

# self management uk

Supported Self-management for Long COVID:

Case for Support

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Registered Company number: 07998365

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(A company limited by guarantee)

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## 1.0 Background

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We exist to improve the health and wellbeing of those who experience one or more long-term conditions and believe everyone should have access to the high-quality self-management education and support that they need. We do this by providing supported self-management education, training, advice, signposting and support. Our results are some of the best nationally.

We are a registered charity, and our Theory of Change has been developed from our 20 years of experience of delivering self-management in England. We always place the person at the centre of what we do, and this is reflected in our approach.

Our courses are peer led by volunteer and staff tutors with lived experience of having or caring for someone with one or more long-term condition. Our evidence-based courses give the practical tools that provide a framework for dealing with the multiple challenges having a long-term condition can present, including 'Goal Setting,' 'Action Planning,' 'Problem Solving', 'Medicines Management', 'Navigating the Health and Care System' and 'Communicating with Friends, Family and Health Care Specialists'.

We know, from the feedback we receive, that attending one of our programmes can have a profound impact, often with the smallest of goals being achieved. The tools and techniques we support people to implement into their daily lives are based on cognitive behaviour change methodologies and holistically look at the individual and not just their health conditions. Additionally, our courses are designed to allow people to share their experiences creating informal networks of support amongst their peers. In fact, our participants often stay in touch for many years, and we have groups who still communicate with, and support each other after a decade of first attending a course.

We offer a range of self-management education packages tailored to the needs of the populations we support whilst also ensuring exceptionally high levels of retention and value for money to the health and care system.

Our range of programmes are trialled, researched, and validated by us or in partnership with others in health and social care for individual or multiple conditions, groups not able to access support and employers.

## 2.0 Introduction – The Challenge

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“Long COVID” is an informal term that is commonly used to describe signs and symptoms that continue or develop after an acute infection of COVID. Depending on how long you have ongoing symptoms for, it can be called one of 2 things:

- **Ongoing symptomatic COVID**  
This is where your symptoms continue for more than 4 weeks. If your symptoms last for longer than 12 weeks, it will then be called;
- **Post-COVID Syndrome**  
This is where your ongoing symptoms continue for longer than 12 weeks and cannot be explained by any other condition.



An estimated 1.3 million people living in private households in the UK were experiencing self-reported long COVID (symptoms persisting for more than four weeks after the first suspected coronavirus (COVID-19) infection that were not explained by something else) as of 6 December 2021<sup>1</sup>.

Long COVID symptoms adversely affected the day-to-day activities of 836,000 people (63% of those with self-reported long COVID), with 244,000 (18%) reporting that their ability to undertake their day-to-day activities had been "limited a lot"<sup>1</sup>.

Fatigue continued to be the most common symptom reported as part of individuals' experience of long COVID (50% of those with self-reported long COVID), followed by shortness of breath (37%), loss of smell (37%), and loss of taste (28%)<sup>1</sup>.

The 'Coronavirus and the social impacts of 'long COVID' on people's lives in Great Britain: 7 April to 13 June 2021' reports 6 in 10 (57%) of those surveyed who may have experienced long COVID reported this had negatively affected their general well-being; around 4 in 10 (39%) reported it had negatively affected their ability to exercise and 3 in 10 (30%) reported it had negatively affected their work<sup>3</sup>.

Those with long-term conditions have faced a higher risk of severe symptoms of COVID-19, increased isolation, reduced access to planned treatment or ongoing support<sup>2</sup> and a higher risk of neglect in the management of long-term conditions<sup>4</sup>.

Collectively we have faced the biggest challenge in population health in modern times. The health and care system has, and continues to, rightly focus on supporting those with severe COVID-19 symptoms whilst delivering a national vaccination programme. As a result, the NHS waiting list now stands at 6 million people, over 300,000 of whom have waited more than a year and with increasing concern that the number of people waiting for treatment could continue to increase.

1 -

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/3february2022> (Accessed 9th February 2022)

2 - NHS Digital. Appointments in general practice August 2020—experimental statistics. 2020. <https://digital.nhs.uk/data-and-information/publications/statistical/appointments-in-general-practice/august-2020>

3 -

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/coronavirusandthesocialimpactsolongcovidonpeopleslivesingreatbritain/7aprilto13june2021> (Accessed 22<sup>nd</sup> February 2022)

4 - Jamie Hartmann-Boyce, Kamal R. Mahtani. Centre for Evidence-Based Medicine, Nuffield Department of Primary Care Health Sciences. University of Oxford

### 3.0 NICE Guidance

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Section 5 of the 'COVID-19 Rapid Guideline: managing the long-term effects of COVID-19' issued by the National Institute for Health and Care Excellence (NICE), the Royal College of General Practitioners (RCGP) and Scottish Intercollegiate Guidelines Network (SIGN) recommends healthcare professionals caring for people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome who have been assessed in primary care or a multidisciplinary assessment service, are provided access to supported self-management.

### 3.1 Consensus Recommendation – Self-management

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The consensus recommendation states:

After the holistic assessment, discuss with the person (and their family or carers, if appropriate) the options available and what each involves. These should include:

- advice on self-management, with the option of supported self-management (see the section on self-management and supported self-management) and

Additionally, the panel recommends that advice and information should be provided on:

- ways to self-manage their symptoms, such as setting realistic goals
- who to contact if they are worried about their symptoms or need support with self-management
- sources of advice and support, including support groups, social prescribing, online forums and apps
- how to get support from other services, including social care, housing and employment, and advice about financial support
- information about new or continuing symptoms of COVID-19 that the person can share with their family, carers and friends (see the section on common symptoms).

### 3.2 Evidence to Decision

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The guidelines review panel agreed that:

- There was a need for patient information, including advice for patients on trends in symptoms, management of symptoms, and when to call professionals.
- There are likely to be waiting lists for referral into services and that people should be provided with clear information about what to expect, red flags and who to contact during this time. Patients could feel more empowered, with heightened sense of agency and control, if there are things they can do at home while waiting for referral, including potentially to aid their recovery.
- Self-monitoring at home can be useful and is used in practice although without the right information and support unnecessary anxiety can be caused.

There was little evidence on interventions, but the panel agreed that everyone should have self-management support and information. There was a lack of COVID-19-specific evidence on managing many of the common symptoms related to COVID-19, such as fatigue, dizziness and cognitive problems (such as 'brain fog'). However, there are established treatments for managing individual common symptoms.

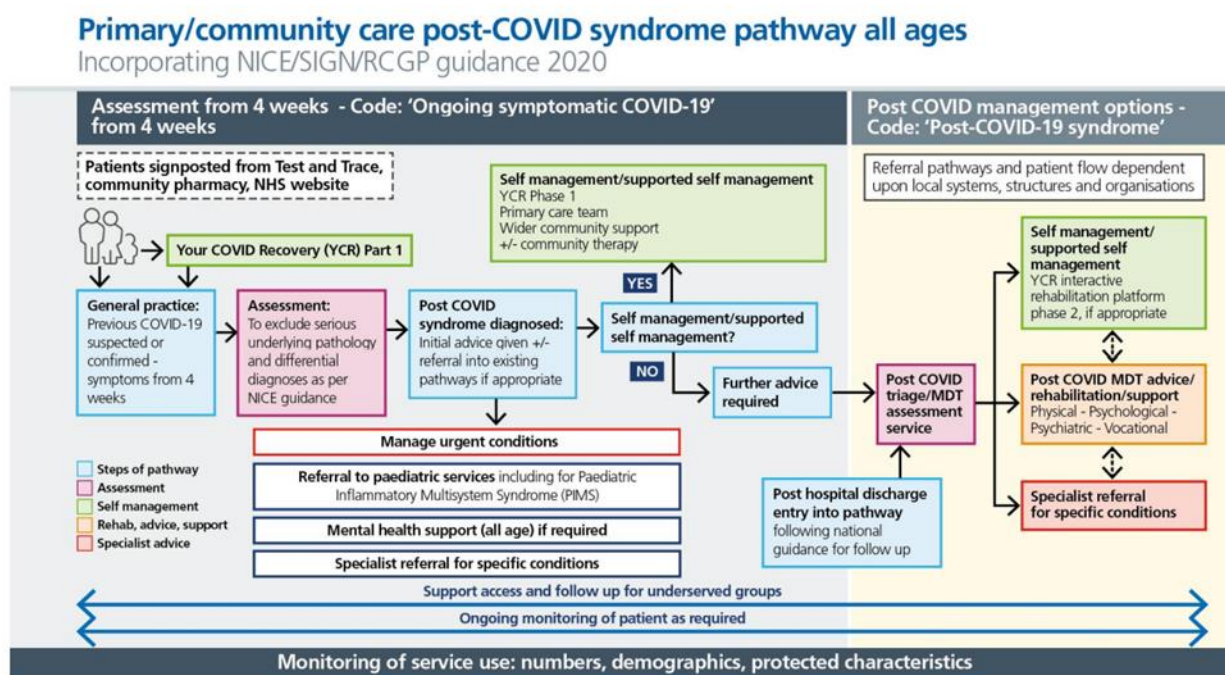
Whilst no evidence was identified in the evidence review, the panel regard it as important to give a recommendation for self-management by consensus.

Patient organisations and online support groups can help to support self-management. The Your COVID recovery website was also highlighted as a potential source of reliable, up-to-date information and support.

Lived experience suggested that access to appropriate care was a challenge for some, and fragmented care was also a contributing factor.

To ensure people get the right care and support, the expert panel agreed that a tiered approach could be used in which everyone gets advice for self-management, with the additional option of supported self-management if needed. People can then also be offered care from different services to match the level of their needs. The recommendation applies to all age groups and therefore the panel updated the recommendation in November 2021 to allow for discussion with the family or carers of the person if appropriate.

Chart 1 shows the Primary/ Community care post-COVID syndrome pathway



The National Institute for Health & Care Excellence (NICE), The Royal College of General Practitioners (RCGP), the Scottish Intercollegiate Guidelines Network (SIGN). COVID-19 Rapid Guideline: managing the long-term effects of COVID-19. P64-P69.

## 4.0 Our post-COVID Self-management response

### 4.1 Background

The impact of the COVID-19 pandemic on those who have one or more long-term condition cannot be underestimated. The COVID-19 pandemic has had a disproportionate impact on those experiencing existing inequality, particularly in areas of economic disadvantage and in Black, Asian and other minority ethnic groups<sup>1</sup>. This has been devastating, particularly considering the impact of inequality on the propensity and severity of long-term conditions.

Prior to March 2020, our supported self-management courses were delivered face-to-face to groups of up to 18 people. Due to the advice on physical distancing and shielding, in March 2020 we suspended all face-to-face services and began investigating alternative ways, via online platforms, of providing supported self-management. Despite the support on offer, including funding from our commissioners and the potential to access furlough support, the importance of continuing to provide our services was paramount.

An underpinning principle of our self-management courses is the interaction between people. Our courses are designed for groups of up to 15 people and their carers to attend at one time. We create an inclusive space for people to be able to safely share their experiences of having one or more long term conditions and to develop a sense of community and network support. The interaction between volunteers, tutors and participants is an important part of the impact our courses provide, particularly where attendees experience significant isolation and poor mental health, and it was therefore essential we develop an alternative that reflected the interaction between attendees and facilitators.

To safeguard the principles important to us, we made sure our response to the pandemic was truly co-produced with the people with whom we work and that we would meet the challenges faced collaboratively. Ensuring our change in delivery mode to online was relevant and met the needs of those we support, we asked our volunteers, tutors, people who attend our courses and staff if they would lead the development of our online services.

Online platforms exist to support those with diabetes, but little provision exists for those with multiple long-term conditions or experiencing poor mental health. Where digital self-management platforms do exist, they lack the interaction our courses provide and are not peer-led. Too often digital health platforms require an individual to complete an intervention in isolation. This requires a high level of self-motivation and does not foster the support or motivation that a group setting provides, and which is a fundamental part of the success of our courses.

In May 2020, we launched a pilot of our virtual X-PERT Diabetes course, consulting with staff, tutors and people attending, incorporating the feedback received into the course. We were surprised by the popularity of the course and by the end of the summer of 2020 we were operating at pre pandemic capacity. By March 2020, we had delivered 10 further X-PERT courses at no cost to our commissioners, to ensure we could meet the demand of those wanting to attend, increasing course retention rates from 86% for our face-to-face courses, to 90% for the virtual format.

**“We are the only provider in the region who has developed an alternative way of delivering services and able to provide support”** *(NHS Diabetes Commissioner May 2020)*

We launched pilots of our virtual Any-condition course (available to groups of up to 18 with ‘any’ long-term condition) in the Autumn of 2020 and our Mental Wellbeing course (available for those with a primary diagnosed mental health condition) in January 2021, both in the London Borough of Southwark. Again, the virtual alternatives have been exceptionally popular, and the feedback received overwhelmingly positive. In fact, our Mental Wellbeing course is operating at full capacity and experiencing a higher number of referrals and attendance per course than our face-to-face equivalent.



**“This is a good news story for the whole of the ICS. It has been challenging to reach those we need to, and this demonstrates we are taking the right steps for our populations”** (*NHS Long Term Conditions Commissioner March 2021*)

## 4.2 Long COVID Supported Self-management

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We are now developing a supported self-management course for long COVID. The course covers the key fundamental principles of supported-self-management and elements of our Any-condition and Mental Wellbeing courses.

The course will be available as a ‘live’ face-to-face course and virtual online option. Additionally, options will be available for a Train the Trainer model and online access to each virtual session at the viewers convenience for those unable to access a ‘live’ course.

The course subject areas include:

1. **Session One:** Introduction; What is long COVID?; Symptoms and symptom diaries; Self-awareness
2. **Session Two:** Fatigue; Energy management; Pacing
3. **Session Three:** Mental wellbeing; Asking for and accessing support

Each session is planned to be 1 hour 15 minutes long.

The courses will be delivered to groups of up to 25 people by peer volunteers and staff tutors.

The NICE COVID-19 Rapid Guideline: managing the long-term effects of COVID-19 document clearly identifies a lack of evidence supporting the consensus recommendation for supported self-management whilst acknowledging the strength of lived experience as a guiding principle in self-managements recommendation.

One of the central challenges to the development of post-COVID syndrome course is how to effectively evaluate the impact, given the absence of a nationally recognised self-management evaluation tool.

## 5.0 Our Ask

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We are funded primarily through NHS commissioning, for the provision of our supported Self-management. Whilst this allows us to continue to support those experiencing one or more long-term condition, our innovation and development is unfunded, and we do so from our own reserves and resources. Whilst we continue to innovate and develop our courses to meet the rapidly changing needs of our partners and audiences, our ability to do so across multiple areas of focus and need is restricted.

Whilst the NICE guidance on post-COVID support is welcome, it clearly identifies a number of gaps in the provision of supported self-management.





## 5.1 Our Vision

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Anecdotal evidence through feedback from our audiences suggests that getting support for ongoing symptoms after a positive diagnosis for COVID-19 is not straight forward. COVID-19 is a new challenge for the health and care system and treatment is complex, particularly considering new and emerging evidence of the widespread physical and mental changes that can occur because of infection.

Long COVID presents a complex challenge for the health and care system at a time when the system itself is experiencing multiple challenges. This is compounded by the need for diagnostic analysis to rule out experienced symptoms being caused by a non-COVID-19 pathology.

Our view is that supported self-management has a significant role to play in both the period pretesting and after a recorded diagnosis for Long-COVID.

NICE state that 'The panel expressed concern over the use of interventions to manage short term symptoms that might cause harm in the longer term, indicating the need for the guideline to advise caution over such interventions, including over the counter medicines.'

With this concern in mind, we believe those experiencing Long-COVID symptoms would benefit from access to supported self-management in helping management of symptoms through tools and techniques that do not require or encourage other interventions that may cause harm.

Increasing the number of those experiencing symptoms, to better manage, will help reduce the increasing demand on the health and care system.

## 5.1 Current Status

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We already have 2 successful variations of our Self-Management for Life courses – Any-condition and Mental Wellbeing. Both are available in face-to-face and virtual face-to-face delivery modes and variations of length (4-week and 7 week).

We also have an outline of a long COVID course, taking elements from both our Any-condition course and Mental Wellbeing courses.

## 5.2 Support Required

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We are now looking for support to:

- Continue the development of our supported self-management Post-COVID Supported Self-Management Course.
- Support the development of an effective evaluation and outcomes assessment methodology.
- Pilot the course and assessment of its' impact.
- Build capacity for adoption

## 5.3 Continue to develop our Long COVID course

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We have a draft course structure in place. The next steps are:

- Write the full Long COVID course manual
- Write the course tutor training manual

- Further engage individuals and groups for their feedback on the course content, structure and materials

#### 5.4 Develop an evaluation criteria

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There is currently no national consensus for the evaluation of the effectiveness of supported self-management. Additionally, NICE acknowledge the absence of specific evidence supporting the recommendation of supported self-management. We would like to:

- Engage with key partners including:
  - Primary care
  - Clinical teams
  - NHS England
  - Individuals and groups supporting long COVID
- Build consensus on how the effectiveness of supported self-management for Long COVID should be evaluated
- Evaluate the impact of our Long-COVID course through the pilot phase
- Evaluate the longer-term impact of the course over a 12-month period post course

#### 5.5 Pilot our supported self-management course for Long COVID

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We want to assess the effectiveness of our supported self-management course, particularly:

- Accessing the course (referral pathways)
- Quality of delivery (tutors, materials, platforms)
- Self-reported outcomes (quality of life)
- Long term outcomes (clinical – benefit to the health and care system)
- Participant feedback

### 6.0 Conclusion

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The demands on the health and care system have never been more acute, with a workforce stretched by the demands of COVID-19 and a population continuing to need care and support for their long-term conditions, health and wellbeing.

An estimated 1.3million people have reported experiencing symptoms of long COVID, the most common symptom of which is fatigue. Long COVID is having a significant impact on the quality of life of those experiencing symptoms including an ability to carry out day-to-day tasks being ‘limited a lot’ and for some, their ability to continue to work.

Long COVID presents a significant challenge to the health and care system, one that is already stretched in its capacity due to the COVID-19 pandemic.

The ‘COVID-19 Rapid Guideline: managing the long-term effects of COVID-19’ recommends self-management as a valuable tool in supporting those experiencing long COVID. The recommendation highlights an absence of evidence in supporting the recommendation but does acknowledge the importance of lived experience in forming the guidance issued.



*Your choices for better health*

We believe self-management has a critical role to play in supporting individuals, communities and the health and care system impacted by long COVID and believe we are ideally placed to contribute, through our 2 decades of experience, to the development of a supported self-management course for long COVID, its evaluation, effectiveness and impact on quality of life.