



Llywodraeth Cymru
Welsh Government

POLICY AND STRATEGY

Adferiad (Recovery) long COVID programme

How we will work with NHS Wales to support people with long-COVID.

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Contents

Ministerial Foreword

What is long COVID

Developing a response to long COVID

Research

How we are investing in services

What patients can expect when accessing support from the new Adferiad (Recovery) programme

Mental health and Well-being for people with long COVID

How to support someone you know with long COVID

Supporting NHS Employees

Other employers

Role of Public Health Wales

Ministerial Foreword

As we begin to focus on aspects of recovery from the Coronavirus pandemic we must not forget those for whom the virus has caused lasting harm. For some individuals, even though they may have had a very mild or asymptomatic experience of the virus itself, they may have been left with one or more

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symptoms including breathlessness, brain fog, fatigue, joint pain and the list goes on. There are also a significant number of people whose health and wellbeing has been impacted even though they did not contract the virus themselves. Our NHS in Wales is working extremely hard to ensure the recovery supports the whole population equitably.

Long COVID is an outcome of the virus that we do not completely understand. We do not yet know why some experience it and others do not, we don't know how long it will last or why the range of symptoms is so very wide. Nor is there a particular pill that can be prescribed for symptoms to go away. Whilst we actively support and monitor the research in these areas we must help people to manage the symptoms of this condition and live as full a life as they possibly can. That is why I have announced a £5 million package of support for the introduction of a new suite of services and new patient pathways called 'Adferiad' (Recovery) to support these and other individuals who have additional needs as a result of the impacts of the pandemic.

I want to reassure those experiencing ongoing symptoms, who may be worried about the future that we have not forgotten about them. The Welsh Government and our Healthcare professionals in Wales are listening to patients, and learning from international experience to ensure we adapt services to meet the needs of patients with long COVID. We are still learning, but we will do our very best to support you.

Eluned Morgan
Minister for Health and Social Services

What is long COVID

'Long COVID' is a term used to describe signs and symptoms that continue or develop after someone has had COVID-19. It includes both ongoing symptomatic COVID-19 (4-12 weeks) and post COVID-19 syndrome (over 12 weeks). Signs and symptoms of longer term effects of COVID-19 are varied and range in severity.

There is no definitive test to diagnose long COVID and people do not need to

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have a positive test for COVID-19 at any point in order to receive this diagnosis. Many people have mild symptoms and can self-manage with support and guidance and a few people have complex symptoms and require a multidisciplinary approach.

Signs and symptoms

The most frequent symptoms of long COVID include fatigue, breathlessness, and brain fog but there are many other symptoms that have been reported which include a range of physical and/or psychological impairments. Symptoms can also present differently on different days and may reduce or go away entirely for a period before returning. This can make it difficult for sufferers to plan and manage their condition.

The symptoms associated with long COVID do not necessarily link to severity of the disease experienced by individuals and people can present with long COVID symptoms even after a very mild or asymptomatic infection. This means that for some individuals the after effects of a COVID infection can be worse than their original experience.

How many people have long COVID?

As not all people who experience long COVID symptoms will need to access services for help and support, it is challenging to provide a complete assessment of the number of people experiencing symptoms.

The ONS regularly publishes estimates of the prevalence of self-reported "long COVID", and the duration of ongoing symptoms following confirmed coronavirus infection, using UK Coronavirus (COVID-19) Infection Survey data. **In the latest publication on 4th June** this data estimates that there are 50,000 people experiencing long COVID in Wales and of these, ONS estimates that 9,400 (18.8%) will be limited a lot in their day-to-day activity.

Adferiad (Recovery) is the name of our new programme which is specifically designed to stand by those who suffer from long COVID and which will continue

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to evolve and develop as we learn more about this new condition.

Developing a response to long COVID

With any new condition it is important for healthcare professionals to be able to access advice and support on how to help their patients. Where referrals are required to other services, it is necessary for those referral mechanisms to be clear, particularly as all healthcare services are working under challenging circumstances.

As long COVID is a new condition, when we first started to see patients with these symptoms we did not have all of the referral mechanisms and services in place to support them. Healthcare professionals across Wales have been working as hard as they possibly can to change that, and we now have a full range of support available – both for healthcare staff to assist in diagnosing and treating patients and for patients themselves.

Colleagues from NHS Wales took an active role in working with **The National Institute for Health and Care Excellence (NICE) to develop a clinical guideline to support health and care professionals which was published on 18 December 2020**. The guideline covers identifying, assessing and managing the long-term effects of COVID-19 and provides advice on the planning of services. For the first time, there is now a clinical case definition for long COVID meaning this is recognised as a real condition by healthcare professionals across the UK.

The new Adferiad (Recovery) programme has ensured that IT platforms have been developed with colleagues from NHS Wales to provide advice for Primary Care and GPs around referral advice and diagnostics **Long Covid Syndrome Resources - HEIW (nhs.wales)**

On the 18th June the Adferiad (Recovery) All Wales guideline for the management of long COVID will be launched. This guideline is based on the **All Wales Community pathway** and offers health professionals the latest information for managing long COVID across NHS Wales, and is supported by a package of comprehensive education and resources. This includes the referral

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process into secondary care where needed and clear guidance on when to arrange diagnostics for people living with long COVID. Updates will be provided direct to users of the guideline as new evidence, and changes to guidance emerge. Most importantly, it will mean that across Wales health professionals will have access to the same information and treatment advice on this condition and will also have clear guide on when and how to refer onwards for treatment and support.

There is much for us still to learn about long COVID and the importance of understanding the lived experience of those with the condition is recognised by our policy teams, health boards and health professionals. NHS Wales is actively engaging with individual patients and patient groups to ensure the services offered meet their needs. Engaging with people with lived experience of the condition has already proved invaluable and will continue to be important in the future. Health boards also recognise the benefit of learning from each other and have developed a community of practice to ensure services are standardised and learning is shared across Wales. Welsh Government will be seeking assurance from health boards that the services they are developing meet the needs of their patients. Adferiad (Recovery) will be a programme which will require updating as and when new research and information becomes available.

Research

Through the work of Health and Care Research Wales, Welsh Government continues to play a key role in the UK wide effort to gather evidence to address the impact of COVID-19.

Wales is taking part in the UK study called 'The Post-Hospitalisation COVID-19 Study (PHOSP COVID)', funded by the National Institute for Health Research (NIHR) and MRC UK Research and Innovation and led by the NIHR Leicester Biomedical Research Centre. This Urgent Public Health study has been established to assess the long-term effects of COVID-19 on patient health and recovery in 10,000 participants across the UK. Wales remains one of the highest recruiters with sites across Wales.

The 'Inspiratory Muscle Training (IMT) post COVID-19 recovery study' has also

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been set up by Swansea University to address patient recovery from the impact of COVID-19 for example, shortness of breath and fatigue. The aim of the study is to assist patients to re-train respiratory muscles to improve breathing technique thereby alleviating suffering of the patient and pressure on the NHS through potential re-admission to hospital.

In response to the pandemic, Welsh Government has established the COVID-19 Evidence Centre. This is a 24 month investment of £3M to provide a Welsh-specific programme of research, evidence synthesis and knowledge mobilisation to meet priorities and urgent needs arising from COVID-19, including the long-term effects of the pandemic.

As this is a new condition it is important that we know as much as possible about people who are experiencing long COVID in Wales. We will ask the Bevan Commission to make recommendations on how we should set about establishing a voluntary registry, so that we can undertake long term monitoring of this condition and provide support and opportunities for volunteers to participate in trials if new treatments are forthcoming.

The Technical Advisory Group published a paper in February 2021 **Technical Advisory Group: Long-COVID** which sets out what we know about long COVID and what we still need to understand.

How we are investing in services

Welsh Government is providing a £5million package of support for the new Adferiad (Recovery) programme to expand the provision of diagnosis, treatment, rehabilitation and care for those suffering from the long term effects of COVID-19, including long COVID in Wales.

Targeting funding at pathways where patients can get personalised treatment for their needs, as well as ensuring care is provided as close to home as possible, are the key aims of the Welsh Government's rehabilitation framework for COVID recovery.

The package of funding will further develop primary and community services to

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support individuals who have specific needs as a result of the impacts of the pandemic.

The money will go towards:

- Helping healthcare workers and Allied Health Professionals develop infrastructure to flexibly deliver services to help people recover from COVID-19, long COVID and those more widely impacted by the pandemic.
- Providing high quality, evidence based training and digital resources to assist in diagnosing, investigating and treating long COVID and supporting people in their treatment and rehabilitation.
- Investing in digital tools which will provide data about service demand and capacity modelling and ensure the NHS helps people make the right treatment decisions for their care and treatment.

What patients can expect when accessing support from the new Adferiad (Recovery) programme

All health boards have developed multidisciplinary recovery services that GPs and health professionals are able to refer their patients into, after screening for more serious symptoms. These were not in place when we first had patients experiencing long COVID but are now available across all health boards. All services also have a comprehensive assessment tool to ensure patients are treated holistically and individually.

Mild symptoms

For many people, recovery from COVID 19 can be self managed. Where this is appropriate, support can be provided via the NHS Wales Recovery app. (Search 'covidrecovery' on the [Apple](#) and [GooglePlay](#) app stores.) The NHS Wales COVID Recovery App was commissioned at the end of January 2021. In less than 6 months there have been 6000 downloads - 96% of these are confirmed Welsh residents, representing 87% of all GP practices in Wales. The uptake by

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health board area broadly follows the distribution of COVID-19 cases, with slightly higher proportion of downloads noted in Cardiff and Vale UHB and Hywel Dda UHB areas.

Persistent issues – contact GP practice

People who experience symptoms that don't respond to self help initiatives alone should contact their GP practice.

Our approach seeks to minimise the number of referral points and hand-offs for people. The majority of people accessing services will therefore be able to do so directly via their GP practice. Following an initial assessment with a member of the multi-disciplinary team, people may be supported by a range of healthcare professionals including nurses, physiotherapists and occupational therapists depending on their individual needs.

Our multi-disciplinary teams have access to high quality, evidence based training and to a new suite of digital resources, to assist in diagnosing long COVID and supporting people in their rehabilitation. This includes the most up to date information being provided by NICE.

Complex Cases

In some cases the initial assessment may indicate that a referral to one or more specialist service is required. We know that this can be an anxious time for patients so under the new Adferiad (Recovery) programme health boards will consider opportunities to coordinate referrals to specialist services to limit the stress and practical challenges of attending hospital.

Where long COVID has exacerbated long term conditions

There will be many patients who will have found that COVID has exacerbated long term conditions. Expert medical professionals who have a long term relationship with patients will be encouraged to ensure that they are following the

latest clinical guidance relating to COVID and the pre-existing issue.

Children with long COVID

So far very few children have presented with symptoms of long COVID and so children will usually be referred directly to paediatricians for specialist advice.

Mental health and Well-being for people with long COVID

Whilst some people will have symptoms directly affecting their mental health as part of their long COVID diagnosis, many will find their mental health and well-being are affected by the limitations or frustrations of feeling unwell. The details below are not intended to replace the advice of your GP or healthcare professional.

Taking care of your mental and physical wellbeing is important. These are some ideas about how you can do that:

- Noticing how you are doing and thinking about if you can do anything differently. Thinking about ways to take care of your wellbeing can help.
- Not judging yourself when you are having a hard day. There are different ways you may be able to reassure yourself. Why not try some calming activities, such as relaxation exercises or talking to others.
- Focusing on what you can control, like your thoughts and behaviours. This will have a big impact on how you are feeling.
- Connecting with others. Reach out and ask for help from friends and family or from local organisations. Use technology and phone calls to stay in contact.

There are also services to support you and others you might be worried about. Talking about worries and problems can make things easier.

There are a number of helplines and information services that provide guidance and information tailored for people with particular health conditions. Further

information on **looking after both your physical and mental health and wellbeing is available on the Public Health Wales website**. For those with specific health conditions or requirements click on the 'Charity and Support Organisation Directory'.

ACTivate Your Life (on Public Health Wales) is a four session taught course that aims to teach people about stress and suffering caused by emotional issues, like worry, or chronic pain.

SilverCloud (on silvercloud.com) is an online course which offers support for anxiety, depression, and much more, all based on Cognitive Behavioural Therapy (CBT).

CALL Mental Health Listening Line provides a confidential mental health listening and emotional support line which is open 24/7. CALL can also signpost to support in local communities and a range of online information. Call 0800132737, text "help" to 81066 or visit the **CALL website**.

Mind Active Monitoring provides six weeks guided self-help for, anxiety, depression, self-esteem, and more. To get started, talk to your GP, any other health professional, or **sign up directly at Active Monitoring Wales**.

The **Young Person's Mental Health Toolkit** links young people, aged 11 to 25, to websites, apps, helplines, and more to build resilience.

If you are still struggling after several weeks and it is affecting your daily life, please contact your GP or call 111.

How to support someone you know with long COVID

As long COVID is a new condition it is reasonable that many of us do not know about the condition or how to support a friend, family member or colleague experiencing symptoms.

This new Adferiad (Recovery) programme underlines the fact that both the

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Welsh Government and NHS Wales recognise long COVID as a serious and potentially debilitating condition.

Many patients have told us that this lack of knowledge and support can make them feel more isolated and they also feel that people do not believe that long COVID is real.

Every person is different in the support they need but for many someone to listen to them and ask 'what can I do to support you?' will be helpful.

Supporting NHS Employees

Following partnership discussions between NHS employers, health unions and Welsh Government, from 01 December 2020 the position regarding absence management for those absent due to COVID-19 related illness is as below:

- Those already on long term sickness absence prior to 01 December 2020 had the clock re-set and from then are entitled to 12 months full pay from that date if they don't return to work.
- Where an absence started after 01 December 2020, the entitlement is for 12 months full pay from the date their absence commenced.

Based on this, no-one would move from full pay until 1st December 2021, at the earliest.

There is also a provision in place that indicates that where an individual exhausts their sick pay entitlement, employers have the discretion to extend the period of sick pay on full or half pay where there is the expectation of return to work in the short term and an extension would materially support a return and/or assist recovery.

Where an individual has returned to work and is still in the process on rehabilitation any subsequent episodes of sickness absence will be paid as per an individual's normal contractual sickness entitlements.

This may mean that individuals have exhausted their entitlement to full pay or half pay for any further sickness absence and so in such situations, managers have the discretion to apply the provisions set out in Section 14.13 of the Terms and Conditions of Service Handbook section on Sickness Absence which allows for sick pay to be increased or extended. Whilst this is discretionary, it is expected that managers will exercise this discretion. Due to the Terms & Conditions being different we have ensured that the same considerations/ flexibilities are afforded to Medical and Dental staff as well.

We continue to work with NHS employer and union partners through our well-established social partnership mechanisms to ensure that we are responsive to the needs of the workforce and offer a provision that is fair and supportive. [Frequently asked questions for NHS managers and employees \(nhsconfed.org\)](https://nhsconfed.org)

Other employers

We will be working with trade unions business and other employers to ensure that they treat long COVID seriously as a condition and put support measures in place to help their employees.

Role of Public Health Wales

By supporting us to understand the local, national and international picture in the support and treatment of long COVID, Public Health Wales will play a key role in how the Adferiad (Recovery) programme develops.

Adferiad (Recovery) is a new programme which seeks to stand by people suffering with long COVID. The Welsh Government will constantly monitor the developments relating to long COVID and in particular seek opportunities to activate support as and when new information and treatments become available. Officials in Welsh Government will be asked to revisit the Adferiad (Recovery) on a six monthly basis building on best practice here and around the world.

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