



healthwatch
Warrington
Your local health and social care champion

Long Covid

Warrington Residents Experiences of
accessing support and diagnosis

July 2023

Supported by

Warrington
Disability
Partnership

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Introduction

Healthwatch Warrington is your local health and social care champion. If you access GPs and hospitals, dentists, pharmacies, care homes or other NHS support services in your area, we want to hear about your experiences. As an independent statutory body, we have the power to make sure NHS leaders and other decision-makers listen to local feedback to help shape and improve standards of care. We can also help you to find reliable and trustworthy information and advice. Last year, the Healthwatch network helped nearly a million people like you to have your say and get the support you need.

Healthwatch uses your feedback to better understand the challenges facing the NHS and other care providers and we make sure your experiences improve health and care for everyone both locally and nationally. We can also help you to get the information and advice you need to make the right decisions for you and to get the support you deserve.

We received substantial feedback from Warrington residents regarding the ongoing symptoms of Long Covid. This included people saying that they were dismayed at the lack of support that was in place. There were also residents stating that they were very happy with the service that they had received from the Long Covid Support Service at Warrington Hospital so Healthwatch Warrington undertook a patient survey and conducted several feedback sessions to gather feedback and experiences from people living with Long Covid.

Warrington Disability Partnership (WDP) have a Long Covid Support Group that they operate both online and in person. We approached them to see if we could access the group to speak about their experiences and share our survey with them.

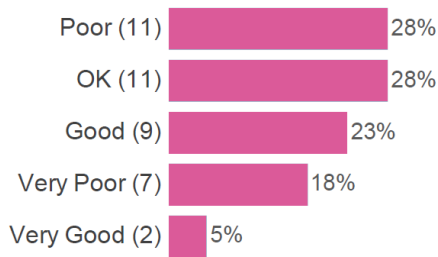
In partnership with Warrington Disability Partnership Healthwatch Warrington held a coffee morning at the Gateway Centre and attended two of the Long Covid support groups. The surveys were shared with the members and a total of 94 responded, 52 opted to complete the form and a further 42 via our Digital Virtual Voices platform.

Methodology

The survey was distributed via the Long Covid Support Group and the Long Covid Support Service at Warrington Hospital. We also sent a poll via Virtual Voices to gather extra feedback from those who wanted to do so digitally.

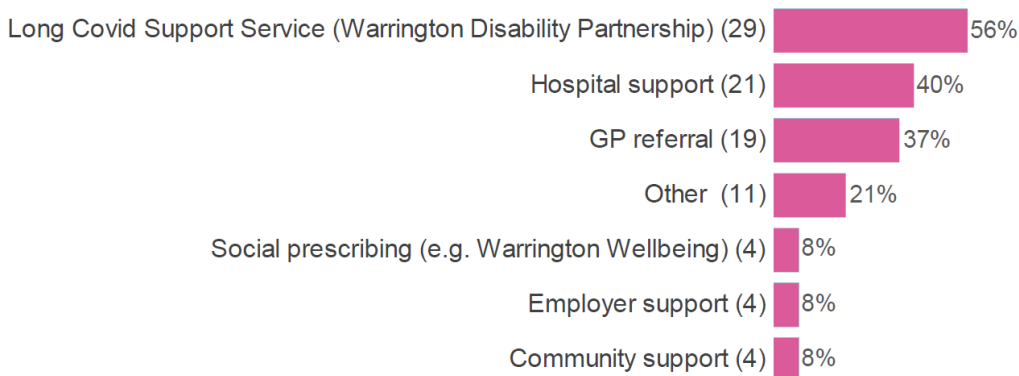
Findings

How was your GP Practice with your Long Covid Journey



Those that replied stated their GP surgery was either Greenbank, Stockton Heath, Culcheth, Birchwood, Hood Manor, Chapelford Medical Centre, Fearnhead Cross, Holes Lane, Folly Lane, Westbrook, Guardian Medical Centre, Fairfield Dallam Lane or Four Seasons.

What has worked best during your Long Covid care journey?



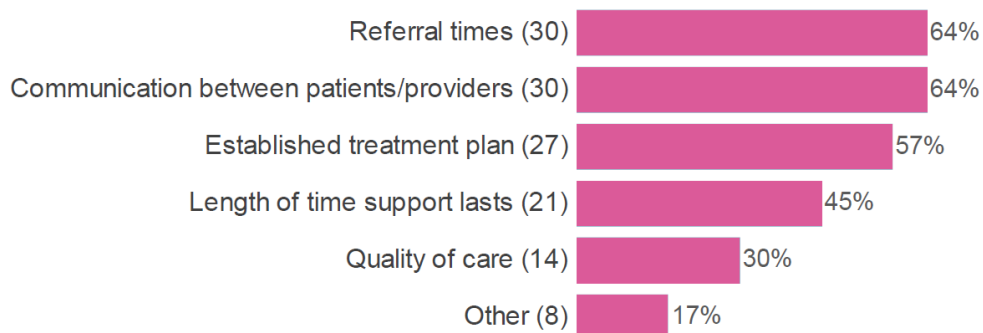
"The Long Covid Respiratory Team have referred me to other practitioners that I need to see, this has taken 2 years from my first Covid19 infection. The Long Covid Support Group are assisting with and supporting my journey.

I found them online and without their support I would not have been referred to the Long Covid Clinic by my GP. My GP actually didn't want to refer me and kept telling me there was a "criteria to referring" despite me clearly meeting it.

Have only received a referral to speech therapy and WDP.

I used to work in nursing homes as a night care assistant and practical skills and knowledge from that time have kept me alive. No direct support. No Family support. Hard getting outdoors".

What could be improved?



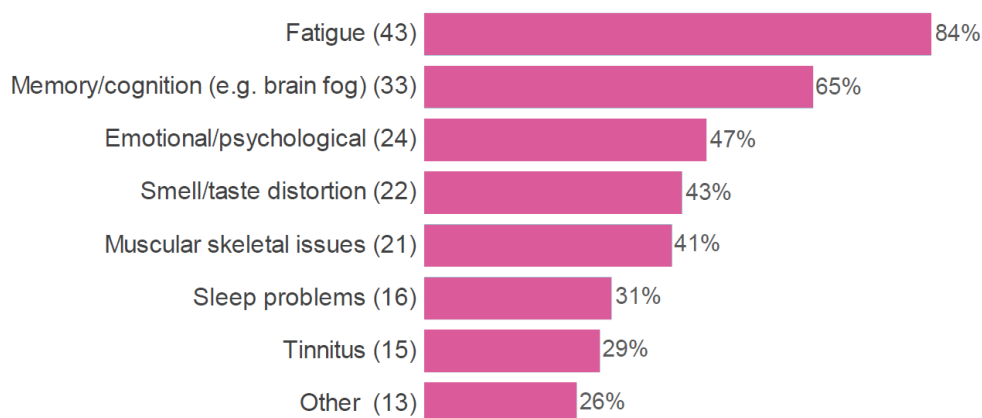
Comments included:

"Needed to know communication between patients/providers, established treatment plan, quality of care, length of time support lasts".

"Referral times- not being referred when I needed to be seen, or referrals not being sent- told they have but haven't or told nothing else they can do".

"My GP clearly doesn't understand Long Covid which is understandable as they are overworked, however, there needs to be a clear structure for them to refer us to people who do. I should not have to explain the referral process to my GP. There is a breakdown of communication between various organisations- A&E diagnosed me with Long Covid 8 weeks in, yet my GP had no record of all the tests that were done on me at all. I must have them done again. The WDP Support group has been a lifesaver as my symptoms continue to change. 1 year in and it is ridiculous their service is only for 12 weeks. I was very lucky and was referred almost straight away".

What is the most misunderstood symptom of Long Covid?



Other feedback comments included:

"Fatigue: You may look ok but you're not, the problem with memory cognition. smells sometimes come from nowhere or unpleasant smells occur when eating so you can't finish. Emotional psychological issues and some people don't understand. Can't sleep and wake up for no reason due to noises in lungs, pain and joints".

"People only really hear about the taste/smell & fatigue. My family and friends are continually shocked at how Long Covid has affected me . I am a MUCH different person now to how I was".

"All symptoms are mis-understood and a lot of the doctors think that it is all in your head because it comes and goes . Stuttering and neurological issues".

"The detrimental impact it has on your entire body, mind & wellbeing. Brain fog, chest pains"

"I cannot remember things, short time it is very distressing, and I have had to give up my job as a primary school teacher. It has affected my mental health as I have always worked even when my children were young. This feels like a life sentence and I'm worried about my safety as I may have left the oven on and forgotten for example. My husband is very good and has had to take early retirement to support me".

"I got Covid at the very start of the pandemic so did the other girls in my office. We all took time off and went back after. I was never right after that, I struggled to get up the stairs and my breathing was laboured all the time. My employer was unsympathetic as this was the very early days and no one knew about Long Covid. I ended up being made redundant and I have now been referred to the Long Covid team at the hospital and they are very good. But that took almost 2 years".

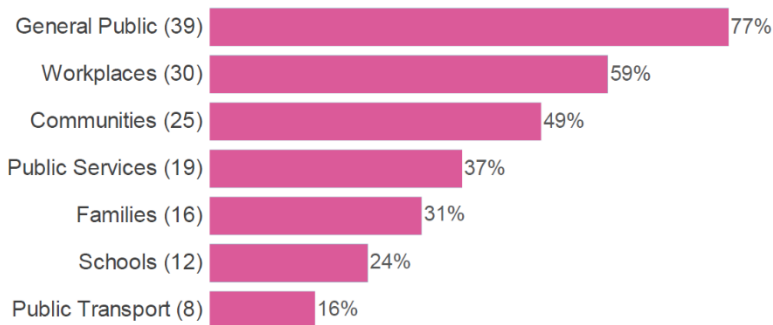
"Weight loss, I have lost 3 stone in weight which makes me even more tired".

Do you feel there is a need to raise awareness of Long Covid?



What areas need to be focused on?

Please tick all that apply

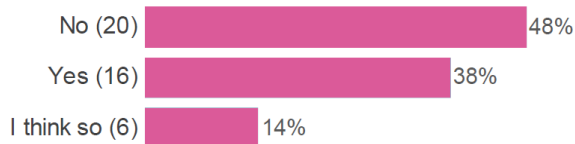


Virtual Voices Response

Do you know how to spot the signs of Long COVID?



Do you know where to access support/ treatment for Long COVID?



Do you feel there is enough information around about Long Covid?



Is there anything you would like to add?

"More understanding and training need to be done for long term effects and treatment. More support and information need to be made available".

"There are support groups in Warrington for Long Covid, but they don't get enough publicity, it would be good to see these promoted more within the town so people knew how to access them".

"Long Covid reported signs are so wide and in danger of being all encompassing. As a result, it is not possible for anyone to definitely say that they know the signs".

"Doctors need to have a better understanding and be more supportive. There is a need for a clearer pathway for those at the start of their journey".

"The impact of Long Covid can vary in longevity and I've not seen much info on the signs to look out for. Most people are treating Covid as a mild condition now that does cause significant harm and are considering Long Covid as a post viral complication".

"I feel there is a need for more information regarding Long Covid. GPs need more information/education on the effects of Long Covid and your survey has shown me that I need to be more informed!"

"There needs to be more community awareness and understanding of Long Covid, and more support for employers to support staff whose health has been negatively affected by it".

"I am a nurse so know the signs, but most don't know".

"There are so many people suffering and are not aware of the various & different side effects".

"Tinnitus/brain fog are also signing people don't know about, there should be more info and it's not just breathing issues".

Conclusion

Long Covid appears in some cases to have been shrouded in mystery as people are suffering a wide range of symptoms and they can often struggle to understand the cause, care and treatment for this condition.

The definition of Long Covid includes symptoms that could develop within the initial infection stage and then continue beyond a 12-week period. There are over 200 documented symptoms, the most common being fatigue, breathlessness, fast heart rate, palpitations, chest pain, brain-fog, lack of concentration, as well as muscle aches and pains.

Healthwatch Warrington will share this report at board level at Warrington Place.

Recommendations

Recommendations made from the findings

1

To keep the Long-Term Covid Support Group in place at Warrington Disability Partnership. This provides invaluable peer support from a non-clinical viewpoint.

2

To ensure that the Long Covid Support Service at Warrington Hospital continues to help support people living with Long Covid. We envisage that this will be an ongoing piece of work.

3

That all PCNs are signposting to peer support via their social subscribers. That PCNs are aware of and are referring to the Long Covid Support Service at Warrington Hospital when appropriate.

With Thanks

With thanks

To the patients that shared their experiences
Warrington Disability Partnership Long Covid Support Group.
Warrington Virtual Voices.
Long Covid Support Service, Warrington Hospital.

Healthwatch Warrington
The Gateway Warrington
Sankey Street
Warrington
WA1 1SR

www.healthwatchwarrington.co.uk

t: 01925 246 893

e: contact@healthwatchwarrington.co.uk

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