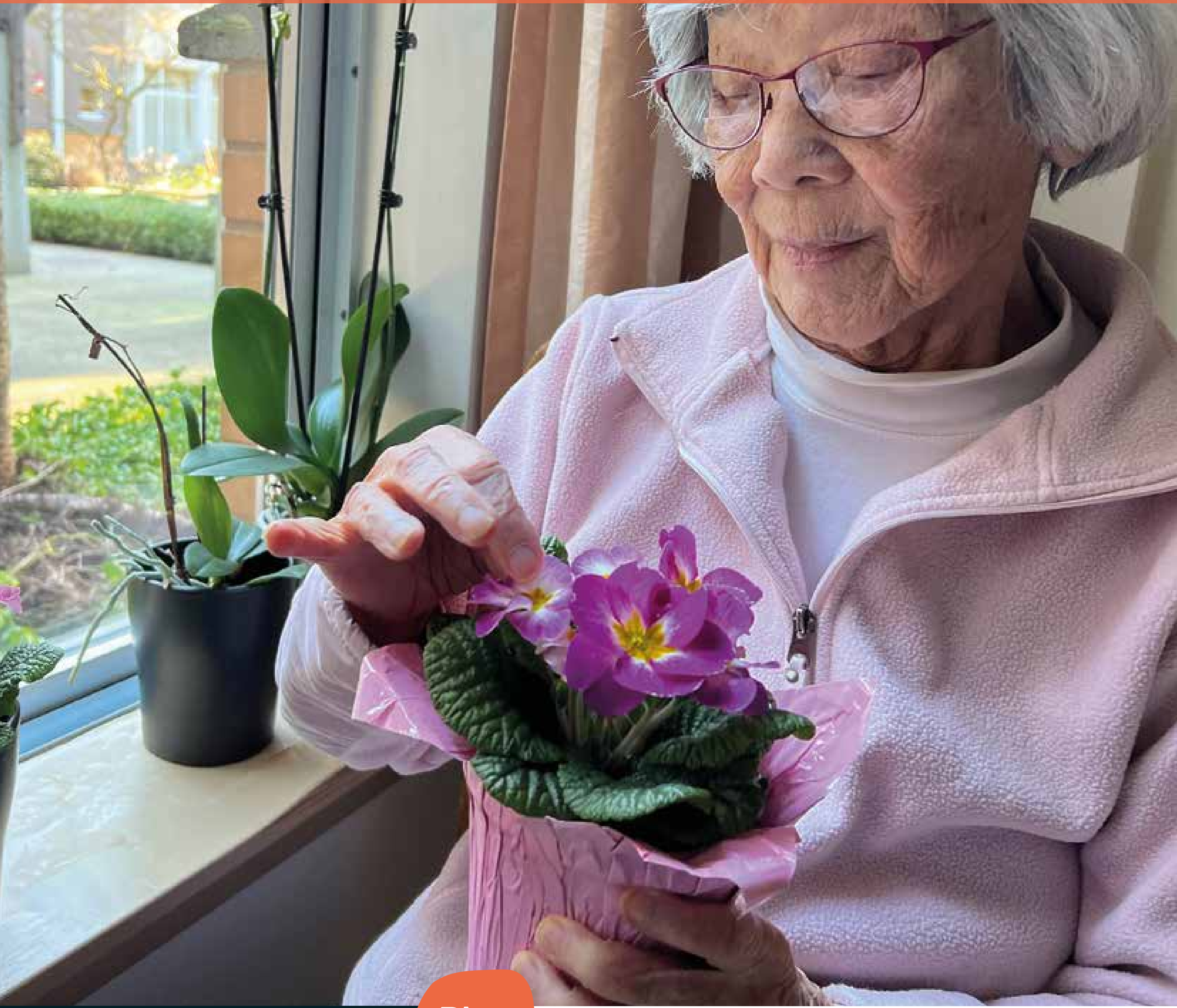
Issue 119 • Spring 2025

Our vision is a world without ME

InterAction

Debunking myths about ME

for World ME Day 2025 p 6



ACTION FOR M.E.

Plus

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More to be done

Welcome to your new issue of *InterAction*, our magazine for Supporting Members.

As I write, news has come in that the proposed final Delivery Plan will be published by the end of June 2025. We, like you, have been frustrated by the constant delays to the publication of the plan. We are also profoundly disappointed about the Government's decision not to allocate funding for research on ME, which was a strong focus of our own response to the consultation phase (se p 4). Without this urgent research funding, the impact of the plan will be limited to small short-term improvements, like the NHS e-learning resources on ME (p 17).

We continue to push for better understanding, support and funding for the future. For this year's World ME day, we will work with other charities and patient campaigners to highlight six myths about ME – and facts to counteract them (see p 6). It is a travesty that there is still so much misunderstanding and poor education surrounding this life-devastating condition. Through World ME Day, we harness our collective power to raise awareness around the globe.

Education and awareness surrounding ME is so important, especially in the face of discrimination. You can read the distressing story of how NoLoyiso has been treated by social and care workers as a Black woman with severe ME on p 24. In our Reaction pages, readers share the exhausting experiences they have faced when seeking support with disability benefits, something I know is of great concern to many of you (p 36). We strive to advocate for the needs of those with ME in so many areas.

You'll see from these pages that we have a new look. A long overdue refresh of our website and resources has taken place, including our ME Friends Online forum (see p 18). Our previous website was no longer fit for purpose, limiting our growth and opportunities to raise vital awareness and funds to support people affected by ME. Our new website gives us greater opportunities to provide support to even more people affected by ME and to create more impact through our research and campaigning work. We know we still have more to do, but we are committed to working with you to help us achieve this.

With all best wishes

Sonya

Sonya Chowdhury
Chief Executive

Contacting Action for ME

Information and Support service

Our friendly team can share information, support, resources and signposting, and refer to our other services. Email or call Monday to Thursday 10.30am to 3pm to request a call-back. We get back to everyone within five working days and usually much sooner.

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

Find us on social media
Instagram: @actionform.e
Facebook & LinkedIn: @actionforme
Bluesky: @actionforme.bksy.social

InterAction enquiries

To submit a letter or notice, give feedback or reply to a box number
Call **0117 937 6620** Email **interaction@actionforme.org.uk**

If your prefer to send by post, please write to us at

Action for ME, Unit 2.2 Streamline, 436-441 Paintworks, Bristol BS4 3AS
(please note postal enquiries take longer to process).

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 ME. 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.

Please donate to support our work at www.actionforme.org.uk/donate or call 0117 927 9551

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Please note the email for contacting our Information and Support team has changed. Enquiries should now be sent to **infosupport@actionforme.org.uk**. Emails sent to the previous ‘questions’ email will be forwarded to the new address for the time being.

Hot topics

- Congratulations to all the winners of our Winter Raffle. Enter our **Spring Raffle** for another chance to win – see the back cover of this issue to find out more!

- **Blue Sunday** is taking place on Sunday 18 May – time to wear your blue pyjamas! See p 7 for how to take part.

- You can direct healthcare professionals to **e-learning on ME** modules from NHS England (see p 17 for more information and links).

- Astrid has published a new guide for people with long-term health conditions on disability disclosure and discrimination at work.
Find out more:
tinyurl.com/astridguide

- Our last **Big Survey** was carried out in 2019 and was vital in supporting our awareness-raising and policy activities. We’ll be conducting another Big Survey this year, which you’ll find in our next issue. To find out more about our Big Survey research, see p 17.

- Our ME Friends Online forum has relaunched as part of our website update (p 18).
www.actionforme.org.uk/forum

- **Visible** are kindly gifting us with some nearly-new wearable armbands to share with members. (Note: you’ll still need to subscribe to Visible to use this wearable health tracker with the app). For a chance to get one of these devices, see p 37.

Delivery Plan due in June

The long-awaited final Delivery Plan on ME/CFS is due to be published by the end of June 2025, but no funding has been allocated.

Speed read...
In December 2024, the Department of Health and Social Care released a summary of the consultation responses on the Interim Delivery Plan (IDP) on ME/CFS. According to Government sources, the final plan is due to be published by the end of June 2025. We have been told that no extra funding will be made available to improve care or fund research for ME, which is incredibly disappointing.

On 12 May 2022, World ME Day, the former Secretary of State for Health and Social Care, Sajid Javid, announced the Government's intention to develop a cross-Government Delivery Plan on ME/CFS for England.

At the time, our CEO Sonya Chowdhury commented: "It is fantastic to see that this devastating and disabling condition is being explicitly acknowledged by Government as priority."

Three years on, following significant input from patients, carers, charities and professionals led by the Department of Health and Social Care, the ME community awaits publication of the plan – which, we are now told, will be by the end of June 2025.

In February this year, Baroness Finlay of Llandaff submitted a written question in the House of Lords, asking how the Delivery Plan will "ensure collaborative work with patient advocates, philanthropy and industry partners to leverage additional funding for biomedical research."

Baroness Merron replied that the government "cannot comment on the exact content of the final delivery plan at this time, but it will be shaped by responses to the 2023 consultation on the Interim Delivery Plan, alongside continued stakeholder engagement via the ME/CFS Task and Finish Group, with three broad themes of boosting research, improving attitudes and education, and bettering the lives of those living with ME/CFS."

According to Government sources, the extension to the publication timeline is to allow further engagement with the ME/CFS Task and Finish Group and those responsible for actions in the final delivery plan. "Through this engagement, we will further scope and develop new and stronger actions seeking to deliver meaningful change for the ME/CFS community," they claim. You can read the DHSC statement on the Delivery Plan here: **tinyurl.com/DPStatement**

Helen Morgan MP
© House of Commons/Roger Harris

Ashley Dalton MP
© House of Commons

The story so far

In August 2023, the Department of Health and Social Care (DHSC) published the cross-Government Interim Delivery Plan on ME/CFS.

This set out actions on research, attitudes and education of professionals, and living with ME, with an aim to bolster care and support for people living with the condition.

The DHSC launched a public consultation to seek views from individuals and organisations on how well the interim plan identified and addressed key issues that the ME/CFS community faced, and where further action may be needed. This consultation closed in October 2023.

Responses

The DHSC released an 8,000-word document in December 2024 summarising the responses, which can be read in full at **tinyurl.com/IDPconsultation**

In addition to actions proposed in the Interim Delivery Plan, further key actions were proposed by respondents (outlined on opposite page).

Research
Respondents asked for:

- a research funding commitment
- a targeted research plan
- more research, particularly biomedical research, to understand causes and treatments.

Attitudes and education
Respondents asked for:

- training for professionals, including compulsory training for healthcare professionals
- a shift in public understanding
- better guidance for schools
- a stronger action plan.

Awareness and understanding
Respondents asked for:

- a public awareness campaign
- SMART actions, with a timeline for implementation
- inclusion of patient voices.

Statutory support
Respondents asked for:

- stronger actions and language to enforce proposed actions
- reform of support systems, such as DWP assessments
- broader public sector support, such as funding for charities' support services
- rebranding and a public apology to correct misconceptions
- mental health support.

These responses, alongside continued stakeholder engagement, have informed the development of the final plan, along with further input from the Task & Finish group (see panel below right).

What happens now?

While waiting for the final plan to be published, we have learned that no extra funding to improve care or research for ME will be made available.

In a statement to parliament in February, Ashley Dalton, Minister for Public Health, said: "There are currently no plans to allocate additional funding towards the ME/CFS final delivery plan [...] We do not anticipate setting up a new centre of excellence for care and research specifically for post-viral or infection-associated conditions."

This is incredibly disappointing. The delivery plan is an important step forward for the ME community but, without additional funding for much-needed and overdue research, its impact will be limited.

Establishing a centre of excellence for care and research for infection-associated chronic conditions, including ME, would co-ordinate research efforts and drive innovation. This could potentially be the catalyst for unlocking crucial treatments for people living with ME. We will not develop these without urgent research funding.

MPs have put pressure on ministers to provide more funding for ME. Writing for The Times, Liberal Democrat MP Helen Morgan said: "Over the past 12 years, the Government has invested just £8 million in ME research. While the UK has committed strategic funding to dementia, motor neurone disease and mental health conditions, similar funding for ME has been considered an impossibility. A well-resourced plan should be seen not as a sunk cost but an investment in 1.3 million patients and their carers across the UK."

Labour MP Jo Platt, chair of the APPG on ME (see p 8), said: "People living with ME have waited far too long for real research funding and have been let down by the NHS for decades. We owe it to them to deliver a solid plan backed by strong leadership and the resources needed to make a real difference."

Who responded?

The consultation received **3,338** responses. Of these:

- **3,113** were from individuals sharing their personal views
- **125** were from individuals sharing their professional views
- **53** were from individuals responding on behalf of someone else
- **47** were from organisations.

Most organisations were from the voluntary or third sector (including Action for ME), although there were also responses from organisations in the public and private sectors, as well as other professional bodies and organisations.

Action for ME's research-focused response, calling for ring-fenced funding, was published in *InterAction* issue 115 (p 9).

What is the Task & Finish Group?

The Task & Finish group is made up of patients, carers, local ME groups, clinicians, social care and education professionals, Royal Colleges and charity representatives, including Action for ME. It met three times in January and February 2025 to discuss the final plan.

Before each meeting, we were sent a pre-agreed agenda and relevant documents to consider in advance. At the meetings, we helped draft wording and agree on content/actions, informed by consultation responses.

Myths about ME

Debunking misconceptions for World ME Day 2025.

This year's World ME Day (on 12 May) will highlight six myths and facts everyone should know about ME. At the time of *InterAction* going to print in March, the wording and graphics for these were still to be finalised. Here's a taster of four of the myths.

Myth: ME is a mental health condition.
Fact: ME is a biological illness that disrupts metabolism and impairs the brain, immune system and autonomic nervous system.

It often starts after an infection, flu or Covid. Millions of people worldwide have ME, with about 75% of them being women. Many struggle with daily activities, up to 75% cannot work or attend school, and at least 25% of patients are so severely affected that they are housebound or bedridden.

Myth: ME is just about feeling tired.
Fact: The defining symptom of ME is Post-Exertional Malaise (PEM) - an extreme worsening of symptoms after even minor physical or mental exertion. This can trigger a 'crash' lasting for days or longer, making even basic activities difficult or impossible. Attempting to push through can significantly worsen symptoms and may lead to long-term deterioration.

For those with severe ME, even minimal exertion – such as sitting up, light conversation, or sensory stimuli like sound and light – can be intolerable, leaving them extremely disabled and dependent on full-time care.

Myth: You can exercise your way to recovery from ME.
Fact: Exercise can be dangerous for people with ME.
Unlike other chronic conditions where exercise can help, structured exercise programs often make ME symptoms worse as patients end up pushing themselves too far.

In the past, graded exercise therapy (GET) was recommended, but after reviewing the evidence, health organisations like NICE in the UK and the CDC in the US have warned against it. Instead, people with ME are encouraged to pace themselves – balancing activity and rest – to avoid deterioration.

Myth: Doctors cannot help people with ME.
Fact: Doctors can help people manage ME symptoms.
While there is no cure for ME, there are compassionate ways to help patients manage their symptoms, in addition to pacing to prevent PEM. Treating co-existing conditions and providing medications to address sleep disturbances, pain, and cardiac and neurological issues can offer significant relief. Offering at-home visits, online consultations and palliative care can make a big difference to someone suffering from severe ME. (Examples of resources for medical professionals include NHS e-learning modules – see p 17 for more information on these.)

World ME Day takes place every year on 12 May and is coordinated by the World ME Alliance and its members. By focusing on a single day and collaborating across many organisations, we aim to maximise our collective power.

To find the full list of myths and facts, together with World ME Day graphics and social media resources, please check our website for World ME Day news, or visit ***www.worldmealliance.org***

Future directions for research

In March, Action for ME held a research consultation in partnership with St George's House. Titled *Future Directions and Opportunities for Long Covid and ME Research*, the event brought together 28 international experts to explore collaboration, research priorities and ways to accelerate treatment development for ME and long Covid.

Attendees included representatives from biotech companies (eg. PrecisionLife), research foundations (eg. Metrodora Foundation), academia, government bodies (eg. NIHR, the Office for Life Sciences, and the Science and Technology Facilities Council), and people with lived experience.

The event was a great success, with engaging discussions and a strong commitment to working together. Some key outcomes included plans to update the consensus document on ME and long Covid research priorities. There was also a proposal to establish the group more formally and expand the network.

This was an important step forward, and we look forward to building on this momentum.

Podcast on severe ME

The final podcast of the Learn About ME podcast series focuses on severe ME. Dr Robin Kerr and the 25% ME Group's Helen Brownlie joined Action for ME's Clare Ogden and Avril McLean to discuss practical support for people with severe and very severe ME. Find this and other podcasts here: **www.buzzsprout.com/1717775**

Resourcing GPs in Northern Ireland

In March, GPNI hosted a webinar for GPs in Northern Ireland, aiming to empower GPs in the assessment, diagnosis, support and treatment of ME.

The webinar used the Learn About ME presentation and the panel included three clinicians with a mixture of personal and professional experience on ME - Dr Nina Muirhead (developer of the CPD-accredited learning module on ME/CFS), Dr Robin Kerr (GP and Action for ME doctor), and Linda Campbell (Chair and Healthcare Professional Education Advisor for Hope 4 ME & Fibro).

Their insights helped highlight the crucial role primary care plays in supporting those affected with ME.

Blue Sunday is on the way

Join Anna Redshaw, Action for ME and many others on 18 May 2025 for tea, cake and community!

Anna Redshaw's Blue Sunday Tea Party is back for 2025. Last year's event raised £2,170 for Action for ME. The money raised helps our vital support services reach more people with ME.

For ways to donate and other information, visit **bit.ly/AFME-Blue-Sunday-25** (or scan the QR code). You can also contact our friendly fundraising team for more information on 0117 927 9551 or email **fundraising@actionforme.org.uk**

Unable to work, Anna spends her months preparing for Blue Sunday, and then recovering from this effort, each year. We want to express our heartfelt thanks to Anna for spending her precious energy in bringing the community together and supporting Action for ME.

Find out more about Anna: **www.the-slow-lane.com**

How to take part

- Wear something blue (pyjamas count!)
- Dig out your best cups and saucers
- Bake or buy your favourite cake
- Post a photo of your tea party set up on social media.
- Invite others to enjoy tea and cake with you in-person, via video call, or by sharing photos
- Donate the price you'd pay in a café to an ME charity
- Connect with others online who are doing the same, by commenting on their posts.

Do one, a few or all to show support for the ME community.

ME in parliament

APPG on ME

The inaugural meeting of the new All-Party Parliamentary Group (APPG) on ME was held in December and the group was formally registered. Jo Platt MP was confirmed in appointment as Chair.

At the most recent meeting in March, there was a detailed discussion surrounding the Delivery Plan and the lack of strategic funding to back the plan (see p 4). Members also approved the APPG's proposed workplan, which included additional suggestions from other charities and members of the ME community.

It was also agreed that two of the APPG on ME's meetings this year would happen alongside the APPG on long Covid, which is also chaired by Jo Platt MP. The group's next meeting will be on Wednesday 14 May – the first meeting alongside the APPG on long Covid. It will focus on research and the relaunch of the severe ME enquiry.

The minutes of the March APPG meeting are available here: **tinyurl.com/APPGMarch**

> **"As Chair of the APPG on long Covid and ME, I will keep pushing for greater recognition and support for the long Covid and ME community. Their voices deserve to be heard."**
> Jo Platt MP


Joanne Platt
©House of Commons/Roger Harris

Championing our cause

Our network of Parliamentary Champions continues to grow. Recent additions include MPs Tessa Munt and Paul Waugh, following separate meetings with our CEO, Sonya Chowdhury.

"It was great to have the opportunity to talk through the importance of the impending Delivery Plan, the need for strategic research funding into the condition, and the day-to-day challenges faced by people living with ME," says Sonya.

"This cause is especially important to me as I have seen firsthand the devastating impact of ME amongst friends, colleagues and constituents," says Tessa. "I hope to see stronger commitments in the months and years ahead with the Government prioritising much-needed research into this debilitating disease so our NHS can improve its care for people with ME."

"This role will allow me to advocate for those living with ME and campaign for much-needed change, as improving the lives of people with ME is a cause that demands greater attention," says Paul.

Our network of Parliamentary Champions is essential for raising awareness of ME, helping to include ME and related issues in parliamentary business and working with the media.

Our champions also assist by tabling written and oral questions on ME, sponsoring events in Parliament, and writing opinion pieces for local and national press. **tinyurl.com/ParliamentaryChampions**


Tessa Munt
© House of Commons/Roger Harris


Paul Waugh
© House of Commons/Laurie Noble

Migration to Universal Credit

What you need to know.

The Government has said that it intends everyone on ‘legacy benefits’ (which includes means-tested ESA and housing benefits) to move to Universal Credit by the end of the year. This isn’t an automatic process – it will require action from you in order to ensure that you don’t miss out. However, the good news is that you shouldn’t need to have an additional assessment as part of the move (unless you were due to have one anyway, or haven’t yet had one at all).

If you’re on a legacy benefit, you will receive a letter (if you haven’t already) from the Government which states it is a ‘Universal Credit Migration Notice’ and explains that the benefit you’re on is being replaced by Universal Credit.

It’s important not to ignore the deadline on this letter, because this might affect how much money you get in future.

A benefits adviser will be able to help you work out exactly when it’s best to start your Universal Credit claim, but the Money Saving Expert website says “[a]s a general rule, it’s best to claim as soon as possible after receiving a benefit payment”. If you don’t think you will be able to make your claim by the deadline on your Migration Notice letter, you should ask the DWP for an extension *before the deadline* is up by calling the **Universal Credit Migration Notice Helpline on 0800 169 0328**, explaining why you need more time.

Once you make a claim for Universal Credit, it usually takes five weeks before you are paid. This means that you’re likely to have a longer period between benefit payments than you’re used to. If this will leave you without enough to live on you can ask for an advance payment of Universal Credit, but this will be a loan not a grant, and repayments will be deducted from your Universal Credit payments once you start to be paid regularly.

You can get help to start your claim from Citizens’ Advice here:
tinyurl.com/HelpToClaimUC
See also
Benefits and Work:
tinyurl.com/BenefitsWorkUC
Money Saving Expert:
tinyurl.com/MSAUCguide

Serious concerns about benefits

We understand and share the concerns and anxiety that the proposed changes within the recent health and disability Green Paper have caused. It is important to remember that even the proposals which are not being consulted on still require legislation to become law, meaning they may still change.

Until then, we will work to ensure that your concerns are heard by those making decisions. We will do this through engaging our Parliamentary Champions to share your voices directly in Parliament, ensuring people with ME are not negatively and unfairly impacted.

We will also seek to collaborate with and support other organisations in our shared calls for the Government to protect people with disabilities and provide them with the support they need.

The wider consultation is open until **30 June 2025**. We will be producing a survey to provide you with the opportunity to feed directly into our organisational response, highlighting how proposed changes to the benefits system will impact you. You may also wish to submit your own consultation response.

Link to consultation: **tinyurl.com/GreenPaper25**

Safeguarding vulnerable claimants inquiry

Written evidence submitted as part of the Work and Pensions Committee inquiry, “safeguarding vulnerable claimants”, is now available on the Committee’s website: **tinyurl.com/SVCEvidence**

This inquiry focuses on health checks that assess individuals’ eligibility for disability benefits such as PIP and ‘fit for work’ tests that qualify claimants for the disability elements of universal credit.

We submitted our own response, explaining that people with ME face considerable challenges when trying to make a new benefit claim and highlighting the long-standing and considerable stigma attached to ME.

We were pleased to be given the opportunity to provide evidence as part of this inquiry, ensuring the experiences of people affected by ME were heard.

Voting for Trustees

Please cast your vote for new and returning Trustees to the Board by 11 July 2025. You can do this digitally as well as by post.

Our Trustees ensure that the Board has all the necessary skills to govern the charity effectively.

This year we have two new candidates standing for election and four candidates standing for re-election (one of these for an exceptional term). They will be formally appointed subject to the votes of our Supporting Members.

Please indicate your vote either by:

1. Using the form on p 12. Return it using the envelope provided to arrive on or before 5pm on 11 July 2025. (You can use the same envelope for your vote and your Spring Raffle entry!)
2. Casting your vote online on or before 5pm on Friday 11 July 2025 by visiting **tinyurl.com/AfME-vote**

Only candidates who receive more 'yes' votes than 'no' votes are appointed to the Action for ME Board of Trustees.

Results will be announced at our online AGM in September (details to follow).

For full terms and conditions, please see the notes on p 12.

Introducing Wendy and Ros

Wendy Lippmann

Wendy Lippmann is a civil servant who has also worked in the NHS and Adult Social Care developing strategy, implementing national policy and running projects and services. She brings a wealth of insight into these public services due to this range of experience.

Wendy also understands the challenges faced by people who have ME first hand, as her daughter was diagnosed with mild ME aged 17 after struggling for several years with unexplained pain and chronic fatigue during secondary school. This experience brought home how empowering it is to have a diagnosis to help explain the condition to others and draw on appropriate support. Wendy is delighted to support Action for ME in its mission to raise awareness about the condition, expand research and improve the quality of life for everyone affected by ME.

Ros Boyle

Ros has 30 years of experience in the voluntary sector in a variety of large and small charities, with services across health and wellbeing, disability, young people, housing for the homeless and overseas development. Her expertise is in fundraising, particularly from Trusts and Statutory Organisations.

Ros became aware of Action for ME whilst looking for information and support for her son, who has had ME for several years. "I found amazing advice and understanding from the charity both for myself as a carer and for my son," Ros explains. "As a result, I wanted to get involved to support the charity's mission and ensure those living with ME get the care and support that they need, whilst also looking for greater understanding of the disease and a cure."

The following Trustees are up for re-election:

Philip Courtney

Philip is Head of Tax (EMEA and APAC) for Cantor Fitzgerald. Philip has specialised in international tax since qualifying as a Chartered Accountant in May 1988, first in the profession and, since 1995, in industry with Fiat Group and Clifford Chance – one of the world's pre-eminent law firms.

Philip has firsthand experience of the challenges faced when doctors and healthcare professionals run out of traditional medical solutions. One of Philip's best friends at university has had ME for many years and approached Philip to be a founding Trustee of the ME Trust. This merged with Action for ME in 2022.

Julianne Devine

Julianne is a commercial solicitor. "I am delighted to be a Trustee on the Action for ME board," says Julianne. "I am passionate about making a difference to the health and social care that is available to people living with ME – whether that be as a result of the vital healthcare services the charity provides or by lobbying for action and research."

Julianne's brother has ME. "I have seen how difficult the disease is to manage, both in terms of accessing effective care and support, as well as socialising and integrating into society," she says. Her two young children keep her on her toes – "they inspire me every day to do better for myself and others."

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 of Global Services at Oxford Nanopore Technology (ONT), a company whose mission is to democratise DNA sequencing, so that all human disease can be understood to enable the vision of personalised medicine.

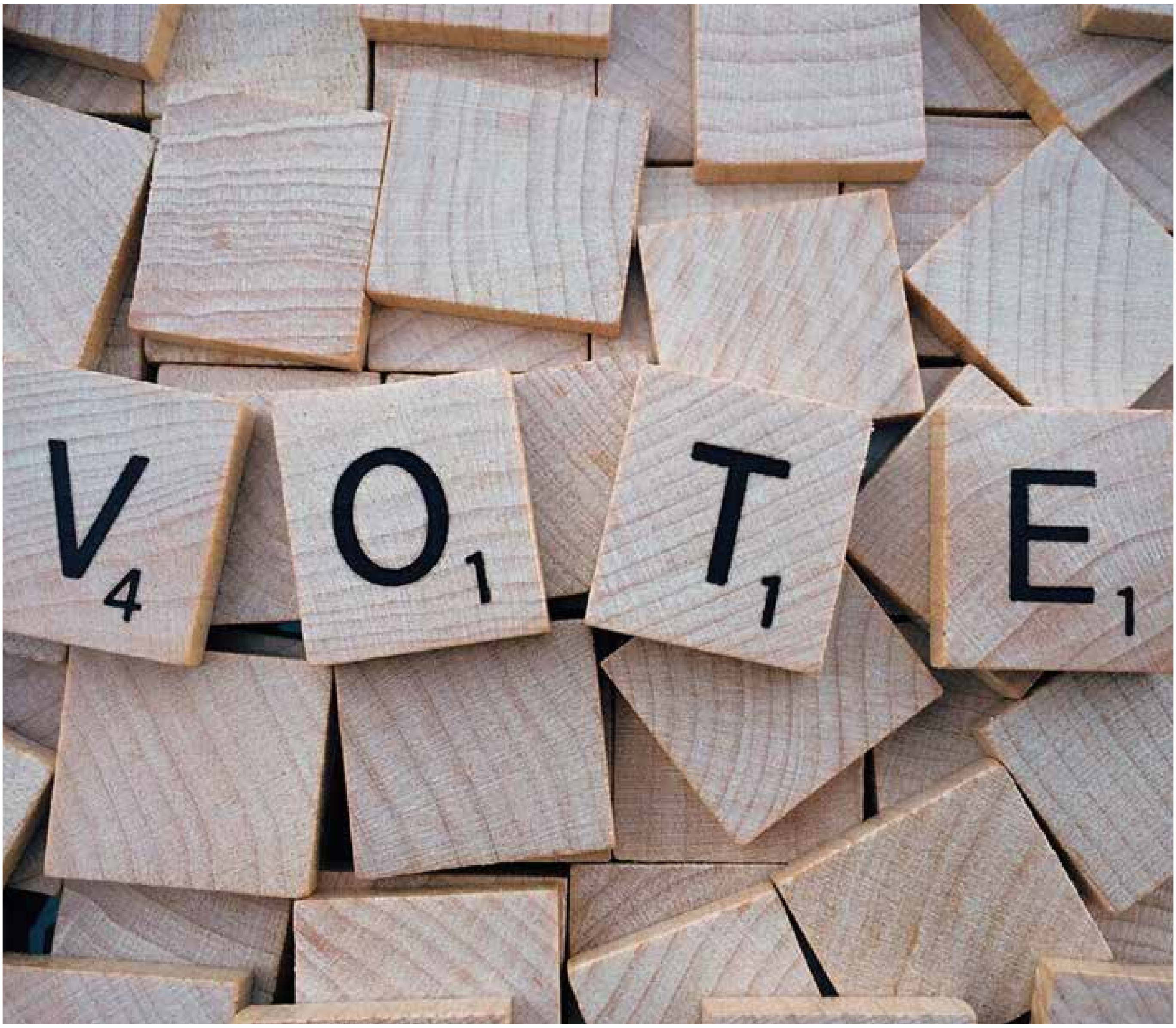
"There is so little understanding of the underlying genetic drivers for ME which in turn is impacting the development of diagnostic and treatment options," says Nirmala. "I believe that patients with any clinical condition should have the benefit of the best tools at hand to research the condition, making personalised medicine a reality for all."

Roger Siddle

Roger Siddle is standing for an exceptional term. He took up the post of Chair of Trustees in March 2020, bringing with him a broad range of business and charitable experience. Currently non-executive Chairman of a number of private businesses, he also has experience advising the NSPCC on techniques for corporate fundraising and was previously a member of their National Volunteer Board.

"I have been struck and frustrated by the lack of knowledge of ME, and ways to manage the illness, by those who should – and need – to know," Roger says. "I believe that much more can and must be done on both research and awareness raising."

Find your voting slip overleaf.



Thank you Sue and Rollo!

Rollo Hope and Sue Hardy are standing down as Trustees.

Rollo was formerly Chair of the ME Trust and was instrumental in helping the merger with Action for ME and the subsequent launch of Action for ME's Healthcare Services. Since joining Action for ME, Rollo led our Healthcare Services Committee until recently, ensuring that people with ME using our services have continued to enjoy the standards achieved previously through the ME Trust. Rollo has brought challenge, rigour and valuable support to the Board of Trustees.

Sue was working as a senior lecturer in nursing at the University of Bedfordshire when she was diagnosed with ME in 2013. Her personal and professional insight as a valued Board member, including sitting on our Policy and Healthcare Committees, have helped shape our medical education work, improving knowledge of ME among health professionals. Sharing her story in the local and national press have helped raise public awareness of the condition, too.

Thank you Sue and Rollo for your support.

Notes for Trustee voting

1. Only Supporting and Lifelong Members of Action for ME (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 ME as a company limited by guarantee. The Trustees of Action for ME have resolved that those candidates who are endorsed by the Supporting Membership will be elected as Trustees by the members of Action for ME 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 ME.
3. Any votes received from persons who are not part of the Supporting Membership or who cannot be identified by Action for ME 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 ME on or before 5pm on Friday 11 July 2025. 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 ME's Annual General Meeting, Wednesday 17 September 2025, 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 ME shall be final and binding.

Only Supporting Members of Action for ME 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:

Wendy Lippmann	☐ yes	☐ no	☐ no preference
Ros Boyle	☐ yes	☐ no	☐ no preference
Philip Courtney	☐ yes	☐ no	☐ no preference
Julianne Devine	☐ yes	☐ no	☐ no preference
Nirmala Santiapillai	☐ yes	☐ no	☐ no preference
Roger Siddle	☐ yes	☐ no	☐ no preference

Please return this form using the envelope provided to
Action for ME, Unit 2.2 Streamline, 436-441 Paintworks, Bristol BS4 3AS
to arrive on or before **11 July 2025**, **marked for the attention of the returning officer**.
(See above notes on Trustee voting.) Thank you.

Education updates on social media

Our Information and Support team has begun using our social media channels to share important calendar dates for school and college. The hope is that parents and young people might find these useful to put in their diaries, to better support them in their education. Posts include advice on things like: extra support with exams, how to get adjustments in place to help you access education, transitioning from primary to secondary school… and more.

Keep an eye out for these updates by following us on social media:

Instagram: @actionform.e
Facebook & LinkedIn:
@actionforme
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You did it!

Thanks to you, this was our most successful Big Give Challenge yet.

Christmas Challenge
BigGive

A huge thank you to all our incredible Big Give supporters last year. Because of you, we can invest in high-quality research to improve treatments and care, deliver services to reduce the isolation experienced by young people with ME, and ensure that medical professionals have an increased understanding of how best to support people living with ME.

We were delighted to be approached by the Big Give team in July 2024 with an opportunity to double our target from £100,000 to £200,000, thanks to a generous offer from the champion and founder of Big Give, The Reed Foundation.

Although this was a big step up, we were confident that, along with our incredible community, we could rise to the challenge. We weren't wrong – together you raised an incredible **£276,337!**

We really appreciate all of you who donated this year and made this our best Christmas campaign so far.

"Thank you so much for this community."
Bella, aged 10.
Young People's Forum member

Young People's Counselling – now from 11 years old

Our FREE Young People's Counselling Service has previously been available for young people with suspected or diagnosed ME aged 13 to 18. Thanks to generous funding from The Prudence Trust, **this service is now also available to young people aged 11 and 12**.

"The young people who are part of our peer-support community often talk about the difficulties they face with loneliness and isolation as they find themselves no longer able to fully participate in their education, social lives, their hobbies and interests," explains our Young People's Peer Support Officer, Sam Agombar. "They often express their anxieties and worries about medical appointments. Being able to signpost them to a counselling service specifically about ME, knowing they have one less hurdle and burden of explanation to either a medical or mental health service that may never heard of ME – or know little about the impacts – is wonderful."

"It makes such a huge difference to young people and families to have an offer of free counselling support," adds Anna Pearce, part of our Information and Support team. "There are such long waits for other wellbeing and mental health services for young people and such a lack of knowledge and understanding about ME. There are enough challenges being a young person, let alone coping with a chronic illness – so to be able to talk to someone who understands is invaluable."

tinyurl.com/CYPcounselling

LOCOME: initial research findings

Our Research Manager, Daphne Lamirel, explains more about the LOCOME (long Covid and ME) project.

Speed read...
Recent findings from LOCOME include identifying potential sub-types in ME and long Covid, looking at how genetic variants work together to increase the risk of developing ME. Researchers are looking at repurposing existing medicines to help long Covid and ME patients and these will be tested in clinical trials.

The LOCOME project looks to improve diagnosis and treatment for those with long Covid and ME. It is led by biotechnology company PrecisionLife, which specialises in researching and developing treatments for different diseases. It is funded by UK Research and Innovation (UKRI), a government body that supports research and innovation across the UK.

Action for ME is an active partner in this project. Our role is to ensure that the voices of people with lived experience are heard throughout the research process. This involves organising Public and Patient Involvement (PPI) activities, where people with ME and their carers can contribute their insights on various aspects of the research.

A unique approach

PrecisionLife uses combinatorial analysis, a method focused on identifying 'disease signatures'. These are sets of genetic variations which, when they occur together, are linked to a higher risk of disease – such as ME.

Traditional approaches to genetics research, like Genome-Wide Association Studies (GWAS), examine individual genetic variants by comparing people with a disease to healthy individuals. GWAS identifies genetic differences that appear more frequently in people with the disease.

In contrast, PrecisionLife's combinatorial analysis looks at how multiple genetic variants work together to increase the risk of ME. This can help identify sub-groups in a disease.

Consider the analogy of tornado formation. A tornado requires a combination of factors: warm air at the surface, dry air higher in the atmosphere, changes in wind speed and a thunderstorm. It is only when these factors combine that the risk of this storm sub-type (the tornado) strongly increases.

In the same way, PrecisionLife's approach identifies how multiple genetic factors must work together to contribute to the development of ME and how different combinations of genes are associated with specific sub-types within the disease (such 'fatigue-dominant' or 'autoimmune').

Findings so far

PrecisionLife's initial findings identify 199 genetic mutations across 14 genes associated with ME, in two UK Biobank populations. They also analysed subgroups of patients with mutations in these genes, and looked at how their symptoms matched the role of those genes in the body.

For example, the gene *AKAP1* helps recharge the cell's energy supply after exertion. People with ME who had mutations in *AKAP1* reported fatigue and post-exertional malaise (PEM) at significant levels, indicating they may be part of a 'fatigue-dominant' sub-group of ME.

PrecisionLife is investigating whether these findings can be found in other large groups of people with ME (this is often done in research to help confirm or replicate findings). Specifically, they are looking at people with ME who participated in the DecodeME project. Many of the findings from the original study have also been found in the DecodeME participant group.

PrecisionLife has also identified 5,000 genetic variations and 73 genes associated with long Covid. Interestingly, 9 of these genes overlap with the 14 genes previously linked to ME. This suggests a strong genetic connection between long Covid and ME, reinforcing the idea that both conditions may share similar underlying mechanisms.

How will this be applied?

Finding new drugs from scratch can take decades, but the LOCOME project has taken a faster route – repurposing existing medicines.

The researchers have identified nine generic drugs that could potentially help both ME and long Covid patients. These drugs, which are already in use for other conditions, will now be tested in clinical trials to see if they can relieve symptoms and improve quality of life.

We all know that one of the biggest frustrations for people with ME and long Covid is the lack of reliable diagnostic tests. Many patients struggle for years to get a diagnosis. The LOCOME team is currently developing a new type of genetic test that could provide a faster and more accurate way to identify these conditions.

Instead of looking for a single faulty gene, the test identifies combinations of small genetic changes that increase a person's risk of developing ME or long Covid. Early results suggest this approach could offer doctors a much-needed tool for helping to identify ME and its sub-groups.

Acknowledging limitations

The scientific findings from the LOCOME project and PrecisionLife's research on ME and long Covid are promising, but there are limitations to this type of research.

First, the identification of genetic mutations associated with ME and long Covid does not necessarily mean these mutations cause the conditions. The relationship between genetic variations and disease is complex, and while certain genes may be linked to ME or long Covid, it can be difficult to prove direct causality without further research and longitudinal studies.

Secondly, while PrecisionLife's approach focuses on genetic 'signatures', the exact role and mechanisms of many of the identified genetic variants in ME and long Covid are not fully understood yet. Some genetic variants may have complex effects on cellular processes, and the precise biological pathways through which these variants influence disease progression remain speculative.

Finally, in studies that use large datasets and multiple genetic variables, there is a risk of 'overfitting the data'. This means that the model may identify patterns that are statistically significant but not reproducible in other cohorts. While some findings have been found in multiple patient groups, more research is needed to confirm PrecisionLife's findings.

Protective genes: why some people avoid severe illness

One interesting finding is the discovery of 'protective' genes. These are genes that seem to reduce the risk of developing severe ME or long Covid, even in people who have been exposed to common triggers such as viral infections.

Understanding how these genes work could help better understand how to develop new treatments in the future. Research could explore how to boost these protective mechanisms, for example, through diet, lifestyle changes or new drugs, which could be used in the context of prevention or management of ME and long Covid.

SequenceME: partnering for potential

Together with Oxford Nanopore Technologies and the University of Edinburgh, we are seeking to secure funding for an exciting new study.

Should funding be successful, the SequenceME study aims to build on the DecodeME project and will analyse the genetic code of up to 17,000 people with ME.

It would seek to uncover the root causes of ME and to determine whether ME is one illness or an umbrella condition encapsulating multiple diseases, such as long Covid and other chronic conditions.

The research team would use advanced whole genome sequencing technology to look at every location in the three-billion-letter genome, enabling the identification of rare genetic variants (small changes to DNA sequence) and structural variations. This detailed picture would help researchers advance the biological understanding of ME with more precision and lay the foundation for progress in diagnosis and treatment.

By advancing understanding of this complex and debilitating illness, the study has the potential to deliver profound health, social, and economic benefits, from reducing the strain on healthcare systems to empowering patients with personalised treatments and plans.

SequenceME would be the first genetics study in ME to use Oxford Nanopore's new generation of nanopore-based technology. "DecodeME created the world's largest ME/CFS study, and we are proud to take the next step with SequenceME," says Dr Gordon Sanghera, CEO of Oxford Nanopore Technologies. "Using Oxford Nanopore's any-length read sequencing technology, this project will uncover genetic insights that could transform patient care and open the door to personalised medicine for those living with ME."

"The SequenceME study will focus in its initial phase on severe and very severe cases of ME, ensuring that the people who live with its most devastating impacts are central to advancing understanding and driving meaningful change," explains our CEO, Sonya Chowdhury.

We will keep you updated on whether funding for this project is successful. We believe SequenceME would be a much-needed step forward in understanding and addressing ME.

The power of person-centred care

Winner Bhanu Wahi-Singh reflects on the experience of entering the Learn About ME medical essay competition in Scotland.

What was valuable to you about taking part in the competition?

While most people think of the medical curriculum as scientific and clinical in nature, one of the most important skills we learn is how to reflect on and develop ourselves. This allows us to integrate events with our clinical knowledge to better make sense of – and thus better learn – from life.

I have encountered many people with ME/CFS – both in a personal capacity, visiting my aunty, and in a professional capacity, as a medical student… However, it can be difficult to reflect without that background knowledge or without parameters in which to focus your thoughts.

Taking part in the competition let me learn much more about ME/CFS and its profound impact. It gave me a chance to contextualise this within my own interactions of people living with ME/CFS.

Writing the essay helped me clarify a recurring theme – of how imperative practising person-centred care is in managing not only ME/CFS but as a clinician in any context.

How will you use what you learned from the Learna CPD training module on ME/CFS?

Beyond the implications of the knowledge, I think the Learna module was really helpful in demystifying some of the historical views of ME/CFS and clarifying best practice.

For better or worse, I think medics tend to like categorisation and pattern recognition. While this is useful for diagnosis of many pathologies, in the case of ME/CFS and other complex conditions, particularly ones which have been historically misunderstood, the complexity and myriad presentations these conditions can have can sometimes result in worse care.

The Learna module does a great job of demystifying ME/CFS to an extent, helping to clarify diagnostic guidance and helped me understand the tremendous impact it can have in people's lives. It also illuminates some of the advances in research and clinical practice that many doctors not working directly with many ME/CFS patients may be aware of. A good example of this is the clarification that graded exercise therapy, once recommended for ME/CFS, is not only no longer recommended but can actually cause harm.

Why is it important for medical students to learn about ME?

I think an important thing for medical students to remember, myself included, is that a lack of understanding or a lack of knowledge on our part does not mean that something is not real, that it is not important, or that it does not concretely impact people's lives.

Sometimes, more complex conditions like ME/CFS can be difficult for us to grapple with because there is both a difficulty with diagnosis (due to less education about it in medical school curricula) and because most of the therapeutics and medications we can rely on in many other contexts may not necessarily be helpful or as impactful for symptoms of ME/CFS. This is something which is frustrating, as the reason we go into medicine is to help people, and this can lead to a sense of powerlessness at times…

Being able to act as an interface to healthcare for a patient is in itself really impactful, and empathy and focusing attention of care from the condition to the person really helps in that.

More information on the Learn About ME project: **tinyurl.com/AfMELearning**

"Beyond teaching me about ME/CFS, the Learn About ME initiative really exemplifies the power that collaboration can have in advancing patient care and clinical practice, something which I've found truly inspiring."

Bhanu

E-learning on ME from NHS England

Alongside the existing Learna CPD training module developed by Dr Nina Muirhead, there are two NHS England e-learning modules on ME that you can highlight to professionals.

The first module, *Introduction to ME/CFS*, is accessible to all and aims to provide an introduction to the complex nature of ME/CFS. It explains what ME/CFS is, discusses the potential causes and diagnostic challenges and provides an overview of possible management strategies:
tinyurl.com/hubMEintro

The second module, *ME/CFS: guidance for community-based healthcare practitioners* aims to inform and empower community-based healthcare practitioners with the knowledge and tools needed to effectively diagnose, manage, and support patients with ME/CFS:
tinyurl.com/hubMEguidance

A third and final module will be added later this year. This will focus on long-term management of ME/CFS, treatment recommendations and pharmacological solutions. This module is aimed at clinicians.

To access the modules, people need to register for the NHS Learning Hub. The NHS and social care workforce are classed as Learning Hub full users and can access all resources, plus additional content marked as appropriate.

Those not within the NHS or social care scope can register for a Learning Hub general user account. General users will then be granted access to resources that are accessible to the wider audience. See **learninghub.nhs.uk** for more information on how to sign up.

Our Big Survey is coming soon!

Action for ME is excited to announce that 2025 will mark another Big Survey.

Every few years, we conduct this important survey to gather insights into how ME affects people's lives. The last Big Survey was carried out in 2019 and, thanks to the fantastic responsiveness of our community, it received over 4,000 responses. This survey was vital in supporting our awareness-raising and policy activities.

This year, we plan to use the Big Survey findings to continue highlighting the devastating impact of ME on individuals' quality of life and ability to function. We will explore key themes such as employment, access to healthcare and social care, the NICE guidelines, and gather information on people's symptoms and the effectiveness of various treatment approaches. The findings will play a crucial role in shaping our advocacy efforts and driving meaningful change for the ME community.

You can expect to receive the survey in the next issue of *InterAction*.

Meet your Big Survey researcher

This year the work on the Big Survey will be carried out by researcher Katharine Cheston. Katharine is a postdoctoral research fellow at the Institute for Medical Humanities, Durham University.

For the past five years, her work has been examining why illnesses like ME are so stigmatised, where this stigma comes from, and how it adds to the burden of suffering. Katharine has personal experience of ME and, before studying for her PhD, she used to volunteer with Action for ME in her university holidays. She has fond memories of working with Clare Ogden on *InterAction*!

Katharine's work on the Big Survey will be supported by a fellowship from the Discovery Research Platform for Medical Humanities, which is funded by Wellcome and hosted at Durham University's Institute for Medical Humanities.

Medical humanities researchers use methods and materials from the arts, humanities and social sciences to improve our understanding of health and human experience. Through schemes such as this collaboration with Action for ME, the Discovery Research Platform aims to support medical humanities researchers, people with lived experience and practitioners from the health and charity sectors to work together to develop new approaches to urgent health challenges.

Find out more about the Discovery Research Platform and medical humanities here:
www.medhumsplatform.org

Katharine Cheston

Our new look

You'll see that this issue of InterAction looks a little different – including a new logo and other stylistic changes.

Our mission is to improve the lives of people affected by ME, better meeting their needs today, while taking action to secure change for tomorrow. We want our information, services and wider work to be accessible to as many people as possible, ensuring that people affected by ME can receive the understanding and support they deserve, when they need it most.

With this in mind, we have redesigned our website, added new accessibility features and key resources, and updated our resource library. We also used this opportunity to review our brand and the way we talk about our organisation. This will help ensure we can fundraise more effectively and grow more awareness and understanding of ME, securing positive change for the future.

We thought long and hard about the decision to invest in this work. Ultimately, we concluded that these updates were essential for people with ME coming to us for advice and information.

Over 300 members, supporters, and service users shaped this project through surveys, a Steering Group, and user testing. A full review of specific resources, including our 'Step-by-step pacing guide', is also underway, with input from those with lived experience.

We are often told how much *InterAction* means to our members. Be assured that we will continue to work to make our magazine accessible, supportive and informative for our much-valued members.

ME Friends Online forum – relaunched!

Our previous website was outdated and not as accessible as it could be, making it harder to find resources, raise awareness, and support people affected by ME.

As part of this, our outdated ME Friends Online forum has not been meeting users' needs. An upgrade was essential. Our wonderful forum community has had a change of housing as part of this update – it's the same community, but the platform is now fit for purpose.

As with other site and resource updates, this was not a change we took lightly. Our motivation was to give forum members a better, more accessible user experience, as people living with ME, in a safe space. There is also a place for carers and loved ones to find support.

If you are an existing forum user and haven't already, you'll need to sign up again at **www.actionforme.org.uk/forum**. It's also a great time for new members to join. Full instructions on how to do this can be found at **tinyurl.com/ForumUserGuide**

We look forward to seeing our wonderful forum community continue to offer peer support and friendship to those affected by ME.

Action for ME's Advocacy Service

"I feel much more empowered from the exchanges I've had with Action for ME."

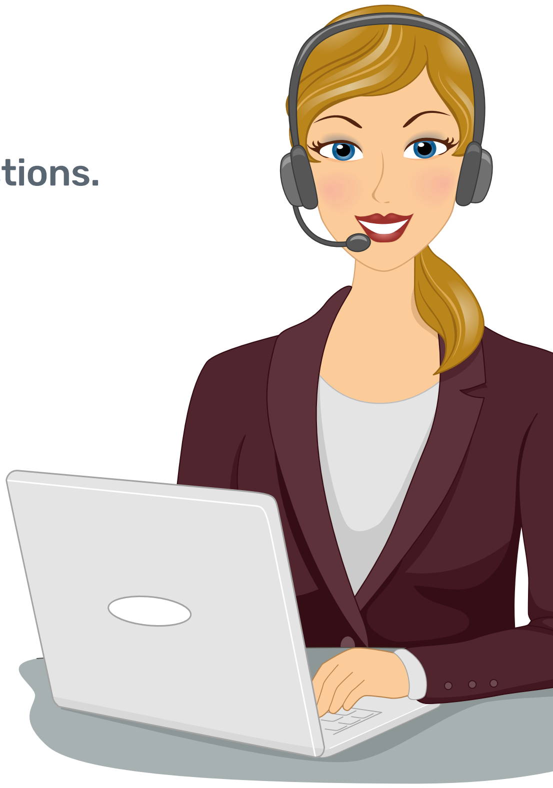
Are ignorance and stigma stopping you accessing services and/or care you're entitled to?

Our Advocacy Service helps adults with ME understand their rights and feel more confident to self-advocate.

Contact our Information and Support Service (see p 2) to find out more.

Dear team

Our Information and Support team answer your questions.



Q. I am a 43-year-old adult with moderate ME, living with my parents. Without them I wouldn't manage to get some basic jobs done, such as cooking, cleaning, shopping and getting out and about. They are currently my only carers but are elderly with their own health issues. We are anxious about who will look after me once they are no longer able. What are my options?

A. It's perfectly understandable to be concerned and feel vulnerable in these circumstances but we'll try to help you plan in order to future-proof your care, for as long as it's needed.

What's involved?

A care plan is a key resource which identifies and communicates your care needs. This is reviewed regularly and will exist as long as you need this care.

The information below focuses on the process as it is in England. You can contact our Information and Support team for information on variations elsewhere in the UK.

The process to getting a care plan can be daunting: filling in forms, communicating successfully your care needs, getting the right care in place, etc. Action for ME can help you to get the information you need to work through these processes including the possibility of local advocacy support (statutory provision under the Care Act*).

The first step is to request a **care needs assessment** from your local Adult Social Services, which is commonly carried out by a social worker. If this establishes that you have care needs, a further assessment looks at how this care will be delivered and paid for, depending on your financial circumstances. Even if you know you will be funding your care yourself, you can still request a needs assessment to kick-start this process.

You might want to consider employing a carer or a Personal Assistant (PA) directly. There's a reasonable amount of paperwork and responsibility involved in this relationship, which you need to consider (it could feel overwhelming, depending on your health). For a fee, it is possible to pay an agency to provide and manage carers for you. Although a more expensive option, it's likely that they can also provide respite staff when your usual carer(s) have time off.

If it seems that you might need some alterations in and around your home, for example a grab rail, a ramp or mobility aids, you might also be referred for a separate **home assessment**. This is often carried out by an Occupational Therapist.

Your unique set of care needs

The care needs assessment can establish what day to day support you need, but will it translate into care that recognises you as an individual?

We have resources and templates that can help you plan for your future and contribute towards how you want your care to look. You can use them to highlight your wants and needs to professionals, and help them understand the impact of ME. Our experienced team can talk you through the most effective way to use them.

You can find these on resources in our resource library on the Action for ME website at: **www.actionforme.org.uk/resources**

You can contact us for further help with communicating your ME care needs, including signposting to information for care workers regarding the care needs of people with severe/very severe ME.

Support for your carers

Feel free to get in touch with the Information and Support team if you would like to know how better to support friends and family that currently provide your care, be it financial, practical, emotional and/or peer support.

See p 2 for details on how to contact our Information and Support Service.

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*Care Act Advocacy only applies to England, but equivalent support is available in Northern Ireland, Scotland and Wales. We can provide further information.

Making your voices heard

In our last issue, we shared the news that the British Psychological Society is producing guidelines for psychologists working with people who have ME/CFS. Action for ME volunteer Katherine Langford gives us an update.

Speed read…
In response to the recent survey, people with ME said that psychologists can be helpful, but only when they validate the person with ME and acknowledge it is a physical condition. These guidelines aim to give psychologists a deeper understanding and allow people with ME to seek this kind of support without fear of being disbelieved.

"Psychologists should provide belief, validation, and support, helping us endure the challenges of living with this illness. The focus should be on helping us navigate the emotional toll, such as self-blame, isolation, and grief, rather than attempting to fix or change the physical reality of ME/CFS." – *response from survey*

ME is a physical condition. People with ME can experience the trauma of having to deal with medical professionals who haven't taken them seriously or the grief of losing their old life and the person they once were. These are examples of the psychological impact of the illness – and of how a psychologist might help.

It's been really interesting speaking with the psychologists on this project. I've had ME for 24 years and I've volunteered for ME charities for over two decades. The team is incredibly knowledgeable and, despite all my experience, I've still been learning new things about ME. The wealth of knowledge being collected will be a useful resource.

the british
psychological society
promoting excellence in psychology

An overwhelming response

My main role is to make sure that people with ME have input into the guidelines. That has involved organising a survey to collect your opinions. We were unable to give people as long as I would have liked to fill in the survey. Despite this, we were overwhelmed with responses – including a high proportion from those who are severely affected.

The data we have collected has been so rich that we now intend to try to get a research paper published. The BPS Division of Clinical Psychology are funding an assistant psychologist for the project, including to help us analyse the data in more detail.

We are immensely grateful to everyone who spent their precious, limited energy on helping us. Many people shared incredibly personal and moving stories, including several people saying they were not well enough to raise awareness of ME and would like people to do it for them. We want to do your responses justice by sharing them with the wider medical community, so I'm excited to be collaborating on a research paper to share your opinions.

It won't come as a surprise that people want us to include in these guidelines that ME is not a psychological condition. This will be made clear. The survey indicates that seeing a psychologist can be helpful when the therapist is supportive, listens, validates the person with ME and believes ME is a physical condition.

However, it can also be extremely damaging and cause a significant negative impact on someone's physical and/or mental health if the therapist tells them their symptoms are all in their mind, that they could get better if they wanted to or pressures them into doing inappropriate 'treatments' like exercise. We hope that these guidelines will help to stop misconceptions and mismanagement of the condition.

I've been attending lots of meetings about the guidelines and making sure that what you said in the survey is included at every step. We want the guidelines to be filled with quotes from people with ME, so I've been going through the survey and collecting them together.

One person raised a really good point, saying "it's hard to understand why psychologists should be involved. If someone needs psychological support, whether for illness or some other problem, then surely that should come under a general set of good practice guidelines for everyone. Singling out this one disease just seems odd." See next page for the reasons why.

Why will psychology guidelines on ME be helpful?

- Having guidelines from the UK's leading psychology organisation, *which explicitly states that ME/CFS is not a psychological condition*, should make things easier for people having to fight for the medical support that they need. It will also allow us to address other common misconceptions about ME.

- Guidelines will help psychologists, including those who don't often work with people with ME, know what is in the NICE guidelines and what people with ME want.

- There are specific challenges faced by people with ME. For example, many people have trouble with pacing, as they know they are overdoing things, but struggle to stop themselves. A psychologist can help people get the hang of proper pacing and avoid a boom-and-bust cycle.

- Having one set of guidelines for multiple conditions would encourage a 'one-size-fits-all' approach, when people want a more tailored approach to fit the individual. The BPS already has guidelines on other physical conditions, such as care for stroke survivors and Parkinson's Disease. Even within the ME community, different people have different needs. Some stated that appointments need to be online or on the phone as they aren't well enough for in-person appointments, while others said they need these, as screens and phones give them migraines.

- ME is a fluctuating condition which poses particular problems. People don't necessarily look ill all the time, which can make it difficult for others to understand. ME currently has no cure, has been massively under-researched and is frequently inappropriately psychologised. People with ME often face disbelief.

- As our survey has indicated, many people with ME have seen a psychologist. This means there should be suitable, up-to-date advice about it, particularly as many have been made worse by improper treatment. These guidelines should help to address that.

People with ME are often reluctant to see a psychologist for various reasons, including fears that it will be seen as a mental health problem, or cause doctors to focus on their mental health rather than their physical health. I hope these guidelines will help address these concerns and enable people to seek help with the psychological impact of a physical illness.

Keep watching this space for further updates. If you want to share your thoughts, then you can sign up to the mailing list at: **tinyurl.com/BPSMEguidelines-stayupdated**

More survey responses

"It was great [seeing a psychologist] to have an outlet where I could be truly angry and upset about being ill and have a space to express that safely. Just being able to identify that rush of emotion and learn to sit with it has been incredibly beneficial."

"ME is a neurological condition. It is a fluctuating life-limiting condition that affects every part of the patient's life."

"It should be possible to judge an intervention as 'successful' even if the patient ends up doing less. For example, it could be seen as successful if the patient is having fewer PEM set-backs, fewer problems with activities of daily living, and/or a more comfortable life."

Fundraising from my sofa

Danny Redhead shares his story of making a difference.

Speed read...
Danny fundraises for (and with) ME in low-energy ways. These include growing a moustache for Movember, setting up an ink cartridge recycling scheme, using easyfundraising.org.uk and selling Action for ME's raffle tickets. He also set up a birthday fundraiser instead of having a party – all from his sofa and with help from his family.

November 2014: I was living a happy healthy life, studying at the University of Sheffield and actively fundraising for the charity Blood Cancer UK (I raised over £85,000).

During that month I turned 20, attended a reception at Clarence House with the then Prince Charles and received an award at the Houses of Parliament. I was working hard and enjoying an active social life.

My whole life was ahead of me.

An all-too familiar story

On 29 November, I woke up with a virus. Over 10 years later I'm still not better – a story many of you will find all too familiar.

I guess I am one of the fortunate ones, as I managed to find some improvement three years in. My symptoms became milder, but still present. This lasted for about two years. Then, after an emergency appendectomy in 2019, my ME flared back up with a vengeance.

Nothing that helped before seemed to make any difference. I was back to trying everything and anything to improve my situation. I continue with that to this day, in the hope that one day I will find improvement.

In 2020, the pandemic hit. I was terrified that the difficulties faced by ME charities to fundraise would push back the day we found a treatment even further. I know that, ultimately, we need a cure. Without it, the rest of life is destined to be this way.

To find that cure ME charities need money they can spend on research, so I felt that I had to do something.

Low-energy fundraising

Much of my fundraising is done lying on the sofa using my phone at very small intervals. Like everything these days, there's no way I could do this without the help and support of my parents. They do so much for me as I grapple with this debilitating disease.

So far, we have raised almost £20,000 for Action for ME. I am sharing some of the initiatives we have undertaken in the hope that they will inspire others to do something similar.

Fundraising with facial hair

In 2020 I took on the **Movember challenge** with a group of family and friends. We received match funding from Lloyds Banking Group thanks to an old college friend, and corporate donations from Biffa, Blakemore Foundation (Spar) and Persimmon Homes. As a group we raised over £8,300. Ironically, not shaving actually saved me energy. It's easy to think that sponsored challenges have to be physical, but there's lots of low-energy things we can do.

Recycling for a cause

I have also set up an **ink cartridge recycling scheme** with my local GP surgery for people to donate used ink cartridges. Thanks to match funding from my local Lions club, Action for ME receives up to £4 per cartridge recycled. The scheme continues to be a huge success and has raised over £3,550. Wherever you are in the country, you can recycle your used ink cartridges to raise money for Action for ME at no cost to you, or better still set up a public collection point like we have – visit **recycle4charity.co.uk** for more information.

A different kind of birthday

On 10 November 2024, I turned 30. I should have had a big birthday bash to celebrate turning 30, but due to the severity of my illness that would be impossible. Instead, I set up a **birthday fundraiser** and asked family and friends to consider donating to Action for ME instead of spending on a night out.

I was blown away by the love and support I received. I managed to raise £1,500 for Action for ME. Birthday fundraisers are one of the easiest low-energy ways not only to raise vital funds to improve the world for people with ME, but to raise awareness and understanding among family and friends. If this is something you fancy doing for your birthday, feel free to check out mine if you need ideas: **www.justgiving.com/page/dannys30thbirthday**

Action for ME raffle

Every year we sell **Action for ME's Spring Raffle tickets** – we even managed to sell the winner in 2022! It's a real family effort with my mum and auntie taking them to work, my dad the bowls club, and my grandma selling them to wider family. We manage to raise about £150 each year, and we will be doing the same again this year.

Last year the Spring Raffle raised about £2,800. If everyone who receives this magazine bought or sold just one book, Action for ME would have £60,000 they could spend on more research, campaigning and support for people with ME. The cumulative effect of a small act can make a real difference, so if you've received a book with your magazine, please think about getting involved and buying or selling that book. You can even go one step further and order extra books to sell. You can also buy tickets online (see back cover for details).

If you shop online

As a family **we use *easyfundraising.org.uk* every time we shop online** and companies donate to Action for ME, at no cost to us, every time we shop. This is a really simple way to get involved and it really adds up, especially if you do a weekly online grocery shop. We have so far raised over £500. It's worth checking out if you shop online.

Danny's royal handshake in November 2014

Why I fundraise for Action for ME

Action for ME is an amazing charity, with a great team of staff, trustees and volunteers dedicated to improving the world for people with ME, but their biggest constraint is money.

The majority of research funding for all diseases comes from charities, which is one of the reasons ME is so far behind. Given the scale and complexity of the ME/CFS challenge, Action for ME's annual income (approximately £1.5 million) is insufficient to drive the necessary research breakthroughs we need. This is why is it essential we come together as a community to help generate the funds needed, in simple low energy ways, to help them move further, faster.

In a situation that often leaves me feeling powerless, raising money for further research is rewarding, and gives me hope for the future. Every pound helps bring the day a little closer when we get the treatment we need – and deserve.

Top fundraising tips from Danny

- Share your story – tell people what has happened to you.
- Explain the lack of treatment, support and understanding of those with ME – and the lack of funding that ME research receives.

Where does the money go?

All income raised for Action for ME is spent on:

- improving lives through information, advocacy, peer support and healthcare services for adults, young people and families with ME
- campaigning and influencing work on the issues important to people with ME
- investment in collaborative biomedical research, leading to enhanced knowledge and improved treatments and care
- fundraising (in the 2023-2024 tax year we raised £3.62 for every £1 invested in fundraising).

We also spend a small amount on governance to ensure our charity is legally and effectively managed.

If you would like to explore fundraising for Action for ME then please call us on 0117 927 9551, email **fundraising@actionforme.org.uk** or visit **tinyurl.com/fundraiseforAfME**

"Why are you like this?"

NoLoyiso Jolobe shares her experience of receiving care and interacting with UK Social Services as a Black woman with severe ME.

Speed read...
Noloyiso reached out to Social Services for support as someone with severe ME. However, her experience of help and support from both Social Services and the care sector has been distressing. Here she shares just some incidences of the racial prejudice, discrimination and ignorance that she has experienced as a Black person.

It had been some months since I had been diagnosed with Severe ME. My savings were depleted. I knew nothing about care or the benefit system. In despair, I picked up the local telephone directory and phoned Social Services: "I am desperate. I need help. I am close to giving up on my life."

I had heard about reaching out to Social Services on a random programme I had watched. Everything was random for me in those days. The GP knew about my diagnosis, but had not even signposted me.

Now, at least a skeleton of a care plan was put in place, with a view to assess me within a week.

Layers of implication

Crying daily, I clung on as the ground I had stood on dissolved. I did not recognise the person I had become. Where was the vibrant, intelligent, independent woman I was? In the mirror, she looked like me, but inside, she was lost.

I was assaulted by notions that had not even occurred to me. Being suffocated by severe ME, my mind was bound and numbed, devoid of everything but the intrusive severe pain and debilitating fatigue. I began to realise that this neuro-immunological condition had layers of implications on my life as a Black woman.

An employee from Social Services had been sent to assess my living conditions: a large crack was widening on my bedroom wall. The doorbell rang. I picked up the bedside phone with the button I could press to allow visitors in. "Hello. I'm from the Social Services. May I come in?"

I gently turned my body and struggled to sit up. "Yes, of course", I replied. "I am upstairs in bed. My bedroom door is the one at the top of the landing."

"Oh! You are black!" That was the first thing she said to me.

Lost for words, I looked at her as blood rushed to her face, neck and chest. After several seconds, I managed to find my voice. "Well, the last time I looked in the mirror, I was," I replied.

"Sorry, I was confused," she stuttered. "I mean, your English is perfect and you are so well spoken."

I decided not to reply but to let her hear her own words.

"Oh, I shouldn't have said that, but seeing you took me by surprise," she went on to say.

Still, I said nothing but merely looked at her as her words stumbled over each other. I closed my eyes whilst she assessed the health and safety of my home.

She did this in silence. However, before she left, she could hold her tongue no longer. "I see your house is full of African art."

I took a breath and asked her, "What kind of pictures do you have in your home?"

"Oh, you know, normal things from around the country… I mean England. I come from Devon", she replied.

Very intentionally and speaking softly, I said "I come from South Africa."

Again, I observed that red flush spread over her. With no more said, I bid her goodbye.

Ignorance in care

It was on a different occasion that I had an experience that still makes me laugh. I had decided to spend my Respite Break with my parents, an hour-and-a-half's drive from my home. Social Services had chosen a care provider for me whilst I stayed there.

The carer who came was the manager and owned the company. With me lying on my back in the bath, she washed my feet. Well, actually, she scrubbed the upper part of each foot repeatedly for a surprisingly long time.

Eventually she said, "I am so sorry. I cannot get the dirt off your skin. The skin on the top of each foot is so dark, but under your foot it is so much lighter."

I did not reply but watched her as she scrubbed my hands similarly.

"Look. Even with your hands: you have lines of dirt on your palms; I cannot rub them off. Why are you like this?"

It was obvious that the lady had never given care to a Black person. With my eyes close to watering, with gurgles of laughter in my chest, I answered, "I am sorry. The answer to your question is way above my pay grade. Why don't you ask the One who made me?"

Prejudice is real

There are other incidents I could write about. I have had severe ME since 2007, and my skin colour has remained black. Of course, some of the events were distressing. I have needed community advocacy when my care providers treated me differently because of my race and culture. After a thorough investigation, office staff had to be replaced; others were re-trained in diversity. Even Adult Social Services' behaviour towards me has sometimes reeked of prejudice. A social worker had to resign after another investigation.

One time, a carer claimed that she could not give care to me because I did not speak English well enough. Ironically, this was within a month of the employee from Social Services saying that my English was perfect and that I spoke so well that she was shocked that I was black. A different carer informed me that she had been telling other carers that she could not bear to touch black skin.

Unfortunately, political events give credence to the assessment that race and culture are still issues in the UK. Ignorance and prejudice are very much alive in the care sector as well as in Social Services. My experiences demonstrate that they exist in the care of people with ME, too.

The team at Action for ME are deeply saddened at what Noloyiso (Lolli) has experienced as a Black woman with severe ME. There is so much work to be done when it comes to tackling prejudice and ignorance in UK health and social care services, as her experience (and that of so many others) shows.

As an organisation, we aim to promote awareness and understanding of diversity, and inclusion, and ensure equitable access to our services and resources. We do this by striving to involve people with experience of ME from diverse backgrounds to influence and shape our work, including our campaigns and awareness-raising with professionals and policy makers.

We are so grateful to Lolli for sharing her story with us.

Noloyiso © Temba Jolobe

If you have experienced racial discrimination

The **Equality Advisory Support Service** can help you to explore whether you have experienced racial discrimination and how it might be resolved: **www.equalityadvisoryservice.com** or **0808 800 0082**

If you wish to report an incident of racial discrimination, **Stand Against Racism and Inequality (SARI)** can put you in touch with someone who can help you: **saricharity.org.uk** or **0117 942 0060**

Black Minds Matter UK connects Black individuals and families with free 1-2-1 talking therapy delivered by qualified and accredited Black therapists. **www.blackmindsmatteruk.com**

Young Minds provides support to young people experiencing racism and strategies to look after their own mental health in these circumstances: **tinyurl.com/YoungMindsRacism**

All things green

Catherine Saunders shares the hope she found through gardening in her journey with ME.

Speed read...
A small potted plant gave Catherine hope when she was bedbound with ME. Gradually, as her symptoms allowed, she could make a brief trip outside in her wheelchair to her tiny garden. So began her love of gardening, eventually leading to her new vocation, as a magazine columnist. She shares her tips on low-energy gardening.

Once a successful marketing consultant in London, my life changed dramatically at the age of 32, when I collapsed in a car park.

Plunged into darkness

I'd had mild symptoms for six months following a summer virus. Then a psychologist 'specialising' in ME/CFS encouraged me to return to work part-time. Just three days later, I collapsed completely. Worse still, when my condition deteriorated, the psychologist refused to take my husband's calls for help. I was left alone in the dark – literally – in a confined room, with no guidance or support, for over two years.

The onset of severe ME left me completely disabled, in pain 24/7, unable to walk, talk, or even feed myself, relying entirely on the care of my devoted husband. Even as my sensitivity to light receded, I remained bedbound for another three years.

Eventually, I received care through two hospital admissions, as well as the Stockport ME Nurse Outreach Service – a groundbreaking, lottery-funded initiative that provided home visits through the local ME support group. Yet, despite these interventions, my progress remained painfully slow, punctuated by debilitating relapses.

Then one day my mother, a keen gardener, popped a small potted plant on my windowsill.

The power of plants

It might sound silly, but that plant helped me enormously. It gave me something other than my situation to think about and reminded me of how much I needed that connection, albeit tiny, to nature.

It would be another year before I was physically able to attempt getting outside – and this required the installation of a stairlift – but finally, in my wheelchair, for just one minute, I made it into my tiny garden.

From that moment, I was hooked on all things green.

I know only too well how frustrating it is when a well-meaning friend or relative says, "Try this, do this, take this – it will help." So, let me reassure you that I would never claim gardening is the answer to all your woes. However, I can say with certainty that once I was strong enough, it became a source of comfort for me.

The emergence of Lady Muck

As I slowly improved enough to get into edible gardening, I found gardening articles so dull. But I had hilarious stories to tell, and I suspected there had to be others who would enjoy them.

So, *Lady Muck Style* was born – a magazine column designed to entertain, to educate, and most of all, to encourage people to have fun with gardening. Writing under my pen name of Lady Muck, I wanted to make readers smile.

My husband and I now live in Andalucía, Spain, in a cortijo overlooking the sea. It is here that I write Lady Muck Style. Read by audiences around the world, the fun-loving character shows that growing your own food can be anything but boring.

My love of gardening – born from adversity – blossomed into my second chance at life.

Ways to connect with nature

Catherine's tips for ME-friendly gardening.

Do only what you can, when you can and always stay within your limits.

So, where to start? **If you are not light-sensitive but still bedbound**, perhaps a carer could place an easy-care plant near your bed. A small peace lily, for instance, is wonderful for purifying the air, while a jade plant thrives on a sunny windowsill. Even three stems of bamboo in a vase can bring a sense of nature into your space. Something green and vibrant can be a small but powerful source of comfort.

If you try a peace lily, keep it out of direct sunlight and ensure the soil is moist but not overly wet. Jade plants love bright light and need watering from above only when the soil is dry. Bamboo stems, a symbol of good luck in many cultures, simply require about an inch of filtered water covering their roots.

For those housebound but able to reach a windowsill, small pots of herbs might be an idea. Even if you can't tolerate eating them, herbs like rosemary, basil, sage and thyme are easy to grow, need little water and fill your home with a wonderful scent. A friend might be able to pick up a few pots from a local garden centre, as growing from seed can sometimes be a bit unpredictable.

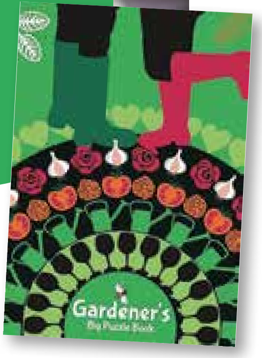
If you can get outside for even ten minutes a day, why not try growing something edible? Cherry tomatoes, cut-and-come-again salad leaves or strawberries are all rewarding choices. To conserve your energy, keep the pots on a table with a chair nearby, so you can tend to them comfortably while seated.

Gardening doesn't have to be all about effort – it can be about connection. A tiny plant, a few moments of fresh air, even if just having a window open, or the gentle scent of rosemary can be enough to bring a little glimmer of joy to your day.

Do what feels right for you, in your own time, and let nature work its quiet magic.

Catherine's latest book, *Grow Your Own Food, Lady Muck Style*, brings together a collection of her most-loved columns, complete with illustrations. This is accompanied by a matching gardening planner and puzzle book. For more information, visit **www.ladymuck.style**

WIN a copy of Lady Muck Style's *Gardener's Big Puzzle Book* in our giveaway on p 28!



InterAction

The magazine for Supporting and Lifelong Members of Action for ME

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Giveaway

Win this green-fingered prize!

For this issue, we're giving away a copy of Lady Muck Style's *Gardeners' Big Puzzle Book*, plus a kit to grow your own herbs.

How to enter

For your chance to win, please send your name, address and telephone number to:

- **interaction@actionforme.org.uk** with the word 'Giveaway' in the subject line
- or on a postcard to InterAction Giveaway, Action for ME, Unit 2.2 Streamline, 436-441 Paintworks, Bristol BS4 3AS

The deadline for entries is Friday 11 July 2025.
Good luck!

Terms and Conditions

The Promoter is Action for ME, Unit 2.2 Streamline, 436-441 Paintworks, Bristol BS4 3AS.

Draw closes at midnight on Friday 11 July 2025.

Please note the herb kit image is for illustrative purposes only and actual contents may vary.

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

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 ME 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 ME. Their decision is final in every situation and no correspondence will be entered into.

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

Entering implies acceptance of these rules.

True friendship

"My article is dedicated to my dearest friend Jazzy who sadly passed away in February 2025." – Rose

Editor's note: Rose's diary gives insight into a life lived with severe ME. It's a tough read at times, but we believe it is important that the voices of those with severe ME are heard.

Harsh winter

I was very poorly after Christmas with a horrid virus and sinus infection. I have had three courses of antibiotics, and my body is trying to replenish. Not easy when you have a chronic illness at the severe end of the scale, living with constant severe symptoms. Resting in bed, my body is often stuck on high alert. I do my best not to tune in to the symptoms, because I do not want them to expand – but they keep tugging away at me!

Self-care

I know I cannot ignore that I am in a bad crash. My neurological auras are constant, and they were this bad when I was first diagnosed with severe ME. I have had so much stress and no one to shield me. I am also experiencing menopause symptoms and seem to be constantly dehydrated. I need to pay attention to self-care, which is hard when you are so exhausted and dependent solely on paid care.

Being mindful

My plan is to try and be more conscious with what helps me and what does not. I am still incredibly sensitive to harsh energies. However, in life we are always going to encounter people that do not align with our energies and that is so difficult. What matters is how we respond to these difficult situations. The best way is being mindful not to be too 'open' and not allow yourself to fully engage. Instead immerse yourself in things that make you happy; that will help you bloom.

Spring abloom

Spring evokes new beginnings; every bud promises a new bloom. Each bloom represents purity, hope and celebration. Spring flowers are uplifting and healing, a promise that not all is harsh and dark in this world. I love daffodils, tulips and bluebells. What is your favourite spring flower?

Honouring change

I rejoined Action for ME's ME Friends Online forum in 2017, after facing extreme isolation. I was reluctant to join as I did not want to focus on ME, because I am not defined by the illness. When I joined, I was welcomed not only by Jazzy but also by some lovely kind people. I found my Forum Family.

Focusing on the forum as a platform for friendship and community has helped me and my forum friends to shine our characters through humour, strength, hardships and celebrations. The forum has now relaunched on Action for ME's new website (see p 18). Sudden change is scary, but change is also a positive. Jazzy would want us all to see the blessings of this transition and view it as a fresh start.

Jazzy Blue

Jazzy was a special soul who befriended everyone. She is incredibly missed by all the forum community. She had the ability to connect with everyone, whatever age and whatever character.

Jazzy and I shared an invisible bond that I did not fully recognise until she passed. We shared cards and gifts by post, but never met or spoke on the telephone. However, the connection was genuine. She would call me her true friend. Jazzy was older than me but that does not matter. Age is not relevant in true friendship.

We shared virtual birthday trips on the forum because our birthdates were so close. She would call me her birthday twin. The Forum Family have had years of fun, laughing so much behind the screen and feeling alive, connected and loved.

When you have no one else, the Forum Family can become your real family – that is how it is for me, anyway. I am now feeling the loss, grieving Jazzy and the old times.

One of my favourite posts from Jazzy (which I view as a metaphorical message – whatever life throws at you, you can always choose to be playful):

"It's strange (especially at my age!) but one of my most frequent urges is to skip down the road! I can't imagine the neighbours' responses to that. On my better days I have tried to skip around the house, but the consequences weren't good." – **Jazzy Blue**, forever in our hearts.

Creative Corner

If you are an artist, poet, writer, painter, photographer, crafter or cartoonist, please get in touch using the contact details on p 2.

Daniel’s love for photography

Daniel Painton is 47 and lives in Ruan Minor, Cornwall. He has had ME for a few years.

“I have been interested in photography since 2011, mainly landscape and seascapes with the occasional portrait picture, but gave it up, selling my equipment due to the illness,” says Daniel. “However, when talking to friends and family about photography it rekindled my love for it and so I purchased a camera and all necessary equipment. It also helps give me motivation to get outside.”

Daniel’s picture is of a boat in the larger cove situated in Cadgwith, Cornwall, which is used by local fisherman, the occasional artist and sunbathers too.

“The land mass to the right of the boat is called The Todden,” explains Daniel. “It overlooks not only this cove but the smaller, less popular cove to the right.”

Lynda shares her creativity

Lynda McEwan lives in Dumbarton, Scotland. She is 54 years old. “I’ve had ME since around 2000, when I contracted glandular fever whilst pregnant with my first daughter,” says Lynda. “I wrote this poem, *Living with ME*, when I went into a crash.” Lynda is also an artist doing mainly portrait drawings – she sent us this wonderful picture.

Living with ME

Friends peel away from you like old, tatty wallpaper in an abandoned house
Family disbelieve you, belittle and mock you whilst simultaneously finding ways to blame you
Careers become distant memories along with dreams and ambitions
Doctors gaslight you so expertly that you leave their surgery in a daze
Words, your love and passion, are lost in the depth of a mind fogged up like the windows of a car on a frosty morning
Hobbies become impossible as PEM makes gravity feel like it’s doubled and is pulling you mercilessly into the earth
Unable to move your body feels twisted and broken a silent scream echoing in your mind but no words pierce the air and even if they did there’s no one there to hear because no one wants to know about the devastation that ME leaves in its wake
Grief becomes all consuming for everything you’ve lost to an illness that’s supposedly all in your head
Darkness replaces the light wrapping you in its terrifying embrace
Hopelessness settles on your shoulders no cure or end in sight
Suffering and pain your new best friends except they come bearing no gifts and want nothing good for you
Fear claws at your heart until you can no longer breathe and you wait
For relief. A cure. A tiny change that might signal a transition from this private hell
And you wait, and wait and wait...

Drawing by Lynda McEwan

Sylvie speaks up for those with severe ME

Sylvie Lara Lake is a poet in her 20s who has severe ME. She discovered her ability to write poems in her head, starting with haiku, in February 2023. Sylvie hopes her poems will raise awareness not only of the under-acknowledged suffering, but also of the under-acknowledged strength, of the severe ME community.

Haiku

Those with feet on sheets
unable to touch the ground
can still make footprints.

We Will Reach this Beach

All we want
is to grab youth
with both hands.
Instead health
slips through our fingers
like sand.
But we hope
it will fall
into a beach
of gratitude.
Where with strengthened arms
in the sunrise
we will build castles of belief.
The proof being
that their towers will reach
creativity skies.
Their moats will run deep
with insight
and flow into the sea
of many friendships,
where the waves will gleam
with the light
of mutual understanding and respect.

Monitoring ME

Emily Skye trialled Visible for six months. Here shares her own experience of using the health tracking app and armband.

Speed read...
Emily outlines what Visible does in tracking activity and helping users pace effectively. She explains what she has found helpful in terms of understanding her symptoms and the benefits of being able to contribute to research. She also reflects on how it could be unhelpful, especially if you struggle with anxiety and don't have other support or some existing knowledge of pacing.

Emily's experience and views are her own and offer a valuable first-person perspective. Please note that this does not constitute as medical advice.

What is Visible?

Visible combines a wearable armband heart rate monitor with a corresponding app. It requires a smartphone. Based on patient-led research, it is designed to help us with illnesses which require pacing to manage post exertional malaise (PEM)/ exacerbation of symptoms.

What Visible does

- It uses 'PacePoints' to help us budget the energy we use throughout the day.
- It shows the impact of our activities, so we can prioritise.
- It tracks our heart rate variability (HRV), symptoms and medication to see what is making us better or worse.
- It uses breathing exercises with HRV biofeedback to drive deeper rest.

Acknowledging the limitations

Visible only knows what we and our bodies tell it. The more information we give it, the more it can help, especially over time. However, I also found that the more I told it, the more hyper-focused I became on my illness and symptoms.

In the first two weeks of using the app, I became more ill. My anxiety was high. Seeing that anxiety reflected in my heart rate was unhelpful. It had an audible exertion alarm at that point, which was alarming.

Our cognitive and emotional overexertion does not register as quickly. I found I could log and track this using my own judgement, but because it did not impact my heart rate to the same extent that movement might, I would not always recognise my over exertion when my numbers looked good. PEM still happens whenever it does, so this did nevertheless show up in my 'stability scores' (these show whether we are on an even keel or not).

It seems likely to be helpful if

You want to be able to understand your illness and your baselines and to explain this to loved ones, health, social care and benefits providers or as part of awareness campaigning. I have used the information with preparing adjustments with dentist, communicating with ME clinic for assessment, communicating with DWP, and campaigning via my MP.

Contributing to research is enjoyable and satisfying for you. There is an option to make your data available to ongoing research on these illnesses. This is a big motivator for me. I had felt frustrated and helpless. This was a way to contribute.

You are reasonably confident with using apps. It is user-friendly and I was able to use it even when struggling to sit up and with persistent cognitive impairment.

You are familiar with processing basic data in the form of graphs. Despite being severely limited in capacity for months prior to using the app, it had been possible for me to tick predesigned boxes daily and monthly and gradually make sense of trends and correlations. That was an important stepping stone for me.

You have good supporters to help you. Loved ones have helped me recognise this as *one* tool and not the whole picture. Because of this, together with my own professional and personal mental health knowledge, I was able to address the anxiety I was experiencing from using the app.

It seems less likely to be helpful if

You have significant electromagnetic sensitivity. I noticed mild discomfort when I was more ill, but not now.

You are in a particularly unstable or declining phase with your illness. I had two stressful coinciding events – losing my job and an ESA application. These events led to a sharp decline from 38% functional capacity back to 28%. Seeing my decline on the app prolonged the decline.

You are experiencing high levels of anxiety and do not have support or strategies that help you manage this.

You have had no specialist input or information or practice with pacing.

Technology is a source of stress for you. It's not for everyone and there are other resources that can help you with pacing

Untethering myself

I waited until I had written the main part of this review before removing the armband. It was a relief to unplug. I had arrived at techno saturation point and needed a digital detox. It had added a layer to feeling imprisoned in my home and body, on top of the existing tethers from the illness.

It is difficult to make a final judgement, as I am not the same person I was when I began using the app six months ago. It provided useful data when I needed to assess my sleep routines, leading to sleep improvements. As I am now, I feel better without the app, because I have learned to listen and respond at subtle levels.

As a research and campaign tool it is a powerful mobilising force. I may continue to engage with it as a research participant after a break and to learn from the contemporary research summaries available via the app.

In conclusion

Using a wearable health tracker can help to inform us about and interrupt our habits of pushing or being overly determined. However, it can exacerbate fear and sense of threat.

It can helpfully rein us in as needed. However, it can add stress (and exertion) to all activity and inhibit us unhelpfully.

It can disrupt our unhelpful habits that might hinder our effective pacing. However, it can undermine our confidence in our judgement.

It has potential to be helpful in managing this illness, improving pacing skills and where possible, improving choice and functional capacity. However, it is important to see this as just one tool and to use it in conjunction with our own judgement and experience of living with ME.


PacePoints

Mon, 4 Nov

You ended the day 1.3 PacePoints under your daily budget.

Previous 7 days

See p 37 for a chance to receive a **free**, donated Visible wearable armband. (Note you will still need to pay a subscription to use it with the app).

Visible is a health tracking mobile app and one that increasing numbers of people with ME are letting us know they are using. This 'wearable' – the name given to devices you attach to your body to gather health-related data – is one of a number available that aim to help people with energy-limiting illnesses pace more effectively. Other apps include ME/CFS Pacing, Trackuility, and The MindfulPacer from the University of Zurich.

Not everyone can afford or has capacity to use technology in this way. If these tools don't suit you, you can apply similar principles through gentle self-management. Pacing aims to balance energy and rest. It is not a treatment, but a way of coping with the impact of ME. You can find resources on our website to support you with understanding pacing and how it might help you manage your symptoms: **www.actionforme.org.uk/managing-symptoms**.

If you have questions about pacing, you can also get in touch with our friendly Information and Support team (see p 2).

Reaction

Send your letters and notices to the editor at the address on p 2.
You can also email interaction@actionforme.org.uk

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

Star letter

The reality and validity of online life

Now that so much, wonderfully, is available to us bedbound folk online, this is a plea for people (including *InterAction*!) to please never, ever refer to such things as 'virtual'. There are no virtual medical appointments, virtual communities, virtual meetings. These are all events with real people doing and saying real things, just online rather than in-person.

Calling it 'virtual' leads people to perceive things less seriously, as if your presence online has less effect than in 'real' life. But online speech – and online harms – impact us all just as much as 'real-life' communications do.

(Though curiously, the word 'digital' has now completely changed the other way! It used to mean manual, using your fingers. Now it means the opposite, something involving your phone or computer, being digitally savvy.)

Whatever the words we use, having so much available online these days – a small silver lining to the Covid pandemic – has made my life immeasurably better. So please let's all do what we can to promote the validity of online life, if not for yourself then for those of us who really have no other options.

Sylvia Rose

Editor's note: *As our star letter writer, Sylvia wins an Action for ME goodie bag.*

Thank you, Sylvia, for raising this important point. We'll reflect on the value of online communication and community in a future issue, so if you want to share your thoughts, do drop us a line.

Elvis hits the spot

Really, the last thing I wanted to do today was read a sentimental story about a Christmas Elf! How low has *InterAction* got? (118, p 32)

But then I read it anyway… and found myself not just laughing, but shedding salt tears into my porridge (which improved its flavour, actually).

So true.
All of it.
Thank you.
Keep it up.

Paul
(Crusty middle-aged man, and certainly not given to crying at breakfast!)

If you fancy listening to Elvis the Elf read aloud (beautifully) by InterAction *volunteer Chris, find it on our Soundcloud channel* ***tinyurl.com/ElvisElf***

Not just a nap

Many healthy people take naps or 'power naps' and find them generally helpful. In hot countries it is common to take naps at the hottest time of the day, when doing anything would be too arduous.

The situation with ME patients is quite different. We don't lie down because we feel slightly tired, as in 'normal' people, or have a quiet nap to recharge batteries.

Many with ME have little or no control over their 'consciousness period'! We are often incapable of doing anything as our cognitive functioning shuts down totally. No reading, watching TV or doing the simplest task. All we can do is lie down and hope that it will pass in a few hours if we are lucky. This is not 'napping', but a major symptom of ME.

Michael Dunn

Manatees and mondegreens

Steve writes in response to Emma Baker's song for the season (*InterAction* 118, p 28) – in which she refers to mishearing "love is like an energy" as "love is like a manatee".

Welcome to the Sirenian Lyrics Appreciation Society.

Further mentions of Sea Cows in song lyrics: There's a very fine Bob Dylan song about growing old, called *Not dark yet*.

The line "My sensitive manatee has gone down the drain", is heard by many people. Bob's "sense of humanity" appears to have to survived intact.

There was also a rather shouty hit single in the mid-70s called *It should have been me*, by an American singer Yvonne Fair, I believe, about being aggrieved at a wedding. The only reason it's at all memorable (for me, at least) is for the heard line "That woman down there is a Dugong thief".

There's a name for such mis-hearings – 'Mondegreens'. Apparently, the name dates back to the 1950s, and a mis-heard line in a ballad, *The Bonny Earl of Murray*. The phrase "laid him on the green" was heard as "Lady Mondegreen".

I was quite strongly affected early in life by mis-hearing a line in a birthday song in the early 60s, one which was sung for Infant School pupils on their special day. It went something like "More for the others, all the day long". I heard "More for the rathers, all the day long".

I became convinced that 'Rathers' were dangerous – probably a kind of dinosaur, which might be hiding in the woods as I walked home from school, looking to eat passing children.

Funny what the imagination gets up to. It certainly alerted me to the amusing possibilities of misheard words and phrases.

Steve Smailes

An accessible orchestra

I was interested to read Katherine Langford's letter in your winter issue for 2024, in which she describes the difficulties of playing the violin with ME. I can identify with this.

I am a pianist but struggled to play at all in the first few years I had ME, due to exhaustion and pain in my hands. When my ME improved enough for me to play the piano more easily, I wanted to take up the violin again as well, even though I hadn't played it for many years. But it was so painful trying to turn the stiff pegs to tune the strings that I had to give up. Then one day I had a random conversation at a church coffee morning that changed my life.

I spoke to the conductor of a local amateur orchestra about how I once played the violin in a youth orchestra but that this would now be impossible due to my ME. She persuaded me to attend a rehearsal of her non-auditioned orchestra for players of different abilities to see how I got on. I was told not to worry if I couldn't play most of the music and that it was OK to leave early if I felt unwell. I went and could barely play anything but I still enjoyed it and was made to feel welcome. They offered to help with tuning my instrument on a regular basis, and took it to their 'violin hospital' to fit new strings.

Over the years I've gained confidence and become a better player, even though I can't do much practice outside rehearsals due to fatigue. I've found a local violin repairer who has offered help and advice on modifying my instrument to make it slightly easier to tune and play. I still struggle with tuning it myself and cannot put on new strings, so this is really helpful.

My ME is mild to moderate so I have rough patches when I have to drop out of musical activities and voluntary work, sometimes for months, but I can keep up with my orchestra online. All rehearsals are recorded on video and then put on the orchestra's website so I can play along later, even if I can only manage 10 minutes. This is a real lifeline for me. I eventually got promoted to first violin and although this can be challenging it is also very rewarding.

Jennifer Keevill

Penalised by the system

Before, during and after the journey to an ME diagnosis, my lovely daughter never even considered not working. It's what you do as a functioning adult, right? In the event that someone is unfortunate enough to become unwell and needs some financial assistance, that's okay, because we've made sure, through the tax system, that benefits are available. Right?

Encouraged by me, my daughter applied for Adult Disability Payment (Scotland). I felt this was straightforward. I happen to have a professional forensic knowledge of the conditions for which ADP is awarded. Her entire life is dominated by pain, fatigue, limitations about walking, standing, working, socialising… she has to factor in a day's rest after washing and drying her hair!

The letter came in to say *no*.

My daughter is nothing if not diligent. She followed the appeal process and was awarded fewer points, with voluminous extra information submitted, letters from GP, consultant and so on.

Down but not out, her belief in justice prevailing, she asked for the determination to be reviewed by the First Tier Tribunal.

The questions asked over the 110 minutes were bizarre to say the least:

Do you buy fashion online?

Do you go to church?

Where did you and your partner meet?

I can't even repeat the more humiliating ones. Memorably, though: "you can always open a tin of soup if you're too fatigued to prepare dinner". And "you say you have communication difficulties, you've been pretty articulate here today".

We sat in stunned silence, confused about the nature of the questions, but unwilling to jeopardise her opportunity to better explain the impact of her condition by becoming irritable or defensive.

The process of preparing, travelling to the meeting and enduring strangers firing intrusive and strangely irrelevant questions from across the table, having to request a comfort break, left her even more mentally and physically shattered than before.

The determination that she is not eligible for Adult Disability Payment was upheld by the First Tier Tribunal.

A scoring system is never intended to encapsulate the entirety of a human situation: professional judgement is always a qualifier. My daughter was made out to be lying or at best exaggerating the impact of illness. She is being penalised for trying to remain in the workforce, for trying to live independently in her thirties, for trying to avoid strong painkillers that cause bowel symptoms and worsen brain fog, for having the sheer audacity to ask for financial assistance from the state to mitigate the impact of a truly debilitating condition. She kept trying when the first application was a gross misrepresentation of what she said and was paraphrased by a Social Security Scotland representative who misworded and misquoted throughout.

To think that we encourage our kids to learn, then work hard, so that they can provide for themselves, their families, and give in taxes to help those less fortunate through the bad patches that life throws up.

Look how well that has worked for my beautiful, brave daughter.

Marie

This is an abridged version of this powerful story. If you have had similar experiences and would like further signposting on where you might find help, please contact our Information and Support team (p 2).

For example, VoiceAbility provides advocacy services and resources on topics such as benefits, including a dedicated section on Scotland: **www.voiceability.org**

The (totally avoidable) tribunal ordeal

Further to your magazine's (Winter, issue 118) Noticeboard comment regarding the recording of disability assessments. This is really important.

Around 10 years ago, I lost *all* my Disability Living Allowance (DLA), because of a visiting assessor writing things down that I did not even say (eg. where I go shopping; how far I can walk; my limitations etc, etc).

I tried to appeal against this, but because the interview was not recorded I was powerless. Consequently, I was made much more ill by having to then attend an 'accusatory' tribunal (accompanied by a magistrate friend of mine) to get all my money back.

Fortunately, I was successful and all my benefits were restored. Unfortunately, though, I never fully recovered from the experience – it felt as if I had been summoned to a police interview for the 'crime' of being ill.

However, things have moved on: my recent PIP telephone assessment gave me the option of asking the assessor on the phone to online-record the whole interview (I also made my own lesser-quality recording using the voice recorder on an old phone as a back-up – not taking any chances).

The assessor told me that the online assessment recording would be kept for six years. It would also be accessible online for a short while via a passcode, and after that time it is possible to request a physical CD copy (good for those who cannot use the internet) of the assessment by calling the PIP (Capita) helpline number.

Henry

Noticeboard

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).

Are you eligible to join?

If you have any of these documents you can register with Purpl

Blue Badge PHOTO side
Access Card
Disabled Bus Pass
Disabled ID (DID) Card
Disabled Rail Card
CEA Card
PIP Award Letter with NI reference
DLA Letter Adult or Child
Attendance Allowance Letter
Scottish Disability Living Payment Letter
War Pension with Disability Component
Access to Work Award / ESA Letter

Door safety stickers

Able Community Care are live-in care specialists, based in Norfolk, but serving families across the UK. They've sent us this notice, which may be of interest to our readers:

Did you know? While cold calling itself is allowed, traders must respect "No Cold Callers" notices – it's actually against the law if they don't! As a dedicated home care provider since 1980, we've made it our mission to help protect older and disabled people in our community. We're proud to have distributed over 250,000 of these protective stickers since 2019.

Do you know of someone who would like to receive one of these? If so, simply email us at info@ablecommunitycare.com. Rest assured, we keep privacy in mind – we don't store any personal information or share it with others.

Find out more: **www.ablecommunitycare.com** or phone 01603 764567

Discounts for those with disabilities

Purpl is a website offering online shopping discounts for those with disabilities. You do need to be verified and provide evidence (see above for what you'll need).
www.purpldiscounts.com

Have you used Purpl? Would you recommend it?

Are you on pension credit?

If you are on pension credit, you can ask your utility company for their social tariffs, and save you money.
Miriam

Nimodipine query

Does anyone know of a doctor who prescribes the vasodilator nimodipine? I think Dr Vinod Patel has retired.

Thank you.
Ann, box number 4997

Constant whining noise

I can hear a constant high-pitched whining noise, sometimes it's louder than others, indoor only. This causes inability to sleep and anxiety, making my ME worse. Can anyone else hear this? Nothing seems to cancel it.

Thank you.
Margaret, box number 4998

Visible device offer

Visible got in touch with us to say: "Over the past year, we've had people return their armbands to us for various reasons (double order, didn't fit etc.). We can't resell these devices as they're not technically 'new', but we also don't want to throw them away as they're barely used and work perfectly. Would Action for ME be interested in receiving some devices to pass on to their members free of charge?"

We think this is a brilliant idea and would like to say a huge thank you to the folks at Visible for their generosity. Please note that anyone who receives a free device free of charge from us in this way will still need to buy a subscription to be able to use the device with the Visible app (£14.99 monthly or £131.88 annually). The devices also work with other apps too, if you don't want to use them with Visible.

If you would like to be put in the draw to receive a device, please complete our short online form at **tinyurl.com/visibleoffer** by **11 July 2025**.

If you are not able to go online, you can call or write to us with your full name, address and date of birth (we ask this as you need to be 16 years or over to register to use Visible) using the contact details on page 2.

Read Emily's reflections on using Visible on p 32

Giving up the fight

There’s so much power in changing your perspective, says Ellie Finney.

Speed read...
We often use ‘fighting’ terminology to describe living with illness. Ellie has found that changing her vocabulary has helped her feel more peaceful. By seeing ME as her invisible twin, she approaches it as a part of herself she needs to care for. She acknowledges that ME is not a welcome house guest, but she has achieved a degree of acceptance in how she thinks about it.

Reading Miranda Hart’s new autobiography recently made me reflect on the language of combat I slip into using when I’m talking about my health. Miranda has ME and chronic Lyme disease and shares her diagnoses and years-long battle publicly for the first time in her book, published last October.

Fighting words

I’ve done it already; I’ve used the word ‘battle’. I can’t be the only one who does this. We call chronic illness a fight, we say our immune systems are under attack, we call ourselves (or people call us) warriors. But reading the lessons Miranda learned from her own journey, I realised that a big leap forward in managing my own illness was when I stopped seeing my ME as my enemy and started seeing it as a part of me.

I’m not saying I’ve learned to love it, that would be a few stages too far. But I’ve learned to see it as an invisible twin I need to care for (picture Peter Pan and his shadow). For me, that ties in with caring for my inner child and paying attention to her tantrums when my type A behaviours take over (example: being so organised that I buy people born in July presents in January).

Throughout my bedbound and housebound years, I learned to listen to and take care of that inner child and learned to reacclimatise when we were well enough to be out in the world again (my inner child really resents me having to work, even though the rest of me is grateful to be well enough to earn money).

I’m not fighting this invisible twin, I’m living alongside her. That’s why I say I’m living with ME now, where I previously said battling or struggling with it. Fighting is exhausting; I’d rather be living. That sounds like giving up, but there’s so much power in changing your perspective.

Living with limitations

People with ME are understandably angry. We feel under attack from a medical profession that’s neglected and ignored us and a society that doesn’t believe we’re ill. I do feel the need to fight back against these injustices. I also feel the need to protect myself. I realised the only thing my anger was doing was harming me, so I let it go. Having ME isn’t fair, but so what? It gives you a unique set of obstacles, but they’re obstacles just the same. They’re not necessarily better or worse than other people’s obstacles.

Over the last ten years, I’ve accepted my invisible twin as part of my life. I wouldn’t say she’s a welcome house guest, but she’s here for life and she’s taught me a lot. There’s no ‘me’ without her. Trying to pretend she wasn’t there and trying to destroy her got me nowhere. I probably won’t get over her and ‘recover’, but I also won’t waste energy fighting the limitations she imposes.

The opposite of war is peace. In recognising that, things started to improve for me.

> **“I stopped seeing my ME as my enemy”**

Action for ME supporting you

People with ME contact our Information and Support Service for a range of reasons. But a common underlying theme is the lack of understanding they face from professionals, and even sometimes family and friends.

"People with ME have to advocate for themselves so often," says Juliet Gilchrist, one of our Information and Support Officers. "They come to our Information and Support service because we understand ME." The team offers information, resources and signposting to other services. These might be Action for ME's Healthcare, Family Support, Adults Advocacy services, or our peer-support communities for all ages – or other organisations better placed to help. See p 2 for their contact details. Below is feedback from people we have supported recently.

"Having ME over a long period of time and dealing with health professionals who still appear to have little understanding on the illness has been very frustrating. It feels like you are constantly battling just to receive the right treatment plan from the right service (ME specific). Talking to Action for ME helped with feeling you were talking to someone who understood your situation without having to explain it."

"I've felt very unheard by my medical practice, to the point where I've almost asked myself if I'm just making it all up! When I found Action for ME online, and found there was a way to ask for support/advice, I started to feel more empowered and more seen. The response exceeded my expectations and has given me a lot more knowledge and confidence to move forward with… Hopefully, I can find a way for my GP to listen to me."

"It was such a relief at last to talk to someone who understands and who has given me a greater context for understanding our daughter's condition."

"Very compassionate, understanding and lots of really helpful advice and resources I haven't been able to find anywhere else. I was lost, alone, and feeling very scared and vulnerable. Now I don't feel so alone and I know what next steps to take."

"I feel so much more supported and less overwhelmed by my issues after contacting your service."

"You do amazing work and I love your magazine."

Our young people's Breaking Isolation workshops remain popular. A recent attendee said: "It was so helpful and very beneficial. I felt like I wasn't alone for the first time in ages."

A big thank you!

We would like to say a huge thank you to all our donors, funders, fundraisers, supporters and volunteers. Without your support, we would not be able to continue our work in supporting people with ME now and creating positive change for the future.

Our Action for ME Spring Raffle is back!

From Thursday 24 April 2025 our Spring Raffle is live.
Now is your chance to win the first prize of £1000.
Five more of our wonderful supporters will also be lucky winners, each receiving £100.

Funds raised from each raffle help us to provide our vital support and healthcare services, campaign for change and invest in much-needed research.

How to enter

Enter online at **bit.ly/AFME-Spring-Raffle-25** or scan the QR code below. Tickets are £1 each. You can buy as many tickets as you like and share the link with family and friends

Enter by post by returning your paper stubs with a cheque using the freepost envelope enclosed or to the address shown on the tickets (you can include your Trustee voting form in the same envelope). Tickets are £1 each or £20 for a whole book. Buy tickets yourself or sell them to family and friends!

The last date to return paper ticket stubs or buy tickets online is **Friday 11 July 2025**.

To request paper raffle tickets, or to opt out of receiving them:

- Email **fundraising@actionforme.org.uk**
- Call 0117 927 9551 (choose option for fundraising)
- Write to us at Action for ME, Unit 2.2, 436-441 Paintworks, Bristol BS4 3AS.

Winners will be drawn on Thursday 17 July 2025.