# People at the Centre Update 22

**On the 11 November 2020 the ALLIANCE held an event for people with lived experience of long Covid which was attended by 12 individuals.**

## What has worked well?

All participants in the group found the pandemic and their experience of long Covid to be extremely challenging physically, mentally and emotionally. For some participants, this experience was alleviated by the support of reassuring and responsive healthcare services. GP services were positively reported by some participants, through which they had experienced quick testing and regular follow on contact.

*"The pain got me the worst, but they put me through all these tests, heart tests, ECG, bloods etc. they were fantastic, my GP would phone spontaneously to ask how I was doing."*

*"NHS were good at responding to any acute issues that have come up, I told my GP that I've been having persistent thirst, they got me a test in half an hour to rule out diabetes."*

Whilst these participants were appreciative of the treatment from healthcare services they had received, they also shared that doctors have been limited in how they can respond and support them due to limited understanding of the condition.

*"GPs were great in terms of supporting me but didn't really know what to suggest or didn't know where to go to."*

**What has not worked so well?**

However, the majority of participants in the conversation reported that, for a variety of reasons, they had had negative experiences when accessing healthcare services.

Members of the group reported that when they attended their GP they experienced a lack of recognition, empathy and belief in their experiences, including healthcare professional "downplaying" or dismissing their symptoms.

*"In the worst cases it feels like individual symptoms are belittled or not treated."*

Multiple participants shared that when in discussion with their GP it had been purported that they were actually experiencing anxiety rather than long Covid. One individual shared that they had actively avoided accessing services for mental health support in case this undermined their efforts to be treated and supported for long Covid.

*"I would not dare phone my GP and say I need to access mental health services at this point. If I phoned and said I am feeling anxious, that would be it for me. No more cardiology. I'm nervous about being pigeonholed. I've had so much stigma when I hadn't even had anxiety, we probably all have some post traumatic stress. So I've gone to a private therapist and would go to a private GP if I wanted to discuss mental health."*

Where participants felt their experiences were being recognised, they still reported that their symptoms were only being addressed in isolation and not as part of an interconnected condition.

*"They have been supportive but not offered me any test or treatments for any other symptoms. I've gone to them with fatigue, chest palpitations, breathlessness, and they seemed to focus on fatigue only they are receiving based on testing."*

The result of these experiences was that many members in the group felt the need to access support elsewhere. Many individuals undertook their own research into the condition and support available, while others ended up utilising private healthcare services instead.

*"I’m not a pushy person so I’ve not asked my GP for a specific thing, but I have found myself researching my condition myself.”*

*“I have started doing an online pulmonary rehab bootcamp online, from America. Basically, we’re doing it for ourselves, going away and finding it, because that support has not been made available through the health system.”*

*“We’ve been having to do a lot of this ourselves, that applies financially as well. A lot of the things I’m doing that seem to be vital for my recovery I’m paying out of my own pocket. It shouldn’t be that people have to use personal finances to get acupuncture, counselling etc.”*

Many participants in the group had found help and support through the use of Facebook Support Groups. There were mixed feelings on whether these were the most appropriate form of support, but people were grateful to have a place to share research and provide peer support to one another.

*“chatting to people who are going through similar experiences was very useful.”*

The importance of advocacy when accessing services was also highlighted by the group. Many had themselves felt the benefit of having people and family members advocate on their behalf whilst they had been unwell.  Worry was expressed within the group that people who are less forthright may not be able to navigate their way through the healthcare system appropriately without an advocate.

## Impact of the pandemic

Regarding the wider impact of the pandemic many participants shared how experiencing long Covid has impacted their employment and economic situation. Many people present had had to take long term sickness, and as such were under pressure from employers to provide evidence of their condition. This was particularly challenging for individuals who were diagnosed with COVID at the start of the pandemic, prior to widespread testing, and who did not have a positive Covid test on their medical record.

> *"Yes, very much agree with highlighting problems around employment. I have been very lucky with my employer and have been on paid sick leave so far, but that is now reducing to SSP because of length of time. The support of GP sick note was vital here to ensure employer support – that's the most practical useful thing the GPs have done for me."*

## What matters to them?

In closing the conversation participants highlighted the need for specialist generalists who are experienced across the board, who can understand and recognise the way in which a number of different conditions present. It was also felt this should be underpinned by the ability to self-refer.

It was also shared that further information and research regarding long Covid should be a priority, in order to inform both health professionals and people who are themselves experiencing the condition.

The most prevalent requirement shared for the future was the need for healthcare services to listen to the people who are accessing them and to recognised their expertise as individuals experiencing long Covid.

> *"Listening, believing, empathy"*

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People at the centre

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