

What people have told us about living with long COVID and other post viral illness

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About us

A little information about Healthwatch Suffolk, and how we work with the Suffolk and North East Essex Integrated Care System.



We are your health and social care champion.

If you use health services, or need social care, we want to learn about your experiences. We make sure NHS and social care leaders consider your feedback, and improve standards of care. We can also help you to find information and advice about local services and support.



For more information about us, or to feedback about your local services, please visit our website (www.healthwatchsuffolk.co.uk).

Our role as an independent partner in the Suffolk and North East Essex Integrated Care System (SNEE ICS)

Our relationship with the ICS has been underpinned by a Memorandum of Understanding (MOU) based on principles that we are independent, and equal partners in the ICS, and that we are lead partners for engagement and co-production.

This report forms a part of the work our SNEE ICS Engagement Officers (funded by the SNEE ICS) complete to shape and inform the development of health and care strategies and services within SNEE. We work together with Healthwatch Essex to cover the whole of the ICS footprint.

Our team completes time-limited focussed engagement on specific topics of interest to the ICS. Our data is shared with relevant leaders, commissioners and providers, Public Health Suffolk and also Waveney Primary Care Networks where relevant.

This report is about people's experiences of living with long COVID and other post viral illnesses.

We want everyone to be a part of our work

This is our inclusivity statement:



Our differences are not always visible, and we embrace them all with respect and kindness. Healthwatch Suffolk wants everybody to feel equally valued, listened to, seen and heard.



Developed in co-production, it is our promise to include everybody in our work. They're not just words – we take them seriously, in all aspects of what we do. Learn more about how we strive to be inclusive: www.healthwatchsuffolk.co.uk/inclusivity

The survey

We asked people to share their lived experiences of long COVID and other post viral illness. Learn more about the background to this project, and explore our key findings.



Introduction

Following the pandemic, there are an emerging number of people experiencing symptoms associated with the COVID-19 virus long after the estimated twelve-week recovery period.

Symptoms of long COVID vary in type and severity, and they can have a huge impact on physical and mental wellbeing. As well as long COVID, there are many people who are experiencing other post viral illnesses, or post viral fatigue syndrome, which impact on their daily life.

Healthwatch Suffolk and Suffolk and North East Essex Integrated Care System (SNEE ICS) are interested in finding out from the people in Suffolk who have experience of long COVID or other post viral illnesses, how they have managed their condition, and what support and treatment they have received during the period of the pandemic.

The results from this feedback will be shared with the SNEE ICS. Responses from Waveney residents will be shared with Waveney primary care networks. This information will help health and care leaders to assess the long-term impact of the pandemic on people's health and wellbeing. It may also provide an indication of people's need for health services in the future.

Participation was completely voluntary, and responses are anonymous. This feedback report is based on 53 responses from those living in Suffolk.

Question 1

We asked respondents if they were

Table 1: The location of respondents.

Locality	Respondents
Babergh	6
East Suffolk	17
Ipswich	11
Mid Suffolk	7
West Suffolk	12

giving feedback about long COVID only, sharing lived experience of any other post viral illness (e.g., ME/chronic fatigue syndrome), or both.

Of the 53 respondents who answered this question, 37 were answering about long COVID only, six were commenting about living with post viral illness only, and nine were living with both long COVID and another post viral illness.

Question 2

We asked if respondents had been formally diagnosed as having long COVID.

Seventeen respondents confirmed that they had received a diagnosis from a medical professional, and 29 said that they had not received a professional diagnosis but that they had symptoms of long COVID. Seven respondents did not reply to the question.

Question 3

The 17 respondents who had been diagnosed with long COVID were asked

to give the month and year they were diagnosed. Two of the 15 who responded were diagnosed in May and September 2020; 12 between January and October 2021, and one person in February 2022.

Diagnosed	Respondents
May 2020	1
September 2020	1
January 2021	3
February 2021	1
March 2021	2
April 2021	2
June 2021	1
October 2021	3
February 2022	1
Total	15

Table 2: The month and year that people received their diagnosis of long COVID (15 respondents).

Question 4

We asked respondents to identify how long after developing COVID symptoms they waited to contact their GP about long COVID. It should be noted that not all those who contacted their doctor may have received a diagnosis that they had long COVID.

Most people waited less than three months (11 respondents). Six people waited between three months and six months, and one person said they did not know.

Question 5

We asked respondents if they had been referred to the SNELCAS service (Suffolk and North Essex Long COVID Assessment Service).

Seventeen people responded to the question, and ten confirmed that they had been referred to SNELCAS. Seven respondents had not been referred.

Question 6

Of those who had been referred to the SNELCAS service, eight respondents commented on their experience of using the service. Their experiences were mixed.

Amongst the issues raised were:

- Long waits for referrals.
- Lack of referrals to specialists or services.
- Distance made travel to the service difficult.
- Poor communication between professionals, and between SNELCAS and GP practices.
- The length of appointments had been tiring.
- Lack of continuity of care within primary care.
- Difficulty in obtaining a referral to SNELCAS in the first place.

Positive aspects were:

- Thorough examinations.
- Some people were positive about access to the SNELCAS service.



"A good service as far as access. I didn't have to wait too long, they always called back when they said they would. I was a first wave and they were very much learning as we went along! They didn't arrange any appointments for me with specialists, so I paid for this privately as was quite unwell, it transpires that they saved my letters sent to my doctor requesting urgent referrals in an area of EMIS that the GP didn't even know existed! (surveys section).

"I found it really useful to have someone to talk to as I had been gaslighted throughout the first six months by primary healthcare not knowing what to do with me etc. I would've liked the opportunity to have had consultants do a quick webinar about loss of taste and smell and how to manage orthostatic intolerance and fatigue etc."



- Call backs were arranged as promised by the service.

One person commented:

"I was referred April 2021 and seen at the clinic beginning of October 2021. Due to my symptoms I am not driving longer distances therefore I had to ask my husband to take an AL day from work to drive me to the face to face appointment which was 27 miles from my home. There was no parking available, so my husband was unable to come into the appointment with me as he needed to stay in the car.

"The appointment lasted over three hours and although I was very grateful for the time spent by the consultant gathering information, I felt that the time was far too long for one appointment which left me feeling completely shattered over the following days. I have since been referred to

various disciplines on the back of the long COVID assessment, some of which are still pending.

"A very detailed report was sent to my GP surgery. However, I have no named GP and therefore I have had to discuss the contents with various GPs when I have requested a call... Unfortunately, I feel that there has been little communication between the assessment clinic and the surgery which has impacted on the progression of onward referrals."

Another said:

"Had to fight to get referral to SNELCAS, as originally had negative test. Even when referral was submitted by GP, another GP called to warn that my referral was likely to be declined by SNELCAS even though no evidence of this.

"Appointment had already been received, so when I attended the appointment, I was anxious about being turned away. I found the app useful but on the whole feel misunderstood that SNELCAS is actually an ongoing referral service to other specialist services. The regular questionnaires aren't helping me, as just show me how I'm not improving and at times declining.

"It feels like I'm there to provide data only. On bad days when my scores are low or my symptoms are worse, maybe people would welcome a wellbeing call."

Question 7

We asked respondents why they had made the decision not to make contact with their GP about their long COVID symptoms at this point in time.

Eight respondents commented on the non-availability of, and difficulty in making, doctors' appointments.

"Too much effort to get an appointment."

"Too much effort and energy to get a face to face appointment."

Three respondents commented that the NHS was very busy.

".... I could and still do cope without recourse to busy NHS resources."

Two respondents commented that nothing much would be done about it.

"Nothing will be done about it."

And one respondent felt there could be no treatment for their symptoms.

"No treatment for loss of taste or smell, ongoing cough."

Two respondents commented that long COVID was not recognised when they first began to suffer from it.

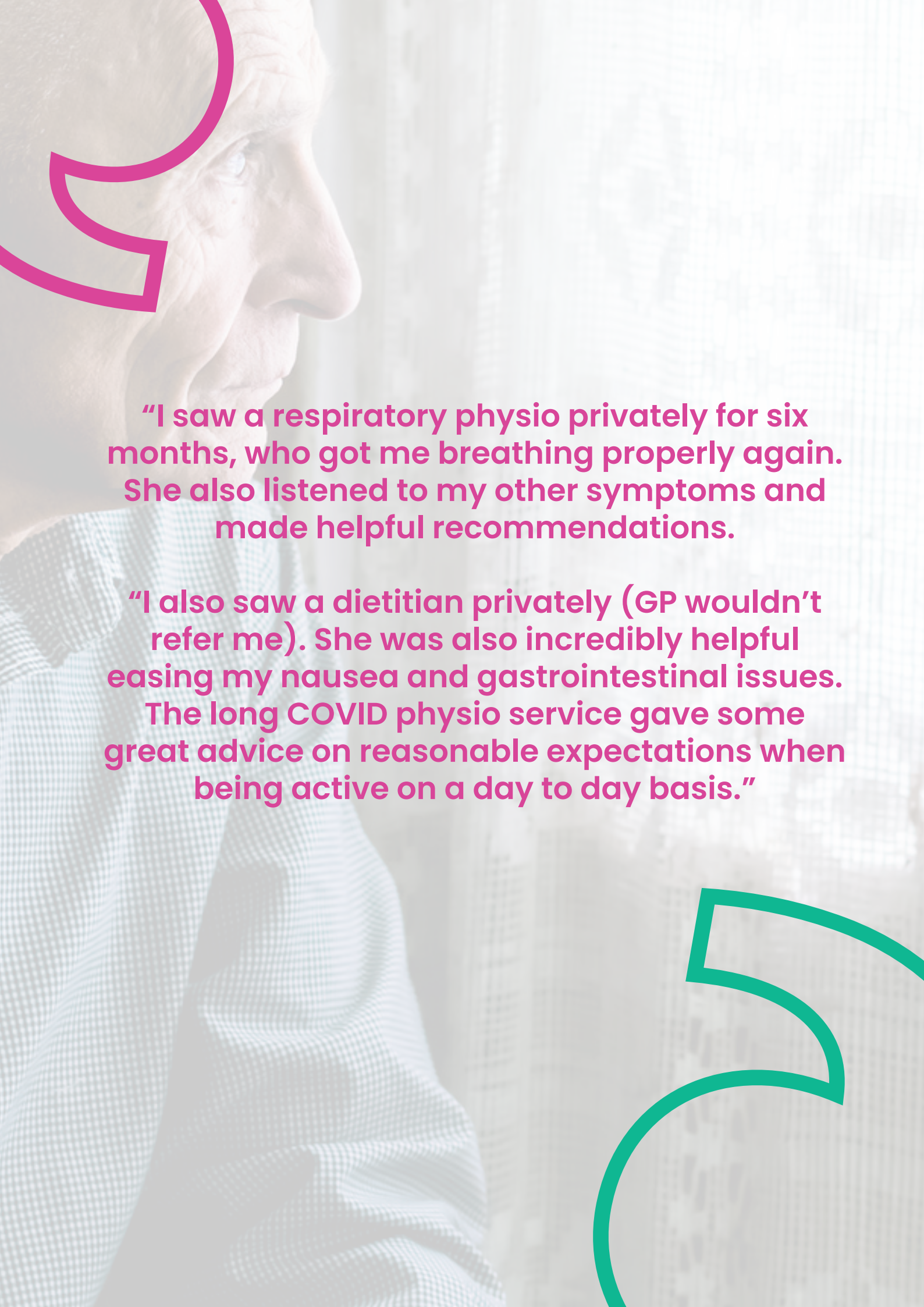
"I did contact GP but before long COVID well recognised. I am married to a consultant who deals with many patients with long COVID and I am managing symptoms myself - I'm not sure medicalisation will help at this point."

One respondent was waiting for an advised 12-week period to pass for their child.

"This is for my 7-year-old son who I believe is or will have long COVID, he has had symptoms for eight weeks after his positive test. The doctor has said until it's 12 weeks he will not refer him to the hospital for any tests."

Symptoms similar to menopause:

"I have mentioned it to my doctor but issues quite similar to menopause which I am struggling with."



"I saw a respiratory physio privately for six months, who got me breathing properly again. She also listened to my other symptoms and made helpful recommendations.

"I also saw a dietitian privately (GP wouldn't refer me). She was also incredibly helpful easing my nausea and gastrointestinal issues. The long COVID physio service gave some great advice on reasonable expectations when being active on a day to day basis."





"No outside support. I have just talked to my sister and try to find out which of my issues are menopause, or if it is long COVID."



Question 8

We asked people what support, if any, had helped them to live with long COVID. Twenty-five respondents replied positively, stating from where they had received support.

Eleven respondents commented about support from family, friends and work.

"A helpful family."

"Reduced working hours, support from my family."

Eight said their GP, mental health nurse and other health professionals had supported them. Their comments included:

"Support from Norfolk long COVID assessment team. Support from GP, support from occupational health mental health Nurse."

"I saw a respiratory physio privately for six months, who got me breathing properly again. She also listened to my other symptoms and made helpful recommendations. I also saw a dietitian privately (GP wouldn't refer me). She was also incredibly helpful easing my nausea and gastrointestinal issues. The long COVID physio service gave some great advice on reasonable expectations when being active on a day to day basis."

Four respondents had received support from several people and organisations. Their comments included:

"Long COVID groups (fellow long COVID individuals), Sympathetic listeners (GPs, Specialists including mental health input, friends, family and work)."

"Cardiology; occupational health; Gilmour Piper Long COVID Clinic; family and friends."

Three respondents had carried out research on the internet:

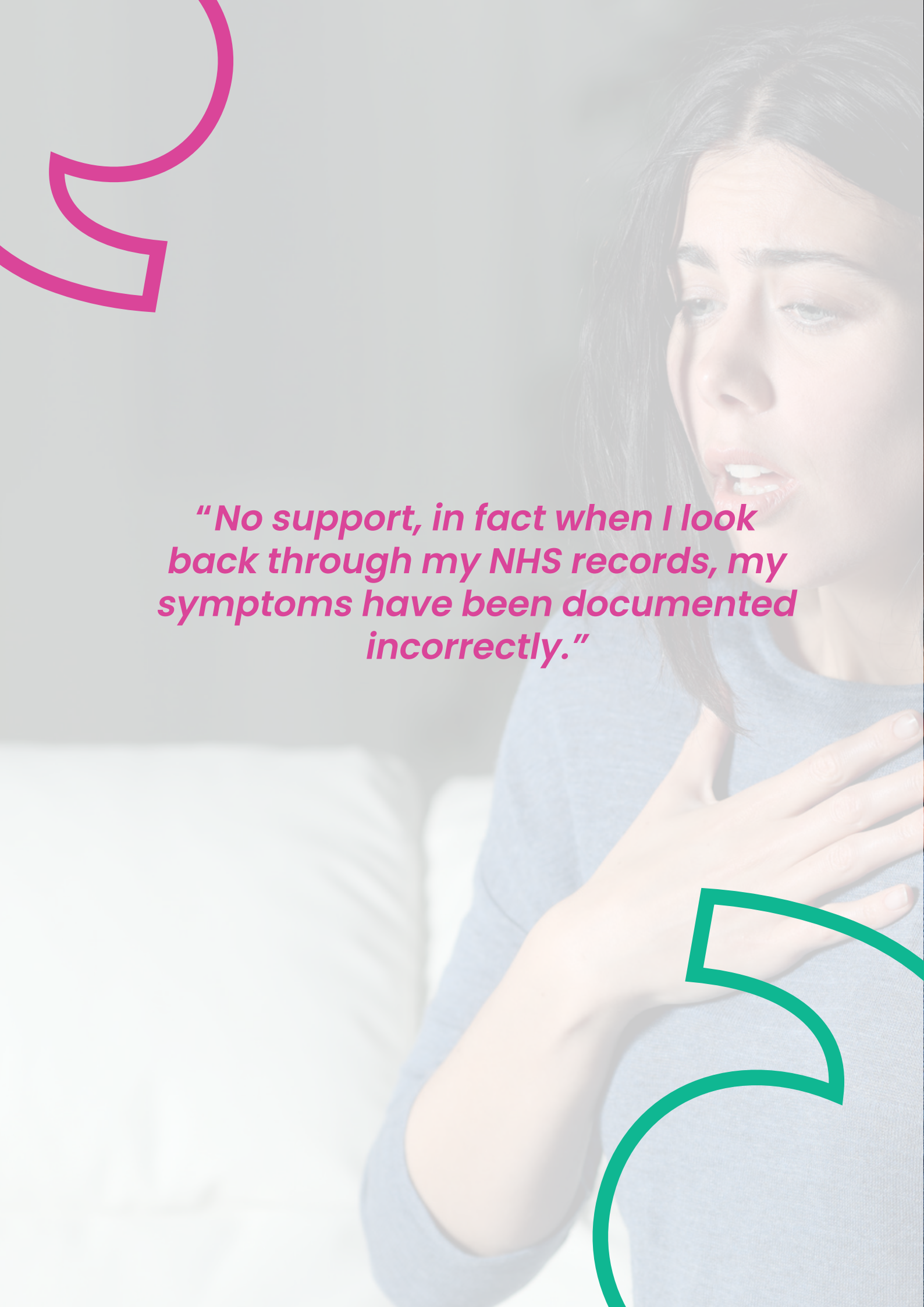
"Information on resting lots and pacing found through Facebook groups and the internet while on the waiting list for things."

Two people felt exercise, such as gym, yoga, and breathing exercises, had helped them.

"Joining gym and yoga."

Sixteen respondents had received no support at all, with nine of these answering 'none'. Others commented:

"None as I've not been offered any. I'm still fighting for PIP, and am awaiting tribunal date."



"No support, in fact when I look back through my NHS records, my symptoms have been documented incorrectly."

Post viral illness

Question 9

The second part of the survey, from question nine, asked respondents if they would also like to give feedback about a post viral illness.

Eleven respondents stated that they would like to respond. However, 17 responses were given to question Q10.

Question 10

We asked if respondents had been formally diagnosed as having a post viral illness, such as ME/chronic fatigue syndrome (ME/CFS).

Seventeen responses were given. Nine people had been formally diagnosed as having a post viral illness. Eight respondents had not been formally diagnosed as having a post viral illness by a medical professional, but felt they had symptoms of ME or chronic fatigue syndrome.

Question 11

We asked when respondents were diagnosed as having a post viral illness, such as ME/CFS. Only eight responses were given.

Diagnosed	Respondents
March 1991	1
April 1998	1
2001	1

March 2007	1
August 2008	1
July 2015	1
January 2020/21	1
September 2021	1
Total	8

Table 3: The month and year that people received their diagnosis of post viral illness.

Question 12

We asked how long after developing ME/CFS symptoms respondents waited to contact their GP. Nine responses were received.

How long did you wait to contact your GP	Respondents
Less than three months	4
3 - 6 months	1
6 - 12 months	2
Over a year	1
I don't know	1
Total	9

Table 4: The length of time respondents waited to contacted their GP about post viral illness symptoms.

Question 13

We asked if respondents had ever been referred to the ME/CFS service. Seven respondents reported that they had been referred, and two had not.

Question 14

There was a mixed response to question 14, which asked about people's experiences of using the ME/CFS service.

We asked how quickly respondents were able to access the service, how easy it was to access, what had been helpful, and if anything could have been improved.

Three respondents were very positive about their treatment and comments included:

"I was contacted after having no support whatsoever by a London GP Specialist in ME/CFS. He invited me to an appointment with him in Ipswich. I found him to be the most helpful holistically aware acknowledging and treating me with great compassion and understanding."

"My GP referred me after other investigations/tests came back negative. The ME service was very good at getting in touch and they had a satellite appointment very close to my home. The ME doctor did her assessment and was very thorough."

Two respondents said advice about how to pace themselves had been helpful:

"Great at the time. Helpful to plan days

and pace myself."

"After diagnosis, the appointments were with an OT about how to pace myself and generally manage living and working with ME."

The person who was diagnosed in September 2021 is still waiting to hear from the service.

Three responses were less positive about the ME/CFS service. Their comments included:

"Quick access. Not helpful at all, no help in claiming PIP or any practical support."

"It seems a waste of time and simply a tick box exercise for collecting statistics."

"It took three years to be seen by the ME specialist at hospital and he was able to confirm my GPs diagnosis but unable to give any follow-up appointments as he was so booked up with appointments... He was also about to retire and said there was no one to take over from him. He did refer me to his specialist physiotherapist clinic which I attended for over a year. It was very helpful but again my appointments stopped through lack of availability."



"My GP referred me after other investigations/tests came back negative. The ME service was very good at getting in touch and they had a satellite appointment very close to my home. The ME doctor did her assessment and was very thorough."



One respondent mentioned the ongoing stigma connected to ME.

"It is the stigma attached to ME that I struggle with and tend not to talk about it to others. I am sorry there is such a thing as long COVID but I hope it helps people to understand that ME is no different and it is REAL."

Question 15

We asked why respondents had chosen not to make contact with their GP, at this point in time, about their post viral symptoms. Seven people responded.

Four respondents said it had been too difficult to obtain an appointment with their GP.

"...too much hassle."

"GP difficult if not impossible to get hold of."

One respondent said they:

"...didn't get the impression that there was anything they could do about it."

Three respondents had received treatment.

"I have seen the rheumatologist which is when I was diagnosed. I've lived with it for years just didn't know I had fibromyalgia."

Question 16

We asked what support, if any, had helped respondents to manage/live with ME/CFS. There were fourteen responses to the question.

Three respondents said that learning to pace themselves had helped.

"I have learnt to pace myself because of the information provided by the OT at the ME Clinic."

Two respondents said medication was helping them.

"I take medication and have help daily with getting dressed cooking bathing and daily living as I struggle with this daily."

Family support was quoted by two respondents.

"Just my husband."

Two respondents commented that they had support from workplaces.

"I have learnt how to achieve a work/life balance and cope with it well."

"Working from home/hybrid."

Two respondents were supported by carers.

"ME support groups and my long personal carer who knows how to support me and does far more than I can afford to pay her for."

One respondent said their faith had helped them.

"My faith, a prayer, WhatsApp group and a few friends to communicate with. My understanding myself and being kind to myself."

Two respondents had not received any support.

"No support at all. I'm seriously struggling, exhausted and depressed."

"Haven't had any. Am having to look online for guidance."

One respondent simply answered with 'nothing'.



Summary

A short summary about our survey findings.



Although small in number, the feedback from respondents to this survey provides an indication to show what is working and what issues need addressing for those with long COVID and post viral illnesses.

The problems arising from long COVID are still being studied, and as research results are examined, treatments are being found that appear to be effective. But as can be seen from the feedback received, treatment is not always consistent and difficult to access.

Problems arise from:

- Difficulties with accessing doctors and being referred to experts who may be in short supply can be an impediment to receiving appropriate treatment.
- Some medical professionals have little understanding of, or sympathy with, those with long COVID and post viral illnesses.
- The treatment for the physical and medical symptoms of long COVID and post viral illnesses is an ongoing research project, and the symptoms are varied and unique to the individual. This can make treatment complex.

Positive aspects of care can be seen from:

- Support from family and friends as this is crucial to the mental and physical progress of the person with long COVID or post viral illness.
- The role of occupational therapists providing advice and support.
- The recommendation to pace oneself and rest.
- The use of the internet to get information and advice.

- Support from online groups of others with long COVID and post viral illnesses

It is apparent from the responses to this feedback request that we are still discovering the effects that long COVID, and other post viral illnesses, have on physical and mental health. There is however an awareness of the actions and people that have helped and supported those with these conditions.

These included:

- Prompt referral to long COVID clinics.
- Support from those medical experts who can give accurate and helpful advice.
- Ongoing medical tests to assist in appropriate treatment.
- Practical help from people around them.
- Medical interventions (e.g., inhalers, pain killers).
- Advice about self-care (e.g., diet, exercise, rest).
- Support from family and friends is crucial.
- Support from workplaces in organising time off work and gradual return.
- More support groups.
- Easier access to accurate information and advice online and in print.

We will be making this report publicly available by publishing it on our website.

We confirm that we are using the Healthwatch Trademark (which covers the logo and Healthwatch brand) when undertaking work on our statutory activities as covered by the licence agreement.

If you require this report in an alternative format, or language, please contact us on 01449 703949 or by email to info@healthwatchsuffolk.co.uk

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Contact us

Email: info@healthwatchsuffolk.co.uk
Tel: 01449 703949

Healthwatch Suffolk CIC
Office Poonsook
Main Road
Little Blakenham
Ipswich
Suffolk
IP8 4NF

Explore our work on: www.healthwatchsuffolk.co.uk