

How well are people with Long COVID recovering?

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On behalf of NEL Long COVID/Post
COVID Services









Is Long COVID still around?





Estimated prevalence of 1.9 million in UK (ONS 2023)



1.5 million people (79%) report day-to-day activities adversely affected



381,000 (20%) report "limited a lot"



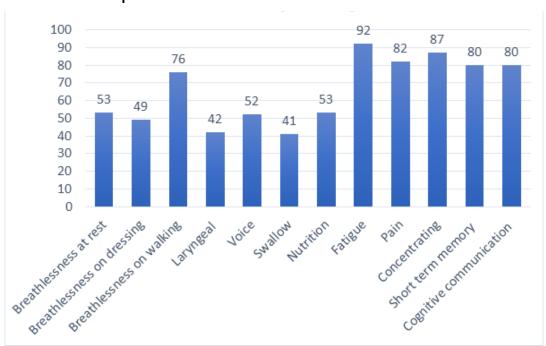
First had suspected COVID-19: 12 weeks previously: 83,000 (4%)

>1 year previously: 1.7 million (69%)

> 2 years previously: 762,000 (41%)

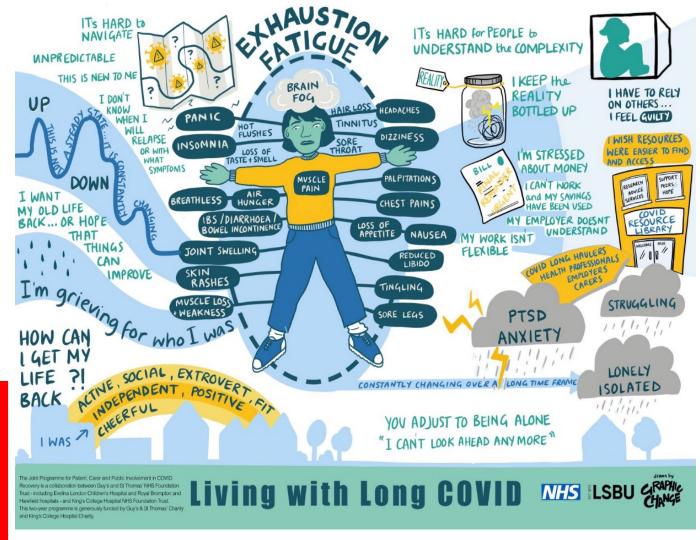
What does Long COVID look like?

Snapshot of most common symptoms reported by patients referred to NEL services



200+ symptoms 67% moderate to severe depression

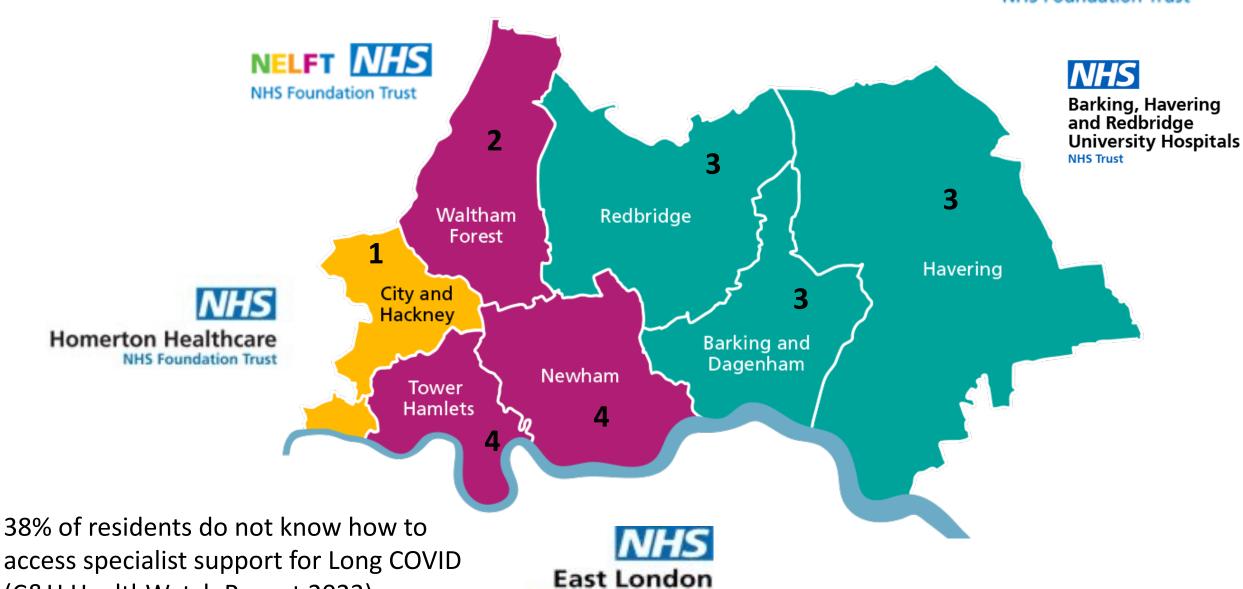
42% moderate to severe anxiety



Long COVID Services in North East London (NEL)

(C&H HealthWatch Report 2023)





NHS Foundation Trust

Consistent service offer in all Places



Multidisciplinary assessment

- Up to 5 clinicians involved
- Average is 2; waiting times less than 6 weeks

Rehabilitation package

- Up to 5 clinicians
- Average is 3

No. treatment sessions

- Average 11
- Range 1-24

Duration of treatment

- Up to 36 months
- Average 12 weeks

Teams include: physiotherapy,
occupational therapy,
psychology, GP, respiratory
consultant, nurse, speech and
language therapy, care coordination, expert patients,
engagement lead

Community outreach

 Partnering with voluntary sector organisations to raise awareness, scope unmet need

slido



What do we mean by recovery?

Research on recovery?

4%
fluctuating
recovery and
health
impairment



17% did not recover by 24 months

Of those symptomatic at 2 months, 85% still symptomatic after 1 year

5% worsened

19% did not recover by 12 months

13% overall improvement over time

23% of those infected **did not** recover by 6 months

68% had continued recovery over time

BMJ 2023; 381: e074425

Tran et al 2022, Nature Communications, 13: 1812

Outcomes



Work & Social Adjustment

75% improved with psychology

70% improved with Physio/OT

Mood

96% improved with psychology

87% improved with Physio/OT

Confidence

88% improved in fatigue management

96% increased confidence at end of treatment



Outcomes measuring mood ratings, impact of symptoms on work, home activities, socialising

82% improved

4% same

14% worse



Ability to do things that are important

67% much improved

22% improved a little

11% no change



Case study 1







41yo Married COVID-19 2021 NHS admin staff
Working reduced
hours

Unable to help look after children

Severe breathlessness

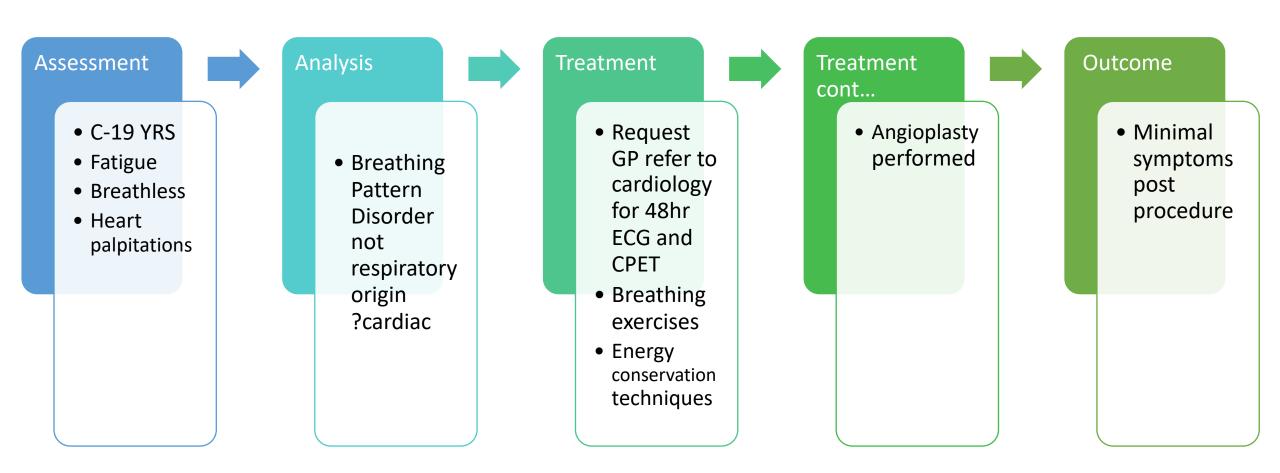
Fatigue

Heart palpitations

*NAD 12 lead ECG, bloods, CXR

Case Study 1







Case study 2







41yo COVID-19 Feb 2021 Referred 16 months later Mother of 2
On maternity leave with 4-month-old baby
Had struggled working prior

Fatigue
Pain
Breathlessness
Difficulty focusing in afternoons

Case Study 2



Biopsychosocial Assessment

- Bloods, CXR NAD
- Feeling frequently 'on edge'
- Impatient and frustrated
- Low mood
- Returned to work 2 days per week
- Reserves energy for work and childcare, not socialising
- Feeling isolated
- Already had Talking Therapy support – helped a little

Treatment

- 8 week condition management group programme:
 - Intro to dysregulation model
 - Balance, Sustain, Nudge model
 - Energy bank
 - Values
 - ACT tools
 - Activity analysis
 - Mindfulness, selfcompassion practices
 - Making behaviour change

Review

- Struggled to put strategies from group into practice
- Persisting high levels of fatigue, stress, irritability with challenges of prioritising health in context of busy family life
- Opted for psychological support

5 area model

What if others doubt my symptoms?; What if they think I'm no good at job?; If others can't see that there is something wrong, they can't understand; How will I manage people's expectations of me?; Am I dealing with the symptoms in the right way?

Tension in upper body
Mind goes blank
Need to move - fidgety/twitchy
Mind goes blank
Loss of concentration

Environment Thoughts Physical Feelings reactions Behaviours

Self-critical thoughts: I should know better

Anxious, frustrated

Historical influences:

Felt pressure of high expectations from parent growing up
High expectations of self academically – worked hard for internal and external validation

Try to find answers
Push through/carry on
Pretend its not there
Hide symptoms from others

Intervention



Raising awareness of interconnection of areas Adjusting rules for living/rigid expectations Self-compassion Behavioural change Mindfulness practices Non-judgemental and acceptance attitudes

Outcome



- Ongoing symptoms of Long Covid
- 2. Less stress associated
- 3. More able to make helpful choices that support living well alongside Long Covid

"My responses to stressful and challenging events are more adaptive and balanced, I feel proud of myself again".

"I'm able to savour the moments of connection with my family despite the challenges I face."

"I'm more able to notice worrying thoughts and show compassion to myself"

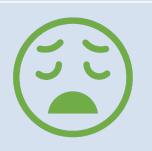
"I'm not as swept along by the train of thoughts as I used to be – I have more choice"



Case study 3







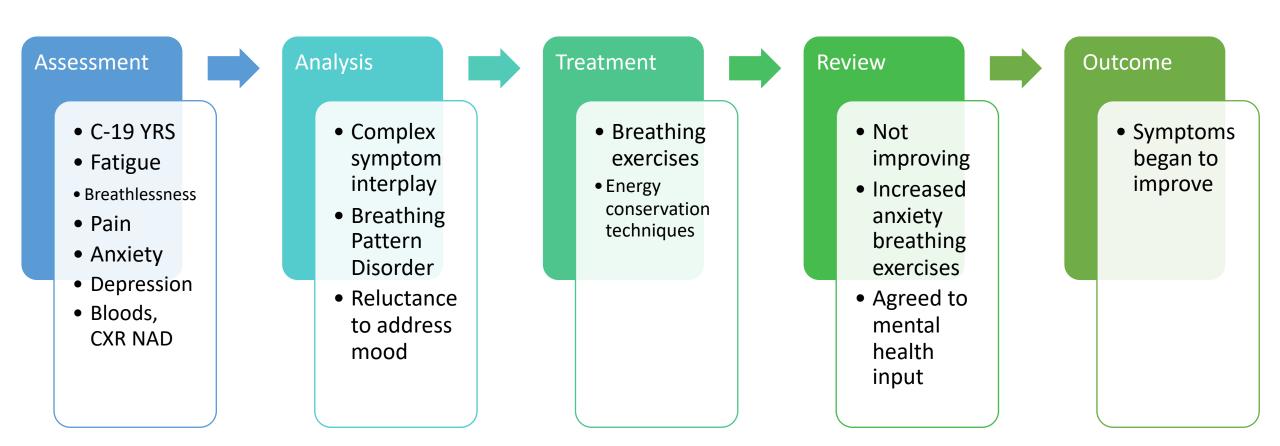
39yo Single COVID-19 2021 Lawyer – unable to work

Moved in with parents

Referred with severe fatigue
Breathlessness
Pain

Case Study 3



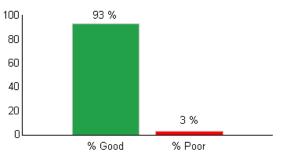


Patient Experiences

"This service has been invaluable. You've been the first people to understand this illness and make me feel like I'm not exaggerating or going crazy. The support group aspect has been wonderful to connect with others, and the tips you've given have made a real impact in my everyday life. Slightly anxious about what will happen once the group ends!"

"Learning about models which describe the impact long Covid has on my body [was good]. Using this as a foundation for strategies to manage my condition. All of the sessions on this were hugely useful."

Friends and Family Test





"Before I started these long covid sessions I was in a very bad place, I find this has help [sic] me to be able to deal with some of the issues I face whilst battling most days, it has really been a long journey, but after attending these group sessions I realise a change, not 100%, but I am positive things will improve."

"I feel like I came into the program in a crisis and although I still have long Covid, I am exiting in a really different place - I have learnt so much in the groups and in my 1-2-1 occupational therapy work... I have also been able to keep in touch with three people from the...group on WhatsApp and this has provided a type of peer support.

I feel so lucky to have received the support to understand what's happening in my body and to meet my situation with acceptance and compassion. Long Covid can feel very unsafe and I feel the support I have received from your service has been essential for creating the safety needed for recovery to begin.

I also have to say that your support has also enabled me to manage my long term anxiety and symptoms connected to trauma. Techniques such as mindfulness have been life changing for me.

I feel very aware that the journey ahead will probably not be straight forward in terms of health, and that's a bit scary, but I feel so much more able to manage it all and it's also really helpful knowing that I can reach out to you for support in the future if I need to.

I just feel full of gratitude for everything you have done and I think you deserve an award for the work you do to support people with long Covid! Thank you!!!"