Overlapping Illness Alliance

Overlapping Illness Alliance

FOREWORD

Every day, thousands of your constituents live with overlapping illnesses that rob them of their health, independence, and dignity. These conditions are complex, underfunded, and often misunderstood.

In Parliament, you are the voice for those who feel unheard and unseen. Your advocacy can drive real change: better research, increased funding, and services that reflect the complexity of real lives.

But your power to change lives goes beyond shaping national policy. By listening to your constituents' experiences and connecting them with support, you ensure they are not forgotten.

The Overlapping Illness Alliance is here to support you. We are a coalition of charities offering tools, information, and networks to empower your advocacy, in Westminster and at home.

Your voice can transform neglect to recognition, can turn isolation into inclusion.

Together, we can build a fairer future where these conditions are recognised, respected, and properly treated.

CONTENTS

Ehlers-Danlos Syndrome (EDS) & Hypermobility Spectrum Disorder (HSD)

Ehlers-Danlos Syndrome (EDS) is a group of 13 genetic disorders in which connective tissue is abnormal.

This results in abnormally fragile and hyper-extensible tissues throughout the body, which can lead to a range of debilitating symptoms.

The effect on the body is widespread and not limited to one body system as connective tissue is everywhere. 12 types of EDS are rare, the 13th type Hypermobile EDS (hEDS) is more common just rarely diagnosed. It can be managed in the same way as hypermobility spectrum disorder (HSD).

EDS and HSD are complicated conditions with many co-morbidities, including pain, gut issues, fatigue, cardiovascular autonomic dysfunction (PoTS and low blood pressure), mast cell issues, musculoskeletal matters and head and neck issues.

EDS and HSD can lead to physical disability, reduced quality of life and some rarer types can be life-limiting.

EDS
EHLERS-DANLOS SUPPORT UK

The Ehlers-Danlos Support UK (EDS UK) was set up in 1987 to support, advise and inform those living with the Ehlers-Danlos syndromes. Almost 40 years later, we are the largest UK charity that exclusively represents and supports people with all types of EDS and HSD. We work to minimise the impact of EDS and HSD by making its diagnosis, treatment, and management accessible. We provide support through local physical and virtual support groups led by trained volunteers and via our freephone adviceline. We maintain a website, issue regular newsletters, and publish materials to inform the EDS and HSD community, those with a specialist interest in the condition, and the wider public. We engage with members of local and national public policy communities to achieve systemic change.

"I went onto the website, read the strapline 'making our invisible visible' and burst into tears of relief. The website perfectly captured everything I was experiencing and gave me lots of new information that I didn't have about my condition. The knowledge that there was a community of people out there who understood what I was going through was so overwhelming. It gave me such a great sense of hope, clarity and community."
"Without EDS UK, I would feel completely isolated and misunderstood. The charity has changed my life forever. We urgently need more support so we can reach more people and make sure there are fewer people who feel lost, terrified, alone." **– Sarita**

Long Covid

Long Covid is a complex, chronic multisystemic condition with over 200 documented symptoms. Common issues include fatigue, cognitive dysfunction ("brain fog"), breathlessness, palpitations, pain and post-exertional malaise, where even limited activity causes symptoms to flare.

As of March 2024, two million people in England and Scotland are affected, including 111,000 children. Over a third have been unwell for more than two years.

Research shows the functional impact of Long Covid can be worse than stroke, comparable to Parkinson's, with a lower quality of life than advanced cancer.

As of 2025 there are no approved biomarkers to diagnose Long Covid and no approved disease-modifying treatments. Clinical management is based on alleviating individual symptoms but services vary in quality and access is a postcode lottery. Many services have closed or scaled back so some parts of the UK have no specialist Long Covid services at all.

Alan Chambers, 49, went from being *"a fit, healthy, working member of the community who would do anything to help anyone"* to being *"ill and isolated in our bedroom"*, blind in one eye and no longer able to walk unaided, his wife Vicki said.

The father-of-two is no longer able to work and also suffers from *"intense pain, constant headaches, chronic fatigue and an erratic heart rate"*.

Long Covid Support was founded in May 2020 in response to the urgent, unmet needs of people not recovering as expected after acute Covid-19. What began as a peer-led Facebook group has grown into the UK's largest charity representing those affected. Our work spans community support, advocacy and research, always grounded in lived experience. Our mission is to build a supportive community and a strong network for change, accelerate the search for treatments, push for access to dedicated health and care services, enable fair access to work, welfare and wider support, and help prevent new cases of Long Covid.

Paediatric Long Covid

Long Covid causes ongoing or relapsing symptoms that disrupt children's daily lives, education, and wellbeing.

Symptoms vary by individual and age: younger children may experience sleepiness or poor appetite; school-aged children often report concentration issues or stomach pain; adolescents frequently face fatigue, pain, and memory problems.

Recent studies estimate Long Covid affects up to 10% to 20% of children post-infection, and show that children are twice as likely to develop Long Covid after a second infection.

The World Health Organization recognises its impact on children's development, learning, and daily functioning.

Despite its prevalence and impact, Long Covid has not yet received the structured recognition or support given to other chronic paediatric conditions. None of the specialist NHS hubs are funded beyond March 2026.

There are no approved condition specific treatments. However, symptom-based treatments are available but access to these and general care or support remains inconsistent.

"It feels like we are being written off, how, when you get a Long Covid diagnosis nothing happens. We are just left for years, often bed or housebound, unable to attend school or live a normal life and yet nothing happens. No one even seems to notice. We need more support and research so that a Long Covid diagnosis is not a life sentence."
– Rachel, now 18

Long Covid Kids is the only UK-registered charity representing children, young people, and families living with Long Covid. Founded in 2021 by parents with lived experience, our mission is to improve the lives of affected children through support, research, education, and advocacy.

We provide support and signposting, raise awareness, share evidence, and collaborate with clinicians, researchers, and policymakers to ensure children's needs are recognised across health, education, and social care. Our campaigns on clean air, infection prevention, and inclusive education aim to create safe environments where every child can recover, learn, and thrive.

Myalgic Encephalomyelitis (ME)

Myalgic Encephalomyelitis (ME), sometimes referred to and diagnosed as Chronic Fatigue Syndrome (CFS), is a chronic, fluctuating disease, causing symptoms such as post-exertional malaise, sleep problems, problems with thinking and memory (brain fog), pain and crushing fatigue.

The hallmark symptom of ME is post-exertional malaise. This means that simple physical or mental activities, or combinations of activities, can leave people with ME feeling utterly debilitated. They can also experience an increase in other symptoms. You may feel the impact of this straightaway, but it typically takes a day or two to kick in and doesn't significantly improve with rest.

While there are key symptoms that must be present for an ME diagnosis, not everyone with ME experiences the same set of symptoms and the illness can vary enormously, including how long symptoms last.

One in four people with ME are so severely affected that they are house or bedbound.

Action for ME is the only charity in the UK providing support, including healthcare, to people of all ages affected by ME. As an organisation providing direct support and working to secure long-term change, we've been working to improve every aspect of life with ME since 1987.

We take a holistic approach so we can make an impact on multiple fronts - from amplifying the voices of people affected by ME in Government and leading on breakthrough research, to providing "lifeline" support and unique healthcare services on a daily basis.

Debi and her daughter, who also has ME

Following a bout of glandular fever when she was 17, Debi struggled through her A Levels but was able to begin training to be a nurse - something she had always dreamed of doing. Sadly, a year into her course she experienced an adverse reaction to a Hepatitis B vaccine and her health rapidly deteriorated.

"I collapsed on the ward one evening. I saw a doctor from occupational health and he diagnosed me with ME. I had heard of it but didn't know anything about it."

Due to her ME, Debi had to give up her dream of becoming a nurse and move back with her parents.

"I was virtually bed bound and my mum had to feed me. Then it got so bad that I couldn't even chew because of the fatigue. One by one my friends dropped off. They continued on their journey and my life stood still. That was over 30 years ago now. Today I am lucky enough to have mild to moderate symptoms. I still feel very sad that I couldn't finish my nursing training."

Forward ME
We are a collaborative alliance uniting national and local ME charities, clinicians, researchers, patients, and carers to share knowledge, build understanding, and speak with one voice.

Our current focus is on securing the full implementation of the DHSC Long-Term Plan for ME/CFS, ensuring that clinical pathways are effectively designed and that NICE-compliant services are then commissioned. People with ME need early diagnosis and then coordinated health, social care, and educational support – particularly vital for children & young people and those living with severe or very severe ME. We are also advocating for a significant increase in funding for research into ME, commensurate with the disease's impact and burden.on a daily basis.

Mast Cell Activation Syndrome

Mast Cell Activation Syndrome (MCAS) is a condition where mast cells, a type of blood cell, become overactive and release chemicals inappropriately. Mast cells normally help protect the body from infection and injury, but in MCAS they can be triggered too easily, or without a clear cause.

This release of chemicals can affect many systems in the body, leading to a wide range of symptoms which can present as allergic-type reactions such as hives, flushing, swelling, stomach pain, diarrhoea, headaches, and fatigue. Many people experience severe reactions, including some with anaphylaxis, which can be life-threatening.

Triggers vary widely and can include foods, medications, temperature changes, stress, and fragrances amongst others. Because symptoms overlap with many other conditions and affect each person differently, MCAS can be difficult to recognise and diagnose. With treatment, which often involves medication, diet, and lifestyle changes, many people are able to manage their symptoms and improve their quality of life.

"Living with Mast Cell Activation Syndrome (MCAS) means enduring daily uncertainty - never knowing when a new trigger will cause a debilitating or even life-threatening reaction. The impact is relentless, affecting food, environments, work, and mental health. What patients need most is belief, compassion, and real support. Doctors can help by listening, validating, and coordinating care, but systemic change is urgently required. We call on the NHS to act: raise awareness among frontline staff, establish clear specialist pathways, fund research, provide equitable access to essential medications, and deliver patient-centred care. Without this, people with MCAS will continue to fall through the gaps. With action, we can give them the chance of safer, more stable lives."
– Jessie

MAST CELL ACTION

Mast Cell Action exists to improve the lives of people affected by MCAS. Our vision is of a world where everyone affected by Mast Cell Disease has their symptoms acknowledged and experiences listened to, to achieve a correct diagnosis, and to receive the care and support that they need. At Mast Cell Action, we believe in the power of community, the strength of passion, and the boundless potential of collective action. We support people with MCAS through advocacy, information, and by building a compassionate community of understanding and support.

PoTS

Postural tachycardia syndrome (PoTS) is a common, under-recognised and debilitating condition that mainly affects older children and young adults. An abnormal nervous system response makes it hard for sufferers to adjust to standing upright, causing symptoms like lightheadedness, palpitations, fatigue, nausea and fainting. Many struggle to attend school, university or work.

PoTS is often misdiagnosed and dismissed by healthcare professionals. It is linked to Long Covid, ME/CFS, hypermobility, MCAS and other conditions, and is one of the few aspects of these conditions that is amenable to treatment. Despite its prevalence, there are no patient care pathways in the UK, and many regions lack specialist services.

Recognising PoTS as an NHS priority would enable equitable healthcare access and support national guidelines and care pathways across the UK.

"My life has been destroyed by PoTS and my quality of life is abysmal. I was healthy and active until I was struck with debilitating symptoms. I was a dancer and had recently completed a degree in Musical Theatre. Now I can no longer work; I do not even have the strength to get up the stairs most days. I cannot shower without feeling incredibly unwell, I cannot stand nor walk for prolonged periods, go shopping, clean my house, nor walk my dog anymore. This is all impacting on my mental health. I am one of many people in this situation and at just 23 years of age, it feels hopeless. There is no access to care where I live, and the situation is largely the same across the UK. Something needs to change!"
– Sophie

PoTS UK

PoTS UK is the national charity supporting and educating patients, family, friends and healthcare professionals within the United Kingdom about this under-recognised and commonly misdiagnosed condition. We work with healthcare professionals and other charities to advocate for better NHS services, more research, and targeted treatments for people with PoTS. We are passionate about our peer support programme and aim to connect patients in a safe environment to empower them to self-manage their condition and reduce isolation. We produce evidence-based educational content for healthcare professionals to improve awareness, diagnosis and management, and improve health services for patients.

How to help in Parliament

Join All-Party Parliamentary Groups (APPGs) focused on these overlapping illnesses, such as the APPG for ME and the APPG on Long Covid.

Ask Parliamentary Questions to raise awareness, seek accountability, and build the evidence base for policy change.

Propose debates to highlight inequalities in health, education, disability, and social policy for those living with overlapping and under-recognised illnesses.

Sign Early Day Motions to show visible parliamentary support for relevant causes and campaigns.

Lobby ministers, officials and colleagues to recognise the impact of these overlapping illnesses across health, disability, and social policy:

Department of Health and Social Care to advocate for inclusion in NHS strategies and frameworks such as training, clinical guidance, and commissioning.

Department for Work and Pensions to encourage the department to issue guidance on these under-diagnosed conditions to outsourced providers for PIP and disability allowance.

Department for Science, Innovation and Technology to lobby for investment in biomedical and social research to better understand these conditions

Department of Education to highlight the impact on young people's education

HM Treasury to raise concerns about the wider economic cost of inaction.

WE ARE HERE TO SUPPORT

We can help draft letters, parliamentary questions, and briefings.

We can connect you with expert researchers, clinicians, and people with lived experience.

Reach out to us to join relevant APPGs, co-host awareness events, or become a Parliamentary Champion for these overlapping conditions.

How to help your constituents

By listening to your constituents' experiences, connecting them with support and lobbying for local change, you ensure they are not forgotten.

Contact your local health board. Write to the Chief Executive of your health board to lobby for clear referral pathways for these illnesses, and request contact details for specialists responsible for these illnesses

Meet with constituents affected by overlapping illnesses to hear their experiences. Meet with researchers, and clinicians to hear directly from those affected.

Share constituent stories to inform parliamentary questions, letters to ministers, and casework.

Be vocal on social media on this topic, sharing their stories to help validate their lived experience.

Champion recognition and understanding of overlapping illnesses in public communications: on social media, in newsletters and in other communications.

Advocate for equitable access to healthcare, social care, education, and employment support.

WE ARE HERE TO SUPPORT

We can help you by providing information you need to contact your local Integrated Care Board, and helping you to help your constituents access the care and support they sorely need.

CONTACT US

Action for ME	policy@actionforme.org.uk actionforme.org.uk facebook.com/actionforme
EDS Support UK	membership@ehlers-danlos.org ehlers-danlos.org linkedin.com/company/ehlers-danlos-support-uk
ForwardME	forward-me.co.uk
Long Covid Kids	info@longcovidkids.org longcovidkids.org facebook.com/longcovidkids
Long Covid Support	Info@longcovid.org longcovid.org facebook.com/LongCovidPage
Mast Cell Action	info@mastcellaction.org mastcellaction.org x.com/MastCellAction
PoTS UK	enquiries@potsuk.org potsuk.org facebook.com/PoTSUKCharity

The Overlapping Illness Alliance (OIA) is a coalition of charities working to improve recognition and care for people living with complex, overlapping conditions.

SCAN HERE FOR MORE INFORMATION