

Cross-Party Group on Long Covid

30 May 2023, 18:30

Minutes

Present

MSPs

Jackie Baillie

Alex-Cole Hamilton

Sandesh Gulhane

Invited guests

Helen Goss

Susan

Cass MacDonald

Alison Keir, RCOT

Chris White

Jane Ormerod

Veronica Mcildowie

David Inglis

Cameron Smith

Dorothy Grace Elder - CPG chronic pain

Sheila Traschler on behalf of Foysol Choudhury MSP

Lesley Walker

Dr Claire Taylor

Leanne Quinn

Helen Gibson

Helen McDade

Terri Lloyd

David Broadfoot

Esperanza Miyaki

Rob Simpson
Freja Lundjberg
Shabeen Begum
Shereen
Shaun Tophen Cooper - NASUWT
Stuart Mclver
Allana Hoggard

Apologies

Professor Kate O'Donnell
Dr Katrina Whittingham
Alice McLean
Rob Gowans (The ALLIANCE)

Agenda item 1

Introductions – the group introduced themselves one by one.

Agenda item 2

Summary of Covid-19 recovery committee report recommendations:

Chris White spoke about how members of the call have given evidence in the Covid-19 Recovery Committee's Long Covid enquiry.

On 26th of April it produced its report, and there were broad themes throughout. Chris touched upon the topic of awareness and recognition, with GPs and employers having a limited understanding of Long Covid, which has resulted in discrimination and misunderstanding.

People with chronic illness like ME and CFS have been experiencing this for some time and the report found that no learning from these experiences has happened, with many encountering difficulties in accessing healthcare and forcing high numbers to seek private medical care. This is concerning, and many cannot go down this route of private care.

The report called for the training of medical professionals on long Covid.

The report found that Long Covid is affecting people in numerous ways, with many being dismissed from their jobs and employers terminating employee contracts.

Additionally, children are also missing out on school and being deprived of fully experiencing their childhood, which has been going on so long that they are now transitioning to already stretched adult services.

Data collection and data collecting must also be improved going forward.

Agenda item 3

Open discussion:

Jane Ormerod spoke about the disconnect between what clinicians and the Government are saying and what people who have had long Covid and worked in the NHS are saying.

A gap was outlined between what is said to exist and the reality of the condition.

Additionally, a lack of clarity is palpable around the topic of expenditure, treatment and developing services that are available.

Cass MacDonald communicated the experience of Long Covid sufferers in relation to gaslighting and disbelief of the condition. They said that the First Minister claimed that GPs denying and ignoring long Covid is a rare occurrence, when in fact it is reiterated by countless sufferers.

Cass shared a story of a friend who continues to be told that the problems she is encountering are mental health based, with the same advice being given to others suffering from chronic fatigue syndrome, which has been disproven by the National Institute for Health and Care Excellence (NICE).

Rob Simpson reiterated the point previously made, regarding the gap between what the Government claim they are going to do and what is actually being done. He spoke of his own experience, being told by GPs that he has postural tachycardia syndrome (POTS), only then to get this referral rejected and be told there is no service available to help him.

Shaun Tophen Cooper, who is a primary school teacher, referred to the mistreatment by the Government towards teachers, with no support available for poorly staff. Throughout the pandemic schools were highly unsafe, with the mitigations that were put in place in schools not being strong enough. If this isn't addressed teachers will not put themselves back on the front line in future pandemics as their workplace is simply not safe.

One person with Long Covid, who wishes to remain anonymous, spoke about their experience of a phased return at work in the Scottish Government, and how supportive the workplace has been of this. However they recently found themselves having to do an event in person mid-week, leaving them exhausted by Friday and unable to work.

On return they found that they were not able to self-certify as being off with Long Covid and had to go through Human Resources for it to be logged accurately. They feel that this is very alienating for people with Long Covid as this seems to be the only condition this happens with, and the Scottish Government could be setting the tone for best practice as an employer. They would be interested to know why sickness absence due to LC is being directed via HR.

Helen McDade spoke about the crossovers in relation to Myalgic Encephalomyelitis (ME), outlining that not everyone with Long Covid experiences chronic fatigue, but quite a lot do. It is important that these symptoms are understood and by GPs as well being made clear to everybody else. Those suffering from Long Covid must be aware of the crossover of the two conditions. Appreciation was shown for the acknowledgement of failures for ME and CFS in the report. There is also need for those with Long Covid to heed the advice given to those with ME – ‘Stop, Rest, Pace’.

Dorothy Grace Elder encouraged people to question everything they are told in relation to where Long Covid money is being spent by the Government.

She highlighted that in evidence to the committee, Dr Amy Small raised the topic of Long Covid clinics, and the lack of information that is being provided to Scotland regarding such clinics.

She also raised that Jackie Baillie MSP exposed that the £3 million was not in addition to the package of £10 million, only that it was a part of this package.

Dr Claire Taylor spoke about the difficulty and unfairness regarding initially being diagnosed. Many have to seek diagnosis through the private sector, and when they return to her for treatment, she is told that the issue then needs to be treated privately, according to the NHS.

The risk of suffering from Long Covid after being positive once is 10%, and then increases to 20% if they are positive a second time. The risk of removing mask requirements in health care facilities is putting both staff and patients at a huge risk. Additionally, swabs and testing have also been taken away in care homes.

Dedicated health care professionals and pathways are needed to improve the experiences of those suffering with long Covid, as CBT will not work.

Dr Taylor tried to raise these points at the Committee, but found that no one was interested in what she had to say. She was offered a visa to go to Australia and help them in their efforts to tackle Long Covid, showing that their Government is taking this seriously. That is different to Scotland, where Dr Taylor is a doctor, but isn't listened to despite her work on the illness.

Helen Goss made a call for action, saying that we cannot just complain, that we must act on securing a strategy.

Jackie Baillie MSP shared the frustration she feels and asked Dr Taylor not to leave for Australia.

She said that whilst the Committee had expressed their concern for what was going on, some of the recommendations they made were unfocussed. A focus should be placed on areas of the report that can be taken forward.

Training for doctors and health professionals should be manageable, with pathways in all 14 health board areas, not just the current 6.

She highlighted that based on Barnett consequentials, £21.7 million has been passed to the Scottish Government by the UK Government – but only £10 million has been dedicated to Long Covid.

It is essential that money being spent has been allocated is accounted for. The first research cycle is coming to an end. Questions must be asked regarding what the findings were, what will the new research be, and what has happened.

Many are feeling pressure from their employers, and others in their life, who don't believe the seriousness of the condition. Something to tackle this disbelief must be put in place and must be driven forward.

With the likelihood of people getting Covid-19 again with every cycle, there is higher risk of contracting Long Covid. A strategy must be put in place to ensure that we are prepared to tackle this obstacle.

Jackie expressed her hope for the future, and that a meeting between Long Covid groups and Michael Matheson is urgent.

Alex Cole Hamilton MSP outlined the need to replicate last year's press conference.

Helen Goss questioned how it would be possible for families to go through it again, when last time nothing came from it.

Shaun Tophen Cooper said that Scottish Trade Union Congress and other unions would support future calls for support.

Terri Lloyd asked how many teachers are currently on long term sick leave due to Long Covid. Others responded that this data is extremely hard to get a hold of, further illustrating the need for better data gathering by Scot Gov.

Chris White suggested everyone come together to organise something through the CPG, such as sending an email to everyone as well as the organisations.

Cass MacDonald spoke about doing media around keyworkers with long Covid, as they are now losing her career and filling out retirement paperwork. If keyworkers come out and talk about their experiences and show that the Government cannot afford to lose these workers, that is another angle that may be successful.

Dorothy Grace Elder suggested contacting the auditor general to find out exactly where the £10 million Long Covid monies have been used.

Sandesh Gulhane MSP discussed the prevalence of requests for improving GP education but said that there are too many illnesses for GPs to be expected to manage this. He said that proper pathways are essential here and GPs must have access to proper routes and referrals when they do spot long Covid. The point for meeting Michael Matheson was reiterated, furthermore the point of Mr Matheson needing to hear these stories first hand.

Alex Cole Hamilton made clear that this is a serious issue and it will not be forgotten about, and expressed his thanks to those who attended.

The meeting closed at 7:30pm.