



Long Covid Nurse Group Meeting SUMMARY

'Supporting health care heroes and over-the-counter treatment for Long Covid sufferers'

Monday 29 January 2024
10am - 11.30am, via Zoom



1. Welcome and Introductions

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

- Welcome everyone to this meeting.
- 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.



1. Supporting health care heroes

Dr Alison Twycross and Dr Michaela Barnard, Supporting Healthcare Heroes UK, @SupportingHH_UK

- Dr Alison Twycross: I caught Covid on 12 March 2020 and didn't get better. As a result of it, I took early retirement. I am a Long Covid advocate and with Michaela we created this charity, 'Supporting HealthCare Heroes UK.'
- Dr Michaela Barnard: I was critically ill in hospital in the first wave of the pandemic. A lot of healthcare workers saved my life. I remember thinking, why are these people wearing a face shield but not a mask or why don't they have adequate PPE, I'm coughing and they're not protected! I have Long Covid - this charity is personal for me.
- For the first year after Long Covid, it felt very isolating, peer support experience is crucial. Understanding what's available for people is very important.
- There is lots of Long Covid support out there, but it's finding your place in amongst it. We hope to get on the map as a trusted network.
- Once the government decided it wasn't going to pay covid sick pay anymore, there was a problem.
- People were and are losing financial security, professional as well as personal identity because of their symptoms, they're scared to speak up to their employers about their symptoms.
- So about a year ago we decided to set up a charity to help.



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- The charity is for all people working in healthcare, not just doctors or nurses, but the porters too or the kitchen staff or the medical secretaries.
- We've seen how catastrophic, how soul destroying it's been for some and we wanted to help.
- Our mission is to stand shoulder to shoulder with healthcare workers (HCWs) living with Long Covid.
- Our aims are to reduce financial hardship caused by Long Covid, relieve isolation and ensure HCWs living with Long Covid have a voice; disseminate research and raise awareness of Long Covid; Support and advocate for HCW living with Long Covid; advocate for improvements in indoor air quality in healthcare settings.
- It's predominantly for staff working in the NHS.
- Because we're a charity we can only provide grants to relieve financial destitution, and we have a robust system for people to apply. We can help with travel costs for treatment, adjustments to home; disability aids; recommended activities for health reasons.
- We can also help with a temporary inability to cover usual expenses due to a drop in income as a result of Long Covid (for example going from full to half pay as a result of sick pay)
- We also can help with counselling or therapy: it can be so devastating for people and this can help them move forward.



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- We've recently been awarded charity status and we have our website up and running, please visit it: <https://shh-uk.org/> and become a member.
- We're setting up support groups with cognitive dysfunction and we are piloting 2 forum Q&A, one with NMC revalidation and one for returning to work with Long Covid.
- We work with companies such as PayPlan debt advice and others (see below)
- We're looking for 2 new trustees and we're always on the lookout for stories/experiences from those affected, please email us:
alison@shh-uk.org or michaela@shh-uk.org
- Our biggest piece of work is fundraising this year, we want big pots of money to be able to give out and we want a regular income stream.
- Please follow us on social media:



Supporting Healthcare Heroes UK

Already operational 2

- PayPlan debt advice:
Call free on 0800 072 1206
Visit www.payplan.com/SHHUK
- Benefits advice from entitledto
<https://www.entitledto.co.uk/>
- Collecting stories/experiences from those affected
- Meeting with policy makers, professional bodies and regulatory bodies
- Social media – don't forget to follow us

Logos for PayPlan and entitledto are shown at the bottom right.

2. Managing Long Covid with Self-Care and OTC - how community pharmacy can help

Dr Vincent Cheng, Pharmacist, Academic & Evidence Synthesis Research, University of Bristol and Ade Williams MBE, Superintendent Pharmacist, Bedminster Pharmacy

- What we know works for some people, doesn't work for others
- Licensing of supplements is very different to medicines.
- Two groups of GSL medicines you can find anywhere, these are small packs of medicine which can be retailed by anyone. P medicines - as they're known - are only available at pharmacy counters, they have licence restrictions.
- Community pharmacies are champions of self care
- The Self Care forum (of which Ade Williams MBE is also a trustee) has many resources and fact sheets which can be of help
see: <https://www.selfcareforum.org/long-covid-and-post-covid-syndrome-in-adults/>
- Pharmacy advice for some of the symptoms of Long Covid: **breathlessness and cough**: some cough preparations can help. Pelargonium, a herbal medicine, is sometimes used for over 12s as are cough remedies using guaifenesin. Honey and lemon can also help.



2. Managing Long Covid with Self-Care and OTC - how community pharmacy can help

Dr Vincent Cheng, Pharmacist, Academic & Evidence Synthesis Research, University of Bristol and Ade Williams MBE, Superintendent Pharmacist, Bedminster Pharmacy

- **Cardiovascular symptoms:** for this group of patients it's wise to avoid over-the-counter NSAID oral formulations and decongestants.
- **Neurological symptoms:** Vitamin D supplementation is helpful, natural remedies such as Nytol Herbal contains a blend of herbs to soothe and aid restful sleep. For brain fog, ginkgo biloba and omega 3 Fish oil are said to be helpful although evidence isn't yet supported.
- **Gastrointestinal symptoms:** probiotics, loperamide, bismuth subsalicylate (pepto-bismal)
- **Musculoskeletal symptoms + ENT symptoms:** NSAID gel is more evidence-based than oral NSAID formulations; nasal rinses can relieve nasal congestion and pain relief, including local anaesthetic throat spray.
- **Dermatological symptoms:** pharmacy can help with symptomatic control and relief of skin rashes. Finasteride and minoxidil are the main treatments for male pattern baldness. Minoxidil can also be used to treat female pattern baldness. Women should never use finasteride. We don't yet know who Covid causes hair loss.
- Do come to the pharmacy team, we can help inform and help especially those patients with many questions, we can look at herbal / drug interactions etc. We are here to help.
- Feel free to email us: vincent.cheng@bristol.ac.uk, ade.williams@nhs.net, @adewilliamsnhs



Next meeting:

21 March 2024, 10am - 11.30am - theme will be women's health, with a focus on menopause. More details available soon.

2024 meetings:

All meetings take place from 10am - 11.30am

- Thursday 21 March
- Tuesday 21 May
- 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:

Thanks so much for such a great session.

Thanks you for your time and presentations, most useful.

Thank you great meeting

That was very informative, thank you. Underlines the complexity of these conditions.

That was great, thank you

Thanks to all, interesting talk.

Thanks for a fantastic presentation.

