Open long Covid one-stop medical hubs / clinics

Y Pwyllgor Deisebau | 29 November 2021 Petitions Committee | 29 Tachwedd 2021

Reference: SR21/1251-1

Petition Number: P-06-1217

Petition title: Open long Covid one-stop medical hubs / clinics

Text of petition: There are 1,000s of people suffering from long covid who are not getting any medical help. We feel ignored and helpless. Our lives have

been decimated.



1. Background

Long COVID is a new and complex condition and isn't yet fully understood. Most people will recover from COVID-19 after a short illness. But some people are left struggling with symptoms including lasting fatigue, persistent pain and breathlessness, for months after a COVID-19 infection. This is known as Post-COVID-19 syndrome – or long COVID.

The National Institute for Health and Care Excellence's (NICE) <u>clinical definition</u> for long Covid is:

Post-COVID-19 syndrome: signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis.

NICE has also published <u>clinical guidance</u> on how to identify, assess and manage the long-term effects of COVID-19. It says that long COVID usually presents with clusters of symptoms, often overlapping, which may change over time and can affect any system within the body. Two people with long COVID can have very different experiences.

According to the latest ONS data (4 November 2021):

- An estimated 1.2 million people living in private households in the UK (1.9% of the population) were experiencing self-reported long COVID at 2 October 2021. Symptoms adversely affected the day-to-day activities of 65% of those with self-reported long COVID, with 19% reporting that their ability to undertake their day-to-day activities had been 'limited a lot'
- Prevalence of self-reported long COVID was greatest in people aged 35
 to 69 years, females, people living in more deprived areas, those
 working in health or social care, and those with another activity-limiting
 health condition or disability.

A Senedd Research article <u>Coronavirus</u>: <u>long COVID - "it's a game of snakes and ladders"</u> (March 2021) provides further background information on long Covid.

2. Welsh Parliament action

In March 2021, the Fifth Senedd's Health, Social Care and Sport Committee.carried out a brief <u>inquiry into long COVID</u>. The Committee heard evidence regarding the need for specialist, multidisciplinary services for long COVID and that these specialist services could help to develop a greater understanding of the condition and the services needed, rather than referring people to existing services which already have long waiting lists.

However, the Committee heard differing views from <u>Long COVID Wales</u> (a support group for people living with long COVID) and health professionals about whether or not these specialist services are best delivered by multidisciplinary specialist long COVID clinics. The Committee also heard that these services need to be separately funded and resourced, and not an add-on to already overstretched rehabilitation services.

In Plenary on 15 June 2021 the Minister for Health and Social Services made an oral statement on services supporting people to recover from COVID-19. Following this statement, some Members of the Senedd raised the issue of specialist multidisciplinary clinics / 'one-stop-shop clinics' for long Covid. The Minister highlighted the difficulty in putting together clinics that specialise in everything, and went on to say:

So, I do think that the model that is being developed in places like Aneurin Bevan, where they will wrap around the individual and make sure that there is a team really looking at every aspect of how the individual responds, looking at their mental health, looking at their diet, looking at the really specific issues that they may have and the need to see both a specialist in lung surgery and a specialist in heart. Those things, I think, offer a much better route to go down rather than the clinics, and that's why we've gone and we've taken advice from clinical experts in this, and that's certainly what they have recommended. [para 258]

When asked further about the decision not to set up dedicated long COVID clinics, the Minister said:

I've made a point of listening to patients, of looking at what is being said on social media channels. But also I think it's incumbent upon me to listen to the clinical advice that I'm given, and the advice that I have been given, very clearly, is that the route that we want to follow in Wales, and the route that conforms with our approach, which is to give care as close to home as possible, actually makes sense for us, to make sure that that route is through the GP. What we need to do is to strengthen the understanding of people in primary care, and to make sure that then they are directing into secondary care if and when necessary. [para 276]

The issue of long COVID was raised at the Sixth Senedd's Health and Social Care Committee on <u>23 September 2021</u>, when the Committee held a general scrutiny session with Ministers including the Minister for Health and Social Services.

The Senedd has a <u>Cross-party Group on long COVID</u>, with the purpose of promoting the medical and other needs of long COVID sufferers in Wales and to raise awareness of the issues facing those living with long COVID.

3. Welsh Government action

As mentioned above, the issue of long COVID has been raised at the <u>Fifth</u> <u>Senedd's Health</u>, <u>Social Care and Sport Committee</u> and the <u>Sixth Senedd's Health</u> <u>and Social Care Committee</u>. Written evidence provided by the Welsh Government for these meetings gives the following information on action taken in relation to support and treatment for long COVID.

- The <u>NHS Wales COVID Recovery App</u>, launched in January 2021, has been developed to support anyone recovering from COVID-19. It provides advice from therapists, psychologists, dietitians and consultants.
- In June 2021, the Minister for Health and Social Services announced £5 million funding to support a new patient pathway programme Adferiad (Recovery) and improve the diagnosis, treatment, and rehabilitation and care for people suffering from the long-term effects of COVID-19. Further details on how the funding will be spent is set out in the announcement.
 - The Adferiad programme will be revisited on a six-monthly basis to take account of emerging evidence and best practice.
- Alongside the Adferiad programme, an all-Wales guideline for the management of long COVID has been introduced. This guideline for

health professionals, based on the All Wales Community Pathway, offers the latest information for managing long COVID across the NHS in Wales. The aim is that health professionals across Wales will have access to the same information and treatment advice on this condition and will also have a clear guide on when and how to refer onwards for treatment and support.

In communication to the Petitions Committee on 26 October 2021, the Minster for Health and Social Services states that each health board in Wales has worked with its GP practices and community services to establish clear local pathways to ensure people with long COVID can access the services they need. The majority of these can be provided as close to home as possible from primary and community care services.

The Minister also notes that people who require access to more specialist services available only from hospital-based services are referred to the most appropriate expertise to improve their health, and GPs can access specialist advice from hospitals to support people in the community.

Online advice and self-management resources are available on each health board website. It is highlighted by the Minister that for many people, recovery from COVID-19 can be self-managed and where this is appropriate, support can be provided via the NHS Wales Recovery app. The Minister goes on to say:

Our approach seeks to minimise the number of referral points and hand-offs for people and to ensure that people are managed holistically and only referred to specialised medical services in the minority of cases in which the assessing health professional identifies a specialist need.

Every effort is made to ensure that the information contained in this briefing is correct at the time of publication. Readers should be aware that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.