InterAction

Changing the face of M.E.

Research special

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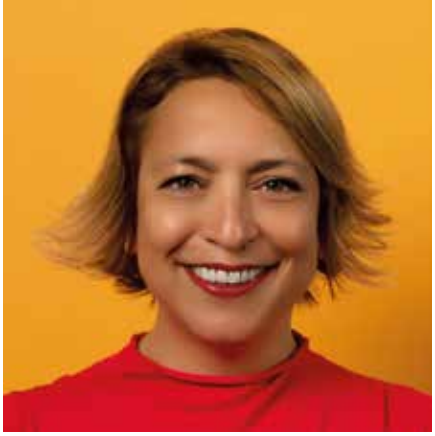
OUR VISION IS A WORLD WITHOUT M.E.

action for m·e

Moving forward



As I hit my 10-year anniversary with Action for M.E., I have been reflecting on what has changed over this period and where we are now. For many years, it felt like there was little progress and we were sadly hearing the same stories, mostly about how men, women and children living with M.E. felt ignored and forgotten.

Fast-forward to 2022 and I can honestly and unequivocally say that never have I felt so optimistic about how the charity will achieve its ambitions and move closer to seeing an end to the number of lives being destroyed because of M.E.

When Action for M.E. set out its five-year strategy (see p 4) calling for a national strategy for M.E. with a clear delivery plan, yes, it seemed ambitious. But then we are an ambitious charity and I make no apologies for this. However, the speed in which this has taken root and progressed has been remarkable and here we are today, looking back on what I consider to be an extraordinary few months.

The Government chose the first World ME Day to announce it would publish plans later this year for a new cross-Government delivery plan on M.E. At the same time the then-Health Secretary Sajid Javid brought our M.E./CFS Priority Setting Partnership report *Prioritise ME* (see p 10) into the spotlight by acknowledging its huge importance in identifying research priorities.

Just weeks later, the All-Party Parliamentary Group on M.E. launched its report, *Rethinking ME*, which makes 20 key recommendations, including those on biomedical research and research funding (see p 7).

Some of you will understandably be concerned due to the Rt Hon Sajid Javid's resignation and the ensuing leadership contest – we won't know until early September who will be Prime Minister and what their cabinet will look like – but please be assured the delivery plan is a commitment made by the Government, not an individual minister, although we are beyond grateful for the Rt Hon Sajid Javid's support. Alongside people with M.E., carers and health, education and social care professionals, our work with civil servants across the Department of Health and Social Care and other organisations to drive forward the M.E. delivery plan continues and we will keep you up-to-date on the latest news via our website and social media channels.

In light of this, it makes complete sense that this edition of *InterAction* should have a research focus where we share the latest on our plans. I hope you enjoy reading about them.

Sonya Chowdhury
Chief Executive

Contacting Action for M.E.

Information, Support and Advocacy Service and Healthcare Services

Our friendly team can share information, support, resources and signposting, and refer to our other services as needed. Opening times vary but are usually Monday to Friday 10am to 4pm.

Call **0117 927 9551**
Email **questions@actionforme.org.uk**
Visit us at **www.actionforme.org.uk**

Find us on social media
www.facebook.com/actionforme
www.twitter.com/actionforme
www.instagram.com/actionform.e

InterAction enquiries

To submit a letter or notice, give feedback or reply to a box number
Call **0117 927 9551**
Email **interaction@actionforme.org.uk**

We are still able to receive post but please note this is taking much longer to process. Thank you for your patience. You can write to Action for M.E., 42 Temple Street, Keynsham BS31 1EH

The views and opinions expressed by our contributors do not necessarily reflect those of Action for M.E.

Medical advice

Please note that while we cannot give medical advice in response to specific enquiries, we do have a wealth of information that we can make available on request. The advertising of a product, therapy or clinic in *InterAction* does not mean that it has been tested or its use is endorsed by Action for M.E. We strongly advise people to examine with scepticism any treatment, therapy or other approach which claims to offer a cure, has not been subject to research published in respected peer-reviewed journals and requires the payment of large sums of money.

Contents

Inside this edition of *InterAction* you will find an order form for our fabulous charity **Christmas cards** – all proceeds will go towards supporting men, women and children living with M.E.

Hot topics

• Champion fundraiser Anna Redshaw has helped raise more than £30,000 for M.E. charities, including Action for M.E., with her **Blue Sunday Tea Party** event, which took place on Sunday 15 May. What an amazing achievement. Congratulations, Anna!

• Our Chief Executive Sonya Chowdhury appeared on **BBC Politics North** in July talking about the fight to access specialist services and concerns about how some are implementing the 2021 NICE guideline for M.E./CFS. She also spoke about the UK Government's ambitious delivery plan for M.E., announced on World ME Day in May (see p 6).

• Eliza Coady has written, recorded and released a **charity song** called *You're not alone (you are loved)* with all funds raised going to Action for M.E. Eliza, who received support from the charity during her experiences with severe M.E., said: "I have recorded my song from my bed, in very small stages, at a pace that my limited health has allowed." The three-minute song is available on Apple Music, Amazon Music and Spotify. Thank you, Eliza – you are a real star.

• Action for M.E. held two successful **webinars** in July – one discussing housing-related issues for adults with M.E. in England and the other talking about areas of employment people with M.E. may find difficult, such as looking for employment and adjustments at work. These are now available online by visiting **tinyurl.com/youtube-ActionforME**

Shaping our future

Action for M.E. strategy 2022 – 2027: working together to end the ignorance, injustice and neglect of people with M.E.

Action for M.E. launched its new five-year strategy to coincide with World ME Day on May 12.

Developed in partnership with people with M.E. of all ages, carers and professionals, it sets out four ambitious outcomes which we believe will help us end the decades of ignorance, injustice and neglect faced by people with M.E.

These outcomes are:

1. The lives of people with M.E. are improved by effective access to the information, support and advocacy they need.
2. The health of people with M.E. is improved via access to our holistic Healthcare Services, and the National Institute for Health and Care Excellence (NICE) guideline for M.E. being effectively implemented across NHS services.
3. Increased funding for high-quality research by more researchers leads to effective treatments for M.E.
4. The UK Government establishes and leads a national strategy for M.E.

We are Action for M.E.

We are an organisation for people with M.E. led by people with M.E. Over half of our Board of Trustees have direct experience of M.E. as do many of our staff and volunteer colleagues. Researchers and healthcare professionals work with us, using their personal, professional and clinical experience to help shape our work and our priorities.

This is a key overview of our ambitions for the next five years. We are developing our strategy in partnership with children, young people and adults with M.E., their loved ones and carers, and others who share our values and ambitions. This has included learning from the services and support we provide, our surveys and consultations, workshops and discussion groups, and from wider engagement with the M.E. community.

Our ambitions

We have set out four ambitious outcomes which we believe will help us end the decades of ignorance, injustice and neglect faced by people with M.E.

Underpinning each ambition is our focus on ensuring we reach under-served communities, so they have better access to healthcare, information and services.

Ambition 1: The lives of people with M.E. are improved by effective access to the information, support and advocacy they need.

Action for M.E. will:

- grow our support services to reach more children and adults with M.E. and their families
- increase our reach to currently under-served communities with a specific focus on people from

Black and other minority ethnic groups and those with more severe M.E.
- address the isolation and loneliness of people with M.E. via our online forums, workshops and podcasts
- address the ignorance and stigma of M.E. by providing resources to people with M.E. and education and healthcare professionals.

Ambition 2: The health of people with M.E. is improved via access to our holistic Healthcare Services, and the National Institute for Health and Care Excellence (NICE) guideline for M.E. being effectively implemented across NHS services.

Action for M.E. will:

- evidence the need and benefit of holistic M.E. services by measuring and evaluating the impact of our Healthcare Services
- launch a new children and young people's counselling service
- increase access to counselling for adults
- increase the number of appointments offered by our doctors

- explore and implement the most effective way to expand our nursing service
- explore and establish the most effective way to provide a regional outpatient provision
- provide 100% bursaries to increase access to healthcare services
- work collaboratively with Forward-ME (www.forward-me.co.uk) to ensure the 2021 NICE guideline for M.E. is effectively implemented across NHS services.

Ambition 3: Increased funding for high-quality research by more researchers leads to effective treatments for M.E.

Action for M.E. will:

- aim to deliver £2 million investment via our Breakthrough-ME research strategy (**www.actionforme.org.uk/breakthrough-ME**)
- drive M.E. genetics research forward through a virtual Genetics Centre of Excellence and Genetics Research Summit with the Medical Research Council Human Genetics Unit at the University of Edinburgh
- ensure patient and public involvement is at the heart of driving research forward
- address the shortage of M.E. researchers by investing in a Future Leaders programme
- co-deliver DecodeME (**www.decodeme.org.uk**), the world's largest genetic M.E. study, and seek to expand this research model to provide greater insight and research opportunities
- work collaboratively to ensure progress in M.E. research is accelerated, ensuring M.E. is included in Long Covid research.

Ambition 4: The UK Government establishes and leads a national strategy for M.E.

We want a national strategy for M.E. led by the UK government with a clear implementation plan and outcome measures, overseen by a national lead for M.E. This must include a specific research strategy with increased investment leading to validated treatments and, one day, a cure.

The life-changing symptoms experienced by people with M.E. are being mirrored by more than half of those with Long Covid, already an estimated 1.3 million people in the UK alone. Some are starting to be diagnosed with M.E. and face the same lack of care and treatment – a direct result of historical neglect of M.E. and other post-viral illnesses.

We will not stop until we end the ignorance, injustice and neglect experienced by children and adults with M.E.

Action for M.E. will:

- continue to advocate on behalf of people with M.E. and ensure the voices of people with M.E. are heard
- evidence the need for investment in services, healthcare and M.E. research
- ensure that improving the lives of people with M.E. stays at the forefront of investment by the UK Government.

New government approach to M.E.

SPEED READ...
Former Health Secretary Sajid Javid pledged to "drive forward progress" and "improve experiences and outcomes for (M.E.) sufferers". He published a pioneering statement on May 12, the very first World ME Day, setting out plans for a new cross-Government delivery plan on M.E. for England, aligning with other devolved nations of the UK.

The statement also welcomed the launch of the M.E./CFS Priority Setting Partnership (PSP) report *Prioritise ME* (see p 10), which sets out the top ten M.E. research priorities.

Former Health Secretary Sajid Javid chose the first ever World ME Day to publish a pioneering statement pledging a new approach to M.E.

The statement sets out plans for a new cross-Government delivery plan on M.E. for England, aligning with other devolved nations of the UK. The statement, which was made to Parliament on May 12 by Health Minister Lord Kamall, is the first time that Government has made an explicit and dedicated statement on M.E.

Acknowledgement

The statement acknowledges the suffering that people living with M.E. endure: "Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome affects the lives of children and adults across the country. It can be an incredibly disabling condition with fluctuating symptoms making it difficult to take part in everyday activities, enjoy a family or social life, access services and engage in work or education – especially for the estimated 25% of people who have severe or very severe symptoms."

The Government's statement to parliament also welcomes the launch of the ME/CFS PSP report *Prioritise ME* (see p 10), which sets out the top ten M.E. research priorities identified entirely by people with M.E., carers and healthcare professionals. This initiative, led by Action for M.E. and facilitated by the James Lind Alliance, completed a participatory process to identify the Top 10+ M.E./ CFS research priorities to change the M.E./CFS research landscape in the UK and beyond.

The former Health and Social Care Secretary said: *"The UK is a world leader in research and Action for M.E.'s priorities lay out clear next steps in learning more about Myalgic Encephalomyelitis M.E. can be an incredibly disabling condition and not enough is known about it – we must drive forward progress in this area to ensure those living with the condition can be better treated and supported. I am committed to improving the lives of people affected – later this year we will develop a delivery plan to understand how we can improve experiences and outcomes for sufferers."*

Fantastic

Welcoming the Department of Health and Social Care's statement and launching the ten priorities, Action for M.E.'s Chief Executive, Sonya Chowdhury, said: "For too long people with M.E. have struggled to get their condition diagnosed, understood and acknowledged. On the first World ME Day, it is fantastic to see that this devastating and disabling condition is being explicitly acknowledged by Government as a priority. This announcement complements the work undertaken through our PSP, where people of all ages with M.E. have identified their Top 10 list of priorities that would have most impact on their lives to shape future research.

"The report has been a powerful opportunity for the voices and lived experiences of children and adults with M.E. to be heard, and empower them to set the priorities for M.E. research themselves, and we look forward to working with Government on their action plan. Through greater partnership working we hope to able to better understand this debilitating disease, with the aim of finding effective treatments and ultimately a cure."

Reassurance

Following the Rt Hon Sajid Javid's resignation, people with M.E. have been left concerned about the future of the Government's delivery plan. Sonya has reassured people that work is continuing on the much-needed delivery plan. She said: "I'm pleased to continue working with such a dedicated and personally committed team of civil servants across the Department of Health and Social Care and other organisations to drive work forward with the M.E. delivery plan and continue to make a real difference for all our community."

Rethinking ME: report published

SPEED READ...
Rethinking ME is the first report of the All-Party Parliamentary Group (APPG) on M.E. The document makes 20 key recommendations for biomedical research and research funding; diagnosis, symptom management and services; children and young people with M.E.; welfare and health-insurance based benefits; and Covid 19 and the M.E. community.

The first report of the All-Party Parliamentary Group (APPG) on M.E has been launched.

Entitled *Rethinking ME*, the report makes 20 key recommendations for biomedical research and research funding; diagnosis, symptom management and services; children and young people with M.E.; welfare and health-insurance based benefits; Covid 19 and the M.E. community.

The group is made up of backbench members of parliament, from all political parties and from from the Commons and the Lords, who meet to discuss M.E.

The event, on 25 May, reflected on the progress being made to improve recognition and understanding of M.E. amongst the medical profession and other relevant professionals.

Better care

People with M.E. addressed the event, speaking of their desire for better care, and discussions included the steps needed to positively transform the way people with M.E. are treated in the UK.

During the launch, the then Health and Social Care Secretary Sajid Javid revealed that a young relative's life had changed completely after getting M.E. at the age of 12.

He described her as thriving at sport and being head of her school team: "Within a week she just couldn't do it anymore. She just changed completely as a person. She became so frustrated that she knew exactly what she wanted to do, but she couldn't anymore."

The Rt Hon Sajid Javid said the relative is now 18 and has experienced no improvement in her symptoms: "I had not realised how serious this issue is. It has been neglected for far too long now."

Pledging more research into M.E., he continued: "We will work together and do this properly for the very first time."

Delivery plan

In his statement, the Rt Hon Sajid Javid referenced the recommendations and work of the APPG: "I am announcing the Government's intention to develop a cross-Government delivery plan on M.E./CFS for England, aligning with other devolved nations as appropriate. In particular, we are engaging with the Scottish Government to explore areas of potential shared interest and learning, especially in terms of research into M.E./CFS.

"This will build on the recommendations of the Priority Setting Partnership, the recently updated guideline for M.E./CFS from the National Institute for Health and Care Excellence, and the comprehensive work of the All-Party Parliamentary Group on Myalgic Encephalomyelitis to date.

"At the heart of the delivery plan will be two core principles. Firstly, that we do not know enough about M.E./CFS, which must change if we are to improve experiences and outcomes. Secondly, we must trust and listen to those with lived experience of M.E./CFS."

Disconnect

The report states: "The findings of this report highlight that there has been a long-term disconnect between the treatment deserved by people with ME and what they experience in reality.

"This disconnect stems from myriad factors, most notably, a lack of understanding of the biomedical nature of M.E. amongst many professionals associated with caring for and supporting people with M.E., the absence of sustained research funding to develop our understanding of the underlying disease mechanisms, and a scarcity of evidence-led clinical services.

"We view these recommendations as a starting point on which to build creative strategies across the governments of the UK, service providers and research institutions for the transformation of our society's approach to M.E. Furthermore, we wish to see the UK take a pioneering stance towards M.E. research and a compassionate attitude towards people with M.E. at a time when we are seeing an increasing trend in the development of M.E.-like symptoms as a result of Covid 19."

You can view the report by visiting **www.appgme.co.uk/publications**

Join our research symposium

The Medical Research Council Human Genetics Unit at the University of Edinburgh and Action for M.E. have teamed up to launch an ME Genetics Centre of Excellence, with the aim of transforming genetics research and driving forward advances as a first step in detecting, preventing, diagnosing and treating M.E.

The Centre of Excellence aims to create a network of scientists, researchers and charity funders who want to understand more about the genetics of M.E. It will establish an evidence-based vision for M.E. research and focus on creating a ten-year programme of M.E. genetics research. This will include forging collaborative links with researchers who do not currently focus on M.E.

Together with Prof Chris Ponting (HGU), we will hold a research symposium on Wednesday 14 September with speakers and researchers from the genetics field, alongside people with lived experience of M.E. The aim is to share knowledge and encourage collaboration. The research symposium is available to join online. To view the programme and register to join please visit **www.actionforme.org.uk/research-event**

You can find out more on our website or by contacting the Action for M.E. team on 0117 927 9551 if you are unable to access the information online.

Pioneering PhD studies

Action for M.E. has announced two ground-breaking PhD-level research projects in addition to two ongoing projects.

The first is jointly funded between ME Research UK and Action for M.E. and will be hosted at King's College London. The project will be supervised by Dr Alfredo Lacoangeli and will focus on the genetic basis of M.E./CFS.

The second project is in conjunction with the University of Oxford. Dr Karl Morten, Director of Graduate Studies, will be supported by a student to explore the role for the microbiome and leaky gut as a symptom of M.E./CFS and other conditions associated with chronic disease.

Action for M.E. is funding two additional PhDs which started in 2018 but are continuing due to delays caused by Covid.

The first is led by Prof Chris Ponting at the Medical Research Council Human Genetics Unit, University of Edinburgh. Prof Ponting is supervising PhD student Joshua Dibble who is comparing immune cells (T cells) from people with M.E. with those from controls.

The second involves studying brain inflammation and is led by Dr Neil Harrison, Clinical Professor in Neuroimaging at the Cardiff University Brain Research Imaging Centre. Recruiting PhD student Marissa Amato, this project is focusing on differences in brain activity between people with M.E./CFS and fibromyalgia using state-of-the-art HCP (Human Connectome Project) resting state functional connectivity imaging.

Sonya Chowdhury with Dr David Strain in Nevada

Internships

We are delighted to be offering two students an eight-week internship with Dr Daniel Peterson at Simmaron Research in Nevada, US. Earlier this year, Sonya and our Medical Adviser, Dr David Strain, visited the clinical and research facility run by Dr Peterson and his team.

The aim of the visit was to better understand the tests and treatments provided by Dr Peterson and the research being undertaken on anti-viral drugs for people with M.E. The trip was funded by a generous donor.

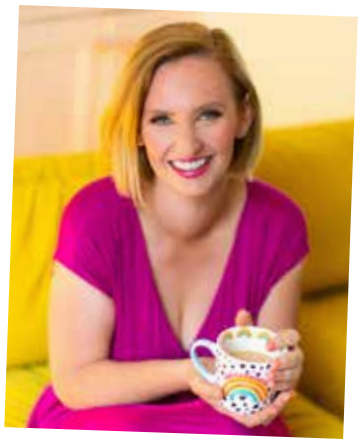
It is hoped that the learning and insight gained from the visit will feed into the national delivery plan (both David and Sonya sit on the working groups) and into developing new clinical research studies.

Future Leaders

As part of the Centre of Excellence, we want to support the next generation of scientists. We have agreed to invest in these 'Future Leaders'. We will do this by supporting their networking so that they can learn from each other, from us and from researchers in the field.

We held our first meeting in June and since then have set up a summer school. This will take place at the Human Genetics Unit in Edinburgh, supported by Prof Ponting and our Chief Executive, Sonya Chowdhury. The students will have opportunities to meet and learn from eminent researchers like Prof Julia Newton and learn more about patient and public involvement from some of the people with lived experience who are part of the DecodeME team.

Meet the team



Action for M.E. has a strong team behind its drive to lead and deliver its exciting and transformative research strategy.

Zoe Raw
Research Director

Joining in August 2022, Zoe is Action for M.E.'s latest recruit and our first ever Research Director. She holds a PhD in Biological Sciences from the University of Bristol and has a strong background leading scientific research programmes focusing on both human and animal health. Zoe is passionate about using scientific evidence to guide and inform research strategy, programming, and health interventions.

Prior to joining Action for M.E., Zoe led and managed the global research programmes for one of the UK's largest animal welfare charities. She delivered projects which focused on One Health, veterinary and human health, and system strengthening in international settings. Her work has been used to drive changes in international policy, and has been published extensively in peer-reviewed scientific journals.

Zoe has lived in Africa, working on animal and human health programmes, and has experience of raising awareness of other rare diseases within the UK.

Zoe has an intimate knowledge and understanding of M.E., since her mother was diagnosed with M.E. when Zoe was eight.

Sonya Chowdhury
Chief Executive

Sonya has been Chief Executive of Action for M.E. since 2012 and is the driving force behind the charity's mission to ensure the people with lived experience of M.E. are at the heart of all research.

She chairs the Management and Patient and Public Involvement (PPI) groups for DecodeME, the world's largest M.E./CFS DNA study, and was responsible for the funding for the ME/CFS Priority Setting Partnership (PSP).

Partnering with Prof Chris Ponting, Sonya has pledged to establish the first Genetics Centre of Excellence, establishing a virtual network of M.E. researchers and has been instrumental in organising a research summit focused on genetic research and knowledge gained from other post-infectious diseases, including Long Covid.

Sonya is part of the Department of Health and Social Care's working group specifically looking at research in order to take the Government's M.E./CFS delivery plan forward.

Claire Tripp
Research and Public Involvement

Claire joined Action for M.E. earlier this year to support us in our partnership in DecodeME. A carer for her daughter who has M.E., Claire has been involved in the M.E. community over the past six years through her advocacy work with other M.E. charities and now as a member of the PPI Steering group on the DecodeME study.

Issy Lewis
Research Officer

Issy works on DecodeME, working closely with the team at the University of Edinburgh. She works predominantly on marketing and communications as well as sitting on the Cohort Delivery and Genetics Delivery teams. Issy also assists with administrative duties relating to other aspects of the study including the PPI facet.

Claire Dransfield
Research Manager

Claire works on a sessional basis, bringing a wealth of experience from various roles across the NHS and Civil Service.

Dr David Strain
Honorary Medical Advisor

David joined Action for M.E. in 2021, bringing a wealth of clinical and academic experience. He is Senior Clinical Lecturer at the University of Exeter Medical School and a consultant to the Devon M.E./CFS specialist service.

David has been heavily involved in the NHS Long Covid Taskforce and has given evidence at the All-Party Parliamentary Group (APPG) Long Covid meetings. He also attended the recent M.E./CFS APPG.

Sir Prof Stephen Holgate
Honorary Scientific Advisor

Stephen was knighted in 2020 for services to medical research. He has spent his entire 47-year career studying human disease and is deeply involved with research into M.E.

Stephen is a member of the Action for M.E. Research Panel, which helps develop our strategy for research and monitors the progress of research funded by our charity. Stephen has also been one of the leading forces behind securing funding for DecodeME. He is also Chair of the Science Advisory Board for DecodeME.

Shaping future research

SPEED READ...
Following a two-year process led entirely by people with M.E./CFS, carers and health and care professionals, the 10+ questions on the opposite page have been identified as research priorities.

The ME/CFS Priority Setting Partnership (PSP) has completed a participatory process to identify the Top 10+ M.E./CFS research priorities to influence future research funding.

The questions, outlined in a new report called Defining future ME/CFS research and presented on the opposite page, give a clear direction for research priorities to drive forward better treatments for people living with M.E. It is hoped these will change the M.E./CFS research landscape in the UK and beyond.

The partnership was led by people with M.E./CFS, their carers and clinicians, facilitated by non-profit making initiative, the James Lind Alliance (JLA), and coordinated by Action for M.E.

"We now have our Top 10+ priorities, but this is just a start. It is essential that we work together with researchers, institutions, funders and policy/decision-makers to form programmes of research to take the priorities forward."
Sonya Chowdhury, Chief Executive, Action for M.E.

How the process worked

To complete this exercise, the JLA's well-established processes were followed, but adapted for the needs of people with M.E./CFS. A steering group was convened from the M.E./CFS organisations that initiated the Partnership, plus people with M.E./CFS, carers and health care professionals recruited via open advertisement.

The steering group's job was to define the scope of the project, ensure equitable access, oversee all stages of the process and write the final report. Action for M.E. was funded to provide administrative support and coordination throughout, but every decision was taken by the steering group as a whole.

The first stage was to gather ideas for research questions from people with M.E./CFS, their carers, and health care professionals.

A survey was launched in May 2021, with a very strong response: over 5,300 research ideas were submitted. These were categorised into key themes, which were then summarised into a single overarching question for each theme, producing 59 summary questions. The next stage was to assess whether the summary research questions had already been answered by research. It is a reflection of the lack of high-quality research into M.E./CFS that none of the summary questions were able to be ruled out at this stage.

People with M.E./CFS, their carers and healthcare professionals were then asked to choose their Top 10 questions from those submitted in a second survey. This ran from October to December 2021 with 1,752 respondents.

From the results, the steering group produced a shortlist of 18 questions. Finally, three online workshops were held to finalise the top ten priority research questions from the shortlist of 18. Applications to attend the workshops were accepted from people who had expressed an interest in doing so in the second survey, as well as from the wider public. A total of 36 people were selected, ensuring that all demographics, severity of M.E./CFS, and roles were represented.

Attendees held small group discussions until the final Top 10+ priorities were identified and agreed.

What happens next?

What the ME/CFS PSP will do

The ME/CFS PSP is committed to promoting the Top 10+ research priorities as widely as possible. To do so, the aim is to publish their findings in a peer reviewed journal. They will promote the Top 10+ through their own networks, and continue to promote the power and necessity of patient and public involvement.

What Action for M.E. will do

Action for M.E. commit to progressing research into the Top 10+ and ensuring that people with lived experience are at the heart of all research they support or fund. They are also actively engaged with the government calling for a national strategy for M.E./CFS that will:

- invest in the necessary expansion of capacity in the M.E./CFS genetics research field
- utilise, engage and invigorate existing research excellence from across the UK and global research community
- catalyse and facilitate collaboration and partnership opportunities
- exploit potential for crossover learning from Covid 19 and Long Covid research
- develop funded research programmes on the Top 10+ ME/CFS research priorities determined by this PSP.

The ME/CFS PSP has been made possible by funding to Action for M.E. from the National Institute for Health Research, the Medical Research Council and the Scottish Chief Scientist's Office.

The list of priority research areas as well as downloadable and audio versions of the project report can be found at **www.psp-me.org.uk**

Priority 1

What is the biological mechanism that causes post-exertional malaise (symptoms caused or made worse by physical, mental or emotional effort, which can be delayed) in people with ME/CFS? How is this best treated and managed?

Priority 2

Which existing drugs used to treat other conditions might be useful for treating ME/CFS, such as low dose naltrexone, or drugs used to treat Postural Orthostatic Tachycardia Syndrome (POTS)?

Priority 3

How can an accurate and reliable diagnostic test be developed for ME/CFS?

Priority 4

Is ME/CFS caused by a faulty immune system? Is ME/CFS an autoimmune condition?

Priority 5

Are there different types of ME/CFS linked to different causes and how severe it becomes? Do different types of ME/CFS need different treatments or have different chances of recovery?

Priority 6

Why do some people develop ME/CFS following an infection? Is there a link with long-COVID?

Priority 7

What causes the central and peripheral nervous systems (brain, spinal cord and nerves in the body) to malfunction in people with ME/CFS? Could this understanding lead to new treatments?

Priority 8

Is there a genetic link to ME/CFS? If yes, how does this affect the risk of ME/CFS in families? Could this lead to new treatments?

Priority 9

What causes ME/CFS to become severe?

Priority 10+

Does poor delivery or use of oxygen within the body cause ME/CFS symptoms? If so, how is this best treated?

The world's largest DNA study of M.E./CFS is launching in September – and it needs you to be part of it!

SPEED READ...
DecodeME, the world's largest DNA study of M.E./CFS, will be launching in September. This £3.2 million study is a historic chance for people with M.E./CFS all over the UK to help with research that could finally uncover the root causes of the disease.

Everyone who has a diagnosis of M.E. or CFS, is 16 or over, and lives in the UK is invited to take part in the study and in doing so, will contribute to greater understanding about M.E./CFS.

All you need to do is fill in a questionnaire and some people will also be asked to provide a DNA sample by spitting in the provided tube and posting it back to the lab, free of charge via any postbox. The study is accessible to everyone and there is support for severely ill people to take part.

The data collected will be invaluable to understanding more about M.E./CFS and will direct further research as well as inform the development of treatments. Visit the website **www.decodeME.org.uk** to sign up and join the study.

Study update

The DecodeME DNA study of M.E./CFS will be launching in September. If you're 16 or over, live in the UK and have a diagnosis of M.E. or CFS, you can take part.

DecodeME is the biggest study ever carried out on people with M.E./CFS, and it could transform our understanding of the disease. They need to collect DNA from 25,000 people aged over 16, who live in the UK and have received a diagnosis of M.E. or CFS. Of that number, 5,000 will be those who became ill with M.E./CFS after contracting Covid 19.

Participants will be asked to fill out a questionnaire about their experience of M.E./CFS. This will gather vital information about the M.E./CFS community, how it affects your lives and the many symptoms that people with M.E./CFS regularly experience.

People with M.E./CFS and those who care for them have been at the heart of the study from the beginning, working alongside M.E. charities and the research team.

The DecodeME questionnaire has also been tested by some early participants who have already taken part and provided valuable feedback.

By listening to this feedback and working with the Patient and Public Involvement (PPI) team members, they have been able to make sure that the DecodeME questionnaire wording is brain-fog-friendly and that people can stop and rest and come back to it as often as they want. They've also made sure there are print versions and phone support for those who need that.

Visit the DecodeME website at **www.decodeME.org.uk** to join the study or read the FAQs.

How can DecodeME help?

There is a great need to understand more about the causes of M.E./CFS and ultimately find new treatments. By studying the DNA of 25,000 participants, DecodeME hopes to be able to help answer these questions and contribute to the Government's pledge to develop a new M.E. research plan.

Researchers will compare the DNA of 25,000 people with M.E./CFS with that of people who don't – and any genetics differences will help future research pinpoint causes of the disease, which should ultimately lead to treatments. If any of the causes are shared with diseases that already have effective drugs, those treatments can be trialed on people with M.E.

The answers you provide on the DecodeME questionnaire will also create the world's biggest and most representative set of data on people diagnosed with M.E./CFS.

This will give researchers reliable data on tens of thousands of people about how long they have been ill, how severely affected they are, and what proportion got ill after an infection. The data could even show whether people fall into groups with different symptoms. All this data together could help research to move faster.

'I've been waiting for years for a top-class study like this that can help get us real answers. We just need everyone to join in. Let's get started!'

Simon McGrath, who has been severely ill with M.E./CFS since 1994 and blogs about M.E. research

Spread the word

Researchers particularly want to make sure they reach members of the M.E./CFS community who aren't on social media and may not have already heard about DecodeME. Many people with very severe M.E./CFS can sometimes have limited access to news about M.E./CFS or that people with mild M.E./CFS who manage their daily lives by pacing could think that DecodeME doesn't apply to them. But, as with all scientific studies, they need a good range of severities of M.E., ethnic backgrounds, age and gender to make the data and analysis as meaningful as possible.

You can help by spreading the word about DecodeME and encourage others to sign up. The sooner they recruit participants, the sooner they will be able to start analysing the samples and publishing results.

How to take part

- The quickest way to participate is to sign up at the website **www.DecodeME.org.uk** and **complete the online questionnaire**. This can also be done via proxy (with your consent).
- You can arrange a telephone appointment where someone from the 25% M.E. Group can guide you through the process over the phone or input your answers directly into the online questionnaire for you. To arrange this, call the DecodeME team on 0808 196 8664 or email **info@decodeME.org.uk**
- We can send you a **paper version of the questionnaire** which you can complete at home and return to us by post. To request this, contact the DecodeME team on **0808 196 8664**

A note from from DecodeME's Patient and Public Involvement (PPI) group

"DecodeME isn't just a study for people with M.E./CFS. It's a study by people with M.E./CFS"

Claire Tripp and Sian Leary (DecodeME PPI group members)

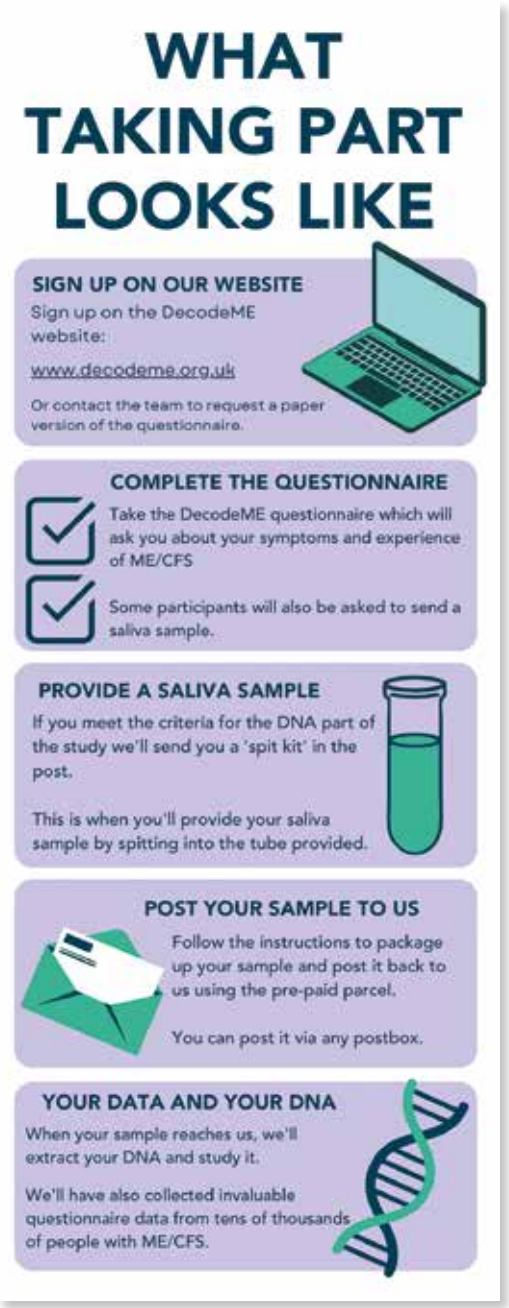
One of the things we are most proud of at DecodeME, apart from offering hope and biomedical research for people with M.E./CFS, is the involvement we have from people with lived experience of the disease.

DecodeME has a very strong Public and Patient Involvement (PPI) steering group at the heart of it and across all our delivery teams. This includes people from M.E. charities, people with M.E./CFS themselves and those who care for people with M.E./CFS.

Our PPI members oversee and input into every aspect of the study. From designing the DecodeME questionnaire to liaising with the project management and technical teams to make sure the project is progressing well, everything has been carefully considered by PPI to make sure that everyone with M.E./CFS can take part.

This expert patient involvement is crucial for a study into a disease like M.E./CFS. We know that M.E. is a horribly misunderstood condition and that it's only really those who live with it that really know it. Our PPI members bring huge knowledge to the table and can tell us what researchers might not be aware of but need to account for. For example, they need to know that people with M.E./CFS have to prioritise their tasks and energy. Or that that people with M.E./CFS can often have specific cognitive challenges that must be taken into account when phrasing questions.

PPI has had significant impact on the DecodeME study by making sure it is appropriate and accessible to people with all severities of M.E. We are setting a new standard for patient involvement in research studies like these which we hope will be replicated by other patient research groups in the future.



Details of the PPI steering group members and everyone else who contributes to the DecodeME study can be found on the 'About us' page on the website: **www.decodeme.org.uk**

Need to talk? Call us today

Our Listen to M.E. helpline launched on Wednesday 25 May, and is open to anyone affected by M.E. (including carers and family members) who wants to talk to someone who understands.

We set up this helpline because we know that that living with M.E. or looking after someone with M.E. can be distressing. Our volunteers understand this, and are here not to give advice but to listen, with empathy and understanding.

We have set up an online survey that allows callers to leave feedback, which so far has been overwhelmingly positive.

One caller told us: "I think this is a fantastic service to offer people with M.E. The volunteer who I spoke to was very kind and caring. She took the time to listen to me which was much appreciated."

The survey also shows that, as a result of their contact with the Listen to M.E. helpline:

- 100% of respondents agreed that they feel less isolated
- 100% of respondents agreed that they feel their wellbeing has improved.

Feedback from our M.E. community on social media to our posts promoting Listen to M.E. has also been very encouraging, including:

- "I think it sounds brilliant. Would be lovely to talk to someone who understands what this illness is like instead of having to explain all the time."
- "What a fantastic idea. I wish there had been something like this over the 30 years since I was diagnosed."

If you have used the Listen to M.E. helpline, please share your feedback with us at **www.actionforme.org.uk/listen-to-me** (or call to let us know – our contact details are on p 2).

With two volunteers available to take calls each day, Listen to M.E. is open:

- Mondays and Tuesdays 11am–1pm
- Wednesdays and Thursdays 1–3pm.

Please call 0117 927 9551, and choose the Listen to M.E. option.

Poetry tells poignant story

Action for M.E. and poet Alec Finlay launched *descriptions* at the Scottish Poetry Library in June. Scottish actor Mark Bonnar was the narrator of the audio version of the piece. Audio segments were played throughout the event, which was held to illuminate the impact M.E. has on people's lives as well as telling the wider story of living with a chronic invisible illness.

The event gave Alec the opportunity to answer questions alongside our Chief Executive Sonya Chowdhury.

Alec said: "*Descriptions* has been the most painful project I have worked on, and one of the most important. The pain came in reading so many accounts of loss, anguish, and experiences of prejudice, but that is also what makes this work so important. I was humbled by the length and depth of the responses, and aware of the energy this will have cost. It was a reminder that this community has felt so erased for so long."

Alec became ill with M.E. at the age of 21. His mum, Sue Finlay, founded Action for M.E. in 1987 after submitting an article about M.E. to] *Observer* and receiving 15,000 letters in response.

You can now purchase physical copies of *descriptions* at cost price in our online shop (**www.actionforme.org.uk/shop**). An online PDF version of the poem can be accessed for free by visiting **www.actionforme.org.uk/descriptions** and an audio version narrated by Mark Bonnar can be accessed via Soundcloud (**tinyurl.com/Soundcloud-descriptions**).

Nomination for Sonya

Action for M.E.'s Chief Executive Sonya Chowdhury has been nominated for a prestigious award.

She has been shortlisted for Charity Chief Executive of the Year in the Third Sector Awards, an annual event celebrating the achievements of charities, voluntary organisations and social enterprises across the UK.

The results will be announced at an awards ceremony which takes place at a lunch and drinks reception on 30 September at The Brewery in London.

All welcome at our AGM

You are invited to our 2022 Annual General Meeting (AGM) where you can meet Action for M.E. staff and Trustees and hear how we've worked with and supported people with M.E. over the past financial year, along with our ambitious plans for the future, as set out in our new five-year strategy, pictured below (see p 4), launched earlier this year.

Please join us from 4-5pm on Tuesday 20 September, online via Zoom. All are welcome, and registration is free.

You can find the full agenda and registration link at **www.actionforme.org.uk/AGM2022**

Covid booster and flu jab update

Back in February, the Joint Committee on Vaccination and Immunisation (JCVI) said: "Despite the known uncertainties in the year ahead, Winter will remain the season when the threat from Covid 19 is greatest both for individuals and for health communities. It is JCVI's interim view that an autumn 2022 programme of vaccinations will be indicated for persons who are at higher risk of severe Covid 19; such as those of older age and in clinical risk group."

On 15 July, the Government shared JCVI's final recommendations for this autumn's programme.

Under the advice, those eligible for a further dose will be:

- all adults aged 50 years and over
- those aged 5 to 49 years in a clinical risk group, including pregnant women*
- those aged 5 to 49 years who are household contacts of people with immunosuppression
- those aged 16 to 49 years who are carers
- residents in a care home for older adults and staff working in care homes for older adults
- frontline health and social care workers

*Clinical risk groups are set by the JCVI in its Green Book, Chapter 14a. While this doesn't specifically list M.E./CFS under its "Chronic neurological disease" category, it does make the following clear (page 17): "The examples above are not exhaustive, and, within these groups, the prescriber should apply clinical judgment to take into account the risk of Covid 19 exacerbating any underlying disease that a patient may have, as well as the risk of serious illness from Covid 19 itself."

In addition, the Department of Health and Social Care will be widening the offer of the free flu vaccine to more eligible groups. These additional groups will only be eligible once the most vulnerable, including previously announced pre-school and primary school children, those aged 65 years and over and those in clinical risk groups, have been offered the jab.

The additional groups set to be offered the free flu vaccine in England will be all adults aged 50 to 64 years followed by secondary school children in years 7, 8 and 9, who will be offered the vaccine in order of school year, starting with the youngest first.

The NHS will announce in due course when and how eligible groups will be able to book an appointment for their Covid 19 autumn booster, and when people aged 50 to 64 years old who are not in a clinical risk group will be able to get their free flu jab. People in these groups are asked not to come forward until further information is announced.

*See p 24 for your Covid stories

The UK Health Security Agency's leaflet *Covid-19: Your guide to booster vaccination*, says: "If you had serious side effects after any previous dose you may be advised to avoid or delay further vaccination. You should discuss this with your doctor or specialist."

It's coming...

The Big Give Christmas Challenge 2022

Our Big Give Christmas Challenge runs from 29 November – 6 December. This year, our campaign will focus on our new and ambitious strategy to end the ignorance, injustice and neglect experienced by people with M.E.

The Big Give Christmas Challenge is the UK's biggest match-funding campaign, where for one week only, all donations are doubled, meaning that every pound you give has twice the impact. Lifestyle and family magazine Candis Group have generously supported us by being our Big Give Champions for the last five years. We are so grateful to them, along with a group of dedicated supporters, for kindly providing our Big Give match-pot to double every donation, meaning that with incredible support from members like you, last year we were able to raise £133,804 both on – and offline.

Because of you, our Information, Support & Advocacy team has been able to help more people like Trace to access the support they are entitled to.

Trace recently contacted our Info & Support team about access to mindfulness apps. The team provided her with a number of free resources. Trace said:

"I am always very appreciative of Action for M.E. and how they respond on the rare occasions I ask for support. Wish there wasn't a need for your help but been a long term member and will be remaining so. Thank you all for everything you do (fundraising, advocacy, support, research, arguing our case when we can't, newsletters and the list goes on) to support those of us who are ill (and carers). Answer to my query today went above and beyond what I had hoped for."

Thanks to you, we have also been able to continue our work campaigning for change and advocating for people with M.E. on a national level. After the publication of the National Institute for Health and Care Excellence (NICE) guideline was delayed last year, Action for M.E. attended a roundtable to ensure that the voices of people with M.E. are heard when decisions around their care and treatment are being made. As a result of listening to patients' experiences, the new 2021 NICE guidelines were published and GET was removed as a suggested treatment.

This year, funds raised via the Big Give Christmas Challenge will allow us to:

- continue to provide information, advocacy and support through our services to improve lives
- increase access to our Healthcare Services and ensure the NICE guideline for M.E. is being effectively implemented across NHS services
- increase funding for high-quality research, bringing more researchers into the M.E. field leading to effective treatments
- continue to work with the UK Government to ensure the voices of people with M.E. are heard and evidence the need for investment in services, healthcare and research.

To take part in the Big Give Christmas Challenge this December, follow these three simple steps:

1. Save the date! This year's Big Give Christmas Challenge starts at midday on 29 November and runs for seven days. You can stick this reminder on your fridge or noticeboard to help you remember.
2. Visit the Big Give website from midday on **Tuesday 29 November until Tuesday 6 December** and every donation above £1 will be doubled, at no cost to you.
3. Tell a friend and see their gift doubled too! Last year, one in every four Big Give donations was from someone who had not donated to us before, so we need your help to keep spreading the word.

To find out more, please call us on 0117 927 9551, email our team at fundraising@actionforme.org.uk or visit www.actionforme.org.uk/BigGive2022

Voting for Trustees

Please cast your vote for returning Trustees to the Board by Monday 12 September 2022. You can now do this digitally as well as by post.

Our Trustees ensure that the Board has the necessary skills to govern the charity effectively. Many of the Board have or have had M.E.; the majority of the rest have strong connections with M.E., usually through a family member or close friend.

This year we have two candidates, Sue Hardy, an existing Trustee who is standing for an exceptional term, and Roger Siddle, also an existing Trustee who is standing for a second term. They will be formally appointed subject to the votes of our Supporting Members (see notes overleaf).

Please indicate your vote for each candidate either by:

1. Using the form on the opposite page and return it using the envelope provided to arrive on or before 5pm on Monday 12 September 2022.
2. Casting your vote online on or before 5pm on Monday 12 September 2022 by visiting **www.actionforme.org.uk/voteforTrustees**

Only those candidates who receive more 'yes' votes than 'no' votes will be re-appointed to the Action for M.E. Board of Trustees.

Results will be announced at our online AGM on Tuesday 20 September 2022. Please see p 15 for more about this event.

Meet your candidates

Sue Hardy

Sue enjoyed a 33-year career as a nurse before becoming a senior lecturer in nursing. Her career came to an abrupt end in 2013 when she was diagnosed with M.E. Sue credits the information she gained about the condition from Action for M.E., particularly on pacing, as invaluable to her getting back on her feet. She became a Trustee of Action for M.E. in 2016 because she wanted to help other people with M.E.

As a Trustee: "Since joining the charity I have seen the work we do expand into providing tailored support to adults and children and their families/carers. And with the recent ME Trust merger, the provision of holistic clinical services. As a former nurse I fully support the new NICE guidelines, and our new clinical services will be very important for this purpose.

"I am a member of the Healthcare Services Sub-Committee and the Public Affairs Oversight Committee.

"It's my privilege and pleasure to work alongside a dedicated Board of Trustees as well as the amazing and hardworking team at head office. Meeting people with M.E. (face to face or on the phone during the Big Give) is always amazing, as well as an opportunity to share stories and give support.

"To be given the opportunity to be re-elected is very humbling and I hope that I will be able to bring my six years' of experience to support the Board and charity over the next three years as I anticipate exciting times for progress ahead."

Continued overleaf...

Roger Siddle

Roger Siddle, who is standing for a second term as Chair of Action for M.E's Board of Trustees, has a broad range of business and charitable experiences. He is currently non-executive Chair of a number of private businesses after a successful period as Group CEO of two publicly quoted companies and as Managing Partner UK of Bain and Company, the global management consulting firm. He has an MBA from Harvard Business School and an MA in Mathematics from the University of Cambridge. He joined our Board of Trustees in 2019 and became Chair in early 2020. He has a son with M.E.

As a Trustee: "Since joining the Action for M.E. Board of Trustees, I have come to understand that my own frustrations in helping my son navigate his condition are recognised and often greatly exceeded by the challenges of other people with M.E. There have been a number of developments over the last three years however which give me a positive perspective – developments such as the launch of DecodeME, the setting up and delivery of the Priority Setting Partnership, and finally the recognition by the Government of the need for a national strategy for M.E., with the Secretary of State confirming in his statement on 12 May 2022 that he will lead the development of a plan for patient care and new research into the condition.

"Action for M.E. has set out what I believe to be an exciting and ambitious strategy for the future – I am committed to playing a full part in delivering that strategy."

Dr Nirmala Santiapillai

Nirmala has more than 30 years of global commercial experience in the Life Sciences and MedTech sectors. She is currently Vice President, Global Services at Oxford Nanopre Technology (ONT), a UK Life Sciences company whose mission is to democratise DNA sequencing such that all human disease can be understood to enable the vision of personalised medicine. Prior to joining ONT she spent 16 years in GE Healthcare where she built her knowledge of global healthcare systems. Nirmala has a PhD in Neurochemistry from University of Cambridge and a BSc in Biochemistry from Imperial College London.

"Whilst I have not been personally touched by M.E. I was struck by the fact that there is so little understanding of the underlying genetic drivers for M.E. which in turn is impacting the development of diagnostic and treatment options. I believe that patients with any clinical condition should have the benefit of the best tools at hand to research the condition, making personalised medicine a reality for all. Being a cancer survivor I know the critical importance of fundamental disease research and the important role patient advocate groups play. I hope to meet you all and be able to meaningfully contribute to your journey to transform the lives of patients living with M.E."

Notes

1. Only Supporting and Lifelong Members of Action for M.E. (known collectively as Supporting Membership) are eligible to vote in the election of new Trustees.
2. Supporting Membership does not mean membership of Action for M.E. as a company limited by guarantee. The Trustees of Action for M.E. have resolved that those candidates who are endorsed by the Supporting Membership will be elected as Trustees by the members of Action for M.E. as a company law matter. Conversely, the Trustees have undertaken that those candidates who are not endorsed by the Supporting Membership will not be elected as Trustees by the members of Action for M.E.
3. Any votes received from persons who are not part of the Supporting Membership or who cannot be identified by Action for M.E. as such shall be deemed invalid.
4. An individual Supporting or Lifelong Member shall only be entitled to one vote for each candidate. Any further voting slips received from that individual shall be deemed invalid.
5. All votes must be received by Action for M.E. on or before 5pm on Monday 12 September 2022. Any votes received after this time will not be counted.
6. A candidate shall be eligible for appointment or reappointment as a Trustee on and from Action for M.E.'s Annual General Meeting, Tuesday 20 September 2022 in the event that he or she receives more valid 'yes' votes than 'no' votes. Any 'no preference' votes or non-indicated votes shall be disregarded for these purposes.
7. In the event of any dispute regarding this ballot paper or the voting process, the decision of the Board of Trustees of Action for M.E. shall be final and binding.

Only Supporting Members of Action for M.E. are eligible to vote.
Please fill in your contact details here, including your postcode and membership number.

Name: _____

Address (including post code): _____

_____

Membership number (if known): _____

Please indicate your vote for **each and every candidate:**

Sue Hardy	☐ yes	☐ no	☐ no preference
Roger Siddle	☐ yes	☐ no	☐ no preference
Dr Nirmala Santiapillai	☐ yes	☐ no	☐ no preference

Please return this form using the envelope provided to Action for M.E., 42 Temple Street, Keynsham BS31 1EH to arrive on or before **Monday 12 September 2022, marked for the attention of the returning officer.**
Thank you.

Meet our new Trustees

Action for M.E. is pleased to welcome three new Trustees who have joined our Board of Trustees as a result of our merger with The ME Trust.

SPEED READ...
Action for M.E. has welcomed three new Trustees to our Board of Trustees – Julianne Devine, Rollo Hope and Philip Courtney. The trio were previously Trustees at the ME Trust and now join our Board of Trustees automatically following the merger of the two organisations. All three come with considerable experience in their various fields as well as having their lives touched by M.E.

Julianne Devine

Julianne is Global Antitrust Counsel at Diageo PLC and leads the team in advising the business on all aspects of competition law and merger control laws. Julianne previously was a Supervising Associate at Simmons & Simmons LLP in the Competition and Antitrust team in London. She studied law at the University of Bristol before going to BPP Law School in London.

Julianne's brother has had M.E. for the last 15 years and she has seen first-hand how difficult the disease is to manage, both in terms of accessing effective care and support, as well as socialising and integrating into society.

Julianne is delighted to join the board at Action for M.E. and is passionate about making a difference to the health and social care that is available to people living with M.E.

Rollo Hope

Rollo Hope is a civil servant in the Department for International Trade leading a team to drive UK technology exports and also works with international tech companies looking to set up here. Prior to the civil service, Rollo was Chief of Staff to a senior MP for five years.

Rollo chairs Action for M.E.'s Healthcare Services sub committee and was previously chairman of the ME Trust which merged with Action for M.E. to provide healthcare support to people living with M.E. Having had M.E. from aged 15 to 25, Rollo is delighted to be able to continue to support this crucial work of providing care and support to people struggling with this devastating illness.

Philip Courtney

Philip is Head Tax EMEA & APAC for Cantor Fitzgerald. Philip trained as a Chartered Accountant at Arthur Young McClelland Moores & Co and qualified in May 1988. He has specialised in international tax, working in the profession with Arthur Young and Touche Ross and then in industry with the Fiat Group and Clifford Chance, one of the world's pre-eminent law firms.

He has experienced at close hand some of the challenges faced, especially for children, when doctors and other professionals run out of medical solutions.

Philip employed an amazing and inspirational woman who suffered with M.E. to help run a two-year project and one of Philip's best friends at university has suffered with M.E., and approached Philip to help her start and build The ME Trust, which merged with Action for M.E. in February 2022.

Hypermobile Ehlers-Danlos Syndrome

New research shows there can be an overlap between Hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorder and M.E./CFS. In this issue, we look at these conditions with Action for M.E. physiotherapist Gina Wall.

SPEED READ...

- Hypermobile Ehlers-Danlos Syndrome (h-EDS) and Hypermobility Spectrum Disorder (HSD) are genetic conditions resulting in body wide symptoms, of varying severity, which can impact day-to-day activities and quality of life.
- There is emerging research that there can be significant overlap of these conditions with M.E./CFS, however all three conditions remain poorly understood and none of them yet have a biomarker or laboratory diagnostic test.
- Thorough screening for h-EDS/HSD is important for people with M.E/CFS and there are guidelines for this.
- Knowing whether you have h-EDS/HSD can enable more informed management of symptoms.


Gina Wall

What is Hypermobile Ehlers-Danlos Syndrome/Hypermobility Spectrum Disorder?

Hypermobile Ehlers-Danlos Syndrome (h-EDS) and Hypermobility Spectrum Disorder (HSD) are inherited/genetic conditions affecting connective tissues body wide. Connective tissues are the scaffolding for the body, providing support and structure, similar to how the white rind in an orange holds the segments together. People with h-EDS/HSD can experience hypermobility of their joints (being able to move joints further than expected) and may have increased stretchiness of skin and more fragile soft tissues (Malfait et al., 2017 **tinyurl.com/EDSclassification**).

Connective tissues contain collagen fibres and protein molecules and are vital to every bodily function. Connective tissues keep our internal organs in place, cover the whole surface of our body (skin) and anchor skin to muscle. They support the walls of blood vessels, the oesophagus (food pipe), stomach, intestines, the trachea (windpipe) and pelvic floor. Connective tissues also attach bones to muscles (tendons), stabilise joints (ligaments), provide shock absorption (cartilage), and act as a building block for bones.

Our genes provide the blueprint for collagen formation from amino acids (like beads threaded on a necklace) and correct collagen fibre arrangement (like strands in a wicker basket). In h-EDS/HSD, some of these genes may mutate or be deleted, changing the blueprint for how connective tissues are produced. Imagine those beads being threaded in the wrong order/ some beads missing, or the strands in the wicker basket placed incorrectly.

Gene mutation/deletion may also affect the "extra-cellular matrix" (ECM), the jelly-like substance that surrounds cells in our body, connecting them and assisting with cell growth and tissue repair (Gensemer et al., 2020 **tinyurl.com/WileyEDS**). The result is connective tissues that are more elastic, with poor recoil.

Currently no gene/s have yet been isolated as being responsible for h-EDS or HSD.

Symptoms

People with h-EDS/HSD can vary greatly in which symptoms they experience. Imagine a spectrum from mild to severe effects. This makes researching the conditions difficult, and why there are still unanswered questions about them.

Symptoms can affect every bodily system: musculoskeletal, cardiovascular, gastrointestinal, autonomic nervous system, immune and endocrine systems. A list can be found by visiting **tinyurl.com/EDS-symptoms** as well as:

- Mast Cell Activation Syndrome (MCAS)
- allodynia
- postural issues: difficulty tolerating prolonged sitting/standing, feeling "fidgety" or sitting in contorted positions.

Symptoms of h-EDS/HSD may change over the course of a person's life as they age (Castori et al., 2013 **tinyurl.com/Castori-symptoms**) with symptoms worsening for some people in their twenties and thirties in terms of pain severity and the range of body systems affected. Factors such as viral infections, sleep deprivation, emotional trauma or surgery can also trigger increased symptoms.

Misdiagnosis of fibromyalgia can occur, therefore correct screening for h-EDS/HSD is vital.

How is h-EDS/HSD diagnosed?

Diagnosis of h-EDS/HSD can be a challenging and lengthy process, involving seeing many different health care professionals. As "invisible" complex illnesses, without specific diagnostic laboratory tests, people with the conditions can feel disbelieved or have difficulty accessing specialists (Sulli et al., 2018 **tinyurl.com/EDS-clinical practiceguidelines**).

Of the 13 types of Ehlers-Danlos Syndrome, the hypermobile type is the most common, but the only one without a diagnostic genetic test. Diagnosis is based on history, physical assessment and excluding other pathology. In 2017, The Ehlers-Danlos Society (**www.ehlers-danlos.com**) released diagnostic guidelines to be used by doctors (tinyurl.com/EDS-checklist). These criteria are not exhaustive as they do not yet consider all h-EDS/HSD symptoms.

People who have symptomatic joint hypermobility, but do not meet the criteria for h-EDS, would be given the diagnosis of Hypermobility Spectrum Disorder (Forghani, 2019 **tinyurl.com/HSDdiagnosis**). However, there is currently no genetic or laboratory test that separates h-EDS from HSD.

It has been suggested that h-EDS may manifest with greater symptom severity than HSD (Copetti et al., 2019 **tinyurl.com/hEDS-pilotstudy**).

You may be referred by your GP to a rheumatologist to rule out other conditions.

h-EDS/HSD and M.E./CFS

The question has been raised in research of whether some people with M.E./CFS may also have h-EDS that has not yet been identified, given that fatigue can be one of the major presenting symptoms in h-EDS and could mean other features of the condition are not assessed (Hakim et al., 2017 **tinyurl.com/chronicfatigue-EDS**).

The discussion around this topic in the world of research again highlights that the current diagnostic criteria for both M.E./CFS and h-EDS are inadequate. There has been difficulty investigating how much the conditions overlap as a diagnosis of M.E./CFS must exclude other conditions; therefore it can be challenging to develop research trials to study people who may have both h-EDS and M.E./CFS.

I have led on conducting an audit of new patients presenting for initial assessment at a hospital-based fatigue service in 2017, which found that 25% of a sample of 140 assessed patients met criteria for HSD as well as for M.E./CFS (**tinyurl.com/YouTube-audit**).

In 2021, a study examined people meeting diagnostic criteria for either fibromyalgia, or M.E./CFS, or both, for signs of h-EDS or HSD. This study found that 81% of the sample (63 patients) with either fibromyalgia or M.E./CFS, also met Brighton Criteria for HSD and 18% of that sample also met the 2017 h-EDS criteria (Eccles et al., 2021 **tinyurl.com/symptom-overlap**). More patients with M.E./CFS and/or fibromyalgia, also met criteria for HSD or h-EDS, than the "control" or symptom-free subjects. Interestingly, of those people found to have symptomatic hypermobility, only 23.5% (12 people) had had this diagnosis picked up prior to the study.

Further research is required to understand whether h-EDS and HSD are separate conditions or part of a spectrum, and whether such a spectrum could also include fibromyalgia and or M.E./CFS (Hakim, 2019 **tinyurl.com/severity-classes**).

How can I manage h-EDS/HSD?

Self-care

- self-compassion: we may yet not have a genetic test, but the conditions are no less real
- listen to your body: recognise your body's signalling for rest/recuperation, rather than "pushing through" to finish a task/please others
- practice balancing activities. Ensure room for enjoyment, connecting with loved ones, and rest/recuperation – not just "have to do "activities (**tinyurl.com/Get-self-help**)
- practise setting boundaries.

Pain management

- request a medication review with your GP/referral to a multidisciplinary pain management programme
- explore use of TENS (transcutaneous electrical nerve stimulation)
- acupuncture.

Psychological support

- Acceptance and Commitment Therapy (ACT) can be a helpful to support you living with a long-term condition
- accepting your condition does not mean giving up, it means dropping the struggle of trying to "get back

to normal" and instead focussing on living by your values (what really matters to you/the type of person you want to be)
- you can develop a "new normal", setting goals for the near future and longer term towards making life rich and fulfilling.

Mobility/functional aids
- explore mobility aids. Ask your GP to refer you to Occupational Therapy, or explore self-funded options (**www.abilitysuperstore.com**)

Exercise or activity
- this must be led by YOUR body: what works for someone else may not be appropriate for you. It is helpful to have the support of a healthcare professional
- hydrotherapy/gentle movement in water can be helpful
- chair-based, hypermobility-specific yoga can be helpful (**tinyurl.com/Youtube-chairclass**).
- healthcare services at Action for M.E. can provide an individually tailored programme and support you with implementing it (**www.actionforme.org.uk/healthcare-services**).

Support groups
- connect with others living with these conditions through virtual support groups
- Ehlers-Danlos Society: **www.ehlers-danlos.com/virtual-support/**
- Ehlers-Danlos Support UK: **www.ehlers-danlos.org/support/support-groups/**
- EDS Awareness: **www.chronicpainpartners.com/what-is-eds/**

Shaelynn's story

I was born with Hypermobile Ehlers-Danlos Syndrome. While I struggled with different things off and on since birth, my condition and its major symptoms appeared when I was only 15, after a series of stressful and traumatic events, and after taking a medication that I reacted badly to.

For the next eight years, I would battle with doctors and specialists who put my symptoms down to a psychosomatic disorder, depression, or being a hypochondriac. No one took me seriously, and I was left to suffer.

Geneticist

Finally in my early 20s I found a geneticist specialising in EDS who changed my life. Unfortunately there is no cure for Ehlers-Danlos/hypermobility. I continue to cope everyday with chronically severe sometimes debilitating joint and overall body pain, joint dislocations/subluxations, digestive abnormalities/chronic nausea/delayed gastric emptying, trouble sleeping, easy bruising and tearing of my skin, POTS (postural orthostatic tachycardia syndrome) / fainting / heart palpitations/circulation issues, menstrual disorders/endometriosis, MCAS (Mast Cell Activation Syndrome), chronic headaches and migraines, temporomandibular joint disorder, and M.E./CFS which was triggered around the same time my EDS flared dramatically.

Benefits

The combination of severe pain and fatigue I deal with on a daily basis is as exhausting as the fatigue itself; it's meant I've needed help in basic personal care and it's meant I ended up going on disability benefit in order to have an income to live on.

Thankfully I've been able to sustain myself on this income, I've finally been able to find some medications and exercises/treatments through physiotherapy that help ease my pain. I graduated college, became a certified Medical Assistant, recently just became certified as a Community First Responder and First Aid Instructor, and I've been able to move out and get my own apartment.

Fulfilling life

It's taken a long time, and I'm constantly in the process of learning to recognise my physical and mental limitations – but I've never let them stop me. I learn how to work with them to accomplish my goals. I rest as much as I need to, take my medications to ease pain and supplements like L-carnitine to help my body produce more energy, do light but invigorating exercise every day, practice mindfulness and awareness like I learned in therapy, and most importantly never ever give up hope. I've proven to myself that even living with debilitating fatigue from M.E. and chronic pain and injury from EDS, you absolutely can live an enjoyable and fulfilling life. I hope my brief story inspires many others.

Dear team

Q. I'd like to apply for PIP because of my M.E. but the prospect of completing the long form feels very daunting. I'm finding it hard to describe the difficulties I have and to explain the fluctuating nature of M.E. Can you help?

A. Thank you for getting in touch with us. Unfortunately, we hear from a lot of people with M.E. who feel the same way. Whilst we are not Benefits Advisers and can't help you to complete the form, I can signpost you to some information about PIP and filling in the form. I hope this will help you to explain the difficulties you face and to feel less daunted when making your application.

How to prepare for filling in the form

Whilst you are waiting for the form to arrive, you should start to gather any medical evidence that will support your claim. Options might be:

- copies of diagnostic letters for any conditions you have
- a recent letter from your GP or specialist. You can request this yourself but your GP may charge for this service
- a statement from a carer, friend or family member which might include a description of things they do for you and why you have difficulty with them
- a needs diary. You can find template diaries online.

About the form

The assessment for PIP eligibility is very formulaic. A decision maker looks at your ability to do a specific list of activities and awards you points based on how much you struggle with each activity. They do this by comparing your difficulties with the activity in question to a number of "descriptor" phrases, and deciding which one most closely describes your situation. Citizens Advice have a list of the activities and descriptors on their website.

Two key PIP rules are particularly important for people with fluctuating conditions such as M.E.:

- you shouldn't be considered able to do something if you can't do it "reliably"; that is safely, repeatedly, in a reasonable amount of time and to an acceptable standard
- you shouldn't be considered able to do something if you can't do it more than 50% of days.

It's worth noting that when the descriptors are looking at an ability to prepare a simple meal using a microwave, this doesn't mean a ready meal. It still means preparing a meal from fresh ingredients, just using the microwave rather than the hob to heat/cook those ingredients.

Filling in the PIP form

While waiting, it might be worth starting work on a draft version of the big PIP form, so you don't have to do it in such a tight space of time once they send it to you. You can find a specimen copy of the PIP2 form online. For each question on the form, consider the following:

- look at the descriptors sheet. What is the descriptor for this activity that best applies to you?
- can you do this activity at all? Can you do the activity less than 50% of days? How many days in a week/in a month can you do it?
- can you do it safely? If you do it, will it cause symptoms such as pain and fatigue to flare up? If you do this activity, could you accidentally hurt yourself?
- can you do this activity repeatedly? Meaning: can you do it as many times as you need to in the day?
- will this activity take you more than twice the amount of time it would take someone without your health issues to do it?
- can you do it to an acceptable standard?
- do you have to use anything or anyone to help do this activity?
- can you link the above to your M.E. and/or any other health conditions you have?

For each question you should also try to give a real world example which explains the reality of your difficulties in relation to the points above.

Don't feel that you need to be constrained by the amount of space given to write an answer – you can always use an additional sheet of paper. If you do this, remember to write your name and national insurance number on each additional sheet, so that they don't get lost.

If you want to find out more about any of the above, please do take a look at our website: **www.actionforme.org.uk** or call the Information, Support and Advocacy Service on 0117 927 9551 and there will someone who will be happy to guide you through your choices.

M.E. and Covid: your stories

With the last remaining Coronavirus restrictions now lifted, how concerned should people with M.E. be? We asked the M.E. community to share their experience of catching Covid. Here are some of your stories.

Covid wasn't as bad as I'd feared but my body also didn't deal with it as well as I'd hoped. I woke up with an incredibly sore throat in the night but didn't test positive until the day after and for about a week the symptoms were different from a usual M.E. crash; I had a cold and slept on and off all day. After that, it was more standard M.E. territory with headaches, muscle pain and tiredness. I'm still building back to my baseline, but it's only been two and a half weeks.

Ellie

I caught Covid in January 2022 and since then my M.E. is a lot worse. I am suffering more with pains, being so very tired and drained more, my weakness in my muscles is worse. I get so light-headed at times and my arms and legs can feel like weights. Piercing headaches and stabbing pains. Everything is just so much worse. I am trying to hold down a part time job of 15 hours a week but since catching Covid, I am struggling more and this is more of a challenge. I was off sick from January until the start of June because of how the Covid affected my M.E.

I am now at the point of trying to be back at work with adjustments but this is still a massive challenge.

Laura

I've had mild-moderate M.E. for approximately 15 years and took the risks of Covid very seriously. My M.E. has improved in many ways since early 2020, despite getting Covid twice. I chose not to have any Covid injections after much reading.

I felt it incredibly important to be prepared for Covid infection and so read as much as possible about early home treatments. Consequently, when we caught Delta in Nov 2021, I had a bag full of supplements, medications and as usual, plenty of healthy foods on hand to support my immune system (using home treatment protocols from the Frontline Covid-19 Critical Care Alliance and the World Council for Health). I wanted to reduce the severity of symptoms and avoid risk of Long Covid complication if I could.

Delta was unpleasant for a few days and I felt unusually weak and short of breath for a couple of weeks, but continued with recovery protocols and quickly returned to normal. The early strain of Omicron we had in March 2022 was a VERY snotty cold, with no after-effects, except for a trail of tissues in every pocket!

Anonymous

I am female, almost 56 years old, and describe myself as moderately affected, with some bouts of more serious illness. I decided not to have the vaccine.

I found that the only real difference Covid made to me was the awful cough. Apart from that I did not feel any worse than I normally do with M.E. It did not seem to make any of my M.E. symptoms any worse. However, over the last year or two, my symptoms have been somewhat worse on many days. I definitely feel more tired and unwell than I did prior to getting Covid, so I think it may have had a delayed effect on me. I can't be sure of course, as M.E. fluctuates anyway. Also, going through the menopause, some of my symptoms are probably affected by that.

Anonymous

Two jabs floored me for months at a time. Not having any more. Covid was horrible but it didn't make my M.E. worse, something I was dreading.

@jusstar2021, Instagram

I had one jab. I caught Covid just as we were about to leave for a holiday in Kent. I still went as we were in a lodge but I felt better and all my clarity came back. I don't understand it. When we came back it was another week before my M.E. showed up and the weirdest thing is I am in the severe/very severe bracket. Mostly bedridden or in a wheelchair. I need answers.

@chronicallyoncharge, Instagram

My boyfriend tested positive for Covid this Spring. Once he had, we tried to keep to separate rooms in the house and I slept in the spare room. I got it but my symptoms were pretty mild, and mostly just felt like a run of M.E. "bad days", with some digestive symptoms which were unpleasant but not unmanageable. My boyfriend (who is generally very healthy) got it much worse than I did. I was back to my usual levels of energy and functionality within about a week and a half.

I also had a virus in late March 2020 which I think was likely Covid. That affected me worse, and I was off work for over a week. It took me a few weeks after that to return to my usual baseline. However, post that initial infection and vaccines, the next time was much improved. So even if you have had it badly on one occasion, it doesn't necessarily mean that you will feel as bad if you get it again.

Staff member, Action for M.E.

I caught Covid for the first time in April (and having three vaccinations). The illness was like a nasty flu virus for around a week to 10 days and I had pretty much every symptom going. (Rapid heart rate, sore throat, aches, chills, fever, breathlessness). After about two weeks, just as I was recovering, I was hit by a really severe 24/7 fatigue, and became worried that I was having a major M.E. relapse. This lasted around a month and then I slowly began to return to my normal M.E. baseline.

Tom

I caught Covid in April 2022. The day before I tested positive I felt very hot and generally unwell with a sore throat and aches. My main symptoms were like a bad cold but I did have a cough which made me feel breathless at times, as I also have asthma. I needed to rest more in bed. I had sinus/cold symptoms lingering on a while. It was probably a total of two weeks I was unwell. I feel that I was back to my usual level with my M.E. maybe a couple of weeks afterwards but this is usual for me when I have had a virus.

Anna

I have had three vaccines including the booster and have experienced Covid 19 on two occasions. I noticed that on the booster vaccine my M.E. went into hiding and I felt like I was cured, but then slowly the standard everyday M.E. symptoms returned.

The first encounter, my underlying peripheral neuropathy flared up but none of my M.E. symptoms nor Covid floored me as I had first anticipated. This was in December of 2021 when the Omicron variant was at its height. I had awful pins and needles, tingling and an internal tremor that would not leave.

On the second encounter, I caught the virus shortly after landing from my holiday. I found the second occasion wiped me out for three days with M.E. symptoms also flaring. This time, I had the worst symptoms from the cough, sickness, upset stomach, tight chest, loss of appetite, fatigue and a very sore throat that felt like I was swallowing splinters. My M.E. symptoms were at their highest in the days after I began to test negative – I found my brain fog and fatigue were at their peak during this time. I imagine this was when my body was attempting to make its recovery.

I feel relieved neither occasion was as scary as I'd predicted. I can only thank the fact I took up the opportunity to be vaccinated.

Kendall

I had Covid three weeks ago. My immune system is still battling like it was Winter (permanent flu-like) and does not feel good. Fatigue is definitely back.

@DPhilvon, Twitter

I had Covid in the Spring of 2020 and am nowhere near as able as I was before 2020. I experienced painful breathing, unable to get enough air unless breathing through the mouth, had to start sleeping on my front, excruciating migraine, profuse sweat from doing any household chores – but with cold extremities, increased dizziness, diarrhoea, random bruising, tachycardia and taken by ambulance to get checked out because heart rate wouldn't go down, bloodshot eyes, coughing up clear foam for two months (not mucous), sleeping 12-14 hours per day, pale complexion, noticeable weight loss, increased weakness and lowered activity level for a year.

The lockdowns helped me rest because there was so much less to be able to do at all and therefore less expectation to "do", and I benefitted from the imposed Winter-Spring rest time by the time summer 2021 approached as I seemed to have more energy and ability.

I made the mistake of trying driving lessons because not driving with M.E./CFS is so isolating and it exacerbates the illness if we try to walk. The stress of the repeated and elongated lessons plus the exam made me crash and I have not recovered. I am still worse than pre-2020 but not as bad as I was in 2020-2021, touch wood.

Anonymous

Would you like to share your Covid experience with other readers? Please get in touch by emailing **interaction@actionforme.org.uk** or writing to us at InterAction, Action for M.E., 42 Temple Street, Keynsham BS31 1EH.

Spreading the word

In the latest in the series about people with M.E. and their hobbies, we meet three authors who are raising awareness of the condition through their literary work.

KT King

I've had M.E. for 30 years in varying degrees of severity. Since 2012 I've been unable to work or look after myself but it has meant that I've been able to fulfil my life-long dream of being an author.

I write my novels in my head whilst resting, seeing them like films in my mind, then I type them up (which takes at least two years). I go through long periods unable to write at all, due to fibromyalgia flare-ups, M.E., migraines and chronic pain.

You may be asking why I bother but the simple answer is, without it, I wouldn't still be here. It is my purpose, my escape and my hobby – when I need a reason to carry on I think about my next novel.

I find solace, peace and joy in my novels. My readers say they are a comfort, "a sanctuary from their sofa" and a wonderful escape from reality. Saying they want to live in Little Eden (the town where they are set) is the greatest compliment ever!

You may also be wondering how I can write with aphasia (brain fog) and the answer is I can't – it all comes out as gobbledygook restricting the times I can type and luckily my sister checks my manuscripts for errors!

My heroine, Sophie, has M.E. I try to show how friends and family can help us as well as highlight some of the problems we encounter. Since reading my novels, friends have become much more empathetic so I'm hoping that this will be the case with my readers too. I also want to show that we can still be heroes and heroines despite our disability.

I've published three novels so far and am currently writing the fourth. You can find them on Amazon Kindle and paperback (I'm self-published as deadlines and promotions are impossible) and if you would like to become one of my dear readers you'll find all my links to the books, reviews and my blog here on **linktr.ee/ktkingbooks**

I hope you, your friends and family enjoy Little Eden novels. Together we can help raise awareness through literature!

Sally Doherty

As a child, I loved writing stories, but when life became busy (GCSEs, A-levels and subsequently university and work), I lost my drive for creativity. After I'd been working in London for a year following graduation, I unexpectedly fell ill with severe M.E.

In the first few years, the symptoms were all-consuming. Gradually though, and after learning to pace, a space opened up in my brain and a story flew into my head and demanded to be written. It took many years before I was able to start writing it – just five minutes a day to start with. And many more years before it was published last year as *Toby and the Silver Blood Witches*. It's a magical adventure but, not surprisingly, it features the theme of chronic illness, as my main character is a young carer whose mum has M.E.

Writing whilst living with severe M.E. is obviously tough and progress is very slow. It can be frustrating as I have so many stories fully formed in my head, but getting them onto paper (or laptop) is a mammoth task. That said, I feel lucky that I can write at all. I know what it's like to have to use all your little energy on eating and washing, when you're basically living only to stay alive. I also know that I'm lucky to live with my husband who takes care of all the cleaning and cooking etc so I can use any spare sprinkles of energy on writing.

Having a hobby gives me a much needed distraction as well as sense of achievement. It can be easy when you have M.E. to lose all feeling of self-worth and identity. But recently, I am no longer Sally-the-poorly, I'm Sally-the-author. This isn't the path I thought my life would take, but I definitely try to appreciate the silver linings. I love that the vocation I wanted as a child has unintentionally ended up becoming reality. I'm pretty sure that if I were well and working full-time, I would never have become an author.
www.sallydohertyauthor.com

Sophie Buck

When I became sick in 2019 (with M.E./CFS, then fibromyalgia), many things I used to do slipped through my fingers; writing was one of the few low-energy activities possible from bed that remained – and it's become a lifeline.

Writing, for me, is a way of making sense of my tangled thoughts and experiences. It is a way of remembering through the brain fog, forgetfulness and repetitive days. It's a way of saying my everyday experiences are worth writing about, that small things are actually big things, that my sick and disabled life is valuable and valid. It's also a way of forgetting, of getting distance from and offloading thoughts, such as into a bedside journal.

There's benefit in writing for oneself but there's also power in sharing writing with others. Words, while intangible, have impact. They can inform someone, change their perspective, make them feel less alone. It feels amazing to hear someone say "I feel this way too" or "I hadn't thought about that".

I first began to write through Instagram, in the captions under pictures. It was late 2020 when my frustrations about reductive autism representation in the media broke my writing floodgates (I'm also autistic/ADHD), spilling into a caption that transformed my account (**@BusyBeingDisabled**) into one of advocacy and awareness, and led to my first article, for *Dazed*, which empowered me to write more.

Slowly and sporadically, I've since written for publications from Vogue Italia and Novara Media to PosAbility magazine and Able Zine, on topics from adaptive fashion and inaccessible environmentalism to "illness faking" myths. My social media has become a space for my disability-related thoughts, amassing an audience of more than 7,000, and I've connected with fellow sick writers via **@TheRemoteBody**. In a world that makes me feel forgotten, writing makes me feel heard and connected.

Writing is not without difficulty though – finding the right words, reading and editing is hard with brain fog, and trends and news move quickly in capitalist society. When writing, I'd recommend many breaks, avoiding wasting energy going off topic or on perfectionism, and asking others for help. Publication-wise, those disability-run are more access-friendly and slower-paced. Being selective with topics you want to cover is also important – however frustrating, I often need to let things pass me by to conserve energy.

Writing, however slowly and sporadically I do it, keeps me going.

People with M.E., including those living with severe M.E., may benefit from using voice recognition software, says Katherine Langford.

These days all Microsoft computers come with free software called "Voice Typing". You just press the Windows key (the one that looks like four squares) and the "H" on your keyboard at the same time and it should start working if you're connected to the internet. Just put the cursor in a textbox, make sure the Voice Typing microphone icon is on and then start talking. You need to say any punctuation, etc, you want (like "full stop", "comma", "new line", "new paragraph").

It's probably worth people having a go with that before purchasing other voice recognition software as it might be sufficient for your needs. However if you need software that is a bit more advanced, then I've used Dragon NaturallySpeaking for years and find it really useful. It has extra features like being able to create custom commands.

Tips from our authors on writing when you have M.E.

- Envision the whole book and each chapter in detail before sitting down to type it (if you are able) to save energy.
- Have a thesaurus/dictionary at all times to help with brain fog.
- Pace your writing time.
- Edit as you go and keep control of your word count. It's much harder to edit the book afterwards. Most novels published are 80 – 100k words.
- In terms of word count, it may help to write a children's book (around 45k for a book for nine to 12 year olds). And books for younger children can be much shorter than that.
- Keep chapters short for M.E. readers and yourself.
- Kindle Create is easy and free. You can upload your whole manuscript from Word and edit again. It's free to upload a Kindle book on Amazon.
- Try not to compare your progress with other writers as it can be frustrating. Take it day by day and be proud of every word.
- Get a friend or family member to help you with edits if possible so you can save your energy for writing.
- And finally, everyone is different and manages their illness differently so do what works best for you and your health. Don't push yourself beyond your capabilities.

Do you have a hobby you would like to share with readers? We are especially interested in featuring hobbies suitable for people who are living with severe M.E. Our contact details can be found on p 2.

InterAction

The magazine for Supporting and Lifelong Members of Action for M.E.

Please note that Supporting and Lifelong Members of Action for M.E. are not members of Action for M.E. as a company law matter. As a consequence, Supporting and Lifelong Members do not have voting powers or legal responsibility as company members of Action for M.E. The Trustees are the members of Action for M.E. as a company law matter and are also its Board of Trustees (as that term is defined in the articles of association of Action for M.E.).

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Giveaway

Win this fantastic prize

We are giving away this clever **eye-mask with built-in bluetooth speakers** which can be used for blocking out light and white noise whilst listening to music, audiobooks and meditations.

Picture for illustrative purposes only

How to enter

For your chance to win, please send your name, address, telephone number and email address on a postcard to:

- *InterAction* Giveaway
  Action for M.E., 42 Temple Street, Keynsham BS31 1EH
- Alternatively, enter by emailing **interaction@actionforme.org.uk** with the word 'Giveaway' in the subject line.

The deadline for entries is Monday 28 November 2022.
Good luck!

Terms and conditions

The Promoter is Action for M.E., 42 Temple Street, Keynsham BS31 1EH.

Draw closes at midnight on Monday 28 November 2022. The winner will be notified via telephone or email. The prize consists of one SKYEOL bluetooth sleeping eye-mask headphones (5.2 wireless bluetooth headphones adjustable and washable music travel sleeping headset with built-in speakers microphone, hands-free for sleeping in the colour grey), RRP £28.99.

The sending of the prize will be confirmed by Action for M.E.

Entrants must be 18 or over.

Winners may be required to take part in or co-operate with publicity. Winners agree to keep confidential any knowledge about Action for M.E. charity, its organisation and its personnel received by them as a result of the free prize draw.

No cash alternative is available and all prizes are non-transferable and non-refundable. Prizes are not for resale and cannot be used for commercial use or use in further promotions.

The prize winner will be selected at random by Action for M.E. Their decision is final in every situation and no correspondence will be entered into.

Action for M.E. will not pass your personal details to any other organisation without your permission, except for the purpose of awarding your prize if necessary.

Use of false name or address, ie. name by which the entrant is not usually known, will disqualify them from receiving any prize.

Action for M.E. reserves the right to amend these rules at any time.

Entering implies acceptance of these rules.

"It feels like a miracle"

After enduring M.E. for three decades, Rosemarie Cook found changing her diet made a huge difference to her condition.

SPEED READ...
Rosemarie Cook, 80, has had M.E. since her early 50s. In August 2021, she picked up a book she had on her bookshelf called *10 Steps to Energy* by Leslie Kenton. The book advocates the Hay diet which involves not mixing protein and carbohydrates. By Christmas, Rosemarie felt 30-35% better and now feels 50% better.

I have suffered with M.E. for 30 years, from my early fifties until my present age of 80 years.

Nothing seemed to help, least of all exercise. I was bedridden at first for weeks on end and slowly improved to being housebound.

I had to suffer the remarks of "You don't look ill" many times but I was too exhausted to retaliate (perhaps if I didn't have M.E. I would wonder how someone looking well and smiling could possibly be ill).

Action for M.E. has been a lifeline, with letters, information, articles, poems and the latest news.

Between the ages of 50 and 60, I received Incapacity Benefit, seeing three doctors over the 10 years with each saying I had M.E. I received my state pension at 60 (you did in those days) and my Incapacity Benefit ceased.

Tribunal

I seemed to be getting worse by the age of 66 and my husband was finding it hard to cope as he had asthma, so I applied for Attendance Allowance. My doctor didn't "back me up" and I had to go to tribunal which wasn't successful. Luckily, I had a family: a husband and three children who loved and supported me. My husband died in December 2016 and I slowly found my way through the many challenges I faced.

Last year I found a paperback on my bookshelves called 10 Steps to Energy by Leslie Kenton which years before I had thumbed through and ignored.

The book does mention chronic fatigue but in the past when trying to cook meals for my family, it didn't seem credible that my diet could possibly help my debilitating illness, and when your mind is tired, it would just be another challenge to cope with.

The book recommends the Hay diet which involves not mixing protein and carbohydrate together in one meal. I started following it last August and slowly my M.E. improved beyond belief.

No payback

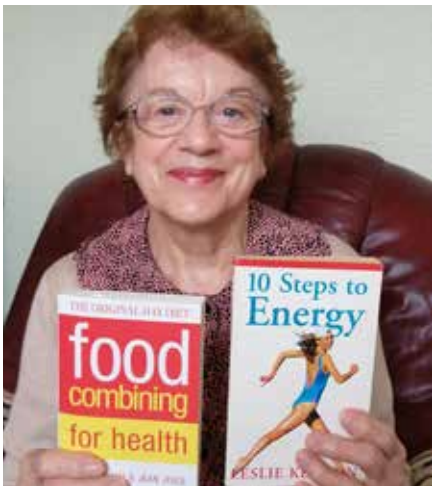
By Christmas I felt about 30-35% better and now I can say I feel about 50% better. With M.E. you have a terrible exhaustion where you can hardly do anything and, if you do, you pay for it later with flu symptoms and aching but now I don't have to live like that. I can do jobs and I don't pay for it later.

I go to a local Methodist church and they are used to me attending only once a month. Now I'm there every week.

My daughter picks me up to go shopping and usually the whole day would revolve around getting ready and then resting. Now I can put a load in the washing machine, peg it out and then go shopping. That's unheard of.

My family say "We can't believe it, mum!" They are so glad for me.

There's nothing else I've done, so I believe it must be down to the diet, although I appreciate it won't have this effect on everyone. After 30



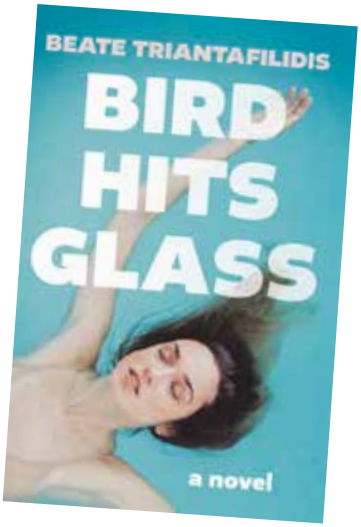
years, it feels like a miracle. I'm not advocating the particular book I used as there are many books out there which contain information on the Hay diet, but rather wanted to share the benefits I have experienced by food combining.

The Hay diet, also known as food combining, advocates avoiding eating certain foods together because some combinations hinder digestion and increase levels of acidity in your system. There is no scientific evidence that this works or can help people with M.E. In high concentrations protein and carbohydrates can increase cholesterol levels and limiting carbohydrates can result in vitamin and mineral deficiencies. The NHS recommends a balanced diet (tinyurl.com/NHS-Eatwellguide).

We advise people to examine with scepticism any treatment which has not been subject to research published in respected peer-reviewed journals. It is important that anyone considering changing their diet should seek the advice of a medical professional to ensure it is safe for you.

Book time

Ellie Finney reviews *Bird Hits Glass* by Beate Triantafilidis



Grace is in denial about being seriously ill.

In this novel we watch her attempt to push through her crushing fatigue to continue in the rat race in corporate London, only to eventually sink into her symptoms and attempt to live her life in line with her energy limitations. I was very keen to read what was billed as one of the few depictions of chronic illness in fiction, but I was left disappointed. It didn't just describe M.E. – it was the entire plot. Nothing else really happened. It was relatable, but not enjoyable. It wasn't escapism, and I needed something more. All the right themes were there, but they were strangely static. There was no light relief, and the combination of first-person narrative and present tense really didn't work for me.

Neither the novel nor the characters had any depth. The narrative unemotionally skimmed past scenes as if the action takes place through a window we're far removed from, which could be a deliberate allegory for life with M.E. – you can see life happening but you can't really explore it properly.

Although clever, it doesn't make for satisfying fiction. I did like how Triantafilidis resisted a happy ending and instead opted for what I'll call micro-progressions. It ended with budding hope for the narrator and her sister with fertility issues, rather than out-and-out happiness or their problems resolved.

She didn't try to make it palatable either, which I admire, but leaves me wondering who the audience is for this novel. I can't imagine healthy people sticking with it. I'd describe the writing style as deliberately accessible; again, I needed more. I did enjoy how she depicted pacing; painstakingly charting how long Grace spent scrolling on her phone vs walking vs eating. It was through this that she began to rebuild her energy levels and Triantafilidis described it well. I was also interested in her growing obsession with an influencer, but that didn't really go anywhere.

At a house party Grace can just about attend, an artist tells her, "Creating the thing, that's what matters. The rest is just noise (p 212)." The fact that I didn't enjoy this novel should take nothing away from the achievement of getting it published. Triantafilidis has made the literary world listen and put a book about M.E. on shelves.

FUNDRAISING

Walk with M.E.

Walk with M.E., which began at the end of May, is nearing completion. Teams have each been counting their steps over 100 days, aiming to count one million steps per team.

One of our brilliant fundraisers, Vick, decided to get creative with her Walk with M.E. step count. Vick finds walking very tiring, but can manage to go indoor climbing every few weeks. So she decided to change one million steps into 420 climbing routes, and has been asking friends and family to join her.

Another team, Team Rocket, is made up of friends who met as part of an M.E. support group. Team ToleFrees is made up of mother Charlie and her son, 11, who wanted to do something to raise awareness and funds for research, as his mum has lived with M.E. for many years.

Congratulations to all our brilliant teams – together they have so far raised a fantastic £936 which, thanks to a generous family trust, will be doubled.

You can see their fundraising progress at **www.justgiving.com/campaign/walkwithme22**

walk with m·e

A solitary adventure

Judith Wilkinson's M.E. led to dreams about the desert, which would later form the basis of her new collection of poetry.

After a viral infection, M.E. changed my life radically. I went from being an active person, freelancing in London as a writer and translator, to becoming bedbound and living with my parents in Holland where I grew up.

During the first decade of the illness I stayed mainly in a dark room, unable to focus or do things for myself. I felt trapped in my body and was often in despair. The unwavering support of my family helped me through, as well as the small improvements in my health that each year brought, suggesting a better future lay ahead. Gradually, through pacing, diet, meditation and perhaps just luck, I got stronger. Today I have a new and increasingly active life in Holland; I'm working part-time again, writing my own poetry, and translating the work of Dutch poets.

Although for years I lacked the concentration that writing demands, I tried to jot down some of my most vivid struggles, dreams, and realisations. I remember someone saying that being bedbound with M.E. must be very boring. But it was never boring. It was overwhelming, scary, but always an intense experience. I frequently dreamt I was in a desert, and as I got stronger, I started reading about people who'd spent time in the desert: adventurers, artists, recluses, refugees, but also people whose desert stay was a figurative one, the result of illness or imprisonment. I became interested in various solitary journeys, stories of courage, when people are thrown back on their own resources. What from the outside can look like a period of stagnation, is often a time of discovery, with new interests and strengths developing in a person.

Eventually I was able to write my new poetry collection, *In Desert*, drawing on my own notes and on the desert literature I'd immersed myself in. The encounter with this stark and magical landscape is never a static event, and those who have trekked through it inevitably emerge changed.

Desert snail

I travel by inches. If the whole world
travels by light years, I shall stick to my inches,
my immeasurable slow-dance, here, in this desert,
and glide and slither as if there were no geography.
I am not carefree. I have my tentative misgivings,
my pace being so slow, the world so large.
Its whirlwinds might overwhelm me, its colours blind me.

An eternity ago I spiralled into being.
Meditation is my forte.
I don't chase mirages.
The agonies of exile pass me by,
though my eyes are on stalks and follow the caravans
until they melt into the horizon.
I take in the nomads from every laborious angle,
see how the camels creak and bend
across dizzying immensities of sand.

I shall be enough for me.
No dreams of latitude pull me away
from myself. I breathe my way forward
patiently, close to my own apex,
my locomotion slower
than the rocking of the calmest sea.
No claustrophobia catches me,
no heatwave desiccates me.
Sealing myself off from the sun
I'll sleep foodless homeless at home through lengths
of years
and wake like Rip van Winkle
and thrive, my alphabet intact, my muscle-tone
unchallenged,
as if time had curled itself up in me and dwindled
to an irrelevance.

This is where I shall live, in this flesh
that has no wanderlust, the shell of myself
still inhabited.

Note: When temperatures get too high in the desert, desert snails are able to sleep (estivate) for years, before re-emerging.

In Desert by Judith Wilkinson, published by Shoestring Press, is available from many online retailers, including Centralbooks.com, at the RRP of £10.
www.judithwilkinson.net

Rose's diary

When all seems so hopeless, I find focusing on nature a real tonic – my garden is my haven, and I am so blessed to have a lovely gardener to plant beautiful summer flowers.

Editor's note: *In this regular feature, Rose opens the pages of her diary to provide a frank insight into a life affected by severe M.E. It is a tough read at times and some readers may find it upsetting, but we feel it is important that the voices of people with severe M.E. are heard.*

I glance out of the patio doors that are open on this warm summer's day to see the bees buzzing happily from hollyhocks to foxgloves. The cosmos is gently swaying in the breeze. Butterflies are taking a breath on the patio, with wings spread out seemingly needing a rest. Nature is a gift, and we are blessed to have nature around us.

When I feel so low and emotional I write in my diary so that I can have the release. I often sob through it but then I feel a sense of relief afterwards. I always try to be thankful and add a positive affirmation.

My personal diary pages:

11/05/22

Woke up feeling very low and frustrated. So much whirring through my mind. My pain is not just physical it is also emotional. The deep sadness of living with a long-term illness and moreso not having a partner. I am SO lonely for a partner; I just want someone to love me.

It will take me more strength to carry on than give up. I am crying so hard; I'm having a tough day. I won't give up, I have travelled this far. I am holding onto Hope's hand.

Thankful for: The rain that watered the garden and the rainbow that followed.

Positive affirmation: I am worthy of better; I do deserve love.

25/05/22

Bad day. In tears as I write, just deep sadness of all the losses. Never married, never danced at my wedding, never had my babies. Twenty-three years of being a prisoner in my home. Facing another lonely summer. I am a sociable person, too ill to socialise but would love the opportunity to have a partner – a cuddle, a smile, a laugh, a friend; someone to share life with.

Feelings of missing out,I am only human after all.

Thankful for: My two beautiful fur babies who remind me that I am a Mummy, and they love me unconditionally.

Positive affirmation: I am strong, and I am loved.

06/07/22

The tinnitus is so loud, and I am doing my best not to listen to it. I have mastered a way of not tuning into my body simply because it heightens all the symptoms. I keep feeling as if bugs are on me, but it is my nervous system. I am over exerted and so flared. The peace of no one in my home is a blessing but I need the help. I am hoping to have new carers soon but the exhaustion of trying to interview and train them is so hard.

Thankful for: The support I do have.

Positive affirmation: I am worthy of attracting lovely carers to support my needs.

Coping with noise

I am still adjusting to living in a neighbourhood. I know I am still blessed to be in a village, but a development means people. People make noise and even the sound of a banging door can stress our nervous system when we are ill with M.E.

I live next door to a young couple with a very vocal five-year-old. My nervous system is trying to build up resistance to the noise. Last year I found it intolerable because I had been rural for 14 years living in secluded settings. My anxiety would heighten because it was such a huge adjustment. I love hearing the little one giggle, but her screams and squeals are too much for me – especially if she has little friends over. Also, the young adult loves to play football and the noise is so hard for me as the gardens are like postage stamps. I used to feel that I needed to tolerate the noise and endure it rather than find a way to soothe myself. So now I try and distract myself and know the noise is "temporary". If I am really struggling, I take a Valerian herb capsule to help soothe my nervous system.

Pockets of peace

I am finding if I can embrace the pockets of peace in that present moment – when the neighbours are out – then it is more appreciated. Where I am now is a stepping stone, it is not aligned with where I want to be, as I long to be more secluded but for now I can work on building up my resilience and enjoying my wonderful pockets of peace.

Creative corner

If you are an artist, poet, writer, painter, photographer, crafter or cartoonist with work to share, please get in touch (see page 2).

Autumn flame

Sharing a moment

I have suffered with M.E. for around 13 years now. I have been married to my wife Melanie for the same time and we have two children together.

I have at times struggled with finding the balance between enjoying my hobbies, and surviving them, so with some discipline I have had to abandon some, scale back others, and find some new interests that are a better fit.

I have always had a vague interest in photography, but it was the gift of an old Sony manual camera right before lockdown 2020 that motivated me and I have been snapping ever since.

I enjoy it as it gets me and the family out exploring the world, is at a pace I can manage, and it provides me with a real creative outlet for the first time. I also edit my photos, sometimes from bed during recovery, as it gives me a low-intensity activity to focus on.

I love photography as it's welcoming to everyone at all skill levels, can even be done in your own back garden, and can be a wonderful way of sharing a moment with the world.

Paul Stevens
Instagram: **contrast.and.imperfection**

Mallard in low sun

Building a Sandcastle by Cupcake

"Not until we are lost do we begin to understand ourselves" Henry David Thoreau

This quote made me reflect on my M.E./CFS journey, how the first year of this illness totally broke me. I felt like an undead person, an amoeba, my body couldn't produce enough energy to even sustain basic physiological functions, let alone personality and me-ness.

As I rested and rested and rested, waiting for my body to rebuild itself, I had to even change the way my brain thought. I felt like a destroyed sandcastle. Carefully built and crafted over a lifetime, it's all I've ever known, suddenly washed away by the sea. The loss unbearable.

Slowly, grain by grain, rebuilding my castle. It's so slow, on a daily basis you wouldn't see the difference. Over months, you notice some progress. Still, the tide would come up and wash away most, sometimes all, of what I'd made, and I'd weep in frustration, anger and grief and then keep building, grain by grain.

In the first two years I desperately clung on to the image of the sculpture I'd been, grieving its loss, and scrabbled to build as fast as possible back to the exact same form I'd been. Then, slowly slowly, as the new build kept being washed back and rebuilt over and over, I learned a new level of patience, acceptance, and to appreciate the beauty of the new sculpture, that it's okay if this one looks different, just as wonderful in its own way, that every sandcastle is unique. The essence of being, however, is quintessentially you, not even M.E. can take that away, your youness. And so, that very different, beautiful sand sculpture still carries the unmistakable signature of its unique artist.

And we keep building, grain by grain.

Building a Sandcastle by Cupcake was first published on Action for M.E.'s online forum, M.E. Friends Online. To join please visit **www.actionforme.org.uk/forum**

Get in touch and share your art

Reaction

Send your letters, news and views to the editor at Action for M.E., 42 Temple Street, Keynsham BS31 1EH or email interaction@actionforme.org.uk

Please note views expressed here are not necessarily those of Action for M.E. We reserve the right to edit submissions.

Star letter

Tinnitus experience

(My partner Ian is typing this for me).

I have had M.E. for 34 years, including an initial 13 years bedridden and now seven more years bedridden and counting. This current bedridden period began with tinnitus. I experience pulsatile tinnitus, incessant banging inside my head that can last for many hours, which makes sleeping virtually impossible.

It happens mostly in the evenings and at night but has recently begun happening more frequently at other times of day. I can hear my heart beat in my right ear all the time but tinnitus is excruciating when it starts in earnest. It can be triggered by slight movements of the head, conversation, trying to focus on a person, screen, etc. As a result, my partner and I have to avoid conversation in the evenings and I am even less able to distract myself from my M.E.

The banging is immensely distressing and often leads me to despair, as nothing I have tried is able to provide relief. My hearing has also deteriorated considerably over these last few years. Hearing aids helped with this for a period but they did not reduce the tinnitus as the audiologist had hoped they might.

Maria Moore

We are grateful to Maria for sharing her experience following our feature in *InterAction* 110 on tinnitus. As author of our Star Letter, Maria receives an Action for M.E. goodie bag.

Severe ME Day 2022

"They only see us on our better days and that might be once every three months but people judge you on that one meeting. Don't see me on bad days when I don't eat and try and make it to the toilet."

Liam Pike, on Facebook

Vitamin D3 testing

Did you know that you can do a vitamin D test at home via **www.vitamindtest.org.uk**? You send a spot of blood to an NHS lab for analysis. It costs £29. Or you might persuade your GP to test you for free.

In *The Health Delusion*, Glen Matten and Aidan Goggins recommend a daily dose of 1,100 – 1,200 IU (27.5 – 30mcg) of Vitamin D for most people in the UK during the six winter months. They say you don't need to supplement in summer if you are getting regular sun exposure – 'little and often' is best. But ideally you should get your vitamin D level tested.

Frances

Clarification

In our last issue (*InterAction* 110, p 25) we said that "M.E. shouldn't be treated with antidepressants." We would like to clarify that while the 2021 NICE guideline advises that health professionals should "not offer any medicines or supplements to cure ME/CFS" it does give advice about treating individual symptoms, which may include tricyclic antidepressants to help with sleep, or the management of chronic pain. Using antidepressants does NOT mean that M.E. is the same as depression, or that it is a mental illness. The doses used to help with sleep and pain are much lower than the doses used to help manage depression.

Jill's story resonated with me

I was glad but sad to read Jill East's article in the Spring edition. It rang so many bells with me. I am in my late 60s and have had M.E. for over 16 years. There must be a lot of us older sufferers who now have to deal with the added challenge of age-related health issues and uninterested/ill-informed medics. For myself, as well as M.E.-related nerve pain and fatigue, headaches and balance problems, I have similar symptoms related to spine deterioration. So medication for one aspect does not necessarily help and sometimes aggravates the other. And don't start me on brain fog! There must be a lot of us older sufferers out there.

Helen Moore

Speed read feedback

Just about finished reading the Spring edition. The speed read blocks are indeed helpful. I don't read every article depending on my well-being at the time, having a précis is perfect for me.

Great suggestion from Ken Manley and love that you took it up straight away.

Andrya

Kindness at Christmas

Our popular Christmas Angels initiative is back again, returning for its 12th year.

If you would like to take part, please turn to our back cover where you can find out more about the scheme and how to sign up.

Here's some of the lovely feedback we received following last year's project:

"Having severe M.E. is very isolating and lonely, especially when friends lose touch. Getting a Xmas card from someone, even a stranger, makes you feel part of a community and less isolated. It is just a card, but it means so much more when you are struggling with M.E., especially if the person has taken the time to write a kind message inside. "

"Amazing initiative. Thank you!"

"I loved this project and it made such a difference to be able to take part. The message in the card that I received was so kind, understanding, and empathic. I never come across that in my normal life. In fact, not in eight and a half years of having M.E."

"It's lovely to be part of something special."

"I love taking part in something so meaningful at this time of year. It's such a relief to have one small thing I can manage to do that might support another. The messages I receive from others in return are beautiful and heart-warming to one who lives alone. I love this project!"

"The cards always cheer me up and make me feel that I am not the only one struggling at Xmas."

Get in touch and share your views

FUNDRAISING

Knitting for M.E.

One of our lovely supporters, Carol, picked up her knitting needles again this year to knit woollen sheep hats to raise money for Action for M.E.

Carol said: "Action for M.E. is a cause close to my heart as my daughter Catriona became ill with M.E. when she was 15. She is now 29. And still battling every day. She is amazing. She struggled through university and is now working in wildlife film production. She has to manage each day so carefully."

This year Carol has raised a fantastic £200 by selling her fabulous creations to friends and family. She said: "I beat my total from last year, so I'm very pleased". Congratulations and thank you so much, Carol.

Noticeboard

Get in touch and share your notices and tips

To place a notice (up to 80 words) here or to reply to a box number, email or write to the editor (contact details are on p 2).

Art exhibition

Raising awareness through art

The Sheffield ME and Fibromyalgia group will be hosting a hybrid awareness art exhibition from 26 September to 8 October both online and at Sheffield Winter Gardens.

If you live around Sheffield, please get in touch to share your artwork. It could be a painting, drawing, writing, sculpture, craft, photograph or a live performance. If you aren't local but would like to contribute to the virtual exhibition, please send us your photo/video. Contact myself (Elyane) and Pippa on **info@sheffieldmegroup.co.uk**/ 07753 948186. Our website: **www.sheffieldmegroup.co.uk**

Elyane Bardou

Butterflies for M.E. by Penny using watercolours

Support group

Members needed

Do you live in Manchester and are looking to join an M.E. support group? An informal group to support people with the condition is being set up. To find out more please contact Shaun on 0161 2563571.

Pen pals

Seeking pen pals

I am 53 years old and have had M.E. for 16 years. I am 80% housebound.

I would love to hear from any females who would be interested in becoming a pen pal. I don't use the internet as I can't manage it and I'm not very good on a computer. Our email address is **sjclparsons@hotmail.co.uk** and my husband will pass any messages to me.

I love writing and reading and have a Christian faith. I would be most grateful to hear from anyone who is feeling isolated due to the illness.

Colette

FUNDRAISING

Congratulations to our Edinburgh runners

This year we had four fantastic runners take part in the Edinburgh Marathon, each running 26.2 miles around the Scottish capital to raise funds for Action for M.E.

Ken was diagnosed with M.E. when he was six years old. He remembers: "Throughout my childhood I suffered through illness, including being hospitalised, missing a lot of time at school and struggled with daily life. I also suffered the stigma of doctors, teachers, school friends and others believing that I was 'putting it on'." Ken's M.E. became much less severe after his childhood. He decided to run the marathon "to raise money, but also raise awareness for the 250,000 M.E. sufferers in the UK."

Jamie's sister has lived with M.E. for years. He decided to run and fundraise for us, saying: "I think this chronic condition is not taken seriously enough or given adequate attention by the mainstream medical community. My sister has lived with M.E. for almost seven years now and during that time I've been able to see what a detrimental impact it can have on day-to-day life."

Our other two runners, Stuart and David, both ran in honour of their mothers, who have lived with M.E. for many years.

The whole team completed the mammoth challenge in May, and together raised a brilliant £4,446.

Jamie at the finish line with his sister

Spotlight on...

Chair Eileen Longworth tells *InterAction* about Dumfries and Galloway ME and Fibromyalgia Network and what the group is doing to support members.

Dumfries and Galloway ME and Fibromyalgia Network (otherwise known as DGMEFM Network) is a charity registered in Scotland for more than 20 years. At the present time, we are in transition to SCIO status (Scottish Charitable Incorporated Organisation) as of 1 August 2022.

Our aim is to support people within the Dumfries and Galloway region who live with M.E./CFS, fibromyalgia, and the post exertional malaise symptoms of Long Covid.

The Network raises awareness of the issues surrounding these conditions. We investigate and provide information about all aspects, symptoms, experiences, and treatments available for M.E./CFS/FM and Long Covid. We offer support to any person living with these issues, and any matter concerning them. We also facilitate a mutual support network.

Facebook

If you use Facebook, there is a public page where anyone can find us, but if you live in our area I would recommend that you ask to join our private group at DGMEFM Network (support for M.E., CFS, Fibro, Long Covid) on Facebook (**tinyurl.com/Facebook-dgmefm**) then introduce yourself when you're ready, and chip in with a post or comments. Members can interact on any subject ranging from how to cope, how to explain the conditions to family and friends, and a bit of humorous banter always goes down well. There's also linked groups for crafts and the 'Social Cafe' for general chat and jokes.

Pop-up meetings

We have a few pop-up meetings planned across the region during the summer. These are our first face to face meet ups since the beginning of the pandemic. In some areas people are more reticent to get-together, but we have had a couple of meets so far which have been very positive.

For the last couple of years, we have been holding weekly Zoom meetings. Our plan moving forward is to have hybrid meetings monthly from October, where members can attend in person or via Zoom, whichever is most convenient for them. These will be the first Thursday of the month, 2-4pm. The event and Zoom link is advertised on our website, and Facebook group.

There are often speakers at these meetings, which are all advertised on our Facebook group too, and our website **www.dgmefm.org.uk**

Website

Our website is designed to be easily accessible for people living with these conditions. We have a monthly personal blog, and a monthly informative blog relating to research, or articles posted on our Facebook group.

There is the opportunity to join as a full member of the charity, for which there is no charge. There is an option to request to have newsletters sent by post or via email, and these can also be found on our website.

The website has a world of information on all these conditions which we are living with, so plenty to keep you occupied.

We act as a central point for representative consultation between our members and other agencies, including Dumfries and Galloway Council, the NHS, benefits agencies etc.

Over the past year we have been lucky enough to be awarded funding from Health and Social Care Alliance Scotland for a feasibility study regarding our hoped for future projects, namely a befriending scheme, an expert patient mentoring scheme and also the further consideration of a Clinical Lead in this specific area. After that report, by Sleeping Giants CIC, we are now waiting to hear the result of further funding applications to undertake the above projects.

For newly diagnosed people with M.E./CFS, fibromyalgia and the post exertional malaise symptoms of Long Covid, life suddenly becomes a minefield of information, misinformation, misunderstanding, confusion, frustration and helplessness. There is also a certain amount of grief or bereavement when the realisation dawns that this is your new life.

If anyone reading this article lives within the D&G region, please do not hesitate to get in touch. We are a board of trustees made up of volunteers from all over the region, so there is always likely one of us who will be close by.

Tired? really?

We need more words for tired, says our new columnist Ellie Finney

For me, there's only one way to start my regular column: the word tired.

How many times do I say the word every day? How many times do I hear it from other people? My life revolves around the word: it's the thing I complain about the most. But the word isn't sufficient; it's overused to the point where it doesn't really mean anything anymore. Sometimes, I add other words. I'm quite tired. I'm deathly tired.

And my M.E. is mild.

The first thing I usually want to know about people with M.E. is how they would self-categorise. I was mild for ten years then had a three-year spell in moderate (with an occasional drop into severe) but I'm back to mild now. If I balance everything well, I can pass as a healthy person for short periods of time. I'm so grateful for my current quality of life, but my life is still governed by the word tired.

Sometimes I repeat the word (I'm tired-tired) but it's still not enough. We need a word for tired that is just ours, one that healthy people can't commandeer. Fatigue no longer fits the bill, and really, it's just French for tired. Inuits have one hundred words for snow because they need them to categorise all the different types of snow, so it's only fair that we get the same for tired. Run-over tired. Bone-tired. So-tired-it-hurts. Zombie-tired. Helpless-tired. Sad-tired. Heavy-head tired, but in one neat little word. It can become our own secret language. Healthy people won't be allowed to use it.

Limited sympathy

I don't know about you, but I have a physical reaction every time a healthy person tells me they're tired. I try to have sympathy. I try to tell myself that tired isn't the norm for them, so it's worth mentioning, but I'm not the right audience for that sort of complaint. On bad days, I have very limited sympathy for parents (you chose to have kids, I didn't choose to be chronically ill), people who work too hard (I'm so sorry that you're well enough to work and not look after yourself, get paid loads of money and have never had to fill out a PIP form) and people with hangovers (this doesn't need justifying).

Sometimes I find it helpful to use numbers instead. 1 is a background hum of tiredness and 10 is being scared I'll have to live in the bath forever because I'm too tired to get out. The best thing about a scale is that it can be your scale; you define your best and your worst, it's not a universal tiredness scale. It also helps give friends and family a sense of where you're at without having to use words they throw about so flippantly. But it makes me sad that I've had to resort to numbers because words have failed me.

Perhaps I'm so sensitive about it because I'm tired of having to communicate my tiredness. If I know how tired I am, why am I trying so hard to get everyone else to understand? Unless they swap bodies with me, they won't ever understand. If I'm not trying to get understanding, am I trying to get sympathy? This isn't the best illness to get sympathy for. I think what I'm really trying to do is to get people to stop relating. Some friends now describe themselves as 'healthy-person- tired' to stop me from grinding my teeth.

Badge of honour

But why do I want to win the tiredness Olympics so badly? Because society has made tiredness a badge of honour. Tiredness proves you either have a fun life or a productive one, and in the eyes of society, I don't have either. So, when healthy people complain about being tired, they're subconsciously saying 'look how bountiful my life is, I've had to deprioritise sleep because of how busy I am.' I can't relate to that: sleep is my everything.

How do you describe your tiredness to others? Do you feel the same when other people complain of being tired? I know the answer to this issue is to probably stop getting so annoyed about it, go and meditate and generally save my energy.

Create or update your Will for free this October

SPEED READ...
Free Wills Month starts on 3 October and gives over 55s the opportunity to meet with a solicitor who will create or update your Will for free. Appointments are limited so make sure you sign up as soon as the service starts. Please go to this website **www.freewillsmonth.org.uk** to sign up to receive a notification when the service starts and to download your Free Will Guide.

What is Free Wills Month?

Free Wills Month takes place each year in March and October and offers individuals or couples the chance to have an appointment with a solicitor who will create or update their Will for them. This year, Free Wills Month starts on **Monday 3 October 2022**.

It is free of charge and the solicitors taking part are doing so in selected locations across England, Northern Ireland and Wales. The solicitors will aim to make you feel as safe and comfortable throughout the process as possible, so should offer a range of ways to meet including video calls, phone calls or socially distanced in-person meetings.

In order to participate, you must be over 55 years of age and willing to set aside time to speak to a solicitor who will then create or update your Will for you.

Why have a Will?

Did you know that 54% of adults in the UK don't have a Will? Having a will can help to prevent issues that could arise after your death.

Writing a Will is also a sure way to ensure that your wishes are respected and carried out after you are gone. By creating it now, it means that you won't have to think about it later and your loved ones can mourn in peace when the time comes.

Once you have provided for your loved ones, you might consider leaving a gift to a cause that is close to your heart. Gifts left in Wills make a huge difference to charities. A gift left by a member in their Will helped Action for M.E. to launch the pilot project of our Advocacy Service, which now runs nationally and provides support to hundreds of people with M.E. each year.

You are under no obligation to leave a gift but if you decide to do so, it is a gift that will cost you nothing now but can make a huge difference to someone's future. Leaving a gift in your Will is a way for your memory to live on and be remembered. No matter the size, gifts left in Wills to Action for M.E. are so important in helping us to work towards ending the ignorance, injustice and neglect experienced by people with M.E.

How to get involved

Visit **www.freewillsmonth.org.uk** to find out more about the solicitors taking part in your area, and to sign up to receive a notification when the Free Wills Month begins. On the same website, you can also download the Free Will Guide, which will help you prepare for questions the solicitor will ask at your appointment.

After the month begins, you will be able to book an appointment with a solicitor to create or update your Will. Please note that appointments are allocated at a first come first served basis, so make sure to book your appointment as soon as the service starts to avoid disappointment. It is also worth knowing that you may be asked to cover the costs of the service if your Will is complicated or you have a large estate.

If you have any questions, please get in touch by emailing **legacies@actionforme.org.uk**, calling 0117 927 9551 or writing to us at 42 Temple Street, Keynsham BS31 1EH.

Be an angel this Christmas!

Action for M.E.'s Christmas Angels project – now in its 12th year – enables people with M.E. to send Christmas cards to each other via the Action for M.E. office.

If you would like to send or receive a card from another Action for M.E. Supporting Member this Christmas, or know someone severely affected who would appreciate a card, please get in touch by:

- sharing your details via our simple and secure online form at **www.actionforme.org.uk/christmas-angels**
- writing a note to the editor at *InterAction*, Action for M.E., 42 Temple Street, Keynsham BS311EH
- calling us on 0117 927 9551.

We will then contact you to let you know what to do next. All it will cost you is the price of a card and a stamp. Please let us know whether you would like to take part by **Monday 17 October 2022.**

And don't forget your Action for M.E. Christmas cards!

You will find your Action for M.E. Christmas card leaflet inside this copy of *InterAction*. You can order cards by post, phone or online, and postage and packaging is included in the price.

Each card says a little bit about M.E. and the work we do to support those affected by it. If you would like to order more Christmas card leaflets, please do get in touch.