**Coronavirus: Government’s lockdown decision ‘deliberately puts disabled people at risk’**

Disabled people have attacked the government’s decision to start lifting the lockdown that has been in place since March, and have warned that some people with long-term health conditions could pay for that move with their lives.

The prime minister, Boris Johnson, [announced on Sunday](https://www.gov.uk/government/speeches/pm-address-to-the-nation-on-coronavirus-10-may-2020) that his government would now begin to ease the lockdown in England, while devolved governments in Scotland, Wales and Northern Ireland opted to retain stricter measures.

One key step announced by Johnson was to change the government’s advice to those in employment, which means that those who cannot work from home are now “actively encouraged to go to work”.

He also spoke of plans to begin the phased reopening of shops, and for some primary pupils to return to school, potentially as early as 1 June.

But concerns highlighted by at least four disabled people’s organisations about these moves have been shared by scientists who set up an independent group of experts in parallel with the government’s own SAGE committee of scientific advisers.

The Independent Sage Group [said the government’s decision](https://twitter.com/IndependentSage/status/1260158687185743872) to ease the lockdown was “dangerous” and could lead to further localised epidemics.

The same day, researchers from University College London [said in a study](https://www.ucl.ac.uk/news/2020/may/lockdown-ease-could-lead-tens-thousands-excess-deaths-unless-vulnerable-are-protected) published in the Lancet that easing the lockdown too soon could lead to thousands of avoidable deaths among people with underlying health conditions such as heart and kidney disease, diabetes and severe obesity.

Most of this group are not on the list of about 2.5 million people across the UK considered by the government to be “clinically extremely vulnerable” to the virus and who have been advised to “shield themselves for some time yet”.

Two days before Johnson’s announcement, [a snap poll](https://twitter.com/BuDs_UK/status/1259173976108130306) of more than 600 disabled people who are most at risk from the virus showed nearly nine in 10 of them did not want the lockdown relaxed.

The poll of people who are shielding or clinically vulnerable to the virus was carried out by the user-led organisation [Buckinghamshire Disability Services](https://buds.org.uk/).

The day after Johnson’s announcement, BuDS said it had spent the morning “reassuring frightened and confused people” who had watched his speech.

Three days before Johnson’s speech, disabled activist Ellen Clifford, a member of the national steering group of [Disabled People Against Cuts (DPAC)](https://dpac.uk.net/), [told an online rally](https://twitter.com/disabmurals/status/1258696654770909184?s=19) held by the [People’s Assembly Against Austerity](https://www.facebook.com/watch/live/?v=536797000330660&ref=watch_permalink) that if the lockdown ended too soon, many more disabled people would lose their lives.

She pointed to the loss of the disabled activist and DPAC member Manjeet Kaur, [who died last month](https://dpac.uk.net/2020/05/tribute-to-manjeet-kaur/) from coronavirus.

Clifford told the online rally: “If lockdown ends too soon, we will lose many, many more, either through the virus or through over-stretched NHS resources, not being able to respond to the illnesses or pre-existing impairments that disabled people have.”

DPAC confirmed last night that it believed Johnson had eased the lockdown too soon and that the government was “deliberately putting more disabled people’s lives at risk”.

Clifford told the rally that DPAC was particularly concerned about disabled workers who were receiving letters from the government telling them they needed to continue to self-isolate while they were also being pressured back into work by their employers.

She said: “Who will gain from all this? Not disabled people.

“COVID-19 has made it sharply apparent how little worth society places on our lives.

“And not the undervalued frontline workers, upon whom the running of society is dependant.

“It is of course the bosses, who already have way more than their fair share, who will benefit.

“The right-wing media are doing their best to help them, with headlines comparing the end of lockdown to a return to freedom, to sunny walks in the park and day trips to the seaside.

“In reality, a premature end to lockdown will mean a return to the daily slog surrounded by yet more death.

“And that’s why we need to continue to focus on the fight for PPE (personal protective equipment), for testing and to protect our communities.”

The grassroots disabled people’s organisation [Bristol Reclaiming Independent Living](https://twitter.com/BrilLiving) (BRIL) said it believed that easing the lockdown rules would put disabled and chronically-ill people at further risk.

BRIL questioned how any disabled person could feel safe when, [in March](https://www.gov.uk/government/publications/guidance-for-social-or-community-care-and-residential-settings-on-covid-19/guidance-for-social-or-community-care-and-residential-settings-on-covid-19#guidance-on-facemasks), the government said it “was unlikely that people receiving care in a care home or in the community will become infected”, but this week it [had been shown](https://www.theguardian.com/world/2020/may/13/coronavirus-real-care-home-death-toll-double-official-figure-study-says) that the number of deaths in care homes in England and Wales linked to coronavirus was likely to be more than 22,000.

One BRIL member also warned that the prime minister appeared to have “misrepresented the existence of adequate legal protection” for employees who feel unable or unwilling to return to work or fear the risk to themselves or an immediate family member who is disabled, chronically ill, or is otherwise at risk or shielding.

[Greater Manchester Coalition of Disabled People (GMCDP)](https://gmcdp.com/) also raised concerns about the lifting of the lockdown, although it pointed out that some disabled people had found lockdown “utterly inaccessible” and had been pushed into crisis due to isolation and the change of routine and therefore could be glad to see it lifted sooner.

But Dennis Queen, a GMCDP spokesperson, said her organisation was concerned about the measures being taken to loosen the lockdown.

She said: “Many of us cannot perform the social distancing required, so we will be reliant on others avoiding us.

“Many disabled people who are vulnerable to infection (and won’t qualify for certain intensive care unit treatments) are not on the shielding list, but are still not safe to be out in public spaces.

“More people being around in general means care, health and support staff will be exposed to more risk of COVID-19.

“Some people feel they will be locked down until there is a cure or a vaccine – and will be locked down longer if we lower lockdown too early and this causes another spike.”

GMCDP urged all disabled workers to join a union and seek support if they were being asked to return to work too soon for their welfare, and called on the government to ensure there was live British Sign Language interpretation, captions and audio description on all public announcements about lockdown, and to produce it in accessible formats.

Queen added: “We urge the government to invest in and subsidise development of clear-view masks and then make them available for free to everyone who needs them – many people struggle to communicate when they can’t see faces, so this is an access issue.”

[Disability Rights UK (DR UK)](https://www.disabilityrightsuk.org/) was another disabled people’s organisation to highlight that some disabled people were alarmed at the lockdown being eased so soon, while others were desperate to be freed from its restrictions.

A DR UK spokesperson said: “We would hope the government is following the best scientific and medical advice, and not just basing lockdown easing on economic advice.

“Many disabled people quite rightly fear the consequences of catching coronavirus and the potential impacts of easing lockdown.

“The guidance is so new, we don’t know what its impacts will be yet.

“Our role as an organisation is to listen to disabled people. We are receiving a range of opinions from disabled people.

“We are hearing people’s fears that lockdown is being lifted too soon, and that it puts people receiving care, both at home and in care homes, at serious risk.

“We are also hearing from disabled people who want to get on with living independently, and being allowed out of lockdown, with the necessary safety precautions and adaptations we need firmly in place.

“The low value placed on our lives has been evident in how the care home situation has been handled, along with [the frailty scale released](https://www.disabilitynewsservice.com/coronavirus-legal-action-seeks-clarity-on-disabled-peoples-right-to-treatment/) and conversations about [[Do Not Resuscitate notices](https://www.disabilitynewsservice.com/coronavirus-joint-action-from-disability-movement-secures-nhs-treatment-pledge/)].

“It is for the government to decide when lockdown should be lifted, not organisations without specific scientific advice.

“Within that, we are lobbying strongly so that government is reminded that disabled people should be considered front and centre, and not as an afterthought.”

**14 May 2020**

**Coronavirus: Second NHS trust accused of ‘respiratory roulette’ discrimination**

A second NHS trust in England has refused to provide people with neuromuscular conditions with the replacement ventilator filters that help keep them alive, because they were being reserved for patients with coronavirus.

Last week, [there was outrage on social media](https://twitter.com/johnpringdns/status/1258485597070647297) after Disability News Service (DNS) revealed that Royal Brompton and Harefield NHS Foundation Trust (RBHFT) in London had told people with muscular dystrophy that they could not be sent new anti-bacterial filters for their ventilators because they were needed for patients with COVID-19.

Although RBHFT did not admit it was prioritising those with coronavirus, an email sent by a trust staff member stated that colleagues had been “instructed by management not to send any antibacterial filters until further notice” and that the “limited stock we have is being directed towards patients infected with COVID-19”.

Now an email has emerged which shows a second NHS trust – University Hospitals Bristol and Weston NHS Foundation Trust (UBWFT) – made a similar decision.

This email was sent to Mitch Coles, a campaigner with muscular dystrophy, who had questioned why the trust made the “totally unacceptable” decision to stop sending him replacement filters.

He was told last week in the email that there was a “national shortage” and that the filters were “essential for acutely unwell inpatients with coronavirus with the aim of reducing the spread of coronavirus between patients and healthcare workers during the peak of the pandemic”.

He was told: “We do not yet have [the] supplies available to routinely start sending out filters for ventilators again, however I have taken your request forwards for discussion and I will get back to you once it has been decided if we have the resources available to start to at least look [at] this on a case by case basis.”

He and Angela\*, another person with muscular dystrophy who receives services from the trust – who Disability News Service has also been in touch with this week – were both told to use their ventilators without an anti-bacterial filter until the shortage was over.

Angela said she felt “cheated” by the trust.

She said: “When you are provided with the machine you are normally advised on how you should take care of the non-invasive machine, and to keep yourself free of bacterial and chest infections you need to change your filters every so often.

“I normally change mine once a week. However, when I am using the machine with the humidifier you need to change the filters every single day.”

She said the trust’s actions were “very wrong”, and she added: “I called them on Monday and I was told they will send me some filters. I am still waiting. Our lives are being put at risk.”

The trust admitted yesterday (Wednesday) that it had stopped sending out filters in order to reserve them for COVID-19 inpatients, but that it would soon begin sending filters to outpatients like Mitch Coles and Angela again.

Coles said: “I’m angry that my own local NHS trust is giving out such awful advice in the first place and that they are quick to backtrack when approached on the matter of bacterial filters.

“It’s still not completely clear what their stance is.

“I feel I’ve been provided with a good service up until now.

“Coronavirus has come along and NHS trusts across the country have shown their true colours by deeming people like myself expendable.

“It’s respiratory roulette and we are losing out.”

The trust yesterday (Wednesday) admitted and defended its actions, and it said it would now be able to restart supplying filters to outpatients who use non-invasive ventilation.

A spokesperson said: “The trust temporarily stopped providing replacement anti-bacterial filters for non-invasive ventilation patients to outpatients due to a global shortage of stock.

“The use of routine filtering with home devices is not a compulsory recommendation by the manufacturers but we do, and will continue to, offer this for our patients.

“During this time we have continued to advise patients on the safe use of their home devices according to manufacturer’s guidelines, and have provided additional support through virtual clinics and some home visits.”

She added: “It is essential that ventilators are filtered when in use with a patient who is COVID positive to reduce exposure and virus transmission and protect patients and staff.

“We have used our stock appropriately based on clinical risk whilst we sourced more filters.

“The trust has since received more stock and is in the process of contacting patients to distribute these.”

The charity Muscular Dystrophy UK declined to comment on the trust’s admission, or to criticise its actions.

But Rob Burley, director of campaigns, care and support at Muscular Dystrophy UK, said in a statement issued earlier in the week: “Ventilation equipment is a vital part of the support that is required by some people who live with muscle-wasting conditions.

“It is important that people who use ventilation equipment are able to access replacement parts like filters, and trusts need to ensure that this is possible as they manage supplies in the face of increased demand.

“We are seeking assurances from trusts that the safety of people living with muscle-wasting conditions is not being put at risk, and urge anyone who experiences difficulty in getting the supplies they need to contact us.”

*\*Not her real name*

**14 May 2020**

**Coronavirus: Crisis ‘has led to cuts in support and struggle for food and treatment’**

Significant numbers of disabled people in Scotland have had their care and support packages cut or stopped because of the coronavirus pandemic, new research by a national user-led organisation suggests.

Inclusion Scotland said that 30 per cent of those who responded to a question on an online survey had seen their support reduced or removed.

And nearly two-thirds of disabled people and carers who responded to another question said they were struggling to access food and medicine.

Inclusion Scotland [said the survey responses](https://inclusionscotland.org/covid-19-evidence-survey/) painted “a very disturbing picture of personal and collective despair during lockdown” but also provided “intriguing glimmers of hope for what could come next, if disabled people’s voices are heard during and after the crisis”.

It pointed out that the pandemic had provided a new focus on the need for investment in social care, remote working, online resources, accessible information and flexible working, which disabled people and disabled people’s organisations had long called for.

But Inclusion Scotland also said the pandemic had highlighted how disabled people are stigmatised as “vulnerable” and “problematic”.

It said that disabled people and disabled people’s organisations (DPOs) must be involved in rebuilding services after the crisis was over, while DPOs must be adequately funded to carry out this work and support disabled people during the pandemic.

Even though the survey did not ask about “do not attempt resuscitation” (DNAR) forms, four of those who responded said they had been asked to agree to a DNAR notice being placed on their medical records, or had been told that they would not be offered ventilation if they contracted COVID-19.

One of those who responded said: “I have been told already that I would not be ventilated.

“I was in hospital last week with suspected COVID-19 and the doctor stated I would not be treated.

“There is no DNR in file but this was put in my discharge letter. I feel written off before I start.”

Another said: “I was contacted by my GP who was making sure I was aware that I was at very high risk and following guidelines.

“I was also asked to give permission to [put a DNR on my] medical files. I agreed to this without realising it could mean that I wasn’t offered treatment.

“This has impacted negatively on my mental health.”

A third respondent told Inclusion Scotland that disabled and older people seemed to be treated like “worthless people”, adding: “My friend had first hand experience of this last week when her disabled son died of COVID.

“He was written off in the first few minutes by doctors – and he is a healthy disabled person like my son – both have [cerebral palsy].”

More than 800 disabled people and carers responded to the survey, which ran throughout April.

About 15 per cent of those who responded – including those with and without pre-existing mental health conditions – said their mental health had been negatively affected by the need for isolation and social distancing.

And more than one in 10 of those who answered a question about employment said they feared losing their job due to the pandemic.

One of those who responded to the survey said: “Can’t get any slots for online shopping.

“Can’t get up early for the elderly/vulnerable hours at supermarkets due to the medication I take to help me sleep.

“Can’t stand in queues for long periods of time due to disability and mental health issues.

“I have no family members near me who can help.”

Dr Sally Witcher, chief executive of Inclusion Scotland, said: “Solutions once deemed ‘impossible’ are now becoming a part of the picture.

“Social care support, cut back to the bone by austerity, is getting much-needed ring-fenced investment.

“Remote working and participation is now part of the mainstream, all things disabled people have fought tirelessly for.

“If we are to see any silver lining to this terrible cloud then it has never been more important to involve disabled people in finding solutions, and ensure we retain and build on the more positive responses to this crisis.

“Inclusion Scotland is here and ready to help build the ‘new normal’ in Scotland.”

**14 May 2020**

**Seán McGovern: Tributes paid to ‘principled and tenacious fighter for rights’**

Disabled and union activists have joined family, friends and politicians in paying tribute to Seán McGovern – a principled, tenacious and influential fighter for disability rights – who died last week.

He died suddenly, only a day after the death of his mother, Delia.

His three surviving sisters, Collette, Christine and Maureen – his other sister, Angela, died last year – said the “devastating” news “felt as though the ground had been pulled from beneath us”.

Many fellow activists paid tribute this week to McGovern’s commitment to the disabled people’s, union and Labour movements over three decades.

Among his many roles, he chaired the disabled members’ committee for his union, Unite, for 12 years, and represented disabled workers on its executive council; co-chaired the TUC disabled workers’ committee; and represented disabled workers on the TUC general council.

Before their closure, he was branch secretary of London’s five Remploy factories for Unite, and was disability officer for Labour in London.

Marsha de Cordova, Labour’s shadow women and equalities secretary, said McGovern had been “a friend and a comrade” and they had shared many platforms and marched and spoke at many rallies together.

They met first at a Labour party meeting about 10 years ago in Vauxhall, where they were both living at the time.

They had worked for different organisations at the “amazing” 336, an accessible disability hub in Brixton where many disabled people’s organisations are based, and, she said, “Seán was at the heart of that”.

She said: “Seán encouraged me to get active in the trade union [they were both members of Unite], he encouraged me to stand for parliament, he was a solid socialist, he was a trade unionist, but he was also a friend and a comrade to me.

“He was a campaigner for disability rights and an advocate for disabled workers’ rights as well.”

She added: “Seán was for the cause. But it was never about Seán, it was always about the voiceless, it was always about the movement, it was about advancing the movement.

“He was quite a dapper guy. He knew how to dress, from the shoes, all the way to the hat, he was such a cool guy.

“He was a great supporter and encourager. He was just such a flipping brilliant man. I am going to miss him hugely.”

[On his blog](http://bombasticspastic.blogspot.com/), McGovern described himself as “someone who views life though a glass half empty”, but Claire Glasman, a fellow disabled activist who dated him for about three years after they met at a meeting in the late 1990s, remembers him as “cheerful and upbeat, with a twinkle in his eye”.

She also remembers his fierce commitment to Remploy workers when the government ordered factory closures on the grounds that those disabled workers were employed in “sheltered” workplaces, an issue that divided the disabled people’s movement at the time.

He also [spoke from the stage](https://dpac.uk.net/2011/03/speech-by-sean-mcgovern-at-the-tuc-26th-march-rally-hyde-park/) at the TUC’s march and rally in Hyde Park in March 2011, in front of hundreds of thousands of anti-cuts campaigners, where he attacked the coalition government’s cuts to disability benefits, care and support, and employment support, and the Remploy closures.

He told protesters: “Not content with attacking our jobs and benefits they’re bent on depriving us of life-enhancing resources. And calling it the Big Society!”

His last post on his blog, on 1 April, described how, following his intervention, Lambeth council was sending out letters to people on direct payments so their personal assistants could use them to show supermarkets they were shopping for their disabled employers during the pandemic.

McGovern had worked most recently as a direct payments officer for [Disability Advice Service Lambeth](https://www.disabilitylambeth.org.uk/), which said he would be “hugely missed” by his colleagues and those he supported, and added: “We will always miss his humour, knowledge and personal support.”

Ann Galpin, his co-chair for the last two years on the TUC disabled workers’ committee, described him as a “friend, mentor, pathfinder”, who had encouraged her from her first days on the committee in 2010 to use her lived experience to campaign for mental distress and invisible impairments to be given more prominence on the committee’s agenda.

She said they had shared a passion for “forging deeper understanding and greater formal co-production between trades unions and the Deaf and disabled people’s movement”.

She pointed to a parliamentary meeting on the need to “stop and scrap” universal credit, which they co-organised with de Cordova, the then shadow minister for disabled people, in December 2018, and the committee’s involvement in the Reclaiming Our Futures Alliance (ROFA) of disabled people’s organisations and grassroots groups.

She said the coronavirus lockdown had failed to interrupt his work.

She said: “In his final weeks working from home, he was as active as ever in promoting disability equality.

“At the virtual meeting of the TUC general council on 22 April, he put a question to [Labour leader] Keir Starmer, asking for the creation of a National Independent Living Service.”

Five days later, there was an online meeting with TUC deputy general secretary Paul Nowak and Alice Hood, its joint head of equality and strategy, which discussed how the disabled workers’ committee could act on the urgent need to campaign for disabled people to have equal rights to medical treatment and personal protective equipment during the pandemic.

Galpin said: “Picking up the many threads Seàn was working on is going to be a huge task for his friends and colleagues in both trades unions and disabled people’s organisations.

“But, as Len McCluskey, general secretary of Seàn’s trade union Unite, has said: the greatest memorial to Seàn's life and work must be to pick up and carry forward the cause of the rights of disabled workers, which he championed to the last.”

Among his many achievements, McGovern had a significant role in persuading both the TUC and the Labour party to move from their “pause and fix” position on universal credit to one of “stop and scrap”.

He also worked closely with ROFA [to persuade fellow disabled union activists](https://www.disabilitynewsservice.com/tuc-disabled-workers-conference-unions-back-plans-for-national-support-service/), then the TUC, and [finally Labour party members](https://www.disabilitynewsservice.com/labour-conference-activists-set-for-fight-to-persuade-leadership-on-independent-living/) – at their annual conference last autumn – to back calls for a National Independent Living Service that would give disabled people new rights to free support.

He spent years campaigning for such a national service, telling a protest outside the Whitehall offices of the Department for Work and Pensions in September 2013: “We need a national care service, based on national criteria, not a service where postcodes determine the level of care you are given.

“We need a national care service that delivers care free at the point of need.”

It had been his idea to combine the end of the TUC Disabled Workers’ Conference in May 2013 [with a protest in central London](https://www.disabilitynewsservice.com/tuc-disabled-workers-conference-activists-demand-fight-back-against-cuts/) against government cuts, which de Cordova took part in, and led to disabled activists blocking the key Tottenham Court Road crossroads.

He said afterwards that the protest “showed that disabled trade unionists are also active.

“We are not passive, we do not just sit in committees passing motions. We are also pro-active in the movement.”

He was also a committed, active and influential member of Disabled People Against Cuts (DPAC), which described him as “a beloved friend and comrade”, and said: “His commitments to socialism, disability rights and trade unionism will be greatly missed.”

Mark Harrison, who worked with him through DPAC and the wider ROFA network, described him as a “principled and tenacious fighter for disability rights”.

He said: “Seán was a natty and stylish dresser with a great taste in music and sense of humour.

“His contribution to forwarding our rights is immeasurable.

“He was liked and respected by everyone who knew him in the disability, Labour and trade union movement and will be sorely missed.”

Michelle Daley, chief executive of The Alliance for Inclusive Education, worked with him on the independent living campaign and to push for the involvement of more young disabled people in the disabled people’s movement.

She said: “I will always remember Seán as one of the great, principled, driven campaigners.

“His powerful impact taught us the importance of harnessing solidarity, unity and valuing the movement to end oppression, injustice and inequality we experience on a daily basis.”

She was another to point to his sense of style, and said: “When it comes to outfits, Seán had swag. I always had positive comments on his style of dress and I just loved his shoes.”

Paula Peters, a disabled activist who worked closely with McGovern, including through DPAC and the Community branch of Unite, said she was “shocked and deeply saddened” by his death.

She said he had been “tireless in his efforts in the fight for equality and inclusion for disabled people.

“He really cared about the right for independent living for disabled people and support for access to work and disabled workers’ rights in the workplace.”

McGovern’s family said they had been left “in awe and overwhelmed” with the flood of messages of condolence and tributes since his death.

They said: “Our brother, uncle, and great uncle made such a significant difference for the good. His life’s work with the union and his employment was his legacy to the world.”

He was, they said, from “a proud, working-class Irish background”, and his interests included politics, music (among his favourites were Amy Winehouse and The Pogues), art and culture, and he was a long-time Chelsea supporter.

They said he was both quick-witted and short-tempered, both competitive and a “sore loser”, and had a taste for rich foods and statement shoes, hats and shirts.

His sisters added: “We could not be more proud to call Seán our brother. Seán McGovern fought for human rights, those less fortunate, those without a voice.”

McGovern’s local MP, Helen Hayes, said she was “shocked and very sad” to hear of his sudden death, and said they had spoken the week before his death, and that he had been “vigorously speaking up for disabled people suffering during lockdown”.

Among other Labour figures paying tribute was former shadow justice secretary Richard Burgon, who described him as an “inspirational socialist, trade unionist and disability rights campaigner”.

Unite’s general secretary [Len McCluskey said McGovern](https://unitetheunion.org/news-events/news/2020/may/statement-from-len-mccluskey-on-the-death-of-sean-mcgovern/) was “a tireless champion for disabled people, and he ensured that their particular interests were never overlooked in any of our debates.

“He was always well-briefed, and everyone from government ministers down knew from experience how persistent he could be in championing the rights of disabled workers.”

Sarah Veale, TUC’s former head of equality and employment rights, said: “Seán was able to use his own experiences to inform his campaigning and his input into the committee.

“He was a caring and deeply committed man with a real knack of bringing the committee together.

“He would question TUC briefings constructively when he felt it was necessary but never just for the sake of it.

“We kept in touch on social media after I retired. His untimely death is a big loss to the campaign for the rights of disabled workers and I shall miss him.”

TUC’s general secretary, Frances O’Grady, described him as “a great trade unionist and a passionate campaigner”.

She added: “We couldn’t have hoped for a more dedicated champion for disabled people’s rights on the TUC general council – or for a more kind and decent man.”

**14 May 2020**

**Coronavirus: Success for disabled duo after NHS England backs down on visitor policy**

NHS England has agreed to change its policy on hospital visitors so that it no longer discriminates against disabled people, in the face of at least two legal challenges.

It was facing the threat of legal action after refusing to update guidance on visitors that currently prevents disabled people with high support needs being accompanied into hospital if they become ill with coronavirus.

Disabled campaigners [Fleur Perry](https://twitter.com/perry_fleur) and [Mark Williams](https://twitter.com/MarkAwilliams65), who were both poised to seek judicial reviews of the guidance – issued last month in response to the pandemic crisis – have now been told that NHS England will amend its guidance “as soon as possible”.

[The guidance](https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0030_Visitor-Guidance_8-April-2020.pdf) (PDF) currently only allows a visitor to visit a patient in hospital in four situations: if the patient is in labour; if the patient is receiving end-of-life care; if they are visiting their child; or if the patient is experiencing significant mental distress.

But it does not allow a personal assistant (PA) or family carer to accompany a disabled person with other physical or communication support needs, even if they have been trained to meet those needs.

Both teams of lawyers are waiting to see the new guidance before withdrawing the threat of legal action.

Perry said: “The visitor guidance as it stands at present puts disabled people at an unacceptable and unnecessary level of risk.

“I’m really glad that NHS England have taken our concerns seriously and will be changing the guidance ‘as soon as possible’.

“We haven’t been told when this will be yet, but I’m looking forward to reading the new guidance and making sure it’s going to work for disabled people.”

Perry, who was represented by [Fry Law](https://www.frylaw.co.uk/), said: “Disabled people need to be able to access hospital treatment safely and on an equal basis to everyone else, and there are legal mechanisms in place to protect that.

“I look forward to these rights being respected again quickly.”

She also thanked the more than 50 people who were involved in the campaign to secure a change in the guidance.

Williams, co-founder of [Bristol Reclaiming Independent Living](https://twitter.com/BrilLiving), welcomed the response from NHS England to a “pre action” legal letter sent on his behalf by solicitors [Rook Irwin Sweeney](https://twitter.com/ris_law).

He had been concerned that he would not be able to communicate with medical staff if he was not allowed to bring a PA with him into hospital if he was admitted during the pandemic.

He had said this was a failure to make reasonable adjustments under the Equality Act, and a breach of his human rights.

He said: “The idea of being in hospital and not being able to communicate with hospital staff, to tell them how I am feeling or ask them questions about what treatment they have planned, was terrifying.

“I knew it was important to take this action not just for me, but for all other people with communication and sensory needs that were facing similar worries.

“I would like to thank NHS England for listening to my concerns and agreeing to make changes to their guidance so quickly.”

He has also been told by both Bristol’s hospital trusts that he will be able to be supported by his PAs if he needs to be admitted to hospital, and that they will review and amend their own policies.

Polly Sweeney, a partner at Rook Irwin Sweeney, who represented Williams on a pro bono basis, said her firm would be checking with NHS England that it intends to carry out a rapid consultation before issuing the new guidance, as they had requested.

She said: “We are reassured by NHS England’s commitment that it will address our concerns but of course will be reviewing the document carefully once it has been issued.”

She added: “Whilst the responses of all the public bodies are welcomed, this case acts as an important reminder that even in these emergency times it is essential that there is consultation with the public and representative groups before policies such as this are produced so as to avoid steps like these having to be taken.”

BRIL said it was “an important result, not only for Mark, but for many disabled people and families across the country.”

But BRIL said the case was also “further evidence that excluding disabled people and our organisations from decision making results in at best flawed policies, and at worst breaches to our human rights.

“The discrimination and barriers faced by disabled people using public services can never be justified, whatever the circumstances.”

NHS England had not responded to requests for a comment by noon today (Thursday).

**14 May 2020**

**Coronavirus: Industry brushes off EHRC concerns over discrimination by supermarkets**

Retailers have brushed off a call from the equality watchdog for supermarkets to ensure that disabled people can shop for food and other essentials during the pandemic crisis.

The Equality and Human Rights Commission (EHRC) said [a mass legal action](https://www.disabilitynewsservice.com/coronavirus-supermarkets-face-biggest-class-action-of-its-kind-over-discrimination-claims/) being taken by more than 300 disabled people suggested “systemic” discrimination by the major supermarkets.

The commission said the industry had failed to acknowledge that it had legal duties to make reasonable adjustments for disabled people under the Equality Act.

[In an open letter](https://www.equalityhumanrights.com/en/our-work/news/equality-body-calls-retailers-do-more-disabled-customers-during-corona-crisis) to the British Retail Consortium (BRC), the watchdog’s chief executive, Rebecca Hilsenrath, said retailers had failed to acknowledge disabled people’s right to live independently.

The consortium [previously told EHRC](https://www.equalityhumanrights.com/sites/default/files/letter_from_british_retail_consortium_brc.pdf) (PDF) that the “primary aim” of supermarkets during the crisis had been to help ensure that “clinically shielded groups” identified by the government “could easily access food without added risks to their health”.

But Hilsenrath told BRC in her letter that the definition of disability under the Equality Act was “much wider than the Government’s definition for shielded individuals” and by only supporting shielded individuals “your members risk leaving many disabled people isolated and unable to shop for essentials”.

She pointed out that there were also concerns about the way shielded individuals had been treated.

Hilsenrath told the consortium that EHRC was reviewing [more than 300 legal cases being taken against supermarkets](https://www.disabilitynewsservice.com/coronavirus-supermarkets-face-biggest-class-action-of-its-kind-over-discrimination-claims/) by disabled people who have alleged that they have been discriminated against, through a class action managed by solicitors Fry Law.

She said: “Issues are wide ranging and include websites which aren’t accessible, visually impaired people refused the support of sighted carers, wheelchair users refused support in accessing high shelves, people with hidden disabilities such as certain diets or autism unable to access items that they need due to policies limiting the number of items, people with mobility difficulties not being able to rest in long queues and many more.”

Hilsenrath said disabled people were “facing particular hardship as a result of the pandemic and are entitled to be able to rely on their rights”, and she said she was “keen to understand” what action the industry was taking to support its disabled customers.

But when asked by Disability News Service for a response to the EHRC letter, Andrew Opie, BRC’s director of food and sustainability, dismissed the commission’s concerns.

He said: “Retailers have a long and proud record in serving vulnerable and disabled consumers.

“We have prioritised hundreds of thousands of customers in the clinically shielded group for online delivery, special hours for the elderly, and dedicated access for disabled groups and carers.

“Nonetheless, safety remains the highest priority and retailers cannot implement changes that would put other staff or customers at risk.

“We are disappointed the EHRC has failed to appreciate the enormous steps retailers and their workers have made to serve customers in these exceptionally challenging times.”

In response, an EHRC spokesperson said: “We understand, and have recognised, the extraordinary challenges facing the retail sector in the current circumstances.

“But now more than ever retailers have a legal duty to ensure the people who need their goods and services the most can access them safely.

“We look forward to hearing from the BRC formally whilst we review the legal claims shared with us.”

**14 May 2020**

**Coronavirus: Disabled women ‘facing greater risk of abuse and mental distress’**

Disabled women have described how the COVID-19 crisis has forced them to increase their dependence on others and has placed them more at risk of domestic abuse, while the need for social isolation has increased their levels of mental distress.

Their concerns have been collected in a paper by the disabled women’s collective [Sisters of Frida](http://www.sisofrida.org/), which focuses on the “intersectional” impact of the COVID-19 crisis on disabled women as both disabled people and as women.

Among the concerns raised are access to food, support and health services, and the impact on disabled mothers, domestic violence and employment, the rights of disabled women, and on disabled women in prison and detention.

[The paper](http://www.sisofrida.org/the-impact-of-covid-19-on-disabled-women-from-sisters-of-frida/) has been submitted to MPs as part of [the inquiry](https://committees.parliament.uk/work/227/unequal-impact-coronavirus-covid19-and-the-impact-on-people-with-protected-characteristics/) by the Commons women and equalities committee into the impact of the pandemic on groups – including women and disabled people – who are protected under the Equality Act.

The paper points out that disabled women are likely to be disproportionately affected by the rising number of deaths in care homes, [with potentially more than 22,000 deaths](https://www.theguardian.com/world/2020/may/13/coronavirus-real-care-home-death-toll-double-official-figure-study-says) of care home residents in England and Wales now linked to COVID-19.

It points to Office for National Statistics figures from 2014 which showed that, in 2011, almost three-quarters of the care home population aged over 65 were women.

The paper also raises concerns about the impact of the crisis on disabled mothers.

One new disabled mother described how the pandemic meant she had not been able to have the usual post-natal appointment with an epilepsy nurse.

She said: “I’m not being monitored at all. I’m not getting my postnatal check up and although his vaccinations are planned to go ahead they said that could change.

“He isn’t registered as being born either.”

L, the disabled mother of a disabled son, said her son’s two preferred care workers were in lockdown in Poland, while they had had to turn down a potential replacement because they lived in a house with seven other people in a high-risk part of the country.

L said: “Not knowing whether he’d be allowed treatment or refused an [intensive care unit] bed is adding to my fears.

“As a disabled mother I am also worried that I might not be able to care for him myself even if there was no other alternative.”

Fiona Anderson, of [Enabled2Parent](https://enabled2parent.org/), told Sisters of Frida that social services departments were failing to prioritise disabled parents for support.

She said: “Many disabled parents rely on their child being at school or nursery immensely to allow them to recharge.

“Not having a rest causes their symptoms of their condition to worsen, frequent falls and feeling like they’re failing their child through increased pain and fatigue making them unable to do quality time activities and adequate home schooling.”

And an advocate at a disabled people’s organisation told Sisters of Frida: “I am supporting two female clients who have learning difficulties, both of these clients’ children are subject to care proceedings.

“Their children are currently not living with them. Before the lock down, they were still having contact in a contact centre supervised.

“Since the lock down, they have not been allowed to have contact due to contact centres being closed.”

Another key issue highlighted by the paper is the impact of the crisis on disabled women’s independence and control over their lives.

Dr Sarabajaya Kumar, a Women’s Equality Party candidate for the now-postponed London Assembly elections, said: “We all feel uncomfortable with the lack of certainty – disabled and non-disabled alike – but as a disabled woman I have felt Covid-19 has meant I have also lost what little control/agency I had, because of the strict, albeit necessary, requirements of ensuring I and my family and the NHS are safe.

“In other words, my dependence on others seems to have increased; and that has put strain on me and other family members.”

The paper also points out that disabled women are between three and four times more likely to experience domestic abuse than non-disabled women.

There has already been “a dramatic increase in calls to domestic violence helplines and support services during the coronavirus crisis”, the paper says, while many women “will find it much harder to flee dangerous situations, or to find the refuges and services they need to make that decision”.

This will affect most those who have already struggled to access support and justice, says Sisters of Frida, such as disabled women, black, Asian and minority ethnic women, and migrant women.

[Stay Safe East](http://staysafe-east.org.uk/), a user-led, London-based organisation which supports Deaf and disabled survivors of domestic and sexual violence, and has been working on amendments to the government’s [domestic abuse bill](https://services.parliament.uk/Bills/2019-21/domesticabuse.html), said COVID-19 restrictions had been causing extra problems for its clients.

Stay Safe East says women with learning difficulties no longer have one-to-one access to advocates, deaf women are facing further communication barriers, and advocates working from home are finding to harder to support their disabled clients.

The paper concludes that there is “a common thread running through all the disabled women’s stories shared with us, that social isolation during this pandemic is causing psychological distress”.

And it calls on the government to seek the input of disabled people’s organisations, including disabled women’s organisations, on all policies during the crisis, and carry out equality impact assessments on all its COVID-19 policies.

**14 May 2020**

**Coronavirus: No 10 faces legal action threat over inaccessible information**

A disabled campaigner has warned the UK government that its failure to provide vital public health information about the pandemic crisis in an accessible format is risking the lives of blind and partially-sighted people.

Rachael Andrews, who uses screen-reading software, has told 10 Downing Street she will launch a legal action if it fails to promise that its future communications with the public on COVID-19 will be accessible to her and others.

She contacted lawyers after only discovering through a care worker that she had received a copy of a letter from Boris Johnson – sent to every household in England – about COVID-19.

Her action came as about 300 Deaf people [began a legal class action against the UK government](https://www.disabilitynewsservice.com/coronavirus-bsl-users-launch-mass-legal-action-over-government-discrimination/) over its failure to provide a British Sign Language interpreter at its televised coronavirus briefings.

Johnson’s letter to the nation was sent out shortly after he had declared a nationwide lockdown, and explained the importance of staying at home, provided guidance on social distancing rules, and warned that police officers would issue fines if the rules were broken.

As well as the inaccessible letter, other COVID-19 public health advice has been published online using infographics that do not have text descriptions and so are useless to people who use screen-readers, while videos have been shared without audio.

Andrews’ lawyers, [Leigh Day](https://www.leighday.co.uk/), have now sent a “letter before action” to the government, warning that its communications are unlawful and fail to comply with the Equality Act because of the failure to make reasonable adjustments for disabled people like Andrews, and the failure to comply with its public sector equality duty obligations.

As well as Number 10, the letter has been sent to the Cabinet Office, health and social care secretary Matt Hancock, and Public Health England, who could all face an urgent judicial review application if they fail to take action.

[Only last month](https://www.disabilitynewsservice.com/disabled-woman-renews-five-year-battle-over-accessible-vote-humiliation/), Disability News Service reported how Andrews was taking fresh legal action against the government after it failed yet again to ensure that she had an accessible way to vote independently in December’s general election, the latest stage in a five-year legal battle.

Andrews, from Norfolk, said: “The onus should not be on me to go asking the government to provide the information in an accessible form; they should be thinking in advance about how to communicate with sight impaired people.

“It makes me feel anxious that I will not be aware of or able to access important updates or public health information in the future.”

Kate Egerton, from Leigh Day, said: “It is obvious that our client should be able to access information about COVID-19 in the same way as everyone else and we are surprised that the government has not taken steps to address this.

“There are around 350,000 people who are registered blind or partially sighted people in the UK and it is critical that they are accessing information about the pandemic on an equal basis to others, both to protect themselves from the virus and to avoid its spread.”

Number 10 had not responded to a request for a comment by noon today (Thursday).

**14 May 2020**

**News provided by John Pring at** [www.disabilitynewsservice.com](http://www.disabilitynewsservice.com)