

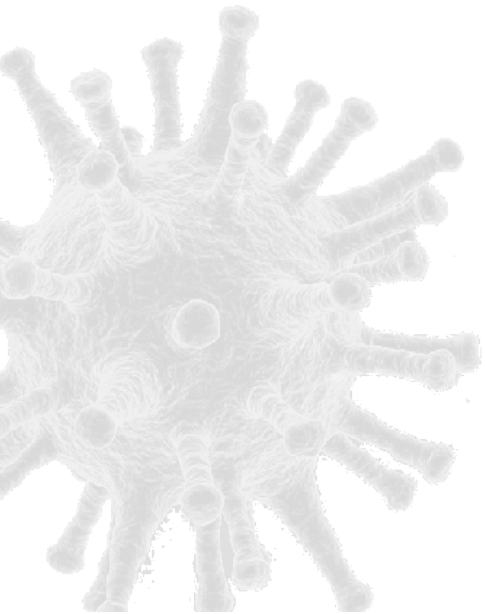


Long Covid Nurse Group Meeting

Summary

'Current epidemiology in Long Covid and current treatment options and approaches'

Wednesday 10 July 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 current epidemiology in Long Covid and current treatment options and approaches.
- 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. It 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 below:
- Thank you to the [National Garden Scheme](#) for their continued support of the network.



Long Covid: Epidemiology and health inequalities

Professor Nisreen Alwan MBE, Professor of Public Health, University of Southampton; Honorary Consultant in Public Health, University of Southampton NHS Foundation Trust; n.a.alwan@soton.ac.uk

My background in Long Covid

- I'm a Public Health doctor
- I got Covid in the first wave of 2020 - I didn't completely recover and struggled with symptoms I thought I was going crazy because there was nothing official in the world about Long Covid then
- I saw social media posts from people and health professionals talking about their symptoms, fatigue, palpitations, aches, pains etc and that kept me sane.
- A few months later I started talking about Long Covid from a public health angle, I started asking how do we quantify it. Later on that year, we did research that, we did an online survey. We identified that fluctuating/relapsing-remitting pattern is common and that the common triggers are: physical activity, stress, sleep disturbance, cognitive activity.

Definition of Long Covid

- A reminder of the definition of Long Covid: signs and symptoms that develop during or after an infection consistent with Covid-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. One of the first things we noticed is that could happen in so called 'mild' Covid-19 cases.



Long Covid: Epidemiology and health inequalities

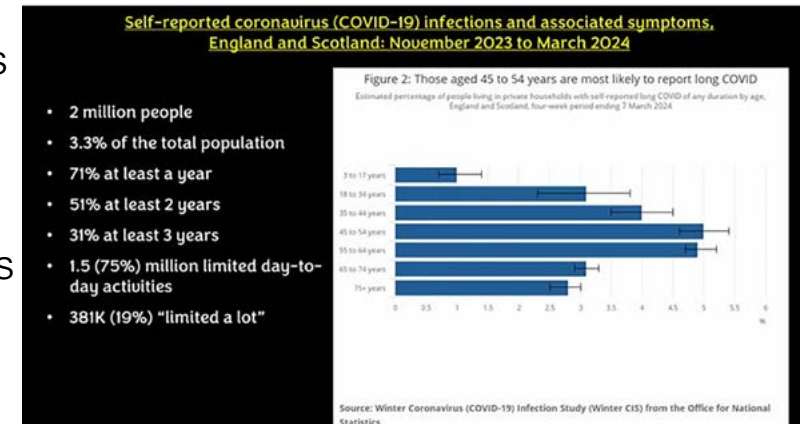
Professor Nisreen Alwan MBE, Professor of Public Health

Studies

- We carried out 120 studies, mostly done before vaccination and we found a huge prevalence in Long Covid. The most important finding was the variation in prevalence - it depended on how Long Covid was measured
- The diagnosis depends on professional guidelines, basically: who's diagnosing it. How you count Long Covid depends on how you ask the questions...

Count of Long Covid

- November 2023 to March 2024, 2 million people had Long Covid, see slide below.
- It's difficult to answer 'when did your Long Covid symptoms start' because of the nature of Long Covid, it stops and starts.
- At the start of Long Covid there was a narrative that it was predominantly in females but now it's only slightly more common in females
- Long Covid prevalence increases with deprivation. There's a variation by profession, obviously front line profession higher prevalence. See the Wheel of Power/privilege: <https://tinyurl.com/yc8btbnu>
- There's now consistent evidence that vaccination protects against Long Covid.



Long Covid: Epidemiology and health inequalities

Professor Nisreen Alwan MBE, Professor of Public Health

Long Covid stigma

- A study was carried out estimating burden and validating scale in a UK based sample: 888 people in the UK, 34% regretted having told others about their illness; 61% very careful about who they tell about their Long Covid.
- 3 different kinds of stigma were discovered: 1. inactive stigma, 2. internal stigma, 3. anticipated stigma.
- I have experienced this personally too - even though my position on the wheel is more privileged. You are anticipating what other people might say about your Long Covid in a negative way.
- We found a very big prevalence of stigma: <https://doi.org/10.1371/journal.pone.0277317>

Epistemic injustice in Long Covid

- We found several kinds of epistemic injustice: testimonial injustice, hermeneutical (interpretative) injustice, these create barriers for people seeking care.
- This is a very well established framework in society eg diabetes. See the study here: <https://doi.org/10.1111/hex.14037>
- Those most in need of care are the least able to get it: Long Covid Inverse Law.
- See here for tool: <https://long-covid-care.org.uk>



NHS Long Covid Services: Lessons and Legacies

Dr Melissa Heightman, Consultant Physician and Clinical Lead Post Covid Service University College London Hospitals NHS Trust/North Central London Integrated Care System, National Specialty Advisor for the Long Covid program, NHS England

- It's been a rollercoaster for patients and clinicians - and Covid is increasing in the wards at the moment
- Rate of respiratory support changed hugely with advent of vaccination - it had a huge impact
- The growing emergency of Long Covid became apparent to us because of discharge - more noticeable in people with mild Covid who became very poorly afterwards
- Funding was announced by the then Head of NHS Simon Stephens for post covid clinics to look after populations that were suffering.

Pathological basis of Long Covid

- multi-system inflammatory disease: dysregulated innate inflammation; endothelial dysfunction, circulating 'exhausted' CD8-PD1 + T cells, polyclonal auto-antibody production, exercise-induced inflammatory muscle necrosis, mitochondrial dysfunction.
- There's so much we need to understand - there's debate about persistent viral protein that's driving ongoing inflammation.
- Exercise makes it worse - but we still don't have the whole picture, we need to keep an open mind.
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NHS Long Covid Services: Lessons and Legacies

Dr Melissa Heightman, Consultant Physician and Clinical Lead Post Covid Service

When to seek help

- Any time if you have severe symptoms: breathlessness, chest pain, dizziness should always be assessed by GP/111/999
- After 4 weeks if you still feel unwell after Covid
- No positive test needed
- People can be re-referred for support if needed
- All ICBs are obliged to provide appropriate care for patients
- Long Covid services around the country operate differently
- What happens when you come to clinic, see slide below.

Treatment approaches in Long Covid







- Person-centre plan: pharmacological, non-pharmacological, leaflets/online resources
- Self management support: living with app, KiActive, C19 Yrs
- Peer support: group sessions, webinars, social media

Resources

- <https://long-covid-care.org.uk/>
- <https://www.clinicalpcs.org.uk/>

What happens when you come to clinic?

- Physiotherapist and doctor in person review
- Confirm the diagnosis - clinical judgement. 1/20 not long covid
- How does long covid affect you?
 - Questionnaires: Severity of fatigue, PESE, pain, impact on work
 - Physical assessment : Breathing pattern/ Dysautonomia
 - Psychology
- Tests? Blood tests/ Heart rate / Scans/ Lung function
 - Tests done to exclude other causes/ plan treatment
- Develop a holistic treatment plan
 - Treatable traits approach- "rehab"/ medicines
 - Address wider well-being/ cardiovascular risk.....
- Lots of case discussion in multiprofessional meetings
- RESEARCH



Next meeting:

- **Friday 20 September: Long Covid occupational health and revalidation after long term illness**, featuring speakers: Dr Alison Twycross, Chair of Supporting Healthcare Heroes UK, Dr Clare Rayner, Consultant Physician in Occupational Medicine and Anne Trotter, Assistant Director of Professional Practice, Nursing and Midwifery Council (NMC)

2024 meetings:

All meetings take place from 10am - 11.30am

- **Tuesday 19 November: Long Covid where are we now? Causes and impact** featuring speakers Prof. Trish Greenhalgh, Professor of Primary Care Health Sciences at the University of Oxford and Prof. Danny Altman, Professor of Immunology at Imperial College London.

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:

Excellent 2 sessions, thank you!

Thank you for a great session!

Thank you for a great meeting I have to go on a OH call which is appropriately with an employee with Long Covid.

Thank you Melissa for an informative presentation

Excellent information, thank you

this is really useful and I would like to update the OH team I work with - I am the Long Covid lead for our group thanks in advance excellent presentation

Fantastic presentations thank you.

