

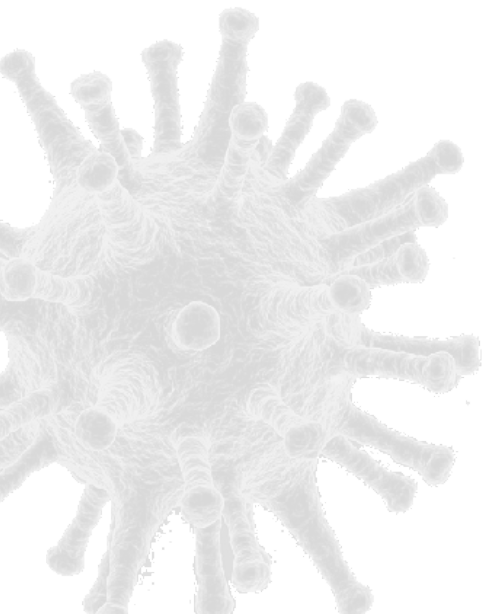


Long Covid Nurse Group Meeting

Summary

'Long Covid:
where are we now?'

Tuesday 19 November 2024
10am - 11.30am, via Zoom



Welcome

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

- Welcome everyone to this meeting. Today's session is devoted to 'Long Covid: where are we now?'
- 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.



1. Long Covid, where are we now?

Professor Trisha Greenhalgh MD, University of Oxford

- Long Covid is almost an occupational disease
- We've written a new paper, 'Long Covid, a clinical update' which was recently published in the Lancet [you can read it here.](#) Or for the lay version, [read that here.](#)

Background

- Four framings of Long Covid: 1. A slow crisis; 2. A distinct patient narrative; 3. Multiple and diverse clinical manifestations; 4. A variable clinical trajectory
- In 2020 Covid was acute, mainly affected lungs, breathlessness. Some people had to go on ventilators. The assumption was you either got better or you died. The NHS mobilised like never before in my lifetime, it was unbelievable.

1. Long Covid as a slow crisis

Why did we not anticipate post infectious syndrome afterwards?

The post infectious syndrome follows all SARS, MERS infections ('Long SARS') we just assumed it would get better.

Women get LC slightly more than men, but not that different. LC does also affect men.

- 40% of people who get LC now have had it since 2020
- The slow crisis is the 800,000 people in the UK who have Long Covid that affects them in life-changing ways and is not getting better.
- My heart goes out to those on this call with LC, it's a big challenge: for medicine and for society.



1. Long Covid, where are we now?

Professor Trisha Greenhalgh MD, University of Oxford

- People with asymptomatic Covid with severe Long Covid are unusual.
- If you get recurrent covid infections, it all gets worse. Snakes and Ladders.

2. Long Covid as a distinctive patient narrative

- There are something like 200 symptoms
- We published an article in the Lancet on this, [read it here](#).
- Online support communities were very important, particularly at the beginning when medical community was slow on the uptake.

3. Long Covid: multiple and diverse clinical manifestations

- One common typology: young, female, previously well, now brain fog, breathlessness, fatigue, dysautonomia (often joined online support groups)
- Another typology: older male, pre-existing conditions, cardiovascular events, metabolic upset, delirium, sarcopenia (mostly didn't join online groups)
- Are there different types of Long Covid? Have you got a more fatigue-based one for example?
- Clinical phenotyping in Long Covid: big data studies suggest 3 clusters: mild, moderate and severe. But will deep learning uncover real pathophysiological clusters?

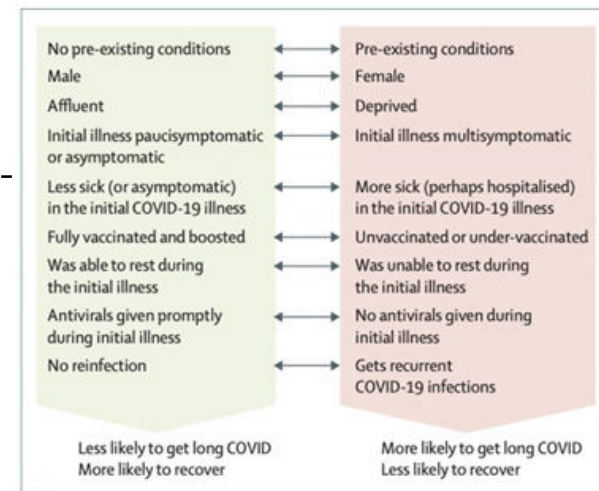


Figure 2: Summary of risk factors for long COVID

1. Long Covid, where are we now?

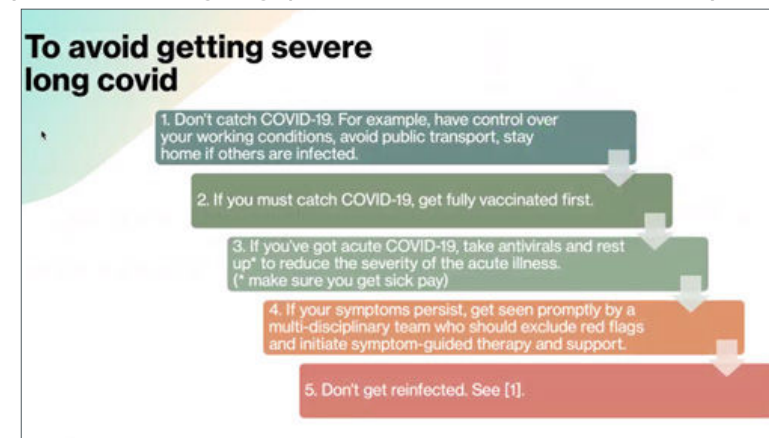
Professor Trisha Greenhalgh MD, University of Oxford

4. Long Covid a variable clinical trajectory

- Am I going to get better? That's the question all patients are asking.
- Different types of patients: the patient still coughing at 4 weeks but improving and fully recovered by 12/15 weeks; the patient still symptomatic at 12/15 weeks + responding gradually to MDT care; the patient who remains multi-symptomatic, tries but fails to return to work and becomes a person with a disabling long term condition: we need urgent research into this - the problem with this group of patients was that they caught Covid before the vaccines.
- There are some small studies that have shown that non-inflammatory Long Covid tends to get better and inflammatory Covid is less likely to get better.

Some things we don't yet know

- How can we persuade politicians that the slow crisis of Long Covid is real + urgent and that current policies (eg restricting boosters >75s/ignoring indoor air quality, encouraging presenteeism) are likely to worsen it?
- How can we optimise and personalise all elements of MDT care? Particularly: how should we modify rehab for patients who have responded poorly previously?
- What's the role of vaccines in treating people with severe Long Covid? How can we bring the exciting developments in the basic science of long covid (especially immunology) into dialogue with clinical management?



2. Long Covid update

Professor Danny Altman, Professor of Immunology at Imperial College London

Where are we now?

- It's hard to answer this as people in academia pubmed is the place we go to look up medication publications and if you search Long Covid, we now have over 40,000 publications peer reviewed.
- You'd think we'd know a lot and have cracked it!
- But we're not making people any better - we should be doing much better at this stage.
- Interesting piece of research on Long Covid science, research and policy from 2024, [read it here](#).
- Global burden of Long Covid 400 million
- Why are we finding it hard? It's a bit like fighting an ongoing world war: it's a large and significant burden.
- The Long Covid Handbook - I wrote this book with Gez Medinger, there are some interesting things in the book, [read more about it here](#).

Post viral

- We never knew coronavirus could hang about in the body, most clearly in the gut, with inflammatory damage
- Some say that it reactivates Epstein Barr virus, which is latent in many of us.
- We really need agreement on bio markers - this is now an urgent need. The lack of agreed bio markers for diagnostics is a bottle neck.

Wilco Study

- 'Working out the Immunology of Long Covid' most symptoms are unchanged across a 2 year span



2. Long Covid update

Professor Danny Altman, Professor of Immunology at Imperial College London

- A persistent virus reservoir driving inflammation?
- Very cutting edge study done on tissue-based T cell activation - [read it here](#) - holy grail for immunologists in real time in real life, PET imaging gets you close to that. In this study they used a very fancy experimental PET tracer, it allows you to make out where the T cells are going.
- Even years after acute covid, some people have tissues in their gut. Other studies have found traces in people's serum even years later.
- Some studies think it's a defect of coagulation and there is great evidence for this which highlights a mechanistic model for Long Covid depending on auto coagulation - [read study here](#).

Immunology

- My frustration with the inertia in Long Covid is because in immunology we have such a great tool box of goodies, antibody treatments for MS or diabetes or arthritis, immunology has been good at making people better, we should be able to do a lot better than we are doing at the moment to treat people!
- This protracted time course was predictable from prior experience with the very similar Long-SARS in 2003-2004. A 20 year perspective found, 'None of our 50 patients got their old life back with time and treatment. Some were never able to return to work.' Dr John Patcai, Dept of Medicine University of Toronto, [read study here](#). They went on to get Long-SARS after SARS.
- Those 2 million people suffering with Long Covid, desperately want us to do better.



2. Long Covid update

Professor Danny Altman, Professor of Immunology at Imperial College London

Next steps and unmet needs

- Mechanism insights: Need synthesis and consensus to avoid fragmented silos.
- Learning potential: Could reshape understanding of long-term post-viral effects.
- Clinical guidelines: Urgent need for symptom cluster-based standards.
- Biomarkers: Lack of consensus stalling diagnostics, care, and trials.
- Therapeutic trials: Time for ambitious, large-scale RCTs like RECOVERY, but momentum lacking.
- Access to LC clinics: Future remains uncertain.
- We so desperately need consensus on bio markers which would help us with NHS clinical diagnoses.

Do we need to wait for another 40,000 publications for randomised trials at scale? The longer this goes on the more momentum we lose in terms of treating those patients, they're drifting away on those trajectories of those Long Sars patients...sorry to end on a downer but I'll leave it there.



Next meeting:

Tuesday 21 January, 10 - 11.30

Theme: 'Looking after yourself'

Featuring speakers:

- George Plumptre, Chief Executive, The National Garden Scheme,
- Salli Pilcher, Queen's Nurse, Collaborative Lead Nurse, NCIC, Long Covid Nurse Group member
- Andy McGowan, Policy and Practice Manager, Carers Trust (TBC)

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:

Thank you also to Helen for organising fantastic speaker

Thank you Helen, great meeting

Thank you for a fantastic meeting

Many thanks to all of you for your presentations today

Great meeting as always Helen , thank you

Thank you for this meeting has been extremely informative

Thank you for excellent presentations

