

# Survey of RCN Members' Experiences of Long COVID 2024



## Acknowledgements

The Royal College of Nursing (RCN) would like to thank Dr Alison Twycross, Chair of the RCN Long COVID Working Group and members of the group for their assistance in developing and promoting the survey and supporting the publication of this report.

This document has been designed in collaboration with our members to ensure it meets most accessibility standards. However, if this does not fit your requirements, please contact corporate.communications@rcn.org.uk

#### **RCN Legal Disclaimer**

This publication contains information, advice and guidance to help members of the RCN. It is intended for use within the UK but readers are advised that practices may vary in each country and outside the UK. The information in this booklet has been compiled from professional sources, but its accuracy is not guaranteed. Whilst every effort has been made to ensure the RCN provides accurate and expert information and guidance, it is impossible to predict all the circumstances in which it may be used. Accordingly, the RCN shall not be liable to any person or entity with respect to any loss or damage caused or alleged to be caused directly or indirectly by what is contained in or left out of this website information and guidance.

Published by the Royal College of Nursing, 20 Cavendish Square, London, W1G ORN

© 2024 Royal College of Nursing. All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means electronic, mechanical, photocopying, recording or otherwise, without prior permission of the Publishers. This publication may not be lent, resold, hired out or otherwise disposed of by ways of trade in any form of binding or cover other than that in which it is published, without the prior consent of the Publishers.

# Contents

Int	roduction	4
1.	Experiences of long COVID	6
2.	Employer response to the COVID-19 pandemic	10
3.	Employment situation	12
4.	Occupational health and support and long COVID clinics	14
5.	Future action and support	18
Red	commendations	19
Ref	ferences	22

## Introduction

Long COVID continues to affect nearly 2 million people in the UK (Office for National Statistics, 2023). Of these, 1.3 million had symptoms that had lasted for more than a year and 762,000 had symptoms lasting for more than 2 years. Fatigue was the most common symptom (reported by 72% of those with long COVID), followed by difficulty concentrating (51%), muscle ache (49%) and shortness of breath (48%).

It is widely recognised that health care workers, including nursing staff are at greater risk of contracting COVID-19 and subsequently long COVID (Rhodes et al., 2022; Foulkes et al., 2024; NHS Race and Health Observatory, 2022). In 2022 the Industrial Injuries Advisory Council (IIAC) (2022) reported that there was convincing and consistent evidence for health and social care workers presenting with 5 serious pathological complications following COVID-19 that had been shown to cause persistent impairment and loss of function in some workers and recommended that these be added to the list of prescribed diseases.

People with long COVID are 3 times at higher risk of leaving employment than those without (Reuschke et al., 2024). A figure that employers and Governments cannot ignore in the context of a nursing workforce crisis and the need to retain experienced staff. Persistent or fluctuating symptoms, functional impairment and fatigue can have a negative impact on people's ability to work (Ottiger et al., 2024).

The National Institute for Health and Care Excellence (NICE) in their guidance (2021), define long COVID or "Post-COVID-19 syndrome" as:

"Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body".

Symptoms can persist over a long period and a Canadian study (Kuang et al., 2023) found that almost 80% of adults who experienced long-term symptoms after a confirmed or suspected case of COVID-19 infection, had been experiencing symptoms for 6 or more months and about half reported no improvement in their symptoms over time.

The term "long COVID" may be being used to describe multiple conditions that people are experiencing in the aftermath of COVID-19. This may include fluctuating multi-system symptoms, post-viral fatigue, lasting organ damage and, for those who were admitted to an intensive care unit with the virus, post intensive care syndrome (Ziyad et al., 2024). There have been more than 200 symptoms reported by those with the condition, covering respiratory, cardiovascular, musculoskeletal, neurological, gastrointestinal and even dermatological issues. People with long COVID are also reporting mental health issues – predominantly depression and anxiety (Taquet et al., 2024).

Reinfection with COVID-19 poses a significant risk for developing long COVID. Each reinfection increases the likelihood of developing long COVID. As well as the risk of developing long COVID with each new infection existing symptoms can be exacerbated. Research indicates that the risk of developing long COVID increases cumulatively with each infection (Greenhalgh et al., 2024).

This survey report gives a snapshot of our members' experiences of long COVID from a personal and professional perspective. The quotes illustrate the life changing financial,

emotional and physical consequences of long COVID and at times is a difficult read. However, there are some encouraging examples of where our members have received good support from their employers.

The recommendations set out at the end of this report are not only informed by these findings, but the current lived experiences shared by our members via our peer support group and from intelligence received from calls to our advice centre.

#### Methodology

This research was conducted in conjunction with the 2023 RCN Employment Survey which gathers information about the employment conditions, experiences, and challenges faced by nursing staff across the UK. The survey, which was conducted among 11,287 RCN members, included questions relating to their experiences of long COVID. All respondents who indicated they were either on sick leave or currently working while experiencing long COVID symptoms were invited to complete a further online survey relating to their employment experiences. The link to this survey was also provided to members of the RCN peer support for long COVID group. In total, we received 298 responses from members working across health and social care settings in the UK.

# 1. Experiences of long COVID

Respondents were asked about their personal histories of long COVID, with results showing that the majority of those taking part in the research were experiencing symptoms associated with long COVID and that this is based on a formal diagnosis.

#### **Long COVID histories**

- 3/4 (73.8%) are currently experiencing long COVID symptoms.
- 1/5 (20.8%) have partially recovered but still experiencing long COVID symptoms.
- 5.4% have had symptoms in the past but have completely or mostly recovered.
- The majority of respondents (78.9%) have had long COVID for over 18 months (Figure 1).

#### Diagnosis

- 8:10 (80.7%) have had a formal diagnosis of long COVID.
- 1:6 (16.2%) haven't had a formal diagnosis.
- 3.1% are waiting for a formal diagnosis.

Figure 1: How long have you experienced long COVID symptoms?

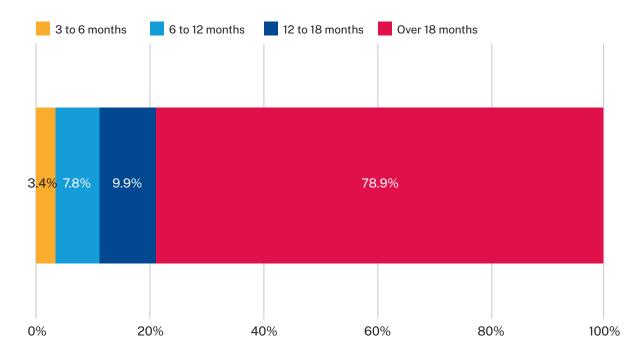


Table 1 indicates the range of symptoms experienced by respondents with long COVID, with almost all stating they experience chronic fatigue and brain fog or cognitive problems. When we asked respondents if there is 1 symptom that affects them more than others, most stated that they suffer from a combination or cluster of different problems, usually allied to chronic fatigue.

It is understood that for some people, symptoms remain the same, but for others, long COVID symptoms can be episodic in nature and can change or fluctuate (O'Brien et al., 2022). In particular, many respondents reported that their symptoms get worse after

physical or mental effort. Symptoms can also set off a chain reaction with the onset of one symptom leading to another. People with long COVID will get fatigued, which can then affect concentration and also memory. These lapses of memory can increase anxiety, which increases fatigue.

While symptoms are varied and multidimensional, they were grouped into the following categories for this survey: cognitive, fatigue and dizziness, sensory, cough/sore throat, respiratory and heart, mental health and insomnia.

We also heard from respondents that symptoms also include migraines, changes in the menstrual cycle, digestive problems, sensitivity to the cold or finding it difficult to get warm.

Table 1: The range of symptoms experienced by respondents with long COVID

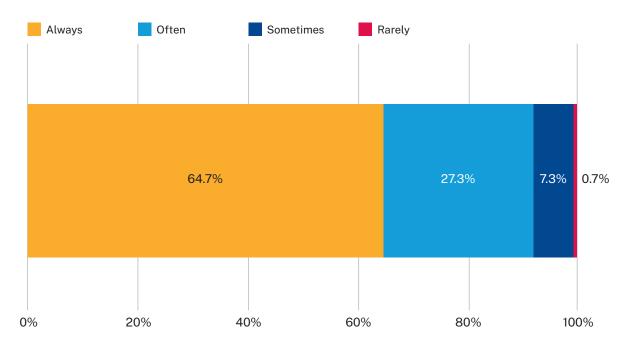
Cognitive problems		Fatigue and dizziness		Sensory problems	
Brain fog (difficulty with thinking and concentration)	91.6%	Fatigue	95.7%	Pins and needles	48.8%
Memory loss	78.6%	Physical weakness	84.3%	Problems with vision	42.5%
		Dizziness/loss of balance	64.5%	Loss of smell	40.5%
				Loss of taste	34.4%

Cough/sore throat		Pain related symptoms		Respiratory and heart problems	
Cough	48.2%	Joint pain	74.6%	Shortness of breath or difficulty breathing	72.6%
Sore throat	41.8%	Muscle pain	74.2%	Fast-beating or pounding heart	71.2%
		Chest pain	51.2%	Pulmonary embolism	4.3%

Mental health issues		Insomnia or sleeping problems	
Anxiety	66.2%	Trouble staying asleep	71.9%
Mood change	62.5%	Trouble getting to sleep	64.9%
Depression	52.2%		

Figure 2 highlights the impact of chronic symptoms on respondents' lives, with almost two thirds (64.7%) stating that their long COVID illness always impacts on day-to-day activities and just over a quarter (27.3%) that they often have an impact.

Figure 2: How far would you say your symptoms impact on your day-to-day activities?



We heard from respondents about the physical, cognitive, mental and emotional health impacts of long COVID, including difficulties carrying out daily activities, challenges to social inclusion, and worries about their future health and impact on their professional and personal lives.

"It has had a huge impact on my life as a social person. If I want/need to work, I do not have the energy to socialise, so it feels like I'm living only to work."

Female, aged 45-54, long COVID symptoms for over 18 months

"Can't play properly with my kids. I go to work. come home and go to sleep 5 days a week now because I can't manage long days anymore for less money and less time with my kids so I can pay the bills but then when I get in, I'm asleep."

Male, aged 35-44, long COVID symptoms for over 18 months

"I do believe my personality has changed, can't always process conversations straight away and although memory is back recall takes time. I still have sleep problems, my throat/voice take a hit each time I am fatigued."

Female, aged 55-64, long COVID symptoms for over 18 months

Many respondents explained that they are only now coming to terms with the long-term impact of working through the pandemic, with several referencing the distress caused of working in the nursing profession at that time.

"... working through the pandemic and at high risk of contracting a virus with which you had no idea how it would affect you, whether no symptoms, mild, life threatening, even death or the unknown long term effects... The stress and PTSD from working under such conditions is extreme... the public have moved on and put the pandemic behind them, I can't because it still impacts my every day. And that shouldn't be the result of just doing your job."

Female, aged 25-34, long COVID symptoms for over 18 months

We also heard from some respondents that long COVID has had an almost existential impact on them, with feelings of isolation, alienation, emptiness and being abandoned. Living with long COVID is causing significant disruption to daily routines as well as professional and personal identities and relationships. Respondents spoke of feeling like a 'shadow of who I used to be' and that many had gone from being fit and active to someone unable to do to the things they used to love. Some likened the process of adjusting to the change to their life as 'grieving' and accepting that they are in effect a 'new version' of themselves.

# 2. Employer response to the COVID-19 pandemic

Respondents were asked about their employer's actions during the COVID-19 pandemic in relation to protecting staff members and initiating preventative measures.

Figure 3 indicates that almost six in ten (59.2%) of all respondents think their employer did not put in place adequate preventative measures against contracting COVID-19 during the pandemic. Just 17% believe their employer protected them and their colleagues adequately.

We heard from several respondents that they did not think their employer provided sufficient personal protective equipment (PPE), particularly at the start of the pandemic. We also heard that fit testing was patchy.

"There was mask rationing (4 masks per shift), the trust stopped fit testing staff in maternity and prioritised emergency areas such as A&E and ITU, I was wearing a plastic apron, makeshift goggles and a flimsy blue surgical masks whilst caring for unwell pregnant COVID patients."

Female, aged 25-34, long COVID symptoms for over 18 months

"We were told we didn't need masks at the beginning of the pandemic because we were working in patients' homes as community nurses and the risk was low. Months into the pandemic we were suddenly told masks were mandatory."

Female, aged 45-54, long COVID symptoms for between 6 and 12 months

"I worked in respiratory oncology. I didn't even get a surgical mask until 6 weeks post-lockdown."

Female, aged 45-54, long COVID symptoms for over 18 months

Figure 3: Thinking about working during the pandemic – do you think your employer put in place adequate preventative measures to protect you and your colleagues from contracting COVID-19?

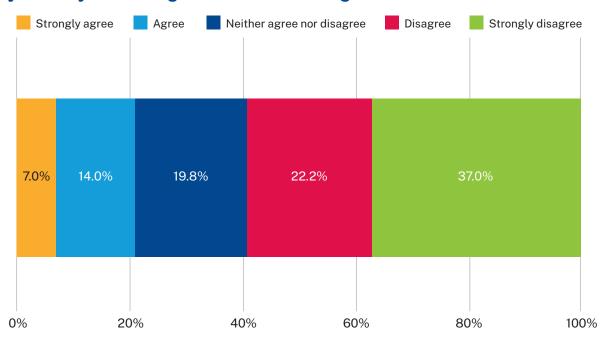


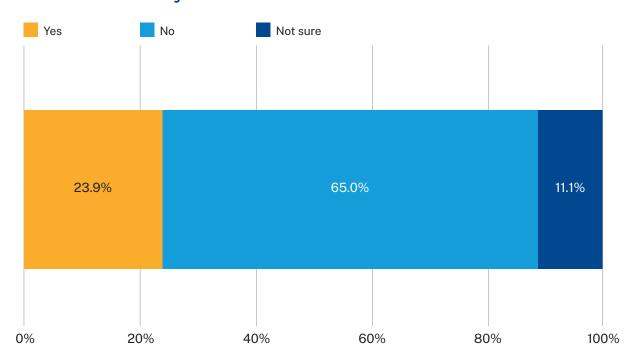
Figure 4 shows that only a quarter (23.9%) reported that their employer had provided an individual risk assessment before having contracted COVID-19. While health and safety legislation imposes a duty on all employers to undertake a 'suitable and sufficient risk assessment' proportionate to the risk arising from exposure at work, many nursing staff did not receive these at the start of the pandemic.

We heard from several respondents about their frustrations that their employer failed to put in in place necessary risk assessments and make adjustments to their employment circumstances.

"Put me at high risk, the GP and occupational health should have advised I should be shielding/working from home. Instead I was told I could remain patient facing and visit only COVID negative patients, even after I questioned this with GP surgery and my direct manager."

Female, aged 55-64, long COVID symptoms for over 18 months

Figure 4: Did your employer provide you with an individual risk assessment before you contracted COVID-19?



## 3. Employment situation

We asked respondents about their employment situation and whether it had changed since having started to experience long COVID symptoms. Table 2 shows that almost a third of respondents (30.4%) stated they were not working due to ill health, 8.7% had returned to work but were on sick leave while a further 5.9% had retired due to long COVID symptoms. The table also shows that one in six (15.2%) had changed roles or working patterns due to their health issues.

Table 2: Impact of long COVID upon employment situation

I'm not able to work at the moment	30.4%	
I've changed roles or working patterns due to long COVID symptoms or other health issues	15.2%	
I've returned to work but had to go off sick again		
I've changed roles but not due to long COVID symptoms or other health issues		
Retired	5.9%	

# Financial impact of change of employment circumstances

Seven out of ten (69.3%) reported that they had experienced a loss of earnings due to a change in hours or working patterns related to their health circumstances. Many went on to describe the impact of financial difficulties on their emotional and mental wellbeing.

"Living with these symptoms is very debilitating but the worry and stress of having to take time off work or no longer being able to do the role you've always done and the financial implications has made things worse."

Female, aged 45-54, long COVID symptoms for over 18 months

"Long COVID has changed my life irrevocably. The impact cannot be underestimated. I feel unwell every single day and it's draining. I am a single parent with a mortgage and bills to pay and I am fighting to stay in work to keep what is left of my life afloat. I've often felt forced to go into work due to the financial pressure."

Female, aged 35-44, long COVID symptoms for over 12-18 months

## Respondents on sick leave

Among those respondents on sick leave due to long COVID symptoms at the time of the survey, just over half (52.7%) said that their line manager had been in regular contact over their sick leave, while 44.9% said they felt their employer was putting them under pressure to return to work.

Among those respondents on sick leave, 93.9% stated their employer had arranged for an occupational health assessment, and 95.4% had a fit note from their GP.

## Respondents in work

All respondents at work at the time of the survey and not on sick leave were asked about their treatment by their employer or line manager. Just over half (54.3%) reported a positive experience while one in four (38.3%) stated they had not been treated well.

A small number (7.4%) had not informed their employer, with the main reason being they had not yet had a formal diagnosis to share.

Figure 5: How have you been treated by your employer/line manager in relation to your symptoms?

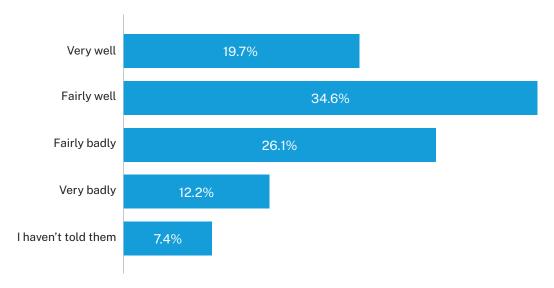


Table 3: Treatment by line manager in relation to long COVID illness

Why I have been treated well		Why I haven't been treated well	
They have treated me with respect and understanding	21.5%	They have not treated me with respect and understanding	15.1%
They have put in place appropriate adjustments at work	18.1%	They have questioned my symptoms	10.7%
They allow me to work flexibly	14.4%	They have put pressure on me to work when I am not well	11.7%
		They have put me through a disciplinary process	7.4%
		They have not allowed me to work flexibly	9.7%

We heard from respondents who had managed to secure adjustments to their role, including working remotely, flexible working hours and lighter physical duties.

We also heard from many who had positive support from their line manager who ensured that their workload was manageable, and that regular contact was maintained to discuss any health or work issues.

Many respondents also told us that line managers are the key factor in making working life manageable and being able to stay in their jobs. Line managers also often have discretion over how or whether any directions or advice from occupational health services are put in place and are therefore instrumental in supporting nursing staff in the workplace. With this in mind, several respondents pointed to the need for line managers to be provided with information about long COVID symptoms, their impact on individuals and how they can best support members of their team.

# 4. Occupational health and support and long COVID clinics

Respondents were asked if they had used occupational health services since experiencing post-COVID ill health.

8 in 10 (81.9%) said they had used occupational health services and of these, just under half (44.1%) said their experiences had been excellent or good, while a quarter (25.4%) said they had a poor experience.

Respondents' positive comments related to individual staff and their understanding of long COVID, as well as practical steps in facilitating a phased return to work or reasonable adjustments in the workplace.

"My occupational health doctor has been the most supportive person during the 3 and a half years I have been suffering long COVID. He has always tried to help me and has supported me with my ill health retirement application."

"Occupational health have been very supportive. I had a 6-month phased return after being off sick 18 months. Occupational health initiated all work changes." Female, aged 45-54, long COVID symptoms for over 18 months

Critical comments given by respondents were often related to their employer not following occupational health recommendations.

"Occupational health have been very supportive, but my manager hasn't followed recommendations citing business reasons."

Female, aged 35-44, long COVID symptoms for over 18 months

Figure 6: How would you describe your experience of occupational health support for post-acute COVID ill health?

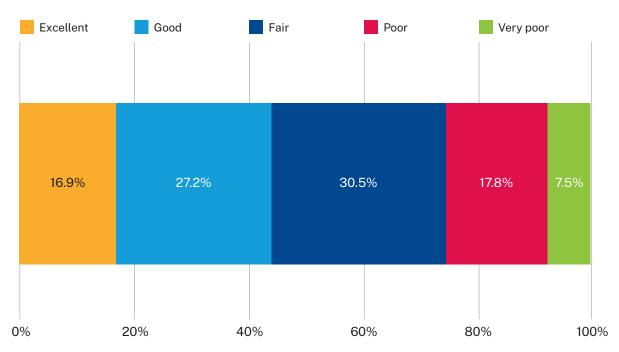


Table 4 goes on to show that around two thirds of respondents (68.2%) have been referred to and attended an NHS long COVID clinic or centre, while a small number (5.3%) are waiting for an appointment. The remainder (26.5%) have either not been referred or stated they were not nearby facilities to support them.

Table 4: Have you been referred to an NHS long COVID clinic or centre?

Yes, and I have had at least one appointment		
Yes, but I'm waiting for my first appointment	5.3%	
No, I haven't been referred	16.7%	
There are no long COVID clinics in my area	9.8%	

We asked respondents to provide further comments on their experiences of accessing support and treatment and whether their needs have been met. In general they can be categorised in relation to the following factors:

- Timing the stage at which support and treatment was accessed. As more is understood about long COVID and the management and treatment of symptoms, support services are improving
- Access to services the availability of support services and referral by GPs or occupational health
- The quality of support services treatment of multiple and episodic symptoms
  affecting mental and physical health, incorporating the latest understanding of long
  COVID.

## Timing of access to services

Based on the comments we received from respondents, it appears that levels of satisfaction with long COVID services and support depends on whether they were accessed towards the beginning of the pandemic or more recently. As understanding of symptoms and appropriate treatment has developed, respondents accessing services more recently are more likely to report having a positive experience, compared to those developing symptoms in the first year of the pandemic.

"When I first went to a long COVID clinic it was very early on in their development and it was only slightly helpful. I'm back now with an MDT long COVID team and it's excellent and they listen."

Female, aged 45-54, long COVID symptoms for over 18 months

#### Access to appropriate services

We heard that access to appropriate services has often been problematic due to long waiting lists or to lack of service provision in local areas.

"Very long waiting times to be seen and not sure if they know how to treat it as seems to be a lack of resources. Also long wait between consultant at clinic deciding what medication to try and GP receiving letter and me getting a prescription."

Male, aged 35-44, long COVID symptoms for over 18 months

"I keep being told my trust has services, yet there's nothing in my postcode area and nothing appropriate for support, my GP has tried. GP also tried to refer patients with long COVID to another board which does have an long COVID clinic, but they refuse to sanction out of board NHS referrals. So if you don't meet criteria for services you get nothing."

Non-binary, aged 45-54, long COVID symptoms for over 18 months

"There should be a direct link between occupational health and the clinics/centres to support staff with long COVID. Get staff seen quicker, and the necessary care they need. Instead it's very dependent on your GP doing the referral to them, waiting, and then finally getting that first appointment."

Female, aged 45-54, long COVID symptoms for over 18 months

## Quality of support and treatment services

The range and complexity of long COVID symptoms and differential impact on individuals was highlighted in table 1. These findings showed that respondents are experiencing a range of symptoms affecting their physical and mental health and this is reflected in comments provided by respondents when asked about their experiences of accessing support and treatment. In general, the most positive comments related to both timely access to support as well as receiving services designed to reflect the complex and diverse nature of both the symptoms and recovery treatments.

We heard many positive stories about successes in finding the right treatment and support, particularly through dedicated long COVID clinics. Reflecting the complexity of long COVID symptoms, we heard several positive accounts of how their treatment had been multi-disciplinary in nature, with different clinicians working together to provide specialist but complementary support and treatment.

"They have been amazing, supportive and understanding. They have tried to support me through anxiety and stress at work. I have seen physio, breathing, dizzy clinic, cardiac and psychological, occupational health, occupational therapy and work support." Female, aged 35-44, long COVID symptoms for over 18 months

"The long COVID clinic is helpful and reassures you that you are not on your own. They assess and refer you to the relevant services to tackle your main symptoms and keep your GP in the loop. I am grateful for their support, help, sign posting, referrals, treatment and understanding. Everyone is learning together and there is a lot still to learn and research is in its infancy."

Female, aged 55-64, long COVID symptoms for over 18 months

Conversely, we also heard that while respondents understood a multi-disciplinary approach would be appropriate, this was not offered in their experience even months after long COVID clinics and treatment programmes had been established. When asked about improvements to support, this area was highlighted by many respondents, pointing to the need for support which reflects the multi-dimensional nature of long COVID symptoms.

"Some specialists only look at their area and not how it links across the other areas eg sleep expert does not cross over to fatigue or metabolism. The clinics have to keep referring patients to each individual specialty, but if there was an actual multi specialised long COVID team we may get more continuity of care and it not be so costly, meaning more people can access the service. Less waiting in different queues for months. COVID is not going away any time soon."

Female, aged under 24, long COVID symptoms for between 12 and 18 months

We heard from a minority of respondents that they had been treated by some clinicians who they felt did not 'believe in long COVID,' or dismissed it as a psychosomatic condition.

"My long COVID doctor referred me to fatigue clinic linked to the long COVID service – very helpful. He has also referred me to cardiology (doctor said he didn't believe in long COVID so would only offer age related investigations) neurology (doc said he hadn't bothered to learn about long COVID)."

Female, aged over 65, long COVID symptoms for over 18 months

"I waited months to be seen, only to hear that my symptoms are psychosomatic. Physicians see you for a few minutes and prescribe antidepressants, they should be more informed about long COVID and what causes the symptoms." Female, aged under 24, long COVID symptoms for 12-18 months

## 5. Future action and support

We asked respondents about what support is needed for staff working in health and social care who have long COVID symptoms. Overwhelmingly, we heard that more research is needed to properly understand long COVID, its causes and how it can be treated. We also heard that as an essentially 'invisible' illness, many called for better understanding and support from employers and for them to make reasonable adjustments in the workplace. We also heard that workplace and wider support could be boosted by recognition of long COVID as a disability while others have called for long COVID to be classed as an industrial injury.

"Having suffered from long COVID for 18 months, and been through a roller coaster of health issues, with little understanding from my employer, who makes you feel like you are 'milking' the absence. If only they knew how bad day to day life with long COVID symptoms. Not to mention the financial impact. When you have managers saying – we may need to pay you off on capability terms without me even having yet returned to work – talk about putting the pressure on. Feeling like you are holding people up/back also impacts on your mental health. Anxiety of how long will this last. How will I cope going back to work etc. No one fully understands the true impact."

Female, aged 55-64, long COVID symptoms for 12 to 18 months

"We need to be protected, we need to be heard. We need financial protection and support to recover. We need to be supported by our place of work to recover and not pressurised to return until symptoms allow. Take into account previous sickness records and what be given to the NHS."

Female, aged 45-54, long COVID symptoms for 6 to 12 months

"We need to use the disability act to give us reasonable adjustments, to help find redeployment posts without being terminated because there aren't any available. We need compulsory long COVID training for both management and colleagues. I recently got laughed at for telling a colleague I had long COVID."

Female, aged 35-44, long COVID symptoms for over 18 months

"We should be pushing for this to be recognised as an industrial injury especially for those who caught COVID at the beginning of the pandemic."

Female, aged 35-44, long COVID symptoms for over 18 months

## Recommendations

While we await the findings and recommendations of module 3 of the UK COVID Inquiry on what should be done to prevent future COVID infection in health and social care workers and subsequent risk of long COVID, there are actions the Government and health and social care organisations can and should take now to support workers suffering from long COVID.

#### **UK Government**

The UK Government must take action to limit the spread of COVID-19 and thus reduce the number of people developing long COVID. This requires a multi-pronged approach including vaccination, surveillance, effective preventative measures and mitigating actions in health and care environments. Given the personal, professional and economic costs of long COVID, an approach that only considers the risk of death or hospitalisation, in the acute phase of infection, and not the risk of developing long COVID is limited.

Long COVID must be formally recognised by the UK Government as an occupational disease for nursing staff who were exposed to COVID-19 through their work. In 2022, the European Commission recommended that member states recognise COVID-19 as an occupational disease in heath and social care (European Commission, 2022). More than 50 countries worldwide already provide formal legal recognition for key workers who contracted COVID-19 as a result of workplace exposure and offer corresponding compensation and support schemes (International Labour Organisation, 2021). The UK must follow suit.

As a minimum, the UK Government must enact the recommendations of the Industrial Injuries Advisory Council (IIAC). The IIAC Command Paper, dated November 2022 (Industry Injuries Advisory Council, 2022), recommends that the list of prescribed occupational diseases for which Industrial Injuries Disease Benefit can be paid should be expanded to include health and social care workers with 5 serious pathological complications following COVID-19 infection. This should be the starting point, paving the way to recognition of long COVID as an occupational disease and the subsequent benefit paid to workers who have suffered financial losses as a result of occupational exposures.

It is evident from the survey that access to specialist services is sporadic and there remains a lack of understanding of the condition. The Government must support further clinical research into long COVID and ensure the health service provides effective care, accessible treatment and rehabilitation services for health and social care workers.

With high levels of sickness absence there needs to be a return to national level data collection on cases of long COVID in health and social care workers in order to assess the impact on staff and the delivery of health and social care services. Data should include ethnicity so that disparities highlighted can be understood and addressed.

Finally, the Government must act on recommendations made by the UK COVID Inquiry in relation to improved protection of health and social care workers from the risks of COVID infection.

## Health and social care organisations

#### **Organisational support**

First and foremost, organisations must reduce the risks of COVID-19 infection and subsequent long COVID in health and social care workers by following their legal duties under the Control of Hazardous to Health Regulations outlined in the RCN's Respiratory Risk Assessment toolkit (RCN, 2024a).

Organisations must value and support their nursing workforce who have long COVID, as it is more likely than not these were occupationally acquired. Setting an inclusive and supportive culture at the very top of an organisation is important in order to retain staff who are experiencing long term and fluctuating symptoms of long COVID. The health and social care sector can ill afford to lose these skilled and experienced nursing staff.

Organisations must comply with their duties under the Equality Act 2010 and Disability Discrimination Act (Northern Ireland) 1995 and ensure that reasonable adjustments are made for those whose condition is likely to fall under the definition of a disability under the relevant act.

Organisations should provide education and awareness raising for managers on duties under the respective acts to ensure reasonable adjustments are put in place. Education and awareness raising for all staff is recommended to ensure a shared understanding of the challenges colleagues with long COVID may face in the workplace and how they can be supported.

Organisations must ensure that nursing staff can take sufficient time off sick, without financial detriment, during the acute stage of a COVID-19 infection. Resting during the acute stage of an infection is one of the ways to prevent someone developing long COVID (Greenhalgh et al., 2024).

#### Line management support

Responses to the survey illustrate how important line management support is to members' experiences in the workplace. Having an empathetic manager and team colleagues who understand the fluctuating nature of the condition and the need for reasonable adjustments is important in creating a supportive culture.

Managers, with the support of their organisation should following good practice as set out in the RCN's long COVID guidance for managers Supporting staff who are living with long COVID | Royal College of Nursing (rcn.org.uk) (RCN, 2024b) and the Society of Occupational Medicines guidance (Society of Occupational Medicine, 2024) on supporting people to return and stay in employment.

Managers must be clear on the legal requirements of the Equality Act 2010 and Disability Discrimination Act 1995 and ensure that expert advice from occupational health service is taken into account, particularly when supporting a phased return to work or flexible working options. Even where the condition may not be classed as a disability, adjustments should still be made as good practice. A creative approach to supporting skilled and experienced nursing staff stay at work is needed with the affected individual working with their line manager, alongside the support of Occupational Health and Human Resources to develop a practical solution. The RCN's Health Ability passport provides a

framework for employers and managers to discuss with employees what adjustments are needed in the working environment.

#### Occupational health services

As with line management support, the advice and interventions of a workplace multidisciplinary occupational health service can shape a members' experiences and help them to stay in employment.

Nursing staff should have access to and be able to self-refer to occupational health services. Such services should be resourced to support and advise line managers and workers.

Access to effective mental health support and Employee Assistance Programmes is also important, as stress and burnout is common in people with a long-term condition, alongside anxiety related to the personal financial impact of long COVID.

#### Royal College of Nursing

Throughout the pandemic the RCN has been vocal on the risks to nursing staff and failures by Governments, statutory bodies and employers to fully protect our members. From a lack of risk assessments to a lack of robust control measures such as ventilation to access to appropriate respiratory protective equipment, there are significant gaps in health and safety protections. A continued focus on prevention of COVID-19 and the subsequent risk of long COVID remains a priority, and working with partners, we have developed a comprehensive toolkit to support nursing staff and their managers risk assess for COVID-19 and other infectious diseases transmitted via the respiratory route. The risk assessment toolkit (RCN, 2024a) also outlines the legal duties on organisations to protect staff under the Control of Substances Hazardous to Health Regulations, including the provision of suitable and sufficient respiratory protective equipment and effective ventilation.

The RCN will continue to advocate for our members who, by the virtue of their occupation, are now suffering from the physical, psychological and financial effects of long COVID. Providing support and advice on their working situation, helping them navigate the welfare system, including supporting members to gain Industrial Disease Injury Benefit through the work related accidents route, facilitating peer support and lobbying on their behalf.

## References

Al-Aly Z, Davis H, McCorkell L, Soares L, Wulf-Hanson S, Iwasaki A and Topol EJ (2014) long COVID science, research and policy, *Nat Med* 30, pp.2148–2164. Available at: doi.org/10.1038/s41591-024-03173-6 (accessed 4 October 2024).

European Commission (2022) Commission recommends recognising COVID-19 as an occupational disease in certain sectors and during a pandemic. Available at: ec.europa.eu/social/main.jsp?langId=en&catId=89&furtherNews=yes&newsId=10463 (accessed 4 October 2024).

Foulkes S, Evans J, Neill C, Bishop J, Khawam A, Islam J, Atti A, Brown CS, Hopkins S, Price L and Hall V (2024) Prevalence and impact of persistent symptoms following SARS-CoV-2 infection among healthcare workers: A cross sectional survey in the SIREN cohort. *Journal of Infection*, 89(4), 106259. Available at: journalofinfection.com/article/S0163-4453(24)00193-2/fulltext (accessed 4 October 2024).

Greenhalgh T, Sivan M, Perlowski MD and Nikolich JŽ (2024) Long COVID: a clinical update. *The Lancet*, Volume 404, Issue 10453,2024, pp.707-724. Available at: **thelancet.com/journals/lancet/article/PIIS0140-6736(24)01136-X/fulltext?** (accessed 4 October 2024).

Industrial Injuries Advisory Council (2022) *Independent COVID-19 Occupational Impacts*. Available at: **gov.uk/government/publications/covid-19-and-occupational-impacts** (accessed 4 October 2024).

International Labour Organisation (2021) State Practice to Address COVID-19 Infection as a Work Related Injury. Available at: ilo.org/sites/default/files/wcmsp5/groups/public/@ed\_emp/@emp\_ent/documents/publication/wcms\_741360.pdf (accessed 4 October 2024).

Kromydas T, Demou E, Edge R, Gittins M, Katikireddi SV, Pearce N, van Tongeren M, Wilkinson J and Rhodes S (2023) Occupational differences in the prevalence and severity of long-COVID: analysis of the Coronavirus (COVID-19) Infection Survey, *Occup Environ Med.* 2023 Oct; 80(10), pp.545-552.

Kuang S, Earl S, Clarke J, Zakaria D, Demers A, and Aziz S (2023) Experiences of Canadians with long-term symptoms following COVID-19. Statistics Canada. Available at: 150.statcan.gc.ca/n1/pub/75-006-x/2023001/article/00015-eng.htm (accessed 4 October 2024).

NHS Race and Health Observatory (2022) *REACH-OUT: Caring for the Healthcare Workforce Post-COVID-19.* Available at: nhsrho.org/research/reach-out-caring-for-the-healthcare-workforce-post-covid-19 (accessed 4 October 2024).

NICE (2024) COVID-19 rapid guideline: managing the long-term effects of COVID-19. Available at: nice.org.uk/guidance/ng188 (accessed 4 October 2024).

O'Brien KK, Brown DA, McDuff K et al. (2023) Conceptualising the episodic nature of disability among adults living with long COVID: a qualitative study. *BMJ Global Health* 2023;8:e011276. Available at: **gh.bmj.com/content/8/3/e011276** (accessed 4 October 2024).

Office for National Statistics (2023) Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK. Available at: ons.gov.uk/peoplepopulationand community/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoing symptomsfollowingcoronaviruscovid19infectionintheuk/30march2023 (accessed 4 October 2024).

Ottiger M, Poppele I, Sperling N, et al. (2024) Work ability and return-to-work of patients with post-COVID-19: a systematic review and meta-analysis. *BMC Public Health*, 24, 1811. Available at: doi.org/10.1186/s12889-024-19328-6 (accessed 4 October 2024).

Reuschke D, Houston D, Sissons P (2024) Impacts of long COVID on workers: A longitudinal study of employment exit, work hours and mental health in the UK. *PLoS ONE* 19(6): e0306122. Available at: journals.plos.org/plosone/article?id=10.1371/journal.pone.0306122 (accessed 4 October 2024).

Rhodes S, Wilkinson J, Pearce N, Mueller W, Cherrie M, Stocking K, Gittins M, Katikireddi SV, Tongeren MV (2022) Occupational differences in SARS-CoV-2 infection: analysis of the UK ONS COVID-19 infection survey (2022), *J Epidemiol Community Health*. 2022 Jul 11;76(10), pp.841–6.

Royal College of Nursing (2024a) *Respiratory Risk Assessment Toolkit*. Available at: rcn.org.uk/COVID-19/respiratory-risk-assessment-toolkit (accessed 4 October 2024).

Royal College of Nursing (2024b) Supporting Staff with long COVID: Guidance for Managers. Available at: rcn.org.uk/COVID-19/Supporting-staff-who-are-living-with-long-COVID (accessed 4 October 2024).

Royal College of Nursing (2024c) *Health Ability Passport Guidance*. Available at: rcn.org. uk/Get-Help/Member-support-services/Peer-support-services/Health-Ability-Passport (accessed 4 October 2024)

Society of Occupational Medicine (2024) *Long COVID: A Manager's Guide*. Available at: som.org.uk/support-people-long-covid-return-and-stay-work (accessed 4 October 2024).

Taquet M, Nazir L et al. (2024) Cognitive and psychiatric symptom trajectories 2–3 years after hospital admission for COVID-19: a longitudinal, prospective cohort study in the UK, *The Lancet Psychiatry*, 11 (9), pp.696-708. Available at: thelancet. com/action/showCitFormats?doi=10.1016%2FS2215-0366%2824%2900214-1&pii=S2215-0366%2824%2900214-1 (accessed 4 October 2024).

# The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies

RCN Direct www.rcn.org.uk/direct 0345 772 6100

Published by the Royal College of Nursing
20 Cavendish Square
London
W1G ORN

020 7409 3333 www.rcn.org.uk

December 2024
Review date: December 2027
Publication code: 011 838

