

Together Through Long COVID



A practice guide for social prescribing link workers (SPLWs) to support people living with long COVID from ethnic minority backgrounds.



This tool was co-produced using a Person-Based Approach in response to a gap in care for people from ethnic minority communities living with long COVID, identified through the [HI-COVE](#) project.



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One-page summary

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Overview & aims

TTLc COMPONENTS	PURPOSE
1. Long COVID awareness	Increase knowledge of long COVID among SPLWs.
2. Practice guide to support long COVID patients from minoritised ethnic communities	Guide to deliver culturally appropriate patient-centred care, support engagement with services, support navigation of complex care systems, and foster trust.
3. Resource directory	Central point for relevant information and guides for long COVID support and information.

** This document contains hyperlinks throughout. Click them for more information and references.*

Overview

People from ethnic minorities who have long COVID often find that the healthcare system doesn't meet their needs; they can feel ignored, turned away, or not given the care they need.^{1,2} Their care is further complicated by intersecting effects of gender inequality and financial hardship.³

Link workers and community connectors were found to play a particularly important role for people from ethnic minority communities, serving as bridges to the healthcare system, building trust, and reducing stigma. Together Through Long-COVID (TTLc) was developed to support Social Prescribing Link Workers (SPLWs) in providing more effective, equitable support to people living with long COVID from ethnic minority backgrounds.

The tool was systematically developed using a Person-Based Approach (PBA), drawing on existing literature, national guidance, and findings from interviews with patients with long COVID and professionals working with them.

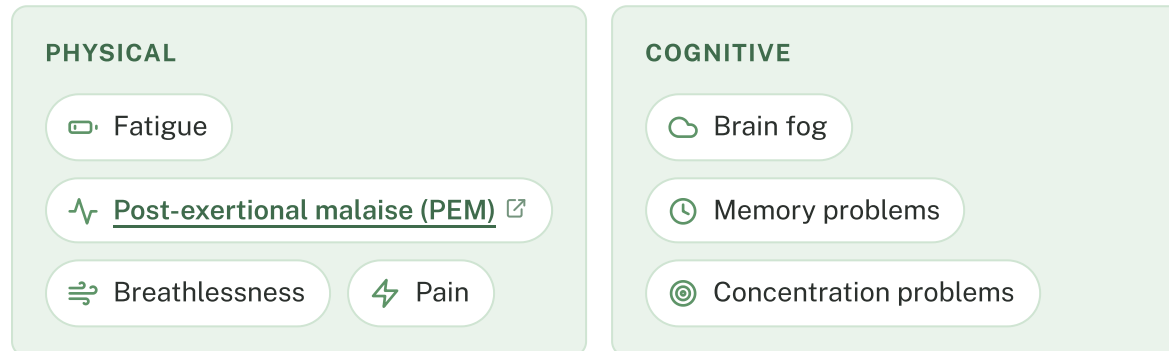
TTLc aims:

- To complement routine social prescribing practice by offering guidance for one-to-one conversations with patients with long COVID from ethnic minority backgrounds.
- To help SPLWs better understand patients' lived experience, social and cultural context, and priorities, to support trust-building and shared decision-making.
- To facilitate more personalised, culturally responsive care planning, to improve access, engagement and continuity of support for patients.

Important note on use: This tool is designed to be used flexibly and adapted to suit the individual needs of the patient and your specific practice context. You are encouraged to take what is most relevant and useful, and to tailor it to however many sessions you would usually offer. Not all sections will apply in every case. Where a suggested action falls outside your scope of practice or role, please refer or signpost to the appropriate external service or organisation.

Long COVID awareness

- This component is designed to support SPLWs in familiarising themselves with long COVID and its wide range of symptoms.
- Common symptoms may include:



- Beyond these, long COVID encompasses a wide range of additional symptoms spanning the neurological, muscular, cardiovascular, and respiratory systems, among others.
- Symptoms can fluctuate over time and vary significantly between individuals, both in type and severity. Because symptoms may not follow a clear or predictable pattern, it can be difficult for individuals to explain or manage.
- Long COVID also carries a significant psychological impact, with many people experiencing anxiety and depression, often compounded by the uncertainty and disruption that prolonged illness brings.
- Long COVID symptoms may occur in people who had a confirmed COVID-19 test, as well as in those who were never tested or did not receive a positive result.
- Long COVID can be severe and significantly impactful even in those who experienced a mild initial COVID-19 infection or were never hospitalised: the severity of the initial infection should not be taken as an indicator of the severity or impact of subsequent long COVID.

SUGGESTED ACTION

Refer to current guidance & support

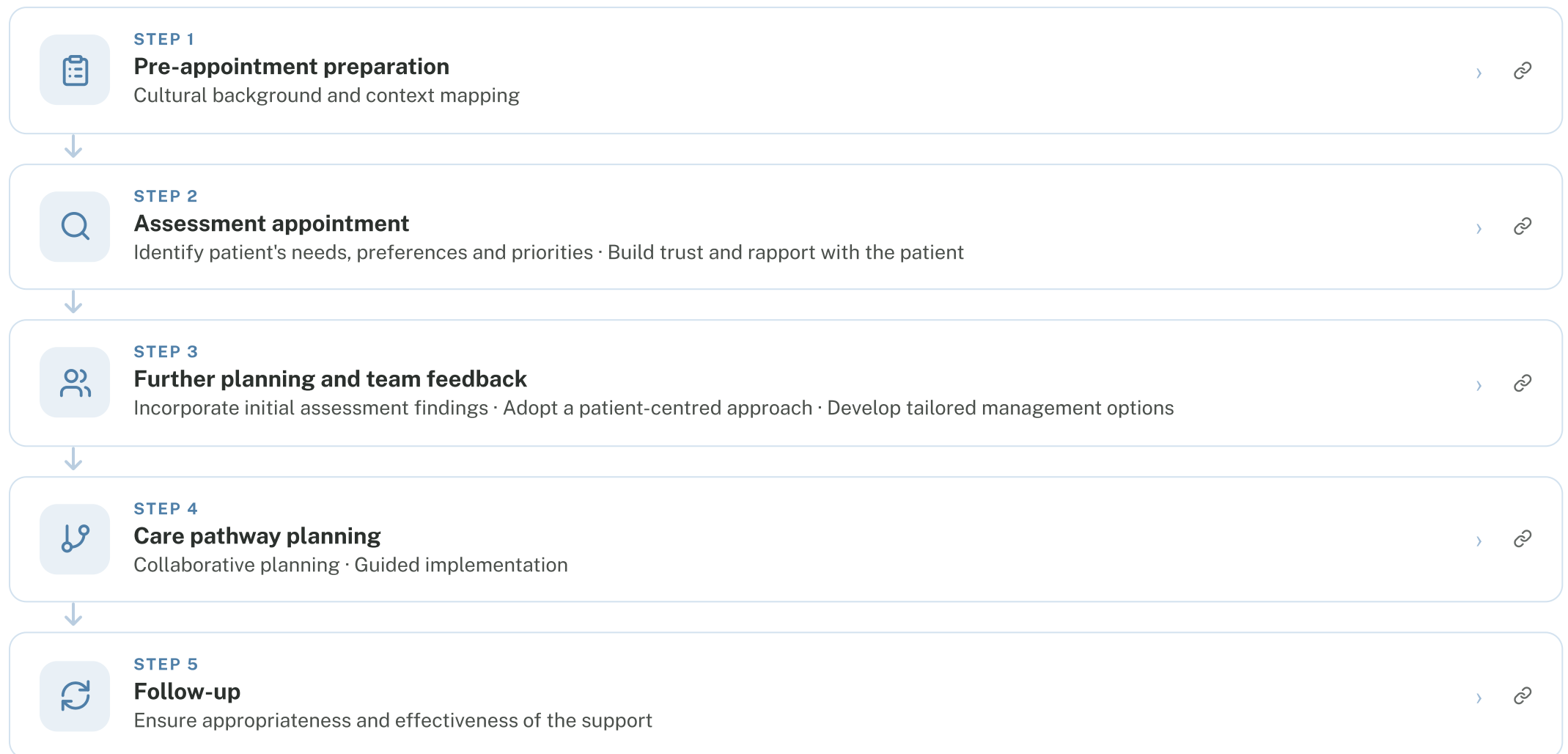
OFFICIAL GUIDANCE

- [NHS UK](#)
- [National Institute for Health and Care Excellence \(NICE\)](#)
- [Supporting Long COVID Care](#)
- [First Community Health and Care for patients and carers](#)
- [World Health Organisation \(WHO\)](#)

CHARITIES & SUPPORT ORGANISATIONS

- [Long COVID Support](#)

Practice guide to support people of ethnic minorities living with long COVID



- This step-by-step guide supports patient-centred one-to-one conversations between SPLWs and people living with long COVID from ethnic minority communities. This tool aims to enable the exploration of individual circumstances, priorities, and challenges, to support tailored care and trust-building.
- Appointments may be conducted by telephone, in person, or at home, depending on practice guidelines and the patient's practical needs and circumstances. This should be clarified with the patient at the earliest opportunity.
- This tool should be used flexibly. What is covered in any single appointment, the duration of appointments, and the total number of appointments should be tailored to fit the patient's needs. Breaks should be offered and built into appointment planning from the outset, recognising the fluctuating and often unpredictable nature of long COVID.

Cultural background and context mapping, building trust and rapport with the patient

KEY AREAS OF ATTENTION

- The patient's preferred language: language preference is not a single, fixed entity. Individuals may have different preferences and varying levels of comfort across verbal communication, written language, and reading. Explore each modality separately where possible.
- Cultural or religious practices that may influence care decisions (e.g., fasting, dietary restrictions, faith practices).
- For some individuals, faith is a central way of understanding illness and recovery, and influences the type of support they are willing to engage with. Where relevant, explore how faith may shape the patient's experience.
- Migration or asylum history, where relevant. Migrant status, like cultural and personal identity, may be something individuals define in ways that differ from what appears in documentation. People may not identify as migrants even if they were born elsewhere.
- Socioeconomic circumstances and time constraints, these may present significant barriers to accessing and engaging with care and attending appointments.
- Whether the patient has a [carer](#), and whether they would wish to have them present and involved in their long COVID care.

BEST PRACTICES

- Where possible, review available medical records, including System One, GP notes, and any other relevant documentation in advance of the appointment.
- Medical records are important for initial context, but be aware that recorded information may not always reflect a patient's personal beliefs, identity, or preferences.
- Seek guidance on where to access the relevant notes from your practice.
- Confirm whether the patient requires a language interpreter and consult [relevant guidance](#).
- Consider connecting with local organisations that work with specific populations, if available.
- For migrant patients, seek to understand the specific [entitlements](#) they have based on their immigration status and residency.
- When a specific risk is disclosed, follow your practice's safeguarding pathway.

FOR MORE HELP

- Refer to the [Toolkit for SPLWs for supporting migrants by Doctors of the World](#).
- Search online or through professional networks to identify and consult with community connectors, cultural mediators, and local community organisations that support specific ethnic groups in your area.

Understand patients' priorities and preferences for care, create safe space, and explore with patients their needs, experiences, and circumstances

KEY AREAS OF ATTENTION

The initial assessment should be guided by what the patient identifies as most important to them, rather than what may appear most clinically impactful. Explore the following areas, pacing the conversation according to what the patient is able to cope with in the session:

- Symptoms the patient considers most important to address in order to feel better.
- Previous and current healthcare and/or community support.
- Any experiences of discrimination from services, including racial discrimination. (Note: this topic may be too sensitive for some patients to discuss in a first meeting. Explore this gradually, when sufficient trust has developed and the patient appears sufficiently at ease to share openly).
- Preferences for type of support (formal care provider or community support) and mode of support (group-based, self-management, home-based, online).
- Whether the patient would like to involve personal networks such as family, friends, or peers. (Note: Explore support systems broadly in the initial meeting, and introduce more specific enquiry into family dynamics gradually in subsequent appointments, once trust has developed.)
- Absence of support and social isolation: Does the patient have social support? Are they experiencing isolation?
- Be attentive to factors that may inadvertently function as exclusionary barriers for some patients.
- Digital literacy: whether the patient has the skills and access to engage with digital tools and technology-based support, to ensure any recommended resources are accessible and appropriate.
- Comorbidities: pre-existing conditions whose symptoms may overlap with and impact long COVID, adding complexity to both understanding and care planning.
- Caring responsibilities: whether the patient has caring responsibilities for others, as these may present barriers to accessing their own care. Where relevant, explore ways to navigate these demands or signpost to external support.
- Demographic factors and family dynamics that may act as barriers to care-seeking, so that the care pathway can be planned in a more informed and effective manner.
- Stigma: whether stigma related to long COVID, mental health, or social and cultural factors may be shaping the patient's willingness to seek and engage with support.
- Practical daily living challenges: including any difficulties with home hygiene or everyday tasks. Some patients may be reluctant to volunteer these needs due to embarrassment, introducing this topic proactively and in a normalising way can be helpful.
- Additional needs, such as home environment, technology support, or community health literacy.
- Hobbies and activities the patient previously enjoyed, with a view to potentially reintegrating these into care and recovery as a means of reconnecting with a sense of their former self and personal identity.

BEST PRACTICES

- Start by explaining your role clearly. Be transparent that your purpose is to understand the patient's preferences and priorities so that any advice can be shaped around their needs.
- Explain that you are not able to provide a formal diagnosis.
- Ask questions instead of assuming context or background.
- Ask permission before exploring personal topics.
- Use a slower pace and a softer tone to help create a calm and supportive atmosphere.
- Offer breaks and ensure that time for breaks is built into your appointment planning.
- Repeat back what you have understood so the patient can confirm, correct, and feel heard.
- Remain attentive to non-verbal cues of distress throughout the appointment, not only when directly asking about sensitive topics.
- Work collaboratively with the patient throughout to support them in determining what is best for them.

FOR MORE HELP

Consider [e-learning training for SPLWs on culturally responsive practice](#) [↗](#).

Build on the insights gathered during the initial assessment and design a set of tailored management options that reflect the patient's preferences, priorities and circumstances

Important note: Refer the patient to appropriate services or organisations whenever their support needs fall outside your time, role, or expertise.

KEY AREAS OF ATTENTION

- Using information from the first meeting to shape an appropriate pathway that aligns with what matters most to the individual.
- This may include feeding back to the wider team and contributing to multidisciplinary planning, where this is in line with your practice guidelines and role.
- Consider non-medical referral routes relevant to the patient's background, such as community organisations, faith groups, and migrant support charities.
- Ensure the services being discussed are age-appropriate, gender-responsive, and aligned with the patient's specific community needs.
- Include broader supportive needs as integral components of a comprehensive plan, including:

Financial support: Many patients may have experienced income loss and financial strain, which directly impacts their ability to recover and engage with care.

Practical support: including help with daily living tasks where relevant.

Mental health support: recognising the psychological dimensions of long COVID, such as anxiety, depression, and frustration.

Best Practices: These three routes can be used separately or combined depending on the patient's needs.

If the patient prefers a more independent approach to managing their challenges

SUGGESTED ACTIONS FOR GUIDED SELF-MANAGEMENT

- Ensure self-management focuses on the challenges the patient identifies as most important to them.
- Integrate cultural practices such as prayer rhythms, community support, family roles, and rest traditions.
- Include examples that reflect the patient's specific everyday life and interests.
- Use existing established resources to inform the plan (e.g., [NHS](#), [Your Recovery](#), [Long Covid Self Management Workbook](#)).

If the patient needs to seek additional services

SUGGESTED ACTIONS FOR CONNECTING TO RELEVANT SERVICES

- Refer to culturally inclusive services or activity groups (e.g., clinics with interpreters, services that are age-appropriate, gender-responsive, and aligned with the specific community needs).
- Identify local community hubs or support groups that are inclusive and safe.
- Create a tailored list of services and organisations based on the patient's location, language, background, and needs.
- Offer guidance on what to expect during appointments with recommended services.
- Offer help in preparing for appointments (e.g., phrases to use, what to expect).
- Share information from credible sources with patients where feasible and in accordance with their preferences, to support informed engagement with their care. Where direct sharing is not possible, connect patients with organisations that can support their understanding of long COVID.

If the patient seeks to involve their family in their support

SUGGESTED ACTIONS FOR FAMILY ENGAGEMENT

- Educate and involve family members to help foster a supportive home environment.
- Arrange family sessions or information leaflets in appropriate languages.
- Discuss the sometimes [invisible nature of long COVID symptoms](#) and how loved ones can help.

Introduce and describe management strategies aligned with the patient's priorities and facilitate access to support

KEY AREAS OF ATTENTION

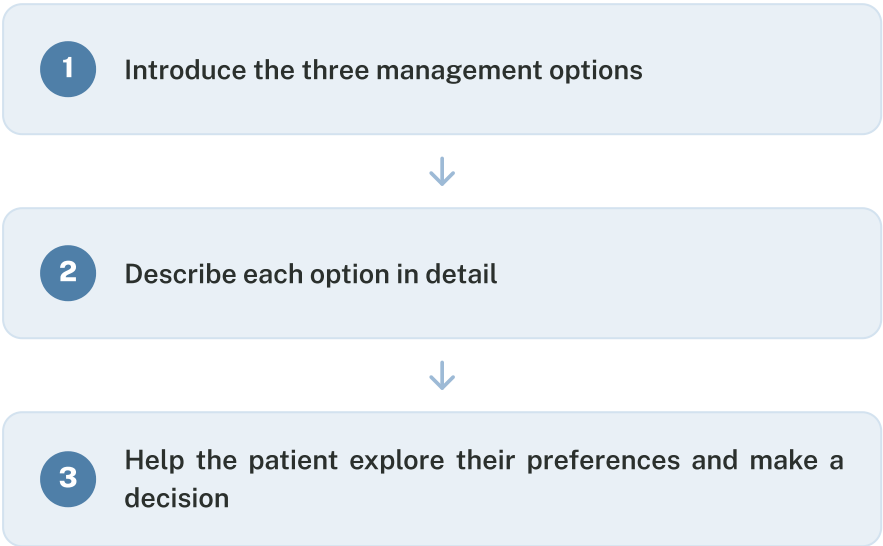
- Explain the long COVID recovery process.
- Understand age-appropriateness. Understand transport considerations. Understand available social support.
- Refer the patient to appropriate services or organisations whenever their support needs fall outside your time, role, or expertise.
- Explore the patient's ability to self-manage.
- Provide family support and engagement where relevant.

BEST PRACTICES

Setting expectations around recovery

It is important to set clear expectations around recovery from the outset of the care planning phase. Key points to communicate:

- Long COVID symptom improvement and recovery are variable between individuals, and progress at different rates is entirely normal.
- Improvement is likely, but adaptations to living with ongoing symptoms of long COVID may be needed.
- Maintain positivity and hope, whilst being honest about the uncertainty of the illness trajectory.
- This information should be communicated with sensitivity and compassion, with space for the patient to respond and process what they have heard.
- Practitioners should be equipped to offer, refer, or signpost patients to appropriate emotional support, should this information prove distressing.
- Patients may also require understanding and support to adapt to the broader life changes that long COVID may necessitate.
- **To introduce and describe management choices:** Consider using the [Three-Talk Model \(NICE-recommended\)](#) to facilitate collaboration:



- If the patient chooses to access additional services, help by making initial introductions, explaining how to access the service, outlining what to expect, and offering support with any required forms or administrative processes.
- If the patient seeks support with family engagement, arrange an additional meeting suited to their needs and help set up a family session.
- Use the [teach-back approach](#) once a care plan has been agreed upon, i.e., invite the patient to explain in their own words what was discussed, what will happen next, and what actions are expected. Reassure them that this is not a test but a way to ensure the explanation has been clear.
- Consider using a translation tool recommended by your practice to share relevant information or notes in the patient's preferred language; general translation tools may not be compliant with data protection laws.

Review whether the support provided has been useful and explore any barriers, emerging challenges, or new needs

KEY AREAS OF ATTENTION

- Explore any barriers the patient encountered in accessing or engaging with the suggested support.
- When experiences of discrimination are raised, use open, non-leading questions to explore what happened. Invite the patient to share their experience broadly. If discrimination is reported, offer an alternative source of support, consider raising it within your practice, and discuss the next steps.
- Consider religious or cultural factors that may have influenced access to or engagement with care (e.g., festivals, fasting periods).
- Understand whether social support has influenced care-seeking.
- Where relevant, explore any new challenges that have arisen since the last meeting, or needs the patient now feels comfortable sharing that they did not raise earlier. This creates space for the care pathway to remain adaptive and responsive over time.

BEST PRACTICES

- Follow-up should be flexible and responsive to the patient's needs and your capacity.
- Consider informing patients that they can proactively reach out between scheduled appointments if anything needs to be addressed or if they are struggling, rather than waiting for the next scheduled contact.

Suggested questions and prompts to follow up

Use open-ended, non-leading questions throughout the follow-up to allow for authentic, patient-led responses. Avoid questions that may inadvertently direct the patient's response.

- ☐ Were you able to follow through with the support or self-care plan we discussed?
- ☐ What has been most helpful? What has been more challenging?
- ☐ Is there anything that has not been useful, and if so, do you have a sense of why?
- ☐ Were you comfortable with the way you were treated?
- ☐ Were you comfortable with the language that was used?
- ☐ Is there anything you would like to try differently or explore further?
- ☐ Is there anything new or emerging that you would like to talk about, or anything you did not feel comfortable raising before?

Resource & services directory

The chart below organises available resources by patient need, inclusivity, and suitability for direct patient sharing. Resources marked as 'patient-facing' are suitable for sharing directly with patients. All other resources are primarily intended for practitioner reference.

KEY ✓ Patient-facing · highly inclusive & translatable Professional / clinical resource

Navigating Long COVID Resources

Symptom Management	Rehabilitation & Recovery	Specific Symptoms	Workplace Issue	Peer and Community	Professional Guidance	Mental Health Support
✓ WHO Self-Management Guide ↗	Leeds Teaching Hospitals & Community Healthcare Rehab Booklet ↗	Tinnitus UK ↗	Society of Occupational Medicine ↗	✓ Long COVID Support ↗	Health & Social Care Professional — Long COVID Tool ↗	Mindfulness for Managing Long Covid ↗
✓ SIGN Long COVID Patient Booklet ↗	First Community Health & Care Rehab Guide ↗	POTS UK (Postural Tachycardia Syndrome) ↗	Long COVID Work ↗	✓ Long COVID SOS ↗	Supporting Long COVID Care ↗	✓ IAPT — NHS Talking Therapies ↗
✓ Long COVID Self-Management Workbook (NHS Scotland) ↗	Long COVID Physio ↗	Smell & Taste Support ↗	✓ Citizens Advice ↗	Chest Heart & Stroke Scotland ↗	Lincolnshire Partnership COVID Booklet ↗	Money and Mental Health ↗
Black Country ICB Symptom Management ↗	Nuffield Health — Long COVID Recovery ↗	Buckinghamshire Nutrition Advice ↗	✓ Shaw Trust (In-Work Support) ↗	✓ Still Looking for Answers — the unheard voices of Long COVID (video artwork) ↗		✓ Mindfulness ↗
✓ Living With App ↗	ENO Breathe (breathing through singing) ↗	RCOT Fatigue Guidance ↗	✓ Law Centres (Employment Legal Support) ↗			
		Pain Management with Long Covid ↗	✓ Debt & Financial Management Support ↗			

[Take part in our evaluation survey](#) [↗](#)

Together Through Long COVID

A co-produced practical tool to provide more effective, equitable support to people living with long COVID from ethnic minority backgrounds.

Tool Aims

- 1 Build Awareness:** Deepen your knowledge of long COVID symptoms, understanding of impact of long COVID, and the barriers faced by ethnic minority communities.
- 2 Deliver Patient-Centred Support:** Apply guided prompts and culturally sensitive language to deliver empathetic, trust-building conversations tailored to each patient's lived experience.
- 3 Resource Directory:** Refer to the curated directory to keep yourself updated with information or to share relevant resources with patients.

How to Use

- 1 When preparing for appointments:** Review the [long COVID Awareness](#) section. Familiarise yourself with the patient's context and relevant cultural considerations.
- 2 During the appointments:** Use the [One-to-One Support](#) prompts to guide the conversation at the patient's own pace, with empathetic and culturally sensitive language.
- 3 Information and Reference:** Use reference material in the [Resource Directory](#) for further information or to suggest for patients' knowledge.

Guide to Support

- 1** Map the cultural and contextual background
- 2** Identify patients' needs and build trust with patients
- 3** Develop patient-centric, tailored management options
- 4** Plan the intervention collaboratively and guide the support
- 5** Follow up to ensure appropriateness and effectiveness of the support

Long COVID awareness

Common Symptoms

Fatigue, breathlessness, pain, brain fog, memory and post-exertion malaise

Impact of long COVID

Long COVID can have a profound impact on a patient's quality of life, affecting their ability to work, maintain relationships, carry out daily activities, and engage with care.

Long COVID progress and Recovery

Long COVID recovery may not only be slow, but it is also highly variable between individuals and progresses at different rates, which is entirely normal.



[Long COVID awareness guide](#)

[Practice guide to support](#)

[Resource directory](#)

[Take part in our evaluation survey](#)

ACKNOWLEDGEMENTS

The team behind this guide

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