

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](#).

CC67: Ymateb gan: | Response from: Unigolyn | An Individual



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I confirm that I'm over 18 years of age. I'm submitting this as an individual. I don't wish my name to be published.

I'm an individual who has been ill with long covid for over 3 years now. Long Covid has triggered in me (or made worse) MCAS (Mast Cell Activation Syndrome) which I had to pay privately to get diagnosed. I also believe I'm now suffering from ME/CFS (as a result of having covid) but my GP has been unable to refer me for diagnosis – referrals to Rheumatology and Neurology were both refused on the grounds that symptoms are very similar to long Covid and there is no treatment (on NHS) for either condition. If I want a diagnosis for ME/CFS I will now have to go private for that too.

I had to stop working completely in 2020 and concentrate on trying to get better.

I now source my own treatments and pay out of my own pocket for them as this allows me to work part-time which I would otherwise be unable to do. These treatments cost me upwards of two thousand pounds per year and are not available on the NHS. This is a big burden to someone only able to work part-time due to limited energy.

In addition, I have been recently diagnosed as Autistic (referred by GP on my own request). Lifelong issues with communication and relationships became worse due to Long Covid and this prompted me to

ask for an assessment. I only waited 10 months for the Autism Assessment which was much less of a wait than expected.

The pre-screening process was quite laborious as I got given the same forms twice to fill out by GP practice and then two further sets of forms were sent by the Autism service. I later found out the GP practice sent the wrong (outdated) forms (which I filled in twice). This was very off-putting as the tone of questions on the outdated forms was very unpleasant and I almost cancelled the referral as a result, as the forms led me to think the assessment would be as hostile as the tone of the questions on the form.

I found the Integrated Autism Service (based in Merthyr Tydfil/Mountain Ash) to be very good, it's clear that staff there are very committed and work very hard. I have had to re-refer back into the service for some post diagnosis support (which I think is very needed for all late diagnosed adults as we have been left to manage on our own our whole lives until diagnosis, not understanding why we have struggled). It comes as a shock to discover that you aren't hopeless/inadequate/useless or whatever in some areas and that in fact you have been doing your best with a brain that works differently to most people's.

Being automatically discharged from the service after diagnosis and having to re-refer back in for post diagnosis support causes a delay of a few months and a quicker process would be much better. Having said that I'm very grateful for what is on offer which is much better than in some parts of the UK as far as I'm aware.

At the same time as requesting an Autism Assessment (in 2022) I also requested a referral for an ADHD assessment, but this was blocked by my GP who showed very little understanding of either condition.

A year later and after the Autism diagnosis I asked again for an ADHD referral (a different GP this time) and the referral was made. I was told I

will have to undergo a full mental health assessment whether I feel I need one or not, which seems unnecessary (and a waste of resources) as I'm not suffering from mental health issues – I believe I've got ADHD in addition to being Autistic (these two conditions are commonly found together).

I'm annoyed at having waited a year to get the referral due to the first GP ignoring my request.

In case you're wondering why I would need a diagnosis at this point in my life, I can tell you that the self-knowledge and self-acceptance that a diagnosis brings is very empowering and it allows you to look back on your life to date through a new lens, with added awareness of your strengths and struggles. Everyone is entitled to know who they are so these diagnoses need to be prioritised for the lost generations (especially women) who were not diagnosed as children and have never had any help or support.

NHS and social care services

- The readiness of local NHS and social care services to treat people with chronic conditions within the community.

Personally, I would be happy to travel out of area to receive appropriate and helpful treatment, in fact I already do this to access private treatment as NHS Wales is not offering any appropriate treatment for Long Covid triggered illnesses such as MCAS (Mast Cell Activation Syndrome) or ME/CFS. So I have to fund travel (100 miles per week) as well as the cost of the treatment)

Any appropriate treatment would be welcome as currently in my area all that's on offer is exercise-based rehab. I'm not well enough for rehab, I need treatment first. You wouldn't send someone with a broken leg for

rehab – you would treat the broken leg first to get the person well enough for rehab.

Updated Nice Guidelines state that rehab/ graded exercise is not suitable for anyone suffering with Post Exertional Malaise (as it can make people worse) and yet rehab/graded exercise is all I have been offered despite suffering from Post Exertional Malaise. This is an issue within the NHS where education is needed to address the culture of exercise programmes and psychology being offered for post viral type illnesses.

It's been a struggle to access an adult assessment for ADHD – perhaps there is a training need to promote awareness amongst GP's of how ADHD and Autism present in adults and in females. I've had to persist and could have easily given up.

- Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds and disabled people.

As no services exist in my area, I have to travel 100 miles per week, Initially I had to go to England to access Hyperbaric Oxygen Therapy as the only centre in South Wales had a very long waiting list. Recently I have managed to transfer to Swansea which is slightly nearer but still costs me £30 per week between paying for treatment and cost of travel. It's a pity the NHS doesn't provide Hyperbaric Oxygen therapy as it benefits so many people with chronic / post viral illnesses. It has made a huge difference to my quality of life, improved my outlook and enabled me to return to work part time as well as enjoy hobbies such as reading which I was unable to do before due to cognitive impairment from long covid.

Paying for the Hyperbaric Oxygen Therapy ongoing is a strain and will prevent some people from accessing the treatment. Anyone without transport will also be effectively prevented from accessing this treatment unless they live close by. Earlier in my illness I was prevented from accessing this treatment as I was too unwell to travel.

The GP's lack of awareness of adult ADHD became a barrier to me accessing an assessment.

Adult ADHD presents differently in women – there is a need for education. For the Autism Assessment I found out later that I could have self-referred into the service which would have been easier than going through the GP. It's a shame you can't self-refer for an ADHD assessment. For those of us who are now seeking a late in life diagnosis, barriers to access need to be removed as we have already missed out on help and support for too long.

Diagnosis of these conditions in adults is important as both groups have higher than average suicide rates and lower than average life expectancy.

Autistic women have the highest suicide rates of any group – autistic women are 13 times more likely to die by suicide than non-autistic women and yet we never hear about this in mainstream media.

Henry Shelford, Chairperson and co-founder of ADHD UK said: "Recent research shows adults with ADHD are 5 times more likely than those without to have attempted suicide (14% vs 2.7%). That rises to one in four for women with ADHD."

- Support available to enable effective self-management where appropriate, including mental health support.

Support for long Covid in this instance would look like help with transport or help with costs (perhaps a prescription for the Hyperbaric Oxygen Therapy or even for home oxygen or perhaps installing Hyperbaric Oxygen tanks in hospitals so people could access them closer to home).

Mental health support is on offer through the local Long Covid services, but it is physical treatment that people with long covid want. In too many instances people with long covid are still being told they have anxiety or they are depressed.

Short term support for those recently diagnosed with Autism is available (though could be quicker to access) but longer-term social support would be very welcome, especially considering the loneliness and isolation encountered by autistic adults. Peer support is really important and empowering for autistic people and spaces for autistic people to meet and socialise would not be costly to provide.

Multiple conditions

- The ability of NHS and social care providers to respond to individuals with multimorbidity rather than focusing on single conditions in isolation.

Long Covid is a multi-system disease and it also triggers many other conditions. Its currently a big problem that there are no One-Stop-Shop clinics in Wales for long covid. Local long covid services are rehab based and don't have the funding or the ability to refer people to specialities for thorough investigations. Instead I've had to wait for

separate consultations involving lots of travel, very strenuous for someone feeling very unwell and I've had to keep battling to get through to my GP on the phone to ask for referrals and/or treatments.

There is a need for doctors to be able to learn about long covid by treating large numbers of patients – we need doctors to become experts in Long Covid. Currently long covid services in Wales are run by Physios and not by doctors – how will doctors in Wales gain the expertise to treat long covid?

Over 3 years of long covid and now research around the world has shown the pathology of this new illness – the micro clots and the endothelial damage that are causing the low oxygen and the debilitating symptoms of long covid. And yet no treatments are being offered and we are still being told we must wait for the research.

The average time it takes for research to turn into mainstream medical treatment is 17 years – you cannot expect people to wait this long.

There are treatments that are being used now by patients (accessed privately) and they are working. In the best long covid clinics in England (such as UCHL) they are prescribing medicines off licence to help people get better and running small trials, funded by charity money or by private companies. Why can't we do this in Wales? Why haven't we got Welsh Government funding for treatment trials for long covid?

During the pandemic there was a rapid response to covid, existing drugs were repurposed and fast tracked through trials. This now needs to happen for long covid, to get people back into the workforce and back to living their lives, caring for their families.

After 2 years of long Covid I asked for an assessment for Autism. The cognitive issues that came with long covid were terrible. I was unable to

read more than a sentence as I could not retain the information to make sense of it.

Simple maths were beyond me and I had almost no memory capacity – could not remember what I was doing from one moment to the next.

I'd thought for years that I was autistic but before long covid I didn't feel the need for a diagnosis. Since having long covid I noticed how much more I struggled with communication and with relationships. I think that in the past I was able to rely more on my memory and cognitive abilities to overcome social difficulties but when my memory effectively stopped functioning I could no longer rely on it to bridge the gap.

All of this caused me a lot of problems in 2020 but it wasn't until 2022 that I was sufficiently recovered to seek an autism diagnosis. Even making the phone call to the GP was beyond me in 2020. Every call to the GP was a struggle so I had to prioritise the more urgent matters which at the time were the debilitating symptoms of long covid.

To have been able to access care in one place instead of having to make repeated requests through the GP via a hostile telephone system would have made things a lot easier. Every phone call could take up to 3 months for me to actually make the call and get through in time to get a GP call back. I would forget for weeks on end to call at 9am or I would remember but feel too ill or not know what to say (to make a good argument). GP calls often felt like a battle to be taken seriously or to get a prescription or a referral.

- The interaction between mental health conditions and long-term physical health conditions.

Living with Long Covid comes with the mental health burden of knowing that NHS Wales is not offering treatment or investigations for Long Covid. Knowing that you have to fight every step of the way to research and access and often pay for your own treatments is very tiring and comes with a mental health burden. Those of us living with long Covid feel forgotten and disregarded, especially now that the Office for National Statistics has stopped counting our numbers.

A recent study has shown that people with ADHD have a higher incidence of long covid than the general population.

Impact of additional factors

- The impact of the pandemic on quality of care across chronic conditions.

I didn't have a chronic illness before the pandemic so I can only say that during and since the pandemic, care on offer has been of a very poor standard. During the pandemic people with long covid were de-prioritised as non-urgent - we understood that acute covid took priority then.

3 years on its time we received some useful treatment from NHS Wales. We were told in 2020 to wait and see if we would get better – we have waited and many of us have been too ill for rehab and we haven't got better.

The contrast in my experiences of trying to get care for long covid and accessing diagnostic services for Autism and ADHD could not have more different. For long covid it's been a nightmare trying to get help

whereas the services for Autism and ADHD have been excellent with little waiting times (much shorter waiting lists than in England).

Sadly, the opposite has been true with long covid; sufferers in Wales are absolutely aware that it's disadvantageous to live in Wales with this illness, we have had the least support and funding out of all the four nations. This is shocking especially in light of the fact that currently 3% of the population are living with long covid, 3 - 4% of the population are thought to have ADHD and 1 - 2% are thought to be Autistic.

- The impact of the rising cost of living on people with chronic conditions in terms of their health and wellbeing.

The rising cost of living means it's becoming increasingly difficult to fund my own treatments – there may come a time when I can't afford to go weekly for Hyperbaric Oxygen Therapy, the only thing which has allowed me to work, to feel better and to live a bit.

- The extent to which services will have the capacity to meet future demand with an ageing population.

Not just an ageing population but a population with increasing levels of disabling Long Covid. (One in ten Covid infections leads to long Covid. Personally, I have had 5 covid infections in the past 3 years, the first infection gave me long covid and subsequent infections have made it worse).

Some people recover fine from their first covid infection but may get long covid from their second or third infection. Just because you have bounced back in the past doesn't mean you will always do so.

Prevention and lifestyle

- Action to improve prevention and early intervention (to stop people's health and wellbeing deteriorating).

ATM with routine covid testing having been withdrawn even in hospitals there doesn't seem to be any action to stop the spread of Long Covid.

- Effectiveness of current measures to tackle lifestyle/behavioural factors (obesity, smoking etc); and to address inequalities and barriers faced by certain groups.
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There are no current measures to stop the spread of long covid.

There would need to be effective measures (such as good ventilation and Hepa filters in public spaces, plus a strong public health message to stop the spread of covid. Long Covid mostly affects women (two thirds of sufferers are female).

In regard to Autism and ADHD there's a lot of misunderstanding about these conditions – education and awareness for professionals and public are needed, especially in regard to how these conditions present in adult women. Lack of awareness effectively leads to barriers to diagnosis and support as well as to stigma around these conditions.

