

# Living with Long Covid

Occupational therapists' experiences



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### Summary

Long Covid is estimated to affect two million people in the UK. Seventy-seven percent of these people report that their symptoms impact their ability to take part in activities and, for around 380,000 people, this ability is limited significantly.

Since the start of the COVID pandemic, occupational therapists (OTs) have actively supported and advocated for people affected by the acute and long-term impacts of the disease. All OTs can use their professional expertise to help address the impact of Long Covid on people's daily lives. But some also draw upon their own experiences of living with Long Covid.

Health and social care professionals are more likely to be affected by Long Covid, as are females and people aged between 35 and 69. A high percentage of OTs fit all three of these categories.

In November 2022 we carried out a workforce survey with OT practitioners across the UK. In this survey we asked OTs how Long Covid had impacted them.

One hundred and fifty-three OTs shared their personal experiences of Long Covid with us. Of these, 126 had Long Covid themselves, 20 were caring for a family member or dependent with the condition and seven were both caring for someone with the condition whilst also having Long Covid themselves.



# Our key findings

- Eighty-five per cent said that Long Covid had negatively affected their quality of life
- Eighty-one per cent of those supporting someone with Long Covid said that their caring responsibilities had increased
- Twenty-nine per cent had been able to access effective health advice and intervention
- Fifty-eight per cent had needed to make changes to their working arrangements
- Forty-two per cent had been able to access effective support from their employer
- Fourteen per cent of those who had attempted to access financial benefits had been successful.



# Our recommendations

Whilst our survey focused on the experiences of OTs, our recommendations are relevant to everyone affected by Long Covid:

- All people with Long Covid must be able to access effective, personalised health interventions to help them manage their symptoms. This should include access to occupational therapy.
- Employers should be flexible and supportive in identifying ways to help employees with Long Covid and those caring for someone with Long Covid, remain in or return to work.
- People with Long Covid should be able to access financial support. This includes classifying Long Covid as an occupational disease.

# Survey findings

## Quality of life

Eighty-five per cent of people affected by Long Covid felt that their quality of life had been negatively impacted due to the condition. There were several common reasons for this including:

- reduced ability to work and loss of income
- reduced ability to participate in leisure activities, including exercise
- lack of understanding from employers, health professionals and family members.



**Eighty-one per cent of people reported that their caring responsibilities had increased** due to a family member or dependent having Long Covid. Others said that having Long Covid meant that they had lost valuable relationships and were less able to support family members.



“Personally, its involved incredible loss of mental health, fitness, relationships, body shape, lifestyle, independence and some fear for the future.”

“Isolation. Hugely reduced quality of life. Lack of understanding and compassion from family, friends and medical fraternity.”

“My child has a chronic health condition as a result of COVID. I planned to increase my working hours due to my child’s age but can no longer do this and cope with carer responsibility. I remain part -time and have stopped clinical work.”

“Having Long Covid has totally ruined my life. I exist, I do not live. I feel totally isolated and alone, abandoned by work colleagues and even some so-called friends... I am no longer able to help and support my elderly mother who has a number of serious long-term health conditions... Friends and family do not understand, no-one does... I do not especially enjoy anything anymore.”



## Access to health advice and intervention

**Only 29% of people said that they had successfully accessed advice and intervention** to help them manage and address their Long Covid symptoms.

**Fifty per cent reported that they had been unable to access support.**<sup>1</sup> Several people noted long waits to be seen by a Long Covid service and some felt that other health professionals were under-informed on how to appropriately support people with the condition.

**Eighty-five percent of people felt that their knowledge and skills as an occupational therapist had been beneficial**, either in helping them manage their own Long Covid symptoms or supporting a family member or dependent with Long Covid.

Despite the noted value of occupational therapy, **60% of occupational therapists had been unable to access support from an OT.**

<sup>1</sup>The remaining 21% answered in one of the following ways – that their experience was neutral, that the question was not applicable to them, or that they preferred not to answer.

“ Referral to a Long Covid service that would accept me took over a year... Unable to see or spend time with family because my body is unable to tolerate travel... I am desperate for help. It's like being left in a ditch.”

“ I am very fortunate that my role includes working with patients with fatigue, so I have the knowledge to help myself and my OT and MDT colleagues have been very supportive.”

“ I have had to sporadically have periods of time off work due to relapse of symptoms. I have been left to manage symptoms independently with no support despite referral to Long Covid service. I work 4 days a week but treated like a full-time member of staff which exacerbates symptoms.”

## Ability to work

People's experience of receiving support from their employer was varied.

- **Forty-two per cent reported positive experiences while 37% felt that support had been lacking**
- **Fifty-eight per cent had made changes to their working arrangements in some way**
- **Nineteen per cent had reduced their working hours**
- **Seventeen per cent had needed to change job**



“ Its delayed my career progression, it has been frustrating, made me feel alienated and led me to change my career path. My work-life balance has been harder to control and I have needed multiple reasonable adjustments.”

“ Very poor support and adjustments from work. They would not support pacing and planning strategies within work or allow me to increase my non-clinical duties to manage physical fatigue within work.”

“ My work forced me back after I tested negative, threatening they will escalate me on sickness pathways despite having fatigue, exhaustion and respiratory problems... They do not care about their staff... I go home crying some days.”

## Financial impact

**Thirty-four per cent of people said that their household income had reduced** because of Long Covid. This was typically due to the need to stop or change work, either because of Long Covid symptoms or increased caring responsibilities.

Seventy per cent of people who had sought financial benefits such as Personal Independence Payment (PIP) said that they had been unsuccessful in accessing them.

Several people said that concern about finances meant they had returned to work even though they did not feel well enough. Worry about current and future income was causing significant worry and distress for some.

“ Had to stop clinical work due to Long Covid. Redeployed into current role, but not really managed a full working week in seven months. I think I will be sacked soon.”

“ As a new graduate I am terrified after working so hard to get qualified [that] I will be out of the workforce forever. I was only in post for three months before I caught COVID in the ward I was on. And have been off two years and about to lose my job. My entire life has been affected – I do not recognise it anymore.”

“ I am awaiting input. I returned to work as financially I could not afford to be off, so I have had to work or lose everything.”

## Implications for occupational therapy

The experiences shared by occupational therapists are not unique to our profession. The financial, social and workplace implications of Long Covid are felt by thousands of people across the UK.

The data shared by OTs is especially concerning as there are significant shortages within the OT workforce.

Seventy-eight per cent of respondents to the RCOT 2022 workforce survey said that their team is not large enough to meet demand and 55% had long-standing issues with recruitment. This is contributing to high levels of stress within the profession, with 71% of OTs rating their work-related stress levels as six or more out of 10.

Enabling OTs affected by Long Covid to remain in work, using flexible and personalised approaches, is essential both for their own wellbeing, as well as for the health of the profession as a whole.