Women's Health Webinar Queries

I was diagnosed with MS while pregnant with my second child. I have since had hysterectomy and bilateral salpingo-oophorectomy. How has this/will this effected my MS?

Removal of both tubes and ovaries (bilateral salpingo-oophorectomy) causes an immediate surgical menopause. If this was performed under the age of 50 (in some cases up to 45) then it would be standard practice to prescribe oestrogen only HRT until around the age of 50 to replace the natural hormones and protect your bones and heart health. As was mentioned in the webinar, at present it is difficult to draw definitive conclusions on menopause and MS, but some studies show a slight increase in disability progression with a reduction in relapse rates in post-menopausal women. HRT wouldn’t usually be prescribed solely for any potential MS beneficial effects, but rather to treat hot flushes, night sweats etc. or in this case to replace the hormones that would normally be present until age 50 or so.

I hear urogestan bioidentical progesterone can help with perimenopause symptoms I experience. But because I have endometriosis I can’t get it prescribed. Do women experience perimenopause earlier due to autoimmunity?

Really interesting question. We know that 205 of patients with premature ovarian failure (menopause before age 40) have previously diagnosed with an autoimmune condition, but MS isn’t specifically associated. Conditions such as Addison’s disease, and of the thyroid, and pancreas are most commonly involved. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5327623/

What about LDN? Is it safe to take before/ during/ after pregnancy?

This is a really interesting question. The short answer is that appears to be perfectly safe in pregnancy and breastfeeding. This YouTube video gives some very interesting insights if you are interested in learning a bit more https://www.youtube.com/watch?v=Lr3RJT-5-HY

Are mood issues, linked to where lesions are in the brain? as I hear a lot mood and anxiety in MS is common.

Over 50% of people with MS experience an episode of clinical depression and/or anxiety. It was often thought that this was due to the many psychosocial aspects of the condition, but recent evidence now tells us that lesions in certain parts of the brain can cause these symptoms directly. https://pubmed.ncbi.nlm.nih.gov/14604264/

When I drink water, it seems to go right through me, is this related to MS?

Bladder symptoms are very common in MS, but they are also very common in women generally (and some men, although typically less so). The common theme is that the detrusor muscle in the bladder wall becomes overactive and contracts before the bladder is actually full, causing urgency. These symptoms are typically managed through a combination of
lifestyle change (avoid caffeine, alcohol etc.) and medications such as solifenacin. I would suggest discussing this with your MS team or GP, as relatively simple changes can make a big difference to your symptoms.

If you suffer from vaginal dryness and have both MS and menopause. How do you know which is responsible and is the treatment the same?

It would be more likely that changes in the vaginal tissues due to menopause are responsible (atrophic vaginitis). In the first instance a moisturiser such as Replens might help, or you could consider talking to your GP about some vaginal oestrogen (gynest or vagifem). This is not considered HRT as very only low levels reach the blood stream, and is usually safe to take long-term.

I experience very frequent UTI's. Is this common with MS? Menopause?

It is unfortunately very common with both conditions I am afraid. It can be rather difficult to manage, with people requiring long-term antibiotic therapy. There is increasing interest in the role of gut health and UTI, and ensuring that you get lots of fermented foods (kimchi, kombucha, sourdough etc.) is a great way of bulking up the good bacteria. Cranberry juice has conflicting evidence, but may be of benefit, as may D-mannose, which is a natural carbohydrate found in certain fruits. It can be taken as a supplement and there is some evidence that it may prevent UTIs. [https://www.frontiersin.org/articles/10.3389/fmicb.2020.01509/full](https://www.frontiersin.org/articles/10.3389/fmicb.2020.01509/full)

Next to natural sources of HRT in brackets it says (limited evidence) - does this refer to the last item listed (evening primrose) or all of them?

All of them I’m afraid!

I take HRT, the progesterone element (Utrogestran) seems to exacerbate my MS symptoms on the 12 days I take it. is this common ? what alternatives are there?

This is indeed quite common, many women on HRT find that the progestogen part of the treatment causes issues, Ms or not! Unfortunately, if the womb is still in place, then it is necessary to protect the lining from the oestrogen effects. There are many different preparations of combined HRT, and it can be a bit of trial and error, but one good option from a side effect perspective might be the combination of an oestrogen patch or gel, with a Mirena coil (IUS). This would offer optimal protection with low levels of progestogens in the bloodstream. I would suggest a discussion with your GP or HRT specialist if it is bothering you.

What Q would be best avenue for Neurologist for living with breast cancer, vulvectomy, hysterectomy and now MS?

Clear communication between your Neurologist, gynaecologist and breast surgeon, as well as your oncologist – but perhaps that is wishful thinking! I imagine one concern would be what effect if any, a perspective MS treatment might have on your breast or gynae malignancies.
This would need to be a highly personalised and carefully considered decision between the respective teams and most importantly YOU, as there simply wouldn’t be formal guidance for this specific set of circumstances. You would need to weigh up the benefits against the benefits, and ultimately come to the decision that feels right for you.

**How much vitamin D should teenage girls be taking?**

If it is to prevent MS in someone with a family history, then we would advise 1000IU/10kg body weight daily until they reach 50kg, at which point the standard dose is 5,000IU daily. If the young person has MS, then we aim for blood levels of 150-225nmol/L or 60-90ng/ml in the USA. This may require doses of between 5000 - 10,000IU daily, but in a teenager with MS it is probably best to alter the doses dependent on their blood levels. We would recommend this is done at the start of Spring and Autumn each year, so the dose can be altered appropriately with the change in seasons. Feel free to reach out to contacts@overcomingms.org for more specific advice if needed.

**What are the risks of relapses while breastfeeding for 12-18 months without taking medication?**

We know that exclusive breastfeeding reduces relapse risk by over 40%, which is more effective than some of the first generation DMDs. Of course, as you introduce foods to baby, your milk supply and therefore hormonal protection will naturally diminish. There are few prospective papers to allow us to accurately predict risks, but it would be the combination of clinical symptoms and MRI findings that ultimately give us the answer for each person. I would suggest keeping in contact with your MS team, and getting your regular monitoring. Should you need to use a DMD at any stage, then have a look at the ABN guidance (included in the Webinar handout) as this has information on the specific drugs and breastfeeding risks.  
https://jamanetwork.com/journals/jamaneurology/fullarticle/2756404  
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7274922/

**I am woken every night with intense aching in my lower leg. Is this MS or menopause or both? I have been seen by so many experts and had tests, but nothing shows up?**

It is probably more likely to be due to MS than the menopause, but it is not impossible that it could be due to either or both. A relatively simple and rather effective remedy for muscle pain/cramps is magnesium, it also has the benefit of making you sleepy at night. Magnesium citrate is one of the preferred forms, and it needs to be taken at quite a high dose. You could discuss a trial of a calcium channel blocker medication, and also please look at some of the general recommendations -  
https://www.medicalnewstoday.com/articles/326327#preventions  
https://betteryou.com/blogs/health-hub/how-magnesium-supplements-for-muscle-cramps-can-relieve-tension

**I am 34 years old and have had hypothalamic ammenorhea / no period for much of my adult life. I wonder, could this have been a trigger for my MS, considering the connection with menopause and MS**
It is quite possible that it might have played a role, or at least sped up the development of your MS symptoms. If you were receiving HRT or taking the combined contraceptive pill to treat your amenorrhoea then this may have afforded you some protection.

**What do you think about taking immunosuppressants DMTs in a pandemic environment? I have RRMS diagnosed 2017 had disabling attack back on my feet but have two kids going to school and been shielding and it’s complicated! Any thoughts?**

With increasing time and data becoming available we are now confident that most DMDs do not increase the risks of developing severe COVID-19 infection. But, as you say, it is complicated, especially when you factor in other health conditions, DMDs, levels of disability and COVID vaccinations. In those taking Ocrelizumab or Cladribine for example, these medications can prevent the immune system from mounting a response to the vaccines and therefore not fully protect against infection. It is really important to discuss this with your MS team, as the timing of vaccine doses and treatments need to be carefully planned, usually with the vaccine given first and allowing time to develop immunity before the next treatment. The other DMDs don’t appear to have any effect on vaccine responses, and still offer protection. For specific queries you should refer to up to date information sources such as the Association of British Neurologists, MS Society and MS Trust.