

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC10: Ymateb gan: | Response from: Gareth Evans

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1. I'd like to contribute to the upcoming consultation on supporting people with chronic conditions. My name is Gareth Evans. I am over 18 years old and speak as an individual about my own personal experience with Long Covid. I give my consent for you to share my details.
2. At the time of lockdown in March 2020, I was 42 with no underlying health issues and was living by myself in a flat in Cardiff Bay. I have always been very active and was in training for a triathlon immediately prior to falling ill. In April 2020, despite taking the necessary precautions, I developed a fever, fatigue, ear pain, POTS, sleep apnoea, brain fog and shortness of breath among many other terrifying symptoms. Although I was not initially hospitalised, I did require help from the 999 emergency response team. At that point in time, PCR tests were not available to the general public. A PCR test from a private company bought three weeks after initial infection revealed I was negative however my symptoms continued.
3. In the months that followed, my health worsened. I was in contact with my local GP on a weekly basis. However, as I did not present a cough and could not provide a positive PCR test, my GP was of the opinion that I did not have Covid. I was referred for blood tests and X-rays but, due to the strain on the NHS at that time, I had to wait some time until I was eventually tested. When my tests did come back, they were found to be normal. During this time, I had great difficulty in taking care of myself. I cannot stress how debilitating Long Covid is. I could barely summon the mental or physical energy to cook meals or watch TV let alone work, exercise or attend doctor's appointments.
4. Having taken sick leave from work, I was admitted to Llandough Hospital in June 2020 where I was given more blood tests, X-rays and CT scans that, once more, came back normal. While I was there, I raised with the doctors the reports I had seen in the media about some patients who were experiencing a prolonged recovery from what was termed 'Long Covid'. One consultant referred to those reports as 'complete rubbish'. Despite my protests, they diagnosed me with anxiety and depression. I was subsequently discharged and prescribed anti-depressants. Again, I was in touch with my GP who referred me to the local mental health team. In my consultation with the team, I reiterated the fact that my anxiety was caused by ongoing physical symptoms. Upon hearing this, they referred me back to my GP.
5. In my conversations with him, the continuing issue I had was the multitude of symptoms I was experiencing. My GP only felt inclined to deal with one issue at a time. Once we had ruled out a cause, I could be referred to another consultant. These appointments were arranged months in advance. I had no choice but revert to private healthcare at great personal cost to seek their advice.
6. When travel restrictions were relaxed in July 2020, I moved into my elderly parents' home in Cwmbran in order that they could look after me. Not only did my symptoms continue, I developed new worrying symptoms including insomnia, body tremors, speech problems, tinnitus and hair loss. I tried to access the local health services here in the Aneurin Bevan Health Board and even admitted myself to the Emergency

Department at the Royal Gwent Hospital, but given that (at the time) I was still permanently resident in another health board, they could not refer me for further investigations.

7. As you can imagine, these events took an enormous toll on my mental health. Experiencing worrying symptoms with seemingly little help, I began to wonder if I would ever recover. In October 2020, having convinced myself I was consigned to a life of chronic illness at best, I attempted to take my own life. As a result, I was sectioned and admitted to a mental health ward in Talygarn Hospital for a month. It was while resident there that I caught Covid-19 a second time. My lower leg became painful and swollen and another visit to the local GP confirmed I had developed a blood clot. Another subsequent blood clot has meant I'm now deemed high risk and I need to take blood thinners for the long term.
8. In the last 3 years, I'm glad to say that my health has steadily improved and I'm now back at work and have resumed exercise albeit on a reduced scale. However, the events of the last three years will stay with me for years to come.
9. Long Covid has drawn parallels to the chronic illness Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS) for which there is little in the way of understanding and available support here in Wales. Rather worryingly, some Long Covid patients are being prescribed Graded Exercise Therapy (GET) which can potentially serve to make their conditions worse. With this in mind, I would like to reiterate my assertion that specialist clinics for Long Covid are the best option for those suffering from this terrible illness. It seems clear to me that patients would benefit from being able to access multi-disciplinary treatments in one location without having to wait months at a time being referred for consecutive appointments. I've gone to the trouble of counting how many Doctor's appointments I've had to attend in those 3 years (outside of my stays in hospital). At the moment (May 2023), the number of appointments stands at 125. Furthermore, patients and medical practitioners alike could benefit from the collective knowledge and experience of those who have been directly affected to arrive at a consensus on how to best treat Long Covid.
10. I do hope that you take my comments on board. My only wish is to prevent others from having to go through the enormous strain and uncertainty that I did. If I can be of any more assistance, please don't hesitate to get in touch.
11. Kind Regards,

Gareth Evans

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