

LONG COVID PATIENTS 'DAMAGING' EXERCISE

WARNED OF PROGRAMME

Test and protect system is 'utter farce', says OAP

EXCLUSIVE

By **Paula Murray**



PATIENTS who develop ME – or chronic fatigue – after Covid-19 infection should not be told to exercise.

Campaigners warn graded exercise therapy (GET), which aims to slowly increase levels of physical activity, will pose a serious risk to those affected by post-viral illness.

ME Action Scotland said it has written to the Scottish Government urging it to ignore any GET-related guidance from south of the Border.

The National Institute for Health and Care Excellence (NICE) is expected to recommend a programme of structured exercise in

CONCERNED: Janet Sylvester, whose daughter Emma Shorter suffers from ME, is worried a controversial exercise regime will be brought in for patients who develop the syndrome



SUPPORT: Dr Charles Shepherd

England, despite accepting the approach may not be suitable for patients with long Covid.

Those guidelines are expected soon, with mounting concerns the Scottish Government will follow.

One of the hallmark symptoms of ME – and increasingly long Covid – is post-exertional malaise (PEM), with even minor physical or mental exertion leading to worsening symptoms following activity. A setback can last for days or weeks.

Janet Sylvester, of the Scottish action group, said scientific evidence from past viral outbreaks shows that a significant subset of people suffering ongoing symptoms after initial Covid-19 infection are likely to develop ME.

She added the group wrote to Scottish Secretary for Health Jeane Freeman in early May noting that emerging evidence shows that graded exercise therapy poses a

risk to post Covid-19 patients, as well as to ME patients.

Ms Sylvester added: "There is evidence of a risk of Covid-19 leading to a large increase in post-viral illness and potentially ME.

The letter requested urgent action to stop GET." She said US officials had already removed its recommendations for exercise therapy amid concerns it was harmful.

She added: "Now the high numbers of people suffering similar symptoms following initial Covid-19 infections makes this a critical action. Although NICE has already issued a statement that GET may

not be appropriate for people with post-Covid illness, we have heard several of the new NHS England clinics for Covid rehabilitation are

'Letter requested urgent action'

recommending graded exercise or its equivalent to patients.

"It is essential all UK governments, the medical profession and the NHS recognise the harm done

by graded exercise therapy to people with ME and the potential damage to thousands more people with long Covid.

"Our #MEAction Scotland and #MEAction UK strongly suggests these agencies talk to and learn from the ME community to ensure no further harm is done."

The ME Association last week backed our Light at the End of the Tunnel campaign, calling for specialist long Covid clinics in Scotland to help those struck by the condition in the long-term, warning the number of specialists here is "scandalously" minimal. Its

medical adviser, Dr Charles Shepherd, warned between 10 and 20 per cent of people who have the coronavirus, even in its mildest form, go on to develop ME and chronic fatigue syndrome (CFS) and become susceptible to PEM.

The group also backed our campaign, with Ms Sylvester saying they were calling on the government to set up multi-disciplinary clinics.

A recent, large-scale survey discovered 80 per cent of people with ME found no benefit or were significantly worse after graded exercise regimes, with previous

'Sizeable minority' suffer for months

A "SIZEABLE minority" of coronavirus victims will continue to have symptoms for 12 weeks or more afterwards – regardless of how ill they were initially or whether they were hospitalised, Scottish experts agree.

Scientists have been looking at the after effects of the virus, with Scottish Intercollegiate Guidelines Network (SIGN), the National Institute for Health and Care Excellence (NICE) and the Royal College of General Practitioners (RCGP) giving more details about the guideline on post-Covid syndrome – to be published by the year end.

The guideline scope defines post-Covid syndrome – also known as long Covid – as symptoms that develop during or following an infection consistent with Covid-19 which continue for more than 12 weeks and are not explained by an alternative diagnosis.

It says the condition usually presents with clusters of symptoms, often overlapping, which may change over time and can affect any system. It also notes many with post-Covid syndrome can also experience generalised pain, fatigue, persisting high temperature and psychiatric problems. Evidence for Healthcare Improvement Scotland director Safia Qureshi, of which SIGN is a part, said: "We understand long Covid is creating great distress

By **Mike Merritt**

and uncertainty for those affected, and that the NHS requires the best available advice to support people effectively, even as we continue to seek to understand it.

"The scope report is a first and vital stage in the production of a guideline which aims to identify symptoms and outline treatment options. We're delighted to work

more afterwards, regardless of how ill they were initially or whether they were hospitalised. "This is a new condition and there is still a lot we don't know. Our aim is that the post-Covid syndrome guideline will begin by setting best practice standards of care based on the current evidence but, as our understanding of the condition grows, be adaptable and responsive to new evidence as it emerges."

Professor Martin Marshall, chair of the Royal College of GPs, added: "The prolonged health effects some patients experience can have a terrible impact on their lives – and, as GPs, we want to do what we can to help them. Now we are clear about its scope, we can move forward in developing guidance, based on the latest evidence, to support GPs to deliver the most appropriate care and support to patients suffering with the long-term effects of Covid-19."

The scope outlines what areas the guidelines will cover. These include what symptoms or signs should prompt a referral for specialist assessment or management, what pharmacological and non-pharmacological interventions improve physical or mental health symptoms following acute Covid-19, and how best to deliver post-Covid syndrome recovery and rehabilitation services.



GUIDANCE: Prof Martin Marshall

with NICE and the RCGP on this important piece of work."

Dr Paul Crisp, director of the Centre for Guidelines at NICE, said: "Recovery from any infectious illness can take time and, although most people with Covid-19 will recover completely within a few weeks from the onset of symptoms, we know a sizeable minority will continue to have symptoms for 12 weeks or

research showing a period of enforced rest from the onset gave patients the best prognosis.

And an analysis of over 18,000 responses to ME management surveys over a five-year period showed 57 per cent deteriorated following GET.

A Glasgow teenager, who asked not to be named, also described how her health deteriorated after GET. She said: "I went from going to dance classes and gymnastics to being unable to walk even a few steps in a matter of a couple of months. I was told to keep going, even if it hurt. I thankfully stopped

and I stopped deteriorating so quickly. I rested as much as possible and slowly started to improve."

Dr Amy Small, a GP in Prestonpans, East Lothian, has been suffering from long Covid since falling ill in April. She said she has struggled to come to terms with the post-exertional malaise, and added: "I've learned from the ME community and the long Covid community that GET is potentially very damaging. I've learned the key to recovery is through pacing. I've managed to pick up my activity levels over the last few months with adequate pacing and rest."



DAMAGING: Dr Amy Small

By **Paula Murray**

A SCOTTISH pensioner waited for seven days to be contacted by the Test and Protect staff after a potential Covid-19 exposure.

The man, who asked not to be named, had been a customer at a local cafe in Ayrshire where a worker subsequently tested positive for coronavirus.

Although he gave his contact details on arrival, as required, it took a full week for him to be contacted and told to self-isolate in case he was contagious.

In an email to the Scottish Sunday Express, the 69-year-old said: "Scotland's Test and Protect is definitely not working."

"Having been a customer of a local cafe in which a member of staff received a positive Covid test result on Friday, 23 October, I received a phone call from the NHS Scotland contact tracers in the evening of Thursday, 29 October, telling me I had to self-isolate until November 6."

"Considering my details along with those of every other customer had been recorded by the cafe, making this surely one of the simplest of contact tracing

exercises, it is unbelievable it took seven days to be contacted.

"So for the past week I have been meeting friends and visiting other cafes and shops while potentially infected. What an utter farce."

The OAP added he is hearing disabled and relies on his wife to handle any calls, saying they

were concerned the call might have been a scam as the contact came from a withheld number.

Although guidance says tracer calls will come from a single, national 0800 number, it can come up as withheld.

The couple have spent hours on the phone trying to find out whether they should isolate or not.

The SNP cabinet implemented the framework of test, trace, isolate and support system in the spring in a push to become a zero Covid country. It seemed to have paid off when First Minister Nicola Sturgeon said in June the nation was close to eradicating the virus before the figures started to climb again towards the autumn.

Despite promises to hire 2,000 contact tracers to run the

service, there has been confusion over how many are in place with reports of delays and capacity problems.

Meanwhile, daily figures have soared above 1,000, with deaths also increasing.

Opposition politicians say the Scottish Government has failed to boost capacity after the first outbreak during the quieter summer months and were now paying for the mistake.

Scottish Lib Dem leader Willie Rennie added: "There's no underplaying how important the test and trace will be in getting us out of the second wave."

"We need to see a step change in test and trace capacity and the speed at which interviews with positive patients are conducted."

"It shouldn't have taken four months to meet basic targets on quarantine spot checks. People are rightly raising questions about whether the government squandered the summer months when the virus had abated."

Latest statistics show there are thousands of individuals with positive tests and contacts that tracers have been unable to get hold of.

Public Health Scotland data says up to October 25 there were 2,841 people – or 7.4 per cent of all individuals – with the virus they've not managed to contact.

There were another 7,808 contacts – 5.3 per cent of the

total – the tracing teams had been unable to communicate with.

Over the seven days to last Sunday, 70 per cent of the week's contact tracing was completed within 24 hours, while 20.8 per cent took between 24 and 48 hours.

Another 349 cases, or 6.9 per cent, took between 48 and 72 hours to complete, while 2.1 per cent – 107 cases – took longer than 72 hours before the case was regarded closed.

A Scottish Government spokeswoman insisted Test and Protect is performing well. She added: "Since the Case Management System went live on 22nd June, 91.9 per cent of people with a positive test have been contacted, as well as 93.8 per cent of all their contacts."



ALL CHANGE: Willie Rennie wants rapid system in place