

Breastfeeding and Medication



What would you like your healthcare team to know about IBD and breastfeeding?

The Facebook page Breastfeeding with IBD (UC and Crohns)

<https://www.facebook.com/groups/BreastfeedingIBD> has 1.4K members from across the world. On 30th June 2021 the author published a question “what would you like your healthcare team to know about IBD and breastfeeding?”. With 24 hours it had been seen by 365 people, and received 15 replies

The feelings of the group broadly fell into 4 categories

1. Professionals not using specialist sources of information on the compatibility of medicines in lactation
2. Lack of acknowledgement of the importance of breastfeeding for the mother and the future health of the baby
3. Misunderstand of extended breastfeeding
4. Need for information on specific needs of mothers with IBD

The most frequent comment from the respondents was that health care professionals need to check specialised information sources rather than automatically suggest that breastfeeding is contra indicated. Many of the comments showed deep frustration about this issue and that sadness lasted a long time.

“Greater understanding of how biologics work and how little if any crosses into breast milk, so women feel more confident upon diagnosis that they aren’t putting their babies at risk!

“That a lot of medication is OK for breastfeeding, and they should take the time to check rather than telling us we have to give up feeding!”

“I just feel that when you are breastfeeding (or pregnant!) the first reaction of most medical professionals is to say no to taking most medication - I don't know if its fear of prescribing

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July 2021 The information on this sheet is based upon my professional experience as a pharmacist with a specialised interest in the safety of drugs in breastmilk, supported by evidence from expert sources. However, I cannot take responsibility for the prescription of medication which remains with the healthcare professionals involved. I am happy to discuss the evidence by email wendy@breastfeeding-and-medication.co.uk

something that could harm, lack of knowledge - or both. I would like them to acknowledge the importance and difficulty of breastfeeding and take the time to really find out if something is OK or not. I've had a consultant give me information regarding sedation that I know wasn't correct, but because my family were there and heard what was said I was put under pressure to not feed for a time"

"That medications are safe and to be familiar with supplementary sources of info dont rely on the BNF and believe it as gospel"

"Explore alternatives if a medication is not compatible rather than tell mums to stop breastfeeding"

"For dihydrocodeine to be routinely given instead of codeine (with the usual pump and dump nonsense alongside!)"

This response perhaps summed up the frustrated feelings of the group.

"Dont get butt hurt if a patient knows more about bf and meds than you, the professional, go and do some research, apologise and acknowledge this newly learnt information.

There were many responses regarding advice to pump and dump milk for sedation during investigations particularly colonoscopy, for CT and MRI Scans. This was exemplified by the comments:

"My doctor asked me could I stop breastfeeding for a few days after my infusions (every 8 weeks) "just to be on the safe side" My answer was simply: no. "

"Pumping and dumping is terrible advice especially because most of the time it's unnecessary"

"You can't just stop feeding on demand especially if you have an allergic baby too!"

"I wish doctors would just say "I don't know, but I'll check and get back to you" rather than give incorrect information. I instantly lose respect for and confidence in any doctor / nurse who tells me to pump and dump "just to be safe" when it's not necessary. I say it all the time, but if we're going to trust the science behind the medicine we take, we MUST also trust the science behind how it may/may not impact breastmilk."

"I was told many times that Hydroxychloroquine was absolutely too dangerous to feed on, so I ended our strained feeding journey because I needed medication (this was nearly 10 years ago)"

"That there is now a reputable sources of information for checking drug safety"

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Several respondents wanted professionals to know and understand how important breastfeeding is to them rather than dismiss it as an add on extra to motherhood. In addition, that sometimes they need additional help with breastfeeding due to the symptoms of the condition of IBD.

"I think some health professionals don't appreciate how hard a Mum may have worked to get where she is on her breastfeeding journey. We're often told to just "stop feeding" in the same way you might tell someone to stop eating chocolate. It needs to be an absolute last resort, with every option having been explored, and researched thoroughly and compassionately"

"It would also be great if medics were more aware of the protective effect of breastfeeding and how it can reduce the chances of our children getting IBD. Maybe that will stop all the usual questions about why we continue to feed into the toddler years and beyond"

"Explaining that we can have low supply due to our IBD, but we need advice and support to help build it up, not just to stop feeding, the effects of dehydration and nutritional deficiencies on breastfeeding and on the feeding parent"

"Breastfeeding reduces the chances of a child developing IBD and therefore they should support women who want to breastfeed rather than create obstacles"

Extended/ term breastfeeding is important to many of the members of the group. The comment is an extension of the previous responses.

"When I tell my Health visitor and a midwife, I am still breastfeeding 3 years old I get: can't he have a milk in a cup? Why don't you stop you are pregnant having a new baby? So frustrating"

"It would also be great if medics were more aware of the protective effect of breastfeeding and how it can reduce the chances of our children getting IBD. Maybe that will stop all the usual questions about why we continue to feed into the toddler years and beyond"

"My gastroenterologist is lovely, been on great terms for over a decade but feeding my little boy past a year I have felt is not frowned upon exactly but sort of almost an inconvenience, I guess. It's unfortunate because it's slightly changed how I feel about him, and this is a man who has saved my life.... twice! Sad actually "

Similarly, respondents commented on the need for information on specific needs of mothers with IBD. This was acknowledged by one professional. There was also acknowledgement of the importance of professionals to the rest of the family supporting the mother.

- Top tips for feeding on the loo (how to make a safe playpen in the bath etc)/slings make toilets accessible with a baby.
- I'm now in here as a breastfeeding peer supporter to keep up to date with current advice and resources, to have a place to signpost to other IBD parents I end up supporting.
- That flare ups and rapid weight loss are not because you are breastfeeding
- Please don't ask parents to feed in the toilets or pump in there either
- To family members the doctor is ALWAYS right, must be, they're a doctor!! Erm no!
- Prednisone ABSOLUTELY effected my milk supply.

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- UC wise I'm lucky in that I've never had flares that effect my quality of life. I just bleed a LOT, which results in bad anaemia. My milk supply has never been an issue because I eat and drink plenty.
- A clear explanation to mums that they recommend delaying the rota virus only and it's not because of risk to baby but to Mum. I've seen mums choosing to quit breastfeeding so their baby could have the vaccine when in reality they would have gotten more protection if they kept breastfeeding (because breastfed babies are a lot less likely to catch rotavirus).

Conclusion

IBD is a chronic condition which these respondents will have to deal with throughout their life, as I myself have had to do because I have Crohns disease. To manage symptoms during conception, pregnancy and breastfeeding is a challenge. To be a mother is an ongoing journey of balancing tests, medication and illness. This blog is intended to make professionals understand how much mothers (and their families) want professionals to listen and understand needs.

I have provided information on the safety of medications used during diagnosis and treatment of IBD <https://breastfeeding-and-medication.co.uk/fact-sheet/inflammatory-bowel-disease-and-breastfeeding> please let us work together to support the many thousands of women of childbearing age with IBD particularly during the time that they have chosen to breastfeed.

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