LONG COVID SUPPORT GROUP CALDERDALE

JH Research
SOCIAL RESEARCH & EVALUATION

Finding a Way

What helps in long covid recovery?



Juliette Hough
July 2025

Acknowledgements

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The Long Covid Support Group Calderdale is an informal, friendly and mutually supportive group offering peer support for people with Long Covid in Calderdale. Find us on Facebook as the Calderdale Long Covid Support Group.
https://www.facebook.com/groups/3780826692148347/

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Foreword

There is much that we still don't know about long covid, and even less about recovery from this distressing condition. We can't even be sure how many people are affected by it in Calderdale, but estimates suggest that over six thousand people may have lasting symptoms. Of these, over one thousand may have significant limitations to their daily living activities. For some, it's a life-changing condition that can result in the collapse of normal life into a state of daily exhaustion and a bewildering variety of other unexplained symptoms.

It can be difficult for medical professionals to reach a diagnosis of long covid, let alone working it out for yourself. So, if symptoms return or are lingering months after Covid 19 infection, it's useful to know, when you consult your GP that Calderdale has a highly regarded specialist team who may be able to help your recovery. And there's more too, with activity groups and peer support to complement treatment that helps recovery.

It does great credit to Calderdale Council that after the height of the Covid 19 pandemic, their public health team acted to set up a peer support group, and with a grant, also enabled the group to commission research that would help us all understand if recovery was possible. And if so, to discover what helped and what didn't work so well.

In Juliette Hough we were very lucky to find not only a skilled researcher but also someone with lived experience of Long Covid. Her findings draw mainly on interviews with people who have lived experience, and these have unmistakable authenticity, as do the contributions made by NHS professionals working directly with patients.

The conclusions offer hope that recovery for many is possible. As individuals, we can learn to manage the condition, and some have found it helpful to share their experiences with others. Others even found ways to breathe easier by singing together with the inspired Shared Harmonies group. We have a valued specialist NHS team available through GPs and support from others. With a little help from our friends, many of us will find a way.

Michael Beazley
Long Covid Support Group Calderdale
May 2025

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Summary

This research, commissioned by the Long Covid Support Group Calderdale and funded by Calderdale Council, explores recovery experiences from Long Covid. Through in-depth interviews with ten individuals who have partially or fully recovered, it identifies key facilitators and barriers to recovery, highlighting service gaps and areas for improvement.

Key Findings

- **Prevalence & Impact:** Approximately 6,800 people in Calderdale are estimated to have Long Covid, with 20% experiencing significant activity limitations. Women and middle-aged individuals are most likely to be affected, but the low number of GP referrals to the long covid clinic suggests that many people are not being diagnosed or treated.
- **Recovery Journeys:** Recovery is highly individualized, often marked by an initial health decline, periods of struggle, crisis points, and gradual improvement. At the time of research, many interviewees remained only partially recovered 1.5 to 4.5 years after their Covid infection, with 50–70% of their pre-Covid health levels restored. Despite this, post-Long Covid achievements for interviewees included returning to hill walking, running a marathon, gaining a black belt in taekwondo, and returning to full or part time work.
- **Facilitators of Recovery:**
    - Specialist support, particularly from the Long Covid clinic.
    - Self-management strategies like pacing, rest, and breathing exercises.
    - Mental health support to address trauma, grief, and anxiety.
    - Validation, support, and hope from professionals and peers.
    - Gradual re-engagement with physical activity and daily life.
- **Barriers to Recovery:**
    - Lack of awareness and referrals to specialist services.
    - Stigma and psychologisation of symptoms, particularly by healthcare providers.
    - Financial pressures and difficulty accessing benefits.
    - Systemic inequalities in access to support, particularly among minoritised ethnic communities.

Recommendations

1. **Strengthen and secure Long Covid services** – Ensure continued funding and accessibility of specialist clinics and support programmes.
2. **Increase awareness and referrals** – Improve GP understanding of Long Covid to ensure proper diagnosis and referrals.
3. **Address health inequalities** – Conduct outreach to minoritized ethnic communities and ensure equitable access to services.
4. **Enhance mental health support** – Provide specialist psychological services tailored to Long Covid recovery.
5. **Public health campaigns** – Raise public awareness of long Covid to support the identification of undiagnosed long covid in the community.

Conclusion

Significant recovery from Long Covid is possible but requires structured support, informed healthcare professionals, and accessible specialist services. Ensuring continued funding and addressing gaps in healthcare responses are critical to aiding recovery and improving the quality of life for those affected.

1. Introduction

Introduction – the Long Covid recovery research project

This research was commissioned by the Long Covid Support Group Calderdale, a peer support group, and funded by Calderdale Council. The researcher had lived experience of Long Covid, and the project Steering Group was made up of people with Long Covid and local professionals.

Our research question was:

> **What can we learn about recovery from Long Covid from people in Calderdale who have partially or fully recovered?**

We conducted in-depth interviews with 10 people who had made a full or partial recovery from Long Covid to find out what we could learn from them. All of the quotations are from people with Long Covid interviewed for the research.

About Long Covid

The World Health Organisation definition[i]

> **'Definition:** [Long Covid] is defined as the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation.
>
> **Symptoms:** While common symptoms of Long Covid can include fatigue, shortness of breath and cognitive dysfunction, over 200 different symptoms have been reported that can have an impact on everyday functioning.
>
> **Numbers affected:** Studies show that around 10–20% of people infected by SARS-CoV-2 may go on to develop symptoms that can be diagnosed as Long Covid.'

The National Institute for Health and Care Excellence (NICE**)** recommends that people with Long Covid are supported by:

1. Self-management and supported self-management.
2. Multi-disciplinary rehabilitation.

Additional support such as short-term care packages, advance care planning and support with social isolation, loneliness and bereavement.[ii]

Long Covid in Calderdale

The Office for National Statistics (ONS) analysis of Winter Coronavirus (COVID-19) Infection Study data from November 2023 to March 2024 shows that an estimated 3.3% (2 million) of people living in private households in England and Scotland were experiencing self-reported long COVID.[iii]

If the same percentage of Calderdale's population has Long Covid, this would mean that approximately **6,800 people in Calderdale have Long Covid**, based on ONS 2023 mid-year population estimates for Calderdale of 208,700 people.[iv]

Analysis conducted by Calderdale Council[v] suggests that:

- Around 20% of these (1,360) have significant activity limitation.
- Those most at risk are women and those in middle age.
- The number of GP referrals is much lower than the estimated prevalence, suggesting **significant unmet need.**

Defining recovery from Long Covid

There is no clear, accepted definition of recovery from Long Covid. Recovery is difficult to assess clinically because the condition has multiple symptoms that vary between people and over time, and there are no definitive biomarkers for diagnosis by which recovery can be measured.

For the purposes of this research, we used interviewees' subjective definitions of recovery – the person's perception of their health, well-being and quality of life, and the extent to which they were able to conduct daily, work, social, physical, and leisure activities.

It was notable that people's own perceptions of recovery differed to those of professionals. Professionals referring interviewees to the research, for example, sometimes used markers such as returning to work or being able to complete a long run as an indicator of nearly-full recovery. Individuals had more nuanced perceptions of recovery, for example explaining how a return to work could come at a high cost to their ability to exercise or engage socially, or that they were only able to run if they rested for several days before and afterwards.

Only one of the 10 people interviewed had returned to pre-long covid levels of functioning. Several had made fundamental changes to the way they lived, choosing to prioritise rest and self-care, in order to maintain a baseline level of functioning.

About this Research

In-depth interviews were conducted with ten people who had made self-defined full or partial recoveries from long covid, and with five professionals working with people with long covid, in summer 2024. A timeline methodology was used as a framework for talking through people's recovery journeys in interviews. Narrative and thematic analysis was conducted.

The research was participatory and lived-experience-led: the researcher, Chair of the project Steering Group and several Steering Group members have Long Covid. The research findings and recommendations were informed by workshops attended by nine members of the local peer support group (the Long Covid Support Group Calderdale) and five people who had been interviewed for the research, as well as by discussions with Calderdale Council officers and staff from the Calderdale Long Covid Clinic.

The research was guided by a Steering Group that included professional and lived experience experts from the Long Covid Support Group Calderdale (LCSGC), Calderdale Council's Public Health Team and Better Living Service, Calderdale Long Covid Clinic, Active Calderdale, Halifax Opportunities Trust and Shared Harmonies.

The research was funded by Calderdale Council's Public Health Team and commissioned by the Long Covid Support Group Calderdale.

The 10 Interviewees

Interviewees were:

- Recruited via Long Covid clinic, LCSGC (peer support group), and word of mouth.
- Two people had had no contact with specialist LC services.
- Seven women, 3 men.
- Ethnicity: British Pakistani: 1 / white other: 1 / white British: 8.
- Aged from 30s to 70s.
- Date of first infection ranged from Mar 2020 to March 2023. Interviewees had had Long Covid for approximately 1.5 - 4.5 years at the time of the interview.
- All had had all/most of the vaccinations they were entitled to.
- Range of symptoms spanning all major LC symptoms, range of severity of infection.
- Six had a pre-existing long-term health condition. 2 developed a long-term condition post-Covid.
- Five currently had anxiety and/or depression.
- Three were in perimenopause.

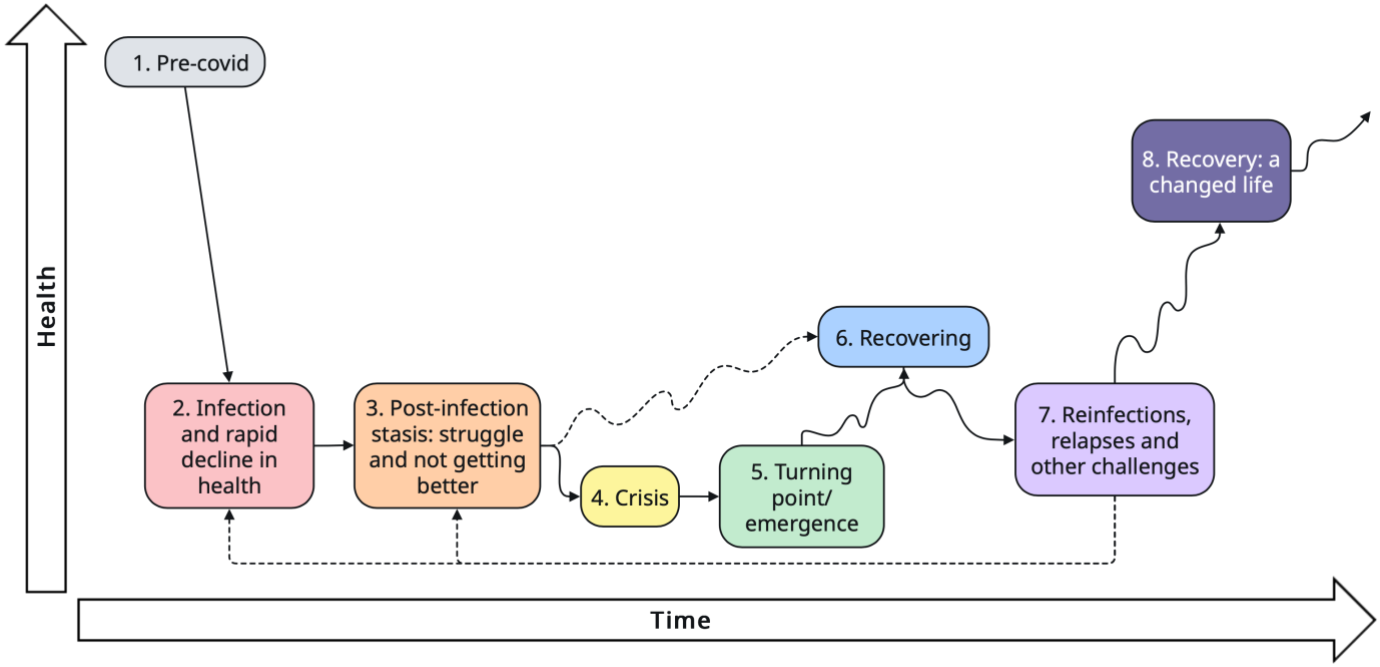
Current states of recovery

- Post-Covid achievements of different interviewees include:
    - Hill walking.
    - Running a marathon, walking an ultra-marathon.
    - Gaining a black belt in taekwondo.
    - Returning to full-time (2 people) or part-time (6 people) work.
- Three people no longer experienced any Long Covid symptoms. Others experienced fewer and less severe symptoms.
- However, only one person felt 100% recovered. 4 people placed themselves at around 70-100% of their previous health; 5 at around 50%, and 1 at around 20%.

- Most people remained acutely aware of the gaps between what they could do now and pre-Long Covid – e.g. able to do less, walk shorter distances, slower running times, less energy, more need for rest.
- There is a notable gap between what individuals and healthcare professionals understand as being recovered – assumed indicators of recovery (e.g. returning to work and exercise) do not necessarily indicate recovery.

2. The Long Covid recovery journey

The shape of the recovery journey



We asked people to draw their timeline from Covid infection to where they were now. Interviewees had first contracted Covid-19 between approximately 4.5 years and 1.5 years ago at the time of interview. See Appendix A for examples of the recovery journeys drawn.

This model shows the stages that were common to many people. Everyone's journey is different, and not everyone experienced all of these stages. Like any model, this is a simplification and people's actual experiences were often more complex and less clearly sequential.

Common features of the recovery journey were:

- Most people experienced a rapid decline from close to 'best possible' health to close to 'worst possible' health soon after Covid infection.
- Up and down recovery, characterized by dips and improvements.
- Several people differentiated between recovery in relation to physical health, mental health and other self-identified important aspects of well-being (such as cognitive function or specific physical symptoms). Recovery in each of these areas could converge and diverge, sometimes to a large extent.
- At the time of the interview, most people placed themselves at around 50% to 70% recovered. One person said they were 100% recovered; one said only 30%.
- Almost everyone's timeline ended on an upwards trajectory, suggesting that recovery is continuing after several years. These stories may only paint a picture of the initial stages of recovery.

1. Pre-Covid

'Before Covid, my health was excellent. I just had so much energy and sense of self and agency. I did a massive amount of digging on my allotment. I was fitter in that period than I've been for a long time.'

- Most people said they were close to their best possible health pre-Covid. Six people had long term health conditions (including asthma, lupus and adrenal insufficiency, rheumatoid arthritis, endometriosis, and mental health issues), but most were managing these. Only one person said they were not living healthily pre-Covid.
- Several people said that the stress, anxiety and isolation of the pandemic had negatively affected their mental health or well-being before contracting Covid.

2. Covid infection and rapid decline in health

'I returned to work … but I was really dizzy, I couldn't shift this. And then a couple of weeks later, my body just went, it just crashed.'

- Some interviewees had mild Covid-19 symptoms, and some had severe and frightening symptoms.
- All experienced a rapid, steep decline in health following the infection, either immediately or in the following weeks or months.

3. Post-infection: struggle and not getting better

'Mentally, I really suffered with being ill. I was feeling really depressed and quite anxious… Crying at times. Thinking no one understands me and I'm, like, some sort of freak. I felt like I'm letting people down.'

Key features of this stage are:

- People's old models of recovery were challenged – you do what you usually do to recover and it doesn't work – but you keep doing it.
- Pushing through; a lack of understanding/acceptance of how ill you are and your limitations.
- Questioning and seeking to understand: what's happening? Is this in your head?
- Stigma including shame, guilt, self-stigma, and lack of validation/understanding from others.
- Seeking support from traditional healthcare providers/system, and often not receiving adequate support.
- Trying different things to get better.
- Isolation.
- Loss, and sense of identity/sense of self challenged.
- Challenges and anxieties around money and work.
- Usual coping/self-care strategies aren't available because of the condition (exercise, social connection, work, hobbies, etc).

4. Crisis

'I did have suicidal thoughts [...] I had such bad anxiety, I honestly thought I was going to die, like literally. Literally laid in bed, I thought this is it, I'm done, I'm not going to get better. And if this is my life now, I don't want to be here.'

Many people described a crisis. This stage typically involved:

- Not getting better and the loss of hope of getting better.
- Decline in mental health - depression was common and several people said they had had had suicidal thoughts.
- Feelings of loss and grief which could be overwhelming.
- Trauma – including the trauma of not being believed/not receiving support; of both acute and chronic illness; of the pandemic; and, for some, the re-emergence of past/childhood trauma.
- Crises often occurred before people received specialist support from the Long Covid clinic and after other support (e.g. GP, other non-Covid specialists) had not met their needs – indicating the importance both of the quality of support received from the first point of contact and of quick referral to specialist support.
- People from minoritised groups are less likely to access specialist support, so may be more at risk of reaching/remaining at this crisis point.

5. Turning point/emergence

The turning point or emergence from this crisis was different for everyone. For some it was a notable shift; for others, a slow, gradual change.

- Some people could identify a clear change that precipitated a turning point for them. Examples include:
    - Receiving support
    - New medication
    - Shift in mindset
    - New activity
    - Learning new tools
- Others said they had experienced a series of small changes that went hand in hand with a slow improvement.

Holly's story: small changes adding up

'There was like, a little bit of hope with [a private Long Covid programme], I'd say a few other things, acupuncture, things like that, started to happen, and then I feel like, even though it wasn't great, and felt like very slow progress, I feel like every week, I had like, a plan, you know, like, I was, could walk a little bit better, and I was having coffee, a lot of people were taking me out, I always tried to make sure that I had something to look forward to every day.'

Richard's story: validation and hope

'I was physically and mentally in a bad place.

Then I got an email and four days later, I was meeting [Long Covid clinic staff], and that was just unbelievable, amazing. Because I sat for an hour and a half with [clinic staff], and they just sat, chatting, smiling, understanding, saying all the right things, listening, responding, asking really good, intelligent, thoughtful, empathetic questions. And they said, we've got a Long Covid recovery programme, and you can do it.

I got back in the car, and I just went, "wow." I felt such amazing relief. I felt really good. They were so amazingly supportive and empathetic, and validated my feelings and my experience. And I thought that if they're doing [the course], which they were, it's going to be good. And it was.

And it's very interesting, because I can remember that day very clearly, and I can remember how I felt over the next couple of weeks. And my psychological, mental well-being just went straight up.

[On that first meeting] they also taught me deep breathing exercises, diaphragmatic breathing. And I started doing it, and it became a habit over the next four weeks. And that really made a big difference, that started to affect my physical health quite quickly. And it was a very profound change.'

6. Recovering

This stage of the recovery journey, including facilitators and barriers to recovery, is explored in Section 3.

7. Reinfections, relapses and other challenges

'I found it really hard to restrain myself [from exercising] and I think there have been times where I've not done myself any favours by pushing too hard.'

Reinfections and relapses

- Reinfections with Covid-19 did not always cause big setbacks – most people recovered from these fairly quickly.
- Relapses and dips could be triggered by:
    - Stress - emotional, work-related or other, including bereavement.
    - Overdoing things physically.
    - Returning to work too soon/for too many hours.
    - Another Covid-19 infection.
    - Other health issues/conditions.
    - Other factors (e.g. weather/seasons).
- There are likely to be physiological processes that we don't yet understand that contribute to the relapsing-remitting nature of Long Covid.

Other challenges in recovery included:

- The frustration of not being fully recovered - you may seem better to others but are still unable to do the things that you enjoy and that made you you - (e.g. exercise, work or socialising). You may have to make sacrifices (e.g. you can work but not be able to do much else/you can socialise but may need days to recover). Healthcare professionals and loved ones may not understand this.
- Dealing with fear of reinfection/relapse.
- Challenges to relationships – the strain on partners/caregivers can last long into and potentially beyond recovery. This can be because of the mental and emotional impact of an often-traumatic period, but also because the person with Long Covid may now have a changed lifestyle, values and priorities.
- The loss of characteristics and abilities that were central to your previous sense of identity.
- Illness fatigue, as experienced by both the person with Long Covid and the people in their lives. For individuals, the boredom and frustration of having to continue to deal with and self-manage illness after many years. And, for some, the experience of friends and family becoming frustrated, emotionally burnt-out, or no longer acknowledging the continued existence of the condition, which could increase feelings of guilt and isolation among the person with the condition.
- Ill health – one interviewee was diagnosed with cancer. Another sprained their ankle and was at another time hospitalized for pneumonia. These things set back both of their Long Covid recoveries.

Relapses and dips could send people back to stages 2 or 3 of this model.

Spotlight: 2020 infections

People who became unwell in the earlier months of the pandemic have faced particular challenges:

- Symptoms were different and sometimes more severe.
- Vaccines (and potential protection from these) were not yet available.
- Experiences of ignorance, disbelief, shaming and stigma from members of the public, employers and health professionals were common. Messages of validation, hope, reassurance and support much less so.
- Specialist services were not yet available.
- Long Covid was a new condition without an evidence base or understanding. As a result, people often received misdiagnoses (e.g. depression and anxiety), and advice from healthcare providers that is now known to be detrimental (e.g. advice to exercise more that was not accompanied by an understanding of post-exertional malaise or the importance of pacing).
- People became unwell during a time of very high public perceived risk and fear around Covid-19, which could exacerbate anxiety during the infection (including fear of passing the virus onto vulnerable loved ones).
- People may be more likely to have fallen through gaps in services, seeking support when it was either unavailable or poor quality, and not receiving later improved support.
- These experiences are likely to have had a bigger mental health impact, and may have been traumatising.
- It is likely that significant numbers of people in this group are still in need of support. They may be more likely to be stuck in the stages of ‘stasis’ or ‘crisis’, and may need different support strategies to those newly diagnosed.

8. Recovery – a changed life

Not all interviewees felt they had reached or could reflect on life post-Long Covid. Those who did described a changed life, with features including:

- Some things are better – e.g. a more balanced life, more tools for managing stress, anxiety and other challenges of life.
- New priorities, including self-care.
- A new sense of identify – letting go of some old aspects of 'who I was', and opening up to new possibilities.
- Reduced activity levels and more rest – no longer pushing yourself either in or outside work.

Getting to this point usually required processing feelings of loss and grief.

Gemma's story: a changed life

'So now I'm running 5k, I'm going swimming once a week, and I'm out dog walking. So probably I'm healthier than I was before I got COVID, but in a different way.

It's finding new enjoyments. I don't drink alcohol anymore. Socially, it's changed quite a bit. But this gave me the confidence to see other people and actually I don't need to chase that life. You can meet new people and find new interests.

When we were out running on Sunday morning, I was like, this is quite free and it's quite nice. It's a new enjoyment. You can see the little goslings and the ducklings out and watch deers and foxes run about.

So I do feel like I've found more enjoyment just in a different way. And that comes with the acceptance of, I can't do that as much, but there's other things that we can enjoy.

I've put my name down for an allotment. I still love being outside. I would never have been like, grow your own veg and do all this. It's just, again, different enjoyment, different things to look forward to.

Now I'm so much more relaxed than I used to be. My perception of what's important has totally changed.'

Richard's story: re-discovering my sense of self

'I'm actually much better than I was [before I got Covid] because I'm much more relaxed. I'm much more at ease with myself and with other people. I've got that sort of stillness and activity in balance. I'm actually feeling better [even though] I'm not as physically fit as I was at all.

I just [feel] like life is normal again. And I've now got that ability or consciousness of not overdoing it. And if at the end of the day I do feel like I'm more tired than I want to be, I'll take it easy the next day.

I've got a real balance back into my life. And I've got a real sense of self again. And if I do start to feel anxious, I can deal with it, and I know how to deal with it.

I was a potter, but I stopped doing it a long time ago. I thought I'd lost the muscle memory of how to do things. But when I started to do [the Long Covid clinic] course, it all started to come back.

There's a [local] pottery, so I've applied to get a space there, so I can make more stuff and start selling it again. And that's a huge, huge change for me.

[After doing the course] I knew who I was again. Just huge confidence, actually.
It's like I'm back, I'm back, I'm doing what I want to do.'

Holly's story: looking after myself

'I feel like as a whole, the situation's really good for me [now]. I will stop and I will rest and I will have lazy days. And I won't feel that guilty about it because it's very important that I do it. So I've got a massage booked in next week… I try really hard to look after myself and, you know, do little things that I would have considered selfish in the past.

My friend came [this week] and we went to the pub and had tea and we were out from seven until nine. And I would never, never have done that [in the past]. [But I said to myself] I think it's really important that you go to the pub with [friend] and then you can talk openly and, you know, I really need that.

I feel strong.'

Conclusions: the Long Covid recovery journey

- **A large degree of recovery from Long Covid is possible**, at least for some people, even after being severely unwell.
- The experience of being unwell with Long Covid is often traumatic, **and the recovery journey can be very challenging**.
- **There is currently no one route to recovery** – the recovery journey and the things that help look different to everyone. Recovery takes time, patience, determination and hope.
- **Professional support from the Long Covid clinic was central to most people's recovery journeys**. This was helpful in: providing information; giving validation and hope; helping people to understand their condition and acquire skills for self-management and self-care; and support in communicating with employers and claiming benefits.
- **Life post-recovery might look different to life before Long Covid**. It might involve more rest and self-care, changed priorities, and a new sense of identity. Several people found learning and meaning in their experience of having and recovering from Long Covid.

3. What helps recovery from Long Covid?

It should be noted that this research focuses on those who have made some recovery and will not fully capture the barriers experienced by those who have not.

Key findings in relation to recovery

- **Recovering from Long Covid can be a long process**, characterised by ups and downs over many months or years.
- **There is currently no one route to recovery** – the recovery journey and the things that help look different to everyone.
- **Recovery from Long Covid takes time, patience, determination and hope, and the active use of a range of tools and techniques** – these might include pacing, rest, breathing exercises, relaxation exercises, and gentle return to movement when able.
- Recovering from Long Covid is not straightforward. It involves many challenges. **Specialist professional support is extremely helpful, and for many people essential**, to help them navigate their recoveries from Long Covid.
- Most people interviewed for this research saw themselves as around 50% to 70% recovered after between 1.5 and 4.5 years. Further research is needed on what helps people to make full recoveries.
- Some people haven't yet made recoveries from Long Covid – further research is needed to explore why this is and what would help them. In the meantime, they continue to need support to live well with a condition that can severely affect their lives.

What helps recovery

Facilitators of recovery that that were common across many interviewees include:

- Being listened to and receiving validation, support and guidance from professionals (in particular the Long Covid clinic).
- Rest, pacing and breathing exercises.
- Specialist mental health support, including processing trauma, grief and loss.
- Hope and inspiration from others who have recovered.
- Balancing acceptance of being unwell, with determination and hope of getting better.
- Finding meaning, purpose and connection with others even within an extremely difficult situation.
- Slowly returning to movement and 'normal' activities (when able to).
- Some medications (including inhalers, anti-depressants and HRT) played an important role in some people's recoveries, but they only formed part of the picture. More research is needed into the mechanisms underlying Long Covid, and effective medication and treatment.

Barriers to recovery included:

- **Not being aware of/referred to specialist support.**
- **Stigma and disbelief by** friends and loved ones, professionals, the wider community, and/or internalized self-stigma, doubt and shame – these still affect many and were particularly prevalent for those becoming unwell earlier in the pandemic before Long

Covid was more commonly recognised. Members of the Long Covid Support Group Calderdale have many recent examples of experiencing stigma and psychologisation of symptoms (the attribution of physical symptoms to psychological causes without sufficient investigation) from healthcare professionals, including being told that their symptoms were psychosomatic and that they should 'think yourself better.'

- **Inadequate support** from the healthcare system including GPs, and from DWP in supporting those who lost their income.
- **Financial pressures** causing stress and/or the need to go back to work before well enough, and for those who lost their jobs, struggles with DWP to explain their condition.
- **Inability to have sufficient rest, because of work, home and/or caring responsibilities.**
- **Systemic inequalities**: specialist support is not reaching people who are members of minoritised ethnic communities.

It should be noted that this research focuses on those who have made some recovery and so cannot fully capture the barriers experienced by those who have not.

Our experiences and needs

What we're experiencing	What we need from professionals
• Trauma	• Listening
• Loss	• Validation
• Guilt	• Hope
• Anger	• Care
• Depression	• Information
• Anxiety	• Tools
• Fear	• Encouragement
• Loneliness	• Support

Professional support that we need

- Specialist support from professionals with an in-depth understanding of Long Covid. Group and 1-1 support both have different, important functions. Support should include:
    - Information about the condition.
    - Support with pacing, including managing household responsibilities and work.
    - Breathing exercises.
    - Relaxation exercises and tools.
    - Support to maintain or improve mobility and get back to movement and exercise (when we are able).
    - Emotional support, advice and encouragement.
    - The opportunity to talk and be listened to.

- Specialist mental health support, including processing trauma, grief and loss, from professionals with an understanding of Long Covid.
- Specialist secondary healthcare by people who understand Long Covid.
- Support with money management and claiming benefits.
- Advocacy and support with employers – to help employers find ways to retain employees and to understand our rights at work.
- Sometimes, we need help from social services with the activities of daily living.
- Opportunities to come together, share experiences with, and learn from our peers.
- Opportunities for social connection, doing 'normal' activities, and doing things that bring us happiness and joy.

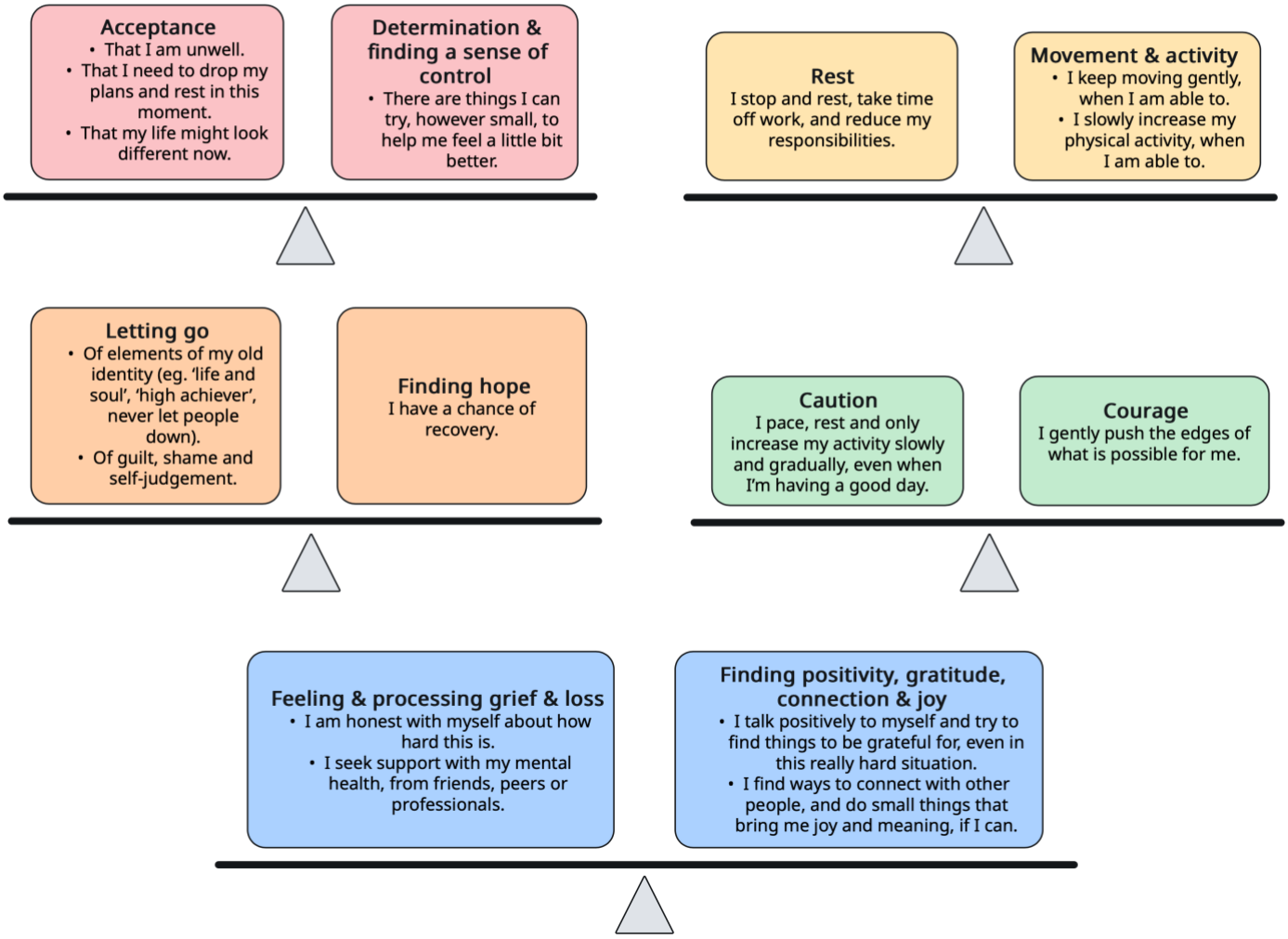
The fine balance of recovery

Recovery: a fine balance

Recovery from long covid can entail balancing multiple ways of doing things that can seem to oppose or contradict each other.

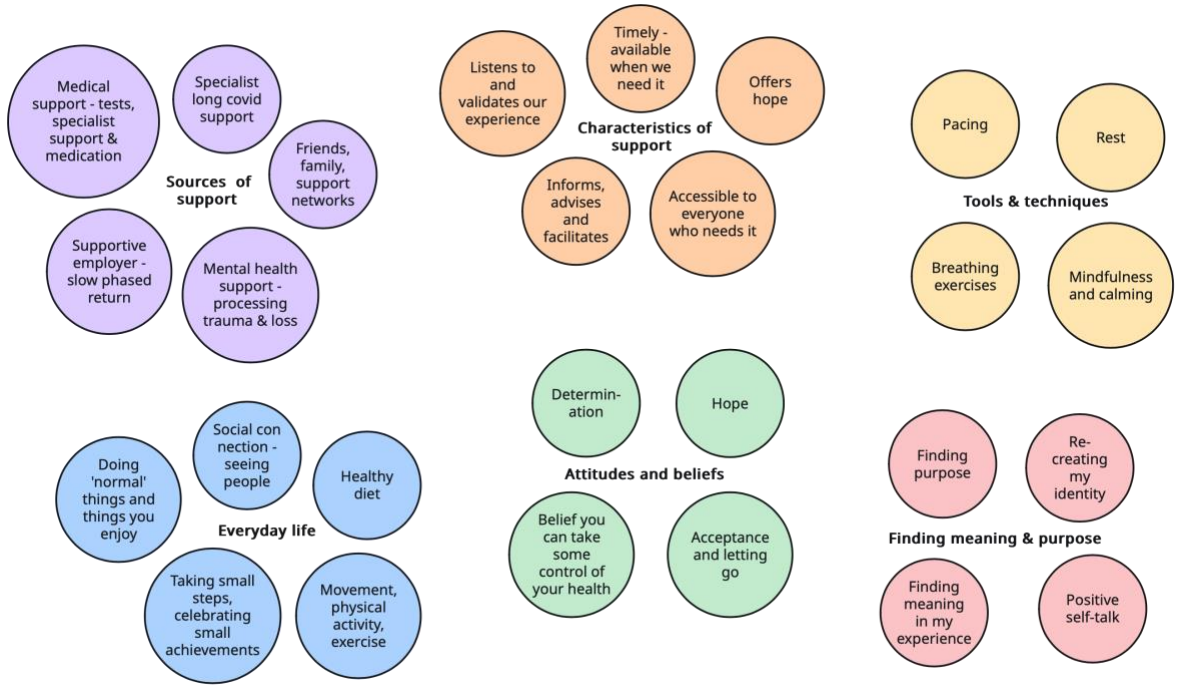
The calibration of the scales changes all the time - there isn't a 'right' balance to guide us. Something that works for us today may not work tomorrow. It's impossible to get this balance right all the time, and getting it wrong can be frustrating and cause small or big setbacks in our recovery.

We need skilled specialist support to help us find a balance and navigate the ever-changing scales.



Helpful factors in Long Covid recovery

People interviewed for this research identified a range of factors that they believed had helped them recover. Themes included the following:

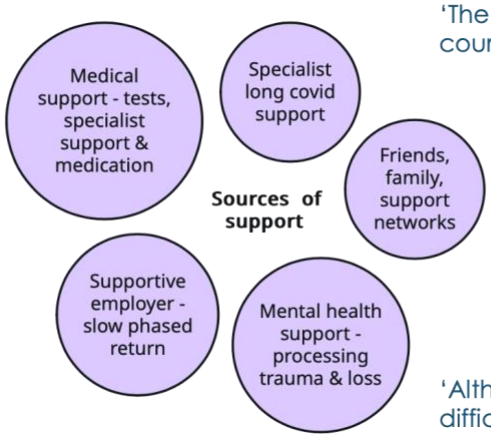


Sources of support

'I have a really great doctor, and in the end she was like, "you just need to stop."'

'Time off work is very important in my recovery story.'

'My work was absolutely brilliant: "If you need that nap, go have your nap."'



'The [long covid clinic] course was fantastic.'

'I'm blessed I have good work colleagues, I have a good wife, so my network was strong'

'I've got the best people around me. People rallied around and took me to all my hospital appointments and brought me food'

'Although the therapy was really difficult, I think that helped.'

Characteristics of support

What really helped was having someone [OT] who just listened. And heard, validated, reassured, was steadfast in the "you can do this, this is doable", that kind of narrative stuff. She would be so kind and compassionate, and these things matter. I kept waiting for her to say, right, that's our last session, and she never did. And that was massively important. '



'My doctor said "it's going to take a while to get better, but you will get better."'

'Everything [OT] says is such an affirmation that by doing this thing that doesn't come naturally to me [resting and pacing], I'm getting what I want, which is getting better.'

'[The long covid clinic group exercises class] was like, take time, pace yourself. With a lot of mindfulness, relaxation, which was amazing. And that really kind of helped me reset.'

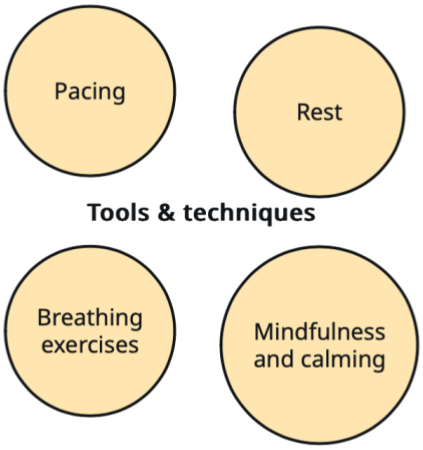
'It made such a difference to me, having [OT], someone to talk to about it, someone validating this thing.'

Tools and techniques

'Pacing was a game changer.'

'I was very motivated to get better, and I accepted that resting and pacing was part of it. I saw resting as a productive activity, that's how I sold it to myself. So it was an activity that I was doing, and that helped me get better.'

'The basic principle is that you close your mouth and breathe through your nose. And that made a massive difference.'



'When I'm feeling well enough to do things, it's about trying to stop myself from doing too much, because I'm really bad at resting. And that's been a really difficult lesson for me. I think learning to rest has been harder than realising I have a chronic illness.'

'The mindfulness side of it really helps.'

Attitudes and beliefs

'I'm going to overcome this. Whatever it is, to the best of my ability, whatever anybody says, I'm going to find what I need to do to get myself going again.'

'I'd get to the top of the hill and there's a bench there, I'm lying on the bench, because I wasn't safe to walk down until I rested properly. But I was just determined to do it. Being positive cannot change the lot that you've got [but] it can change how you experience it.'



'I do think there's stuff that we can take into our control.'

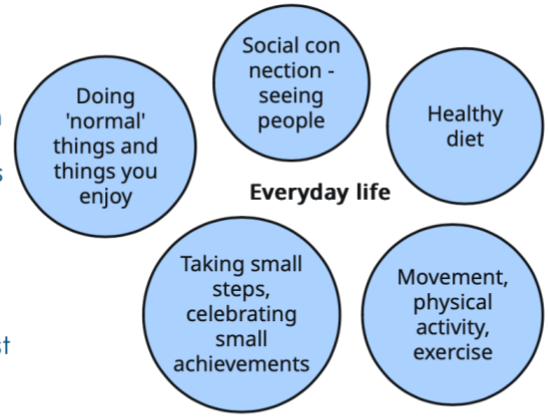
'There is a way, there is hope, there is.'

'Acceptance is really, really key. It doesn't matter externally what's happening in a way. It's the acceptance that you've got to come to that something has changed.'

'One thing I do think has helped me, was to mentally just go, right, I can't control this, and you've just got to go with it. It's acceptance of: this is me. This is how we are. But it does get better.'

Everyday life

'Swimming was easier than walking. I couldn't do very much, but for me, that was amazing, that I could actually do something. It was also talking to people at the swimming pool, having a chat, and I could do that a little bit, and it just felt like a normal activity, like I could do something normal.'



'Not isolating yourself. Long covid is very lonely. I started talking more and letting family in and I think that helped. Going back to being social. I think social interactions, as draining as they are, are really important.'

'I noticed my achievements. Like, I did my food shop, or walked round the block, wow, I did that.'

'Everything is sort of incremental. Step by step. Don't put pressure on yourself.'

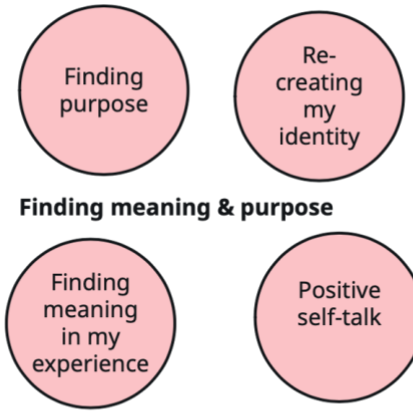
'Once I became able to exercise properly, [my health] went up a lot quicker.'

'I started walking, and then a lot more [...] I got to the top [of a small hill] and I made myself stop at the top. And I said to myself out loud, right, turn around and look at how far you've come.'

Finding meaning and purpose

'Because I coach, even when I'm feeling really rubbish and unable to do anything, I can encourage and support somebody else. I'm able to see the achievements of somebody else and know that I contributed a little bit to that.'

'I'm a big believer in: things happen in life. I've had long covid and that's my story and if you learn something from it you can become a better person. There's a reason this has happened.'



'I honestly feel like [having long covid] has definitely not [been] a negative experience. I feel like it is a positive experience. There are bits where I was sad and it's not that I don't acknowledge that, but equally I don't dwell on it. I don't want to feel sorry for myself.'

'The positivity helps. It doesn't change what you've got, but it really, really makes a difference to whether you're happy or not. Right here and now I'm alive and I'm grateful for that. And I've had a very interesting experience [and] amazing support.'

'I think you can become a bit lost in illness. The illness can become you and [instead] it needs to be: "I am a person, I am whoever who is managing an illness or living with an illness, but I'm not the illness, I have more to me, more to my life than this illness."'

4. Case studies of recovery

Gemma

Gemma is in her 30s and has teenage children. She first got Covid 2 years ago.

A traumatic infection

I've never felt illness like it. I collapsed, couldn't breathe, didn't know what was going on. My heart rate was through the roof, I was in resus, the doctors didn't know what was going on. They were pumping me with antibiotics, and I wasn't recovering. I was in and out of hospital for three months. They put me on inhalers and steroids for my breathing, but then that affected my heart. So then I ended up back in resus because my heart couldn't respond to the drugs.

'The doctors didn't know what to do with me'

I felt like the doctors didn't know what to do with me, so they just kept throwing more tablets at me: take this, take that, take this. And I think it got to about five months and I was like, right, enough's enough, the doctors aren't helping.

'I decided to take control of my own health'

So I think this is when I decided to take control of my own health. I think there's something rewarding about taking stuff into our control. Because when you're doing it for yourself and can say 'I've done this and this is helping', it spurs you on to do more of that. And then it's something positive to focus on.

Diet

I was like, right, where can I look? I went to the recovery stories on Facebook. Diet was a massive thing that always came up. So I was like, what foods cause inflammation? So I went gluten, dairy and sugar free. I did a lot of research around the gut microbiome. I came off all the ultra-processed stuff, went on to kefir, kombucha, sauerkraut, lots of nuts and grains.

The Long Covid clinic

I did the Long Covid clinic's course. It was, "take time, pace yourself", with a lot of mindfulness and relaxation, which was amazing. And that really helped me reset.

Learning to manage anxiety

The Long Covid clinic spoke about the different nervous systems, sympathetic and parasympathetic. If I understand it, I feel like I can control it. I used to get quite a lot of panic attacks during this time, but now I can sense when the panic attacks are coming on, I'm like, "right, I know that I'm in fight or flight. How can I bring that down?"

Getting back to exercise

I was scared. I was so breathless. Anytime I became breathless I would panic. The Long Covid team worked really hard with me – doing little exercises, doing weights, doing a six minute walk. Just reassurance, doing it in a safe environment. I was getting breathless in clinic, but because they put a monitor on you, you could see your heart rate and oxygen levels, and I was like, 'I'm ok. I'm alright'. Still now, I still do get that panic, I'm like, 'I can't

breathe’. But then I'll calm down and I'm actually fine. I'll keep going. The Long Covid clinic really helped with the exercise. And retraining the breathing, that helped massively.

‘Allowing me to grieve’
They brought in a guest speaker who had had Long Covid. And she said, ‘it's about acceptance and accepting that this is you now.’ So I burst into tears because I thought, ‘I'm not accepting this. I'm getting better. I'm trying so hard.’ But actually this allowed me to grieve. Grief kicked in, but it was a positive, I think, like, ‘I'm not going to get this Gemma back. She doesn't exist anymore.’

‘A different person’
Within about 4 months I was a different person. I was back out of bed, I was back in full time work. I kind of just had it in me like, right, OK, [the GP and consultants] can't look after me. What natural stuff is there? What's going on in my body, because your body, I think, is amazing and can heal, can't it?

‘I’m healthier than before I got Covid’
So now I'm running 5k, I'm going swimming once a week, and I'm out dog walking. So probably I'm healthier than I was before I got COVID, but in a different way.

‘More enjoyment, just in a different way’
It's finding new enjoyments. I don't drink alcohol anymore. Socially, it’s changed quite a bit. But this gave me the confidence to see other people and actually I don't need to chase that life. You can meet new people and find new interests. When we were out running on Sunday morning, I was like, this is quite free and it's quite nice. It's a new enjoyment. You can see the little goslings and the ducklings out and watch deers and foxes run about.

So I do feel like I've found more enjoyment, just in a different way. And that comes with the acceptance of, I can't do that as much, but there's other things that we can enjoy. Now I'm so much more relaxed than I used to be. My perception of what's important has totally changed.

Holly

Holly, in her 40s, is a teacher with two young children. She first got Covid about 3 years ago.

Being ill

I rapidly deteriorated very, very quickly. I was in bed, but not 'with it', like a zombie, and then I would use all my energy for that hour when the girls came home. I think I was too ill to even be worried about being ill.

'Time off work was very important'

Time off work, I think that's very important in my recovery story. At first, I had ten days off work, went back to work, crawled around the classroom, and then agreed with my head teacher I wasn't well enough to be at school. I got a sick note for a month which I was devastated about. I wasn't prepared to believe that I needed it, because I wasn't that type of person, because I don't get ill! I am mentally very strong. I had a three-month sick note next, and then I was actually, 'I'm in a really fortunate position that I can take this time off'. The focus then was on me getting better.

'A little bit of hope'

There was a little bit of hope with the Nuffield Health Long Covid programme. I'd say a few other positive things started to happen, like acupuncture, and feeling that other people were getting better. I was reading other people's stories, and that was giving me so much hope.

'Something to look forward to every day'

And then, even though it wasn't great, and felt like very slow progress, I feel like every week, I had a plan. I could walk a little bit better, and I was having coffee, a lot of people were taking me out, I always tried to make sure that I had something to look forward to every day.

Finding purpose

I joined a befriending scheme, I was a volunteer. Because I had no purpose. In truth, the woman I befriended probably was supporting me!

'I accepted resting and pacing'

I was very motivated to get better, and I accepted that resting and pacing was part of it. As soon as I saw resting as a productive activity, that's how I sold it to myself. So it was an activity that I was doing, and that helped me get better. And I still do that now.

Journaling and gratitude

I did a lot of journaling – well, I didn't because I couldn't really write, but I did smiley faces and numbers, and thinking every day of something that I was lucky for. I mean, I'm really lucky, so it was easy to do, and I just wasn't focusing on any of the negatives. I think if you feel lucky, fortunate, and grateful, then you don't feel like, 'oh, this has happened to me, I'm a victim.' I would have lots of internal thoughts to myself, saying, 'you're better than you were a month ago', you know, 'I'm lucky'. So I could always talk myself round.

Going back to work

Eventually, I kind of had an acceptance that I might not teach again. But, after 9 months off work, I went back to work. I did an hour a day, then 2 hours a day. It was really hard going back to work. But then I started teaching groups, which maybe pushed me a little bit more. That was very purposeful. I realised 'I'm going to be ok'. I was so lucky that I got my joy of teaching back. I'm back to working part time now, 3 days a week.

'I try really hard to look after myself'

I've always worked too hard. I used to work till midnight every night – I don't do that now. I've got a massage booked in next week. I try really hard to look after myself and do little things that I would have considered selfish in the past. I will stop and I will rest and I will have lazy days. And I won't feel that guilty about it because it's very important that I do it.

'I feel strong'

It's now a year that I have not really had any symptoms or any thoughts about Long Covid. I feel like as a whole, the situation's really good for me now. My friend came this week and we went to the pub and had tea and we were out from seven until nine. And I would never, never have done that in the past. But I said to myself, 'I think it's really important that you go to the pub with your friend and then you can talk' and, I really need that. I feel strong.

Richard

Richard is in his 70s. Before contracting Covid, he worked part time and was very active on his allotment. He got Covid about 18 months ago.

'I was very, very fit'

Before Covid, my health was excellent. I had so much energy and commitment and sense of self and agency. I was very, very fit. In fact, I was fitter in that period than I've been for a long time.

'In a bad place'

After Covid, I was physically and mentally in a bad place. The medics weren't interested. I did start to improve, and then I just stopped feeling well. I think I'd probably done too much exercise. So, I thought, okay, I'll leave it and wait and rest. Do less exercise. Just go back to where I was at the beginning. And it didn't seem to make much difference, to be honest. And then, well, it then becomes a vicious circle, doesn't it? Because the less you do, almost like the less you want to do it. And psychologically, it's very damaging.

The Long Covid clinic: 'such amazing relief'

Then I met the staff at the Long Covid clinic, and that was just unbelievable, amazing. Because I sat for an hour and a half with them, and they sat, chatting, smiling, understanding, saying all the right things, listening, responding, asking really good, intelligent, thoughtful, empathetic questions.

They said, 'we've got a long recovery programme, and you can do it'. I got back in the car, and I just went, 'wow.' I felt such amazing relief. I felt really good. They were so amazingly supportive and empathetic, and validated my feelings and my experience. I thought that if they're doing the course, which they were, it's going to be good. And it was.

It's very interesting, because I can remember that day very clearly, and I can remember how I felt over the next couple of weeks. And my psychological, mental well-being just went straight up.

Breathing exercises: 'a profound change'

They also taught me deep breathing exercises, diaphragmatic breathing. I started doing it, and it became a habit over the next four weeks. That really made a big difference, that started to affect my physical health quite quickly. It was a very profound change.

'It taught me how to live well again'

The course started, and it was an absolutely brilliant course. They built a little community feeling. We all shared the same experience, however different we were, we were all the same. The sense of togetherness was amazing. We all had the same feelings of abandonment, of loss, and fear, and anxiety, and ill health, and change, and shame, and guilt, and loss of self.

We did things that reinforced that sense of belonging and hope, by looking at how you could improve and change. We did exercises that got more and more intense as the course went on, so you could feel the change in your body. The staff encouraged you, supported

you, validated what you were doing. And then there was the mindfulness and meditation and all these great conversations.

You were always being reminded that good habits make good health, really. Be conscious of the fact that you've got Long Covid and it's going to take time, but you will improve. Step by step. And if you don't feel very well one day, don't put pressure on yourself. Just relax. Learn the quality of stillness and activity, and try and achieve a balance in your life. I felt it just taught me how to live well again.

'I'm more relaxed and at ease'

I'm actually much better than I was before I got Covid because I'm much more relaxed. I'm much more at ease with myself and with other people. I've got that sort of stillness and activity in balance. I'm actually feeling better even though I'm not as physically fit as I was at all.

'I've got a sense of self again'

I just feel like life is normal again. And I've now got that ability or consciousness of not overdoing it. If at the end of the day I do feel like I'm more tired than I want to be, I'll take it easy the next day. I've got a real balance back into my life, and I've got a real sense of self again. And if I do start to feel anxious, I can deal with it, and I know how to deal with it.

'I'm back – I'm doing what I want to do'

I was a potter, but I stopped doing it a long time ago. I thought I'd lost the muscle memory of how to do things. But when I started to do the Long Covid clinic course, it all started to come back. There's a local pottery, so I've applied to get a space there, so I can make more stuff and start selling it again. And that's a huge, huge change for me.

After doing the course I knew who I was again. Just huge confidence, actually. It's like I'm back, I'm back, I'm doing what I want to do.

5. The Long Covid pathway in Calderdale

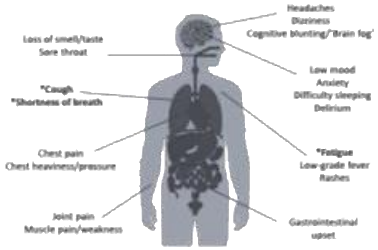
This section focuses on the local Long Covid pathway, what was reported to be working well, and recommendations for improvements.

This pathway was correct at the time of the research.

Calderdale Post COVID-19 Syndrome (Long Covid) Assessment Pathway: Primary Care Flow Chart

NHS Calderdale Clinical Commissioning Group

NICE Definitions (NG 188):



Ongoing symptomatic COVID-19:

Signs and symptoms of COVID-19 from 4 to 12 weeks.

Post COVID-19 syndrome:

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 often presents as a cluster of symptoms which can fluctuate and change over time and can affect any system in the body. Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.

Patients to be coded using: SNOWMED CT code: Post COVID-19 Syndrome

Patient contacts GP Surgery with ongoing COVID-19 symptoms

↓

Patient assessed by GP/ Clinician (Face to Face) (0 - 4 Weeks)
GP/Clinician suspects ongoing COVID-19 symptoms

↓

Ongoing symptomatic COVID-19 (4-12 weeks from onset) :
Please refer to Ongoing symptom management➲ or Arden's for appropriate clinical management to exclude serious underlying pathology and differential diagnoses

↓

Consider referral to appropriate community services

↓

Is the patient still symptomatic after 12 weeks?

Yes ← **Is the patient still symptomatic after 12 weeks?** → **No**

↓ (Yes)

Refer to Long Covid Syndrome Assessment
Complete referral form here➲ or on Arden's and ensure alternative pathology has been excluded

↓

Referral Triaged by Long Covid Clinician and treatment plan agreed

↓ (No)

Reassure and discharge patient

Please Note: *Most patients symptoms resolve within 12 weeks and will not require further action beyond this point*

Community Services

Social Prescriber
Via usual PCN channels

Gateway to Care
Social care or OT needs

NHS Talking Therapies VitaMinds IAPT self-referral
Telephone: 0333 0153 494
Website Link➲

Calder Community Cares
Telephone: 07903 452788
Website Link➲

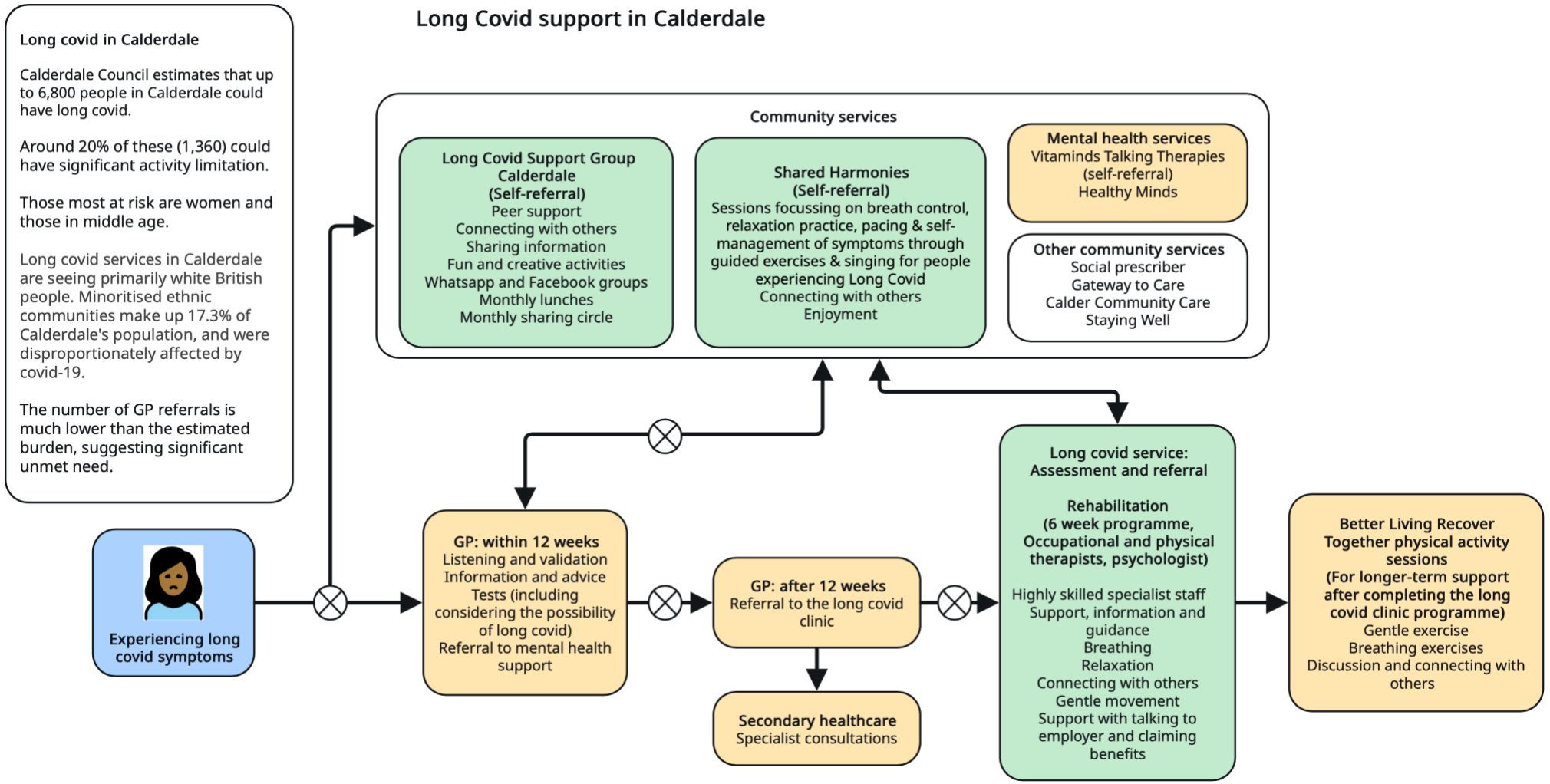
Staying Well
Telephone: 01422 392767
Website Link➲

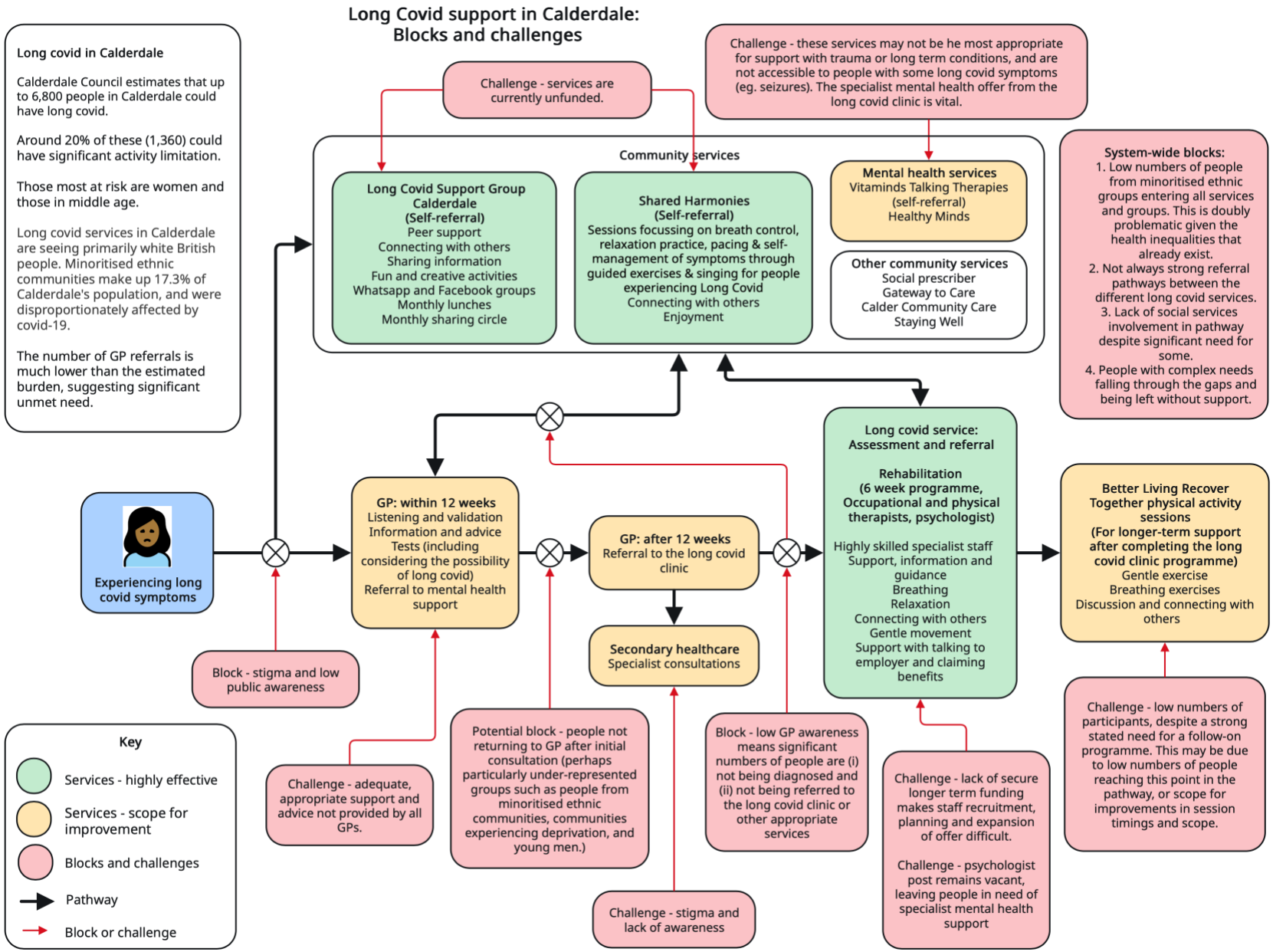
Better Living Service
Website Link➲

Please Note: Most patients symptoms resolve within 12 weeks and will not require further action beyond this point

Long covid services in Calderdale

This diagram describes important services and groups in the local Long Covid pathway and the routes between them, at the time the research was conducted. Because the condition is complex and affects many aspects of people's lives, many people have also used a range of additional services – e.g. private Long Covid support services, and advice and information services – which have not been included for the sake of simplicity. The diagram on the following page shows the blocks and challenges to effective support within this pathway.




Long Covid support in Calderdale:
Blocks and challenges
Long covid in Calderdale
Calderdale Council estimates that up to 6,800 people in Calderdale could have long covid.
Around 20% of these (1,360) could have significant activity limitation.
Those most at risk are women and those in middle age.
Long covid services in Calderdale are seeing primarily white British people. Minoritised ethnic communities make up 17.3% of Calderdale's population, and were disproportionately affected by covid-19.
The number of GP referrals is much lower than the estimated burden, suggesting significant unmet need.
Challenge - services are currently unfunded.
Challenge - these services may not be he most appropriate for support with trauma or long term conditions, and are not accessible to people with some long covid symptoms (eg. seizures). The specialist mental health offer from the long covid clinic is vital.
Community services
Long Covid Support Group Calderdale (Self-referral)
Peer support
Connecting with others
Sharing information
Fun and creative activities
Whatsapp and Facebook groups
Monthly lunches
Monthly sharing circle
Shared Harmonies (Self-referral)
Sessions focussing on breath control, relaxation practice, pacing & self-management of symptoms through guided exercises & singing for people experiencing Long Covid
Connecting with others
Enjoyment
Mental health services
Vitaminds Talking Therapies (self-referral)
Healthy Minds
Other community services
Social prescriber
Gateway to Care
Calder Community Care
Staying Well
System-wide blocks:
1. Low numbers of people from minoritised ethnic groups entering all services and groups. This is doubly problematic given the health inequalities that already exist.
2. Not always strong referral pathways between the different long covid services.
3. Lack of social services involvement in pathway despite significant need for some.
4. People with complex needs falling through the gaps and being left without support.
Experiencing long covid symptoms
GP: within 12 weeks
Listening and validation
Information and advice
Tests (including considering the possibility of long covid)
Referral to mental health support
GP: after 12 weeks
Referral to the long covid clinic
Secondary healthcare
Specialist consultations
Long covid service: Assessment and referral
Rehabilitation (6 week programme, Occupational and physical therapists, psychologist)
Highly skilled specialist staff
Support, information and guidance
Breathing
Relaxation
Connecting with others
Gentle movement
Support with talking to employer and claiming benefits
Better Living Recover Together physical activity sessions (For longer-term support after completing the long covid clinic programme)
Gentle exercise
Breathing exercises
Discussion and connecting with others
Block - stigma and low public awareness
Challenge - adequate, appropriate support and advice not provided by all GPs.
Potential block - people not returning to GP after initial consultation (perhaps particularly under-represented groups such as people from minoritised ethnic communities, communities experiencing deprivation, and young men.)
Challenge - stigma and lack of awareness
Block - low GP awareness means significant numbers of people are (i) not being diagnosed and (ii) not being referred to the long covid clinic or other appropriate services
Challenge - lack of secure longer term funding makes staff recruitment, planning and expansion of offer difficult.
Challenge - psychologist post remains vacant, leaving people in need of specialist mental health support
Challenge - low numbers of participants, despite a strong stated need for a follow-on programme. This may be due to low numbers of people reaching this point in the pathway, or scope for improvements in session timings and scope.
Key
Services - highly effective
Services - scope for improvement
Blocks and challenges
Pathway
Block or challenge

The local Long Covid pathway

What's working well	Challenges in the system	An effective local pathway
•Excellent Long Covid clinic – inc. Occupational Therapy, group programmes and support from Psychologist. •Strong, supportive peer support group. •Excellent support from Shared Harmonies that complements other services.	•Low referrals to Long Covid clinic — not getting diagnosed/referred and low public awareness. •Historically, a long wait for specialist support. •Support not reaching minoritised ethnic groups. •Lack of access to specialist mental health support. •Long Covid clinic has short term funding. Peer support group and Shared Harmonies are no longer funded. •Recover Together physical activity sessions and other gentle exercise classes are not well attended.	•The Long Covid clinic continues as is. •Continued support and funding for Shared Harmonies and Peer Support Group •Timely referral from GP to Long Covid clinic. •Outreach to minoritised ethnic communities. •Quick access to specialist mental health support. •People are supported in communications with employer – time off, phased return. •People are supported to apply for benefits. •Inclusion of social worker/mental health social worker/ psychotherapist in MDT.

The Long Covid clinic

People's experiences of the Long Covid clinic group sessions and occupational therapist (OT) support were extremely positive.

'Anxiety was the biggest thing to get over; irrational fear of dying. I kept thinking I'm going to have a heart attack, my heart's not working, I'm done for. The Long Covid clinic really helped with that, they helped with just calming some of that anxiety and some techniques. Just having someone there releases anxiety because you feel more comfortable. You're not on your own.'

'She would be so kind and compassionate, and these things really matter… What I really needed was patience, and I really got it from [OT]. I would say things to her that I didn't say to my partner or my closest friends, the negative stuff that people don't want to hear. It's about having time and space [to work things through]. These aren't things that just anyone can do.'

'She can see differences in me that I might not notice myself. She's knowledgeable and she's positive. Everything she says is such an affirmation that by doing this thing that doesn't come naturally to me [resting and pacing], I'm getting what I want, which is getting better.'

The role of specialist Long Covid services includes:

- Assessment and specialist referrals.
- Listening, validating and giving hope.
- Giving information and advice.

- Teaching self-management tools (both for the condition and for mental health and well-being) and support people to implement these.
- Supporting people to begin gentle exercise* and movement in a safe environment – and to rest when needed.
- An opportunity for people to be together, connect, share experiences and learn from and support each other.
- Helping people to calm their nervous systems, through guided relaxation exercises.

* **Not** graded exercise which can be harmful for this condition.

The Long Covid Support Group Calderdale (LCSGC)

The local peer support group has 58 members in its Facebook group, and 30 in its WhatsApp group. It meets for monthly social lunches, holds a monthly sharing circle for emotional support, and has supported a range of activities from gentle exercise to creative activities. The peer support group is highly appreciated by members. It both plays an important role in people's journeys towards recovery, and is there for the long term for people who have not experienced recovery.

> *'I'm not sure I'd be at the same point in my recovery if it wasn't for the peer support group. The acceptance, laughter, support and feeling of being part of a community has been so valuable to me.'*

Members value:

- A stigma-free space where everyone understands – you don't need to explain your condition and you can be yourself whether you're having a good or a bad day.
- The validation that comes from knowing that others share your experiences – you're not alone.
- Emotional support - a place to talk and be listened to and to receive validation and caring.
- Learning what professional support is available.
- Learning from others about what has helped them.
- Hearing and learning from others about going through the process of claiming benefits, or getting appropriate support.
- Getting together for activities and outings.
- Fun, friendship and laughter.
- The group is a mix of people, from those who are still struggling with severe symptoms, to those who are no longer significantly limited by the condition.
- The group is always there – there is no time limit on it.

The peer support group has received a small amount of funding from Calderdale Council, but its impact has been significantly amplified by the time and commitment of committee members, volunteers, and the generous support of Elland Christian Centre and the Church of the Good Shepherd in Mytholmroyd who have offered the group places to meet. This collective effort has created value far beyond the level of funding.

General Practitioners (GPs)

Experiences of GPs ranged from positive (in a small number of cases) to very negative. Positive experiences included GPs who acknowledged and diagnosed the condition and offered prompt referral to specialist support. Negative experiences often included lack of apparent knowledge or acceptance of the condition, and not being offered further support, information or advice.

> *'My doctor said "It's Long Covid, you've got chronic fatigue, and it's going to take a while to get better, but you will get better." I got the message from him that it's very hopeful, but you do need to stop, you do need to rest. It kind of prepared me that it was going to be a tough journey, but there was hope.' (this is the one interviewee who recovered 100%).*

> *'The medics weren't interested. The GP just said, in terms of COVID, you can take several months to get back to normal. I didn't get referred. I didn't get any advice or anything actually. So, I just accepted it.' – on a visit to GP after 12 weeks.*

GPs helped best when they:

- Demonstrated knowledge of NICE guidelines on Long Covid symptoms, and awareness that Long Covid might account for otherwise unexplained symptoms.
- Listened to and validated patients' symptoms and experiences.
- Referred promptly for tests to rule out other conditions.
- Referred to specialist services (Long Covid clinic and/or others).
- Recognised mental health consequences and needs and offered a referral for mental health support.
- Signposted to the local peer support group.
- Considered social prescribing, e.g. if the person was experiencing financial pressures.
- Provided information and hope that recovery is possible.
- Were aware of the link between Long Covid and (peri)menopause – interviewees experiences were that HRT can help with both.[vi]
- Did not psychologise symptoms (i.e. attributing physical symptoms to psychological causes), but were aware that anti-depressants can sometimes help with both the mental and physical symptoms of Long Covid.

Employers and returning to work

Returning to work could feel very significant in people's recovery, as people returned to an important source of meaning and identity. But it was often physically, cognitively and emotionally demanding, and as a result could trigger a relapse and decline in physical health that needed to be carefully managed.

A return to work can indicate a degree of recovery but does not equate to recovery. Several people who had returned to work experienced a decline in their ability to perform other everyday activities such as cooking for themselves or involvement in social activities and had to conduct careful pacing in order to stay in work.

Having the ability (and financial means) to take time off work, having a supportive employer and a slow phased return were important facilitators of recovery.

> *'Being back at work, having structure in my week and having colleagues to chat to and a job that I love and seeing people on campus. Listening to the hum of all those multicultural voices and seeing all the students, it's nice to have it back. I really, really value being able to go.'*

> *'My boss is really good. I'll talk to her about things, like [talking] through this last week and what I could have done differently, what I could have said no to. She's really, really supportive. I know that my boss protects me from some [emotionally demanding] stuff, she will do it because she knows it's too much [for me]'.*

> *'My work has been amazing. They took Long Covid very seriously. I had 3 months off work [then went back] very slowly. They gave me training to do at home so I could spread it out, then I came back one day a week for so many weeks, then built it up to two days, then eventually, four days. So now (6 months later) I'm five days a week. I'd turn the laptop on and I'd send an email to say I'm checking in. And that'd be me done then for a little bit and I'd have a drink. And then I'd log on to the training or whatever they'd asked me to do. And I'd do 20 minutes and then I'd have a break. They would say "it's fine, just take your time, do what you can do."'*

> *'Financially, I couldn't not get myself back into work. I think [if I'd not rushed back into work] it probably wouldn't have taken me this long to get better.'*

Employers can help by:

- Being informed about Long Covid and accepting the nature of the condition.
- Minimising stressful meetings/interactions as stress can exacerbate symptoms.
- Offering a flexible and slow phased return to work when the person is ready.
- Providing support and reasonable adjustments.
- Offering people different roles or tasks for a period (e.g. less physically/ cognitively/ emotionally demanding), and ensuring people are able to take breaks.

Key messages for employers are:

- Be aware that someone with Long Covid is very likely to want to be well enough to get back to work.
- A supportive employer can make a huge difference to someone's recovery from Long Covid.
- Time off work is crucial to recovery.
- Understanding and validation from an employer can reduce stress and support someone's recovery.
- Fatigue and brain fog can make it hard for people to manage complicated processes, complete forms or follow complex conversations.

- People are likely to need a very slow phased return to work – for example starting at one hour a day for alternate days of the week, increasing slowly over several months, with opportunities for review and pausing if needed.
- Returning to work too soon, or for too many hours, can cause a relapse.

It is important to note that a return to work is not easily available to some people with long covid; some members of the peer support group involved in this research had lost their jobs, and some probably their careers, with a consequent major loss of income.

The future of Long Covid services

- Long Covid specialist services in Calderdale may lose their ring-fenced funding, with the risk of losing specialist knowledge and expertise, as Long Covid fades from the agenda.
- Referrals are decreasing, but local specialists interviewed believe that this is likely to be because of hidden, undiagnosed Long Covid, rather than because of a decrease in the prevalence of the condition.
- High levels of undiagnosed Long Covid are likely to increase the burden on mainstream health services and the local economy, as people present with unexplained symptoms and become unable to work.
- Long Covid services may merge with other long-term conditions. The benefits of this are:
    - It enables work with those with Long Covid to continue.
    - Where there are overlapping symptoms (e.g. fatigue, nervous system activation), the same tools can be helpful to different groups.
- The risks are:
    - Treating and supporting people with Long Covid is an emerging field of knowledge, and there is a risk that skills will be lost, harder to hone or maintain, in a merged service for long-term conditions.
    - Other long-term conditions like ME/CFS, which also do not respond to traditional treatment models, have been neglected in terms of resources, research and attention, and Long Covid risks experiencing the same neglect.
    - Generally, people with long-term conditions such as ME/CFS are told there is no cure. Having hope that recovery is possible, and hearing stories from those who have recovered, is very important to recovery from long covid. Messages that recovery from Long Covid is not possible will be detrimental to people's chances of recovering.
    - Specialist practitioners learn from working with people with a condition, and this informs research and clinical understanding. If different conditions are merged, it will be harder to identify this learning.

Improving the Long Covid pathway in Calderdale

This research has identified five priority areas for our local Long Covid pathway.

Priority 1: Improve and secure existing Long Covid services

There is a small group of experienced people / practitioners working in highly regarded services in Calderdale. However, all have short term funding, and some are no longer funded. NHS Long Covid services are facing reconfiguration. Shared Harmonies and the Long Covid Support Group Calderdale play important and highly valued roles in the pathway but are no longer funded in Calderdale. The Better Living Recover Together Programme plays an important role as a follow on from the Long Covid clinic, and it is important to explore ways of increasing referrals to it.

Priority 2: Reaching minoritised ethnic communities

> *'We aren't aware of it. I work in this community, with professionals, and with organisations, and it's the first time I've heard this [Long Covid] clinic exists. This makes me question, do [professionals] reach out to the ethnically diverse groups? They need to be out in this community, speaking to mosques and getting announcements done. We all suffered from Covid, we all had losses in Covid, we all found Covid difficult, so [support] should be [available] to everyone.' – British Pakistani interviewee*

The one British Pakistani interviewee was not aware of the Long Covid clinic and had not received specialist support for their Long Covid.

Local Long Covid services are seeing primarily white British people, despite the fact that:

- Minoritised ethnic communities make up 17.3% of Calderdale's population. The four largest minority ethnic groups are Pakistani (8.5%, 17,637 people), Other White (2.4%), Indian (0.9%) and Irish (0.8%). 10.5% of Calderdale's population are Asian, Asian British or Asian Welsh.[vii]
- Nationally, people in minority ethnic groups are more likely to experience both poverty[viii] and health inequalities.[ix]
- Minoritised ethnic populations were disproportionately affected by Covid-19.[x]

Priority 3: Addressing hidden Long Covid

Long Covid is under-recognised and under-resourced both nationally and internationally:

> *'Long Covid has not received anywhere near the same level of attention or resources [as Covid-19]: the result has been widespread harm to health, societies, and economies. 3 years in, more is needed to recognise, treat, and support patients with Long Covid.'*
>
> *- The Lancet editorial (Mar 2023)*[xi]

> *'[T]here are far too few trials evaluating potential treatments for Long Covid, with seeming continual falls in interest and research funding.'*
>
> *- British Medical Journal (Dec 2023)*[xii]

> *'Many people don't realize just how sick millions of [people] are - and the invisibility created by Long Covid's symptoms is being quickly compounded by our attitude toward them […] [A] conviction … that Long Covid is less common and severe than it has been portrayed.'*
>
> *- Ed Yong (Pulitzer Prize Winner for his reporting on Covid-19), the Atlantic (Apr 2023)*[xiii]

Long Covid does not have a strong presence in political or public health conversations in the UK. Systematic testing and detailed data collection have ceased, making it difficult to assess the prevalence of both Covid-19 and Long Covid. Symptoms are many and varied, and individuals may not recognise they have Long Covid.

One healthcare professional interviewed reported that in one area in West Yorkshire, numbers of referrals for cancer testing have increased, as more people present with unexplained symptoms, but cancer diagnoses have remained the same. They believe that undiagnosed Long Covid may account for this increase.

GPs in Calderdale are reported to be often poorly informed about Long Covid, and the research found examples where many did not regard it as a defined illness, or a serious issue.

This means that:

i) There is likely to be a large number of people in Calderdale who have undiagnosed Long Covid and/or are not referred to available support;
ii) Those still recovering from Long Covid are still facing stigma and ignorance from both the public and sub-optimal care from some health professionals.
iii) Short term, precarious funding can make it difficult for Long Covid services to go into communities and broaden awareness.

It is likely that hidden and untreated Long Covid, over time, will result in an increased burden on healthcare services, as people present with undiagnosed and chronic symptoms. It may also affect the local economy, as more people become unable to work, or work effectively, and require benefits.

Priority 4: Encouraging healthcare professionals to adopt and follow NICE Guidelines on long Covid

Several interviewees reported negative experiences with healthcare professionals, including:

- Psychologisation of symptoms (attributing physical symptoms to psychological causes without sufficient investigation) and misdiagnosis – severe Long Covid symptoms being misdiagnosed as mental health issues, not taken seriously, or dismissed as 'in your head'.
- Lack of knowledge about Long Covid.
- Not being offered any information, signposting or support.
- Not being told about/referred to the Long Covid clinic.

There is a particular issue with GPs not diagnosing Long Covid or referring people to the Long Covid clinic:

> *'The doctor said "you sound like you're doing everything, you're diarying, you're pacing, I don't know what [else] the Long Covid clinic is going to give you" [so he didn't refer me]. He said the waiting lists are huge and it's more respiratory.'*

> *'The medics weren't interested. The GP just said, in terms of COVID, you can take several months to get back to normal. I didn't get referred. I didn't get any advice or anything actually. So, I just accepted it.' – on a visit to GP after 12 weeks.*

These could be very detrimental to the person's well-being and recovery.

> *'[People coming to us with Long Covid] haven't seen a GP, they haven't got into primary care, nobody's listened to them, nobody's believed them.' - Professional*

> *'The doctor said "how far can you walk?", and I said, "well, probably half a mile". He said "that's not so bad." Maybe for some people, but it's terrible for me. And that felt awful, because there's just no support. There's no validation of what you're actually feeling. It's like a denial of what you're feeling.'*

Sarah's story: psychologisation of symptoms* and misdiagnosis

"I lost 3.5 stone within two months of getting COVID. I was 13 stone, size 14, I dropped down to 9.5 stone.

I think initially the doctors were like, "you're a woman, you know, you can be quite anxious." And I was like, "I'm not anxious, I'm unwell. You're not taking me seriously." [Mental health service] said "we think you've got an eating disorder". And I said, "I don't have an eating disorder, I cannot physically eat because I'm ill".

So that probably made me more depressed because when I was reaching out to services, the understanding wasn't there. I think that kind of kept me ill a little longer than I needed to be.

I had to take my partner so he could confirm "she is eating," and that's when they started taking me more seriously.

I had an endoscopy where they took biopsies of my stomach. The guy who did it just went, "maybe you should write a book, you'll become a millionaire. Lots of people want to lose weight as quickly as you have" (and provided no other support).

Even though I told them time and time again that I'd had COVID literally weeks prior to this, no one was listening or thinking that this could be linked. So the cardiologist doesn't speak to the endocrinologist, the gut people don't speak to anyone. They need to work more together."

*Psychologisation of symptoms is the attribution of physical symptoms to psychological causes.

Spotlight: a different model of recovery?

'All these old habits and patterns that I had of how to recover from something, they were all wrong. And they probably caused me to have Long Covid, by going back to activity too soon.'

Recovery from Long Covid challenges our common approach to illness and recovery, as a healthcare system, a society, and as individuals:

- At present, there is no drug or treatment that 'cures' Long Covid (although there are medications that can significantly improve symptoms for some).
- Approaches that are often used to rehabilitate people (such as graded exercise therapy) aren't appropriate.
- Recovery timescales can be very long (often years rather than months).
- In the UK, we live in a society that often celebrates setting and stiving towards goals, and can see rest and illness as weakness.

It is essential that clinical research continues, so that we can gain a deeper understanding of the mechanisms behind Long Covid, and find effective treatments. But currently, recovery from Long Covid requires us to think differently:

- As individuals, it requires willingness to engage with a model of recovery that we're not used to (including rest, accepting long timescales, and engagement with mind-body approaches).
- As professionals, it requires support that is longer-term, person-centred and personalised, and includes mind-body approaches.

Priority 5: Access to specialist mental health services

A sometimes-severe decline in mental health is common for people with Long Covid. Depression was common among research interviewees, and several people said they had had suicidal thoughts. People can experience overwhelming loss, grief and loss of hope. The experience of trauma is common – including the trauma of not being believed/not receiving support; of both acute and chronic illness; of the pandemic; and for some the re-emergence of past/childhood trauma.

Support with processing this trauma and loss can be vital to people's recoveries. The Long Covid clinic psychologist was highly effective in supporting people with their mental health, and supporting their recoveries. However, at the time of publication, the post has been vacant for many months, with short-term funding leading to recruitment difficulties. Generic mental health support such as CBT is not always sufficient or appropriate for people with Long Covid. Lack of specialist psychological support is a significant gap in the local pathway.

'I thought I was stuck in [this] dark pit […] I honestly thought I don't want to live anymore […] [Long Covid] was the worst thing that ever happened to me.'

‘I did have suicidal thoughts [...] I had such bad anxiety, I honestly thought I was going to die, like literally. Literally laid in bed, I thought this is it, I'm done, I'm not going to get better. And if this is my life now, I don't want to be here.’

6. Recommendations

The recommendations below draw on both the findings of the research project and the lived experience contributions made by members of the Long Covid Support Group Calderdale. Services for people with long covid have continued to develop during the period of this research, and some changes have already been informed by the research findings. The recommendations below are shown with a reference to actions taken or in progress at the time of publication. Services represented in the project Steering Group have committed to adopting the research recommendation as far as is practicable, including further future actions in areas not yet addressed.

For Calderdale's Public Health Service	
Recommendations	**Action taken or work in progress**
Continue to co-produce service planning and decision-making. This approach inspired effective and imaginative commissioning during 2023.	This will be facilitated via the steering group established for this research project.
Promote and support breathing and vocal therapies, such as those offered by Shared Harmonies. These were highly regarded by individuals in this study as part of their recovery, as an enjoyable way to improve breathing, mental health and social connections.	
Raise awareness of long covid services, how to access them, and how they may link together. This is aimed especially at Integrated Neighbourhood Partnerships and providers of community health services. The relevant services include wellbeing support, community anchors and Better Lives Hubs.	This is being facilitated via network meetings and the Calder Connect Community Directory, which will host a practitioners' section with resources to support front line staff to have conversations about health and wellbeing.

(cont. overleaf)

Improve awareness of, and access to long covid services for members of minoritised ethnic communities; especially access to the Long Covid Clinic and the Long Covid Support Group Calderdale, which offers listening and help in finding effective support.	Integrated Neighbourhood Partnerships will be encouraged to focus on this, and it will be a priority area for the project Steering Group, which will continue to meet in a new form. The Calder Connect site can be translated by google translate - each page and document can be printed in an accessible format in different languages.
Work with the Long Covid clinic and other stakeholders to raise public awareness to reach people with undiagnosed Long Covid.	An upcoming awareness campaign, built on publicising the findings of this research, will highlight the support and resources available for Long Covid in Calderdale with signposting to the Calder Connect resources.
Improve the assessment of undiagnosed or 'hidden' Long Covid, and the estimation of its costs and consequences; working with the Long Covid Clinic. Evidence is needed to assess and demonstrate the need for continued services and funding.	The data and intelligence team have been asked to see if they can improve on current estimations, which are based on a national self-reported survey.
Compile and publicise guidance on self-management for people who have Long Covid symptoms in the first 12 weeks after a Covid infection, to help prevent worsening of symptoms through lack of information.	This information has been collated and published on the Calder Connect directory which will be regularly updated to include relevant guidance.
Support the Long Covid Clinic to improve levels of understanding of long covid among primary care staff, especially GPs.	The council is working closely with the Long Covid Clinic to support this.

For the Long Covid Clinic	
Recommendations	**Action taken or work in progress**
Continue to provide and develop the clinic's highly regarded services, guided by systematic feedback from the clinic's patients.	The clinic currently has funding until 2026
Continue to monitor referral levels from, and outcomes for, minoritised ethnic communities, so that the outcomes of initiatives to increase referral numbers can be understood.	The clinic will continue to do this.
Monitor referral rates across GP practices, identifying and reporting on low rates or inconsistencies.	The clinic will continue to do this.
Assess the viability of self-referral in order to overcome barriers to referral via GPs.	A new patient pathway and SystemOne process for referrals and pathology tests for Long COVID has been updated - this should make referrals easier and quicker.
Explore options for online support for those who cannot attend daytime sessions.	Patients in the clinic will now have access to a new digital platform (Elaros C19 Yorkshire Rehabilitation Scale), to support patient monitoring, reporting and self-management.
Renew efforts to recruit psychological support, considering alternative mental health worker options, in-house or outsourced, if the vacant psychologist position cannot be filled. For example, a counsellor, social worker or psychotherapist.	Funding for an 18 month contract has been made available, but recruitment has proved unsuccessful so far.
Continue work with the Better Living Service to develop the new physical activity recovery pathway between the Long Covid clinic's six-week programme and the community based Steps 2 Health sessions that provide personalised support in a group setting for individuals with long-term conditions.	The clinic continues to work closely with the new Steps 2 Health sessions.

(cont. overleaf)

Continue work with the council's Public Health Team to improve levels of understanding among primary care staff, especially GPs. This might include attending GP practice meetings, building relationships with senior managers, and presentations to Integrated Neighbourhood Partnerships and Community Anchor Organisations.	An updated patient pathway and amendments to SystemOne now makes the referral process to the clinic easier. Evidence-based resources are also now available from the Royal College of GPs via the Long Covid SOS webpage. Signposting to these via Calder Connect will help to raise awareness and understanding. Clinic staff continue to attend networks and meetings to build relationships and raise understanding.

For the West Yorkshire Integrated Care Board

Recommendations	**Action taken or work in progress**
Continue to develop personalised care for people with long term conditions, including long covid, using multi-disciplinary clinical teams, community health and wellbeing providers. The Long Covid service works well in helping people to improve their physical and mental health, recover from the condition, and return to work and resume everyday activities.	
Clarify the future direction for local Long Covid services as soon as is practicable, so that the service is able to develop and plan for the future, including recruitment.	Short-term 12 months funding has been confirmed. Improved pathways for referrals and support for self-management are being implemented. Longer term assurances are less certain.

For the Better Living Service	
Recommendations	**Action taken or work in progress**
Continue to review and evaluate the new physical activity recovery pathway from the Long Covid Clinic to the Steps 2 Health sessions. This new pathway provides an opportunity to continue physical activity recovery without waiting for a new course cohort.	A new service, Steps 2 Health, replaced the previous Recover Together programme during the research period. This aims to address several issues raised in this research, including low attendance, and to provide a smoother and quicker pathway between the clinic and these sessions.
Ensure that Steps 2 Health instructors have an adequate understanding of Long Covid and the approaches to activity that are appropriate (paced, symptom-led activity) and inappropriate (graded exercise). Continue to take advantage of the opportunities for Steps 2 Health instructors to observe and learn from the Long Covid Clinic staff. This will support closer working and facilitate a smoother transition for participants moving on to the Steps 2 Health sessions.	The Long Covid Clinic has offered Steps 2 Health instructors the opportunity to observe and learn from them.
Continue to implement personalised programmes, in partnership with the Long Covid Clinic, for people moving on to the Step 2 Health sessions.	The Steps 2 Health design includes personalised support.
Consider changes to the language used to describe paced, symptom-led physical activity as part of recovery. For example, participants found 'gentle', 'movement' and 'relaxing' less intimidating terms in communications about the sessions.	
Offer opportunities during the sessions for guided relaxation, breathing exercises, peer support and connection.	

For the Long Covid Support Group Calderdale	
Recommendations	**Action taken or work in progress**
Continue to consult and engage with members about future group development	A poll of members has been undertaken to review the value of past activities and gauge interest in a range of future options to support recovery.
Establish priorities for development, taking into account gaps in the system and other support available, and seek funding to continue.	Planning is in progress and will reflect the views of members from the poll above.
Build partnerships with other community organisations to reach members of minoritised ethnic communities, and find ways to overcome barriers to their participation. This might include holding some meet-ups at venues based within a wider range of localities, including those areas with high populations of people from minoritised ethnic communities.	The group now attends meetings with the Calder and Ryburn Integrated Neighbourhood Partnership and will also reach out to Halifax Opportunities Trust to discuss ways of attracting more members from minoritised ethnic communities.

Building longer-term partnerships

The research steering group has committed to continue meeting beyond the research project to share and develop good practice, support co-production with people who have lived experience, and agree how to respond to the issues identified through this research.

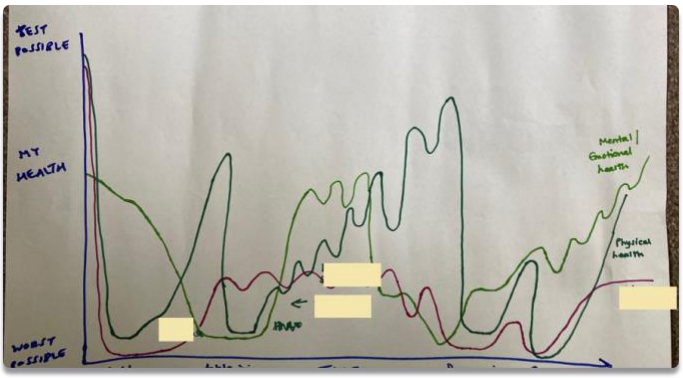
Recommendations	Action taken or work in progress
Seek evidence that people with long covid are benefiting from recent changes made to improve pathways consistent with NICE guidelines, in diagnosis, support and referrals for people with Long Covid.	There is now a clearer pathway for tests and investigations tailored to individuals signs and symptoms via SystemOne which includes a referral pathway to the clinic for triage. This is in line with NICE Guidance. Health and social care professionals engage in MECC (Make Every Contact Count) Good Conversations training.
Take action to reach more people from minoritised ethnic groups and monitor the effectiveness of this.	As a starting point, the Calder Connect site can be translated by google translate - each page and document can be printed in an accessible format in different languages.
Keep Long Covid on the local agenda, by: o Sharing the research findings. o Linking in with other local/national initiatives. o Collecting evidence of local need, the costs of Long Covid to the local economy and the NHS, and the cost-savings of providing specialist services.	The Public Health Data and Intelligence Team are reviewing sources of information about local need to improve estimates that are extrapolated from national studies.

Appendix A: selected recovery journeys drawn by interviewees

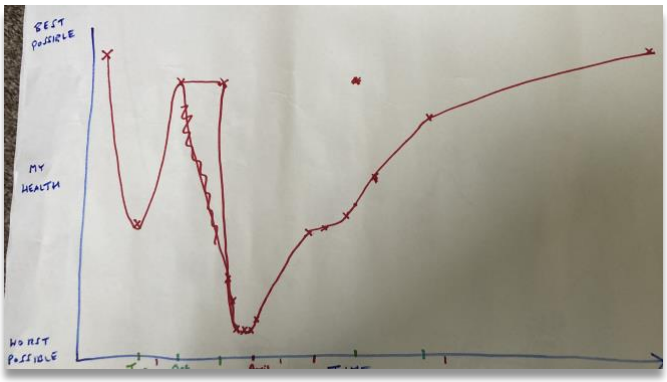
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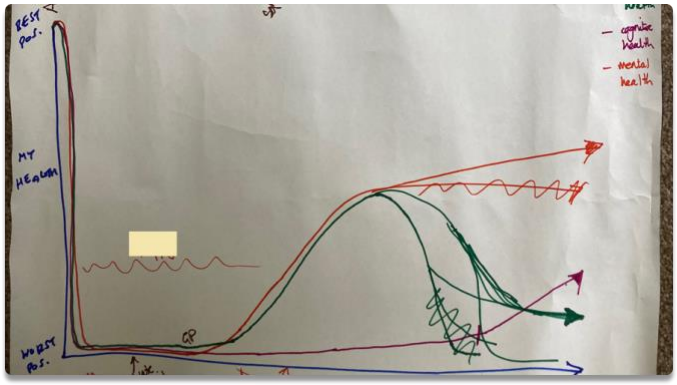
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BEST Pos.
MY HEALTH
WORST Pos.
- cognitive health
- mental health

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