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Long COVID

A framework for nursing, midwifery, and care staff

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Kerry Davies – Living with long COVID

In March of 2020 I developed post COVID syndrome, also known as long COVID. When I was asked to share my story as part of this framework it was a relief and I was hopeful. A relief that people were listening and hopeful that by sharing my story I may help others to be supported and cared for while we learn everything we need to know about this new illness.

As a previously healthy 45-year old woman, devoted mum to two amazing teenagers, wife to the most supportive husband, and a proud nurse working in the NHS for more than 19 years, my journey so far with long COVID has been hard but I know for some it has been even harder.

My initial acute COVID-19 symptoms were mild. It started with headaches, brain fog and rashes on my arms. I was ill for two weeks and then appeared to make a full recovery. I returned to work, resumed running and my usual busy life.

Over the following months I was hit with waves of debilitating and fluctuating symptoms; one moment I could function and the next I couldn't. There was no pattern, but it felt endless. I was plagued by symptoms including body rashes, fatigue, upset tummy, heat intolerance, low oxygen saturations, coughing, headaches, neck pain, tachycardia, bruising, pain in the side of my head and joints, as well as an ongoing feeling of lactic acid build up in my arms, cognitive dysfunction and daily high temperatures. Predicting my energy levels and abilities from one hour to the next was exhausting and made these early months difficult and debilitating

At around eight weeks the cognitive difficulties really hit me, and I struggled to process words, and hold conversations (at times I couldn't read or spell, and I didn't recognise letters). I had developed slurred, muddled speech, and I became more confused. I was unable to recall (and understand) how to do 'basic tasks', such as hanging out the washing, charging my phone, crossing a road, or unlocking a door. Despite this, to the unsuspecting bystander I looked 'fine'.

Back in 2020 long COVID was an unknown. That was one of the hardest parts, the unknown, the unheard of and the loneliness of not recovering. My general practice team were supportive, listening to me and ensuring I got the assessments and tests I needed. I accessed more health services and professionals than I had in my whole life – scans, X-rays, blood tests and numerous specialist assessments, and I had the unconditional support of my trust’s occupational health consultant. I will be forever grateful to them.

Referrals to neurology and speech and language therapy, as well as my local long COVID specialist services, where I learnt to pace my life, have helped me manage some symptoms, but I appreciate everyone’s symptoms are different and this is why a truly holistic person-centred assessment is crucial.

Two years on, I am better than I was – but I’m not better, I’m not recovered.

I have dedicated my working life to the care of others but for now I have had to stop.

I want to ensure those with long COVID have a voice and that this voice is heard in all areas where decisions are made that may affect us. So, I have welcomed opportunities such as joining the University Hospitals Morecambe Bay NHS Foundation Trust National long COVID Network and speaking at national long COVID conferences.

This is my long COVID journey, and I hope by sharing it and supporting this framework for all nurses, midwives, and care staff in England I help you shape good quality care for those in your communities. We need to make a difference by listening to those who need us and understanding that long COVID is real and debilitating. Early support and consistency, more investment, research, and treatments are crucial.

I encourage you all to read this framework and look for those who are struggling with this illness – as well as all those with other long-term chronic illnesses – who need you to listen and be supportive.

Validation, acceptance and understanding help immensely. Please help make things a bit more bearable for patients with long COVID. I know first-hand that this is a lonely, frustrating, and difficult journey to be on.

Forewords

Throughout the COVID-19 pandemic, individuals and teams have done a huge amount to support each other and the services we deliver to our communities. Despite the unprecedented challenges, nursing and midwifery teams have responded with commitment, compassion, and integrity.



As we face the new condition of long COVID, experiences such as Kerry's clearly demonstrate that there is more to do. Within our communities, we all need to consider our response to it, coming together to ensure our patients and our colleagues get the best care possible.

Across the breadth of the healthcare system, our expertise and knowledge positively impact on the lives of so many. I see registered nurses, midwives and care staff across health and social care as integral to the multidisciplinary team response to this complex, multi-system condition.

I am a strong advocate for nurse-led care, from service design through to delivery. This is no different for long COVID. By embracing our professional leadership in the response to long COVID we will continue to drive forward high-quality care and support for those who need our services.

This framework offers an opportunity for our professions to come together with one strong collective voice. Ensuring care is based on evidence and research and underpinned by an understanding of our patients' and communities' needs, we can meet this challenge and help those who require our support. Advocating for our patients, their families and unpaid carers ensures the highest possible quality care is delivered.

At its heart, this framework highlights the true value of holistic person-centred care by showcasing the important skills that nursing, midwifery and care staff bring to the commissioning, design, delivery and evaluation of long COVID care and I thank you for this.

Ruth May
Chief Nursing Officer for England

Long COVID is a pandemic within a pandemic and I see a key role for nursing midwifery, and care staff.

As a significant health problem for many people, we now need to tackle long COVID with the same focus we have held throughout the acute pandemic.



The skills and expertise of nurses, midwives and care staff make us ideally placed to manage the complex array of physical, psychological and, importantly, social impacts of long COVID.

As professions we are experienced in dealing with uncertainty without detriment to the quality of the care we provide. For long COVID it is key that we come together to share our expertise with those who need it most. I thank Kerry and all those with the condition who continue to guide us in the national team, and I encourage you all to think about your role in this response. Considering how you can work with colleagues as part of a wider multidisciplinary team to ensure our services meet our patients' needs. Whether in general day-to-day practice, within specialist or research roles, as commissioners, leaders, managers or as experts in the field, our professions are key. Whether you work in a care home, primary and community care services, a hospital, prison or academia and research – you have a role.

Over the last year my colleagues in NHS England and I have listened carefully to the collective voice of nursing, midwifery and care staff, and I continue to be inspired by the commitment to providing the highest possible standards of care and service delivery. I see this framework as an opportunity to further embrace our leadership potential. It is critical that we familiarise ourselves with the evidence and requirements to diagnose and support those with long COVID – and remember that patients may present in many setting with no diagnosis and a complex set of issues.

I thank you for your ongoing support, guidance, and leadership. I also thank across the broad range of organisations who have supported the development of this framework. This includes the NHS England long COVID team, nurses and midwives from Health Education England, the Office of National Disparities, the Royal College of Nursing, the Queen's Nursing Institute, the Shelford Group, and the University Hospitals Morecambe Bay NHS Foundation Trust Long Covid Network.

Mark Radford
Deputy Chief Nursing Officer for England

Introduction

In the UK it is estimated that 2 million people report experiencing long COVID ([Office for National Statistics](#)). While work is underway to understand the spread and scale of the lasting effects of long COVID, we need appropriate care pathways, services, and treatment options in place for those already impacted.

The nursing, midwifery and care workforce are intrinsic to the commissioning, modelling and delivery of a holistic health offer for our people, and this is no different for the response to long COVID. Professional models provide us with a sound evidence base to embrace a multi-dimensional (and professional) model befitting the health and care landscape today.

This framework supports us as nurses, midwives and care staff in ensuring our care remains at a high standard, as well as demonstrating our significant contribution to the long COVID response. It gives us the opportunity to embrace our collective leadership in supporting the people and communities we serve and showcase good practice as it emerges across England.

This framework is for all nursing, midwifery, and care staff – no matter where you work, no matter what your role.

What is long COVID?

The long-term effects of COVID-19 are often referred to interchangeably as long COVID and post COVID syndrome. The [NICE](#) guidance on managing long-term effects of COVID-19 (updated November 2021) gives the following clinical definitions below:

- **ongoing symptomatic COVID-19:** signs and symptoms of COVID-19 from four up to 12 weeks.
- **post COVID-19 syndrome:** signs and symptoms that develop during or after COVID-19 and continue for more than 12 weeks and are not explained by an alternative diagnosis.

[NICE guidance](#) describes how the condition usually presents with clusters of (often overlapping) symptoms, which can change over time and affect any system in the body.

Nursing, midwifery and care staff are experienced in supporting people when there is uncertainty, change and challenge; they demonstrate the necessary skills every day.

As a complex multi-system condition with more than 200 symptoms ([Davis et al 2021](#)), long COVID's impact can be wide ranging – affecting a person's physical, mental and psycho-social wellbeing. This underlines the importance of a holistic approach to care.

Find out more

Long COVID and the associated symptoms: [Your COVID Recovery | Supporting your recovery after COVID-19](#)

Clinical definitions of this subset of illnesses included within this condition:

- <https://www.nice.org.uk/guidance/ng188>
- <https://www.nhs.uk/conditions/coronavirus-COVID-19/long-term-effects-of-coronavirus-long-COVID/>

The National Institute for Health Research Centre themed reviews on long COVID: [Researching the long-term impact | NIHR](#).

Explaining the framework

This framework aligns with the [NHS plan for improving long COVID services](#) and the [national commissioning guidance for post COVID services](#). It ensures that the contribution of nursing, midwifery, and care colleagues to the multidisciplinary long COVID response is fully recognised. More broadly, the framework embodies the ethos of the [NHS Long Term Plan \(2019\)](#) in seeking to develop new ways of working that are person-focused and provide seamless care across health and social care.

To realise these ambitions, this framework has been developed collaboratively with a wide range of organisations, partners, and stakeholders, showcasing the collective, professional voice of the nursing, midwifery and care professions across systems and settings. Crucially, this includes close liaison with long COVID experts by experience.

This framework is a supportive resource for staff as they navigate and respond to the challenges in responding to long COVID. Throughout the document, 'we' and 'our' refers to all nursing, midwifery, and care staff – but recognises that registered nurses will lead the planning and evaluation of care delivery.

Through using resources such as those included in this document, this framework enables and empowers nurses, midwives, and care staff across England to maintain a strong professional voice within long COVID decision-making discussions.

And through professional curiosity and personal development (underpinned by evidence-based practice, which listens to and responds to the needs of our patients and communities), there is an opportunity for all nursing, midwifery and care colleagues to become experts in the field and positively challenge areas of concern.

Specifically, this framework supports us to deliver care of the highest quality and value by:

- providing support for the modelling and commissioning of national, regional, and local work programmes
- signposting to specific evidence-based tools, theoretical frameworks and resources to enable our professional leadership response and support day-to-day practice
- supporting quality improvement approaches to enable effective and safe patient care
- contributing to your continuous professional development and revalidation.

Find out more

The Institute for HealthCare Improvement (IHI) [Quality improvement essentials toolkit](#) includes the tools and templates you need to launch a successful quality improvement project and manage performance improvement.

Healthcare Quality Improvement Partnership (HQIP) [A guide to quality improvement tools](#) signposts those working, leading, commissioning and using healthcare services to a broad range of quality improvement tools.

The Health Foundation [Quality improvement made simple](#) is especially useful for health and care staff leading fast and efficient service change as a result of the pandemic.

This framework is an iterative document. It will be updated as further evidence emerges. It is intended to spark discussion and consideration to inform evidence-based clinical practice, which flexibly responds to the research on long COVID.

1. Supporting professional diagnosis

Long COVID has a complex symptomatology, and it is important to be aware that how it manifests in one individual may not be the same as in another, and that its symptoms may evolve and fluctuate.

Evidence highlights that patients with long COVID can exhibit involvement and impairment of the structure and function of multiple organs ([Raman et al 2021](#), [Sollini et al 2021](#), [Dennis et al 2021](#)). These long-term symptoms do not directly correlate to initial COVID-19 disease severity. Clinicians need to be able to identify which patients belong to which subgroup of long COVID and understand the associated disordered physiological processes. This supports us in planning the best treatment options for the person, their families, and unpaid carers.

For example, neurological, cardiovascular – including postural orthostatic tachycardia syndrome (POTS), renal and pancreatic symptoms, as well as autoimmunity abnormalities, are recorded in those with long COVID. These symptoms are debilitating and can challenge plans for longer-term rehabilitation as well as ongoing care during recovery ([Raman et al 2021](#), [Dennis et al 2020](#), [Dani et al 2021](#), [Hadi et al 2020](#)).

It is also key as part of holistic care planning and assessments to consider the impact on other organs and tissues, such as the gastrointestinal tract, liver, blood vessels and muscle, as evidence suggests these are also susceptible to direct damage from COVID-19 infection ([Ruggeri et al 2021](#)).

Common symptoms include:

- weakness/tiredness/fatigue
- shortness of breath
- cognitive dysfunction, including difficulty concentrating ('brain fog')
- loss of smell
- loss of taste
- muscle ache
- headache

- worry/anxiety
- low mood/not enjoying anything
- sleeplessness and sleep disturbance.

Individuals may have had COVID-19 infection without recognising or experiencing any symptoms and may not have made the link between their symptoms and the COVID-19 virus. Therefore, raising awareness of the [symptoms and health challenges faced by people with COVID-19](#), and subsequently [those faced by people with long COVID](#), is fundamental to the services and support offered to the individual, as well as the wider implications this may have on them.

Given the complex aetiology, the use of screening and assessment tools may support nurses and midwives to signpost individuals to appropriate, tailored support via further comprehensive assessment. These should include screening for the physical (including cognitive), psychological and emotional impact of experienced symptoms ([NICE guidance](#)).

“General practice nursing (GPN) teams working across England provide a variety of services to the whole practice population, often being the first point of contact for patients and therefore key to supporting and increasing the awareness of long COVID. They are experts in the assessment, delivery, and co-ordination of complex care for all patients, including those with multiple co-morbidities. GPN teams are highly skilled in promoting self-management and self-care, alongside the exploration of differential diagnosis in symptomatic patients, that may be linked to existing conditions or potentially long COVID and initiating onward referral as required. They have strong links and networks across a range of community and hospital-based services, evaluating impact and responding to the changing needs of their patients with long COVID.”



Paul Vaughan, Deputy Director of General Practice Nursing and Next Gen Nursing, NHS England

Find out more

The approaches in frameworks such as [Making Every Contact Count \(MECC\)](#) support us to maximise our impact in day-to-day interactions with people on raising awareness and supporting them to positively change their physical and mental health and wellbeing.

No matter what your role or where you work, your opportunistic delivery of consistent and concise healthy lifestyle information supports every-day conversations about health and wellbeing.

Access the **e-learning for health Long COVID national eLearning package**: [Long Covid - eLearning for healthcare \(e-lfh.org.uk\)](#)

2. Supporting assessment and treatment

As accountable professionals, nurses, midwives and care staff are experienced in assessing need, as well as planning and providing safe, compassionate person-centred care. This may be via initial assessment and facilitation of further investigations at the point of presentation, or for the ongoing care, case management and longer-term support, monitoring the impact of interventions on the ongoing health of the person.

Current estimates of the prevalence of long COVID suggest that whatever the care setting you work in; you are likely to encounter people with the condition. It is this, alongside the expertise and skills we possess as professionals, that provides us with a unique opportunity to ensure we make every contact count.

As practitioners who are highly skilled in providing education to those using our services, we are experts in promoting healthy behaviours, as well as complex problem solving when challenges present.

Throughout their range of activities nurses, midwives and care staff support recovery, physical, mental and emotional, as reinforced by our professions' code of practice ([The Code: The Nursing and Midwifery Council](#)).

Our professional curiosity supports us in understanding the wide impact long COVID may have on a person and, where applicable, in considering the best course of action with the person, their family and unpaid carers.

The NHS plan for improving long COVID services identifies the three principles of care for those with long COVID as: personalised care, multidisciplinary and rehabilitation, and supporting and enabling self-care. Through such holistic approaches we can tailor the offer to meet the person's needs at every step of their care and treatment.



Always:

- listen to people and ask, "What matters to you?".
- work as part of the multidisciplinary team.
- tailor support and rehabilitation to the person's needs.
- ensure care plans address physical, mental, and social needs.
- support and enable the person to manage the aspects of their condition they can; the person must remain at the centre of their care.

[Personalised care and support planning](#) is a series of facilitated conversations in which the person, or those who know them well, actively participates in exploring the management of their health and wellbeing within the context of their whole life and family situation.

The National Institute for Clinical Excellence ([NICE 2021](#)) guidance on managing the long-term effects of COVID-19 covers:

- assessing people with new or ongoing symptoms after acute COVID-19
- investigations and referral
- planning care
- management, including self-management, supported self-management and rehabilitation
- follow-up and monitoring
- service organisation.

“Long COVID specialist nurse roles act as clinical experts and are a professional resource for patients and their carers, as well as for colleagues in the wider MDT. They ensure care and treatment plans adhere to national and local guidelines for the management of long COVID, as evidence emerges, and maintain responsibility for the caseload of long COVID patients, including the delivery of telephone consultations using a comprehensive assessment. These roles provide direction and clinical leadership, using the nursing teams’ clinical expertise and skills for the benefit of patients as well as the development of local and national forums to drive forwards and support a better understanding of the condition. Serving as a champion for evidence-based care and new ways of working the specialist nurse role is fundamental to high quality holistic long COVID care.”



Nicole Tracey, Catherine English, and Jason Mauree, long COVID specialist nurses, The University Hospitals of Leicester NHS Trust

Find out more

[The Humanistic Model \(Paterson and Zderad 1976\)](#) purports that the nurse–patient relationship is key where both the nurse and the patient have influence over the outcome of nursing interventions.

This model sees the patient as an individual with a unique set of circumstances and aids us to think outside pathways, processes and formulas and consider each person’s individual needs.

Information provision

Information and education are integral to supporting a person to make decisions about their care and treatment. This is particularly important for long COVID – a condition with a range of symptoms and long-term effects on a person’s health.

People with long COVID, their families and unpaid carers need good quality information about recognising long COVID and associated symptoms, as do those providing services to ensure people are assessed and supported. As with any new and emerging condition, the uncertainty our patients with long COVID face needs to be acknowledged and they need to know that as the evidence base develops so will the support they can be offered. Information must meet national [Accessible Information Standards](#) to ensure consistent approaches to identifying, recording, flagging, sharing and meeting the

information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.



Remember:

- recovery time is different for everyone.
- new symptoms can emerge, and ongoing symptoms can change unpredictably; they can affect a person in different ways at different times.
- supported self-management techniques are useful.

“The complex environment in which a prison nurse works lends itself to a holistic approach across the mental, physical and social paradigms of health. The prison nurse, regardless of whether an adult nurse, mental health nurse or learning disability nurse, has the opportunity to work in a person-centred approach with other disciplines and agencies to identify, monitor and address needs that may be a symptom of long COVID/post COVID syndrome.”



Fiona Grossick, National Clinical Quality Lead for Health & Justice, NHS England

Find out more

The Queen’s Nursing Institute (QNI) [resource for community nurses caring for people living with COVID-19](#).

The Royal College of General Practitioners [resources for primary care](#).

The [Self Care Forum](#) is a national charity that aims to further the reach of self-care and embed it into everyday life. It offers a range of resources to support self-care approaches.

Assessment

For those with ongoing symptomatic COVID-19 or suspected long COVID, the assessment period can be a challenging time. Therefore, assessments that take a holistic approach are encouraged, including:

- a comprehensive clinical history
- appropriate examinations of the physical (including cognitive), psychological and psychiatric symptoms, as well as functional abilities
- discussion of how the person's life may have changed; this might cover their activities of daily living, whether they are able to work or access education, and the impact on their social life, hobbies and general independence
- consideration of the person's experience of their symptoms, not just the symptoms
- asking for their feedback, so their concerns and any area of priority for them can be addressed early.

Active listening is an important part of an assessment, ensuring the person feels truly heard and their concerns understood. Nurses, midwives, and care staff are highly skilled at actively listening to our services users, their families and unpaid carers, responding with empathy and caring. Acknowledging and reflecting back the understanding you gain about the collective impact of symptoms on the person will help build a level of trust, which will be key as the relationship develops.

Find out more

Post COVID services should offer an integrated multidisciplinary service, including physical and psychological assessments and management or appropriate onward referral to post COVID rehabilitation, treatment and other support: [Coronavirus » Post-COVID Syndrome \(Long Covid\) \(england.nhs.uk\)](https://www.england.nhs.uk/coronavirus/about/post-covid-syndrome/)



Important to consider:

- could there be another underlying cause?
- what treatment options best suit the person's needs?
- what referrals are needed?
- what support and information can be provided in the interim?

As a new condition, you need to consider and acknowledge the uncertainty our patients face and reassure them that care planning and treatment offers will be

responsive to the person's needs. This will build your relationship with the individual as they continue to navigate their condition and treatment options over time.

“Nurses working across secondary care have a key role in helping us understand and respond to long COVID as a complex multi-system condition. Secondary care nurses are highly skilled and practised in the management of acute illness, supporting the person and their family through what can be an extremely challenging time. Working as part of the wider multidisciplinary team secondary care, nurses are experts in assessment, diagnosis, and treatment of new conditions, as well as supporting an understanding of the impact on co-morbidities. Working to expedite a return to health, safe discharge and supportive ongoing care, secondary care nurses are central across the breadth of their roles to ensuring we respond to long COVID effectively and efficiently.”



Corinne Power, Deputy Director of Nursing, NHS England

For people who may benefit from support during their assessment, it is important this is put in place early: for example, undertaking a cognitive assessment; using translation services or support from friends, family or carers (if the person agrees) to describe their symptoms; or adapting your approach to ensure the person can engage. Reasonable adjustments may be needed, including the use of different mediums or information delivered in different ways depending on the person's needs.

Find out more

Reasonable adjustments: <https://www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/>

Maslow's Hierarchy of Needs (1954)¹ This model considers the different levels of need a person has and the impact the more basic needs have on leading happy, healthy lives. Used in assessment processes, this model supports us to understand a patient's strengths, limitations and need for nursing interventions, as well as the interplay between different elements of their lives as one level of need must be met before moving onto the next in the hierarchy.

¹ Maslow, A., 1943. A Theory of Human Motivation. *Psychological Review*, 50(4), pp.370-396.

Planning care

For people with ongoing symptomatic COVID-19 or post COVID-19 syndrome who have been assessed in primary care or a multidisciplinary specialist assessment service, shared decision-making approaches are recommended. Working in this way supports us to reach agreement with the person (and their family or unpaid carers, if appropriate) about what their plan of care will include and how best to facilitate this. It is important here to consider the cognitive abilities of the person and the ongoing support they will need to ensure care plans are developed effectively.

[NICE guidance](#) identifies that post COVID specialist services should include:

- advice on self-management, with the option of supported self-management ([Your COVID Recovery | Supporting your recovery after COVID-19](#))
- one of the following, depending on clinical need and local pathways:
 - support from integrated and co-ordinated primary care, community, rehabilitation, and mental health services
 - referral to an integrated multidisciplinary specialist assessment service
 - referral to specialist care for specific complications.

Consideration should include the overall impact the person's illness is having on their life as well as the trajectory of their symptoms. **Remember:** Symptoms often fluctuate and recur so different levels of support may be needed at different times.

Discussing care plans in a way the person can understand is key to setting realistic expectations and ensuring the person is empowered to take control of their condition, where able. A personalised, tailored approach to care planning is needed.



Questions all patients should be supported to ask:

- what are my options?
- what are the pros and cons of each option for me?
- how do I get help to make the decision that's right for me?

Read more: <https://www.england.nhs.uk/shared-decision-making/>

“Learning disability nurses are qualified experts who work with people with a learning disability and are experienced in supporting complex physical, mental and social support, enabling the person to live an independent, fulfilling life despite their healthcare needs. For those with learning disabilities and long COVID, learning disability nurses are crucial to ensuring they receive the highest possible quality of care that meets their present and future needs. Through lifelong support and care, learning disability nurses are experienced in complex holistic assessment and personalised care planning with the person, their families, and unpaid carers, making them perfectly placed for ongoing concerns such as this.”



David Harling, Deputy Director of Learning Disability Nursing, NHS England

Find out more

Personalised care makes the most of the expertise, capacity and potential of people, health professionals, families and communities. These approaches look for a holistic, universal offer of support to people with longer-term conditions to build their knowledge, skills and confidence, one that allows them to live well with their health condition. Working in this way, seeing the person and not simply the condition – or symptoms in the case of long COVID – allows us to work in an integrated way, empowering people with more complex conditions and needs to have greater input, choice and control over their care.

[NHS England » Comprehensive model of personalised care](#) or access quality training directly at the [Personalised Care Institute](#).

For nursing and midwifery teams working outside post COVID specialist services, it is important to consider how best to support the person in parallel with the assessments and care they receive from specialist services. For example, for people with long COVID and other co-morbidities you may need to adapt the persons care plans for these co-morbidities to ensure it continues to meet their needs. Care may need to be delivered in a different way or be co-ordinated across a wider range of services to ensure the person remains at the centre.

As part of our commitment to holistic care we must all, wherever we work, ensure we deliver this in a culturally competent way. See [the Health inequalities section](#) below for more information. Cultural competence is key to ensuring our services are both high quality and safe for our patients with Long Covid. Nursing, midwifery, and care teams

need to be aware of how culture may influence their communities, particularly in relation to the uptake of health, care and treatment options.

Taking steps to be professionally curious; seeking understanding of our patient's cultures, beliefs, and the impact these have on their acceptance of care offers. underpinned by a recognition and awareness of how our own culture and beliefs may impact on our decisions and judgements.



Questions to consider:

- how much do I know about this person's culture?
- what assumptions may I be making?
- am I relying on preconceived ideas or stereotypes?
- what biases may I have and what impact may they be having?

Read more about culturally competent care: [Cultural Competence - eLearning for healthcare \(e-lfh.org.uk\)](https://www.e-lfh.org.uk/cultural-competence)

Find out more

Leininger's theory of culture care² suggests three models for meeting the healthcare needs of a person in a culturally sensitive and congruent manner. These models facilitate more effective actions, judgements, and interventions, both for the person and the practitioner.

Multidisciplinary rehabilitation

Rehabilitation pathways support improved physical (including cognitive) and psychological outcomes. Rehabilitation offers should be personalised with [NICE guidance](#) recommending they include:

² Leininger, M.M. (1967). The culture concept and its relevance to nursing. *Journal of Nursing Education*, 6(2), 27-39. [Reprinted in Auld, M.E., & Birum, L.H. (Eds.) (1973). *The challenge of nursing: A book of readings* (pp. 39-46). St. Louis, MO: Mosby.]

- areas of rehabilitation and interventions based on the person’s assessment
- information to help the person decide and work towards goals
- symptom management planning for all presenting symptoms, e.g. advice and education on managing breathlessness, fatigue and 'brain fog' (cognitive dysfunction).

Supporting people to keep track of their symptoms and progress through a tracking app or paper-based record may be helpful. This will help the person monitor not just their symptoms but their progress towards recovery goals.

Find out more

Long COVID rehabilitation programmes or to access tracking apps: [Long Covid | Your COVID Recovery](#)

Principles of rehabilitation: [RightCare: Community Rehabilitation Toolkit](#)

Within this management plan there should be an agreement with the person as to how and when they would like to be followed up, what to do should symptoms change and an understanding of what symptoms that may need further investigation (should they arise).

“Community nurses provide invaluable care and support to people in their own homes, care homes, in clinics and GP practices across every village, town and city in the country. They also provide outreach services to those who may not have a secure home. Community nurses use their expert clinical skills, leadership and digital technology to enhance care delivery and are adapting the ways they work to provide the highest standard of personalised care. They are supporting assessment and treatment in complex situations as part of their daily routine, enabling those with long COVID and their families to live well through every phase of their condition and life.”



Sam Sherrington, Deputy Director of Community Nursing, NHS England

Support for older people, those with additional needs and children and young people

Through holistic assessment we can consider what extra support those who are at additional risk – from a biological, psychological or social perspective – may need. Evidence suggests that older age and pre-existing co-morbidities may be associated with the number of symptoms patients with long COVID are experiencing at follow-up ([Thompson et al 2021](#)). [NICE guidelines \(2021\)](#) therefore direct us to consider extra support for older people with ongoing symptomatic COVID-19 or post COVID syndrome, e.g. short-term care packages, advance care planning and support with social isolation, loneliness and bereavement (as appropriate).

For children and young people (CYP), referral for specialist advice after four weeks or longer of having ongoing symptoms of COVID-19 or post COVID syndrome is recommended and should be agreed with the child or young person and their families. Be aware of symptoms and signs suggestive of possible specific organ impairment or ongoing inflammatory or autoimmune response in CYP, as these may need specific investigations and timely discussion with/referral to tertiary paediatric specialists.

“Children and young people (CYP) nurses are highly skilled in assessing, planning and treating the very specific health needs of a child or young person, promoting health and minimising the impact of illness on development. Working in a holistic and collaborative way, CYP nurses work closely with the child, parents or guardians to ensure the voice of the child is at the heart of everything we do. As part of long COVID, CYP nurses play a pivotal role in understanding the impact of the condition as well as supporting the development of robust care pathways and treatment offers.”



Kate Pye, Director of Children’s and Young People’s Nursing, NHS England

Find out more

In July 2021, NHS England commissioned 14 paediatric hubs across England to undertake expert assessment and provide advice to local paediatric services supporting CYP with long COVID: [Coronavirus » Post-COVID Syndrome \(Long Covid\) \(england.nhs.uk\)](#)

Ongoing care

Evidence suggests that patients with long COVID report prolonged, multisystem involvement and significant disability – lasting months or even years post initial infection ([Davies et al 2021](#)). It is therefore important to consider that some individuals may not return to their previous levels of fitness and/or to work and may continue to experience significant symptom burden.

Nurses, midwives and care staff across a range of settings have a pivotal role in supporting those with (or suspected of) long COVID to manage their illness and maintain the best possible health outcomes. We are learning that the symptoms of long COVID, if unaddressed, can have an ongoing impact on the person's ability to complete daily activities, work and maintain their health and wellbeing.

Given the complexity of the condition nurses, midwives and care staff have an essential role to support the comprehensive care offer of specialist services by continuing to join up care at each step of the person's care.



What information does the person need?

- self-management of symptoms, including how to set realistic goals
- who to contact if they are worried about their symptoms or they need extra support with self-management
- sources of advice and support, including support groups, [social prescribing](#), online forums and apps
- how to access support from services, including social care, housing and employment, and advice about financial support
- symptoms of COVID-19 that the person can share with their family, carers and friends or employers, schools, or colleges.

Ensuring the person has a copy of their care plans or records will support them both to be in control of their care and to self-care. As symptoms can change over time, reviewing these records and the nursing care plan is key to ensuring appropriately tailored support.

Consideration should also be given to ensuring care continues to meet the needs of children and young people who may be transitioning to adult services.

During the ongoing care and treatment of a person with long COVID it is crucial that we consider the interplay between services and systems supporting them. Nursing teams are particularly skilled in the ongoing support and case management of those with complex conditions such as long COVID.

“The role of the mental health nurse in long COVID is multifaceted. It includes holistic assessment to explore physical health pathology that presents as psychological symptomology. Mental health nurses are highly skilled in complex assessment and treatment planning. Mental health nurses work closely with our colleagues in the wider multidisciplinary team to support a person-centred treatment plan for our patients and hold a key role in assessing and understanding the long-term biopsychosocial and economic impact and associated factors of COVID during and post the pandemic.”



Emma Wadey, Deputy Director of Mental Health Nursing, NHS England



Areas to consider

- what is my role and the role of my colleagues in supporting the patient to manage their ongoing health?
- what information and education does the person need about managing clusters of symptoms and what ‘red flags’ require action?
- how do I share and access health records and information to support me?
- how can I maintain continuity of care, whether this be with the same healthcare professional or team or across teams?

“Registered nurses working in a care, residential or nursing home are highly skilled in the support and management of healthcare for some of our most vulnerable groups. Requiring an in-depth knowledge of long-term conditions associated with ageing and skills in managing complex multiple morbidities and frailty, nurses working in these settings are well placed to support those with diagnosed or suspected long COVID. Using their clinical as well as leadership skills while maintaining a person- and relationship-centred approach to care, they are experts in assessment, delivery and evaluation of care in a person’s own home – co-ordinating the multi-agencies and holistic support so that it wraps around the person and their families.”



Deborah Sturdy, Chief Nurse Adult Social Care, Department of Health and Social Care

Find out more (nursing models to provide evidence-based care):

Henderson’s (1964) ‘nursing need’ Model³ identifies the role of the nurse and the importance of patient empowerment and personal independence; this supports us when considering what a person with long COVID needs to manage their ongoing illness and care.

Orem’s self-care deficit Model (1959)⁴ supports nurses to identify if there is a self-care deficit that needs addressing through an intervention.

The House of Care model supports us to move away from ‘medical models’ of illness towards approaches that take account of people with long-term conditions. The model can be used at the point of care, commissioning and service design, as well as at a national level to problem solve.

Roy’s Adaptation Model (1976)⁵ outlines that a person is a bio-psycho-social being in constant interaction with a changing environment. This helps us to adapt our approaches as well as support the person to adapt theirs, increasing the likelihood of successful outcomes.

NHS England commissioned the **Your COVID Recovery** platform to help people understand long COVID, including what might be expected as part of their recovery. The platform enables ongoing support, enhanced self-care, including patient information and educational materials, signposting to key resources, tools, and techniques for clinicians.

³ Henderson, V. (1966). The nature of nursing: A definition and its implications for practice, research, and education. New York, NY: Macmillan Publishing.

⁴ Orem, D.E. (1959). Guides for developing curricula for the education of practical nurses. Washington : Office of Education

⁵ Callista ed Roy (1976) Introduction to nursing: an adaptation model. Englewood Cliffs: Prentice-Hall

Find out more about **supporting a person back to work**: [The Faculty of Occupational Medicine Guidance for healthcare professionals on return to work for patients with long-COVID.](#)

Health inequalities

There is evidence that the long-term adverse health effects of COVID-19 may disproportionately impact people from ethnic minority groups whilst the full impact on all marginalised groups is not yet clear. [Current ONS](#) data also suggests that the ongoing symptoms of COVID-19 may disproportionately impact people classified as socio-economically deprived by the Index of Multiple Deprivation Scale (IMD). This picture is further clouded by evidence which suggests that recording of long COVID in primary care remains variable ([Walker et al 2021](#)).

There is a clear need to consider how we ensure equity of access and good outcomes for our patients with long COVID across our communities ([Public Health England 2020](#)).

Action on health inequalities requires us to improve the lives of people with the worst health outcomes the fastest. For long COVID, we need to carefully consider how we come together to support the places where we work, and systems in which we operate, to challenge social exclusion and provide equity of access, high quality service provision and good health outcomes for those disadvantaged in our society.

For example, the [LGBT foundation report \(2021\)](#) suggests that lesbian, gay, bi-sexual and transgender (LGBT) people may be more likely to be severely affected by COVID-19, possibly going on to develop long COVID.

As nurses, midwives and care staff, we all have role in understanding the needs of our patient and population groups with long COVID, carefully considering access, and co-producing services and communications with those with lived experience to ensure they are culturally competent and inclusive.



Questions to ask:

- What matters to you?
- Who matters to you?
- What information do you need?

Think:

- Nothing about me without me.
- Personalised contact.

Read more: <https://hisengage.scot/equipping-professionals/what-matters-to-you/>

Find out more

- [NHS England Equality, Diversity and Health Inequalities Guidance](#)
- [NHS England » Menu of evidence-based interventions and approaches for addressing and reducing health inequalities](#)
- [NHS England » LGBT health](#)
- [Equality and diversity \(skillsforcare.org.uk\)](#)
- [NHS England » Improving equity and equality in maternity and neonatal care](#)
- [Model of Health and Wellbeing \(MHWB\)](#)

3. Supporting families, unpaid carers, and communities

As per the [NHS Constitution](#), patients and the public must always be at the heart of everything we do. By listening to people who use our services, we can better understand their individual and diverse health needs and, crucially, by working with people we can ensure we respond to what matters to them.

“Midwives play a key role in ensuring women with long COVID and their babies receive the best possible care throughout pregnancy, childbirth and the postnatal period. The expertise midwives have in holistic assessment and support offers for mums to be and their babies makes them perfectly placed within the long COVID response. Thinking family, the midwife role offers continuity of carer, promotion of a positive birth experience as well as a continued focus on quality of care to ensure the best possible outcomes.”



Professor Trixie McAree, National Midwifery Lead for Continuity of Carer, NHS England

Support for families

The [NIHR COVID-19 review](#) (October 2020) highlighted the need to consider the wider implications of long COVID beyond those with the condition, e.g. the impact on families and carers as well as on the financial stability of family units.

We need to understand what the illness means both to the individual and their family unit. Shared decision-making approaches to understand major concerns and support needs will help us in creating a truly person and family-centred care plan.

“Domiciliary care nurses specialise in the support and care of those with complex care needs so they can remain in the comfort of their own homes. Highly skilled in holistic, personalised and tailored care provision, domiciliary care nurses offer a range of services and support to ensure the highest quality out-of-hospital care. In long COVID, their skills and support are key in ensuring responsive, joined-up commissioning and delivery of care for the person, their families and unpaid carers.”



Deborah Sturdy, Chief Nurse Adult Social Care, Department of Health and Social Care

Support for communities

Building on this, involving patients in shaping local service delivery and approaches to care commissioning and delivery will help us ensure long COVID services are fit for

purpose now, as well as for the future. We need to ensure communities are awareness of long COVID services and are involved in their design.

Although there are no hard and fast rules for co-production of support offers, we all need to recognise its value, and consider how we implement co-production into our daily practice.



Areas for consideration

[Think Local Act Personal \(2011\) Making it real](#) defines co-production as “...a meeting of minds coming together to find a shared solution”.

The Social Care Institute for Excellence (SCIE) describes some key features present in co-production initiatives, such as:

- do you recognise those with long COVID as assets with skills?
- how does your organisation break down the barriers between people with long COVID and professionals?
- how do your teams build on people’s existing capabilities?
- how do you work with long COVID peer and personal support networks alongside professional networks?

Read more: [Co-production: What it is and how to do it \(scie.org.uk\)](https://www.scie.org.uk)

A [rapid evidence review](#) by the [UK Health Security Agency](#) of the effectiveness of COVID vaccination against post COVID symptoms identified that vaccinated people, who subsequently contracted COVID-19, were less likely to report symptoms of long COVID than unvaccinated people, in the short term (4 weeks after infection), medium term (12 to 20 weeks after infection) and long term (6 months after infection).

“Nurses in vaccination centres (or other settings where vaccinations are offered) play a crucial role in vaccine uptake which actively supports prevention of long COVID.

Through delivery of high-quality care, information, and support as well as dispelling myths, nurses are central to ensuring the best possible outcomes for those using their services. Using their skills and expertise to support people to make healthy choices, seek medical advice and support as well as raising awareness of the condition are all skills nurses are well practised in as part of their day-to-day roles.”



Jennie Hall, Director of Nursing and Clinical Delivery COVID-19 Vaccination Programme, NHS England

Support for unpaid carers

Unpaid carers, who may be children and young people, parents or non-familial carers, are pivotal in supporting the health and care system. Their value both to the person they care for and healthcare staff is undeniable. Healthcare staff rely on their knowledge and expertise to ensure care is delivered to the highest possible standard.

[The NHS Commitment to Carers \(2014\)](#) seeks to give unpaid carers in England the recognition and support they need to care for their loved ones.



Areas for consideration

- identify unpaid carers by asking the question; some may not be aware they have this role.
- document unpaid carers information in an easily accessible way.
- undertake appropriate assessments and offer to refer unpaid carers to services that can support their health and wellbeing needs.
- how you and your organisation respond to the needs of unpaid carers, this includes:
 - what access they have to services,
 - how key messages are communicated to them, and
 - ensuring they are involved in designing offers to meet their needs.

We must recognise that unpaid carers will be under greater pressure if those they care for develop long COVID. Or carers themselves may have long COVID which could have significant impact on their ability to provide care. As we learn more about this condition,

and the impact it has, it is important to remember basic tools and skills we have in supporting unpaid carers.

When supporting or caring for a person with long COVID, we should consider how we can involve their carers in assessment and treatment processes, particularly when care transfers between services and at discharge, as well as how we can support them.

By bringing unpaid carers into all our conversations and decision-making process we will ensure we continuously learn from their experiences to better understand the condition and its impact, and how our service delivery needs to change.

4. Supporting our workforce

The Office for National Statistics ([ONS](#)) data indicates that a significant proportion of those with long COVID are health and social care staff: around 122,000 healthcare workers and 31,000 social care workers are self-reporting symptoms of long COVID.

We need to consider the support available to us from our employers and the wider healthcare services, as well as the clear relationship between staff wellbeing, staff-reported patient care performance and patient-reported patient experience ([Maben, 2012](#)).

Supporting an employee with long COVID

Employers have a responsibility to work with their staff to ensure they have adequate support and can return to work when this is appropriate. The key areas we should consider for all our staff with long COVID cross physical, financial, social, emotional and mental arenas.

Find out more:

Guidelines for supporting our NHS people affected by long COVID

[NHS England » Guidelines for supporting our NHS people affected by long COVID](#)

Unison guidance on supporting members with Long Covid or post COVID-19 syndrome.

<https://www.unison.org.uk/content/uploads/2021/06/Bargaining-to-support-those-who-have-long-COVID-final-v2.pdf>



Key areas for consideration

- **communication with the person affected** – offer regular health and wellbeing conversations to check in and see how they are feeling. Use these conversations to discuss whether any reasonable adjustments to their working pattern would help them, e.g. working flexibly while they adjust back into the workplace. Don't assume that as time passes the person's situation is improving.
- **support and referral** – early exploration with the person as to whether they are accessing or would benefit from any health services such as occupational health/ employee assistance programme /physiotherapy /psychological support. Seek their views on what changes might help them and discuss how to achieve these. Encourage participation in local or national long COVID support groups and peer networks so they can meet others who are experiencing similar symptoms. Colleagues can find details of local groups through their General Practice.
- **problem solving** – supporting the person to identify barriers to returning to work when they are medically fit to do so. Consider how support might help.
- consider what skills and expertise the person has beyond those for the tasks they usually complete (as part of their role) and consider suitable alternative roles if necessary.
- consider the education/training needs of those supporting or working with the person to ensure they are well equipped to support the person to carry out their duties.
- share details of the [wellbeing support available to colleagues](#), including local NHS services and the national support offer.

Occupational health services (where available) can assist in assessing an employee's medical fitness to return to a given job role and advise on adjustments that would allow the employee to return to work safely. They can also help in other ways including:

- an individual health risk assessment, which supports an understanding of the impact symptoms have on the person's functioning
- undertaking an individualised workplace/task risk assessment
- providing ongoing support and monitoring
- making recommendations to support return to work planning.

"The occupational health (OH) nurse provides support, advice and rehabilitation for employees who continue to be affected by symptoms related to COVID-19 infection that have lasted more than 12 weeks and are impacting on their performance or attendance at work. They work closely with specialist physiotherapists, occupational therapists, occupational health consultants and psychologists to support employees to improve their health, functional capabilities and quality of life, leading wherever possible to a return to work. With access to support from the wider OH team, OH nurses are key to supporting employees to access self-management tools that give them a better understanding of their condition and aid their recovery, and offer return to work advice and, for those with more complex symptoms and who meet our inclusion criteria, access to a rehabilitation treatment programme."



**Clare Hill, Occupational Health and Well Being Clinical Lead and Matron,
Morecambe Bay NHS Trust and long COVID Clinical Advisor, NHS
England**

Find out more

NHS England health and wellbeing package includes access to a range of free health and wellbeing support offers. <https://www.england.nhs.uk/publication/guidelines-for-supporting-our-nhs-people-affected-by-long-covid/>

Read more about the wider national health and wellbeing packages available to NHS colleagues: [NHS England » Support available for our NHS people](#)

Read more:

- Occupational Health guidance for those with long COVID: [COVID-19 return to work guide for recovering workers.pdf \(som.org.uk\)](#)
- Faculty of Occupational Medicine guidance for long COVID: [longCOVID guidance managers 02 small \(fom.ac.uk\)](#)
- [WHO Healthy Workplace framework and model](#)
- NICE long-term sickness guidance: [Overview | Workplace health: long-term sickness absence and capability to work | Guidance | NICE](#)
- [NHS Health and wellbeing Framework | NHS Employers](#)

Ilmarinen (1990) developed a concept of work ability, highlighting that an individual's work ability is influenced by many different human resource factors. [Occupational & Environmental Medicine \(bmj.com\)](#)

Supporting our professional leadership

Leadership is essential to supporting us to create the culture that delivers best patient care ([Jonas, MacCay and Keogh \(2011\)](#)). Through setting, inspiring and promoting values and vision based on our experience, skills and knowledge, we as professionals can help shape ‘what good looks like in long COVID care and treatment’ – ensuring the needs of patients are the focus of our organisation’s aims and delivery.

The Royal College of Nursing highlights that nurses can naturally step into leadership roles early in their careers. We are advocates for those who use our services, as well as for our colleagues and our profession more broadly.

Through embracing our leadership, at all levels and across a range of topics and activities, we support each other to achieve the best possible outcomes in everything we do.

As leaders, we can drive forward the long COVID agenda. To best do this, we should access available resources and training to understand this complex, evolving condition.

Find out more

NHS England commissioned **two nursing and midwifery professional networks for long COVID**:

[Morecambe Bay Hospitals NHS Foundation Trust – Nursing and Midwifery long COVID Network](#). This network brings together a range of registered nurses and midwives from across England, offering them a space to work through the impacts of long COVID, whether personal or professional, and where their voice that will be heard.

[The Queen’s Nursing Institutes long COVID Expert Advisory Group](#). This group brings together nurses working in the community to improve care and increase understanding about the physical, mental and emotional effects of long COVID.

NHS England have a dedicated space on the [NHS Futures Platform](#) to help clinicians adapt to and learn about long COVID. This platform enables information sharing across healthcare organisations and staff, as well as easy access to a range of educational and support materials.

[The NMC Standards of Proficiency](#) highlight the key role nurses and midwives have in leading, managing, and co-ordinating care, working collaboratively across teams to ensure the best possible outcomes. Using these leadership skills for a range of activities and roles we are pivotal in improving safety and quality of care as well as advancing our understanding of the condition and the impact it can have on different groups within our society.

Find out more

The NHS Leadership Academy [Healthcare Leadership Model](#) identifies nine dimensions key to successful leadership approaches. Each leadership behaviour is rated on a scale from 'essential' through 'proficient' and 'strong' to 'exemplary'. Presented as a series of questions, the model helps individuals gauge their current skill set and identify areas for growth.

From Novice to Expert (Benner 1982)⁶ is a nursing theory which identifies how nurses develop their expertise over time, through education and experiential learning. This supports us to ensure that we each have an appropriate level of knowledge and expertise.

[The Social Care Institute for Excellence \(SCIE\)](#) provides information and resources on various aspects of leadership. These include the range of approaches that can be taken, roles, skills and key behaviours and values, organisational culture and learning as well as links to additional resources.

[Developing People – Improving Care Framework \(2016\)](#) was developed in response to reports recommending leadership as a key factor in ensuring that our services continue to deliver high quality, person centred care. The framework focuses on health and social care staff developing skills in four critical areas: system leadership; quality improvement methods; inclusive and compassionate leadership and talent management.

- [Support and benefits for carers - NHS \(www.nhs.uk\)](#)
- [NHS England » Supporting carers in general practice: a framework of quality markers](#)

⁶ Benner, P. (1982) From Novice to Expert. American Journal of nursing. Scientific Research Publishing (Scrip.org)

5. Supporting the emerging evidence base

The [NIHR evidence review](#) (October 2020) highlights that as we are at the early stages of understanding long COVID we should be careful not to draw conclusions prematurely from the emerging evidence. A review by [Crook et al \(2021\)](#) supports this, identifying the need for a greater understanding of the pathogenesis, risk factors, symptoms and methods of treating long COVID both to ensure adequate support for those with the condition as well as for healthcare professionals in practice.

The [CNO Strategic Plan for Research \(2021\)](#) sets out the research ambitions for nursing, embracing our learning from the COVID-19 pandemic response and our professional commitment to **‘always practise in line with the best available evidence’**.

Nursing and midwifery leadership in commissioning, delivery or implementation of research is a cornerstone of high-quality, evidence-based care, to inform policy development and continually improve outcomes for the public and the profession. This leadership will be crucial to fully understanding the complex nature and implications of long COVID, as well as how our workforces can best respond to emerging evidence.

Nurses, midwives and care staff working on research into long COVID will help identify gaps in clinical knowledge, develop and lead new research ideas for future work, and maximise the adoption of existing evidence into practice. We need to maximise our engagement and visibility in the research – as well as implementing findings into practice for the benefit of our communities.

The [CNO Strategic Plan for Research \(2021\)](#) identifies the key role nursing and midwifery leadership holds in achieving the NHS research ambitions and considers how to release potential, build systems and develop our skills to support this. As an example, it outlines the research underway into long COVID: investigating treatments, pathways of care, recovery and rehabilitation and the role of supported self-management. These are all areas where nursing practice is pivotal in advancing innovation and evidence-based practice across the life course and health and care settings, and in partnership with patients, families and the public.



Key areas for consideration

- how do I keep up to date with long COVID research to support my practice?
- how does my organisation routinely use evidence in decision-making?
- what role do I have in supporting long COVID research? How can I contribute?

“Research nurses and nurse-led research is integral to the long COVID response as we begin to understand the breadth and impact of the condition. To maximise our support for research and ensure a continued visible nursing and midwifery presence in emerging evidence bases, we must all remain cited in and engaged with research, as well as implement results for the benefit of our communities.”



Dr Joanne Cooper, Head of Nursing Research Transformation, NHS England

Find out more

The **NIHR** has outlined its long COVID research and other long COVID activities, and summarised findings to date:

- <https://www.nihr.ac.uk/covid-19/researching-the-long-term-impact.htm>
 - <https://evidence.nihr.ac.uk/themed-review/researching-long-covid-addressing-a-new-global-health-challenge/>

Find more about **long COVID research studies and their findings**:

- [COVID-19 UKRI funded projects \(strategicfutures.org\)](https://strategicfutures.org/)
- <https://www.nihr.ac.uk/COVID-19/>
- [NIHR evidence - Living with COVID19 - Informative and accessible health and care research](https://www.nihr.ac.uk/evidence/living-with-covid-19-informative-and-accessible-health-and-care-research)
- <https://www.ukcdr.org.uk/>
- <https://www.stir.ac.uk/research/hub/contract/1673971>
- <https://www.england.nhs.uk/publication/supporting-carers-in-general-practice-a-framework-of-quality-markers/>

6. Raising awareness

The [NHS Long Term Plan \(2019\)](#) identifies a need for a shift toward more preventative and [personalised care](#) – to raise the bar on consistently high clinical outcomes for all.

To achieve this, we need to raise awareness of health issues – working across settings and as part of the multidisciplinary team to plan, implement and evaluate awareness raising activities. This is especially important for new conditions such as long COVID.



Key considerations – for you, your colleagues, and your organisation

- work with long COVID patients, their unpaid carers and our communities to learn what matters to and concerns them.
- identify and alert others to the health impact of long COVID.
- identify and analyse long COVID information and data pertinent to your service users and communities, to help target awareness raising.
- consult others so that organisations work together to raise awareness of long COVID.
- communicate the different roles supporting people with long COVID, their families and unpaid carers.
- use evidence-based approaches to make every contact count and ensure those most at risk are specifically targeted.
- identify challenges and barriers to raising awareness and use problem-solving approaches to negate these.
- lead and support others to evaluate the impact of our awareness raising activities, to ensure their effectiveness.

“Public health nurses play a key role in monitoring population health, understanding impacts, and promoting and protecting individual wellbeing. They work with clinical colleagues providing care and support for patients to identify and mitigate wider impacts and influences, including participation in work, school and home life. Public health nurses are also involved in research into the factors that contribute to long COVID and recovery from it, to improve the evidence-base for optimal support in the future.”



Helen Kirk, Office for Health Improvement and Disparities, Department of Health and Social Care

Find out more

The World Health Organization policy brief [In the wake of the pandemic: preparing for Long Covid](#) **All Our Health framework** is a call to action to all health and care professionals to embed prevention within their day-to-day practice:

<https://www.england.nhs.uk/publication/supporting-carers-in-general-practice-a-framework-of-quality-markers/>

Next steps

This framework will be updated as more knowledge and evidence emerge about the condition. Working in collaboration with key partners we will endeavour to ensure the response to long COVID is driven by evidenced-based care. As demonstrated in this framework, nursing and midwifery teams continue to be pivotal to the commissioning, planning, implementation, and evaluation of models of care; working with our patients and our communities to ensure our collective response benefits those we serve.

We will continue to work together, alongside all nursing, midwifery and care colleagues, to lead with confidence and ensure those with long COVID, within our hospitals and communities, receive the best care possible.

NHS England, in collaboration with our colleagues at a national, regional and local level, is committed to supporting this, including an understanding of the value and expertise nursing, midwifery and care professionals hold in this space.

Acknowledgements

Nursing, midwifery and care staff across health and social care have co-produced this framework and we thank them for their time, support and continued commitment to the long COVID response. We have listened to staff, patients and the public who have told us why it is important that we have a framework that supports us to commission, design and deliver high quality care for those with long COVID.

Acting as leaders for innovation and positive change, we bring value to the long COVID agenda as well as to our patients with long COVID, their families and unpaid carers in addition to the communities we serve.

We commit to continuing to work closely with colleagues across health and care to ensure that our professional response supports the NHS plan for improving long COVID services.

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