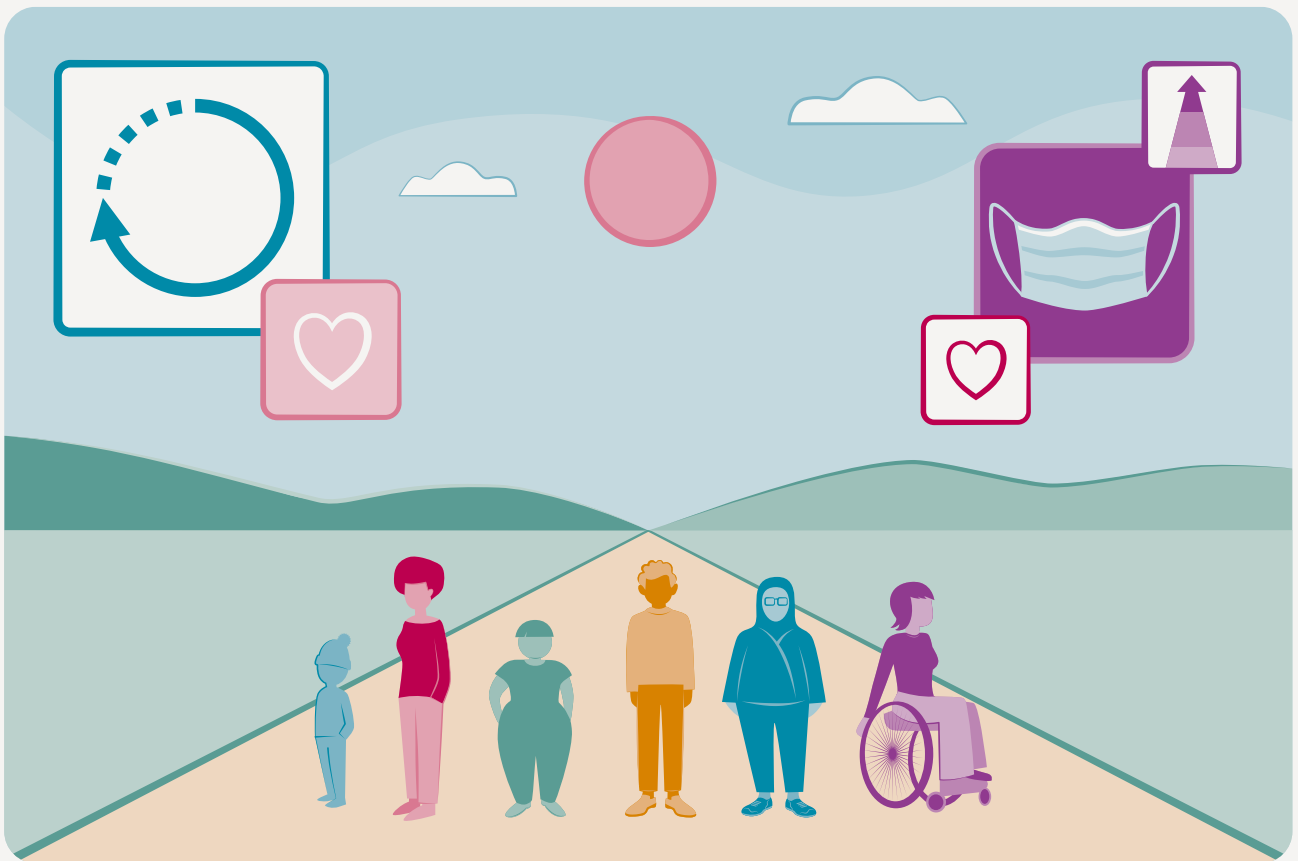


Accessing social support for Long Covid



Research Report

May 2022

Research report by Emma Miller. Commissioned by the Health and Social Care Alliance Scotland (the ALLIANCE) and Chest Heart & Stroke Scotland (CHSS).

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Project background and context

Long Covid: an introduction

This report is being written in April 2022, just over two years after the start of the coronavirus disease 2019 (COVID-19) pandemic. During the early stages of the pandemic the immediate concern was to avoid COVID-19 infection because of the risks of hospitalisation and loss of life. This was followed quickly by concerns about the psychosocial consequences of the pandemic. Over time, the longer-term symptoms of the disease have attracted increasing attention, with the term Long Covid now widely recognised. This largely hidden and enduring wave of human suffering requires attention now.

The National Institute for Health and Clinical Excellence (NICE), the Scottish Intercollegiate Guidelines Network, and the Royal College of General Practitioners have jointly developed the following definition for Long Covid (also referred to as post-COVID 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.”¹

Studies have shown that Long Covid can affect the whole spectrum of people with COVID-19, from those with very mild disease to the most severe forms. Like acute COVID-19, Long Covid can involve multiple organs and can affect many systems including, but not limited to, the respiratory, cardiovascular, neurological, gastrointestinal, and musculoskeletal systems. The symptoms of Long Covid include fatigue, shortness of breath (dyspnea), cardiac abnormalities, cognitive impairment, sleep disturbances, symptoms of posttraumatic stress disorder, muscle pain, mood changes, dizziness, concentration problems, and headaches.²

Longer term effects of COVID-19 started to gain attention following an account published in BMJ Opinion where an infectious disease professor shared his experience of seven weeks on a “rollercoaster of ill health” following COVID-19.³ The patient-made term Long Covid was then made popular following the rise in the use of #LongCovid on Twitter.⁴ This, plus the growing number of peer reviewed articles published since, and the experiences of an estimated 1.7 million people in the UK alone, has highlighted a post-COVID-19 syndrome that can last for many weeks after the acute infection.⁵ Long Covid is now a recognised term in scientific literature.⁶

Long Covid has been highlighted as the only illness to be initially identified by individuals coming together on social media.⁷ Each individual reports a cluster of debilitating and persistent symptoms, which limit day-to-day life to varying extents. Symptoms can be both persistent and sporadic and can be exacerbated by exertion. Symptomology is underpinned by feelings of fear, anxiety, and depression, especially when much needed support is unavailable.⁸

Long Covid currently presents an enigma, with continuing uncertainty about the impact of more recent variants of COVID-19 on its incidence and severity.⁹ While continuing research is required on clinical characterisation and therapeutic responses, it is identified as crucial that people's stories are understood across health and social care, and to support people towards recovery.¹⁰ Guidance by the NHS and NICE emphasises tailored, continuing support on a multi-disciplinary basis, including online provision, with access to expertise when required.¹¹ It is further emphasised that support should build on knowledge about other post-viral syndromes and that new longitudinal evidence about Long Covid is required.¹²

Project aims and objectives

This project aims to build understanding of the life circumstances of people with Long Covid in Scotland, as well as their experiences of accessing social support. It will make recommendations for development of support based on their lived experience.

Recruitment of participants

The Health and Social Care Alliance Scotland (the ALLIANCE) posted calls for participation on their website and newsletter, and on Long Covid Facebook groups on 31st January 2022.¹³ Around the same time, Chest Heart & Stroke Scotland (CHSS) promoted the research through their peer support group. Our original aim was to undertake 20 individual interviews with people with Long Covid in Scotland. Within a week of starting recruitment, 24 people expressed interest, and we took down the calls for participation. A further 14 people got in touch the following week, and we offered those people the opportunity to participate in focus groups. We organised three focus groups for four, three and three people late in February.

A very flexible approach was adopted to scheduling interviews, given the fluctuating nature of the symptoms of Long Covid. Interviews could take place in the day or evening, according to the needs of interviewees, and could also be rescheduled if required, with quite a few people getting in touch to change the time if they were feeling unwell. Of the 24 people who were offered an interview, all but two were interviewed, with one having to cancel due to ill health. Of the subsequent 14 people offered a place in a focus group, 10 participated with the other four not responding.

Our participants ranged in age from their mid-20s to around age 60. There were 22 women and 10 men, with the majority being women in their 40s and 50s. The majority of people live in the Central Belt of Scotland, although there were also participants ranging from the northernmost islands of Scotland to the Scottish Borders.

This project did not include input from children or young people with Long Covid or their parents/Guardians. However, the key questions of this report, about people's access to social support, remain equally important to children and young people with Long Covid as to adults. The needs of children and young people with Long Covid must be considered in strategic planning. There is a need for further, dedicated research into children and young people's experiences accessing social support for Long Covid.

Confidentiality and anonymity

The researcher designed a participant information sheet, with slight variations for focus group participants as compared to interviewees, with a consent sheet attached. The information and consent sheets were emailed to participants, with most people returning the signed consent in advance. In all cases the information sheet was covered again at the start of meetings and participants all agreed to their information being used as set out in the consent sheet. To protect anonymity, it was agreed between the ALLIANCE, CHSS, and the researcher that while recruitment was initiated by the ALLIANCE and CHSS, anyone interested would then contact the researcher directly and all interviews arranged that way. Each participant has been given a pseudonym in the report, and easily identifiable details removed.

More on methods

The researcher completed 22 one-to-one video interviews during February 2022. With the exception of three telephone interviews, as requested by participants, all interviews were undertaken as Zoom calls. Mindful of the exhausting nature of Long Covid symptoms, the researcher offered each interviewee an opportunity to end the interview after half an hour in case they were experiencing fatigue. Despite this, and subsequent checks during interviews, only a few interviews lasted less than an hour. The shortest call was about 45 minutes. Most interviewees were still actively engaged after an hour, with the longest call lasting about 80 minutes.

The interviews were recorded with the permission of participants. While the first interviews were audio-recorded, subsequent interviews and focus groups were recorded by contemporaneous notetaking, given the larger than anticipated number of participants and the time limitations of the project.

The conversations with all participants were largely led by them. The researcher informed that objectives were to find out about their experiences of living with Long Covid, about where they were finding social support and where they were meeting barriers. They were usually invited to identify what they would like to see happening next, and in most cases whether they had found any silver linings or what hopes they might have. A minority of participants seemed more comfortable being asked questions and responding to those, with the majority requiring very few prompts because they really needed to talk.

Following the interviews, the researcher drafted a mind map to set out the key themes arising from the conversations so far, suggesting relationships between themes. The mind map was shared with the focus group participants, providing an opportunity to check whether the researcher's findings reflected their experiences. One participant noted:



It's quite cathartic even just to see that. It feels like you have a grasp of it from my perspective.

Kerry, Focus Group 3

The key change which resulted from checking with focus groups was to reflect in the mind map that it was largely relevant to people with other invisible disabilities, with more on this below. A revised mind map of key themes is included in Appendix A.

The focus groups were scheduled to last an hour, each lasting slightly longer than that. The focus groups were facilitated by the researcher. As is often the case with focus groups, each one took a different direction, with the first being a very emotional exchange of the struggles and fears people are facing, the second more an exchange of experiences, with the third focused on how things could change.

Reflecting on the methods for this cohort of participants, the ideal might have been to offer a choice of interview or focus group from the start. Regarding interviews, having an hour to have your story heard and potentially validated seems particularly important when individuals feel 'abandoned' or 'not understood' and 'still trying to adjust.' On the other hand, of the ten people who participated in focus groups, a few reported feeling better for sharing their experiences with peers, with one comparing it favourably to larger peer group settings. More than four in a group did not seem feasible to us for research encounters with people living with fatigue and brain fog.

Almost all participants asked about the report on the research, and they were assured that they would receive individual emails from the researcher with a copy of the report and its recommendations.

A Project Advisory Board was also recruited. It included people who support people with Long Covid from the third sector, people living with Long Covid, and people living with long term conditions. They provided a sounding board for research plans and approved the final report.

Analysis

All thematic analysis of the data was undertaken by the researcher. There were 25 transcripts which included the voices of 32 people with Long Covid, based on more than 25 hours of conversations. Themes were already being identified as the data were being collected, as represented by the mind map (Appendix A). The validity of these emerging themes from interviews was tested with focus groups participants, whose voices added further to the overall story, as reflected in this report.

In reviewing the transcripts, the researcher paid particular attention to what participants said about what was important to them in their lives; what they had lost as a result of Long Covid; what support they had been able to access and where they had found barriers with support. The themes are set out below.¹⁴

Impacts of Long Covid

Experience of COVID-19 – from mild to severe

Our participants usually described their experience of COVID-19, before discussing their longer-term symptoms. Their experiences of COVID-19 range from relatively mild symptoms over a short period, through to severe symptoms, which in a few cases required hospitalisation. The following is an example of a short term experience of COVID-19:



I wasn't well for 4 to 5 days and I got better, but since, my energy level is just badly... non-existent now

Ted, Focus Group 2

At the other end of the range of experiences, some had more severe symptoms. This could still be difficult for people to talk about, bringing up difficult memories. In the following example the additional challenge of living alone with a frightening illness is alluded to:



I was floored for a week. I couldn't breathe or speak, and I live alone. I contacted 111 but they told me not to phone for an ambulance. At that time, they were thinking it was only old people who were at risk.

Gary

We spoke to three people who had been hospitalised with COVID-19:



It's been an absolute rollercoaster. They thought I was going to die in the first three weeks. They wanted to take me to hospital 35 miles away, but I said wanted to die in my own bed. They admitted me to hospital five days later.

Mo, Focus Group 1

Unfortunately, some of our participants had had COVID-19 for a second time by the time of interview. Some were experiencing different symptoms, both describing more neurological symptoms the second time around.

Most participants identified having very busy lives prior to Long Covid. A few used expressions like 'I never sat from the moment I got up.' It was also important to them that this should be understood, given that they are all now, to varying extents, restricted in what they can do, and due to early misinformation about the profile of people with the condition:



The perception - what we were told - was that people with Long Covid have other health conditions - they are obese, they were already ill, but it is not quite the case. They included long distance cyclers, walkers, and now they can't do any of that.

Charles

The following woman from Glasgow, is currently housebound and requires walking aids indoors. She informed that she had previously been active and a fast walker:



I was so active - a neighbour used to call me Speedy Gonzales.

Moira

The fact that most people, and it seems possibly especially for people who get Long Covid, like to be active and don't invest much time in rest, presents challenges to the requirement to pace to recover, as discussed below.



Physical impacts of Long Covid

One of the most notable – and challenging – features of Long Covid is the pervasive and fluctuating nature of the symptoms. It is not possible to cover all physical health impacts here. Instead, we briefly consider a few experiences of physical symptoms as a basis for exploring wider wellbeing and quality of life. While there are wide variations, a few symptoms are common to most with Long Covid, with Anya's description being typical:



The biggest challenges for me are the fatigue, chest pain and breathlessness. They are my big three before anything else happens. It's in my bones too. I really miss being physically tired. The idea seems so distant now.

Anya

Anya's desire to experience normal tiredness was echoed by others, who described having a very different understanding of the severe and debilitating nature of 'fatigue.' Another woman we spoke to said that it was more like being in 'a black hole.'

A few participants were struggling with incontinence due to Long Covid, and this was described as 'embarrassing' and 'isolating'. Loss of appetite was an issue for a few people we spoke to.



My appetite has gone. I don't know when I need to eat. The other morning my wife had Weetabix with banana, and I wanted to try it because I saw her eating it. But I wasn't thinking about food until then. It's so hard trying to explain it.

John

Some very specific disabilities had resulted from Long Covid, including for Maria, significant loss of use of her hands:



I've been diagnosed with fibromyalgia in my hands, I can't open jars, or do much with my hands.

Maria

Quite a few people were very restricted in their movement in general, having to use either walking aids indoors and/or wheelchairs outdoors:



I asked about a scooter - I needed something that could cope with the rough terrain around here or something that could fold up and go in the car. In the end I got an electric bike and I've used it a few times already. I was able to have a bike race with my kids - it was lovely.

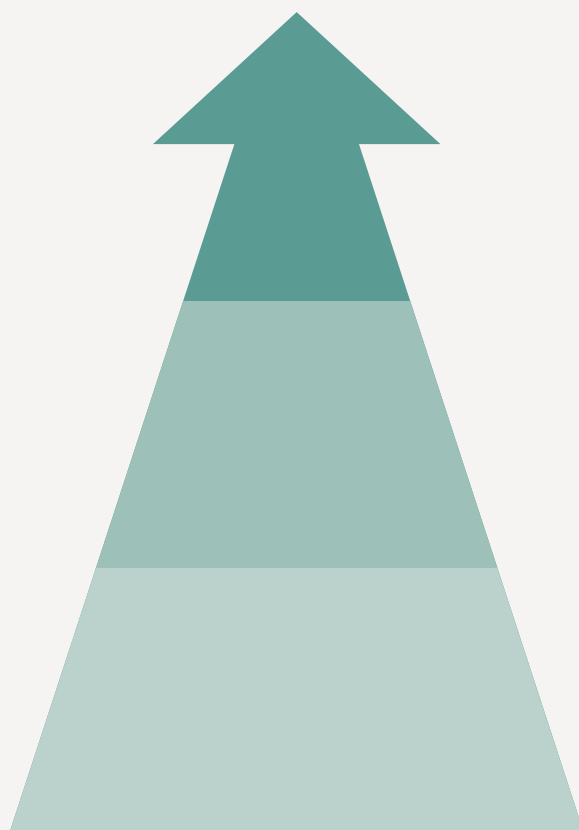
Sue

The alarming nature of some symptoms could lead to hospitalisations:



I had an autonomic nervous system event and ended up in hospital. I couldn't understand what was happening - I thought it was COVID-19 with a rapid heart.

Bernie



Cognitive impacts of Long Covid

'Brain fog' was highlighted as a serious concern by most of the 32 people we spoke to across the project. This could have pervasive effects on diverse aspects of life. Word finding difficulties are very common, and were evident in the interviews, especially towards the end of interviews. Several people described difficulties with managing ordinary household tasks, with the following being fairly typical:



The brain fog is horrific. I found myself putting the kettle in the fridge.

Sharon

Another participant, who used to enjoy cooking, described being unable to work out how to make a sauce he had made many times, even though he had all the ingredients in front of him. Brain fog often means that formerly everyday activities were now out of reach, or had to be restricted, with references to difficulties with using computers, phones and reading:



So reading was a big thing before but concentrating - my long and short term memory are both affected. Whole chunks are gone - it's like the filing system has scrambled.

Angela

The impacts of brain fog could present risks. One participant described a near accident due to cognitive impairment, adding that the concept of brain fog was too limited:



One time I was walking I was nearly knocked down at a crossroads. I just wasn't able to judge the passing traffic. Brain fog does not really describe it enough. It is cognitive disruption.

Steve

Quite a few people found themselves intolerant of light and sound, particularly at an early stage, finding themselves unable to look at screens, and seeking to avoid noise:



When I was acutely unwell, I couldn't look at my phone - the light from the screen was just too much.

Bernie



I thought I could pass my knowledge of my trade on to my grandsons - a bit like my grandad - they are brilliant boys - but I have to take myself out the situation - I get white noise when they are just playing.

Jim

Loss of senses of smell and taste were established as symptoms of COVID-19 during the first year. Most participants had experienced sensory loss, to different extents, with one person informing that he could only remember smells, not actually smell them. While loss of these senses present challenges, including lack of enjoyment of food and possibly missing danger signals like gas, several people also described unpleasant or even disturbing distortions with smells. One example is that a few people were now smelling burning, requiring them to check to ensure there is nothing burning. One woman in particular found the distortions difficult to cope with:



Then I could smell some fumes, smoke. Then developed to all smells being distorted. Main triggers are coffee, which I used to love. Onion, garlic, anything processed is very unpleasant to me, and I call it Covid smell. My favourite perfume smells like toilet cleaner. Most fruit and vegetables smell like garbage.

Ella, Focus Group 1

Another woman was struggling with a re-emergence of childhood abuse trauma due to COVID-19. After catching COVID-19 a second time, her overall symptoms changed, and she found that distorted smells were being directly related to the abuse. She was having counselling which was helping with this.

Mental health

Most participants identified mental health challenges due to Long Covid, sometimes also related to their experience of COVID-19. While physical and cognitive symptoms could cause distress and anxiety, this could be compounded by diminished quality of life, including reduced socialisation, with particular risks for those still unable to work. This was a key concern for Lorna who had already tried to switch to a new type of work to accommodate Long Covid, and had since caught COVID-19 again:



The chestiness is really bothering me. That is why I was crying all last week... I was thinking will I ever be able to work.

Lorna

Another woman, who was still unable to do very much at all without feeling exhausted, the strain on her mental health was overwhelming:



I'm getting a different kind of anxiety than I've had before - it is doom you feel as if your time is running out. I don't have the mental or physical energy.

Angela

We will return to quality of life aspects below. A further challenge to maintaining mental wellbeing was for some due to loss of identity. Social identity has been highlighted as a specific concern by recent research on Long Covid.¹⁵ This research highlights the need to consider interactions between stigma, isolation and social identity for people with Long Covid, as important factors in supporting or hindering recovery. Participants in our research described loss of identity due in particular to being unable to continue to work or study, as well as Long Covid impacting their ability to parent or care for family members. There were identity-related references to being 'a shadow of my former self', to 'grieving for the part of me I have lost' or 'not identifying as me anymore.' Another participant said he felt that he was 'haunting my old life.'



Another woman noted her recent experience of depression, identifying several possible contributory factors, all of which had been exacerbated due to COVID-19.



By October I was quite seriously depressed. It might have been caring for my mum, stress for my work, the worse periods I had since vaccination, I don't really know.

Erin

For those who had been severely ill with COVID-19, particularly if they were hospitalised, there were additional mental health impacts:

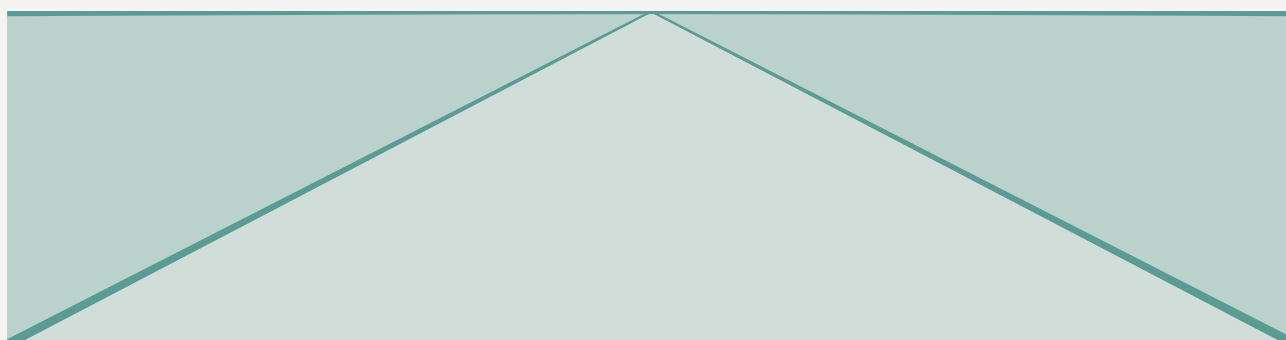


I thought my time had come, honestly, it was horrible.

Jim

Jim also described disturbing flashbacks on the night he thought he was going to die. For those who had gone into hospital at an early stage of the pandemic, there were additional disturbing memories of staff keeping their distance to avoid infection, being sprayed on entry, not being able to get transport and so on. A few people were in counselling and all who mentioned this identified it as helping them to cope.

Several people were also very anxious about getting re-infected. This sometimes resulted in still limited interaction with the outside world, which could be difficult to live with, especially as things were opening up in wider society at the time of the interviews. A few people expressed concern about suicide risks for people with Long Covid. One woman referred to a podcast made by Gez Medinger on YouTube, when he acknowledged that there was a point during his Long Covid journey that if there had been a self-extermination button, he'd have pressed it.¹⁶ She found it helpful that he had said this, adding that she understands things keep changing and her own situation had improved since then.



Most participants identified their own awareness and experience of the links between physical and mental health, and how pressures of life interact with Long Covid:



I am so aware about the link between physical and mental health... I've got young sons. If I felt emotional - I could physically feel that it increased my symptoms. Like at work when I'm busy - it is like I have a skull cap crushing my skull. I'm aware of when I'm experiencing emotional things - the symptoms worsen. Before, like a lot of parents - you are spinning the plates - running the house - my family - my job - all that involves - with Long Covid the stress definitely worsens symptoms.

Frances

Pre-existing disabilities and long term conditions

Around half of the participants described diverse past or present disabilities or long term conditions prior to Long Covid. These included glandular fever, chronic fatigue syndrome, IBS, a skin condition, connective tissue disorder, depression, anxiety, heart attack, haemophilia and sensory loss. Some were also neurodivergent. One woman who had self-diagnosed as autistic noted that autism had featured strongly in Long Covid support groups she attended. A few participants identified that as women of 'a certain age' they were not sure to what extent menopause might be contributing to their symptoms, whilst also clear that key symptoms were Long Covid related:



I have reluctantly started HRT in a desperate bid. But with the brain fog, the aches, I'm trying it, but I felt a bit cheated because I might not be having menopause.

Frances

Another participant described how breathlessness from Long Covid had exacerbated an underlying heart condition. He had since had surgery to replace the faulty heart valve, and the medication had then caused a kidney haemorrhage, resulting in further surgery. He was one of a few people who was attempting to pace himself for Long Covid, while also trying to push himself to counteract other conditions.

Supported self management

The ALLIANCE defines self management as “a way of living and working that means people living with long term conditions feel more in control of their own health and wellbeing. Self management supports people to live their lives better, on their terms”.¹⁷

Crucially, the ALLIANCE also advocates people being able to access the right support when they need it as a central component of self management. The people we spoke to described their efforts to seek the support they required in order to manage their condition as well as possible.

Being believed

Perhaps the key issue for most people we spoke to in their interactions with others was difficulties faced with being believed about this debilitating condition. Long Covid is one of many conditions which is outwardly invisible, which can cause credibility problems for those who have it. Not being believed can have serious mental health and wellbeing implications:



This really bad depression hit me because I'm thinking people aren't going to believe me.

Lesley

Further to the outwardly invisible nature of Long Covid, and despite often very serious symptoms, it is frequently the case that diverse health test results are negative.



You want something to show up somewhere, so you know what to do - how to manage the condition when you are not certain what it is. I'd like to know!

Erin



With Long Covid you want something to show up to say in the tests so you can say Look! It's real - you are not a hanger on-er.

Paula

There is still limited public awareness of Long Covid, and participants were keen to see this remedied:



Along with the fatigue the other biggest thing is attitudes. The more education there is - education is so important - and with that maybe it would be a bit more recognised.

Frances

There was a view that if the public understood that resting is essential for recovery from Long Covid, this would alleviate the guilt and give permission to people who so badly need to pace themselves. The importance of pacing also needs to be acknowledged by others, including family, employers, and social security professionals. As well as a need for public understanding, participants identified other arenas they had had to do battle with in navigating their way through life with Long Covid. These included the workplace and state entitlement agencies. We will consider these further under social impacts of Long Covid below. First, we consider engagement with the NHS.



First port of call: connecting with GPs

Most of our participants spoke about their engagement with their GP practice as their first port of call for support. There was a wide range of experiences. At an early stage of the pandemic, there were many examples of individuals struggling with frightening symptoms then struggling again to connect with their GP. As there was no knowledge of Long Covid at this stage, and services were limited by COVID-19, efforts to connect could flounder. This is important because people struggling with fatigue can find even a positive interaction exhausting, far less a deflating experience:



We were in lockdown, and I phoned the doctor and she laughed and said you can't still have coronavirus. I was in so much pain.

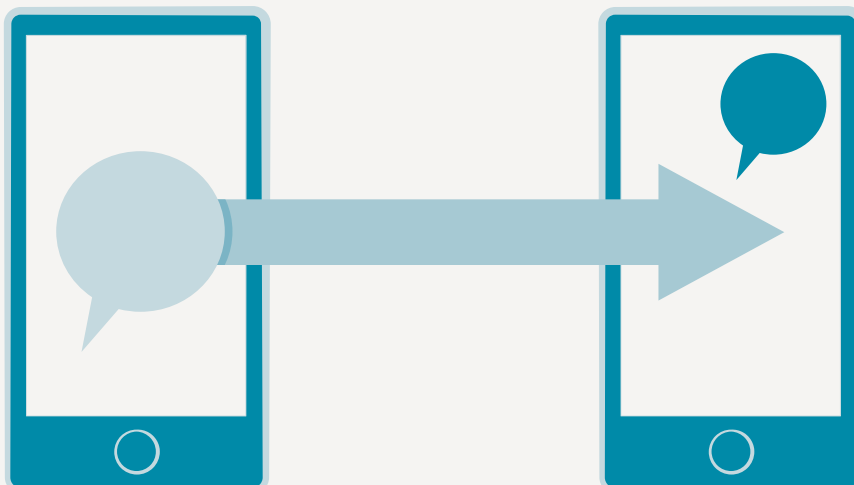
Moira

Another individual was keen to emphasise that his GP had been much more supportive recently, whilst also noting that early attempts for recognition had been frustrating because she had persisted with encouraging him to try anti-depressants. A participant who has a significant role facilitating an online support group referred both to her own and more collective experiences, emphasising that connecting with someone who cares in the health system can have significant benefits, as reflected by the following comment:



I spoke to my own doctor. She has been fantastic. She said when you phone ask for me and she has been fantastically supportive. She listens to what I say. She helps as much as she can.

Paula



People understand that they might not necessarily get answers, as so much of this is still new. There was a plea for working in partnership from a couple of participants, with one of them adding that continuity could provide opportunities for mutual learning:



You have to become an expert patient...the best doctors are those who understand they need to work in partnership with me. What I would love from my GP would be consistency...Continuity of care and testing things with the same person would help.

Erin

The following individual spoke about the need more generally for a holistic approach to complex conditions:



The NHS is not holistic... We are all limited by the boundaries of our area of knowledge. I try to explain my situation by the fuse box analogy. I explain it like if a bulb goes in your house, you remove it and then you might replace it or you need to check the wires. But when you've tried all that, you have to think about the fuse box. That is going to the centre of it all. With COVID-19 you can change and meddle with the lightbulb as much as you want, but you really need to go the fuse box to work out what is going on.

John



Private tests

Six participants identified that they had already or were about to pay for health tests. One woman identified that she had already spent £12,000 through private insurance. On a smaller scale, one woman had paid privately for B12 injections, which she associated with the easing of her symptoms. While private healthcare could be helpful in some ways one participant commented that there was still a range of specialities rather than a more holistic view of the person.



But what about those who can't access that or don't have the confidence to go for it. There is so much health inequality it's unreal.

Allie

Pacing

At an early stage of the pandemic, before Long Covid was identified, many people who were experiencing lasting debilitating symptoms post infection were advised to gradually increase their physical activity to promote recovery. This is now contrary to advice to take more care by pacing and self management, allowing space between any activities (physical and cognitive) and budgeting energy on a daily basis. Some participants were amongst the first wavers and had pushed themselves to recover:



My career was all about physical activity for health. I was that annoying person who was always saying - for the vast majority of conditions - get active and lose weight to improve your condition. Even if I do too much round the house now, I pay for it.

Allie



Most people we spoke to try to pace themselves and accept that they have to choose how to spend their limited energy. Depending on the severity of symptoms, this involves decisions about whether to try to work, do housework, take exercise or socialise in any way. This can also include more sedentary activities like watching TV or using social media:



I call it living in the twilight world, twilight zone. You wake up, don't know what to expect, you go from there, try to curb energy usage so you don't overdo it, and if you do overdo it, you pay the price the day after.

Karen, Focus Group 2

Several participants used fitness apps before and after Long Covid, as a way to track physical activity. A key change was using the apps to limit activity to stay well, with daily limits ranging from just a few hundred steps a day to 8,000 steps. Some apps can also track heart rates which can provide an external arbiter for pacing.

One woman identified a silver lining from Long Covid in that her existing health condition had improved through pacing:



Ironically because I've had to pace even more because of this - I'm not blistering as much through my skin condition - I didn't really realise that would happen - it is a weird silver lining.

Erin

Quite a lot of our participants had caring responsibilities including parenting of children of various ages or caring for older parents. One parent of a young child had had counselling which had been very helpful in enabling her to accept the limitations of her parenting energies for as long as she remains unwell. Similarly, people caring for older parents worried about how they could keep managing. Some found that their concerns about care forces them to limit other activities.

In order to effectively manage pacing, which is generally going to involve prioritisation and slowing down activities, many people felt that they needed permission to get off life's treadmill. This can involve an internal battle with guilt about resting. One young woman whose family attitude is to battle through said that she needs permission to rest:



And to get permission and to hear it doesn't matter if you need a day in bed. It's OK if you can't do anything.

Anya

Another young woman described her own internal battle to cope with the things that she has lost, the uncertainty of it all and her own drive to keep going:



I feel so many things have changed in my life. When will they change? I don't feel like me. It's just the feeling crap - I'm kind of pull your big girl pants up. I cannae. I just cannae. You just need to get on with it. I was generally never off work. Never missed a social event. I feel like I moan all the time. Before I just got on with it. I just cannae.

Ger

With this in mind, it is even more important that others understand and believe the very real health problems that people with Long Covid are dealing with in their day to day lives.



Symptom management

We have already identified some programmes and alternative therapies which people found helpful. However, there was a shared sense that scrambling about trying to find a way was too exhausting, and that more consistent support with symptoms would be welcome:



It would be good if there was more support for that side of it to explain the symptoms and help you deal with them.

Joanna, Focus Group 3

The sharp focus of Long Covid was linked to wider needs of people with long term conditions:



There isn't a support service for chronic condition management. How to manage day to day. Long Covid is throwing it all into sharp relief.

Erin

One focus group participant suggested that existing programmes of physical activity, run in partnership by the NHS, leisure centres and third sector organisations could be adapted for Long Covid.



What I'd like to see is some form of Long Covid management system: the NHS could lead on it, but it would bring in other groups of people to have a discussion about what are we going to do about it, and how? Bringing in people with lived experience too.

Paul, Focus Group 3

Holistic support

The focus group then moved on to talk about how development of hubs could be really useful, as a central point for connecting with others, for reassurance and for signposting. Such resources would need to provide quick responses.



People tend to go to these things when at their lowest ebb, and the last thing they need is to be told we can give you an appt in three weeks' time.

Paul, Focus Group 2

The idea of a one stop shop had been raised previously in interviews such as the following:



There is too much waiting and too much fragmentation of the system. It needs to cover your career, income, family, relationships and home.

Sue

This desire for a holistic resource which also connects people was amplified by Kerry, who was one of the people most disadvantaged by her experience of Long Covid:



What I would like to see is practical, ongoing, long term, group support that is able to grow as we grow eventually helping us through gentle protective channels to re-enter society. Of course, this is reflected by my needs which having fallen out of society entirely.

Kerry

In some interviews and the same focus group as above, the need to link practical support directly to research was seen as essential. This was partly influenced by observations that COVID-19 research happened so fast 'with immediate effects on the street':



I don't think we can wait for the formal evidence to set things up. Learn from it! Make it a learning opportunity and treat it as research.

Anya



Linking research to care centres, then there'd be staff who'd begin to learn about the condition, see patterns. Goes hand in hand with research.

Karen, Focus Group 2



We already have GPs responsible for diabetes. Why not appoint someone who is responsible for Long Covid? Researchers could put their questions to medical centres, whoever is responsible for Long Covid in that centre knows the questions to ask... So many people with Long Covid could be reassured about being taken seriously. Effects of that research could be put into practice very quickly... It should be ingrained that this is how we deal with things from now on, that affects science and people in so many ways... We are twice invisible. To continue that research in that way would be so valuable.

Paul, Focus Group 2

Employment and education

Human Resources and Occupational Health



When I see people in chat rooms, even people who have had Long Covid for 18-24 months - you can see people thinking I never had a health problem. I've never used support - I feel so alone... Here is this group of taxpayers who fund the system - have never claimed against the system and are now dropping out of work and getting no support. And what is the economic and human cost of that - for them, their families, the country.

Charles

This section is about people's experiences of having Long Covid in relation to their employment or education. Of the 32 participants, all but a few were in full time employment or self-employment when they got Long Covid. The few who were not working were in education or training. Most described negative experiences of trying to hold on to their jobs, with particular criticism levied at Human Resources departments for unsupportive or even punitive approaches to monitoring their fitness to work. As well as trying to manage their health symptoms and to get recognition and support in the health system, many of the people we heard from were also battling to try to keep their jobs, with many having worked all their lives up until now.

There were positive examples, including Jill and Charles who both work for separate third sector organisations. They each identified that they knew they were unusual in being well supported to stay in employment. They both acknowledged support from their managers, who had argued for them to retain their jobs. Having that type of support helped to reduce anxieties about unemployment, with beneficial impacts on their wellbeing.

While there are challenging questions to address about how employers can manage to hold jobs open, there are also important considerations about how punitive approaches can exacerbate the very health problems people are struggling with. The following statement encapsulates the experience of many:



HR were awful.

Allie

For Kerry, who was a ‘first waver’ and had lost her job six months into the pandemic, the experience of trying her hardest to perform at work and being held to short timeframes, only to be told “well you’ve had enough time” was “incredibly detrimental” to her health. Although Kerry hopes to recover sufficiently to return to work, she is now worried about the process, particularly with fluctuating symptoms:



We’ve talked about being supported when you’re in work. One of my major concerns is that the road out - I’d hope to be well enough to work at some point, but that road out seems a rocky road too. Finding a job, with a health condition, as well as navigating losing benefits that have been hard-won, with a condition that’s fluctuating.

Kerry, Focus Group 3

Some people who have managed to keep their jobs are fearful of the true nature of their health problems being discovered by their employers, such as the following woman, who is keen to see Long Covid policies being developed in workplaces, and who writes everything she has to do down for fear of forgetting anything at work:



But I’m terrified to admit [how bad my symptoms are] because of my job, so I write everything down.

Mo, Focus Group 1

Many people who are unwell with Long Covid are not only budgeting their energy on a daily basis, they are also calculating how they can possibly hold on to their jobs. It often involves trial and error to see how many hours they can manage in a day or week without a relapse, and sometimes using all holiday leave to create a shorter working week. The following woman working for the NHS was facing this situation:



My work is very supportive. But a big fear - and I woke at 4.30 this morning, I was anxious because I'm thinking when I get to the end of March, I will have used all my holidays. That's me back full time. And in an HR meeting a few months ago the lady said, "maybe we need to accept this is your new normal." I wanted to turn the meeting off. I need to believe I am going to get better. It was a very clumsy thing for her to say. What if at the end of March, I'm back to how I felt last night after work. That is my worry [pauses for a long time].

Frances

A key message from many of the participants in this research was that Human Resources need to place less emphasis on people as resources and more on people as humans, and to work with the complexities rather than trying to iron them out. The Chartered Institute of Personnel and Development has produced guidance promoting their whole system approach and IGLOO framework, including recommendations for the individual, group (colleagues), line manager, organisation and outside (other agencies).¹⁸



We need convalescence time. Work sickness policies are not working. People will keep leaving their jobs and medically retiring. The Protestant work ethic is so ingrained in our culture - it makes it very difficult for anyone to get off the treadmill. But that is dangerous. I'm 25 years as a public sector employee. We are facing a massive skills gap, and this will make it worse. My experience is not easily replicated.

Steve

Occupational Health were also mentioned by some people as unhelpful:



The OH report said that I had agreed that I had moderate depression... That made me very cynical towards the OH person that she was trying to put me in a hole. I understand that mental health symptoms are part of my Long Covid, but I was angry because she didn't understand.

Paula

Education

Participants in education highlighted similar concerns to those in employment. One woman who had begun studies on a postgraduate course had very reluctantly decided that she could not continue. She had deferred her course, with no certainty as to whether she would be able to return, such was the nature of her disabling symptoms. Another young woman, who was in her final year of studies for a vocational qualification had battled for reasonable adjustments to enable her to complete her final placement. She emphasised the need for flexible approaches to support for people with Long Covid:



I'm in my final year - have done 5 out of 6 placements and most have been in a ward - it's very back and forth. There is no support within education - it doesn't feel like they are there for me. Take time out or get on with it.

Ger



State entitlements and support

Finances

All 32 adults we heard from were in full time employment or education when they got Long Covid. Most of those who had lost their jobs or had to leave education were now facing financial challenges that they had never anticipated and were having to find their way around the system. John described the 'ignominy' of having to navigate between HMRC and the Department for Work and Pensions (DWP) who were deducting essential income from him due to miscommunications between the agencies. Gary described a series of very unpleasant encounters in his endeavours to keep getting Universal Credit, where he described having to 'constantly explain myself'.

It was often a real challenge for participants to rethink themselves as dependent in this way, with further implications for their identity. Geoff, who worked as a joiner in the public sector, described how he had had to sell his tools and his bike to try to get by before phoning the Citizens Advice Bureau for help:



I spoke to the Citizens Advice Bureau through the council, and said I was needing support. I've always worked really hard for everything I do. They said to me go to a food bank. And I was like, that's embarrassing. A food bank? First, I can't drive, I can't walk. Second, I'm no a snob, I'm no nothing, but food banks are for people that are really struggling. I've got soup in my cupboards, I don't need a foodbank. Within two hours there was a guy at my door from the food bank. And I tried to turn it away but he said you should have it, the lady called to say to help...

Geoff, Focus Group 1

Finding the system so difficult to navigate was an additional shock. The experience of applying for social security payments was described by almost everyone who had been forced to do so as one of the worst, or in a couple of cases, the most distressing aspect of having Long Covid.



Applying for PIP [Personal independent Payment] has been one of the worst experiences of my life. I have had to go through all phases of the appeal - that is initial appeal, upper-level appeal, mandatory reconsideration. You have to prove that you are consistently, reliably, repeatedly affected by adverse effects which are atypical for someone of my age.

Sue

Participants described how the PIP form is 35 pages long and for a range of reasons, is not appropriate for chronic (fluctuating) conditions. Maria identified that it took her 18 hours to complete and left her floored. A few people had been staggered to find that they scored zero out of 200 points, despite being unable to live a typical, independent life. Others had heard from peers about their experiences and had low expectations as a result:



Regards PIP I'm so frightened of invalidation I'm not quite there with it.

Bernie



It took weeks to complete, with my wife's help...It is the same question over and over again. I know that I have to expect a knockback initially. But it will still be a blow. I will then have to get through an appeal.

Steve

Individuals were also keen to share information about anything they had found helpful:



A lot of people don't know about using DWP access to work for funds to go back to work. Although I applied for access to work in mid-December and still haven't had a reply.

Charles



People don't know that Annex 26 overrules the points system. I spoke to a professional in [third sector organisation].

Sue

Access to social care

Nobody we spoke to mentioned having any connection with Self-directed Support as the main means for accessing social care in Scotland. Some had accessed information and advice from a range of third sector organisations, as detailed below. A few had required mobility aids for use inside and/or outside the house. They mentioned the important role of community physiotherapists and occupational therapists in supporting them to access bathing aids, trolleys, walkers and/or wheelchairs. Otherwise, there was little sense of anyone obtaining help with daily life or sustaining quality of life in a more formal sense.



Community support

Support from family and friends

Families and/or friends were identified as key supports by almost every person we spoke to. Their role has been particularly important in the context of restricted services and ability to see others during the pandemic. Even more so given the anxieties of many with Long Covid about the infection risks of mixing with people:



My husband has been amazing. I don't know how we would have coped otherwise. He is so patient and emotionally reassuring - he knows what to say. I also prefer socialising with him as he will say, "stop - don't do that." It's easier when someone else tells you.

Allie

A few people spoke about how roles had had to change within their family to try to ensure that all needs were met. In particular, those with children had appreciated support from extended family to share the parenting role, where this was available:



My mum has had to be a surrogate mum for my kids. I couldn't talk to them when they got in from school.

Sheena

Conversely, some people identified that family members were less than supportive, resulting in decisions about who to spend time with to stay well:



My family is very practical. They mean well but their attitude is get up and go - blow the cobwebs away - get on with it. That made it hard being at home.

Anya

For people who had less support from family, and particularly for people living alone, the role of friends was very important in terms both of avoiding isolation and in managing the tasks of daily living during periods of being particularly unwell.



My friends have really showed up - just a few people - showing up in tough times. The odd few are just there to help.

Sara

A few identified significant efforts made by friends to include them in socialising:



I don't feel safe, and I need to try to work that through. My rugby pal organised for us to see the Scotland/Japan game. He called them and said although it was a separate thing that I had played rugby in the forces. They let us have easier access parking and were able to take our car round the back. That was a good day.

John

There could also be limits to what could be shared with family, with a couple of people intimating that they held back the worst of their pains and feelings so as not to overburden family members. A few participants identified that key family supports were also struggling with their own health conditions. Some people had limited support from either friends or family. The need for support from external agencies as well as families and friends was clear.



Spending time outdoors was also important to many of the people we spoke to. A couple of people identified that lockdown had already increased their interest in the outdoors prior to catching COVID-19. After developing Long Covid, Jill described how important it was to her that a friend would drive her to a local park to sit outdoors and have a flask of coffee, giving her a taste of her former active life. Iain had found long periods of time outdoors had helped his recovery after his first bout of Long Covid, and he hoped that this would help him this time round. The following participant from Glasgow explained:



I find the relaxation - my partner is a home carer, and she is seven days on, seven days off. We fire off into the country when she's off now... I can sit at Loch Lomond and watch the world go by, which I find very calming.

Robin, Focus Group 3

A recent report commissioned by the ALLIANCE highlights the growing focus on nature based therapies in Scotland, and the particular benefits for mental health and wellbeing as well as physical health benefits.¹⁹

Support from the third sector and community care

Most people had connected with at least one agency to obtain support with Long Covid. Chest, Heart & Stroke Scotland (CHSS) was mentioned most often, which is consistent with the fact that they were awarded specific Scottish Government funding to develop a Long Covid support service at an early stage. Some people identified that they were signposted to CHSS by clinicians or MSPs. There was a sense that this service could be helpful for someone newly diagnosed with Long Covid, in accessing a list of services and supports, but that it 'only takes you so far.' A few people mentioned that CHSS was more likely to engage people with heart conditions, which is only relevant to some with Long Covid.

Quite a few people had attended the peer support group run by CHSS, with mixed views. Although there were some very positive reviews of the facilitator, there were some concerns that it could be difficult for everyone to have a voice in large groups (one participant mentioned 23 people had attended a recent meeting). Another person had found the group useful but was simply too unwell to cope with a large group.

One woman who described herself as socially isolated due to Long Covid had appreciated a kindness volunteer from CHSS, who had visited for 12 weeks and then volunteered to continue the visits longer term.

A range of other examples were identified of support and services which people had accessed at various stages of their journey:



I went to [hospital based facility] which had set up a Long Covid rehabilitation clinic in the early days. They taught me about “pace, plan and prioritise”.

Karen, Focus Group 2



The Nuffield rehabilitation programme started August. Was helpful with mind things, but because of COVID we couldn't meet up, and I can't travel.

Mo, Focus Group 1



Bridie from the homeopathic hospital ran a pilot programme with 8 people - for 16 weeks - to make the case for funding. It included physio, 2-hour weekly sessions - a course on understanding sleep, nutrition, then mindfulness at the end. I had psychology appts and homeopathy. We got tools we could use for pacing.

Tom



With Veterans First Point I have psychological therapy coming up. I'm on the waiting list for Tai Chi. I'm hoping that I will be able to take up their offer of retraining.

John



The job centre is where I got the best help.

Lisa



Thistle [Foundation] has helped, with a Lifestyle management course, mindfulness course and their weekly and monthly catchups as well as weekly zoom movement such as Qigong.

Kerry

One woman, had found an online group helpful, but had struggled with the fact that it was time limited, leaving her with a sense of continued need that was not being met:



I've attended a group, Cognitive Care, and I got that through my GP... I was struggling with PTSD from my time in hospital and not knowing if I'd see my family again. I did feel the discussions in the group about mindfulness and grounding yourself - I found that quite helpful. But once the class finished, you're still back to the situation that you're in. My opinion is that I've just got to get on with it. I just face the challenges and just face things as they come. But I did find that class helpful.

Mo, Focus Group 1

There were also some general observations around what helps with sources of community support. One participant, who himself worked for a third sector support organisation, compared his experiences of contacting condition-specific organisations. He identified that it made a big difference when the agency opened a file on him, signalling that they anticipated future contact and paving the way for a continued conversation.

Additionally, many participants had either tried or were planning to try alternative therapies that were recommended to them. The most frequently mentioned were hyperbaric oxygen therapy, chiropody and flotation tanks, as well as massage and acupuncture.



Online support



It got halfway through 2020 and then people bonded through Facebook and Twitter.

Steve

Online interaction between affected people has been fundamental to the story of Long Covid, due to the double whammy of isolation enforced by a pandemic in general, and then the particular restrictions faced by this community. The importance of online groups was emphasised by many:



My Long Covid group on Mondays are now friends of mine.

Sue



Instagram has been a massive support - there is a huge chronic illness community.

Allie



Patient communities are my main support. They are friends as well as peers. Most of the people in the Long Covid Support group are neurodivergent. It feels like my tribe. I don't feel alone as a result of the group.

Bernie





The Facebook group has a self management focus without calling it that. It was a turning point for me. I felt I wasn't going mad and that I had a right to feel bad. Hearing other people's experiences of pacing... I got survivors guilt about people who couldn't work at all. The host [...] reminded people not to compare themselves to others. It was managed really well. I think it helped it wasn't run by a charity.

Jill

However, the potential pitfalls of such groups were also mentioned by many:



My friend shared a Long Covid group on FB. I know everyone is different but for me I find that more distressing. When I read everyone's symptoms - I thought, I need to disassociate.

Ger



I found through searching online training within the council we have online training- help me manage emotions... I picked up a lot with that online course. Think about what frustrates you and have a wee plan in your head.

Sam



The limitations may have something to do with the size of the groups:



Especially when you have Long Covid, it's too much information, and you feel like your head will explode... I find people like this, talking in this, because you get it, quite relaxing.

Robin, Focus Group 3

There were also links to other online communities which involved sharing information and building a sense of shared experience and purpose. Almost every person we spoke to with Long Covid identified a link to the ME/Chronic Fatigue Syndrome (CFS) community, which they were aware of due to relevant online campaign groups and collaborations between them.



The ME/CFS [community] have laid the foundation and we need research in all of these areas.

Bernie

In a wider sense, thinking of invisible disabilities in general, one participant who works for a condition-specific support organisation drew comparisons when asked to comment on the mind-map for this project:



Looking at this, if you took out COVID-19 and added chronic pain or MS or arthritic conditions, it wouldn't look much different... In terms of invisible disabilities, employers and people thinking 'is it really this bad? Isn't it just a cold, or just a bit of wear and tear?'

Paul, Focus Group 2

Holding on to hope

We specifically asked participants about whether there were any silver linings in their experiences and/or whether they were managing to hold on to hope. Silver linings tended to reflect new interests developed through changed circumstances, with one participant adding that he had developed advocacy skills through Long Covid and could see a future role in the charity sector. For several people, new or revisited creative outlets were identified. These included creative writing, a Long Covid poetry group, an art for health group and a rediscovered ability to draw:



With Long Covid I can draw again. That has switched back on. It is weird. I can draw almost without thinking about it. It has just clicked.

Angela

Some are struggling so much with the symptoms and the losses they have endured that finding hope can be a stretch. Of course, there is a strong wish for the pandemic to end, which a few people specifically referred to when asked about hope. Given the uncertainty about Long Covid, hope, where it exists, is ignited by fragments of emerging research evidence, observing others getting better, and in some cases positive personal experiences. Several participants had been so ill at an early stage (either with Covid or Long Covid) that they had thought they were going to die.



That first year was my daughter's first birthday in November. I was wrapping her presents in October, and I didn't know if I was going to make it until Christmas.

Allie

Still being here, especially if this was accompanied by a sense of possibility of improvement was hopeful:



As for quality of life, I'm an optimistic person. I can moan, but at the end of the day I'm here and a lot of people aren't. I won't pretend it's easy, but there are times - not so bad now, but there were days when I couldn't get out of bed, and I thought is this it? I'd rather think of what I can do than I can't do.

Karen, Focus Group 2



What has given me hope is I am at work, and I am doing a project at work. I'm functioning on a new base line which I don't want to be permanent - I'm hopeful because I'm in doing clinical stuff and that is an improvement, but I just want to be back to work.

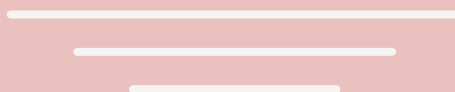
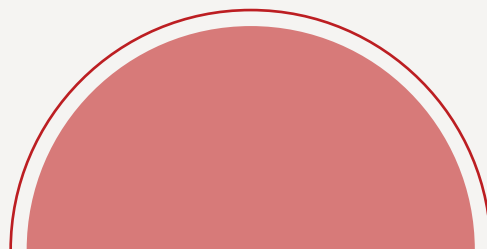
Fiona

Being able to talk about the experience of Long Covid, particularly where this might change things for the better, was seen as hopeful:



I really wanted the opportunity to talk about this. Not just to improve things generally but selfishly for my future too.

Steve



Several people identified a blend of factors which they thought would give them hope:



I struggle to find hope. A change in the benefit system would help. New findings on lung treatments for Long Covid. But what would give me hope would be Scottish independence.

Lorna

As a first waver, Tom found ways through 2020 to recover from Long Covid. He was hit by the double blow of getting COVID-19 again late in 2021, while also losing his father. He now thought he was at a different stage with grieving and recovery was again possible:



My hope is that I recovered from Long Covid before - when I was diagnosed initially with CFS. They said you can manage not recover - but I am a positive person - I have recovered from Long Covid. It was partly my attitude - my belief - I got out the other side. I believe I have the skills and it is possible... I have to consider the impact of my father passing.

Tom

Another participant who was still experiencing significant physical restrictions as a result of Long Covid provided the following reflection:



Hope, not much - it's more of a kind of inner determination, where do you sit with this, and an inner determination is helpful. When do you need to accept life as it is? For anyone new [to Long Covid] you have to find how to get inner peace - if it is about fighting for a while then that is what you need to do, but you have to find your way.

Allie

Next steps

Government responses

Many of the people who contributed to this research have strong views about what has happened to them during this pandemic, and about what needs to happen at policy level. Many people were in key worker jobs when they contracted COVID-19 and feel that restrictions should have been brought in earlier.



We were put out to war, and you come back with a broken leg but you're not given the wheelchair to help you get on. They could have acted faster, but we are in the most disabling event since WW1.

Sheena

People with Long Covid want effective support to regain their lives. They understand that resources are squeezed. However, they argue that failure to support them now will result in more of them losing their jobs and being more marginalised, ultimately at greater cost; a 'hidden iceberg', as one participant called it.

They are concerned about the lack of public knowledge and understanding about Long Covid, and that the public has not been fully informed about the risks from COVID-19, or how to mitigate those risks.



The thing worrying me is public health messaging. The absence of public education and warning about Long Covid is a public health risk to the population. This can happen to anyone. And some people might have taken it more seriously if they had understood that.

Steve

Several participants spoke positively about the Cross Party Group for Long Covid in the Scottish Parliament and All-Party Parliamentary Group (APPG) in the UK Parliament and would like to see them influence future direction. A further opportunity was highlighted by the following participant:



Social Security Scotland will be taking over PIP in August. It is a chance to do something better for Scotland and do that preventative stuff that saves the tsunami later.

Steve

Conclusion

If we listen to the stories of adults with Long Covid in Scotland, we hear about the consequences of an unprecedented mass disabling event, which leaves those affected frightened and struggling with physical, cognitive and mental suffering and distress. To have been battling with this condition, at a time of enforced isolation and lack of the usual services and support, presents a harsh set of circumstances.

We also hear extraordinary survivorship, a shared sense of humanity and a desire to collectively improve the lot of all those blighted, not only by Long Covid, but similar existing conditions which can wreak havoc whilst evading usual medical tests. Research also raises concern that the symptoms of Long Covid, accompanied with inflammatory damage to the brain, may increase suicidal ideation and behaviour in this population, pointing to the urgency of appropriate support and management of the challenges faced.²⁰

People currently living with Long Covid identify a concern that the condition has not sufficiently been acknowledged when calculations of risks are made with regard to the pandemic as a whole. Despite ONS estimates that 1.7 million households in the UK were already living with Long Covid in April 2022,²¹ Long Covid prevalence is not prominent in discussions about risks from the pandemic. This includes what measures should be taken to prevent spread of COVID-19. For those living with Long Covid, apart from humane concerns for the level of suffering involved, there is a compelling economic case for rapid intervention, given the numbers of people of working age who are being prevented from full participation in life.

Considering the common themes arising in the stories we have heard, there are clear links between some of them. These linked themes tell us that some of our standard operating assumptions do not serve this population well. People with Long Covid tell us that they want their experiences to contribute to better futures, resonating with an earlier collective desire for a 'new normal' expressed at the start of the pandemic. In particular, the rigid adherence to a need to be constantly busy – is not serving any of us well and can be harmful to the many with Long Covid.

Further, many assumptions about health and illness are also upturned by Long Covid. Scotland needs a new way of thinking about invisible disabilities which does not dismiss people as malingerers simply because their symptoms do not fit with the limitations of the predominant medical model. And whilst being clear that these conditions are not 'all in the mind', the mind has a significant role in recovery. Clinicians can cause psychological harm through disbelief, in turn potentially causing physical harm through failing to give permission to get off the treadmill, pace and recover. Conversely, when clinicians get alongside the individual with Long Covid, the potential benefits are significant, with regard to validation, reduced isolation and partnership in learning about what works towards being as well as possible. This can also help with recovery of identity, which may well have been compromised through loss of valued social roles, alongside experiences of disbelief and stigma.

Increased attention is being paid to the voice of lived experience in Scotland. The unprecedented challenges of the pandemic, not least as experienced by this population, must be recast as opportunities, to capture and attend to those voices, and to learn how to do things better. Participants in this research have told us about what they want to happen and are keen to continue to be involved in research, to co-create channels within services for their voices to continue to shape support and services. Considering the outcomes important to people with Long Covid, we heard about key outcomes in addition to generic personal outcomes and have produced a draft table to be tested in future research (Appendix 2). At UK level, a range of studies funded by the National Institute for Health Research has been launched in the UK with end dates from summer 2022 through to 2024, variously researching prevalence, causes, diagnosis, treatment, rehabilitation and recovery.²² Public involvement is a feature of all the studies.²³ Our participants go further in recommending support services which themselves also act as research hubs, whereby learning can be captured and directly inform how things are done. As Steve says, action is needed now to prevent an imminent tsunami.



Recommendations

1. All stakeholders, especially medical professionals, should take a considered and empathetic approach when assessing whether someone may have Long Covid, even though their symptoms may fluctuate or individuals may not have had access to testing when they first became ill. It is essential that people (of all ages) are believed when reporting the symptoms of Long Covid.

2. The Scottish Government should run a national Long Covid communications campaign to educate the public about Long Covid and the effect it can have on people, and highlight key resources and supports.

3. The Scottish Government, Health and Social Care Partnerships and local authorities should invest in and facilitate training for health, social care, education, and social security professionals to support understanding of Long Covid and its implications so that people are effectively supported. This training should take a trauma-informed approach.

4. The Scottish Government should facilitate health, social care, education, and social security professionals at a national level to share examples of best practice in supporting people with Long Covid. This sharing of good practice should include direct input from people with lived experience of Long Covid.

5. The Scottish Government and Health and Social Care Partnerships should use a personal outcomes framework to understand the experiences people have been having so far, and the outcomes that are important to them.

6. The Scottish Government should provide support for people with Long Covid to understand the condition and how best to self manage. This includes understanding the need for a balance between cognitive and physical activities and about budgeting energy between them.

7. Health and Social Care Partnerships and local authorities should be able to signpost people with Long Covid to third sector and community-based organisations that provide information, advice and courses for self management on a flexible basis.

8. Social Security Scotland and the Department for Work and Pensions must adopt a person-centred and compassionate response to people with Long Covid.

.....

9. The Scottish Government should review eligibility criteria for Adult Disability Payment and Child Disability Payment to ensure they are appropriate for people living with Long Covid and other fluctuating conditions.

.....

10. Employers should follow CIPD guidance and work in partnership with the individual to make reasonable adjustments and to adopt a flexible approach to phased return.²⁴ This may include non-consecutive days for phased return and trialling a range of reasonable adjustments.

.....

11. The Scottish Government and Health and Social Care Partnerships should explore the provision of hubs or one stop shops to help plan and co-ordinate support for people living with Long Covid. This is particularly important for people who need to conserve limited energy when seeking support.

.....

12. Actions to improve support for people with Long Covid should also be designed to benefit people living with other fluctuating long term conditions and invisible disabilities (e.g. people living with ME/CFS).

.....

13. Health and Social Care Partnerships and local authorities should ensure tailored support, advice and guidance is provided for family members adjusting to new caring roles supporting people with Long Covid, including young carers. Research with Long Covid carers and people with lived experience must inform this support.

.....

14. The Scottish Government should provide sustainable financial support for a range of Long Covid support groups. Sustainable financial support would enable greater variety of support formats, to best suit the diverse needs of the Long Covid community. For example, this could include a blend of face to face, online and telephone communication options. Small peer support groups may be preferable for some people, given energy limitations and cognitive challenges.

As discussed earlier in this report, this project did not include input from children or young people with Long Covid or their parents/Guardians in this project. We suggest that the Scottish Government should prioritise further research and engagement in this area to fill the knowledge gap about children and young people’s experiences of social support, in order to ensure that policy and practice responds to their needs.

Appendices

Appendix A - mind map

Themes from the *Accessing Social Support for Long Covid* project, E. Miller



Appendix B – personal outcomes

The table below is an adapted version of a current evidence-based model of personal outcomes for people being supported by services. The top row below the three categories of outcome identifies three key additional outcomes for people with Long Covid, arising from our interviews. Key findings are as follows:

- **Process outcomes or how people are treated by services, are often as important to people as their other outcomes** and that was certainly the case for the people we spoke to, with being believed as a strong additional outcome.
- **Change outcomes relate to overcoming or reducing barriers to quality of life**, which again were fundamental to people with Long Covid, with an additional outcome of recovering personal identity.
- **Quality of life outcomes are what matters to everybody**. Financial wellbeing emerged as a key concern for people with Long Covid.

Process	Change	Quality of Life
Being believed	Sense of identify restored	Financial wellbeing
Listened to	Improved confidence/ morale	Feeling safe
Having a say	Managed symptoms	Having things to do (including work)
Treated with respect	Improved mobility	Being as well as possible
Treated as an individual		Seeing people
		Living as you want

Adapted table from *Talking Points: Personal Outcomes Approach practical guide for organisations*, A. Cook and E. Miller (2012).

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About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims. We seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.



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people at the centre

About Chest Heart & Stroke Scotland

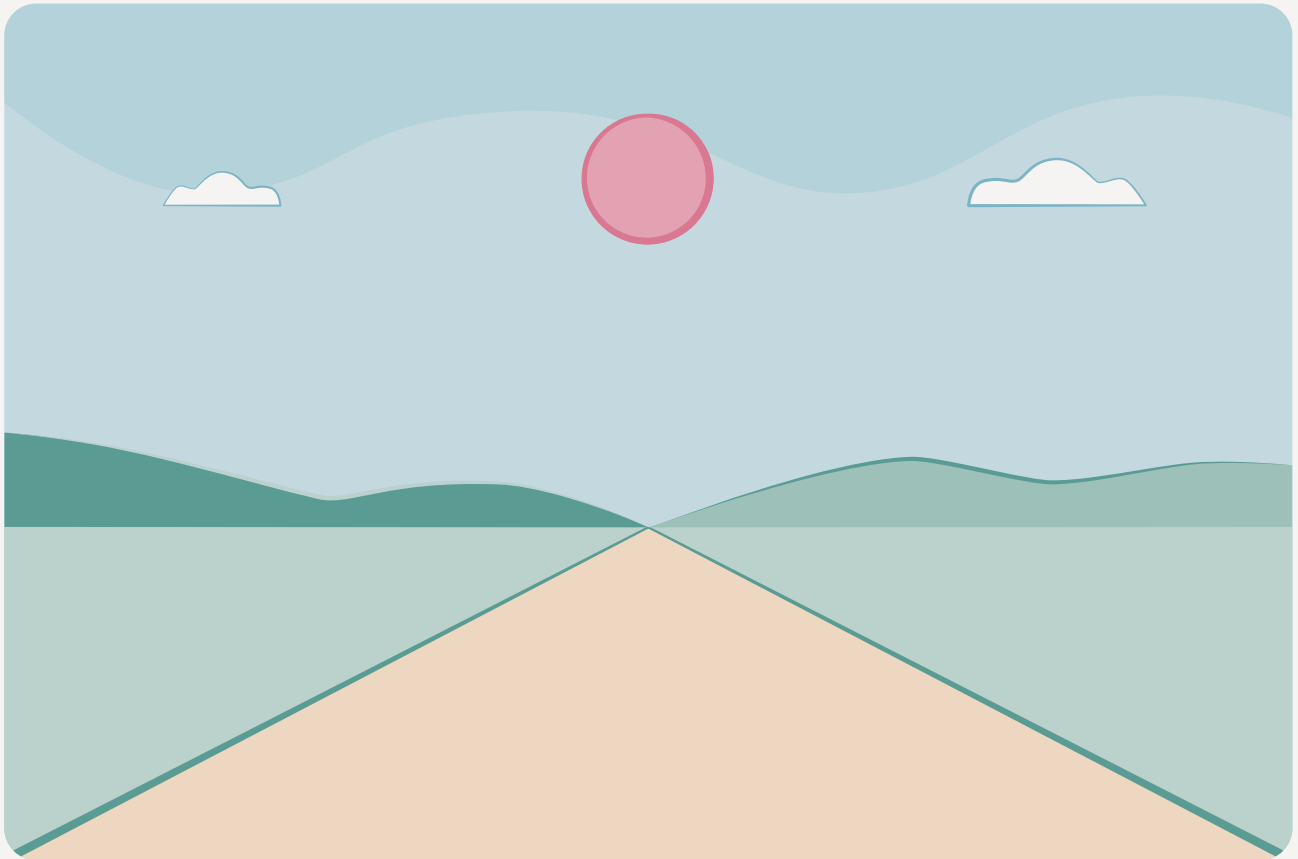
We believe that everyone should have the right to live life to the full after a stroke or diagnosis of a chest or heart condition.

Chest Heart & Stroke Scotland (CHSS) is Scotland's leading charity providing support to people with chest, heart and stroke conditions to live life to the full again. Our Hospital to Home services form a nationwide network of local support groups, nurses, volunteers and one-to-one support teams helping families adjust to life with a heart or lung condition or after a stroke.

Our Long Covid Support Service is co-funded by Scottish Government and is one of the main services providing self-management support for those living with Long Covid.

**Chest
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