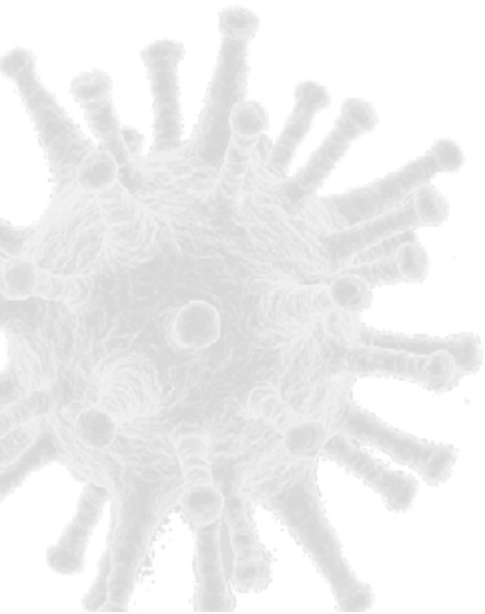# Long Covid Nurse Group Meeting
Summary

'Cognitive-linguistic difficulties in Long Covid'

Tuesday 21 May 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 cognitive linguistic difficulties in Long Covid and the work with the Royal College of Speech & Language Therapists (RCSLT).

- It's just over a year since I took over and it's so good that the network is growing from strength to strength. There are now over 800 members.

- 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 right:

  Thank you to the National Garden Scheme for their continued support of the network.

Cognitive-linguistic difficulties in adults with Long Covid: a follow-up study

Prof. Louise Cummings, Professor of Clinical Linguistics, The Hong Kong Polytechnic University

- This is the second time I've come to a QNI session. This time it's a 6 month follow-up study and I want to present our findings

Brain fog

- Prevalence of brain fog, varies across studies, it's defined as cognitive-linguistic difficulties that manifest as: word-finding difficulties, difficulty following conversation, problems with reading and writing, substituting words in speech, impaired recall of a conversation, problems with speech fluency, reduced desire to participate in conversation.

The study

- 142 adults were involved in the first study, divided into 6 groups: 1. Covid with brain fog (69 participants), 2. Covid without brain fog (11), 3. Healthy (26), L2 English (ie English as a second language) with Covid (22), L2 English without Covid (13), Chronic Fatigue Syndrome (11) (this group was effectively acting as a control group for the fatigue component in Long Covid).

- Mean age: 47.3 yrs; age range: 18 to 64 yrs; gender: 22 men and 120 women; education: 48 under 17 years, 94 over 17 years; based in 7 countries: UK, Ireland, USA, Canada, Australia, Brazil, Belgium

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The tests

- Participants recorded online for 12 language tasks:
    - immediate and delayed recall* (100 word story)
    - picture description (Cookie Theft picture)*
    - sentence generation
    - letter fluency
    - category fluency (animals + vegetables)*
    - procedural discourse tasks (sandwich making / letter writing)
    - confrontation naming
    - Flowerpot incident narration*
    - Cinderella narration*

Main finding

- Covid participants with brain fog achieved significantly lower scores than healthy participants on 7 of the 12 tests (see those above with *). Narration was markedly under-informative, with Covid participants with brain fog achieving much lower scores on the flowerpot incident story and Cinderella narration than healthy participants.

Follow-up study

- This was created to see if their cognitive-linguistic performance improved or worsened or stayed the same over time

Follow-up study: COVID Participant characteristics

	Characteristic		Time since onset and test status
Age	Average: 48.8 years (SD ±9.1years)	Time since onset	Average: 625 days (20.8 months)
	Range: 18.7-61.6 years		Range: 204 days (6.8 months) to 955 days (31.8 months)
Gender	Male: 3 (7.32%)	Test status	Clinical diagnosis: 19 (46.34%)
	Female: 38 (92.68%)		PCR test: 16 (39.02%)
			Antibody test: 5 (12.20%)
Education	Under 17 years: 15 (36.59%)		PCR+ Antibody: 1 (2.44%)
	Over 17 years: 26 (63.41%)		

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- 41 adults with Long Covid from the original study participated in a 6-month old follow-up study

Results

- Gender, age and education effects were examined: no effect of gender on the performance on any of the tasks. Age effects did exist: the older participants tended to have lower scores for immediate and delayed recall but higher test scores for picture description and narration.
- Education effects also found: those with over 17 years of education had higher scores on several tasks compared with those with less than 17 years education
- Immediate and delayed recall significantly poorer in those with Long Covid

Conclusion

- Immediate and delayed recall in Long Covid participants showed no improvement in 6-month follow-up, however there was improvement in picture description, simple and complex narration, letter fluency and category fluency
- Participants with Long Covid performed similarly to healthy adults on discourse production tasks. Their improved informativeness on these tasks could be explained by improved executive functions.

Please note

- It's important to note that many adults with Long Covid obtained 'normal' scores even though they struggled considerably with a task - particularly so in confrontation naming and sentence generation: these poor performances tell us about cognition beyond what is conveyed in the test scores alone.

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Employment outcomes

- Follow-up study also examined employment outcomes of 41 adults with Long Covid: although there was some improvement, employment was still adversely affected.
- 97.3% who had been employed prior to Covid-19 had not been able to return to their full pre-Covid role
- 69.4% had not been able to return to any type of employment
- 8% took early retirement, some had received ill health retirement (28%) or were dependent on social security (48%)

Implications

- Long Covid clinics need to include the expertise of speech-language therapists and neuropsychologists - these experts need to be involved in the rehabilitation of adults with Long Covid
- Occupational health policies must take into account cognitive-linguistic difficulties as well as physical symptoms of people with Long Covid - and how these impact occupational functioning and a return to work.
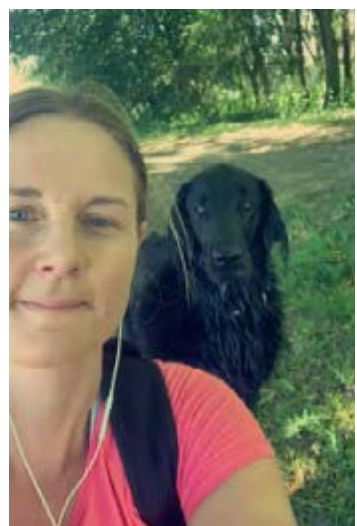
Read more here: Covid-19 and Speech-Language Pathology, edited by Prof Louise Cummings:

https://www.routledge.com/COVID-19-and-Speech-Language-Pathology/Cummings/p/book/9781032190068

Cognitive Communication Difficulties and Long Covid

Kerry Davies, Nurse, Long Covid advocate and Giving Voice Award Winner from the RCSLT

At the start of Kerry's presentation, she presented her educational video which is called 'Relentless' Lesley Goodburn approached and supported Kerry to make the video of her lived experience - Living with Long Covid - The video was played to the QNI group

- I have been a nurse for 21 years and I have lived with Long Covid for 4 years.
- An 11 minute film was created in 2022 by Lesley Goodburn, It was made to support me in presentations because after about 20 minutes of talking, I'd end up with slurred, muddled speech so the video I use for educational purposes. It's to get across my journey.
- I used to be very fit, I'd run 3 times a week, I was very busy.
- I have two wonderful teenagers and a very supportive husband, I couldn't have got through this without him.
- My symptoms have included shortness of breath, rashes, headaches, strange neuropathic pains, joint pains, strange sensations in the left side my head, low oxygen saturation, heat intolerance, rashes after food, temperature, strange bruisings started to appear, muscles twitching, tinnitus. Plus many more, The symptoms fluctuate, come and go. Good days, bad days.
- Debilitating symptoms started to appear: I started to not be able to speak properly, I'd suddenly start slurring words, using nonsense words, getting stuck on words, stammering, not understand what I was doing or saying.

Cognitive Communication Difficulties and Long Covid

Kerry Davies, Nurse, Long Covid advocate and Giving Voice Award Winner from the RCSLT

- Re-watching the video with you now, I can say that there has been some improvement since 2020, but not much since 2022. Many symptoms have gone, but many remain.
- A lot of symptoms are still present, stuttering, stammering, I struggle crossing the road sometimes, reading, processing, having a conversation, remembering. I'm on treatment now, under a private consultant.
- I've always said it feels like there are two things happening in terms of my cognitive linguistics difficulties- brain fog being one, and lack of oxygen getting to my brain.
- Issues after I've eaten, standing static, if I've done too much, it's about managing the condition.
- But I do relate to the brain fog, There must be so many people struggling with the same symptoms that maybe don't recognise what's happening to them, Where are some people getting support from?
- For now, for me, It's still about adapting, modifying, accepting, using accessibility, not speaking, reading, listening or standing for too long.
- Laying down after eating supports me, pacing and resting, cold weather is a nightmare, so much harder on my symptoms. It's just a case of living with it, still battling on to support others that aren't getting support they need.
- I keep advocating, keep banging the drum that Long Covid is still here, and people are still developing it, so many must feel so isolated - it's hard enough going through this as a healthcare professional, but as a patient who isn't getting support, or able to navigate what's out there, it must be so much harder, it's frustrating, so I will keep advocating and support others.

Speech and Language Therapists working with Covid-19

Fiona Gillies, Clinical Lead Speech & Language Therapist – ENT/Voice

Royal College of Speech and Language (RCSL)

- RCSL is the professional body for Speech and Language Therapists (SLTs) in the UK
- Our mission is to enable better lives for people with communication and swallowing needs
- We're a small profession, approx 10,000 of us, roughly 7,500 work with paediatrics, the rest work with adults (although there is a mix)
- As a professional body we're doing a lot of work with relatively small numbers to promote and produce guidance, we do events, we lobby and influence government.

Response to Covid

- We were right in the thick of it from the beginning of Covid - in the early stages we provided surveys. We put together national resources for SLTs and the general public, had a Long Covid working party which was comprised of SLTs, there was a need to standardise the work.
- We decided on 3 streams:
  - 1. raising awareness of SLT role and how we could help (within the profession but also to the public)
  - 2. Supporting SLTs in practice
  - 3. Collating national data and evidence (we put together data as evidence to promote the role of SLTs and get more funding for services.

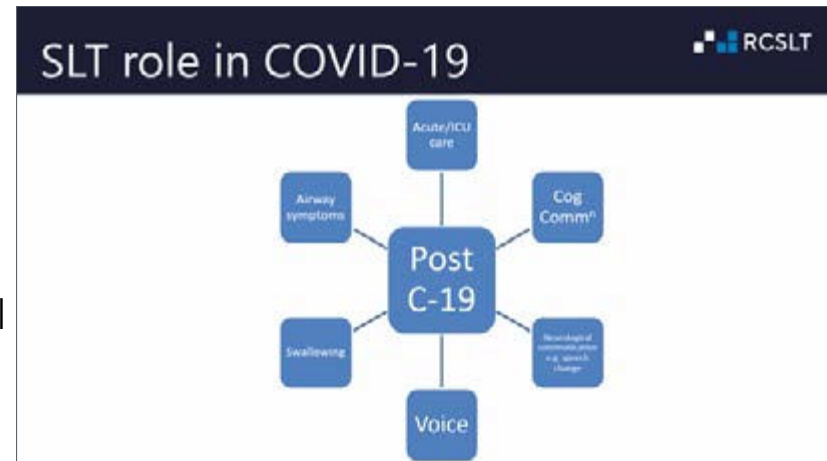# Speech and Language Therapists working with Covid-19

Fiona Gillies, Clinical Lead Speech & Language Therapist – ENT/Voice

Surveys

- We explored the impact of Covid -19 pandemic on SLT services - latest impact report 2024:
https://www.emerald.com/insight/content/doi/10.1108/JHOM-11-2022-0337/full/html
- Voice change and swallowing difficulties were found in the post covid report (2022): ENTs confirm there's nothing in the voice boxes but the patients were losing their tone, it was becoming more robot-like in tone
- Lots of people developed swallowing problems - not just those who were hospitalised - such as food sticking, irritation, difficulty swallowing tablets, globus (sensation of lump in throat)
- SLTs never considered for post-covid rehab
- We needed parity across the 4 nations

Raising awareness

- We felt it was very important to link with RCGP we wanted to make sure they would refer to us, so we produced a one-sided triage prompt to make sure SLT difficulties were identified and referred -find it here:
https://tinyurl.com/3njf6xnf
- We created hubs, factsheets, livingwith app, SLT clinical guidance and patient guidance, find out more here:
https://www.rcslt.org/members/clinical-guidance/long-covid/

Speech and Language Therapists working with Covid-19

Fiona Gillies, Clinical Lead Speech & Language Therapist – ENT/Voice

- We launched a new dataset to capture information about people with long COVID who have speech and language therapy needs: https://www.rcslt.org/news/capture-your-long-covid-data/
- RCSLT's Long Covid resources: https://tinyurl.com/nuapzd4u

Conclusion

- Ask about swallowing, voice changes, throat sensitivity, coughing, vocal fatigue
- Liaise with your SLT colleagues
- Outpatient voice therapists can support voice, upper airways, coughing and throat clearing
- It seems that there are fewer cases of Long Covid in paediatrics, majority of the data reflects adults, but we're keen to work with people with knowledge of Long Covid in those populations, like paediatrics and Learning Disability.

Next meeting:

- **Wednesday 10 July, 10am - 11.30am:** 'Current epidemiology in Long Covid and current treatment options and approaches' featuring speakers: **Professor Nisreen A Alwan MBE** Professor of Public Health School of Primary Care, University of Southampton and Honorary Consultant in Public Health University Hospital Southampton NHS Foundation Trust and **Dr Melissa Heightman,** Consultant Integrated Respiratory & Interstitial Lung Disease Clinical Lead for Integration in Medical Specialities and for the Post COVID service University College London Hospitals NHS Foundation Trust Chair Respiratory Network, North Central London ICB.

2024 meetings:

All meetings take place from 10am - 11.30am

- **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)
- **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:

Very helpful and of great interest.

Really excellent meeting and very helpful for our patients, thank you

Excellent presentation, resources will be really useful

Thank you all, another excellent session. Wonderful resources.

Thank you Fiona - you should all be really proud of the work you and your colleagues have produced. Amazing work :-)

Oh Kerry - I have heard your story before, but it is so powerful listening again, thank you for sharing with us again. Well done and thank you

Thanks Helen, Team QNI and All Presenters and Parcipiants - great session

Menti

How has today's session made you feel?
34 responses

grateful
empowering
positive
emotional hopeful
motivated supportive
informed powerful informative useful links
helpful excellent
empowered competent supported
enlightened validated
very educative thoughtful
inspiring