

# Post Covid Syndrome Public Feedback Briefing

July and August 2022 - Issue 1

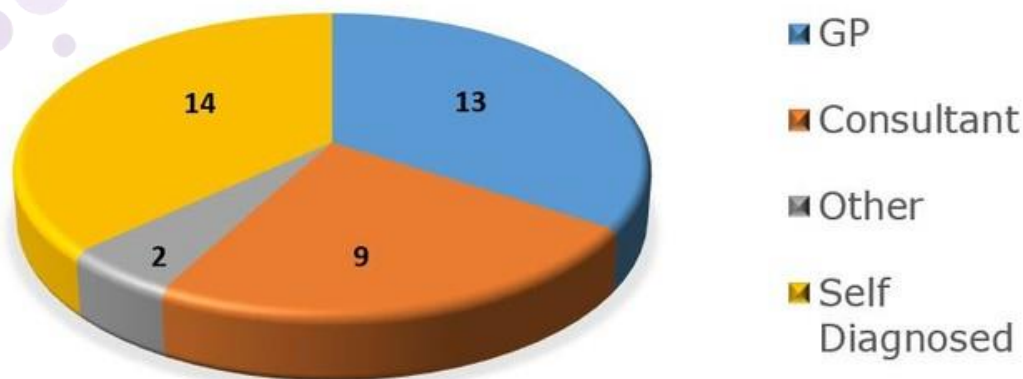
**We heard from **38** individuals in July and August who have or knows someone who has Post Covid Syndrome, and their recent experiences of accessing NHS Services.**

The NHS state that common post-covid symptoms (Long Covid) include; extreme tiredness, chest pain or tightness, shortness of breath, problems with memory and concentration "brainfog", dizziness, heart palpitations, pins and needles, difficulty sleeping (insomnia), joint pain, depression and anxiety, tinnitus, earaches, feeling sick, diarrhoea, stomach aches, loss of appetite, a high temperature, cough, headaches, sore throat, changes to sense of smell or taste and rashes.

**The comments in this report offer a snapshot of people's feedback about Post Covid Syndrome and their access to NHS services. We would like to thank everyone who wrote to us to share their experiences, which will be used to help the NHS learn from your comments.**

## Below is a breakdown of how the 38 responders were diagnosed with having Post Covid Syndrome:

### HOW WERE YOU DIAGNOSED?



**50%**

of people who responded said that they had pre existing medical conditions which have now worsened

### Below are some comments from people who felt their pre-existing conditions have now worsened:

"My asthma is more obvious since having Covid."

"Weight gain Painful bones and ligaments. Cough"

"Fatigue resulting from relapsing glandular fever, chronic pain."

"Hip pain has become worse and tiredness and feeling wiped out if I do too much."

"I have anxiety and depression which I have medication for. I have found this has worsened when I'm feeling unwell due to symptoms described as long Covid."

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**We asked people to rate any of the NHS Services that they may have accessed, in relation to their Post-Covid Syndrome (Long Covid). This was the outcome:**

<b>NHS SERVICE</b>	<b>VERY GOOD</b>	<b>GOOD</b>	<b>OK</b>	<b>POOR</b>	<b>VERY POOR</b>
PHYSIOTHERAPY	<b>1</b>	<b>2</b>	<b>1</b>	<b>3</b>	<b>4</b>
GP SERVICES	<b>7</b>	<b>3</b>	<b>15</b>	<b>6</b>	<b>3</b>
PHARMACY/ PRESCRIPTION	<b>0</b>	<b>3</b>	<b>7</b>	<b>2</b>	<b>3</b>
CONSULTANT SPECIALIST	<b>4</b>	<b>3</b>	<b>5</b>	<b>0</b>	<b>2</b>
111 HELPLINE/ OUT OF HOURS SERVICE	<b>1</b>	<b>0</b>	<b>1</b>	<b>6</b>	<b>1</b>
POST COVID RECOVERY TEAM	<b>4</b>	<b>0</b>	<b>4</b>	<b>2</b>	<b>4</b>
SUPPORTED SELF MANAGEMENT MATERIALS	<b>0</b>	<b>4</b>	<b>8</b>	<b>1</b>	<b>2</b>
COVID 19 RECOVERY WEBSITES	<b>3</b>	<b>4</b>	<b>8</b>	<b>3</b>	<b>1</b>
SUPPORT GROUPS	<b>5</b>	<b>1</b>	<b>6</b>	<b>1</b>	<b>1</b>

### **Along with their ratings people said the following:**

"The Long Covid Wales group on Facebook have been SUPERB ! Don't know where I'd be without them !"

"Recovery app had repetitive intros that was patronising. Didn't find it helpful, I deleted the app"

"The EPP courses were very good, helpful and insightful"

## We asked people if they are aware of the NHS Wales Covid-19 recovery app and if so do they use it?

21

People said that they are aware of the Covid-19 Recovery app.



17

People said that they haven't heard of the Covid-19 Recovery app.

9

People said that they have used the Covid-19 recovery app for support.



### People had the following to say about the Covid-19 recovery app:

"Complete, utter rubbish. Total waste of money. Really patronising. Material covered is very basic, not relevant to post-Covid."

"The post-Covid app has been very good, with information of how to help yourself, we need to get help and has been accessible as I am blind."

"It is the only helpful thing I've found. GPs need to use it, they seem to know less about long Covid than those who use the app."

"I used a for a while but didn't really see the point of it. Not that useful really."



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## We asked, if you needed to access specialist equipment since being diagnosed with Post Covid Syndrome, was it easy to access?

4

People said that they needed access to specialist equipment.

4

People said that they found accessing the specialist equipment easy and straightforward.

34

People said that they did not need any specialist equipment to assist them.

### People left the following comments:

"GP prescribed a 'breath meter' but hasn't bothered with the results - and also suggested a BP / heart rate monitor - which I bought myself"

"Still being assessed for a potential heart valve condition which may lead to specialist equipment being needed."

"This is for the post vaccine, I was provided with a walking aid from physiotherapy."

"I probably could have made use of a shower chair or a wheelchair - but I just wanted to get better. And wanted some help with that from the NHS in Gwent - none came. I feel like LC has pulled the rug out from under my life and whilst I am flailing on the floor the NHS has come and with a finger on their lips quietly pulled the door shut. It is that bad"

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# We asked people if they knew who to contact if they had questions about their Post Covid Syndrome condition?

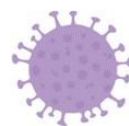
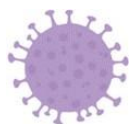


10

People said that they knew who to contact regarding any questions.

28

People said that they were unsure of who to contact regarding any questions.



## People said the following about knowing who to speak to if they have questions about their Post Covid Syndrome :

"I'm guessing a GP but waiting 2 weeks or more is too long - often recovered by then so what's the point? You can spend half your life waiting for attention, sorting out prescriptions and collecting medication."

"My starting point will be the app now I have heard about it."

"I was living in Powys when I was diagnosed, and still registered there for the time-being. I know I can contact the Pain & Fatigue Clinic there, and also a GP"

"I can contact my G.P. - but, whilst being 'supportive' they - like everyone else - are working 'in the dark' with Long Covid. Had it not been for the people who set up the LC Wales group on Facebook - I may not have survived ! I have learnt SO MUCH from the group !"



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## People left us the following further comments ...

"I'm finding it frustrating to access GP services in person, and short staffed pharmacy too. I've been a frontline worker throughout the pandemic, am not able to work from home, and wonder how much longer these issues will last?"

Major eye problems during Covid and rang GP surgery to ask - was unable to source a call from a GP about it over course of a few days. Much better service when I rang and asked a pharmacist who said most likely a viral infection that would pass when the covid infection passed, which seemed to be the case.

GP has been very supportive. I have been referred to long covid clinic out of area by occ health. Been off work 8 months now and it's all self guidance, trial and error with help from LC Facebook groups and my own research and support from GP, Care advice for long covid is poor in Wales.

Our GP practice seems to still be operating at 'lockdown' levels with very little move back to a proper opportunity to see a GP.

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I am surprised to hear there seems to be so much out there to help with continuing symptoms. I can only blame myself for not getting to the GP regarding the symptoms but I feel I need to just buckle down and get on with life even though its really hard.

Non existent offering other than apps and slowly back to exercise. I relapse whether I sit still, change my diet, exercise, non exercise. When is the NHS going to take this illness seriously? We are chronically ill! Our lives have been changed. For 19 months I have been less than 50% of my normal self! With only the Llandough Clinic offering support!

From my experience of post vaccine sequelae which symptoms are exactly the same and was exacerbated by Covid resulting in long Covid , it's difficult to know where to turn to. The waiting lists are extremely long. I don't know if I will get over the lack of help from some in healthcare, the way I've been spoken to, not believed and the way I've been treated. I'm not alone , there are many more out there like me.

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# Your feedback helps us make a difference!

**We will share what people and local communities are telling us with the NHS. This is so the NHS can see what people think is working well and take action to improve care where it needs improvement.**

**As your independent NHS watchdog, CHCs across Wales will continue to play a vital part in reflecting people's views and representing your interests in the NHS at this critical time.**

**We'd still like to hear from you so please keep those comments coming and share your feedback on NHS care during the Coronavirus pandemic by completing the following survey**  
<https://forms.office.com/r/xiNARS7kS2>

**Scan me with your phone**



**If you would like to speak to a member of our team about your experience, please phone us on **01633 838516****

**Alternatively, you can text **WALESCHC COVID** to **62277** with your views about NHS care during the pandemic.**



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## Useful links for people with Post Covid Symptoms:

**NHS Covid-19 Recovery Website - [www.yourcovidrecovery.nhs.uk](http://www.yourcovidrecovery.nhs.uk)**

**Aneurin Bevan University Health Board -  
<https://abuhb.nhs.wales/hospitals/recovery-from-illness/>**

**Welsh Government – guidance: <https://gov.wales/coronavirus>**

### **Accessible formats**

**If you would like this publication in an alternative format and/or language, please contact us. Our publications are also available to download and order from our website.**



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