

Living with Long Covid Summary 21/22



healthwatch
Richmond upon
Thames



Symptoms and recovery

Symptoms are varied and fluctuate over time. The most common ones (in decreasing order) are fatigue, brain fog, breathlessness and anxiety. While pacing and careful nutrition seemed to alleviate some symptoms, many respondents noted the unpredictability of relapses.

Encouragingly, there seems to be a trend of patients improving over time.

Our Research

As healthcare commissioners and providers learn more about Long Covid and set up support services, it is clear that people's needs and voices should be central to the design of support services.

We talked to 93 people suffering from Long Covid and asked them about their experience of the illness, of the support they may have received and about their unmet needs.

You feel alone and that there is no help. Even a diagnosis would mean that you felt like there was a reason for the way you were feeling.

Mental Health

Strain on Mental Health is a core part of Long Covid. People told us they feel isolated, they are not believed and they become unable to exercise or appreciate what used to bring them joy. In many cases, they go from being a carer to being cared for, and tell us that this brings them feelings of guilt.

I miss the person I used to be and the life I used to have. Will I ever be 'normal' or well again?

Impact on Life

Long Covid has a significant effect not just on people's physical and mental health, but also on their financial, social and domestic needs.

Many people had to reduce their hours or stop working, which created a strain on their finances. This was worsened when people felt they had to resort to private health care.

Anxiety and other mental health issues, combined with fatigue, were also reported to have a negative impact on people's social lives and relationships.

Long Covid also prevented people from completing their daily tasks. This ranged from cleaning and cooking, to caring for children and loved ones.

This highlights that people's needs, when suffering from Long Covid, go beyond physical and mental health.

Support and Access

We expect that access will improve as services are developed, but access to support services on the NHS was difficult for patients who did not go to the hospital in July-August 2021. The large majority of our respondents could not access support at all, and those who did faced long waiting times and scepticism. As a result, some people resorted to private care.

I used to care for my wife and do everything for her. Now I can't and she's in a care home that I can hardly visit. I don't think she knows me anymore.



I lost my job.

Our Recommendations

In response to the challenges faced by people living with Long Covid, we have recommended service commissioners and providers to make a number of significant changes:

1. The creation of a peer-led, clinician-aided support group

To alleviate isolation and facilitate information sharing

2. Improved communication and education, including development of self-help support

To help raise awareness of the issue and ensure patients feel believed

3. A more comprehensive screening process

To take into account financial, social and domestic needs as well as physical and mental health

4. Coordination of care

To bridge the gaps in the care of patients who have a multitude of symptoms

Contact Us

www.healthwatchrichmond.co.uk

info@healthwatchrichmond.co.uk

0208 099 5335

Healthwatch Richmond
82 Hampton Road
Twickenham
TW2 5QS