

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](#).

CC68: Ymateb gan: | Response from: **Cymru Covid hir/ Long Covid Wales**



Response from Long Covid Wales (organisation)

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NHS and social care services

- The readiness of local NHS and social care services to treat people with chronic conditions within the community.
- Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds and disabled people.
- Support available to enable effective self-management where appropriate, including mental health support.

The Adferiad / Recovery Programme developed by NHS Wales lacked patient consultation from the start and offers physio and psychology input. We need much more than this to tackle this multi system illness. People with long covid need to see doctors who understand long covid and who are up to date with the latest research findings and treatments for this devastating new illness.

Many patients are too unwell to do exercise as they suffer from PEM (Post Exertional Malaise) / Post Exertion Symptom Exacerbation. Nice Guidelines state that graded exercise programmes are unsuitable for anyone suffering from PEM. Yet the long covid services in Wales are exercise based.

There has been a lack of patient consultation by NHS Wales in regard to shaping long covid services. Long Covid is a new illness and patient input is needed every step of the way in order to make useful and effective services. As a result of the lack of consultation we have ended up with digital apps, and online group programmes which are not very helpful apart from to provide some peer support. Patients with cognitive impairment from long covid struggle to access digital services – for many sitting in front of a screen can be difficult or impossible due to sensory overload.

Where health board representatives or the Welsh Gov Covid Response team have met with long covid patients, its been a case of them telling us what they are planning to do, the concept of patient input has not been put into practice at all.

For the GP pathway for long covid care, we at Long Covid Wales specifically asked to be involved and we were told there was no need as the pathway had already been decided.

There are drugs which are recognised as working to help relieve symptoms of long covid and yet patients are still having to mostly request these from GPs, they are not being offered, and some patients are being refused drugs like anti-histamines even though they are established and safe medications. It still seems to be up to the patient to find out what works and to go to the GP with that information, in the hope that the GP will prescribe.

The current programme developed by NHS Wales is based on the premise that patients with Long Covid are too ill to travel and are better served by visiting their local GP who can refer

them to the relevant specialist. However, Long Covid is a multi-system illness which presents with numerous and varied symptoms. Patients are being offered numerous tests and referrals one at a time to rule out other causes. Due to the strain on the NHS at the moment, this involves long waiting times which only adds to the worry of being ill and can come at great cost in terms of valuable energy expended, time and expense.

Multiple conditions

- The ability of NHS and social care providers to respond to individuals with multimorbidity rather than focusing on single conditions in isolation.
- The interaction between mental health conditions and long-term physical health conditions.

Long covid is a multi-system illness which can trigger or bring forward a number of other illnesses.

Due to the debilitating nature of long covid (many people cannot leave their house or struggle to make phone calls / read information / sit in front of a laptop) people need a simple

system where they can access care. People with long covid don't have the energy to attend multiple appointments and different conditions may affect each other. The current long covid services in Wales are not able to make referrals to hospital departments – they send the patient back to the GP where they may have to battle to get an appointment. For people with little energy this is a very difficult state of affairs.

Accepting you have a long-term health condition is not an easy thing to do. Even more difficult for many people with long covid has been the slow realisation that NHS Wales is not offering a good level of care for long covid. England has some very good long covid clinics where people can access all the care they need in one place and where doctors have been able to become experts in long covid through having seen hundreds or thousands of patients in the past 3 years. These clinics are devising effective ways of treating long covid, backed up by the latest research which has shown that the 50% of patients with long covid who have not got better with time are having to make do with a third of usual energy levels. Having a third of your usual energy doesn't mean you can do a third of the things you normally do (like work or hobbies). It means that almost all of your time will be taken up with self-care – washing, bathing, eating, making food, calling the GP and other essential tasks. These are the things you must do to survive. And they will take up a third of your energy and if you have long covid you won't be able to do anything else so you will end up existing not living. This will come with a mental health burden especially when no treatment is being offered.

Early in the pandemic long covid patients were told to try harder, motivate themselves to do more and long covid was very much treated as a mental illness with some deconditioning thrown in. Hopefully we have moved on from that position as research has shown that physical damage that covid has done to cause long covid.

Symptoms presenting in Long Covid patients are numerous and varied. What may work for one patient may not work for another. Where GPs are being asked to prescribe the necessary treatments, there is a potential for inconsistencies in the way these are offered by the NHS and their effectiveness.

Impact of additional factors

- The impact of the pandemic on quality of care across chronic conditions.
- The impact of the rising cost of living on people with chronic conditions in terms of their health and wellbeing.
- The extent to which services will have the capacity to meet future demand with an ageing population.

While there was very little care and no treatment for long covid in early or mid 2020, three years have now passed and treatments are being developed at dedicated long covid clinics around the world. We would like to see these type of best practice clinics in Wales to help people with long covid.

The cost of living crisis is impacting people with long covid who in many cases have already lost their livelihoods, run out of sick pay and are now dependent on welfare benefits which are

difficult to access especially if your GP hasn't sent you for further investigations (so you don't have any diagnosis except Long Covid). It takes many months to access welfare benefits which is problematic for people who fell ill suddenly and just didn't get better. In addition there's a double blow to finances – more outgoings and less money incoming.

In October 2022 there had been 96,000 reported cases of long covid in Wales. The figure will be considerably higher now 7 months later and does not include the people who don't realise they have long covid. As covid continues to spread and is no longer counted nor curtailed, the number of people living with long covid will inevitably rise. Without treatment 50% of these people will not get better and will be forced to leave work. This is bound to have an ongoing economic impact.

There is a real lack of awareness amongst employers about Long Covid which can be difficult for patients in recovery attempting to get back to work. Some feel pressured to go back to work which can cause relapses and could potentially prolong their recovery. Sickness policies in the workplace and illness insurance policies don't cater for Covid and its potential long term sequelae.

Some Long Covid sufferers are losing their jobs (in some cases, even their partners or their homes). Due to the lack of a diagnostic test, they are finding it difficult to access PIP payments.

We shouldn't forget there are doctors and nurses with Long Covid who are struggling to get back to work which will have an impact on the provision of care within the NHS.

Prevention and lifestyle

- Action to improve prevention and early intervention (to stop people's health and wellbeing deteriorating).
- Effectiveness of current measures to tackle lifestyle/behavioural factors (obesity, smoking etc); and to address inequalities and barriers faced by certain groups.

You are welcome to comment generally or specifically about a certain condition.

Preventing covid is the only effective way to prevent long covid.

You cannot rely on vaccines to prevent long covid as they only reduce the incidence of long covid by 15% compared to the levels of long covid in unvaccinated people.

Improve prevention by providing covid tests for free again, for routine testing in workplaces, hospitals, schools etc

Ensure public spaces have good ventilation (as simple as having a window open) and/or Hepa filters.

Public health messaging about the risks of getting long covid and how debilitating it can be. One in ten covid infections leads to long covid.

The provision of masks and hand sanitisers in public places should be encouraged still.

Among Long Covid patients who are in recovery, there is a real fear of reinfection and worsening of their symptoms. Patients with Long Covid should be classed as vulnerable and offered vaccinations where requested.