1995, when the internet was in its infancy and finding data was difficult. I also began a PhD looking at the experiences of mothers, pharmacists, and doctors in a matched area. Not totally unsurprisingly, there was little agreement.¹ Professionals lacked – and to a large extent still do lack – training on this topic. They based answers on their personal experience – good, bad, or indifferent. I had comments like 'I couldn't possibly ask a mother about breastfeeding; it's far too personal,' or 'if a mother insisted on breastfeeding on medication, I'd report her to social services.' It worried me a lot.

Whilst I was conducting my research and writing my thesis, the [Breastfeeding Network](#) (BfN) was formed and I became a founder member of it, leaving the National Childbirth Trust with whom I had trained. One of the first things the BfN did was to fund a telephone line for me to take questions about drugs in

breastmilk (up until then, they had come in on my home telephone, so they were often answered by other members of my family). That line continued until about five years ago, and it has now been replaced by social media and emails. Over the last two years, there have been around 10,000 contacts a year handled by me and another pharmacist who supports me one day a week.

'This group offers support & ladies that just "get it" ... especially at times when I have needed it the most'

Member of 'Breastfeeding with IBD' Facebook group

I began to recognise that there were a lot of contacts about inflammatory bowel disease – ulcerative colitis (UC) and Crohn's disease. This echoed in my head because I was diagnosed with Crohn's back in 1976, when I was just 22 years old. I have subsequently had three daughters and have never been healthier than when I was pregnant or breastfeeding – hence the passion for breastfeeding. I was lucky enough not to need medication when I was breastfeeding. However, I have had to have three bowel resections over the years. This is where a surgeon removes an affected segment of gut and then re-joins it again. Each time, I had to sign an agreement to have a stoma if necessary, something which terrified me in my younger age. It is major surgery, and I needed a lot of support from my husband and my mother.

So, in 2016, I set up a Facebook page called 'Breastfeeding with IBD (UC and Crohn's)' and invited people who messaged me with questions about drugs in breastmilk to join. It has grown and grown beyond my wildest imagination. As of this month, we have over 1,200 members from across the world, with the age range predominantly from 25 to 44 and 99% female.

'The opportunity to ask questions about practical, day-to-day issues is invaluable'

Member of 'Breastfeeding with IBD' Facebook group

In my mind, when I set up the group, it was somewhere to talk about poo! Those of us with IBD frequently suffer from urgency, so our babies and toddlers get used to having to come with us. One of the topics discussed has been having a bouncy chair ready in the loo 'just in case.' However, it has developed into so much more. It is a place where people ask for suggestions for food to tolerate when ill and encouragement when they feel they need it, but above all (and I guess because of me) a place to seek information on the compatibility of drugs and investigations with breastfeeding. Many health professionals have also joined in order to access the information, although they rarely post!

'A great mix of personal experience and scientific data'

Member of 'Breastfeeding with IBD' Facebook group

When I was asked to write this, I turned the question to the group and felt very humbled by the responses:

'I have found this group immensely helpful. I only wish I had found it a lot earlier. For me it is not usual to know other people who suffer from IBD, so the opportunity to ask questions about practical, day-to-day issues is invaluable and doesn't occur anywhere else for me. This group provides scientific, evidence-led information which is very up to date and relevant, and, I have found, better informed than some doctors, who do not always know or understand intricacies of breastfeeding and use of prescription medications.'

'This group helps me feel supported and less alone. The chance of me finding another pregnant or breastfeeding mum with IBD in my local area seems quite slim, especially without social media, so this group makes me feel less alone with that. I also feel that if I needed to increase my medication or go for a colonoscopy etc. I would feel so much more confident challenging any advice to not breastfeed that I was given.'

'This group and the advice and information you have provided, Wendy, is invaluable. I don't think I would have breastfed for as long as I have (eldest daughter 14 months & currently youngest daughter still breastfeeding at 12 months) without it. Definitely more knowledge in terms of IBD & breastfeeding & medication etc. than the health care professionals that I have seen – from nurses to GPs to consultants. All my friends that have breastfed or are going to breastfeed (IBD or not) I have pointed in the direction of your drugs factsheet, along with said professionals. I feel that this group offers support & ladies that just "get it" ... especially at times when I have needed it the most & would have otherwise felt lost & alone.'

'It's a safe haven to ask questions and get answers from people's experience. No one judges. It's good to know there are people who are sailing in the same boat and some have sailed safely when you are feeling the journey is rough. Gives hope and positivity to get through difficult times we have with the disease.'

'It's a Godsend group. Extremely helpful.'

'This group is amazing. Everyone is always so helpful. ... It's a great mix of personal experience and scientific data. My old GI [gastroenterologist] was so misinformed on medications while breastfeeding. ... I was told I couldn't breastfeed on prednisolone; I was told I couldn't breastfeed on my drugs. I was told I had to pump and dump through my entire colonoscopy prep and for 24-48 hours after the procedure. I was so fortunate to have this group as a resource. I truly feel I never would have achieved 14 months of breastfeeding if I hadn't found this group.'

'The support of online groups is invaluable. It's very useful having people who have been through similar experiences give advice especially when doctors often don't have enough specialist knowledge about certain conditions and medications and breastfeeding.'

These are the words that probably sum up what I had hoped for initially:

'I have never really been able to connect to anyone in person with IBD except in passing. In social media groups I am able to speak openly about struggles, fun yet gross moments that are relatable to others, and ask for valuable support and advice. I find not only support, but community!'

'This group helps me feel supported and less alone'

Social media puts us together in a place with other like-minded people – if you are in the right group! As one comment said, breastfeeding can make you feel alone. Having IBD definitely makes you alone, as no one can see that you have a chronic medical condition, but it affects every bit of your life.

The role of social media and chronic medical conditions

Since I was first diagnosed 44 years ago, because of my resections, my tummy is not pretty! My resections also caused me to develop peripheral vascular disease, which normally only occurs in elderly, overweight people who have smoked and who have therefore laid down cholesterol in their legs. At one stage, I couldn't walk 50 yards, and my consultant told me I would lose a limb within five years and be dead within ten. I can now walk long distances (though only slowly uphill) by opening up small blood vessels to bypass the blocked ones. I bought two Border Collies who needed exercise and they saved my life. Three years ago, I was diagnosed with a melanoma on my heel – not from sunburn, but due to my medication. I had major surgery and have a large hole where the mole was removed, but a six-month delay might have meant a spread and a less positive outlook. In the current pandemic, my medication meant I was in the shielding population, so I missed seeing my daughters and grandchildren from March to August. This is a disease with so many ramifications; we need each other in the special place that our group provides.

I set up the group to help others in the place I had been, but now I get support from them. It feels like they are all my daughters, and I do tend to respond as such! That the group has spread across the continents is amazing: the problems are just the same.

'I find not only support, but community'

Member of 'Breastfeeding with IBD' Facebook group

A few years ago now, several of us were interviewed by *Connect*, the magazine of the [Crohns and Colitis Association](https://www.crohnsandcolitis.org.uk)². An amazing report resulted, and we were all proud. We were over the moon when the

magazine won Member Magazine of the Year and Cover of the Year at the PPA Scottish Magazine Awards against competition from the *Beano* and the *Big Issue*. The cover normalised not just breastfeeding and IBD, but long-term breastfeeding and IBD. What more could I have ever asked?

A member commented:



'I just wanted to say how uplifted I was to open the envelope containing Connect magazine and see the feature on breastfeeding and IBD on the cover. There is so much misunderstanding about medication and breastfeeding so it's just great to see this.'

If you know someone who has Crohn's disease or colitis, please signpost them to us:

www.facebook.com/groups/BreastfeedingIBD.

If you know an interested professional, they are welcome to join, but they will need to explain why when applying so that I can keep the group safe.

I am very proud of what we have achieved together in four years. I wish I could set up groups for everyone with a chronic condition to provide information about medication and breastfeeding, but I can't, which is why the title of my latest book reflects that, [Breastfeeding and Chronic Medical Conditions](#).

Thank you for listening to my thoughts about IBD and I hope you have learned just a little more. Thank you too for the members of the group whose words I have used.

Countries with the most members of the 'Breastfeeding with IBD' Facebook group:

United Kingdom 695

USA 283

Ireland 58

Australia 47

Canada 39

Belgium 17

Slovakia 15

New Zealand 11

Germany 5

Romania 3

Age range of members (%):

18–24 5

25–34 50

35–44 40

45–54 3

55–64 2

65+ 1

Wendy was one of the founder members of the Breastfeeding Network. In her employed life, she was a community pharmacist and also worked in doctors' surgeries supporting cost-effective, evidence-based prescribing. Wendy left paid work to concentrate on writing her book *Breastfeeding and medication* (Routledge 2013, 2nd edition 2018), developing information and training material on drugs in breastmilk as well as setting up her own website, www.breastfeeding-and-medication.co.uk. She has also published *Breastfeeding for dads and grandmas* (Praeclarus Press, 2016), *Why mothers' medication matters* (Pinter and Martin, 2017), and most recently *A guide to supporting breastfeeding for the medical profession* (Routledge, 2020), co-authored with Professor Amy Brown. She was awarded a Points of Light award in May 2018 and was delighted to be nominated for an MBE in the New Year's Honours List 2018 for services to mothers and babies, receiving her award in May 2019.

¹ Jones, W & Brown, D (2000) 'The pharmacist's contribution to primary care support for lactating mothers requiring medication.' *Journal of Social and Administrative Pharmacy*, 17(2). Available at: www.researchgate.net/publication/289301609.

www.crohnsandcolitis.org.uk