Breastfeeding and Medication

Multiple Sclerosis and Breastfeeding

I have multiple sclerosis and I receive 1 monthly infusions of Tysabri. I chose to come of the infusions while pregnant and a month after I had my little boy so I could breast feed a little. I received information but I chose not to continue breastfeeding because I felt nobody actually knew the risks of the drug, I take on breast milk. I felt the sample of people taking Tysabri and breast feeding was too little, and I did not want to risk the health of my beautiful little boy. It wasn't an easy choice to resume my medication and I have had a few emotional moments where I have felt terrible, I couldn't give my boy the breast milk he deserves.

I have been on various self-injecting disease modifying drugs until 2015 when I had two very serious flare ups. I went to see the MS team and the neurologist was horrified and apologized for letting me get so bad, he said I should have been in better drugs to control my flare ups. I shuffled and had little movement in my legs, my right being worse. It was the first time I had ever had to use a stick. On other occasions my stubbornness would not let me use a stick but this occasion I had no choice, I was extremely bad. I was then but on Tysabri.

I found out I was pregnant mid-June of last year and phoned neurology to say I would not be getting my next treatment and did not want treatment while I was pregnant. The MS nurse said that women during pregnancy don't tend to have flare ups, they think mainly because of the pregnancy hormones. I know this was the case for my sister. I received conflicting information about the use of amitriptyline while pregnant from neurologists and the obstetricians. During pregnancy I felt fine. Just the usual tiredness (plus my MS aching which meant I couldn't always sleep) in the first couple of months and then again at the end. I managed to work full time at beamish museum (I'm a project officer helping with the new 1950's town) until two weeks before my due date.

I spoke to the MS nurse while pregnant and she said as soon as I wanted to return to my treatment I was just to ring. I did this after a month of breast feeding. The neurologist believed I would be ok to continuing breast feeding for 6 months but he wasn't 100 per cent sure. Based on this information I continued breast feeding for another two weeks after a month of breastfeeding, I was going to go longer. After my first infusion but George (my little boy) got a temperature and was out of sorts, quite grumpy, etc. I was perhaps a little paranoid but thought my milk was affected by the

medication. You just want the best for your child, and I was worried I was giving him something awful through my milk.

My next infusion, I had a bad reaction, my body went into shock, my temperature was high, my heart rate and blood pressure went up, but I was shivering and my extremities were freezing. The consultant on call said he'd not seen a reaction like it before but after they gave me something, I'm not sure what and draped me in blankets, I was a got better. I guess my reaction made me feel I kind of did the right choice not continuing breast feeding. The cases studying so far are few and everyone reacts differently to medication. My body might have released the drug into my breast milk more or George's body might not have been able to take a small amount of the drug.

Although I think I made the right choice it wasn't an easy choice to stop breast feeding and I have agonized about the choice to resume treatment. I had a few emotional moments, specifically while eating dinner I broke down and my partner had to comfort me (post pregnancy hormones)! I had looked for a local breast milk bank. But there are none, to my knowledge, around here. However, a colleague, who donates to a bank, has recently offered some of her milk which I'll gladly accept. I agree breast milk is best. I eat really healthy and wish my son could benefit from my healthy diet.

I was undiagnosed and had my first symptoms appear after my first who was breastfed. I still wasn't diagnosed until after my second child and a second relapse. I was breastfeeding exclusively and after losing my sight amongst other things, I was encouraged to stop breastfeeding, take steroids and start a disease modifying drug asap. Putting my own health second to breastfeeding was one of the most difficult decisions I have had to make. It effected my relationship with my partner as well, but I am thankful I chose to continue. I chose not to and fed until my son was 18 months and then decided to stop after another MRI with contrast showed I was still highly active. I was offered Mavenclad (immunosuppressant chemo drug) and started that. Although I have a wonderful team there was not much confidence in terms of drugs and breastfeeding

I was being investigated for MS pre-birth of my first child, following birth, my symptoms got a lot worse which I just put down to being a new mum, which I have now realised was MS related and is no surprise to me that I was diagnosed soon after giving birth. I had my baby during a heatwave, which my MS is particularly sensitive to. I can only describe the impact as having the life sucked out of me, like I am not the same person. This impact to my state of mind was huge, but was so breastfeeding, a natural aid that I unknowingly, desperately needed at that time. It was such a balancer for me, gave me purpose and was a huge achievement to know I was sustaining the beautiful life that I had grown, it made me so proud.

MS diagnosed after my second child in 2013. Had baby number three in 2019. Came off all disease modifying drugs in order to conceive and stayed off for ten months afterwards to breastfeed. I was determined to exclusively breastfeed for three months minimum due to research suggesting it

reduces relapse risk after birth. I managed to exclusive breastfeeding until I started weaning. My (female) neurologist supportive and helped me work out a strategy to breastfeed even discussing potential relapse treatment that could be taken whilst breastfeeding. My experience of feeding though was difficult. My milk came in late (day 5) and I had a lot of shooting pains in the breast after feeding. I wondered if the spinal cord damage I had from MS was having an impact here. When I tried to research it there was zero information on experience of breastfeeding for women with MS and whether spinal cord damage has an impact. This surprised me as MS overwhelmingly affects young women of childbearing age.

Description

Multiple sclerosis (MS) is a condition that can affect the brain and spinal cord, causing a wide range of potential symptoms, including problems with vision, arm or leg movement, sensation or balance.

It's a lifelong condition but its effects vary widely between individuals. A variety of medication is used to control symptoms. It's most commonly diagnosed in people in their 20s and 30s, although it can develop at any age. It's about 2 to 3 times more common in women than men.

The main symptoms may be progressive or include times of remission. They include:

- fatigue
- difficulty walking
- vision problems,
- problems controlling the bladder
- numbness or tingling in different parts of the body
- muscle stiffness and spasms
- problems with balance and co-ordination

Nelson (1988) studied 191 pregnant women in a non-progressive phase of multiple sclerosis. During pregnancy they noted an exacerbation rate of 10%. Over the nine months after birth the rate increased to 34% but in the first three months it was 68%. Of the women studied, 96 breastfed for an average duration of 6.3 months. The rate of exacerbation was not significantly influenced by breastfeeding with a relapse rate of 37.5% compared with 31.5% in those who didn't feed. However, Langer-Gould (2013) claimed that exclusively breastfeeding for more than two months produces a five-fold benefit in risk to relapse in the first year.

Pisicane (1994) reported that patients with multiple sclerosis were less likely to have been breastfed for a prolonged period with rates of 55% compared with 76.4% of women in a control group (healthy) who were breastfed for longer than seven months.

Multiple sclerosis patients should be told that if they breastfeed it should be exclusive, because this is more likely to be associated with decreased multiple sclerosis disease activity (Coyle 2016). Some studies suggest that breastfeeding, particularly when prolonged (at least four months), reduces risk for multiple sclerosis in the child (Conradi 2013).

Langer-Gould et al (2017) recruited 397 women with newly diagnosed MS and 433 matched controls. Total ovulatory years and the remaining factors that determine it, including gravidity, parity, episodes of amenorrhea, and hormonal contraceptive use, as well as age at first birth, showed no significant association with the risk of MS. However, among women who had live births, a cumulative duration of breastfeeding for ≥15 months was associated with a reduced risk of MS.

Krysko et al (2019) carried out a systematic review and meta-analysis of 24 studies that include 2974 women with multiple sclerosis. She found a 43% reduced rate of postpartum multiple sclerosis relapses in women who were breastfeeding compared with those who were not breastfeeding, with a stronger benefit of exclusive rather than nonexclusive breastfeeding.

Treatment

Options include:

- Acute courses of prednisolone, usually 5 days of prednisolone 40mg a day
- Interferon beta 1 a (Avonex ™ – I/M injection once a week, Rebif ™ sub cutaneous 3 times a week) – molecule too large to pass into milk and zero oral bioavailability
- Interferon beta 1 b (Betaferon ™ sub cutaneous injection every other day)- molecule too large to pass into milk and zero oral bioavailability
- Peginterferon (Plegidry™ sub cutaneous injection every 2 weeks)-– molecule too large to pass into milk and zero oral bioavailability
- Glatiramer (Copaxone™)– sub cutaneous injection once a day or three times a week) useful if no response to interferons. It is degraded to amino acids and cannot be measure in plasma. Very low oral bioavailability. New data presented in 2021 has confirmed that it is compatible with breastfeeding https://www.tevapharm.com/news-and-media/latest-news/new-safety-data-on-treatment-with-copaxone-glatiramer-acetate-of-breastfeeding-mothers-who-live-with-r/
- Natalizumab (Tysabri™) – an infusion every 4 weeks - molecular weight 149,000 and oral bioavailability zero. In the Piano study of women with inflammatory bowel disease in pregnancy 8 women received natalizumab while breastfeeding their infants. Among those who received natalizumab or another biologic agent while breastfeeding, infant growth, development or infection rate was no different from infants whose mothers received no treatment (Matro 2018).
- Dimethyl fumarate (Tecfidera™) – a tablet taken twice a day. Ciplea studied 2 mothers and noted limited transfer into milk (RID 0.01% - 0.03%), the amount being too small to be harmful. Monitor breastfed infants for flushing, vomiting, diarrhoea, adequate weight gain, and developmental milestones.
- Ocrelizumab (Ocrevus™) – an infusion every 6 months. No research in breastfeeding but while no levels in milk have been published, it is likely they are low, and that present, is probably not orally bioavailable (Hale 2020).

- Cladribine (Mavenclad™) is for highly relapsing MS. The tablet is taken in two courses. Each treatment course consists of two treatment weeks, one at the beginning of the first month and one at the beginning of the second month. This is then repeated a year later. Normally this doesn't need to be repeated. Cladribine is not recommended for use in lactation, withhold breastfeeding for a minimum period of 48 hours after the last dose of medication (Hale 2020).
- Teriflunomide (Aubagio™) tablet taken once a day). No studies in breastfeeding and should be avoided.
- high dose methylprednisolone for exacerbations. Cooper (2015) studied a lactating mother receiving intravenous (1000 mg) doses of methylprednisolone on three consecutive days. Whilst the infant was not breastfed, the measured levels in milk were too low to affect a breastfeeding infant. An interruption of 12 hours following IV therapy would virtually eliminate any risk to the baby. So, the mother could breastfeed overnight and dump milk during the day.

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Further information

Multiple Sclerosis Society https://www.mssociety.org.uk/

Multiple Sclerosis Trust https://www.mstrust.org.uk/