



Long Covid Nurse Group Meeting Summary

'Women's Health and Long Covid'

Thursday 21 March 2024 10am - 11.30am, via Zoom



Welcome and Introductions

Helen Donovan, QN, Long Covid Programme Lead, The QNI, @HelenDon_RN

- Welcome everyone to this meeting. Today's session is devoted to women's health, menopause and how that relates to Long Covid.
- According to Office for National Statistics (ONS): an estimated 2.0 million people living in private households in the UK 3.1% of the population are living with Long Covid.
- The Long Covid Nurse Group (LCNG) is a community of practice for nurses in the community to improve care and increase understanding about the physical, mental and emotional effects of Long Covid.
- The network was created in 2021 and offers an online network of nursing colleagues; bimonthly meetings with expert speakers; regular newsletters; dedicated pages on the QNI website; Long Covid resources.
- Please get in touch if you would like to write a blog for us about either your struggles with Long Covid and/or management options, email me at helen.donovan@qni.org.uk
- To find out more or join the network, go to:
 - https://qni.org.uk/nursing-in-the-community/long-covid-nurse-group/
 - or scan the QR code right:
- Thank you to the National Garden Scheme for their continued support of the network.







Debra Holloway, retired nurse consultant in gynaecology, menopause specialist, RCN fellow. Ruth Bailey MSc BSc (Hons) RGN DFSRH Onc Cert Queen's Nurse ANP Sexual Health Chair RCN Women's Health Forum and FSRH Council Nurse Rep

- We're passionate about women's healthcare and since 90% of nurses are women this is very relevant
- Gynae has some of the largest waiting lists of any specialism, the reality is if you're referred, the wait can be up to 2 years, so we want to explore what you can do in the meantime
- We know that there's been a rise in vaginal bleeding after COVID vaccine COVID infections exacerbated effects of periods. It's an area for further research.
- menti below answered question, 'What do periods mean to you?'









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- The four phases of the menstrual cycle are menstruation, the follicular phase, ovulation and the luteal phase.
- Excessive menstrual loss interferes with physical, social, emotional and quality of life. Possible causes include: fibroids, endometriosis, andenomyosis, perimenopause, cancer, 50% unknown causes.
- This can associate with all kinds of pain: back pain, joint pain and all of these can overlap with Long Covid we need to have a management plan to support women with these issues.

Facts about periods:

- periods can last between 3 to 7 days, the average being 5 days. Any more than 7 is considered heavy (abnormal)
- women often follow the patterns of their mothers it's always worth asking about that history
- the colour of period blood ranges from dark brown, bright red to dark red and will often change during the period
- It's very important to talk about experiences of periods so that what's not normal is not normalised.
- It's key that women manage their periods by using the right product for them (tampons, sanitary towels, cups, period pants etc)
- Taking history is very important ultimately if it's stopping you going out, having sex, interrupting
 your work then you need help.



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- One patient had had years of prolonged bleeding and it was normal for her to take time off work as she was worried about flooding she had the mirena coil fitted and it was life changing for her.
- Self help: lifestyle interventions (weight management, smoking cessation, rest higher BMI creates heavier bleeding for example). Check iron levels to look for anaemia; pain management (don't wait until the pain is very bad to take pain killers). Consider tranexamic acid/mefenamic acid/combined hormonal contraception and mirena coil.
- A great campaign: www.wellbeingofwomen.org.uk/what-we-do/campaigns/just-a-period/

PMDD: pre menstrual dysphoric disorder

• This is associated with very severe symptoms happening in the luteal phase the week before periods. It affects women who have a profound sensitivity to their own progesterone. Experience will vary from woman to woman.

- Often it's a huge relief for women to have their symptoms acknowledged. You're not going mad, this is a real issue.
- There are some lifestyle measures that can help, some supplements have been proven to help such as agnus catus, red clover and B6. SSRI medications are anti depressants but they can help with reducing PMS symptoms.
- Not having periods can be OK it depends, it can be caused by:pregnancy, eating disorder, hypothyroidism etc.

PMS/PMDD Agnus Catus/Red Clover/B6 Continuous Combined hormonal Contraception Bloating SSRI'S/SNRI's (Can be cyclical) Behavioural Mirena Coil and Oestrogen patch Insomnia Lethargy Food craving NAPS - National Association for Emotional Premenstrual Syndromes | NAPS Depression Anxiety What is PMDD? - Mind



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Fibroids:

- Fibroids are very common they can range in size and can be found in the cavity of the womb and
 in the muscle layer, all produce different symptoms, but they can be symptomless.
- Fibroids are a mixture of smooth muscle cells and fibroblasts and they form hard round, whorled tumours
- The uterus is the most common site for fibroids
- They are related to hormones and it's thought that oestrogen makes them grow
- Emerging evidence that a good diet will help prevent fibroids, vitamin C and D and calcium help too. Gut microflora is also important. Green tea has been linked to a reduction in fibroids.

Painful periods:

• Dysmenorrhoea is very common. TENS can help as can over the counter medication (codeine can cause constipation which isn't helpful, try paracetamol first). Pain that stops you going out, makes you vomit or pass out it not normal.

Adenomyosis:

- This is a glandular derangement of the muscle of the uterus, the muscle wall of the uterus is invaded by tissue from the lining.
- It's more common as women get older (most commonly diagnosed in the 30-45 year old age group). It causes pain and bleeding
- It can be mistaken for endometriosis and fibroids.



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Endometriosis

- The presence of endometrial-like tissue outside the womb, which creates a chronic inflammatory reaction.
- The only place it hasn't been found is in the spleen it's been found in the lungs, the eyes, the brain, spine, joints. We don't know why and how it spreads, but it can be anywhere in the body.
- Approx 1 in 10 women will suffer from it it takes an average of 8 years to get a diagnosis. Because of differing symptoms women can be referred to gastro, neurology and then gynae.
- Painful pooing is also another symptom.
- Diet can help eliminating some foods, such as gluten or sugar, but do it as a step by step approach.

Menopause:

- The permanent cessation of menstruation: 2 years without a period under 50, 1 year without a period over 50.
- Average age is 51.
- Diagnosis on symptoms not bloods although under age 45 it's useful to do blood tests to confirm
- Perimenopause: the period of transition approaching menopause
- Early menopause: 40 45



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Premature ovarian insufficiency:

- menopause under 45 this is rare, can be absolutely devastating especially if the woman wants to have children. It can be a very difficult diagnosis.
- The Daisy Network is a great charity offering peer to peer service: https://www.daisynetwork.org/ Hormone Replacement Therapty HRT
- A common worry is whether HRT will cause breast cancer, evidence is that it doesn't, however, each individual is unique you have to look at the histories. BMI of more than 30 and drinking are risk factors.
- Important to talk about the risks and benefits of HRT. You can take HRT for as long as you need, it doesn't delay the menopause, it just tides you

over.

Red flags: recurrent UTIs despite oestrogen; vulva itching, bowel changes, bloating, weight loss, breast lumps, palpitations, HRT not working, no periods under 40, fracture, abdominal mass, pressure, bleeding in between periods, bleeding after sex, no periods, heavy or painful periods that stop you doing things.

Menopause Management Options

Lifestyle Factors



- Rest and restoration
- Controlling the environment
- Movement and exercise
- Nutrition including healthy eating, protein, calcium and a vit D supplement
- ▶ CBT
- Mindfulness and meditation

Medication options



- HRT First Line
- Non-HRT Options
- SSRI'S/SNRI's
- Clonidine/gabapentin/pregabalin
- oxybutynin



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- Long Covid or hormones? Very difficult as so many of the symptoms overlap (those in red are those that don't which are primary Long Covid)
- We would advise doing a trial of HRT for 3 months, if it doesn't work, it's not hormones.
- We need much more research on this.

Resources:

- Promoting Menstrual Wellbeing, RCN: https://tinyurl.com/2dxmu8fc
- The Menopause and Work, RCN: https://tinyurl.com/w3wvccjc
- What are PMS and PMDD, RCN: https://tinyurl.com/2tebu2st

Long Covid or hormones?

- extreme tiredness (fatigue)
- feeling short of breath
- loss of smell
- muscle aches
- · problems with your memory and concentration ("brain fog")
- chest pain or tightness
- difficulty sleeping (insomnia)
- heart palpitations
- dizziness
- pins and needles
- joint pain
- depression and anxiety
- tinnitus, earaches
- feeling sick, diarrhoea, stomach aches, loss of appetite
- a high temperature, cough, headaches, sore throat, changes to sense of smell or taste
- rashes



Next meeting:

Tuesday 21 May, 10am - 11.30am - theme will be cognitive communication difficulties in Long COVID and the role of Speech and language therapy.

2024 meetings:

All meetings take place from 10am - 11.30am

- Wednesday 10 July
- Friday 20 September
- Tuesday 19 November

To book your place or to find out more go to:

https://qni.org.uk/news-and-events/events/long-covid-nurse-group-meeting/



Thank you to all delegates who attended today's meeting.

FEEDBACK:

Very many thanks
really helpful
especially for
consultations in my
OH clinics

Thank you Ruth and Debby for a very interesting talk.

Thanks so much very interesting and thought provoking:)

Thank you, great talk!

Very interesting and informative

Really great session thank you - going to jump into a cold lake - great for both the menopause and Long Covid!

am only sorry that I could not be on the call from the beginning. Thank you so much.