



LONG COVID ACTION PLAN

**NO LIFE
HALF LIVED**

INTRODUCTION

The Office for National Statistics estimates that 62,000 people in Scotland are still unwell 12 weeks after contracting Covid-19 and considered to have Long Covid¹. Many of those thousands of people will be struggling with their daily lives, unable to work and not knowing when they might recover. Worryingly, an estimated 31,000 people in Scotland have had symptoms for at least 12 months.

Long Covid is a complex condition that affects people in many different ways; symptoms like breathlessness, fatigue, heart palpitations and 'brain fog' are typical, but there are many more. It's also a new condition for which there is no cure and the prognosis is unclear, although some of the effects of Long Covid can be treated.

The support that people are calling for to cope with Long Covid is similar to that experienced by people living with other long-term conditions. Chest Heart & Stroke Scotland (CHSS) has many years' expertise in providing that holistic support, which puts people at the centre of their care by helping them not only with their mental and physical health, but also tackling the wider issues they face – social, emotional and practical.

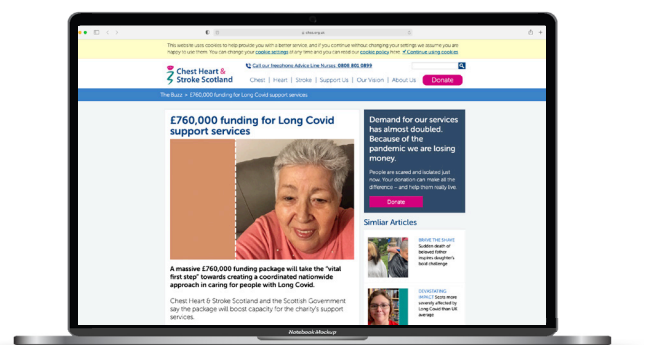
In February 2021, CHSS and the Scottish Government announced a joint funding package of £760,000 to establish a Long Covid Support Service, including £300,000 contributed by the charity. This development followed CHSS' Long Covid Care Now campaign which highlighted the lack of any

coordinated support for people affected by Long Covid. CHSS has expanded its support services to incorporate Long Covid, offering a programme of support based around individuals' needs and the 'Eight Areas of Wellness'².

Since then, evidence has continued to emerge about the scale and the impact of this devastating condition, and the Scottish Government has started to model the number of people likely to be experiencing symptoms³.

Funding the creation of the CHSS component of a national Long Covid Support Service – providing holistic support - was an important first step. CHSS has been working to establish the service, but the charity is only part of the solution, and national action is needed to tackle a number of challenges to ensuring that everyone receives the right help.

Without that leadership, thousands of people will continue to miss out on the support they desperately need, leaving them struggling. This Action Plan sets out four critical challenges, and what we believe needs to happen next as a matter of urgency.



¹ <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/latest>

² Physical, Emotional, Social, Occupational, Financial, Knowledgeable, Spiritual and Environmental

³ <https://www.gov.scot/binaries/content/documents/govscot/publications/research-and-analysis/2021/07/coronavirus-covid-19-modelling-epidemic-issue-no-61/documents/coronavirus-covid-19-modelling-epidemic-scotland-issue-no-61/coronavirus-covid-19-modelling-epidemic-scotland-issue-no-61/govscot%3Adocument/coronavirus-covid-19-modelling-epidemic-scotland-issue-no-61>

CHALLENGE 1: INTEGRATING CARE

People living with Long Covid may be seen by a wide range of health professionals for investigations – or sometimes not at all. They are struggling to navigate a system in which Primary and Secondary care don't join up, and they are often not referred on to the support available to them outwith the NHS. We know for example that CHSS' Long Covid Support Service is not receiving the volume of referrals from health professionals that it should due to the lack of a digitally enabled referral pathway and complexities around data-sharing agreements. As a result, many people are still having to 'self-refer' to the service, if they know about it at all. Not only are people with Long Covid not being supported when they could be, but the opportunity to alleviate some of the pressures on healthcare professionals is being missed.

A complex condition like Long Covid which can require numerous tests, investigations, and different sources of help, needs to have a system in place that enables easy referrals both between clinicians within the NHS, and onto services outwith the health system. This is essential in order to avoid delays and errors, as well as saving health professionals' valuable time, and helping ensure that people don't fall down any gaps in care.



The solutions:

- Digitally enabled referral pathways for Long Covid need to be established in each Health Board.
- A national mandate from the Scottish Government is needed to enable effective data sharing and integrated working between Secondary Care, Primary Care, Health Boards and CHSS.



CHALLENGE 2: TRAINING AND AWARENESS

We know from people who are living with Long Covid that some health professionals are still not fully aware of the symptoms of Long Covid, the impact it has on people's lives, and the steps they should take such as referring people for tests and investigations. Sometimes people still struggle to obtain a diagnosis from their GP or have to repeatedly make their case to different health professionals, all whilst suffering with effects of Long Covid.

In 2020 clinical guidelines⁴ were published for health professionals which provide recommendations for identifying and managing cases of Long Covid, but this has not yet translated into consistent action on the ground within services. The demands on health professionals are greater than ever, leaving them with little if any time to access information about a new health condition. It is clear that the publication of guidelines alone is not sufficient to ensure their adoption.



The solutions:

- Training needs to be made available for all clinicians to ensure they can identify patients with possible Long Covid and are aware of the recommendations made in Long Covid clinical guidance. This could be delivered in one session, minimising the time burden on busy health professionals.
- An awareness-raising programme needs to ensure that all health professionals working with people with Long Covid are aware of the CHSS Long Covid Support Service. This could be coordinated by the Scottish Government in partnership with professional bodies.



⁴ <https://www.nice.org.uk/guidance/ng191>

CHALLENGE 3: CONSISTENT TREATMENT AND SUPPORT

The medical help and the support that people living with Long Covid are receiving varies enormously. Some of that will be addressed by putting in place the solutions described above, but there is more that can be done.

Living with Long Covid and the many different ways it can affect people's health means that self-management is a crucial part of managing the condition. But finding information and advice can be exhausting when someone is already struggling with poor health, in particular fatigue. Supported self-management should be a critical part of Long Covid services.

Also, many people living with Long Covid need to be referred onto a range of services for help, such as physiotherapy and occupational therapy rehabilitation services. These services are dealing with a new condition, often learning as they go and having to provide treatment in very different ways to existing conditions, but as yet there is no central direction for managing their new services. At a local level, rehabilitation services such as physiotherapy are having to develop their own systems and guidance, which is time consuming and leads to variation.



The solutions:

- When first diagnosed, people with Long Covid should be provided with a Care Plan containing information including the support they can expect to receive, information on how to access resources, advice and information on Long Covid, and contact details for key support services.
- Central guidance for allied health professionals' treatment of people with Long Covid should be developed to establish minimum standards of care and consistency.



CHALLENGE 4: RESOURCES FOR LONG COVID SERVICES

The demands on our health services are greater than ever, with backlogs of diagnostics and treatments, an exhausted workforce, and increased caseload. Providing new Long Covid services to meet the needs of thousands of Long Covid patients will not become a reality without additional resources.



The solutions:

- Creation of a Long Covid Capacity Fund for Health Boards to draw on in order to establish local Long Covid services.



CHEST HEART & STROKE SCOTLAND - SUPPORTING PEOPLE LIVING WITH LONG COVID

Summary

The aim of the service is to improve the quality of life for people who are living with the long-term impact of the Covid-19 virus by providing a pathway of support and advice from a team of trained Nurses and Allied Health Professionals via the charity's Advice Line.

The care is delivered through a series of person-centred telephone consultations focusing on physiological recovery, and psychological and social adjustment to the reality of Long Covid. The team at CHSS will support people for a period of up to 12 weeks, dependent on the needs of the individual.

While people are able to self-refer and call Chest Heart & Stroke Scotland themselves, a 'shared care' model between NHS professionals and the charity will ensure that CHSS can shape their advice and guidance to the clinical management of the person. This approach mirrors existing pathways across NHS Boards for Stroke, Cardiac and Respiratory teams to access CHSS support.

Delivery

Support focuses on several areas, borne out of CHSS' experience of helping people living with covid and Long Covid during the pandemic:

- Increased knowledge and understanding of the condition;
- Advice on how to manage common symptoms, for example:
 - Fatigue
 - Breathlessness
 - Pacing
 - Anxiety
- Building capacity to self-manage
- Signposting and referral onto CHSS' or other community-based support

Development

Understanding of Long Covid is still developing, and in partnership with the NHS, CHSS will learn from experience and adapt its support service as appropriate. At the heart of that is the need to ensure that people living with Long Covid are enabled to voice their experience and play a full and active part in the ongoing development of care.





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