

Five patients tell us how their lives have changed since having Covid



March 2021

Thousands of people in Medway have had Covid since the start of the pandemic one year ago.

In this report you will hear from five people who had Covid months ago. They tell us what it was like at the time, what support they got and how Covid has changed their lives up to a year later.

They wanted to share their story and their ideas for what could be done to help others.

The emotional impact of being diagnosed

People dealt with their initial diagnosis very individually depending on their character and what support they had around them.

- “Initially I thought, ok I have it, I’ll weather it out.”
- “I was so busy being ill and feeling so dreadful, I didn’t really have time to think.”
- “All I knew about was people going into hospital with Covid and not coming out. I was very panicked.”
- “I’m a nurse but I felt so ill, I was terrified.”
- “It’s been a complete emotional rollercoaster”
- “Really frightening.”

Medical care varied

None of the people we spoke to had been hospitalised with Covid but all sought medical support. Their experience of medical care varied.

- “Luckily my GP surgery has been on the mark. My experienced GP has been amazing.”
- “Getting hold of my GP is like pulling teeth. I did eventually manage to get strong painkillers but that was it.”
- “I had to go to the huge Covid tent at the hospital for tests. It was really scary. They told me to go home and deal with it.”
- “The hospital had a service where they rang you every couple of days.”
- “I phoned 111 but as I could lie down and talk, they told me to stay at home. They phoned me once or twice a day for three weeks. After three weeks they sent me to the hospital for tests.”
- “I called the paramedics out of sheer terror, but they said my lung function wasn’t bad enough to go to hospital.”
- “I’m waiting for a referral to a neurologist.”

Still struggling with the physical long term after effects

Everyone we spoke to was still dealing with significant life changing symptoms which has affected their day to day lives, even those who had Covid a year ago.

- “I feel like I have a physical disability.”
- “Three months on and I am no better. The only difference is I don’t have a temperature anymore and my smell has returned. But I feel just as ill.”
- “Three months on and I can’t even bend over without being breathless. I feel useless. I can’t do anything.”
- “My sense of smell hasn’t returned although my taste is nearly back.”
- “One year on, the brain fog is awful and I still have bad chest pains. My legs are wobbly and I am exhausted.”
- “One year on and I still can’t walk around. I have a headache constantly and my temperature is up and down. Some days I can taste, other days I can’t.”
- “I’m dizzy, feel sick all the time. I’ve got digestive issues, hair loss and even getting dressed leaves me feeling totally exhausted.”
- “12 weeks on and I still can’t do the most menial tasks.”
- “Covid has completely changed my life. I am 48 and I am broken.”
- “Four months on and I still can’t concentrate on anything. I can’t read a book, or a long email. Working on the computer is impossible.”
- “The brain fog is terrible. Played monopoly at Christmas and realised I couldn’t count. This makes me feel scared.”



Impact on their mental health

All our participants talked at length about the effect on their mental health. The ongoing physical issues had clearly had an impact on their mental health.

- “I’ve had suicidal thoughts.”
- “My husband and I have talked about divorcing, it’s been so hard.”
- “It’s had a huge impact on my family. They don’t understand how I feel.”
- “I had a honeymoon period when you think you’ve recovered, only to feel rock bottom again when the symptoms return.”
- “I did try and get counselling through the NHS (I am a nurse) but at that time I just needed to get back to work and help.”
- “The way the hospital consultant spoke to me, just made my depression worse.”
- “I thought I was the only one suffering like this.”
- “I feel guilty that I’m not looking after my family like I used to.”
- “I am still suffering from mental health issues, one year down the line. It’s made worse because I have been isolating since March last year so I have no real world experience.”
- “My mental ability to accept things is bad.”
- “I am normally an upbeat person but I am really struggling to hold it together.”
- “I have totally lost my confidence.”
- “I just feel so alone. It is a very lonely illness.”
- “I have no life. Life is on hold.”
- “I am a prisoner in my own body.”

Support from GPs varies

Everyone had tried to contact their GP for support. People had very different experiences even though some were with the same GP surgery.

- “My GP has been amazing, I am very lucky. They phone me once a fortnight but they don’t really know how to help me.”
- “I have a totally amazing GP. They send me articles about Covid.”
- “Really hard to get through to the GP surgery. I feel I had to fight for an X-ray and bloods.”
- “I really struggled to get a GP appt and they didn’t have a clue. They just labelled it as Long Covid and left me to it.”
- “The surgery has made me feel like I am trouble because I ring asking for help.”
- “I waited all day for the GP to ring and then I missed it when I went to the toilet so I had to start all over again.”

Communication from the hospital

Not all our participants had used hospital services, but some told us they'd had issues not hearing back.

- “I had an X-ray and bloods done at the hospital 10 days ago but not heard anything.”
- “I had some hospital appointments but I was too ill so I had to cancel. They rang to tell me off.”
- “The hospital consultant I saw made my depression much worse. They told me I couldn't have Long Covid because I hadn't been hospitalised.”
- “I was told that all the respiratory consultants at the hospital were off sick with Covid and then they stopped all appointments. So I had to pay to go private. I don't have the money but that's what I had to do.”

What would help you now?

All of our participants felt that more support would help them, especially to make them feel less lonely and isolated. Better medical support was also a priority.

- “I just want to know what's going on with my chest and have a treatment that works.”
- “I just want to feel better”
- “Other places have Long Covid Clinics which sound brilliant.”
- “A one stop shop where we can get our bloods done, X-rays, breathing specialist, counsellor etc. All the support we need in one place. Like an MOT centre with places that you could rest in between. Getting dressed is exhausting, going to hospital appointments is huge.”
- “Emotional support for families and partners to help them understand. They are caring for us and they need help.”
- “A Kent & Medway Helpline”
- “Definitely a Long Covid Clinic where you could get everything you need with specialist knowledge.”
- “I just want to be taken seriously and get support. It's like they don't believe you and you have to push to get help.”
- “A call from my GP would go a long way, even just someone to ask how I am.”
- “Could we get on the vulnerable list so that we can get shopping delivered?”
- “If GPs would recognise and diagnose Long Covid, it would help people to get PIP. We can't work in this condition.”
- “A blue badge would be really useful, just for the time being. I can't park and walk to the bank or the pharmacy.”

Thoughts for the future

No-one we spoke to felt particularly hopeful for the future.

- “I am now frightened that I won’t be able to do my job again. I feel like a different person.”
- “I have to take every day as it comes and feel blessed for each moment.”
- “I’m worried I’m going to lose my job.”
- “If I could get my symptoms under control then I could manage, even if it’s chronic.”
- “Will I ever be able to get back to work?”
- “It has made me realise how mortal I am.”

How did we go about it?

We spoke to five people in total, two of whom had Covid a year ago. We brought people together for a small online conversation, however two people were too unwell to join the group so we spoke to them individually.

We really appreciated the openness and honesty from everyone involved. We know some of you found it hard to talk about the reality of your situation. Thank you

What happens now?

All the feedback we have heard will be shared directly with decision makers so that they can understand what it’s like for people with Long Covid.

These stories will help the NHS and social care to plan services for people with Long Covid across Medway and Kent.



A bit about us!

Healthwatch Medway is the independent voice for local people in Medway.

We gather and represent people's views about any health and social care service in Medway.

Our role is to understand what matters most to people and to use that information to influence providers and commissioners to change the way services are designed and developed.

Our **FREE** Information and Signposting service can help you navigate Medway's complicated health and social care system to ensure you can find and access the services that are available for you. Call us on **0800 136 656** or email enquiries@healthwatchmedway.com

Have you had Covid? Do these stories resonate with you?

Tell us your story and we can make sure your voice is heard by the right people.

Get in touch [HERE](#)

Or call us for free on **0808 136 656** or email enquiries@healthwatchmedway.com

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