healthwatch
Havering

Community Engagement

Post-COVID Syndrome (Long COVID): The continuing effects in Havering

Focus Group discussions

Volume 2: Full Transcripts

May 2024

Healthwatch Havering is the operating name of
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What is Healthwatch Havering?

Healthwatch Havering is the local consumer champion for both health and social care in the London Borough of Havering. Our aim is to give local citizens and communities a stronger voice to influence and challenge how health and social care services are provided for all individuals locally.

We are an independent organisation, established by the Health and Social Care Act 2012, and employ our own staff and involve lay people/volunteers so that we can become the influential and effective voice of the public.

Healthwatch Havering is a Community Interest Company Limited by Guarantee, managed by three part-time directors, including the Chairman and the Company Secretary, supported by two part-time staff, and by volunteers, both from professional health and social care backgrounds and lay people who have an interest in health or social care issues.

Why is this important to you and your family and friends?

Healthwatch England is the national organisation which enables the collective views of the people who use NHS and social services to influence national policy, advice and guidance.

Healthwatch Havering is your voice, enabling you on behalf of yourself, your family and your friends to ensure views and concerns about the local health and social services are understood.

Your contribution is vital in helping to build a picture of where services are doing well and where they need to be improved. This will help and support the Clinical Commissioning Groups, NHS Services and contractors, and the Local Authority to make sure their services really are designed to meet citizens' needs.

'You make a living by what you get,

but you make a life by what you give.'

Winston Churchill

Community engagement

Under Section 221 of the Local Government and Public Involvement in Health Act 2007, Healthwatch Havering has a statutory duty to ascertain the views of health and social care services and to make them known to the commissioners and providers of those services so that they can be taken into account in the development, commissioning and delivery of services.

We do this in a variety of ways, such as surveys, interviews and focus groups.

We also participate, with other Healthwatch organisations across North East London, in the Community Insights System, which gathers views and comments on health and social care from people across the area. Intelligence gained from Community Insights is used directly in, or to inform, many of the surveys and other public engagement events that we carry out.

The results of our community engagement are shared with Havering Council, NHS North East London, NHS and other provider organisations and Healthwatch England.

"I think part of the problem is that COVID didn't exist as a thing until the end of 2019. Doctors have been trained to take some symptoms and say "You've got that"; and if they can't do that, they're really in bother because the doctor's job is to give you a medication or whatever and then you're going to get better. … With Long COVID, they can't do that, so they find themselves, I believe, in a very difficult situation. But the bit that I really worry about is the fact that it is so difficult to get to the Long COVID team." - Participant E, Session 1

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Methodology: Focus Group discussions

The discussion at each Focus Group session followed broadly the same pattern, although each session had a different dynamic, dependent upon the number of participants and how ready they were to share their personal information – some were naturally more open than others. To maintain individuals' confidentiality, all comments are anonymous and, so far as possible, all identifying data has been removed. The topics covered in the sessions were:

1. What symptoms have had the most significant impact on your ability to do day-to-day activities and your quality of life?
2. Can you tell us about your experience with accessing services to help you with your symptoms (this includes local services):
    - How did you find out about these services?
    - What has worked well for you?
    - What has not worked well for you?
3. What further support or services would help you manage your symptoms?
4. Do you think a peer support group would be beneficial? If yes, why do you think so? If no, why do you think it would not be beneficial?

Generally, the participants' comments stand-alone but, in some places, remarks by the Healthwatch and NELFT Long Covid Clinic representatives present are included to provide context for specific comments. For ease of reading, such remarks are set in italics, as are words directly quoted by the participants.

Where a quotation has been edited, for example to protect an individual's identity, the replacement words are shown in square brackets [ ].

The report is in the accompanying Volume 1. It should be noted that some quotations in these transcripts may be presented differently to the versions that appear in Volume 1 because of editing requirements.

The focus group session transcripts in full

The transcripts that follow are arranged in order of (a) the focus group session at which they were created and (b) the chronological order of comments within the session.

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Session 1: Hornchurch, 28 May

Healthwatch representative:

Thank you for attending today. Would you each tell us something of your stories, please?

Participant A:

I have had Long COVID for a long time – in two weeks' time it is going to be the four-year anniversary - but I am getting a great deal better. It's minuscule now, and it wasn't mega then, but it was enough that my other half had to look after me.

Participant B:

I'm a health and well-being coach, so I work in GP surgeries and I support those that might need help with their any symptoms but I've also struggled with Long COVID. I've had it for two years but I think finally this year I'm almost out of it and I know I'm very fortunate and I'm very lucky.

Participant C:

I've had Long COVID for eight months although over the last month, six weeks it's got better. But I'm still less than 50% of what I was before. I was left with some damage to my heart and I would say last year was a really awful year, I didn't have any strength in any of my fingers or hands, I burnt myself extremely badly due to that. I would say this year seems to be a bit better, three years and seven months on, and although some bits have improved some bits seem to be getting worse.

Participant D:

I've been suffering with long COVID for two and a half years, although things are slightly improving

Participant E:

My smell is still not perfect. I had none of these symptoms before I had Long COVID. My heart is OK, unfortunately I have diabetes. Otherwise, I'm fairly healthy, I go walking, keep myself fit, no one would say I look unwell. But I have these symptoms, and they happened straight away from the COVID. Like say, I would love to have smell back.

Participant F:

I used to suffer with hay fever; the bonus of Long COVID is that the hay fever has disappeared. I was working at St Francis Hospice at the time. I had never worked in that environment before so it was really quite new, quite scary. I gave it to my husband, he was in hospital, my dad died but my husband came home.

Participant G:

I had it quite mild, but I was also a personal trainer and fitness instructor and found that my joints ached and hurt when I exercised and I couldn't carry on. I changed my job 18 months ago, and I've kind of just reset, I took a real big step back and learned to not accept what I've got, but to start again and I've really changed my life again, and I am now exercising. I'm running my first half marathon in a couple of weeks, I've changed my diet, I have very little stress in my life, I don't rush out to exercise classes and personal training, I go to work, I come home, I rest. I just simply just needed to do that, and I feel like I'm probably almost at that age where it was menopause, so I went on HRT and I really do believe that was the start of my plans and other things going well, and I think with that and me working with it, I think I've got there.

Participant H:

We caught COVID badly. The Long COVID that followed, as you were all been saying, left me very breathless and lethargic but I subscribe to the view that, because sometimes it jumps up and bites me, it's like chicken pox and the shingles virus. I think the COVID virus is lurking within you and every so often it gathers up, hops in and says, "Oh bash her again" and I'm mildly unwell and then it will go, when my immune system says, "OK I'll deal with that" and the Long COVID goes away. I've listened to you saying about sense of smell, and I think I might have lost a certain amount of sense of smell, but I think the actual virus doesn't completely leave your body, I notice it in retrospect and I suddenly think I am little bit breathless, I find it goes to my water works, they go a bit mad, and I think "Hello it's COVID again"; and then it goes.

Participant I:

This COVID is a very strange disease, isn't it? It's affected a lot of people, some very badly as we know and yet other people almost shrug it off within 24 hours. It left me within four days and I was perfectly alright but someone I know went down with it and she suffered for 12 months.

Participant J:

My husband and I both tested positive. He was just unwell with a head cold really, but I couldn't lift my head off the pillow.

Healthwatch representative

Please tell us how you have been affected.

Participant E:

When I spoke to my GP about my fatigue, they put that down to the diabetes, that I'm diabetic now, so they say, "Oh you're now tired because you're diabetic," so kind of ignore the possibility of Long COVID. People who have had the virus for a long time tell of loss of smell and I have no smell whatsoever. So two and a half years on, why doesn't my smell return? It's horrible. Sometimes my husband will say "Oh that's smells nice out there", but I can't smell it. That's a minor thing you forget about, but you can't smell it.

Participant J:

I was going to add something to that. I don't think it's just the lack of information. I had quite an ongoing argument with my GP that I was in the menopause and that everything I was experiencing is due to the menopause, and I'm like "That's not menopause". I have a long standing history of the symptoms of post-viral fatigue from nearly 30 years ago so I know the journey: I know what it's like going into it, I know what it's like coming out of it; but he still insisted that it was the menopause and it that does seem to be a long standing issue because even

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the first time there were budgeting issues there are people arguing about who's going to pay for that.

Participant B:

I also feel aware of that the world doesn't know about it do they? So everybody's scrabbling in the dark with the varying symptoms. Listening to you all, I'm thinking about bits of myself that, and I had not put together until now. You could say "Oh I'll jump on the bandwagon, Long COVID" but you're not and I'm where, I think "I haven't got time to be wasting on this", but you are working, I couldn't have done it, I would say the world does not it was necessary service because there's so much experience the just going the hashtag was millions missing.

Participant F:

The ME community for years, for decades even, has been trying to drive awareness about how this does affect people at work, and right the way through to the people that are very severely bedbound. Everything which we're talking about here, will already resonate with people who have ME and they also have wisdom to pass on, like they've done before. There's plenty of information about, you only have to go on YouTube, there's plenty of recovery stories, help for people to regulate themselves, regulate their cardiovascular system, regulate the wiring of their brains, they've got lots of different things. So it's about finding the knowledge where it exists, because if we go to our GP's and find that we've got to wait three to four weeks for an appointment and then we're told that we need a triple appointment, which is actually only 15 minutes long and then we go in with our list. We have bullet points to talk about as fast as we can, when you got brain fog and then you come out and find you've got forgotten something, and you have to wait another three weeks before you can add that thing! It's very desperate. I try very hard to squeeze what I can say in but, as our friend there was told, the reaction is "I haven't got time to do it now," and the attitude is "You are wasting my time".

Participant J:

I didn't go to the doctor, my daughter had got it as well some paramedics arrived and looked at her she was outside, she went out into the yard because the paramedics wouldn't come into the house and the paramedics said "you've got COVID, on a 1 to 10 scale, you're about 4 and if you're 7 or above we'll take you to hospital" and I was at a similar thing, so we didn't go to hospital, she got over it in about 5 days, I got over it in about 7 days and after that I was fine until June, when it all sort of it all kicked off, and before then I don't think I've ever seen my GP, because I wasn't ever unwell, but we now have an extremely close relationship with him, we're almost on exchanging birthday cards, but I would go in to him and say, "I've got another symptom of Long COVID" and he would say "yes, you may have another symptom of long COVID but that symptom you just described maybe XY, so I'm going to send you to be tested" and we were going backwards and forwards, as I got additional symptoms and they were coming on quite rapidly, but in all cases he was starting off by saying "it may not be Long COVID, might be something else which is significant, so go and get tested" and then in 2021, the Long COVID team was starting to be put together, that's when I was sent to see them and then went there on a very regular basis. I was involved with the north team right from the very beginning.

Participant E:

I think part of the problem is that COVID didn't exist as a thing until the end of 2019. Doctors have been trained to take some symptoms and say "You've got that"; and if they can't do that, they're really in bother because the doctor's job is to give you a medication or whatever and then you're going to get better. With Long COVID, they can't do that, so they find themselves, I believe, in a very difficult situation. But the bit that I really worry about is the fact that it is so difficult to get to the Long COVID team.

NELFT clinic representative:

I work with community and networking links, so that I can get this information which is really helpful because it backs up everything that we have been saying to the powers that be, the loudest thing that I'm hearing, is that you can't get seen, there's a barrier between you and me or our team.

Over the last couple of years, we have had waiting lists but we haven't at the moment. That's not helpful for you, it's also not helpful for us because we're there ready, to be able to support you. I'm not suggesting that we're getting everything right and but we're primarily at the moment a therapy-led service, so that's another thing that perhaps, we could explore if it's what you want and what you need from the service, when you *actually get to us but do know that we are hearing you, and it's certainly something so I've been working with, not just Havering but Barking as well, to make sure that we are educating GPs because they don't seem to know, and they do need educating because they are general practitioners, they can't know everything about everything, but that is definitely something that that we are working on because we are there to support you.*

Participant K:

I unfortunately lost my GP, who was a wonderful GP, but they could not take the pressure anymore. It was a nightmare trying to get registered with a new GP, when your GP closes, but I finally found one, and when I got there and had an appointment, there was my previous GP! So please, if you get a good GP, it's like winning the lottery, so I feel like we should be able to self-refer to the Long COVID clinic.

NELFT clinic representative:

One of the things that I wanted to bring up, if we have time, is that something that you think would be helpful, and certainly it's something that we have been thinking about, and how we could integrate that to make it work, that is number one and the biggest priority in my eyes, is making sure that it's a safe self-referral, as well as the other things that need to be investigated, because as I said we have a therapy-led service at the moment, so we can't do tests, we would have to send you back to GP for that, but if you've got somebody that can do that in the community that is definitely something that I will

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take back to the powers that be, and explore that further, if that is that kind of unanimous. I work in GP services, but we don't quite work the same, so if you came to me he was referred to me you've been to doctor, quite a lot of times you then get referred to me so I don't know, if you know, now that we've been your GP surgeries, there are 30 prescribers that will help with everything, finance, whether you're struggling with disability, you want a blue badge they will help you with all that, patients if you're struggling with fibromyalgia, that's quite a common thing after having this Long COVID, and that they might be able to support you with diet and anything like that, or if you're struggling I don't know other symptoms, bowel symptoms, we have a low risk mental health data part of talking therapies, we can refer you into those as well, and they will put you on little courses, six week courses to support you, we have physios, and we have pharmacists on our team, so if you feel like you're not getting anywhere with the GP.

Participant G:

I'm a health and well-being coach so I haven't got any magic pills, I've got no magic, well I've got a pair of ears, I will sit there for an hour with you and will hear everything you say, I can't promise you anything, but I can try and work with my teams, to get you to the next level, I'll do my best, you don't have six sessions with me after you come back, you're fighting to get heard to different things doesn't work at all, but there might be something that works there, this works, you know it's just, tweak everything is tweaking, and we're like, we realise now, you know

Long COVID, any illness diabetes, Long COVID all different unique, no one's got the same symptoms it is in the sheet, there isn't fix for everyone, it's literally just working with each other, and seeing what we can do but that service is out there, there's lots of pieces of the jigsaw. It will say what they're all responsible to, this it will be pinging you here then what is, it you want I said I haven't got the magic pills, and I haven't got the magic wand but what is it that go from there because sometimes you go to the doctor, you get 10 minutes, people that can't always remember,

I'm a health and well-being coach, there's health and well-being coach, there's social prescriber, there's physios, pharmacist, so we're A-Team now about it, the first time because we're going to the new GP practice, Western Road.

Participant E:

[The practice I go to at the Gooshays Health Centre shares] premises with three other surgeries, but they can't put a notice board up because it costs £200 and they've got to pay so this is the problem. We're not just battling the doctor, they can't tell you everything that's going on, the receptionist has 50 calls hanging on for a phone call at 8:00 desperate to get some emergency calls in, but they've got these board but it's going to cost £200 to do it and not every GP surgery has got a decent website.

Participant D:

I had a physiotherapist show about me three weeks ago now how to breath, and it's changed my previous score from three or four seconds to 30 seconds, which is life changing. It's not been like a little step, it's been a leap forwards with recovery, because obviously now the fatigue levels have dropped. I'm probably 50% back to being where I was before and not only strength wise its massively changed my life.

Just someone coming around for 30/40 minutes on all the different courses. The one thing that I think is it permeates through all of them during the first or the second week, you can see that there is a collective realisation that, suddenly, their Long COVID has been validated, they have found people who are not just wandering about on their own like lost sheep in the desert. People have said “Yes you've got Long COVID, their Long COVID is different to your long COVID, but you've all got long COVID” and the fact that somebody has effectively said “Yes we've heard you, yes you have got something wrong with you” and whilst there is no magic pill, there are lots and lots and lots of different things that can be used to help, and that it's a different thing, because the health service is about “take these tablets, take this three times a day” and Long Covid doesn't react to that, it is very different. The new team is very good.

We've got a fantastic resource and we need to break down this blockage that there appears to be in apparently many GPs.

Participant E:

I forgot to mention about insomnia. I've found one of the ongoing things since getting Long COVID is insomnia. Saturday night I slept for quite a few hours and it's like “wow, that’s a miracle”.

I don't have to suffer particularly from stress anymore because I may lose my life and I was told if I hadn't gone into hospital at that moment I'd have died overnight. I don't have stress like I had before, a very stressful job. I think the subconscious brain kicks in and says, “I had better stop stressing”. It might sound barmy but I do think that it's a weird thing for me. I was up all-night worrying. I've got three children and was always worrying and spoke to the children they just say “I'm worried about you. Are you stressed?”. Well I don't think I'm worried about anything, I don't feel I'm stressed but I go to bed and after an hour or two hours sleep, it's ping and I'm wide awake and then I cannot go back to sleep.

Session 2: Harold Wood, 29 May

Healthwatch representative:

Thank you for attending today. Would you both tell us something of your stories, please?

Participant L:

I missed two therapy sessions when I was indoors doing nothing, just completely because one of my symptoms is memory loss. I got discharged from there about a year, year and a half ago: I went for my appointment and I didn't know it was the last appointment. I got there and I gave him this long list of stuff I'm still suffering with. He went “OK well, we'll test you for everything. Nothing we can do, so we'll just discharge you” and then you are back to where you started.

I have kept a detailed notebook that I’ve brought along because it's interesting to see if others suffer similar symptoms. I've got literally four and a half pages in here. I wrote it when I had my appointment with the doctor, you have to note anything down.

You know you're not on your own, but although millions of people have it, you never directly get to speak to anyone like you. And the hoo-hah that was made over the pandemic when they shut the entire world down for nearly two years, basically. It was such a massive, recognised pandemic but as soon as it was over, they've just washed their hands, like it never happened. It just doesn't make any sense.

Every day is a different day, there's no warning, I mean you literally wake up each morning and you don't know how you're going to feel. Some days you can't even get out of bed. My kids and my husband, who's at home, have to literally treat me like I'm completely disabled. Come and literally spin my legs out there and help me to the bathroom. How can you work like that? You know, today is a better day. I used to be running around everywhere, I've got three kids, and all three of them have got their own health issues as well. I have a house to run, I still have to try and do those things.

Even if there's nothing they can do, and they never find out how to fix it, fair enough. It's just having that recognition that there is a problem.

You feel you are just another number. Even the neurologist (he's nice enough, you know?), he sort of listened for the first time. So that was quite nice to get that written down, but he was so quick to say he was going to test for this or that because I requested that myself. I went in with a list of diseases or illnesses or all new things I could think of, so I've done his job for him and he said "OK, we'll test for all these things, but I don't think anything will come back. If not, we'll say it's FND *[a Functional Neurological Disorder]*". They are so quick to say "It's all up here" without doing full testing or research.

There's 11 new conditions that I believe that I have now, some hereditary as well. So that takes 6 to 8 weeks. It's only Monday but even that I fit the bill for that literally to the tee, apart from one thing and he's saying there's like 10 tests for this one, but he's only doing one. And I'm waiting for him to go “Oh, that's negative”. It's not but then I'm going to have to fight to say, do the other test? I've joined the group on Facebook for this particular illness, there for a couple of months, post some conversations and stuff and they're saying as well about all the neurologists, they FND straight away until they delve further but also, they all suffer with continuous pain as well. But when I mentioned it to the neurologist, without even blinking he said, “Oh it can't be”. That’s because they don't suffer the pain. I mean it's not but if he knew he'd researched like, I mean, I'm just a normal human that's done a bit of Google but even I know the pain isn't a symptom, but it's an indirect symptom from the other symptoms. Does that make sense?

It's a constant battle, and when you have very little energy in the first place, it is really exhausting and demoralising a lot of the time.

I'm having to do the research, but doctors don't get It, they really don't. You know it’s like any illness, unless you've got it or been through it, you're just never going to be able to explain it to someone.

My new favourite one started about four weeks ago and it's happened about five times in the past four weeks, but normally it's indoors if it happens, but it happened on the bus the other day. And oh my goodness, that was really difficult not to make this little squeak to deal with it, I had to get off at the next stop. But I get this shock and it's like a lightning bolt down the back of my leg and it takes your breath away, as quick as it comes on.

They [GPs] seem to give you X number of appointments and then they just test the stuff so they can refer you to other places to deal with if they find anything. But if they don't find anything, then it's just "OK, you've had your quota of appointments and there's nothing more we can do, see you later".

I would absolutely love physio or some sort of massage or anything in that sort of genre. But nothing has ever been mentioned about that, just psychology stuff. They call it Cognitive Behaviour Therapy (CBT) but that's not going to help me now this far down the line.

Literally, this was a few days ago. This neurologist, he is actually recommended and I actually cried when I read his letter because he actually put down everything that I said to him, he actually listened even down to it's like my left eye sinks more than the other one, and the more exhausted I get the like lower it gets like, you know, even stuff like that. But he actually has written that he wants my GP to start me on medication that isn't an antidepressant - because that's all they recommended up until now, four years of antidepressants, they reckon it helps pain and fibromyalgia and stuff. I have tried it and I couldn't get on with it, it gave me more symptoms than I had. That made me very ill. I didn't like it. So I've just been surviving on paracetamol right now, but a tablet called Modafinil, which they actually prescribe to people generally for ADHD. It's a stimulant T:o help my fatigue because it speeds up the heart rate and the blood pressure, and it does something to help so you don't feel so exhausted. I'm excited to try it, but I'm nervous at the same time because now I've built this up in my head so much. It might fix everything but it might not.

At Queens Hospital, [Doctor X] is the one I've got so, I'm quite excited, but a bit nervous.

I don't know how I survive every day. Every day is rubbish and you just survive. But you're not living. It makes me sad and it’s just taking my life away, the effect it has on your relationships and your partner or your children. But my husband and my kids are part time carers between them for me because there's so much stuff that I can't do myself. It's frustrating.

I'm permanently tired but some days it's worse than others. The way I can best describe it is that I'm like a really old mobile phone: I wake up in the morning with 30% battery, but I have to make that 30% last all day where someone else would have 100% last all day. My level starts off low and drains quicker.

I don't sleep well at all. Now I can fall asleep quickly because I've been so exhausted, it doesn't matter where and when it is. Your body just takes over, there's no stopping the falling asleep. I can crash out easily but then through the night, I’m constantly waking up.

Living is a combination of exhaustion and the pain. If I could get rid of those two things, I'd happily live with the other symptoms, and there's a long list. But those two things, literally day in, day out, most days. The pain I would say, on a scale of 1 to 10, with 10 being highest, but I'll probably be 7 or 8 every day. But there could be days where I'm at 10, or even 11 or 12, and there could be days where I'm more like a 6 and I think “That's a good day”.

No day is a good day, but it's literally like I'm dragging myself around, to do anything is an effort. It's all from my shoulders and neck and up, here is the worst that that can come and go but from my hips down to my little toe every day. I'm 38 and I feel like I'm 100 and the pain is unbearable, It's literally unbearable.

Because my GP thought I had asthma, they gave me an asthma pump. But the pumps never actually did anything when I took them. I did a lung test, it's an hour long and literally I felt like I was going to die and it came back completely clear even though I smoke. I've smoked since I was about 14/15, I probably smoke between 10 and 15 a day, have done for years, but my lungs literally looked like I don't smoke. They're perfectly healthy.

Healthwatch representative:

Did it take a long time to get from the GP to the Long COVID clinic?

Participant L:

About a year, and then from there I've had multiple blood tests, but it's the basic stuff from the GP. Obviously, it's low iron and you know folate and things like that, and thyroid, so they are just the normal generic testing and that's the only blood test they've ever done. It's taken me four years to get to a neurologist. I requested to have further blood tests for more rare blood disorders or autoimmune conditions and things like that, but it shouldn't take four years to be able to get a different set of blood tests, you know.

Healthwatch representative:

Surgery for physio or any other form of support?

Participant L:

No nothing at all, No support whatsoever.

Healthwatch representative:

Is there anything you think that might help you that isn't currently available?

Participant L:

It’s like I am disabled. That's how it's affected my life. So then I think, other people, what would they need. But they're all things that are never going to be supplied by the Council or any other department. I need a career of some sort to come and do things at home for me that I can't do, there’s a whole list of needs. It sounds like basically you need a celebrity lifestyle to fund it.

In an ideal world, I need someone to go and do my shopping because I can't do that anymore. Even trying to shop online, I just can't because of the brain problem within. There’s so much stuff I need on bad days. Every week I'd have one of those mobility scooters. I don't care I'm 30 if it helps me, I'm quite willing to go out in one, it doesn't bother me. It’s just that all the services that you only get if you are visibly disabled or you receive PIP but I'm assuming people with Long COVID find it very, very difficult to get approved for.

Healthwatch representative:

People with much more serious things find difficulty getting PIP.

Participant L:

Exactly. Much more visible problems get turned down. Basically, I guess, if you can't see it, they won't accept it.

I used to walk everywhere but now I cannot literally get to the end of my road. I would say it's about 100 metres away. On a good day, I can manage to get to my little local parade of shops, the newsagents and stuff (which are near where I live). But I have to get the bus everywhere. I didn't realise you can get a disabled person's bus pass for free or cheap travel. I filled out the form and I sent my diagnosis letter and the reply I got was that, if you get PIP, you send your picture and you get the pass without any questions. But because I don't have PIP, they want an up-to-date diagnosis letter. I mean, how many times do you see these consultants and things like that, not very often, so I asked my GP and they want T:o charge me £30 for a letter just to have a couple of sentences to say, this is what the problem is. They also said that you can only get it if you can only walk less than 50 metres. Now 50 metres, which must mean that you're in a wheelchair then because 50 metres is not very far. So then you're made to feel like a fraud, because you get scared to use it.

I have been to Queens, King Georges and the doctors.

Healthwatch representative:

So if we were to be able to put together a support group of other people with Long Covid? Would you be interested in becoming involved in that?

Participant L:

Yeah, definitely, because I think that's the best help for the mental health, I think. You know, talking at CBT just sort of helps you manage mentally with your symptoms every day, but they don't help with the anger that you feel over how you are now, and the emotional side of it. So talking to other people going through the same thing would help, I think.

When you go to the doctors, you do feel like you're banging your head against the wall because you're saying all this stuff to them and they're just not getting it, just like it's gone over their heads but to talk to people that actually understand what you're going through would be amazing.

I did sessions with this lady as well, and they teach you to breathe through your diaphragm, to breathe a different way that makes sense, which I do. I'll try and do that each day, which helps. It's like there's someone sitting on your chest so you can't get a full breath, but again that's a symptom. There was nothing wrong with my life and then this comes along.

Healthwatch representative:

Covid itself was a very strange disease anyways, wasn't it.

Participant L:

It was, yeah. And the way it literally killed some people, and yet other people had it and it was no more than an inconvenient, nasty cold, which was like me and my husband. We both got it at the same time and it was like “Yeah, right”. He’s never recovered, either. He's five years older than me. He has had similar symptoms, not all of them but he has a lot of the symptoms, I have a lot milder, but obviously being a man has just never bothered to seek help, he just gets on with it, bless him.

Participant M:

I go to a knitter-natter group; it's the only two things I do in the week. I go to one on the Tuesday and one on the Wednesday and the one on the Wednesday there's little lady who sits next to me.

I get headaches that feel like after going 10 rounds with Tyson Fury. It's horrendous on some days and some days it's manageable. On other days it's like I'm just not getting dressed, which I hate doing, because I feel like I'm not achieving anything in life.

Forgetfulness, hence, my notes. I have just driven here but I would never know how to get home again so I have to put the sat nav on to go home again.

I literally forget things. My husband can say something to me at breakfast and he'll say can you do such and such; he'll come down at 10:00 for his tea and I'll make his tea cause I'll hear him come downstairs and I know, "Oh he'll want his cup of tea" so I'll go and make my cup of tea and he'll say "Have you made that phone call?" and I'll go, "No did you ask me?" and he'll say "Yes darling I did", so now I have to write it down.

That is ridiculous. I used to run an office of like 40 people and I had all these people working for me. Now I can't even manage

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my house. I have a cleaner, I have a gardener, I have someone who does the ironing. I'm very lucky I get that.

Because you forget, I came downstairs and my fridge is with the calendar, so I came down popped the kettle on while I'm there and I was like, "Oh doctor's appointment today 9:20". This is probably at 7:30 in the morning, I go to the living room and now I've looked literally an hour before and it didn't even enter my head it just it disappeared somewhere, and then when it's too late it pops back and I've missed it.

I've also got painkillers that I take as well, and when I forget to take those painkillers and then I'll be walking and I'm thinking "This hurts so much, I shouldn't be in this much pain".

To go from running a household and running an office to literally this, my life is fun, I've a blessed life, don't get me wrong, I'm really fortunate with my life and I can afford to have those things.

I shielded because I had asthma, I shielded and shielded and shielded. Literally, I was in the office on my own, everyone else was working from home and I thought "I'll go into the office, I want T:o keep some structure". Then, when I caught Covid, that's it, it's not over but it's just not the best. So I've gone from going out every weekend to never wanting to go out! I go out twice a week to those little knitter-natter classes and groups and that's it. I'll go see my grandkids.

I changed doctors in the middle of Covid because my doctor had died from Covid and his practice was taken over, and it wasn't the best, so I moved doctors. I've been referred to the

Long Covid clinic and I've had to fill out the form. Have you ever seen those forms? Well my goodness, they've got words that are like this long and I had to Google to find out what the words meant. I gave that form to my old GP practice because they were my present doctor at the time, but in the meantime, I've been moved doctors so when my referral came back to my old doctor the receptionist said "Oh she doesn't want T:hat appointment" so I had to start the process all over again. She should have sent it on to the new doctor but didn't so I then got referred by the doctors that I'm with now.

I've been on a couple of courses and that's how I got pulled into the Long Covid patient thing, because you go on these courses. One was about anxiety, because my anxiety is horrendous (I have social anxiety anyway so I hate meeting new people) and it was good and they gave us some meditation to do and I meditate anyway so that was fine. The next one we went to a couple of weeks later it was about interacting with other people and socializing which I don't want T:o socialize, but that's fine so I went to it but then this man used words that were just ridiculously long I could not understand. I can't even remember what the word was but this is how bad it was.

He then asked us just to have like a break for two or three minutes just to chill, so I'm looking this word up on Google thinking, "What the hell is he talking about? I don't know he's talking about?". My degree is in sociology and psychology but I did not know what he was talking about, there was another lady and she came online and she said, "I'm really sorry but can you tell me what this word is, because my degree is in English and I've never heard this word" and I said, "Well that's funny because me neither".

I will also tell them, "What is the point of going to this course, and what is the point you're telling me about the research? I personally don't give a flying fish about the research, all I want T:o know is where can I get help, what can you do for me, how is that going to help me. I don't care that 5 million people have got it, I care I've got it and it impacts on me and my family!". It's not that I don't care about it, you have to be selfish and as much as you want everyone to be well, you're fighting a battle - sometimes you're fighting a battle just to get dressed in the morning.

Because I'm vulnerable, I get the vaccination. I was due to have the vaccination, so they sent the e-mail from the surgery. Although I'm a needle phobic, I will take everything going because I do not want T:o get Covid again. So I went off to the surgery where they said, "We can't give you this because it is the Pfizer and you can't have Pfizer." So I replied, "OK well where can I go where it's not Pfizer?". "Oh I don't know; you have to phone the Covid office".

I went to my doctors two weeks later and asked how I can get vaccinated. They replied, "It's actually not our problem" so I said "It is your problem because I'm your patient so it is your problem". I wasn't allowed to speak to the practice manager but could speak to the supervising receptionist. We went into a private room, which she didn't want T:o do, and I said, "You know this is what I need to have - I need to have this vaccination and I can't have Pfizer". They replied, "Oh it's not my problem, what you need to do is phone 111", which I did. 111 said you can do this all online. I said there has to be someone somewhere who knows that they're giving out.

Eventually, I got a list of every postcode that I could get the vaccine from and I had to phone every single clinic to find everyday what injections they had in. I've never had that vaccination because you don't want T:o use the phone, you don't want T:o phone up people, when you're in pain, you don't want T:o get up, you don't want T:o get up to go and get it.

I was someone who was really stupid. I said, "This isn't China, it's never going to come over here for goodness' sake, don't be silly". But literally it stopped the world. I just want T:o know where I can get my injection, there must be someone who gives out the vaccine, there must be a list of what drugs are going out.

Participant L:

I haven't come across a problem with the injection yet and I've had all of them, which might not be as many as you. I've never had a problem and I've got a mixture, I've had Pfizer, I've had AstraZeneca, which hopefully will do their job.

Participant M:

Like feelings of fatigue, it comes and goes there's no telling on any particular day. I don't know if Participant L gets the same, that would be interesting, but mine still terrible, it's weird every once a month and then it just disappeared like fluctuates

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between taste and smell, so all of a sudden and random. Perfume can smell like a burning smell, as if someone's just lit a match or something like that; weird but it's horrible now.

As to accessing services, the only thing that I've really had is these courses. I love learning, I've got my degree and I love learning. But it was the waste of money and the waste of my time. I think my time could have been better used and I think they could have presented it differently.

They wanted to do it online, and it's great that they wanted to do online; but to be online it's very impersonal and you can't read the room. I like to read the room, maybe that's just me, to read the room because you know whether you're going to too long if that person hasn't said anything and you can say to them, "Well what about you then, how do you feel about that?". As a person who's had it and living with it, we understand it. I'm not saying that people who haven't had it don't understand it because they don't live with it, so I told the conference, "We see it from a completely different perspective than they do" , because they see it as, "Oh this is what's going to happen, this is what's going to help", but what they do is doctors and psychologists and all these people, they put you into a little box, but this doesn't fit in a box because this is so new, they don't know themselves.

It's like asking where the Holy Grail is - nobody knows what it is, it wasn't a thing a few years ago, absolutely and when you say you've got Long COVID people go, "What? Still?" And I reply "Oh well you know because I couldn't wait, going to all these doctors' appointments, I like booking everybody from down the doctors.

I literally wanted them so badly to diagnose me with something else so that I could say, "Actually I've got this …" Long COVID is not taken as seriously as it should be but the problem is what you're describing doesn't lend itself the doctor diagnosing it.

Three weeks ago, I think, I said, "I've got burning on my skin and, literally, it's like it's on fire but you can't put cold on because I've got arthritis then I can't move". It's like you're in this vicious circle, so I put any cream that I'll just grab. I said to them, "I've looked online and people do get this but is there anything that I can do for it?" So the nurse practitioner said, "We'll send you for a blood test" then I get two texts from my doctor, "You need to have iron", the next text says "You need to make an appointment urgently. I had an appointment a week to ten days later, and the doctor gave me tablets for thyroid. My cholesterol was 5 and it should be 3 to 4, so I thought, "Well, I don't think that's that bad" and then some other tablets to help with my weight. My weight does not help, but when you can't walk anywhere you put weight on. I asked to talk about my eye but I was told, "No we can't talk about your eye because that's something different." So I asked if we could talk about my skin because that's why I went to get the blood test but the doctor replied, "I think it's because you're not using the right moisturizer", to which I replied "This burns, it doesn't burn all the time, but coming over to you today, it burnt and I'm rubbing it, rubbing it, rubbing it cause I've not got my cream in my bag. I should carry it around but you just think 'I'm going to be fine, I can do this I can do that' and it doesn't work", but she said, "I think it's your moisturizer. How do you clean your face? with water?". I said OK and you don't get angry with your

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doctor, but it's like "don't patronize me because I came to you because my skin is burning" so now they've referred me to a dermatologist and you just think, "Well what's the dermatologist going to do?" and it's like it's almost I'll just tick that box and pass it on, so they just pass you over to someone else.

So services what would I like? I love alternative therapies, holistic. I went to the workshop, and someone very high up in NELFT, in the SPS unit, led it and he said we should look at the whole body and I said, "I love you! I'm a great believer in holistic treatments and I'll do anything to stop the pain". Reflexology is really good, reiki is really good; reiki you have to believe in as well, so they don't touch you, then you feel the pain going. Reflexology I love but that's quite painful because my arthritis is in my toes and they manipulate your toe, so you can have it on your hands as well, everywhere is connected to your body and on your feet everyone's connected so when I go, I say to her can you put my bladder to sleep because I get up to go to the toilet at night, and then I'll have a whole week of not getting up. I do have CBD balm – I don't buy it here, I buy it in Spain, and I use it on my joints. I'm a believer in CBD absolutely.

Anyway, I do believe in holistic therapies, but I don't think they'll ever come into the NHS completely. The thing is it works, it's not only that it makes you feel better, like last week for example my back just twinged and I couldn't walk so on Thursday I spent most of the day sitting there in tears, because I felt, "I'm never going to walk again, this just hurts so much, this is really bad, I can't walk".

The problem is that it's difficult to convey your internal feelings to other people, for example you can't see that there's damage, there isn't actually a mark on your arm at all, it's probably somewhere in your brain not making connections. You can't see it and because doctors can't see it, they can't X-ray it, they can't scan it. Some of them find it very difficult to believe that it's there, because it doesn't fit, that's the trouble.

Participant M:

The system moves slowly, the system is scared and the system is broken. I'm not downplaying what they do because they do a marvellous job and I never once failed to clap for them. But the problem is this is so new, that most of the doctors haven't got their heads around it.

Physio would be lovely to be able to do but then my mind says, “Oh, somebody else is worse off than me so they might need it”, but then my selfish head thinks “I struggle just to get up some mornings”. A session of 15 or 20 minutes with the physio in the room doing the exercises or whatever it is they show you, and off you go and do it at home absolutely right.

I went to the pain clinic and I couldn't lift my arm up. Sometimes I would need to lift my arm up just to relieve the pain in my arm. It sounds really stupid but I lie in bed and I'll just have to put my arm up just to relieve pain and so they sent me to this pain clinic physio.

Healthwatch representative:

Would you be interested in joining the group if we can get one set up (participant M)

Participant M:

It could be yes, could be no. This is going to sound really rude and I really don't mean it to be, but you know I'm sure you must think, “Does she ever shut up? She's so draining”, but sometimes people drain you, and sometimes I'll say “Yes, the garden’s rosy and if it's not a good day today, well that was only today, tomorrow's different.

Participant L:

I think it would be absolutely yes.

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Session 3. Online, Morning, 30 May

Healthwatch representative:

Thank you for attending today. Would you each tell us something of your stories, please?

Participant N:

I swear I spend most of my time in bed now as a result of long COVID. I have other comorbidities but Long COVID has worsened some of my other issues to the point where…

I had to move home because it could no longer go up and down stairs in my three storey Victorian house to be close to both my kids and went to a park home close to my in laws (which is good because I love my in laws). So it's a plus, not a minus but it hasn't been perfect because there's still steps coming up to the house. And I find that they're difficult for me, even though there's just few because of my breathing and comorbidities. So, I'm trying to figure out how to get around.

But it has helped being able to not have to run all down the stairs to get to the toilet so the move was good in a lot of ways.

Unfortunately, my husband and I got COVID again 3 weeks ago. And I just tested negative on Tuesday. It took me 17 days to get a negative since my first positive. So, it's stuck around. I don't know what it's going to mean in the future.

I've already been impacted with brain fog. Well, they could bring deep sleep. Because I had brain fog previously and this is a whole another animal.

I liken it to looking for a file, and now it's more realising the file may be dumped in somewhere I'll never find or I'm looking in the wrong filing cabinet altogether. Which is difficult for me because language has always been a good friend to me, I used to walk the high school corridors with the source, but I used to just read for fun like people read novels.

My kids always said I should be an English teacher. I love to read. But now I can't hold up a book to read so all my reading now is on my phone or with Kindles or audiobooks. I can't stop buying proper books because I hope one day I'll be able to hold them up but my weakness in my arms is such, I can't hold the book up.

We're going to have to read it Find the inability to communicate. As quickly and as nimbly as I used to maybe the most frustrating part I can't. My handwriting is gone completely, and I can't write. I used to sit and just write just for fun but because of another injury I had I have been working 35 hours a week as a stay-at-home typist.

That went down when I first got COVID to 20 hours and then it went down to 15 hours. Then it went down to 10 hours, then it went down to having to work 3 hours a day for two days a week, and now I haven't worked since October because I find myself unable to concentrate like I used to. I find that the words aren't making it to my fingers like they used to.

I was stopping, not knowing how to spell words that used to be second nature to me and second guessing myself. And my speed wasn't the same, and my ability to remember things wasn't the same.

That's affected something I used to love to do. Well, actually a lot of things I used to love to do. I used to love to read and I used to love to write and I can't really do those things anymore.

And my breathing is weird. Because of COVID, I've always felt like my breathing was not necessarily an automatic thing, like I wanted to think about how to breathe and when to breathe. And I have moments where I'm like "Oh, I've forgotten to breathe for a while". I'm having those multiple times a day as opposed to one or two times a week.

I've tried to do breathing exercises, but I've got such a fear of not having enough breath that I can't hold my breath properly.

I have another coexisting issue. I'm in the long COVID clinic and I went to see Doctor Ainsley but when I went to see him, because I wasn't able to sit upright for at the half an hour that the breathing test takes, I couldn't do the breathing test. Because of that other issue, he sent me to see a neurologist who I'm still waiting to see - they'll see me back when I have seen the neurologist. I have an appointment on the 17th with one of the physios.

I'm hoping that, if the breathing sorts out, maybe the brain will start sorting itself out a bit more.

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Healthwatch representative

Have your symptoms of long COVID got worse since you had the recent bout of COVID?

Participant N:

Well, I was laid up really bad with it, pretty much completely, for three weeks. I'm a little bit better since I've been negative but breathing still seems a bit weird and my head has felt like it's been full of cough since I've had my symptoms.

I just feel like this is all, every bit of It, there's not a physician or medication or anything that stops it. Trying to get a comfortable position at night is very difficult.

Participant O:

I caught COVID in 2021 in the hospital that I actually work in, I was working full time.

Unfortunately, I have had three bouts of COVID since then and now I'm down to part time with a long line of sickness behind me because Long COVID has left me same as [Participant N] with brain fog, forgetting words, headaches that I can't shift.

My sleep pattern is awful. It's constant like: I constantly feel fatigued, muscle aches and pains. I've worked closely with [the NELFT clinic] to help with my breathing, which has helped. But it's like [Participant N] said, you sometimes have to remind yourself "I'm not breathing right". Before I caught COVID, before lockdown, I was a fitness instructor, I was running half-marathons, I was teaching group exercise classes.

I've worked closely with [the NELFT clinic], as I've already said, who's helped me immensely. Just by having someone to talk to.

But I've also obviously seen doctor only while I've been at King Georgia's. I've been referred to University College Hospital which in itself was an interesting trip that wiped me out for three days, just because of the distance to travel there and the concentration that you have to then come back and find that that wasn't much help at all because they were doing the same as King George's were.

I've recently been discharged as Doctor Ainsley is going back to his own duties, but I'm waiting for a referral or an appointment with Queen's. I've been with the vocational rehab and the only answer they can give me is pace myself.

Again, I've worked with [the NELFT clinic] on this, placed myself at work on an acute busy hospital ward. It's sometimes not possible, if I'm with a patient that's losing their life, I'm not going to step away. That's just not what you do. But then that also wipes me out and obviously I'm going round and round in circles with sick leave at work. All of my COVIDs were actually caught at work.

As to peer support groups, I haven't had those because unfortunately the ones I've been sent to have all been focused on anxiety and depression and none of my symptoms are covered.

None of the questionnaires that I've done have said that I've had anxiety or depression around this. My symptoms on my health.

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Yes, I have bad days. Yes, I cry, quite a lot. But yeah, I'd like to eventually one day be able to walk up the stairs without having to stop. I'd like to one day to go back to full time work, in a job that I love.

But having been the same way as I am since 2021, I don't feel that that's going to happen anytime soon.

Participant P:

[Participant O] mentioned something which I also found.

When being offered services, it's very much around psychology, which I found helpful, but it wasn't my main problem, so I just wanted to sort of underscore what [Participant O] said. My symptoms are pretty much, I guess the same as everyone else's. I caught COVID in 2020, Long COVID I think I got in 2022. I honestly don't remember. Everything was such a fog.

The first one was really bad. My son was hit really bad and passed away because of it. So I've been dealing with that as well as the Long COVID.

I think for me, the biggest symptoms are really the brain fog. I didn't even know there was such thing as brain fog. I just thought I was getting super old, I thought "Is this what getting old is all about?" And you just forget everything and get incredible fatigue.

So it got to the point where I had to stop studying. I was doing a postgrad course, couldn't hardly string two sentences together. I was learning an instrument but had to quit that.

I had to have help come in three times a day to help me, to do physical things like get to the bathroom and to prepare my meals. I was a totally different person to the one I had been. I could not have had this conversation like you.

You know what it's like. Sometimes, you start a sentence but you don't even remember what you were talking about. Since then I've had COVID a couple of times. The last time was about 3 months ago.

And that's the problem, it left me with my heart racing and that's only just calmed down. I had to go to the doctor. Eventually. I tried everything under the sun, but it just wouldn't stop. Racing to nearly 100 and that's after five hours of inactivity. And I was missing beats and it was really getting worrying.

And I have a history of chronic illness in my family as well, so I had to take it seriously. So that was that. But this last bout of COVID, although I'm almost through the symptoms now, I found that my brain fog got so much acute. I would literally be watching TV, and if an ad came on or I turned away, I couldn't remember what I was watching.

And that got from being acute and funny to really like "Can somebody to help me here?" It was really, like you can't function as a normal person because bits seem to be missing.

And I have to be very careful with my thoughts because if I'm doing something and I lose my concentration for one second, I literally don't know what I was doing. I haven't got a clue.

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Everyone knows this who's got Long COVID, everything in the kitchen is automatic. For two years my kids thought I was crazy "Why is Mum burning the eggs? She just put them on for 25 minutes?" I literally would walk out and the pot would be black, the smoke alarm would be on, but I had totally no idea, no recollection of putting the eggs on.

The carers were saying "why have you got so many implements?" I said so that I don't burn the house down, you know. You literally have to have everything electric, because I don't remember to switch off the gas.

So anyway, those are my main symptoms, I think.

Healthwatch representative:

What sort of help have you had?

Participant P:

In the beginning, because I had to go on benefits, the benefit people thought that I was pretending. Even though I couldn't breathe and I couldn't do this and I couldn't do that.

And for a couple of years it just wasn't diagnosed. I was in the hospital, and I was so insulted by the doctor that I made a complaint. He said something like "There's nothing wrong with your breathing, nothing wrong with your heart", pretty much "Maybe you need to go somewhere and lose weight or whatever", and that's after I've been in the hospital on a stretcher thing for hours and hours. He was so rude.

But as a result of that me being taken to hospital again with not being able to breathe, I'd literally walk three steps and couldn't breathe. I absolutely couldn't breathe and I'm not a hypochondriac. I know my body. I've had a lot of operations, about 20 operations. So, I'm not someone who runs to the hospital. I actually don't like them at all.

It was horrendous and no one had a clue what was going on. Finally, one of the nurses there apparently contacted my doctor and said, "Have you considered that it might be Long COVID?" I hadn't heard of it, didn't have a clue. So my doctor referred me to the Long COVID team.

And my life began again, because - really, I can't praise them enough. They absolutely knew what they were doing. They had the right attitude. They were not, I don't know, I can't think of the word...

I think the opposite word is they were all inclusive. I can't think of the other word at the moment, but they were "holistic". More than that, they were - I can't think of the word, but do you know, when you speak down to people as if they're idiots?

Healthwatch representative:

Patronising?

Participant P:

Yeah, they were not patronising. They spoke to us as adults. And, you know, that's rare to find. I used to work in the NHS. It's rare to find that kind of modern approach. I still don't come across it very much. "You're still smoking too often", as if you're the patient who knows nothing, but they were very, very good. The

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sessions were good, the support was good. The after aftercare has been excellent.

And you know what I gained from them is what brought me to where I am now, and that's at least I can hold down a conversation, even if I don't remember half the words.

Today's a very good day and I'm getting better. Again, much, much better again.

Participant Q:

I was lucky enough to be with the Long COVID team for referral for 12 weeks, which was phenomenal and that's obviously got me to this point today. However, in 2021, after my booster vaccine. I got COVID but unfortunately my COVID journey has been somewhat different. It was a vaccine that had made me quite poorly with Long COVID symptoms and from then till now I am still having many issues body Turners.

Participant O:

Can I ask what vaccine you had please? Because I had the AstraZeneca which put me in A&E with extremely high heart rate and my blood pressure all over the place and they actually thought that I had COVID. But I tested negative, but they wouldn't allow me back.

Participant Q:

So yeah, I had AstraZeneca too. I had one and two seriously ill multiple trips to hospital.

And again, the hospital wasn't sure whether it was to do with potential COVID or blood clots, or my body's just reacting to the vaccine. I had many strange symptoms. I mean, probably 30 or more. There was a stage where I couldn't see. I had vision issues, body rashes. I mean it was horrendous. After suffering the side effects of the first vaccine, I was told that my immune system was poor and that I needed to have the 2nd vaccination so, stupidly, I had the second one - and went through the same process all over again. You probably think I'm mad, but you are listening to advice that you are given by medical professionals and then on the booster which was the Pfizer a day later or two days later. I was not very well that evening.

I had all my vaccines done at the hospital.

I then had COVID which was horrific and since then, I have had body balance problems, body tremors. I now have high blood pressure. I'm on beta blockers which has broken my heart. I can't exercise. I've tried to exercise. I've been swimming. I've ended up passing out and having to go to A&E.

I've been back and forward to my doctor. Unfortunately, I feel that I have no heat resistance. I have no temperature control and can feel freezing cold or boiling hot.

I'm in full time employment. I'm a manager. I'm devastated because I'm a very busy person as well, like probably all of you used to being very active. I'm finding it a struggle to maintain good health, because this has really knocked me sideways and I've been back to the doctor, they seem to refer me. I wait, I'm less forever. I go back about my heart.

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I'm sitting there and have crippling chest pain, to be told that they don't think that it's related. But I'm waiting to see a cardiologist.

I'm not getting a great deal of health support from having tablets prescribed to me, so I've taken my healing into my own hands by using therapeutic methods like acupuncture, which has a profound effect on keeping me steady. But it's very expensive and I feel it's a real shame that that's not available more widely to use as an alternative. I was very lucky to get a gym referral for three months from the COVID team but sadly I don't think that exercise and supervision of that exercise actually had a positive impact on my health. It's actually put me backwards. So yeah, I I'm like a lot of you, probably hoping for some good news.

Participant R:

I had COVID in 2020 and I had it four times, but I was sent to the hospital and they said to me that it could be Long COVID because I couldn't breathe. I was getting really bad pains in my lower back and I couldn't walk.

It started from there and then all the symptoms just got worse and worse.

Like I have brain fog, really bad, like forgetting the words and forgetting what you're talking about and all those things. I put on loads of weight because I literally was in my bed for like 3 years. Literally just fatigue so bad, but then couldn't sleep but just felt so tired all the time. [A relative] paid for me to go to Turkey and get a gastric sleeve, that's how much I just wanted to feel a bit better. I had that done and I managed to lose 6 stone, but I'm still overweight and still struggling every day.

I can't work with exercise and everything's just too much. I still get fatigued.

I don't really agree with vaccines.

We've got to be able to go out and mix and I didn't go out anyway, but so I did that. And yeah, I've got body tremors now. I like my shoulder twitches a lot, just randomly, twitching and yeah, lots of different things. But I'm under the Long COVID clinic and I've done the cognitive group sessions and things like that, but I've not been put on any tablets or anything. I've been sent now for neurology like a brain scan, which I'm waiting for. And they put me on a sleep apnoea machine as well for nocturnal hypoxia, which is when your oxygen level drops during your sleep. And my heart rate is never below 100 still.

Healthwatch representative:

As I said, one of the things that we're thinking about is setting up a peer support group specifically for people with long COVID specifically to enable them to talk between themselves with some assistance, perhaps from yourself or somebody like me. Do you think that would be helpful?

Participant N:

Yes.

Participant O:

Yeah, I certainly do. I've been asking for something along the lines of other NHS staff that are able to manage their 13-14 hour shifts.

Participant Q

Definitely.

Participant O

How? What do they do? So I've been asking. [The NELFT clinic representative] would tell you. I've been constantly asking this. Every time I go to an appointment, I just add on to mine that you have referred me to vestibular, physio and audiology as well, so it's affected my hearing, my vision, my balance.

Like the brain fog today, I didn't pick up on until others have just said as well. So it is the constant waiting and the constant chasing. It's the having to go to so many different types of specialties.

And not knowing how to present yourself to the consultant.

I'm going to be sexist here, but we're women and we're used to being looked at as if we don't know what we're talking about when we go to a doctor! "Just lose some weight, you'll be fine, dear". I'm sure, all of us have heard that at some point and it's frustrating and it's difficult to explain to someone how your how your life has changed. You feel like you have to justify how much you did in your life before? To explain that you're not a malingerer.

I spent a good part of my life working two jobs at a time. At one point I worked four. And I've raised two kids, mostly on my own for a long time and I didn't shy from work. I moved house on my own twice, on my own, moving here to this country with two children. I commuted to London. I put in the energy for things that needed to be done and then I hit a wall and the wall hit me back and I can't get past it.

Hearing other people say things about the shaking, the tremors, I have been tremoring if I'm upright for longer than 5-10 minutes. I'm tremoring like I'm just everything shakes and it only stops when I lie down. Even just if I sit down, I'll continue to tremor. I have to lie completely down.

And that's the thing that I'm supposed to see the neurologist about but how do I?

Because it doesn't fit the parameters of what they're used to.

You don't know how to explain it so that you look into all of the literature yourself and you try to educate yourself, but doctors don't like that. They don't like it when you come in, they're like, "Oh, somebody's been Googling" and I'm like, "Mate, if I hadn't Googled, I wouldn't have been able to diagnose this - so please trust me when I tell you I know my body and I know how it's changed and I know how my life has changed".

I know that at 55 years old, I thought I would be doing cross stitches for my grandchildren and I'd be sitting and reading them stories, not having half my visits with them, with me lying in bed. I just can't even get dressed.

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This is this is not the grandparenting I expected to be doing.

I was watching her when she was an infant and working from home at the same time. And five years later I can't walk outside with her for any length of time and it breaks my heart.

I went through menopause through all this. Honestly the Long COVID made the menopause seem actually like a walk in the park.

Participant P:

I am in favour of peer support provided there is a positive approach.

When people get together and we all have the same symptoms, you can get yourself into a non-productive cycle as well and then it doesn't become peer support.

A replication of something similar to what the Long COVID group had you know where you have a mixture of peer support, but in a framework of some kind of professional or helpful input, but then again, I know that that that's not easy to put together because you need funding. You need people you need to who have time to commit to that. So I appreciate that, but I think one has to be careful when you put people together that have the same symptoms and there is no one who is able to steer things toward a positive outcome at the end of a meeting because in the end we'll begin to feel so that's my thought on that.

Just another quick comment about the medical field. I'm fortunate. I have a very lovely doctor. She has the will, but she doesn't have very much information and so she just keeps saying, “well, go back to the Long COVID team”, she literally doesn't know.

Before my son passed away, he'd actually got over COVID and so he was one of the early people who had Long COVID.

My brain is running out of energy now, but I'm going to keep it pumping. And he was one of the first people to have Long COVID, but it wasn't recognised then. He'd been to the doctor. He'd been to the clinics. He wasn't breathing. He had gone back to work, working from home. He was involved in long conferences on the day before he passed away. But there wasn't any information. No one knew really much about it.

This Long COVID isn't a joke: there are fatalities from it.

When you know people, certain things come together and you know, it's just kind of an unlucky mix, but he went to doctors, he went to a clinic and the doctors were devastated because they just didn't know. My doctors are very good but they just didn't have and still do not have the information.

Healthwatch representative:

And that is one of the key themes that's emerged from the conversations we've had so far that the communication is not there, the knowledge isn't there and hopefully the contribution that we are making will Improve that. I haven't got a magic wand. I can't wish it better.

But I can promise you that we will be making sure that what you have said today is considered and hopefully we can *develop something locally that will go some way to meeting the needs that you all have.*

Participant Q:

It's a memory thing as well. Just in terms of the peer support like the framework of the Long COVID clinic, which was very, very good and had a profound effect on finding a way forward, I think that also I get what you're saying about we've all got the same symptoms and finding that it can just be too overwhelming, being stuck with feeling no way forward. I think there's so much information out there that's not necessarily in the mainstream media that could have a profound sharing in a peer group, especially people sharing, for example acupuncture, therapeutic things that are actually enabling us to live our life, which could have an influential way of maybe moving forward because it's only on our independent journeys and sharing that with one another that we can actually find recovery cause

Because it's not in a prescription, it's not in our GP, you know service it's with people that have experience, you know in the whole sector and we rely on little snippets of that, independently to help us find a way out of this.

Participant R:

I've done lots of Facebook groups and there are people all over the world that are suffering with Long COVID and they all share different studies and things that have been done.

There is some knowledge like different ways of dealing with it. I've found through those groups as well and seeing people recover as well also gives you that bit of hope, I think.

NELFT clinic representative

Firstly, thank you everyone for giving up your time and your energy to come to this meeting because it's so powerful to be able to feedback to be able to hear from lived experience because it's the only way that we can move forward with the service that we provide.

There are lots of things that are coming through, so sorry, I should probably introduce myself a little bit better for those that perhaps do not know me. I'm a physiotherapist by a background. I work for the Long COVID clinic and have since it started in early 2021, late 2020 actually, and I am the networking and community links lead. That's why I'm sat here. I am the person that's trying to make sure that once you're discharged from our service and it's great to hear that so many of you have had so many positive experiences that would definitely be fed back.

But it's to make sure that there are the additional supports that you need and I am hearing lots of themes and I'm saying this to you now because I'd like to hear any feedback in case, I've interpreted things wrong. But lots of things about having to wait for lots of alternative consultant appointments and not being able to get back in contact with the GPs. You have to wait for so long and chasing lots of different things. And I'm hearing almost *a theme of it's exhausting. I know that categorically even without Long COVID.*

But maybe an area of advocacy for you to be able to support that side of things so that you can concentrate on the things that actually bring you some joy, because I'm hearing lots of themes around not being able to do the things that bring you joy, certainly hearing a lot around vocational rehab, which is something that we don't provide at the moment because we don't have the skill set, but that doesn't mean to say that I'm not going to go back to my boss and say we need to develop that skill set and that's why this sort of thing is really so important.

Education for people in this community, obviously within Havering cause that's where we are. But the other two boroughs that we serve as well, so that GP's and health coaches, social prescribers, pharmacists and anyone in between know what the signs and symptoms of Long COVID are and what services are out there. That's kind of what all of this is about.

One of the things that I'm really interested to know, I'm really keen to understand, is because there are so many of you that have been through our service and I'm grateful for the feedback and that you found it helpful.

But you are all still struggling with symptoms. So my question to you is what else do you need from us or is what you've had enough that then you've been discharged that you can manage?

If anyone has any thoughts that would be great.

Participant Q:

I found the initial 12 weeks amazing and then you have the three months where just before you discharged me, I saw the breathing lady which was great, but I felt like I was discharged too early from the service with a gym membership, which I wasn't really ready for.

It was a great opportunity but I feel that the relationship between being offered the exercise versus the recovery is not shared between the gym and the GP.

So they're completely unaware of what's going on in your body. So when you go back to your GP and say "I passed out" or "my blood pressure is really high (or low) because I've been exercising", they don't correlate the two things together with long COVID it's like being on a roller coaster, you have good days and bad days and bad months, where you think, "Oh my God, am I starting to show signs of some recovery?" and feeling overwhelmed by chasing appointments or trying to sort of understand what's next.

So I feel that there's definitely more support needed. I think there's a real external unawareness in the big wide world, in the workplace, on the trains.

Public knowledge of Long COVID being an actual physical illness that affects you in so many ways and that it's an ongoing disability because you just don't know when it's going to end.

So I don't know if that answers that a little.

NELFT clinic representative:

It does, thank you.

Participant O:

I was one of the early ones at the NELFT Long COVID clinic. I literally had the six weeks via Teams and that was it. So I'm wondering is it possible if you have a record of the people that are still struggling like myself, like many others that you could reach out with the additional knowledge that has been learned along the way?

Long COVID isn't recognised as a disability. It's not covered under the Disability Act. I've had many arguments within my workplace as I have a long-term illness. I'm quite lucky that my line manager is very helpful, however I've had to go backwards and forwards to our occupational health, HR, etc fighting to be listened to in work because it's not recognised as a disability. So for those that are in work and they are struggling, you are covered under the Equality Act. So therefore that's how you should be treated equally. All of your appointments, etc. I fought for probably the last eight months to get that clarified and also when it comes to claiming benefits and things like that. I was pointed in the direction of University College Hospital, however, I've also heard that again is a journey in itself. Not only is it struggling to do the forms because you start halfway through the form or you start typing away what's going on and you suddenly have a breakdown because you think, damn, that's me. That's still me.

Participant P:

Can I just agree with you? It's just nice to see my experience echoed. Sorry about that. But I've not met anyone like me to totally forget herself.

Healthwatch representative:

That seems to be a common thing. You're not alone, that's the important point, you are not alone.

Participant R:

My NHS like record doesn't even state that I have Long COVID, even though the doctor did the referral originally to the long COVID clinic. When it says health conditions, there's nothing there at all about my long COVID which I just don't understand, to be honest. And now the long COVID clinic there's changed.

I've got to go to the neurologist and whatnot. But I just feel like every week I seem to have something different. And I think, "Who do I tell about this because the doctors don't even know?" I've got Long COVID.

Now I've had something to say that the Long COVID clinic have discharged me, but I just feel like there's so many different things all the time, but maybe I've not told them about that. I can't remember when I've been to my appointment. I don't know if I've told them everything. I've literally given him a list before and said, "can you just put that all on the system because I literally forget it. So yeah, like the doctors should have it on record.

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Session 4: Online, Evening, 30 May

Healthwatch representative:

Thank you both for attending today. Would you tell us something of your stories, please?

Participant S:

I caught it late 2020 and again in 2022. I've had massive fatigue, I find I have no energy, I'm really sleepy all the time. If I do anything and exert myself, afterwards I could just go and lie down and have a nap. Muscle fatigue has been a massive issue since then.

I've had a problem with my neck where I've got a constant pain, just on the one side, which no matter what I try, physiotherapy, I've tried going to a chiropractor, I've tried just having massages: it relieves it for a little while, but it comes back within a very short space of time.

I also have muscle fatigue in my legs. I already had issues with arthritis and now find that the muscle tone in my legs, specifically my legs, is much weaker than it used to be.

My sense of smell and taste was lost originally. It has come back somewhat, but it's very altered and smells that are not nice seem to be more prominent than nice smells. I can smell a horrible smell quite strongly but I can't smell nice smells very well. The same with food, things that don't taste very nice, taste horrible, bitter things taste even more bitter. As for sweet things, I just can't taste sweet things like chocolate and stuff like that, which is, you know, a shame because I do like a bit of chocolate.

I don't sleep very well, even though I'm tired. My sleep pattern has been quite badly destroyed, I get an hour or two maybe, and then I'm awake again. It's not nice.

I find I don't remember things as well, especially short term, so if I'm doing something and somebody interrupts me, I forget what I was doing and I can't go back to it. If I'm going to tell you something and you go "Oh", that's it, it's gone. I can't remember what it was. I was going to tell you, and it could have been very important. I just can't remember it because it just vanishes out of my head long term. My long-term memory is great, I can remember what I did as a kid and stuff like that, my long-term memory is not affected. It's just my very short-term memory and when I say "short-term" I do mean like for a matter of minutes and not hours or days. It's just those few minutes in between somebody interrupting me when I'm doing something and me continuing to do it.

I can't remember words as well, and that's another annoying thing, I can see the word in my mind's eye, but I cannot get it out and I can't spell it either! I go to write words down on a piece of paper and look at and think, "Well, that don't look right", but I know it's right. I know, that's how you spell the word. But I look at it and my mind just goes, "That's not how you spell that".

Healthwatch representative:

A lot of people we've spoken to say they've got what they describe as brain fog. Sounds very similar to that. Would you agree that that's a good description?

Participant S:

Yeah, very good description. I do try to do word games, number games and things like that on a regular basis to just try and keep my mind fresh and functioning. I have a very intense job, I do payroll for 200 people, so I can't afford to get things wrong. I can't afford to forget things. So what I find myself doing now is, every time I need to do something, I have to write it down, make a note, make a calendar note, set a reminder, and if somebody does need to talk to me when I'm in the middle of doing something, I have to say, “Just a minute”.

I have to write down what I was doing at what point, what I was in; and then I can answer them and then I go back to what I was doing. Otherwise, if I don’t, I've lost the train of thought.

Healthwatch representative:

So you are actually still in work. Are you working?

Participant S:

I am. Yes. I was one of the few stupid people that even when I had COVID I was working, I ran a company at the time with my boss and we, well, all five of us in the company went down with COVID at the same time. Literally within days of each other, we all went down with it and there was only myself and my boss that were able to function at any point throughout it, and I mean when I say function, it wasn't really functioning, it was, I literally did the bare minimum, went and laid back down, did the bare minimum, went and laid back down, and we did that for nearly four weeks and he was off for about two and that if he hadn't gone back, the company wouldn't have survived. We would have us and 56 other people would have gone down.

Healthwatch representative:

And were you working from home for that or are you working in an office?

Participant S:

For the first part of COVID, I worked from home. Then I went back to work when they said, "Oh, it's great, everybody go back, you can go back to work". So we did and then that's how I caught COVID, because one of the girls that I worked with, I used to take her into work and although we were wearing masks and she was sat in the back of the car, she contracted COVID unbeknownst to her, then passed it to me, and I passed it on, and it just all went round the office before we knew it.

I was down for about four weeks just before Christmas. I did go back into the office temporarily, then I got a letter from the government to say, due to my conditions, my ill health and my diabetes and all that sort of thing, it would be advisable for me to stay and work from home and it was pretty easy for me to do that to be fair, I didn't have to be in the office. I could work from home. So I did. I still do now; I only go into the office maybe 2-3 times a week if I have to. Other than that, I do work from home. Still makes it a little bit easier for me.

Healthwatch representative:

Leaving aside the issue about memory, which I appreciate in your role can be quite awkward, you have found that the Long COVID of itself hasn't prevented you from working.

Participant S:

No, it hasn't, it hasn't stopped me from working, I wouldn't let it. I'm not going to be one of those that could have said “Oh well, you know, I've got long COVID so I'm not going to go to work now.”

I don't let it. I've never let anything let me or stop me from doing things I want. I don't like flying but it doesn't mean I don't go on holiday.

The reason why I work from home is so that I at least three days a week, I don't have to get up that extra bit earlier. I don't have to. It takes me an hour sometimes an hour and a half in the traffic to get home from work so I don't have that journey.

Its 8 miles up the road. You wouldn't think an 8-mile journey could take you an hour and a half, but when you get stuck on the A13, it can take me about an hour in the morning sometimes. An hour and a half to get home but average an hour both ways, so three times a week at least I can avoid that.

Another thing I found as well (and I know this probably sounds probably quite stupid), I get socially fatigued quite easily. I'm OK to mix with people for a very short space of time but actually having to be social and interact for long periods of time, I find quite wearing, quite tiring and I find towards the end of my workday I'm a bit like "Just go away and leave me alone", I just don't want T:o talk to people, don't want T:o be smiley, happy and nice and all that sort of thing. That is not me; it's just I'm tired and I just want T:o go home.

Participant T:

Well, everything that [Participant S:] has said relates to exactly to me, and particularly if I'm having a conversation, I go to say a word and I sort of hesitate. It's like someone that's had a stroke, they hesitate to speak and also to write down a word. And I look at it and I think is that right but the general fatigue and the lack of sleep at night causes confusion.

I rarely actually see the end of a TV programme because as soon as I sit down, I fall asleep. Everything is like climbing a mountain, even to take the dog out, put my shoes on, put my coat on, to put the dog's lead on, to walk down the road. It's just such a big effort. It's something that I never even used to think about. It's this generalised fatigue and my legs, as [Participant S:] was saying. At one time, I was going up the stairs on all fours because I couldn't lift my legs. I've got quite big legs for a small person because I used to do a lot of sport and bike riding. It was really, really scary because I really thought perhaps, I had some underlying illness that affects my muscles.

Like [Participant S:], I am an outgoing person, I like meeting people, having lunch with people and generally socialising. But now it's so tiring and when I get home, I just sit down and I feel exhausted.

It’s got to the point where, when I had a yearly checkup with the nurse, she said to me “Are you all right?” because I didn't know what was going on. I told her that I felt so tired all the time and I became tearful. She took me through to see a doctor and the doctor prescribed antidepressants for me, but I don't think I'm depressed. I'm just so tired, you know?

Everything is tiring. It used to be I would go out in the garden and start doing the garden, I could be out there for hours and enjoy it. But now, after about an hour, I come in and I have to sit down, and if I'm not careful, I fall asleep. I could sleep all day but then when you get into bed, I'm awake at 1:30am, then it's 2:00am and so on. When eventually I fall asleep, well, my dog gets me up at 5:00 every morning anyway, so I'm not ever getting a full night's sleep. And you might say, “Well, that's why you're tired during the day” but I don't think so, because even if I do get a good night's sleep, I'm still tired whenever I start to do anything. I can't stand for long periods in the kitchen and if I started reading something, I'd have to sit down to read it.

When I'm not moving my legs, they are just like lead. And that's how I feel. And because you feel that way, it makes you tired, doesn't it? Because it seems like you're sort of wading through mud the whole time, just doing normal activity.

Participant S:

Yeah, absolutely. That's a good analogy actually, yeah.

Participant T:

I've always sort of been an active person, but now I'm not. I get tired when I'm in a social situation. I can't wait to get away, to be quite honest.

Healthwatch representative:

When you saw the doctor, or indeed you saw the nurse, did either of them say anything about the possibility of it being Long COVID?

Participant T:

No, no, no, the doctor said "I think you're depressed, so I want T:o give you some antidepressants and I'll see you in a week", which, as you know with that practice, was a joke.

I didn't see her in the week, but nobody mentioned Long COVID at all. After a few weeks, I saw another doctor and I explained to him how I felt and he said to me "I haven't got time to talk to you because I've got other patients to see". I said I really didn't know what was going on; "I'm taking antidepressants, but they give me restless leg syndrome, you know? I feel so not like myself and I'm so tired all the time".

And he said "Well, I'm not referring you anywhere because it takes up too much of our time".

So I went online and I self-referred to APT. I went on a waiting list for Zoom-type meetings; eventually that went through from February to April. There were weekly Zoom meetings online, but none of it mentioned COVID.

Healthwatch representative:

Could you tell us what your profession used to be?

Participant T:

I was a nurse, In obstetrics and gynaecology. I qualified when I was 44, so I've always been an energetic, someone that's had a load of energy but now I'm not. You think "is it because you're getting older" but I haven't got any energy. I just haven't got the energy to do what I want T:o do. I used to jet wash the garden but last year I had to pay someone to do it because by the time I got the jet washer out and fixed it all up, I just felt exhausted, I physically could not do it.

Healthwatch representative:

I just wanted you to explain your background because you are a somebody who knows the system and yet you got treated like that by your own GP. I could see the look of horror on the NELFT representative's face when [Participant T:] spoke about her experiencing with the GP. And I really think that's part of the task that we in this group have and that is to get more doctors aware to think "Long COVID" because clearly, they're not even thinking about it.

Participant T:

No, no, they don't. They immediately said it was down to that you are depressed. Well, I probably am depressed, but I'm depressed because I'm not me. I'm not the energetic person, who can take the dog out for hour and a half and come back and then do the garden. I know I'm getting older, but I think there's so much emphasis on mental health, and I'm sure that post-COVID a lot of people are suffering mental health because of what we went through for those years.

But the doctor says "Well, you know, you're depressed, you look depressed, you don't look well" and I know I don't look well because I feel so tired.

Healthwatch representative:

Participant S, Can I ask you, we've heard how Participant T was treated by the GP and so forth. Have you contacted your GP?

Participant S:

Yes, I did. I went to see my GP because of my pre-existing illnesses and obviously contracting COVID, after I got over the original symptoms and was able to sort of get back to some sort of normality. He asked me to come in and see him, and he sent me to my local hospital, where I saw a newly set up team of people that dealt with the after effects of COVID. It was then that I learned that what I had was called Long COVID. But this was probably 12 months after the initial Illness presented itself, so it wasn't a quick thing. The one thing they did say to me because of my diabetes, I take vitamin D orally every day and they said that vitamin D had been recognised as something that could help with the recovery to for patients who had Long COVID and that in fact actually I think they'd started using it in patients that were ill and suffering in hospital as a way to try and help them to recover.

However, I take vitamin D to this day and I still don't feel any better from having taken it.

They did say it possibly might have prevented me from contracting the disease as badly as some people might have done if I hadn't taken it.

But obviously there was no correlation. I don’t think that any studies have ever been done of the effect, but they know that there is some help because obviously vitamin D is there to help your immune system. But on a daily basis now, I don't feel any better for taking it, I take it because I have to because of my diabetes and I don't absorb vitamin D very well.

But I got the help I needed. Initially I went to see a physiotherapist, but that was the one and only time and I never received any other treatment from a physiotherapist for my muscle fatigue. Like [Participant T:] I took the APT course for, I think, 6-8 weeks. They were telling you about your sleep patterns and how to try and get around those sorts of things and what to do when you're tired and all that sort of thing.

Another thing I find is I get very short of breath still and so they put me in contact with the ENO, which is the English National Opera; they run a course for six weeks to try and teach you how to breathe properly - they teach opera performers to sing and where to sing from and how to use your diaphragm and your lungs and all that.

So we had a six week course on that. It was lovely to do. Did it help me? Not particularly. But you know, I wasn't going to tell them that because they were very enthusiastic and they were very, very nice people and actually the bunch of us that were together, we had quite a laugh because they got you singing as well, which was rather quite horrifying but fun. It was fun for that one hour where you sing at the top of your voice and know nobody else could hear you!

Healthwatch representative:

Who was the doctor you saw, and was it at Queens or King Georges?

Participant S:

At Queens. I saw Doctor Mullins, an Irish gentleman, who was very nice.

There were a few people there at the time in the waiting room, so the clinic was obviously quite busy. It was still quite a new thing, I don't think it had been up and running for very long. It was still new to them and the people that were providing the service, I don't think they quite knew what they were dealing with.

I don't think people understand to this day. My husband's a lovely man, he's very caring, but I don't think he understands just how debilitating this is - he's had COVID, twice, but he was lucky and he came away very, very, very mildly. I didn't.

Healthwatch representative:

Thank you. [NELFT clinic representative], would you like to say something about the physio side of things?

NELFT clinic representative

It certainly sounds that you were seen in the very early phases. I've been with the team since April of 2021 it was just in its infancy. You mentioned a six-week course, which was probably predominantly the physios that were running that. I think at that time we had literally just switched to the reverse of everybody else - we were doing face to face when everyone else was doing virtual, and then when everybody started seeing each other again, we switched to virtual because we had such a huge influx of patients and simply not the capacity to get to everybody. That six-week course was right in our very early phases.

We were originally seeing people face to face in their own homes but because of capacity , we switched to virtual. One of the things that I'm trying to seek out, which is why these focus groups are so important, is what are we missing?

What I've heard from both of you here today, and also from a few people on the other calls, is this inability to do the functional stuff that you really want T:o be able to do that adds purpose and joy to your life and which no one can live without. No wonder you are feeling a little bit down! Functional rehabilitation is not necessarily something that we are doing at the moment, but I'm hearing from people that something that perhaps does need to be added in.

One of the questions I wanted to ask back is that obviously you had this input some time ago. Do you feel more input would be helpful or do you think you've gained enough from that?

Participant S:

I did gain some benefit from the online sessions because obviously they were talking about how to manage your day better. One lady had an analogy where you've got 10 spoons and you know it takes 4 spoons to do this, and then you're left with six and then it takes another four to do that. And you are left with two, blah blah. How to manage your day better, how to utilise your energy better?

So if you're feeling that you could do a four-spoon thing, do a four-spoon thing. But then when you come down to the next bit, only do a two-spoon thing because that way then you're not using quite as much energy. You've just used four spoons, which is quite a lot.

Go down to two, or even one, spoon. I know it sounds silly, but that's how she used the analogy and it worked. It made it sense. So now what I tend to do is I do maybe a bit of a bigger job, like maybe putting the washing machine or the dishwasher on or emptying the dishwasher and refilling it, and then I go and sit down and then I think “OK, give myself maybe half an hour to an hour to recuperate, and then I'll go and do maybe a simple thing, like take the dog into the garden, and sit in the garden with the dog”.

That doesn't take up much energy. I might pick up a little bit of poop that she's deposited for me. I might pick up a few weeds, and then I go and sit back down again.

So I now manage my day much better. So that did help me though that initial how to manage your day.

I've tried everything they said, like having a proper bedtime routine, keeping the noise to a minimum and the light to a minimum, and don't do this before you go to bed, don't drink this. I've tried it all and it makes no difference. I might go to bed at normally about 10:30 because that's by the time that part of the day's come, I'm pretty much done. I'll get into bed. I'll lay down. I may nod off – but an hour or two later, I'm awake again and it's like "What do I do now?"

NELFT clinic representative

I'm very conscious that I don't want T:o interrupt you and that you don't forget your thread of what you're saying. But just to reflect, if I may, the lack of sleep, almost insomnia, pattern that you're both describing is one of those things that we have learned through our patients. That's something a lot of people struggle with. One of the things that I instigated, that we've now got running from the team, is a pathway into talking therapies very specifically for support with insomnia.

As you quite rightly pointed out, we didn't really know a lot about it when we first started out and we are still very much learning, but we've learned the sorts of things that we have put in place now, which you wouldn't have known about and you wouldn't have benefited from because you were already discharged from the service. That's certainly something you can self-refer for. I can certainly arrange to get you some information so that you know about that if you wish to.

You've been through the service, you've found it very helpful. It sounds like you're doing an amazing job at using all those principles that we've taught you. So well done and it's great that you're being able to function to some degree using those tips. Are there other things that you feel that we within the NELFT therapy team can offer that you would benefit from?

Participant S:

I don't know. To be fair. I mean the maybe the courses themselves could be a little longer. I think the first one I did was for 6 or 8 weeks, which is not much time. It doesn't give you much time, although it did give me some things.

And they provided an app and they kept the slides on the app and you could go back to the app and you could record yourself on the app, if you could remember to record things! You could contact them if you needed to through the app, which was good, it was nice.

But I think maybe longer and maybe not rush through everything quite so quickly, maybe spread things out a little so people get to understand, and explain a little bit more because I found sometimes, they said things and it didn't always quite make sense how what they were trying to get at. If they'd have had more time, they might have been able to explain themselves a little bit more.

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NELFT clinic representative

Thank you. That that's really, really helpful. One of my bugbears is that I feel we rush people through that. We give you the tools to use, but not enough time to absorb using them.

Participant S:

It would be nice if, for example, we do breathing exercises then, when we come back the following session, "Let's just refresh ourselves. How did we get on with our breathing? Did we do OK? Do we need to go over any areas again?". As it was, they went on to something else without really catching up with people.

They were a really nice bunch and they came from all walks of life, all sort of areas of businesses and stuff like that. It was really nice to talk to people and get an idea of how things had affected them and their families and their lives. But we didn't have time to talk about it.

Healthwatch representative:

I'm fascinated by what you said about that course that you were able to attend by from run by ENO.

Participant S:

It was amazing. I loved it. It was brilliant.

Healthwatch representative:

How did you work out for that, how did you find out about it?

Participant S:

I can't remember now; it was to do with the with the with the course that I'd been doing.

They sent out an e-mail and I was interested. So I applied.

And then they contacted me a few months later and asked me if I would like to join and take part, and I had a little sort of interview, a Zoom meeting, and I was accepted onto the course, you didn't just get signed up, you had to be accepted. I think they were looking for people they thought they could help rather than just anybody. There were about eight of us in the group and it was fun

NELFT clinic representative

The Long COVID team do refer in to the ENO.

Participant S:

It's called “ENO Breathe”. I might have been referred through the Long COVID team, I don't quite remember now, but it was great fun. It really was. The guy running it was so funny and because he was like he wasn't a medical person, I mean, he understood what long COVID was and its effects on people. But because he didn’t have any medical training for us, it was a different perspective and he was trying to get us to open up and to not hunched up and get sort of tiny and get further and further down the camera. His idea was he wanted you to get up and open and be out there and raise yourself up and raise your chest. He made it clear that nobody had to have their mike on when they were singing so you could sing as loudly and as badly as you wanted. There were not songs that we would all sing, like Christmas carols or anything like that. They didn't make any sense to me but it was voice training, how you used your voice and how you used your lungs and your diaphragm and take breath.

I’m definitely not Pavarotti in any way shape or form, but it was fun. And actually, there were days when checked in with everybody – “How has everybody been? Has their week been not so good?”, but by the time that session was over you could actually genuinely see that their faces had changed and that they were not feeling quite so glum. Or so tired. It was just that little bit of a pick me up as well as being able to help you. It was great, I enjoyed it. I didn't think I would. To be fair, I thought it was going to be one of these hippie things, but no, it wasn’t. I could imagine us all sitting there singing “Kumbaya” but you know it wasn't that. And it actually really good fun.

I find that when I'm getting out of breath during the day, I will sit back and take a moment to breathe properly, which is one of the things they teach.

I'm all for people having self-help groups where you can talk to other people but have the similar or go through the same sort of thing, not so that you can moan or gripe or whatever, but just sometimes to listen to somebody else, look back and think “Well, maybe my day wasn't quite as bad then. Or maybe I don't feel quite as bad anymore”. Talking to someone else, actually, the old adage “A problem shared is a problem halved” applies. Sometimes, just saying to somebody “I really don't feel great today. I've had a really bad day” is all you need, especially when you feel like you were locked in.

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I've spent nearly two years indoors. I didn't go anywhere. I didn't see anybody, only my daughter. There was no contact: me and my daughter have got a really close relationship and it was really hard not to see her. Although we did obviously video chat, it's not the same thing as being able to have a cuddle and you know things like that.

And once we were allowed to go out, I found it very difficult. I'm not saying I got agoraphobic or anything, but I then found it quite difficult to go back out into the world, not for the fear of catching COVID or, you know, anything like that. It was just because I'd been locked up for so long, I became quite institutionalised in my own home. It would be nice if I could have had somebody to talk to about it, but there wasn't.

NELFT clinic representative

It's no wonder that that you mentioned things like you get very socially fatigued because actually it's not something that you've been used to. And because of all these other symptoms that you've collected along the way.

Participant S:

Sometimes, just acknowledging that you're not OK is one of the hardest things to do if you're the type of person like, I guess, [Participant T:] probably is. You don't admit too often that you're not doing OK, you quite happily just carry on, because that's what you do.

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NELFT clinic representative

Do you think that it would be helpful, not just to you, but perhaps other people that have been through the service earlier, to be contacted again by our team to check whether you need any more help? Would you like to come through the service again?

I'm not necessarily promising that this is something we could do but it was one of the things that we had been contemplating. I'm just not sure whether that's something that people would want T:hat.

Participant S:

I think it would be a good idea, just to check in just to see if people are genuinely OK - and when people say "Oh, yeah, I'm fine" just push the button a little bit because lots of people will say "I'm fine" or "No, I don't want anything" despite how they actually feel. It would be good if you could just make sure people are really OK.

NELFT clinic representative

We have to be stick to policies and KPI's but what I am hearing is a theme of "When you come into the service, you get almost rushed through it, you're out the other end, and then you're left to your own devices", which is one of the reasons we looked at setting up things like community activities that we sign post people to. There are singing groups, if you're interested.

Participant S:

I got an e-mail about that, but unfortunately because of my working times it just never fitted in with me, because they tend to do it during the day, not of an evening.

NELFT clinic representative

It might be that now we have got more that could be available to you, so that you can get involved in different ways to do those kinds of things.

There's definitely a theme of people wanting almost a little bit more of a check in. I need to speak to the team about how we might be able to manage that even if it is a feedback questionnaire of how things are and then we get back in contact if there is more help needed.

Participant S:

But I think as well, listening to [Participant T:]'s story about how her doctor treated her - which I think is absolutely abysmal, to be fair - is that more doctors need to be made aware that this condition is real. It's not made-up. It was the same with ME; people went for years and years and years suffering with ME only be told “Oh, you're just making it up or you're just exaggerate”.

No, COVID was a real disease, a real illness and it's left people with lasting after effects. I think doctors need to be made more aware and to not deal with patients like they dealt with [Participant T:] because that's just not fair. She's gone away feeling no better. In fact, she probably feels worse because she's been dismissed, quite aggressively “We don't have time for that”. That's not acceptable. I know GP's are busy. I can't even get an appointment with my GP.

Participant T:

I was actually in tears.

NELFT clinic representative

One of the things I've also taken back from that, if I may add because I hear one of the things that the GP said to you, [Participant T:], rightly or wrongly and in my head wrongly was “We don't have the time to do the referral because the referral is such a long piece of paperwork as Long COVID is diagnosed by exclusion.

GP's are asked to check so many things to make sure that they have been excluded because if it's any of those things, they can often be easily treatable, and it's not long COVID.

That is something most definitely that we as a team are looking at, particularly as our service is changing a little at the moment.

Participant S:

If this referral is such a long form, maybe you could ask the patient to fill in the form, ask “Do you suffer with …? Do you have any of these effects?” Then you whittle that down when it gets back to the GP, and we've done his work for him effectively.

NELFT clinic representative

Some of it is actual tests that they need to run as well.

Participant S:

I understand that, but some initial questions could narrow it down even further.

NELFT clinic representative

Absolutely. We have been talking about potential of self-referral but we would need to manage the safety element, making sure that we're not missing anything that that could or should be treated, it's just us being able to navigate that.

Participant S:

I think by now, though, I think most people are fully aware of the symptoms of Long COVID and how it affects people. I think that though there's not enough out there about how to get referred, where to go, that sort of thing.

Participant T:

When I did these Zoom meetings with IAPT, I actually felt a bit of a fraud, because there was a waiting list and the other people were severely depressed where it was impacting on their life. They asked you to speak and I actually felt a bit of a fraud because I thought I'm not depressed like them. I felt quite guilty about it because I thought I'm taking someone's place because the people were so severely depressed. And I'm not.

They were all young people, younger than me, but it was impacting on their life, their work, their family.

Participant S:

But you need the support just as much as anybody else.

Participant T:

Yeah, that's true. That's true.

Participant S:

So don't feel guilty. We have a problem in this country with accepting help for mental health issues.

NELFT clinic representative

We know this is not in people's heads. We know that it is real, even if organically in tests nothing's coming up. You were as valid in that session as anybody else. If it had been a Long COVID-specific Talking Therapies group, which do now exist as well, you'd have felt more validated, I'm sure.

Participant T:

I must say that they were very good. The two chaps that did it were very good. It did help me in a way because I saw that there were other people that were having more difficulties with their daily life than me. Because I live on my own, I'm retired, so I haven't got money concerns, I haven't got work concerns, I haven't got children that are dependent on me. I was surprised that they were all younger than me, because when I was young, I was never depressed. I was too busy, but I suppose.

Participant S:

I think in today's world a lot of what happens in social media causes depression in the younger generation.

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Participant T:

Well, yes, and I think that sometimes they lose their social skills because they're not out mixing in person.

The first time I went to the supermarket, I didn't know where I was. I almost had a panic attack and I couldn't find anything, and I had to ask an assistant. In the end, she gave up and just came round with me because I couldn't find anything. I just wanted to get out and get home. It was a really strange experience to go in the supermarket.

Participant S:

That's why I don't go shopping anymore. If I do food shopping, it's all online.

Participant T:

Doing shopping online for so long and then going into a supermarket and the restrictions in the supermarket and the amount of people in there.

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Participation in Healthwatch Havering

Local people who have time to spare are welcome to join us as volunteers. We need both people who work in health or social care services, and those who are simply interested in getting the best possible health and social care services for the people of Havering.

Our aim is to develop wide, comprehensive and inclusive involvement in Healthwatch Havering, to allow every individual and organisation of the Havering Community to have a role and a voice at a level they feel appropriate to their personal circumstances.

Members

This is the key working role. For some, this role will provide an opportunity to help improve an area of health and social care where they, their families or friends have experienced problems or difficulties. Very often a life experience has encouraged people to think about giving something back to the local community or simply personal circumstances now allow individuals to have time to develop themselves. This role will enable people to extend their networks, and can help prepare for college, university or a change in the working life. There is no need for any prior experience in health or social care for this role.

The role provides the face-to-face contact with the community, listening, helping, signposting, providing advice. It also is part of ensuring the most isolated people within our community have a voice.

Healthwatch Havering Friends' Network

Join our Friends' Network for regular updates and other information about health and social care in Havering and North East London. It cost nothing to join and there is no ongoing commitment.

To find out more, visit our website at https://www.healthwatchhavering.co.uk/advice-and-information/2022-06-06/our-friends-network-archive

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