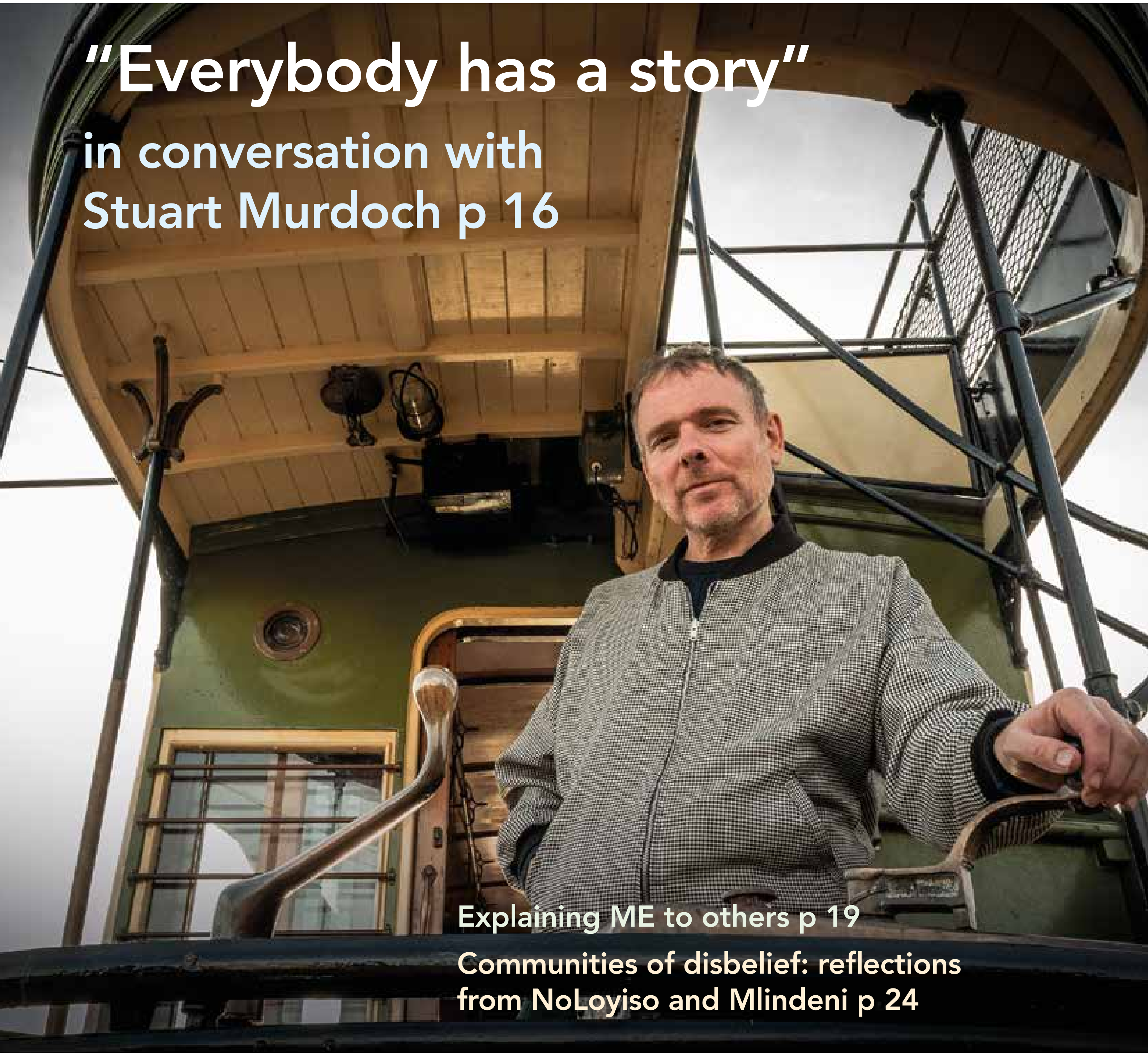
InterAction



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ISSUE 117
AUTUMN 2024

Our vision is a world without ME

action for m·e

Changing the story

Welcome to your new issue of *InterAction*. As we move into Autumn, we see nature's rhythms change and shift.

During the cycle of creating this issue, there have been a lot of changes – not least in our UK Government. We are aware that this causes uncertainty for many and you may well be asking 'what's the story'?

Please be assured that, while things are settling in Westminster, we are working hard to bring your concerns to those in power and to ensure that ME is on the agenda going forward (read further updates on the following news pages). We are also keen to communicate effectively with the ME community.

We continue to be passionate about sharing your stories to raise awareness for those with ME. I'm delighted that Stuart Murdoch, lead singer of award-winning band Belle and Sebastian, is featuring in this issue, sharing more of his own story as well as his heart for people with ME (p 16).

Our amazing fundraisers have their own tales to tell – the family members and friends who inspire them to act, those whose voices they want to be heard. Their efforts highlight those who grapple with feelings of invisibility that can come with this isolating illness, helping them be 'seen'.

We're pleased to include the winning essays from Learn About ME's inaugural competition for medical students in Scotland (p 11). We are encouraged by the winners' passion to learn about ME and to empathise with patients.

ME can be very difficult to describe to others. Many are deeply frustrated about existing terminology. On p 19 the ME community shares ideas for how to convey its debilitating symptoms – while acknowledging that all analogies fall short of reality.

For World ME Day this year, we declared our intent to be a global voice for ME. The day highlighted the diverse nature of the illness, as well as how it can impact differently across various cultures. Find an example of this on p 24.

Severe ME has a devastating impact and we are hearing more about this in the media, including some extremely upsetting cases (see p 5). Inadequate care and treatment for those with ME is a cause of huge frustration, sadness and concern. These narratives are unacceptable.

We want to change the story for those with ME.

Sonya

Sonya Chowdhury
Chief Executive

Contacting Action for M.E.

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 **questions@actionforme.org.uk**
Visit us at **www.actionforme.org.uk**

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

InterAction enquiries

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

Our address is changing!

Until 23 September 2024 our address will be:
42 Temple St, Keynsham, Bristol BS31 1EH.
From 24 September 2024 our address will change to:
Unit 2.2 Streamline, 436-441 Paintworks, Bristol BS4 3AS
Post sent to the previous address will be forwarded.

Medical advice

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

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

Contents

Our new address

Please note that Action for M.E.'s registered address will be changing from 24 September 2024. See opposite page for details.

Hot topics

- At the time of going to press, Labour has committed to publishing **the final Delivery Plan on ME/CFS** (see overleaf – we will also share updates on our website). "It is essential that, once published, the commitments made to people affected by ME within the Plan are implemented as a priority, including urgent action to address the lack of research funding into the condition," says our CEO, Sonya Chowdhury. "We look forward to working with the Labour Government to ensure this happens."

- The inquest into the death of Maeve Boothby O'Neill concluded on 9 August 2024 (see p 5). For further information, please see our website **www.actionforme.org.uk/maeve-inquest**
Please note this contains distressing content.

- Our **AGM** will be held on Friday 13 September at 2pm – see p 6 for details of how to join.

- Our **Christmas Angels** project only costs the price of a card and postage stamp and gets more popular every year. Registration for this year's project is now open – see the back cover of this issue for full details.

In the wake of the General Election

Delivery Plan

We are aware the General Election causes concern for many people within the ME community in relation to the progress of the Delivery Plan. We have been assured on numerous occasions that the plan holds cross-party support.

"We have been working hard to ensure that ME is kept firmly in the minds of each and every MP and minister, and relevant government departments," says CEO Sonya Chowdhury.

"Action for M.E. has briefed all new MPs and departments on the impact that ME has on those affected by it, and the country more widely, requesting meetings and calling for the Delivery Plan to be published as a priority, alongside any commitments it makes to people with ME to be followed through, without fail."

"I've asked my officials to publish the plan, which they will do," said MP Andrew Gwynne, in response to the ME community (as this issue went to press). "Officials are now putting everything together."

We continue to advocate strongly with the new Government to accelerate research and urgently improve support and care for people with ME.

APPG on ME

The All-Party Parliamentary Group (APPG) on ME plays an important part in ensuring that ME is kept firmly on the agenda of the new Government.

As is parliamentary procedure, all APPG's need to be reconstituted once a new Government is in place.

Carol Monaghan, previously Chair of the APPG on ME and MP for Glasgow West, lost her seat in the General Election. All of us from Action for M.E. would like to sincerely thank Carol for her incredible dedication and commitment to people with ME and Chairing the APPG over recent years. It has been an honour to work alongside her.

Parliament's summer recess is not an appropriate time to look at reconstituting the APPG, so we have been using this time to review the APPG's communication strategy.

This means that, once it is reconstituted with a new Chair, we can share information relating to the APPG's work and outcomes more effectively.

An urgent need to act

Sadly, the dissolution of the previous APPG on ME means that its severe ME Inquiry will not continue, despite already having held its first hearing session.

We remain concerned that often people with severe and very severe ME receive inadequate support and healthcare. We hope to work further with journalists to raise vital awareness of ME – including the impact of Severe ME – to ensure that the valuable members of our diverse community are represented and made 'visible' in their experience of this debilitating and isolating illness.

Former health secretary Sajid Javid told The Times: "The party of Government may have changed, but the urgency to act remains. There is clear action that can be taken, and an entire community looking for hope. There will be important lessons to learn from the tragic experience of Maeve Boothby O'Neill (see p 5).

"This new Government should listen carefully, and then finally deliver this new strategy without delay."

Severe ME day took place on 8 August 2024, and aims to highlight the struggle faced by those with severe (or very severe) ME.

Our resource *Supporting people with ME/CFS in hospital* can offer help in advocating for the needs of those with ME, including those severely affected: **www.actionforme.org.uk/useful-resources**

Severe ME in the news

Trigger warning – upsetting content

As our CEO writes in her editorial (p 2), there has been a considerable focus in the news on the lack of treatment and support for people with severe ME. We report on two examples below. **Please be aware these stories are deeply distressing, so you may choose not to read on. We signpost to organisations for emotional support at the end**.

Maeve Boothby O'Neill, who had severe ME, died at home in October 2021, age 27. Maeve had lived with ME since she was 13 and was being treated at the Royal Devon and Exeter Hospital. The inquest into her death concluded as this issue was going to print.

The recorded cause of Maeve's death will be one of natural causes, specifically malnutrition which was caused by severe ME. It will be stated that Maeve died at home after three admissions to hospital where they were unable to treat her ME. The coroner expressed her hope that the inquest will lead to improved care and support for people with ME in the future.

"The inquest highlighted what many of us already know – the monumental challenges that people with ME face in accessing support and care, including those in hospital," says Sonya Chowdhury. "This must change."

Edina Slayter-Engelsman (aged 57) died by assisted suicide in July this year. A Dutch National, Edina also had severe ME. She lived in Scotland for 30 years. "I exist but I don't live," she said. She returned to the Netherlands to end her life.

Edina and her family wanted to share her experience, in the hope of raising awareness of the lack of research and support for people with ME. We acknowledge the complex ethical considerations surrounding assisted dying and respect the diverse perspectives both within the community and more widely.

If you'd like to talk to a trained volunteer or support worker about how these stories have impacted you, contact Samaritans on 116 123 (24 hours a day, seven days a week) or email jo@samaritans.org; or the Campaign Against Living Miserably (CALM) on 0800 58 58 58 (5pm to midnight every day) or visit **www.thecalmzone.net/get-support**

New Patrons

We have two new Patrons: Sarah Dorin and Philip Mould OBE.

Both Sarah and Philip are committed to utilising their extensive networks and skillsets to raise vital funds and awareness.

"ME is a cause very close to my heart and I have been an active supporter of Action for M.E. for several years," says Sarah. "Being a Patron will enable to expand this support, engage with my networks and help raise much-needed awareness and funds for the charity's critical work."

"I have seen the devastating impact of ME on people's lives and want to support the charity in being there for people with ME now and in the future," says Philip.

"The charity's work is a lifeline for many children and adults and I will help raise funds and awareness to reach even more people."

Westminster Hall Debate

On Wednesday 1 May, Sir Sajid Javid led a Westminster Hall debate in the Houses of Parliament, ahead of World ME Day 2024.

This covered topics such as:

- the urgent need for research funding into the condition
- the need for the NICE Guideline for ME/CFS to be fully implemented and followed
- the need to address the research gender bias that exists
- the ground-breaking work of DecodeME and LOCOME
- the link between ME and Long Covid.

Thank you to all those who took the time and energy to contact their MP to request their attendance at the debate, and for sharing their personal experiences of ME, many of which were shared during the debate itself.

250,000: an outdated number

We are aware that the '250,000' figure for those with ME in the UK is outdated. There is also an increasing number of people with Long Covid experiencing ME-like symptoms. We are currently in conversations with other ME organisations to develop and agree on an accurate figure to be used collectively moving forwards. It's important to ensure that any figure that is agreed on is evidence-based, backed by robust research.

We will provide an update on this as soon as we can.

All welcome at our AGM

You are invited to our 2024 Annual General Meeting (AGM) where you can hear about how we've worked with and supported people in the last financial year.

Please join us from 2pm on Friday 13 September, online via Zoom. All are welcome, and registration is free.

Trustee voting details were published in our Spring 2024 issue of InterAction together with voting form and freepost envelope. Voting for trustees closes on Thursday 5 September 2024. **www.actionforme.org.uk/votefortrustees**

You can find the full agenda and registration link for the AGM at **www.actionforme.org.uk/2024AGM**

DecodeME launches data access project

The DecodeME project has announced it is open to receive applications from other researchers to access the data collected through the project.

86% of DecodeME participants consented to sharing their de-identified data with other researchers and 95% of participants consented to being re-contacted for new research projects.

"By allowing other researchers to access this data, the DecodeME team hopes to accelerate research towards possible diagnostic tests and treatments for ME/CFS," the DecodeME team explains. "All applications will be reviewed by the team's Data Access Committee and will only be approved if they meet our high standards, are ethical and worthwhile."

We're #ThereForME.

#ThereForME is a new campaign, founded by Karen Hargrave and Emma Gore-Lloyd. Led by patients and carers, it calls for an NHS that is there for people with ME and Long Covid.

They have published a new report, drawing on data from over 300 people with Long Covid and ME (and their carers). It's been endorsed by 15 organisations, including Action for M.E.

Read more on the campaign's LinkTree: **linktr.ee/ThereForME**

'Researcher Toolkit' for ME/CFS launched

The UK Clinical Research Collaborative (UKCRC) Research Working Group on ME/CFS has launched its *Researcher Toolkit*.

Government funders of research in ME, academic researchers, and people with lived experience of ME worked together to develop the toolkit which provides an important overview of:

- UK Government research funding opportunities
- Guides to embedding patient and public involvement (PPI)
- Resources to develop quality proposals, and more.

You can find the Toolkit here: **psp-me.co.uk/researcher-toolkit**

THE
NEUROLOGICAL
ALLIANCE

Neuro Survey

The Neurological Alliance has launched its 2024 **#MyNeuroSurvey**

1 in 6 people have a neurological condition – a condition that affects the brain, spine and/or nerves. This includes ME.

The survey gives you the opportunity to share your experiences to improve treatment, care and support for people affected by neurological conditions in the UK and the Republic of Ireland. The survey will be open for responses until 15 November 2024.

It's anonymous and can be taken online here: **tinyurl.com/NeuroSurvey24**

For further information or to request a paper copy, email **survey@neural.org.uk** or call 01923 882 590.

Our response to the Green Paper

After receiving valuable feedback from the ME community, we have submitted a response to the consultation on the Department for Work and Pensions (DWP) Green Paper on disability benefits. The current condition-based assessment for Personal Independence Payments (PIP) fails to account for the fluctuating nature of ME and the process is often itself debilitating.

Our response highlighted several key areas where change is needed.

Recognition of the need for a functional based assessment

This is in line with the social model of disability, ensuring that support is always focused on individual need, creating a person-centred system that recognises the complexity of various conditions.

Fair assessment processes

We often hear of assessments worsening someone's condition because of their traumatic and invasive nature. A system is required that removes the need for an assessment when there are such severe symptoms and impact.

The need for greater support

Moving to a system that removes the need for an assessment would be accommodating. However, this would require specialists to evidence a person's condition. Given that specialist ME/CFS services are not commissioned by every Integrated Care Board, it is clear that there is a postcode lottery of care and a distinct lack of specialist services across the country. We remain concerned by the disconnect between nationally administered social security and locally commissioned health services.

By engaging with the consultation, we want to improve the accessibility of benefits for people living with ME. We are pushing for a system where the severity, fluctuating nature and impact of ME is properly acknowledged. Through this type of engagement, we can continue to advocate for greater awareness from policymakers, ultimately leading to more informed decisions.

Sharing real-life experience with policymakers is incredibly valuable in showcasing the effect that decisions have on ordinary people. Thank you to everyone who used valuable time and energy to contribute to the response.

Read more: **www.actionforme.org.uk/green-paper-response**

FUNDRAISING

Here's to making an impact!

We are delighted to announce a new partnership with The Henley Distillery, an award-winning company distilling gin, rum and other spirits based in Henley-on-Thames, Oxfordshire.

Jacob Wilson, Founder and Master Distiller at The Henley Distillery, asked for us to become the company's first ever charity partner. Jacob lived with ME for many years as a young person. Now in adulthood, as a founder of a successful business, he wants to use his position to support other people with ME and raise awareness of the condition.

"We are delighted to announce Action for M.E as The Henley Distillery's dedicated charity partner for the year," says Jacob. "The cause is one that is very close to mine and my family's hearts, myself having been hugely impacted by ME from the age of 14 as well as the impact it had on my parents, without whom I would not have got to where I am today.

"We plan to utilise every tool we have at our disposal to raise as much money and make as big an impact as possible for people with ME working alongside the wonderful people at Action for M.E."

On 30 June 2024, The Henley Distillery hosted an open day in celebration of their third birthday, with a percentage of proceeds going to Action for M.E. So far, this event has raised £3,500, adding to the £500 raised from the sales of their limited-edition Regatta Cup gin.

We are very excited to begin this partnership with The Henley Distillery, helping us continue our mission to empower people with ME to fulfil their potential and secure the care and support they need, while working towards a greater understanding of the illness and ultimately a cure.

We recognise that not everyone with ME recovers, but with this partnership we will be able to raise further awareness of the reality of ME and the desperate need for more research into this illness.

Lizzie, our Fundraising Operations Manager, at the open day in Henley

The power of global collaboration

In April, Sonya Chowdhury, our CEO, and Sian Leary, Head of Advocacy and Communications for the World ME Alliance, spoke at the first International Conference on Clinical and Scientific Advances in ME/CFS and Long Covid in Portugal.

The conference's main focus was on research into ME and Long Covid, but Sian, Sonya and two Portuguese individuals with ME participated in a panel discussion on patient advocacy, highlighting the vital role individuals and organisations play in this field.

"I emphasised the power of global collaboration among non-profit organisations, which amplifies our collective experience and knowledge, ultimately bolstering our credibility as a global movement," Sian explains.

"We underscored the role we all have to play: from individuals advocating directly with their own healthcare professionals; to health professionals with lived experience sharing that knowledge with others; to national charities like Action for M.E. building links with government officials and research funding bodies; and to organisations like the World ME Alliance that are lobbying the World Health Organization for increased focus on ME and other infection-associated chronic conditions.

"By officially endorsing this conference, the World ME Alliance successfully positioned itself alongside key researchers and organisations, fostering connections that will support our future endeavours. Our participation highlighted the importance of international collaboration and aimed to grow our scope and membership.

"It is heartening to see the discussions, learning, and passion of those in the ME research field, and to hear firsthand of their commitment to understanding the causes of ME."

World ME Day 2024

Across the world, individuals and organisations came together in May 2024 to build a #GlobalVoiceForME, raising awareness and fighting for tangible change.

The World ME Alliance shared stories from people with ME across the globe (we feature Mlindeni's story on p 26). These stories not only demonstrate the impact of ME itself, but also show how stigma, culture and belief intertwine to create varied challenges for people living with this illness.

This year's global action asked individuals to call on their country to become a #GlobalVoiceForME. Through dedicated guides for every country and your participation, the World ME Alliance reached 12 WHO National Counterparts. They plan to follow up these connections with further pressure.

tinyurl.com/globalvoiceME

Action for M.E. staff add their own global voices on World ME Day

World ME Alliance

Alliance announces strategic leadership board

The World ME Alliance has established a new Strategic Leadership Board, which comprises of Sonya Chowdhury, Emily Taylor, Petr Homolka, Saskia de Wit, Sam Pearce, Martin Hippe and Sian Leary.

This initiative marks a significant step forward in the mission to combat ME on a global scale. "The aim of this board is to promote an efficient and dynamic decision-making process for the Alliance, which will enable us to initiate more projects, making our work more impactful and sustainable."

Find out more: **tinyurl.com/WMASLB**

Getting together for tea and ME

This year's Blue Sunday tea party for ME raised over £40,000 for 21 ME charities across the world, including £2,170 for Action for M.E.

We are incredibly grateful to Anna Redshaw for being so dedicated to raising awareness of ME and raising funds to support people with ME. Anna shares:

It's such a pleasure and a privilege to organise Blue Sunday each year for a community of people who need and deserve so much more than a virtual tea party.

Again, Blue Sunday has shown our desire to be included and involved, rather than just sit on the sidelines and watch. I am always so proud and impressed by how many people mould and adapt Blue Sunday to work for them: plasters for feeding tubes changed to be blue to fit the theme, blue socks, blue teacups, blue blankets and bedding, ornate teapots and beautiful cake stands adorned with whatever we've been able to bake or buy.

To us it is such a special occasion, one worthy of wearing our favourite blue clothes that sit at the back of the wardrobe now that life has changed so much, due to the restrictions of ME.

I feel very passionately about this community and am always so proud of them for creating a tiny bit of joy for themselves on Blue Sunday.

To hear that so many people were delighted to have been able to join in from their own homes, sofas, beds, or gardens is so heartwarming. A tea party for ME is often a solo affair, perhaps (obviously) because of the impact ME has on our lives. That's why the online/virtual aspect of Blue Sunday is so vital. It was wonderful to see so many people engaging with other peoples' posts and photos online and, in turn, reminding them that they aren't alone.

I couldn't be prouder. And that's before we've even mentioned the fundraising side of things.

Let's do it all again next year!

Anna's gorgeous guinea pigs strike a party pose

We loved seeing the ME community come together and, if you took part, we hope that Blue Sunday gave you a sense of community, connection and hope.

Anna celebrates Blue Sunday 2024

Action for M.E. staff celebrate their own Blue Sunday virtual tea party

Change beyond a lifetime

One person's legacy is funding groundbreaking ME research.

In 2022, we received a notification that someone had left us a gift in their will. We receive around 16% of our income each year from gifts in wills, so this is a significant source of funds, helping us to provide our information, support and healthcare services.

This particular gift allowed us to fund a new, groundbreaking research project, awarding the first ever Clare Francis Research Fellowship (named for our President) to Audrey Ryback, at the University of Edinburgh.

Audrey's research began last year. It aims to identify which factors in the blood of people with ME/CFS cause changes to the mitochondria found in our cells.

Mitochondria produce the energy necessary for the survival and proper functioning of our cells. There is already considerable scientific evidence of abnormalities in the way that energy is produced and used by cells in people with ME/CFS.

This gift, left by one donor, has the potential to bring tangible, positive change for people with ME/CFS through its investment in this research.

If Audrey can identify the specific factors found in the blood of people with ME/CFS, we can move closer to a meaningful and easy-to-measure diagnostic test for the condition. This was identified as a research priority by the ME/CFS Priority Setting Partnership back in 2022, alongside investigating the role of mitochondria.

Patient-public involvement is at the heart of Audrey's research, and our work to secure funding for high quality research to create real change for you, your loved ones, and future generations.

Audrey Ryback

Audrey's research was featured in issue 115 of *InterAction*, p 11. You can also read more on the ME/CFS Research Review website: **tinyurl.com/audrey-ryback-research**.

Audrey will be continuing her research over the next two years and hopes to publish the results next year.

Listen to Audrey's earlier *InterAction* article for free on Soundcloud: **tinyurl.com/AudreyIA115**

Leaving your own legacy

The next time that you make or update your will, please consider the difference you can make by remembering Action for M.E.

Leaving just 1% to a charity can make a huge difference, so those closest to you inherit 99%. However, you can leave any sum or percentage that suits you.

Should you decide to remember us in your will, your solicitor/finance professional will need the details listed opposite.

Our charity name

Action for M.E.

Our charity number

Registered in England and Wales: 1036419
Registered in Scotland: SC040452

Our registered address

Until 23 September 2024:
42 Temple St, Keynsham, Bristol BS31 1EH

From 24 September 2024:
Unit 2.2 Streamline, 436-441 Paintworks,
Bristol BS4 3AS

Learning points about ME

Medical students share their reflections in the winning essays from Learn about ME's inaugural essay competition.

Nearly 30 students entered the 2024 Learn about ME essay competition in Scotland, funded by the Scottish Government.

Learn about ME partners Action for M.E., ME Action Scotland, the ME Association and Dr Nina Muirhead were delighted to award the first prize to Bhanu Wahi-Singh, a fifth-year medical student at the University of Edinburgh.

"Through personal and professional interactions with people impacted by chronic disease states such as ME/CFS, I have been inspired by the immense impact of research and education of both the public and clinicians about these illnesses, and I'm grateful for the wonderful work done by the Learn about ME project," says Bhanu.

Mairi Paterson and Lucy Anderson took second and third place respectively.

"We were looking for entries that offered real insight into what doctors should consider when supporting a patient who may have ME/CFS, with reference to its impact on their quality of life and level of functioning, and emerging biomedical evidence on post-viral illnesses," explains Dr Nina Muirhead.

All entrants were required to access and complete Learna's free CPD training module on ME/CFS, developed by Dr Muirhead, before submitting 500 words on the topic: *What is your most important learning point about ME/CFS?*

Bhanu's essay was published in the *Journal of the Royal College of Physicians of Edinburgh*, introduced by an editorial from Dr Muirhead. She wrote: "It is vital that this topic features more prominently in the medical curriculum, and in our medical textbooks."

Read the three winning essays here. Full references are available on request.
More information on the Learn about ME project: **www.actionforme.org.uk/learn-about-me**

Winner

Bhanu Wahi-Singh (University of Edinburgh)

"The best doctors are the ones that listen and form a relationship with patients"

Growing up, I always loved going to my family friends' house and visiting the nicest aunty, who would greet us with a smile and boundless affection. Yet, even during our joyous visits, there was an unspoken weariness in her eyes, which only became clear when I learned about her long battle with a chronic condition during medical school, a few years after my grief at her passing.

The puzzle pieces fell into place – the infrequency of visits, the choice of her house as the meeting place to minimise exertion, and the perpetual fatigue that belied her relatively young age.

Myalgic encephalomyelitis, commonly known as chronic fatigue syndrome, is a chronic and multisystemic disease with a complex pathophysiology. Despite its association with conditions like post-treatment Lyme disease and Long Covid, the specific cause remains elusive.

Previous and ongoing research delve into its link to viral infections (Hanson, 2023), genetic factors (Underhill and O'Gorman, 2006), and environmental triggers such as mould exposure and metal hypersensitivities (Bjørklund et al., 2020). Rapid advancements in research, fuelled by increased interest in Long Covid, have unveiled new biomarkers and mechanisms, fostering hope for future breakthroughs.

While research progresses, clinical challenges persist. NICE guideline 206 now provides defined diagnostic

continued overleaf

criteria, a crucial step forward. However, historical diagnostic hurdles persist due to a lack of familiarity among clinicians.

Many healthcare professionals, having received little or no education on ME/CFS during their training, face challenges in recognising and understanding the condition (Bested and Marshall, 2015). Negative preconceptions and scepticism further hinder prompt diagnosis (Bayliss et al., 2014).

Complicating matters, the association between ME/CFS and conditions like POTS and fibromyalgia, also poorly understood and viewed unfavourably by some clinicians, further leads to negative perceptions within the healthcare community of ME/CFS itself.

Managing ME/CFS demands a personalised approach. Patients often endure a traumatic journey, consulting numerous doctors before receiving a diagnosis (Broughton et al., 2017).

What has particularly inspired me thus is the role of clinicians specialising in ME/CFS who employ effective listening skills, respect, and trust to build person-centred relationships with their patients (Horton et al., 2010). This empathetic approach, crucial for managing a condition with such diverse and often misunderstood symptoms, serves as a model for clinicians across specialties.

The landscape of ME/CFS is gradually unfolding, revealing both the strides made in research and the persistent challenges in clinical understanding.

As we anticipate further breakthroughs, fostering awareness and education of both the public and clinicians at every level of training are essential in improving the lives of those grappling with the complexities of ME/CFS.

My most important learning point about ME/CFS, however, is how it really exemplifies that the best doctors are the ones that listen and form a relationship with patients.

ME/CFS is often a truly debilitating chronic condition, and it is imperative for us as clinicians to recognise this and understand how it impacts the patient's life, not just dismiss it because it is complex with an incomplete knowledge base.


Bhanu Wahi-Singh

Just like my aunty, there is a person behind the condition. Their suffering is real, even if we do not yet fully understand it.

This first-prize winning essay was first published in Volume 54 Issue 2, June 2024 of the *Journal of the Royal College of Physicians of Edinburgh*, the College's quarterly, peer-reviewed journal, with an international circulation of 8,000. We are hugely grateful to Dr Graeme P Currie, Consultant Respiratory Physician, Aberdeen Royal Infirmary and Editor-in Chief of the journal, for his support. **journals.sagepub.com/home/RCP**

Second place

Mairi Paterson (University of Dundee)

"There are a number of characteristic symptoms that should be red flags for ME/CFS"

With two of my family members being affected by chronic fatigue syndrome, I have always been aware of the distinct impact it can have. Seeing their quality of life be so drastically affected by the associated symptoms has been disheartening and, even more so, is witnessing the attitudes they have faced from healthcare professionals, time and time again.

At their most vulnerable, these young women were discarded as victims of teenage laziness or anxiety. They had to fight to gain support from their GP and their diagnosis took several second opinions and ultimately years.

Throughout my research on this topic, a lack of awareness of ME/CFS among healthcare professionals has been a common theme. Up to 91% of patients in the US remain undiagnosed in part as clinicians lack the knowledge around diagnosis and management of ME/CFS (Bateman et al, 2021). This is a striking statistic.

Additionally, according to the same paper, those who have been diagnosed are often receiving inappropriate treatment. The NHS website suggests that treatment of ME/CFS may include cognitive behavioural therapy.

However, research suggests that cognitive behavioural therapy is not only ineffective, but some patients report the therapy as resulting in substantial deterioration (Twisk and Maes, 2009). Numerous studies report similar results.

In my opinion, this relates to the burden being placed on the patient to improve their condition through mental work and the lack of acknowledgement of well-established biological abnormalities. In essence, it suggests that their symptoms are controllable.

A study found that higher perceived stigma around causal factors being controllable led to lower health-related and social outcomes (Froehlich et al. 2022) indicating that the mental burden of ME/CFS is much greater than simply that caused by the physical symptoms.

Indeed, far from the condition being psychosomatic, ME/CFS is a "chronic, multi-system disease with different patterns of onset and severity" (ME/CFS module) and there are several associated biophysical processes that are often impacted or implicated in ME/CFS. These should no longer be considered conditions of exclusion where diagnosis occurs only after all 'physical' conditions have been ruled out.

There are a number of characteristic symptoms that should be red flags for ME/CFS. Post-exertional malaise is common as is orthostatic intolerance. It is important that ME/CFS becomes part of a physician's differential diagnosis when patients present with those symptoms.

It still remains that ME/CFS are poorly understood conditions and there is yet much we can learn about their treatment and management. However, one thing that really resonated throughout my reading was a line from one particular paper. With all that these patients go through, and the lack of support many of them get from the healthcare profession, I feel that it is a prudent point on which to finish.

As we aim to understand post-viral illnesses, if we approach with compassion, humility and respect for the patient's experience, healthcare professionals can provide the care patients require and deserve (Bateman et al).

Third place

Lucy Anderson (University of St Andrews)

"It is imperative that we educate ourselves to support patients in a way that will not cause further harm"

Admittedly, prior to completing the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) module, I knew little about the condition. My understanding was limited to the experiences of a family friend. I had an idea about its debilitating nature but, I suspect like many fellow medical students, was unacquainted with the biomedical evidence. Now in my final year of university, I wanted to gain a deeper understanding of ME/CFS to take forward throughout my career.

Firstly, ME/CFS is a chronic, disabling medical condition, affecting multiple body systems (BMJ, 2024). It impacts more people than I had imagined, 2-4 per 1000 (The ME Association, 2021), often having a viral trigger. People with Long Covid are presenting similarly, meaning its prevalence is expected to rise following the pandemic (Jason & Dorri, 2022).

The diagnostic criteria (NICE, 2021) include the presence of key symptoms – debilitating fatigue worsened by activity, post-exertional malaise, unrefreshing sleep, and brain fog. These must be present for three months for diagnosis, although the condition can be suspected from six weeks. Other symptoms include pain, orthostatic dysfunction, and sensory hypersensitivity, but this is by no means exhaustive.

Its hallmark symptom, post-exertional malaise (PEM) describes an exacerbation of symptoms following activity. Importantly, this is out of proportion to the level of activity. PEM can take a few days to come on and may last weeks (Vøllestad & Mengshoel, 2023).

The evidence suggests that early rest followed by pacing is the most beneficial approach to treatment, as it can be harmful to encourage patients to 'push through' (Vink & Vink-Niese, 2019). This is due to altered cellular respiration, where cells switch to anaerobic respiration earlier leading to a build-up of lactate, even during activities of daily living (Tomas et al., 2020). As such, ME/CFS is not a functional disorder.

Other biomedical features evident include immune cell dysfunction, disruption to the hypothalamus-pituitary axis and interference in neuronal cell signalling, with visible changes on brain imaging (Cortes Rivera et al., 2019).

ME/CFS is distinct from depression. To distinguish these, it can be useful to consider whether there is a lack of desire to carry out tasks, versus limitation to perform desired tasks due to a lack of energy (Griffith & Zarrouf, 2008). However, as with any chronic condition, it is important to be wary of developing mental health problems and support as appropriate (Action for ME, n.d.).

The severity of ME/CFS is on a spectrum. The most critically affected are bedbound, in constant pain, unable to maintain adequate nutrition or carry out personal care. It has a debilitating impact on quality of life (Vyas et al., 2022). It is imperative that we educate ourselves to support patients in a way that will not cause further harm.

On reflection, I have learned a significant amount about ME/CFS. Contrast to common belief, ME/CFS is not a psychiatric or psychosomatic condition, neither is it medically unexplained or a functional disorder.

My key take-home point is the importance of viewing this condition from a place of understanding, compassion, and empathy.

No one can do it alone

Avril McLean, our Projects & Participation Senior Practitioner, reflects on the challenges of self management for those living with an invisible, misunderstood condition.

I have now worked alongside people with ME for eight years. I am struck time and again by how difficult it can be for them to get the support they need.

People with ME invest so much time and energy to continue to participate and contribute, meaning that many people may not understand just how debilitated and unwell they feel.

At times this means that people's search for support can be harder than it needs to be. There can be nothing out there that meets their needs. This can leave people feeling isolated and alone, while facing very difficult situations.

Someone who is so-called 'mildly' affected by ME may have lost about 50% of their previous ability to function. People who are severely affected may not be able to leave their bed and could be completely dependent on others.

The task of self management

Self management is an essential tool, as pacing is the main strategy that people with ME use to manage the impact of their condition and its key feature, post exertional malaise (PEM). Yet it has always struck me that we are asking people to take on another extra activity that all of us would find difficult to do, while also managing the impact of a devastating health condition.

> "People need support to be able to support themselves"

Pacing itself is something that takes time and energy to learn, and it is still not a cure.

We've been piloting some mindfulness sessions – not because mindfulness will fix people's ME, but because these sessions offer a moment to be with other people in the same situation. It is an opportunity to pay attention to what is happening physically, mentally and emotionally.

Self management requires discipline above and beyond normal day-to-day activities. People often need support to be able to support themselves. They also need opportunities to laugh and chat, when they can, with people who understand their experiences.

Support from professionals

The other side of self management is working in partnership with GPs and other healthcare professionals. Nobody should have to manage ME without a professional who understands how the condition impacts health and quality of life.

Having a professional who listens and is prepared to explore what might help with managing the wide range of symptoms is invaluable. Unfortunately, many people do not have this experience. Our Learn about ME resources (see link on p 11) aim to help address gaps in knowledge and understanding.

I would like it if everyone who has a hidden invisible health condition could feel that they had the support and understanding that they needed to manage their condition.

No one should have to manage ME on their own.

This is an abridged version of an article which appeared on the website of the Health and Social Care Alliance Scotland in the run up to Self Management Week (23 – 26 September 2024).

Dear team

Our Information and Support team answer your questions.

Q. I suspect my child may have ME. How do I proceed?

A. For families embarking on the challenging journey to explore a diagnosis of ME/CFS in a young person, it's helpful to understand what should, ideally, happen.

The ideal pathway

The NICE guideline on ME/CFS provides clear guidance to ensure patients receive accurate diagnoses and appropriate referrals.*

- ME/CFS can be suspected in a young person if symptoms have persisted for more than four weeks
- a diagnosis should be considered in a young person if they have persistent symptoms for more than three months.

These symptoms are: fatigue not significantly relieved by rest, cognitive difficulties, unrefreshing sleep and a sustained exacerbation of symptoms that is disproportionate to activity undertaken (PEM). All four need to be present for a diagnosis.

The reality on the ground

Experiences vary depending on individual GPs, funding, local referral pathways and specific guidelines. We've heard accounts that some GPs might feel confident diagnosing ME/CFS and referring patients directly to specialist services (although we don't usually see this). This is likely to be a good outcome, as patients will get access to specialist support more promptly. However, be aware that the official guidance is that GPs refer them to a paediatrician for further assessment and investigation for ME/CFS and other conditions.

There are only a handful of paediatric ME/CFS clinics in England and, unfortunately, none in the other regions of the UK. Sometimes it is possible for a young person to be referred to a service outside their local NHS area. However, their Health and Social Care Board or Independent Health Care Board (IHCB) needs to agree to fund this, and practice across IHCBs varies.

A GP's acceptance of a diagnosis from a private doctor (including Action for M.E.'s doctors) can be inconsistent. It's worth establishing whether your GP will accept a diagnosis (and any recommendations) from a private doctor before going down this route.

Tips for GP appointments

Do your homework. Research good quality information beforehand. Familiarise yourself with the NICE guidelines and resources from organisations such as Action for M.E.

Know your options. Consider the personality and approach of your GP. You have the right to ask to see a different GP in the practice. You can request a double appointment to have more time. If your child's health is likely to be significantly impacted by a visit to the GP surgery, you can ask for a home visit, but you'll have to have to make a strong case for this.

Document symptoms and questions. Prepare a list of your child's symptoms and any questions you have. This helps you cover essential points during the appointment. If the young person can record an activity diary in the run-up to an appointment, this can be useful for the GP. Apps which record activity can also provide this information.

Clarify the plan. If the GP is reluctant to diagnose or support the diagnostic journey, ask what they feel should be the next steps. Don't hesitate to request a referral to a specialist paediatrician if the GP is unwilling to diagnose.

Ensure the young person's voice is heard – that they inform and agree with each step along this journey. Be mindful of keeping them at the centre of this process.

And finally….

Being prepared in this way can help your child receive the prompt, appropriate care they need.

Remember, you are not alone, and organisations like ours are here to help you navigate what can be a long, draining and isolating process.

Our young people's counselling service

Our free counselling service for young people aged 13-18 provides valuable emotional support. It doesn't aim to replace NHS services, merely supplement them.
www.actionforme.org.uk/free-yp-counselling

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*NICE guidelines automatically apply in England and Wales. In the absence of Scottish guidance, clinicians in Scotland are expected to refer to guidance available to them, including from NICE. The NI Department of Health has endorsed the NICE Guidance.

"Everybody has a story"

We talk to Scottish singer-songwriter Stuart Murdoch about his journey with ME, which he shares in his new book, *Nobody's Empire*.

SPEED READ…
Stuart Murdoch has lived with ME for over 30 years. He has managed to build a slow career in music and is the lead singer in the band Belle and Sebastian. Stuart reflects on storytelling (particularly in his new novel), his journey with ME and his sense of belonging in the ME community. He wants to make a difference and raise awareness. He shares his certainly that no life is ever wasted.

How would you introduce yourself to our readers?

I'm Stuart Murdoch and I'm the lead singer in a group called Belle and Sebastian. I've had ME for over 30 years now. I was quite severe at the beginning, but I managed to make a career – a slow career – in music. I've been well supported throughout. I'm still coping with ME. It's a deep background, affecting everything in my life.

Once it had happened to me, I felt like ME was almost like a verdict. It changed my life forever. Everything that went before got thrown away. It was a complete reset.

The consolation was that I slowly started to write songs and eventually managed to forge a career.

Everybody has a different story, and I've written the story of how it all happened in the novel, *Nobody's Empire*.

The book has been described as part fiction, part memoir. It certainly feels like your own voice.

Oh, for sure. I think the fictionalised part is more the other characters, because I've invented characters, I've merged characters and I've made up many conversations. But when it comes to the thoughts, that's me – some of the thoughts were from me at the time, but then some of the thoughts are those I'm having now, in hindsight.

I don't think I was as wise then. Hopefully I'm a little bit wiser now.

There's a power to storytelling, but different ways to tell stories. Song lyrics, for example, are quite a different style from a novel. How have you found the difference in types of writing?

I think writing a book, you get the chance to flow – to be as simple as possible. You speak your thoughts, you put yourself in your head from a previous time and you say what you felt. That's as simple as you can get. Songwriting can be a bit trickier. There are different kinds of voices that you can employ, but [in the book] I was trying to give them the straight dope.

I have a friend who's been quite severe with ME; I let them read the story a while ago and they really enjoyed it. At the same time, they said, there are a lot of ME people who might not dig this so much. Some might say that you haven't advocated enough or explained enough or gone into enough depth. But I had to put the story first.

It is an ME story, but I didn't let ME hold me back. It is my story – hopefully there's some truth in it.

There is this sense of journeying throughout the book. ME is just one part of that.

In the book, you have the gang: Stephen, Carrie and Richard – the three ME people who support each other. We felt that if you can escape the context of ME – if you could actually think about your own life and what you would like to do – then that's a victory.

> "People feel as if they've been deserted"

When ME impinges itself, which it often did, those would be the rough times. If you were thinking about music, if you were losing yourself in music, or if there was a chance that you could be in a relationship – or some of the other things that the three characters aspire to – then this became a victory.

What are your hopes for the book?
I would like to help people. I don't just mean this with the book. I mean in general. I do want to be useful.

It would be great if it could serve some sort of purpose. I'm hoping that when I do interviews that maybe I'm doing a job, by raising the issue again. Because we all know that there's work to be done, that people still feel as if they've been deserted.

I've just said that we tried to escape from ME and that would be a victory. At the same time, every time I've been involved with Millions Missing, or any advocating for ME, I don't feel I'm in a foreign country.

I feel like I belong. I recognise ME people. I am one.

I'll never not recognise ME people as good people, who just want to get on with it – they want to work, they want to live. I think the powers that be don't understand or don't care that ME people want this chance and deserve it as much as anybody.

Many are still labouring under the false belief that it's "all in your head", and the legacy of that.
There are always mental health aspects that come with any illness, be it cancer or another major illness. Some of these mental health aspects may come before, some of them come during, some of them come after – they're interwoven.

But for the physical aspects to be ignored in the case of ME is unforgivable. A doctor has to listen to a patient, believe what they're telling them and take appropriate action. They need support. We all need support.

One thing that comes through in the book is a love of nature, of being outside. Is that something you find helpful in terms of your wellbeing, while managing the impact of the illness?
Not only that, but nature as a process. Again, I'm echoing what Stephen says in the book, but I used to tell the gang, "look, nature knows how to heal." We had to have that when nothing else was going for us.

That's an interesting existential question for lots of people with ME who find themselves to be stuck. You get to this point, where you throw up your hands: "The trees are still growing. I can see the birds flying. Everybody's got this. Everybody's got the energy, the energy of nature and life. Why don't we? What's gone wrong?"

There's no answer to that at the minute. I redoubled my efforts back in 2014/15 because after I had my second kid, I took a big nose dive.

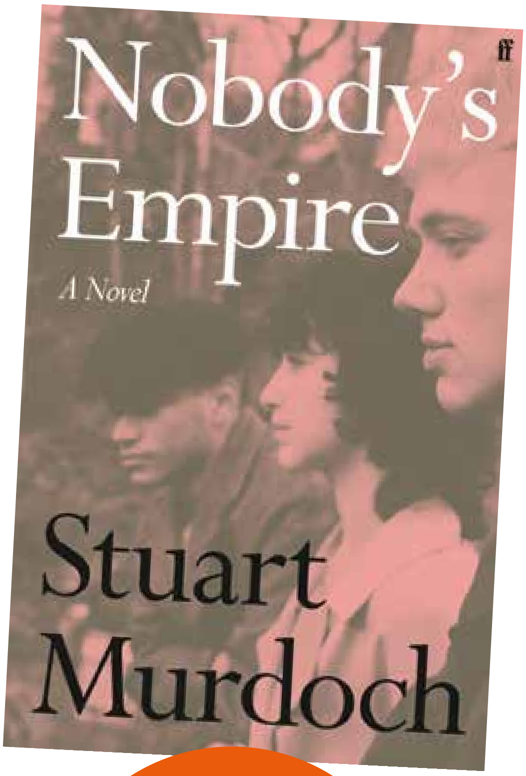
I thought, right, I'm going to get back into ME. I'm going to look for up-to-date research and see what the latest is. I went to a clinic; it was all about breaking it down, peeling back the layers of the onion, taking bloods all the time.

I went through a couple of years of this… sending away my blood and doing tests and changing my diet, and all different types of supplements, so expensive and time consuming. But I felt that I was in a position where I was saying: "Right, make me the guinea pig." I will do anything, if I can open a door somewhere.

I must admit I didn't come to any great conclusions. I didn't make any great leaps.

It was an eye opener. I am so empathetic with people who are going through the same thing, who don't have spare income like I did and don't have energy and time to try that… because it became like another job.

In this issue, members of the ME community reflect on how they explain ME (p 19). How do you feel when you have to describe ME to someone?
I'm doing what I'm doing and I've found a position in which I can survive and so… It's funny, nobody asks me! Even my wife, even the person I'm closest to in the world. I think it kind of escapes her and always has. I could graze my knee and she would make much more of a fuss over the sight of a little blood than the fact that I'm shattered for the whole day. It's so difficult.



WIN!
Enter our giveaway on p 30 to win a signed copy of Stuart's new book.

Going back to the gang in the book, with the three of them – and this is absolutely true – when we used to meet as an ME club in the early 90s, it was like *Fight Club*. We didn't discuss ME outside [of the club]. We thought it was a waste of time. The energy it took to explain it was all the energy we had.

Are you impacted by brain fog?
Funnily enough, brain fog on the whole I'm not too bad with. Me and my best friend Ciara – whom Carrie is based on in the book – we always say, just another threshold. There's always a threshold.

For me, brain fog isn't usually my threshold… it'll be energy or it'll be viruses. For her, it's headaches, they are the first thing that strikes.

Within the framework of the energy I have, my brain does still

continued overleaf

seem to be active, which is a great boon. Even when I need to lie flat, I go through a formal process of meditation where I'm trying to actively calm my mind and slow everything down. That's useful.

There's a deep sense of spirituality in the book.

Yeah, definitely. And that's not for everybody. But then maybe you don't have to share a sense of spirituality to be interested in it. For me, it was something that I wanted to be completely honest about. When there's not much going on, to me, the spirituality… It's life itself.

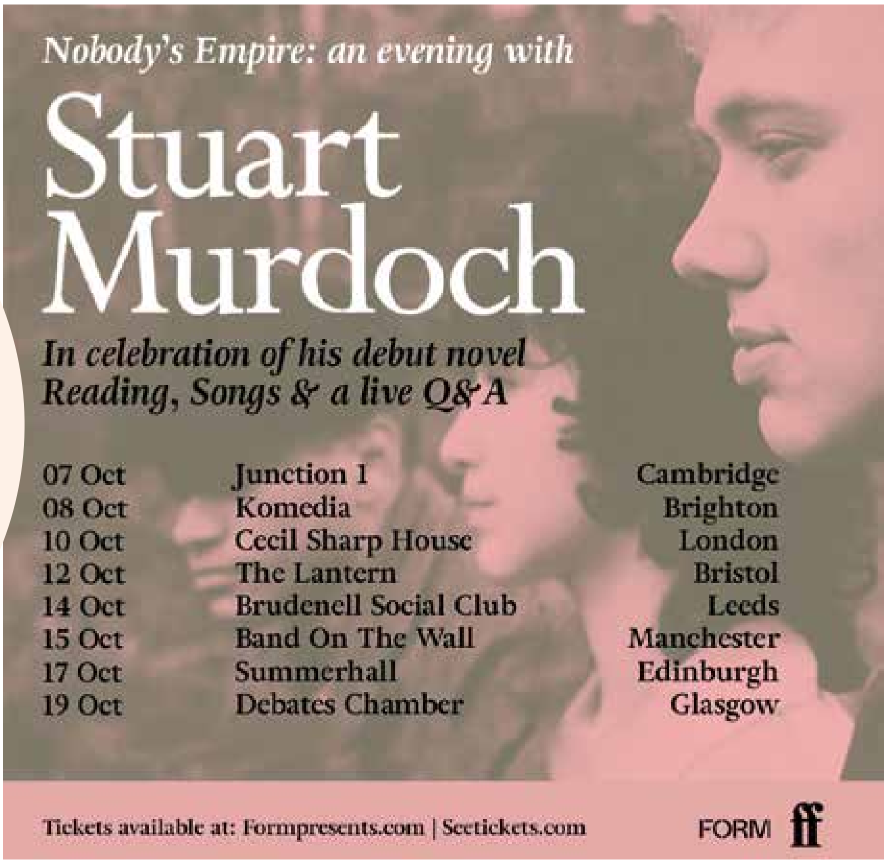
When things stop, I'm so lucky that I have this sense of 'otherness', that I have a sense of what went before, what's going to come after… within this lifetime, sometimes you feel, what a waste. In my own personal faith, it's not a waste. The work that you're doing, with the ME, you have to increase your patience. Your compassion is increasing all the time.

It is not wasted.

Your life is not wasted.

An Evening with Stuart

Stuart is doing a tour to celebrate the launch of his book, *Nobody's Empire*. He is keen to welcome members of the ME community, so if you have the energy and capacity for an evening outing and live locally to any of the venues, he'd love to see you.



Nobody's Empire: an evening with

Stuart Murdoch

In celebration of his debut novel
Reading, Songs & a live Q&A

07 Oct	Junction 1	Cambridge
08 Oct	Komedia	Brighton
10 Oct	Cecil Sharp House	London
12 Oct	The Lantern	Bristol
14 Oct	Brudenell Social Club	Leeds
15 Oct	Band On The Wall	Manchester
17 Oct	Summerhall	Edinburgh
19 Oct	Debates Chamber	Glasgow

Tickets available at: Formpresents.com | Seetickets.com

“I want to live again”

Trying to explain what it’s like to have ME is hard. Here, members of the ME community share their feelings.

ME is relentless. It is also unpredictable. Trying to describe it is incredibly difficult. Not least because the very symptoms you are trying to communicate are impacting your ability to interact with others. When stringing a sentence together is taking every ounce of what you have, how are you supposed to help others understand?

It can also feel highly frustrating that people with ME even have to try and ‘help others understand’ in the first place. So much capacity is taken with getting through each day. Spare energy is not a reality.

We asked the questions: **how do you describe ME? What words do you find helpful or unhelpful? Are there analogies that you use?**

As you might expect, there is no ‘one-size-fits-all’. Some analogies were popular with some and not with others. We’ve shared some thoughts here, while acknowledging that no words are adequate in capturing the extent of life-affecting symptoms.

A thief of time

Jane* got in touch with us to share her thoughts after seeing the World Health Organization (WHO) refer to ME as an energy-limiting disability. She thought it was positive that something affecting energy was framed as a disability, but feels ‘energy-limiting’ doesn’t cover it.

Jane can’t manage mornings at all. “I’m awake for only part of day, which is significantly disabling.” ME is ‘life-limiting’ – a phrase that is increasingly being used not just for terminal conditions but those which have a major long-term impact on the quality of life. Another description could be ‘part-time living’. The lack of time is a disability.

This is hard to explain to others. Medical appointments are a struggle. Jane tries to explain to staff (appointment makers) that she is ‘non-functional’ in the mornings: “Don’t say unable to function, they just assume you are drunk!” People also assume you can work around this, or attend on a weekend instead, but they’ve missed the point.

Different people have different patterns. Hannah, for example, dreads afternoon appointments. “I have a window between 10 and 12 where I can think more clearly,” she explains. “The ME still bites, but the symptoms ease a little. After that, everything gets harder, slower – physically, mentally, emotionally. I get stressed as I can’t explain myself properly, and I just need to lie down. Having to try and talk to someone in that state (and make sense!) is torturous.”

So much effort is taken with planning and putting things in place. When it comes to talking to others, “we have to be clear in everything we say, so that our needs are understood without error,” Jane says. “Those with ME need efficiency – for things to work as required first-time round, without repeating ourselves, so our limited time isn’t taken up unnecessarily.”

Mobility aids can give assistance but they can’t “magically make someone able to work, or be awake when they can’t be!” says Jane.

continued overleaf

Saying you have 'low energy' makes people think of non-energetic, which is not the same thing.

Jane suggests saying we 'pause' instead of rest: "Rest implies that you feel better after doing it, as if it were a choice. But we can't do anything."

Catherine agrees: "Let's change 'resting' or 'unrefreshing sleep', as those people who have a disturbed night's sleep think that is comparable." She suggests the term 'sensory lockdown'.

It can be very difficult to manage the natural frustrations and feelings arising from this. You are, as Andrew puts it, "cramming your life into 10-20% of the energy you used to have on any given day." He asks: "What do you drop? How does that make you feel? In practice it means extremely tough trade-offs and can naturally lead to feelings of guilt for not pulling your weight domestically, professionally or socially. That's certainly how I've felt for vast swathes of the illness."

The battle to be understood

Assumptions, judgements and misunderstandings from others are painful and exhausting.

"Sleep. Sleep. Sleep. You awake now? Are you sure you don't want to sleep again as you love it so much?"

These are words spoken to Rebecca by her carers.

"They don't understand at all," she says. "I try and explain using the spoon theory ((see opposite page) or that I'm always tired. I wake up more tired than I was before sleep. That doing something like showering or cooking drains me really quick and my body is running on empty, which is why I always sleep afterwards."

Rebecca also has Joint Hypermobility Syndrome with chronic widespread pelvic pain and fibromyalgia. "Being in pain 24/7 is incredibly tiring." She also suffers with Non-Epileptic Attack Disorder (NEAD). The seizures make her sleep.

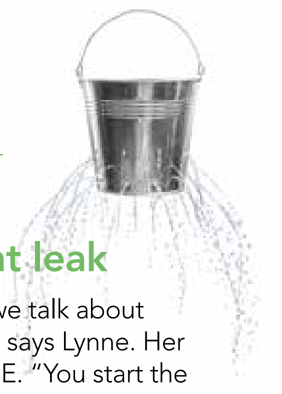
"I wish I could find a way to describe the pain and my ME to people," Rebecca says. "They really don't have a clue and some people just think it's an excuse to be 'lazy'. I wish I was being lazy. It'd be better than this.

"I miss being normal, doing everyday things, going to work. I was 19 when I got ill. I'll be 33 this year. I've spent more time asleep in the past 13 years. I sleep my life away. I want to live again."

Money in the bank

"I sometimes use the analogy of energy being like money in a bank. The more you have, the more it accumulates interest, so you don't want to spend all your energy if you can help it. In an emergency, you can push yourself and go overdrawn by spending more than you have in the bank, but when you do, the bank starts charging heavy interest payments and it will take a long time to pay off.

"If you have ME, the bank charges you really heavy penalties in comparison to healthy people. It's important for me to not spend too much, or it all goes on interest payments rather than actually being able to do anything." – Katherine



A constant leak

"In our house we talk about leaky buckets," says Lynne. Her husband has ME. "You start the day with a bucket only partially filled, yet the bucket is already leaking. Some tasks or events could take almost the whole of the contents of the bucket straight away, but because of the leak it can take almost all day or several days to get back to enough energy to do anything else. An event that takes all the contents of the bucket will mean that anything else is almost impossible, sometimes for weeks."

A punctured tyred could also encapsulate the same thing – in fact Simon often uses the word 'flat' to describe what happens to him.

"ME is like someone pulling out a bath plug, my energy goes down the drain and I end up in a heap on the floor." – Elizabeth

The spoon theory

The spoon theory has become very popular (those with chronic illness sometimes refer to themselves as 'spoonies'), but it polarises opinions.

Introduced by Christine Miserandino as a visual illustration of living with a chronic illness (in her case, lupus), it uses the idea of each person having a limited number of 'spoons' per day.

Spoons represent energy, and are quickly used up. Sitting up in bed takes a spoon, cleaning your teeth takes a spoon, etc. If you have an energy-depleting condition then you may start the day with very few spoons – whether that's ten, five, two or even zero. (Spoons were what Christine had to hand, so, theoretically, you could use any object to represent a unit of energy/activity).

"I used this to explain to my kids when I was first diagnosed," says Viv. "We'd put a glass of spoons in the kitchen, every time I'd used my spoons, I removed them. That allowed them to make choices of what we could do as a family without running out of spoons."

As it's become so popular, the spoon theory has spread through other communities as a way to explain energy limitations – so has become a bit 'diluted'. Some people find it unhelpful and too long-winded to explain.

The faulty battery

Particularly popular, and also touching on role of mitochondria as the powerhouses of our cells, in this analogy, the battery of the body loses charge too quickly. It never starts the day fully charged, and there is no way to effectively recharge it. (Hear about Audrey Ryback's continuing research into the role of mitochondria in ME on p 10.)

"We are always in energy-saving mode so our bodies have to cut out a lot of the basic functions to try and get through the day with the last bit of power before it runs out." – Anna

"The day I got ME, all my batteries were replaced with the cheap 'low energy applications only' ones." – Louise

"My energy battery only charges to 15% but that 15% of energy is in a dysfunctional body of pain and sickness." – Julia

In a similar analogy, when talking to friends, Andrew refers to 90s video games. "In some of those games you had an energy or life bar. Lots of things would take away energy/life but it would gradually improve and refill if you avoided things that damage it for a bit. But, crucially, should you let your energy bar run down to zero, the game would be over and you'd have to go back to the very start. The trick was to protect your energy bar and avoid running out completely at all costs." He equates this with ME. "You learn your energy bar through experience and you have to stick within it. Failure to do so sends you right back to the start."

The dragging weight of ME

These analogies reflect the sheer effort it takes to do anything when you have ME.

"Severe ME is like dragging around a dead body and I'm both the dead body and the person dragging it around." - Helen

"Like walking with lead-lined boots through wet concrete."– Billie

"It's like walking through molasses. I feel like I'm wearing exercise bands on every joint." - Rachel

"It's a rabid dog always at my heels, tugging at my legs, pulling me down." - Hannah

"It's running a marathon on sand, in a metal diving suit full of sand with full blown flu." – Wendy

Again, these are popular, although some find them unhelpful. "I don't think comparisons with flu or marathons help much because healthy people can keep pushing through," Anna says. "We can't."

An illness of devastating potential

Analogies have their limits and descriptions fall short when discussing the sheer extent and severity of symptoms – especially when talking to health professionals. "I'd like to see more patients reassured that they don't have to come up with imaginative ways to explain their symptoms," says Dee.

The focus on fatigue is frustrating for some. "We need, if we are serious about recognition and justice, to have it conveyed that we are not talking about fatigue, but an illness of devasting potential and where any exertion can cause harm," says Kerry.

Chronic fatigue, says Catherine, is "insulting and damaging". She has been a carer for people with ME since the 1980s, diagnosed herself in 1996 and is now a full-time carer for her son (diagnosed in 2017). "It is definitely time for a change to more accurately descriptive terms."

She describes after-effects of any activity as "exacerbation of the array of disabling and pain symptoms that are there all the time, a shutdown of all body systems and functioning" and "sensitivity overload causing an inability to vocalise and tolerate any sensory stimulation including light, touch, noise (any sound at all) and movement."

When loved ones don't understand

"I've pretty much given up as they only hear what they want to hear… I've wasted enough energy trying to explain."- Sophie

It's important to emphasise that you are not responsible for what someone else thinks. It's not on you. You can try your hardest and yet, true understanding outside of experience is impossible. It's difficult when those we love seem unable – or unwilling – even to accept the reality, and deeply painful when we feel labelled and judged unfairly. Someone's failure to understand is not your failure to explain.

Thank you to all of you for taking precious time and energy to share your thoughts with us. We were struck by the sense of solidarity within the ME community and the value of sharing experiences with each other.

Although we couldn't include everything in this article, your input is invaluable and much appreciated.

*some names have been changed

Fatigue

I've tried so many times
to describe fatigue,
but words just aren't enough.
Despite a kaleidoscope of colours,
shapes, sounds, and feelings,
nothing comes close to expressing
the utter helplessness as
your body shuts down from within.
A battery drained, a burst balloon,
a monster just bleeding you dry.
The knowledge that, were the world to end,
there's nothing you could do,
because in that moment, you couldn't move,
even if your life depended on it.
But these words mean nothing,
they're incomplete metaphors,
lost to the inadequacy of words.

Amanda Shortman

Resources

'This is ME'

We have a 'This is ME' template that people with ME can use to help carers and/or other professionals understand how ME impacts them, and the reasonable adjustments they need. Found under 'Living with ME' on **www.actionforme.org.uk/useful-resources**

Explaining ME/CFS

Written by young people, for young people, this serves to help young people to convey the profound realities of living with ME/CFS to others. Found under 'Children and young people' at **www.actionforme.org.uk/useful-resources**

The ME Factsheet

The World ME Alliance have a helpful factsheet, which can be found and downloaded here: **www.worldmealliance.org/what-is-me**

Please do get in touch with our friendly Information and Support team if you want someone to talk to without having to 'explain yourself'. They can also give advice on how to talk to medical professionals and signpost you to additional support. See p 2 for contact details.

Who am I?

Amanda Shortman reflects on issues of identity when you have ME.

SPEED READ...
Getting ME steals so much of your identity. Who you once were becomes just a memory, and who you thought you'd become just a dream. Watching the documentary *I am: Celine Dion* reminded Amanda of this struggle, and how much she has fought to maintain a sense of identity whilst trapped in a very sick body.

I've been thinking about how to sum up my experience with ME for quite some time. How do you condense so much into such a short piece? Even as an experienced writer, I've struggled to know where to begin. There is just so much to say.

Then I watched the documentary *I am: Celine Dion* (which shares Celine's story of having Stiff Person Syndrome and its impact on her ability to sing). Her raw honesty about the struggle to maintain her identity, when the very thing she is so well known for was ripped away, hit me hard.

We all know that feeling, right?

A time of grieving

Getting sick with ME takes away so much of who you are. Wherever you are on the spectrum, from mild to very severe, you lose so much. Independence, autonomy, financial stability, friends, colleagues, even family. Who you once were becomes just a memory, and who you thought you'd become just a dream.

Amanda Shortman

I've had ME for nine years now, although the onset was pretty gradual for me. The virus that first triggered it hit me in the summer of 2015. I was able to continue working in some form or another until the end of 2017. I became mostly housebound in 2018, and since 2020 have had a few periods of being mostly bedbound, but those are thankfully short-lived.

During that time, I have grieved so much for the person I once was. I can't be the mother, wife, and friend I long to be. Nor can I get involved in all the projects that mean so much to me. Who am I when everything I once held dear is now out of reach?

Finding ways to express myself

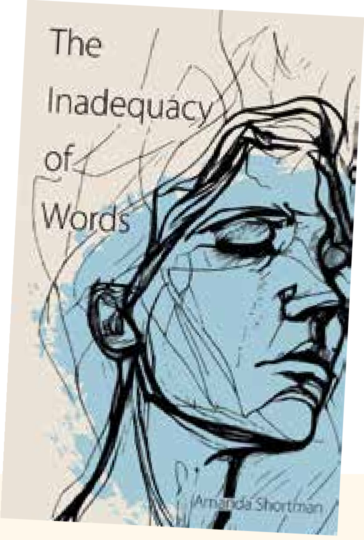
Therapy has helped me a lot in this respect. My therapist helped me to recognise that I'm still in here, still the same person inside this very sick body that I always was. Now, I have to find new ways of expressing that.

I am a communicator at heart. Despite being 'selectively mute' during my teens due to undiagnosed Autism, I chose to do a German and Russian degree. Who chooses to have to speak in two foreign languages when they struggle to speak up in English? Someone who is passionate about communication!

I've been a blogger since 2006, a published author since 2014, and worked as a copywriter when I first got ME. Communication is my thing. It's an intrinsic part of me. As much a part of my identity as singing is to Celine Dion. And yes, ME has made this incredibly hard. I currently have half a dozen books bouncing around in my head that I have not been well enough to get out onto the page. Sometimes I fear I'll never get them out, and that part of my identity will be lost forever.

And yet, as Celine says at the end of the documentary, "If I can't run, I'll walk. If I can't walk, I'll crawl."

For me, that sums up everything about ME patients. Somehow, throughout it all, we find the strength to cling to who we are. And that, my friends, is something we should be so proud of.



Amanda has kindly offered to host a giveaway. Three lucky readers can win a copy of her poetry book *The Inadequacy of Words* (you can read her poem 'Fatigue' on the opposite page).

Email **interaction@actionforme.org.uk** with 'AMANDA POETRY' in the subject line by 10 October 2024 for a chance to win.

Communities of disbelief

NoLoyiso Jolobe, also known as Lolli, was born in South Africa. She first moved to the UK when she was nearly 10 years old. She reflects on having severe ME in two cultural contexts.

SPEED READ...
Lolli describes her journey of diagnosis and the reactions she experienced, as a black South African woman living in the UK, from both black and white communities. She reflects on how the social context of an illness – and the history of a community's collective experience – can impact those with ME across different cultures. She writes poetry as a form of expression in both English and isi-Xhosa.

Journeying with ME

My significant health issues began with a heart problem. This resulted from the distress of experiencing physical and emotional abuse from another adult. I developed Takotsubo Cardiomyopathy (in which heart muscles are weakened by severe stress).

Soon after, I was diagnosed with Viral Myalgia. The GP had said that the cardiomyopathy had lowered my immunity; then I had an unresolved viral infection. (I now know that, after cardiac surgery, my symptoms of severe fatigue, weakness and chronic high levels of pain were signs of ME.)

After 17 years living in the UK, I returned to South Africa to be with family. Little was known about this Viral Myalgia. A neurologist there disbelieved and belittled me, saying that my illness was in the mind. So I kept quiet about it, plodding on, with periods of severe pain, fatigue, and being bedridden.

Years later, I returned to the UK and embarked on a career in academia. I managed to complete a master's degree, but my symptoms meant I often relied on lecture notes from friends. They could tell when I needed them to call a taxi for me.

I began a PhD in 2003, but my symptoms continued. The research element enabled me to pace myself instinctively, only working two days a week, but I still didn't have a name for what I was going through. It was only in 2007 that I heard a radio programme discussing ME and recognised my own experience. That led me to getting a GP referral and a diagnosis of moderate ME, from ME Specialist Prof Lesley Findley.

I was advised to stop my PhD, but this was emotionally devastating and hard to accept. I pushed on with my studies, but my condition worsened, and a few months later I was diagnosed with severe ME.

My world imploded. I had to give up my nearly completed PhD and career. What lay ahead was a journey of negotiating living with ME.


NoLoyiso Jolobe

Reflecting on social context

I am writing from a black woman's perspective. An African woman in the diaspora, my social context is mainly the black and white communities. I have experienced disbelief and invalidation of my experience with ME from both.

The social context of illness is important. It makes sense to me that the historical collective memory of a community affects whether or not people with ME receive understanding.

An English psychologist called Lynch purportedly wrote in 1714 about how to shape and subjugate black people's minds* – useful in the enslaving and colonising processes.

> “I was told I should be ashamed of not walking”

The black community here is largely composed of the descendants of oppressed black people.

I wonder: does this community’s collective experience of trauma mean that they often have little time for invisible conditions? Their emotional resources to deal with life, as less valued members of the society, are depleted. They simply can’t afford to acknowledge more than they can deal with.

Those with ME in this community are disbelieved. Their experience of ME is invalidated. I had to navigate my own journey within this social context. I was often told I should be ashamed of not walking, of allowing my mother to push me in a wheelchair.

I have coped by barely talking about my illness with members of my own community. My faith was my support.

Both black and white communities are descendants of those in that social conversation. Both communities bear the legacy of their ancestors. The development of today’s black psyche can’t be considered alone. We must also think about those involved in their brutalisation – directly or indirectly.

I believe that reflection is needed in both black and white communities if people with ME are to be fully integrated and supported in both.

---

*Anachronisms in this text have led historians to doubt its historicity, but it is still a powerful reflection of a cultural mindset.

Finding expression in poetry

Lolli writes poems in English and in isi-Xhosa, a South African language. She uses speech-to-text software and writes in short chunks to pace her energy.

I matter too

I, yes, I
I matter too
My culture is foreign
So far from where I was born
My own body fights me
Pain is my companion
With work no longer an option
My bed is my home
My pillows my friends
But still I matter
I matter too

Ndinalo ixabiso nam

Nam, ewe, nam
Ndinalo ixabiso
Aph ‘ayaziw ‘inkqubo yethu
Akukud ‘apho ndazalwa khona.
Umzimb ‘am uyandilwa
Iintlungu ziyandikhapha
And’kwazi nokuphangela
Ukhuku lwam lelam ikhaya
Abahlob ‘am yimiqamelo
Kodwa ndisenal ‘ixabiso
Ndinalo ixabiso

Pain

My jailer
Ever present
Reminds of better times
Assumed freedom and agency
Now a slave master
Throbbing
Aches
Spasms
Burning
Writhing
Smells of cruelty and sadism
Hovers with malice
Pain

Iintlungu

Amakhonkxa am
Soloko zikhona
Indikhumbuz ‘amaxesh ‘ayengcono
Inkululeko nelizw ‘ebomin ‘am
Ngoku zindicinezele.
Ukundondoza
Ukuqaqamba
Iinkantsi
Ngathi ndiyatsha
Ukubhanyalaza.
Z’nevumba lobungonyama
Nokwanelis ‘inkanuko
ngokuhlungis ‘omnye
Ulunya buyatshitshisa
Iintlungu

A curse

A curse
Grappling fingertips just to cling on
I must!
Allergy to all but two foods
New drugs, perfume, beautiful nature
All enemies
Isolating
Words seem pointless
My body fails me
It hates me
Pain, fatigue, brainfog, migraines
Swelling and maddening itching
No wonder my planet is vacated
So dark in this place
Reeks of evil and malice
A curse

Ndithakathelwe

Ngeke! Inoba ndithakathelwe
Ndibambelel 'ukuba ndingatshoni
Kunyanzelekile!
Ndaliwa kukutya: zimbini qha izintw 'endingazitya
Amayeza, isiqholo, indalw 'entle kangaka
Zonke ziintshaba kum
Ndiziva ndidedwa
Amazwi ayandixaka
Umzimb 'am akasebenzi
Uyandithiya
Iintlungu, ukudinwa, ubunzima bokucinga, intlokw
'ebuhlungu kakhulu
Ukudumba nokurhawuzel 'okuphambanisayo
Ndiyazi ngok 'uk'ba kutheni abantu bebalekil 'apha
Akumnyama
Kunuk 'ububi
Ngenene, ndithakathelwe

Poetry by NoLoyiso Jolobe

"A man must act strong even if he is in pain"

Mlindeni Gabela, from Cape Town, South Africa, contributed to the global voices campaign for World ME Day 2024.

After I was hospitalised by Covid-19 in 2020, I developed Long Covid and was diagnosed with ME two years later. I lost my job as a mixer in an industrial bakery, as I couldn't physically lift and carry bags of flour anymore. My capacity is less than 50% of what it was.

Gaslighting by doctors is very depressing; it's so painful to be dismissed as mentally ill. South Africans still need to be taught about this sickness. In my community, it's still taboo or a disgrace to be too sick. They believe that if you're not getting better with any illness, there is something wrong, something you didn't do for your ancestors, so you must do a ritual so you will be recovered. My community thinks ME only affects white people.

As a black African guy, you can't tell people you're sick, because a man can't speak like that. A man must work hard for the family and feed his children; he must act strong even if he is in pain. As a man, if you are sick then you are seen as weak. It's taboo even to talk about it.

You can't share details of your illness with people. When you go to public clinics you find only 3% men there, because we believe that men can't be helped in clinics. Our culture and traditions limit us as African men. More awareness of chronic conditions is needed in our country and Africa at large.

I am grieving a lot of things that I can't do without my energy and my brain at full capacity. But I have learned that our mental strength is more powerful than our physical strength. I'm proud that my sickness has never made me give up on life but has made me feel special in this new community of the chronically ill.

Hear more global voices for ME on the World ME Alliance website: **worldmealliance.org/global-voice-for-me/**

Mlindeni

Representing the ‘missing’ through art in St Alban’s

One local group shares the impact they have been making as the 2024 Community of Residence at St Albans Museum + Gallery.

In 2024, the Hertfordshire ME/CFS Group held an exhibition at the St Albans Museum + Gallery for the whole month of May, to commemorate the awareness month of a wide range of related conditions, including ME, fibromyalgia and Long Covid.

All of these related conditions are chronically underfunded and under-researched, with devastating symptoms including crushing fatigue, post-exertional malaise, widespread pain and many other issues. Many people with these illnesses are house or bedbound; they are ‘missing’ from society.

Formed in 2016 by Maxine Ellis to provide support in her home city of St Albans, the Hertfordshire ME/CFS support group has now grown to support members across Hertfordshire. The charity is run by volunteers to support those with ME (and related illnesses) and their carers.

This year, we teamed up with the St Albans Museum + Gallery as their Community in Residence, where monthly free art sessions were held for members. This culminated in a month-long exhibition entitled *Millions Missing*, where members displayed a range of work, including paintings, drawings, photographs, sculptures, a shoes installation representing activities that members can no longer partake in, books members have written, a group sewing tapestry, a group graffiti installation and a video loop. Some contributors were individuals who are bedbound, and it was lovely to be able to represent them.

Sunday 12 May was our main event, with speeches from the High Sheriff of St Albans, Annie Brewster (who has ME), the Mayor and Mayoress of St Albans (whose daughter has ME) and Maxine Ellis, our founder.

There were also readings of book passages and poetry from members, plus music from Aeterna, who performed a piece about ME, composed by a member of the group who lives with the condition.

During the exhibition, we advertised the amazing work of Action for M.E., who have been so supportive of our event, and raised some money for the charity. It was a fantastic day, with so much emotion, warmth and support in the room, although many of us did suffer post-exertional malaise for the days or weeks that followed.

We are already starting to think about what we can do next year!

The volunteers at the Hertfordshire ME/CFS Group run monthly in-person and online meet-ups. They also have an annual boat trip, gentle yoga, art classes, PIP support, speakers and lots more.

Anyone in the local or surrounding area is welcome to join: ***www.hertsmecfs.org/membership***

InterAction

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

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

Box numbers

Contributors who wish to make contact with others but who do not want their address published can be assigned a box number. This is a free service for Members only. Replies to box numbers must be in writing. This service is for non-commercial purposes only and any correspondence generated is considered private.

InterAction audio version

With the help of a team of volunteers, we are able to provide an audio version of each issue of the magazine via Soundcloud (**www.soundcloud.com/actionformeaudio**).

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For details of advertising rates and guidelines, please email interaction@actionforme.org.uk

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The *InterAction* editorial board is formed of Emma Baker, Lucy Cheesman, Sonya Chowdhury, Tilly Rawles, Simon Everitt, Katherine Langford, Clare Ogden and Katrina Pears. Thanks to proofreaders Vicky Anderson, Sherry Brown, David Burton, Jamie Crummy, Nina Crummy, Josie Huntley, Karen Jones and Tracey Taylor.

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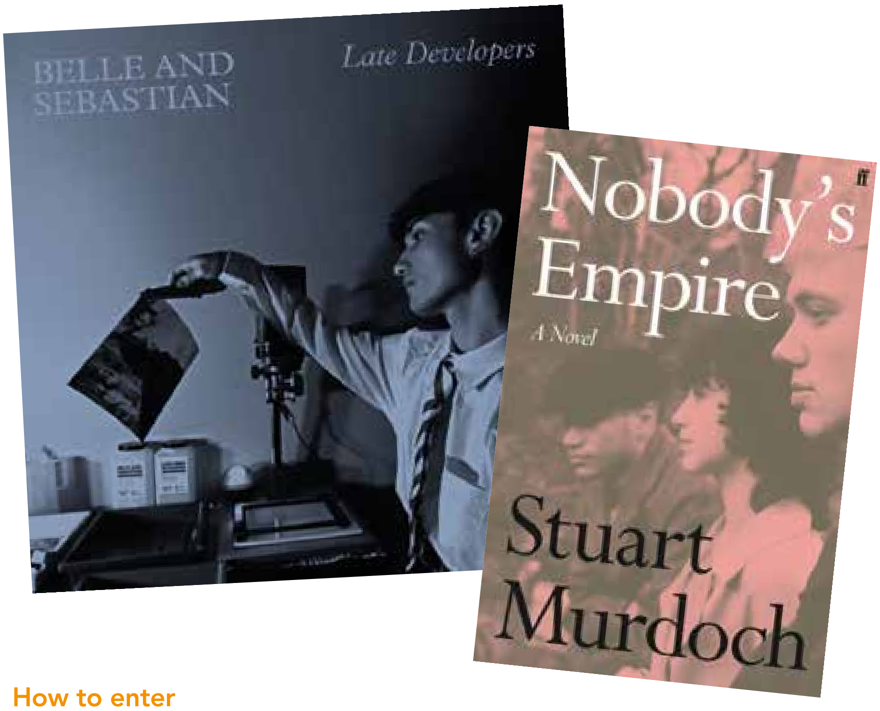
Giveaway

Win this fantastic prize!

For this issue, we're giving away a signed copy of Stuart Murdoch's new book, *Nobody's Empire*, together with a CD of Belle and Sebastian's album *Late Developers*.



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 M.E.,
  Until 23 September 2024:
  42 Temple St, Keynsham, Bristol BS31 1EH.
  From 24 September 2024:
  Unit 2.2 Streamline, 436-441 Paintworks, Bristol BS4 3AS

The deadline for entries is Thursday 10 October 2024.
Good luck!

Terms and conditions

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

Draw closes at midnight on Thursday 10 October 2024. The winner will be notified via telephone or email.

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

Entrants must be 18 or over.

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

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

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

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

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

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

Entering implies acceptance of these rules.

Different perspectives

Rose reflects on acceptance and the importance of living in the 'now'.

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.*

Feelings of missing out

My PA is leaving me soon, to start a new career with British Airways as an air hostess. Ironically, a few years before I became severe with ME, I had applied for the same job. I always wanted to travel, and I worked in the travel industry for many years. I was unsuccessful in the position and that part I am okay with, but it's hard when you have someone in your life near to the age that you became ill. It evokes feelings of missing out.

I have been severe for almost 26 years. I cannot seem to process that! I keep freaking out that I am getting older and worry about my future. I tried to explain to one carer how our lives are *stolen*. How I have not had the opportunity to get married and have children, which is more painful to me than the physical pain I endure.

When everything seems so difficult, we lose sight of what is around us offering us comfort. If we keep looking over our shoulder at the past, we miss what is in front of us now. It's not easy to focus on what we have, when we feel we are missing out on so much, but we can't keep circulating thoughts of missing out – we will lose the importance of living in the now and finding joy in the moment.

Acceptance

Easier said than done! I do not want to accept I have lost all these years and that I am getting older without living my life as a healthy human being, but I must take a different perspective for my mental wellbeing. In simple terms: "It is what it is."

I must accept my path has been different and enjoy the small moments of joy the best I can. I cannot control what has happened in the past – I can only live with freedom in the NOW. Acceptance offers the key to let go and just be. It takes the pressure off. It is natural to feel the loss, the grief, the frustration – but acceptance offers comfort.

Jar of sparkles

I recently suggested to a forum friend that it may help her cope with challenges by having loved ones write uplifting notes and place in a special jar, box or journal. Some of you may enjoy decorating a special keepsake and keeping it nearby.

We all need encouragement, and we all need reminders of our blessings and what offers us comfort. We can also do some affirmations for ourselves, or thankful notes.

Some of my affirmations include: *"I accept myself for who I am in the now", "I love myself enough to accept that my body is doing its very best to heal", "I do not measure my loss; I measure my growth", "I am worthy of receiving all that is good, and I am thankful for my blessings".*

Aligning ourselves with these types of thoughts can help our bodies relax. Our central nervous system calms down. When we are anxious/depressed and stressed, our bodies get 'stuck' in fight or flight mode. Our symptoms flare up and we experience low mood.

We can only do our best. We are of course going to experience life challenges, but sometimes it is how we respond to these challenges that matters. I am no guru! I often have meltdowns, but somehow, I always come out the other side stronger. I believe that is down to inner power that we gain when we have encountered many difficulties.

Comfort

What offers you comfort? The season of autumn is a time to want to feel comfy. Try to do an A-Z of all that makes you feel comfy and offers you comfort. The lovely ME friends online forum community participated here: **tinyurl.com/comfyautumn** *

Wishing you all a very comfy autumn,

Love Rose x

> "If you have the desire to do, you will lose the satisfaction of being."
> – Rose.

Do you have any keepsakes or 'sparkles' you'd like to share with other readers? Get in touch!

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*Please note you need to be a member of the ME friends online forum to participate on threads. Sign up for the forum here: **www.actionforme.org.uk/MEFO**

Creative corner

If you are an artist, poet, writer, painter, photographer, crafter or cartoonist, please get in touch. Please note our office address is changing from 24 September 2024 – see p 2 for details.

A sanctuary for Katie

"I have had ME for 15 years and when I am feeling able to paint in my little garden studio, it really puts a smile on my face," shares Katie Hammond. "I am a little bit obsessed with blues and greens and work with various mixed media materials spontaneously which is very soothing for me. I am not able to have days out very much but when I can, I love to go to local gardens with my partner and we take lots of photos of the nature surrounding us. My paintings hold onto those moments of magic and calm in nature that I am so very grateful to be able to enjoy every now and then.

"This painting is called 'Our Sanctuary' and is inspired by Johnston Gardens, which is near where we stay in Aberdeen. It is a gorgeous little hidden away gem and was where I had my first little day out with my partner David, so it has always felt like a very special place for us."

Our Sanctuary by Katie Hammond

Peony by Helen Cramp

Photography as therapy

"I do a bit of photography which helps with my mental health issues, mainly caused by having ME for over 25 years," says Helen Cramp. "I can't always go out walking to take photos, so many of my photos are taken around the garden."

This is a photo Helen took of one of her mum's peony flowers. "I have edited to give it a soft look and dark background to make the flower stand out more. I like to take photos of plants and animals and landscapes mostly. I am lucky to live somewhere where I can see plenty of all those things."

The love between sisters

We were delighted to hear from two sisters, Amy Garratt and Nikki Gaines, each expressing their creativity in different ways.

"I don't have ME myself, but I wrote the poem 'Nikki and the Millions' for my sister," explains Amy. "She's been living with ME for over a decade, and I wanted to acknowledge how difficult it is for her to be isolated."

"We are extremely close, she's my constant unwavering rock since I got sick," says Nikki. "Amy believed me when no one else did that I knew something was wrong. She never let me down, even when she had/has her own issues, she's been to doctors, hospitals, appointments and tests. She still wanted me to be her maid of honour in 2021 despite me being mostly housebound. And I crafted a lot of her wedding stuff from my bed. We've laughed, cried, fallen and got back up again to carry on the good fight. She's the best!"

As well as ME, Nikki has osteoarthritis in multiple areas. The diamond painting below took her a few months to complete.

Do you have someone you'd like to thank for their support? It could be a family member, a friend, or a medical professional who showed real understanding and care.

Drop the editor a line at **interaction@actionforme.org.uk.**

Nikki and the Millions

My prison.
Not a place, a time, a crime.
Not a ceiling, a meaning, a feeling.
My bodily prison holds me captive.

Shuttered in existence,
Lifetime of resistance,
Advice littering empty space
While you get to leave, I stay in place.

Jailed, yet I'm a victim.
Thief in the night, in the day.
You steal my time…
Lead my mind astray.

I detest my lonely island.
This barren world I hold.
Burning, aching, turning…
Listless, hopeless, yearning.

Request and invites stop,
As I stare down the clock.
Years spent reminiscing…
By the Millions who are missing.

Amy B Garratt

Moonchild diamond painting by Nikki Gaines

Cosy Morning by Jordan

Radical rest is good, says Jordan

"My name is Jordan, and I'm a 32-year-old artist with ME. I was diagnosed in 2022 (after a two-year battle!). I drew this piece, which I'm calling 'Cosy Morning', as a soft and comfortable description of how so many of us spend our days. My character is sheepishly poking her head out from under the covers as the sunlight streams in, and I just wanted to show that radical rest is still good!

"My art style can be described as anime, and I've been an artist for 4 years now. I found art shortly after I got ill."

FUNDRAISING

Chiara shines a light in the darkness

In March this year, pianist and singer-songwriter Chiara Lordi performed an evening of classical and pop music to raise awareness of ME.

"My auntie has suffered from ME for the past nine years," Chiara says. "I hadn't heard of ME before my auntie and I would love to raise money for this charity and, in some way, help raise awareness. I know how invisible she felt and how her life changed completely. She's absolutely incredible and an inspiration and I'm so proud of her.

"This concert was for anyone who feels 'invisible'. I hope I shone a light in the darkness."

The event raised an incredible £837 for us and we're so thankful to Chiara for her dedication and impressive performance!

Claire's virtual travels

Claire Wade has been exploring the UK from her bed.

"I first came up with the idea for virtual holidays over 20 years ago, when I was first bedbound and the Internet was in its infancy," says Claire Wade. "The resources available back then were really limited, but now there is so much more that you can do to explore the world without ever having to leave the house.

"This is perfect since I am bedbound again. I've been struggling with how limited my capacity now is and feeling isolated and frustrated. I decided I wanted something to focus on and exploring the UK seemed like fun."

Month by month Claire is going to 'visit' a new county in the UK. She is doing this by learning about the places, trying the food, reading the books and watching the shows and films that are set in the area.

It's a follow-along adventure – she is posting what she's doing on Instagram and Facebook (as @clairerwade).

"It's gentle and easy to pace to your own needs and energy levels," Claire says, who is keen for people to follow along with her trips. "Do what you want or are able to do, adapt and adjust, it's all flexible."

Wild places for tired people

Created by Clare Reddington and Anna Starkey, *Wild Places for Tired People* is a collaborative map for people with limited energy who want to be in nature. If you are able to get outside, but would appreciate knowing where to find low-energy wild places, this map is for you! **www.wildandtired.co.uk**

You can also add your favourite places to the map at **tinyurl.com/addwildplace**

FUNDRAISING

A spark to ignite a fire

Lee Colligan has been raising awareness in memory of his brother, Josh.

Lee's brother Josh died in August 2023, at the age of 29, having had severe ME for six years.

Prior to falling ill with ME, Josh was passionate about being outdoors. He loved hiking and camping. The illness resulted in him being bedbound and completely reliant on his family for care. This year, in his memory, 35-year-old Lee has walked around Ireland's west coast and Northern Ireland's north coast to raise money and awareness for ME.

Lee's trek started in Kinsale, Cork and finished back in his hometown of Carrickfergus.

"Undertaking the challenge of walking 2500km around Ireland to raise funds and awareness for ME while honouring my brother has given me a purpose," says Lee. "I hope to be one of the sparks that can ignite a fire to get this awful illness the support and recognition it deserves. I've seen first-hand how debilitating this illness can be and I want to be a voice for all those suffering, until they get the support they deserve."

Lee shared his journey via Instagram : **@a_walk_for_m.e**

Reaction

Send your letters and notices to the editor at the address on p 2. (Please note our office address is changing from 24 September 2024). You can also email interaction@actionforme.org.uk

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

Star letter

The impact of word and action

I read with interest your article *Cultivating Creativity* in the Spring 2024 issue of your magazine, and it inspired me to tell you about my own journey from being bedridden to having a semi-active life as a mum and author.

Like you said in the article's introduction, writing can become a vocation for some people with ME/CFS, and that is certainly what it is for me.

I always planned on becoming a scientist. Illness brought a halt to my studies halfway through my degree course in the late 90s. I remember wondering if I would ever find fulfilment, but now I am happily married with a teenage son, and I appreciate every moment of health that I have.

Initially, I turned to writing out of frustration. There were so many ARGH! moments in my life that made me think, *right, that's it, I'm telling my story*. Like when a GP assessed my health by measuring my thighs. Or when friends made 'helpful' comments such as "You're not still ill, are you?" I also wanted to pass on the lessons that the illness taught me and to write the book that I wished I could have read when my condition was at its worst.

After 15 years of writing and relapsing, my story, *It's Not the Strongest that Survives*, was finished and has just been published. The story starts with me contracting glandular fever aged 17, and covers everything from me developing autoimmune diseases and food intolerances, to finally being diagnosed with chronic EBV (the virus that causes glandular fever).

I wrote it as candidly and as openly as possible, because I don't think people are going to understand how this illness makes us feel unless we show them.

I'm hoping that my book will achieve three main things. I want to explain to doctors how crucial it is for ME/CFS patients to be thoroughly investigated to identify their underlying medical conditions. I want to show the friends and families of those with ME (as well as the public) how much their words and actions can affect us – both positively and negatively.

I want to say to people with ME that they can find fulfilment, so please hang on in there.

Lily Whelan

Editor's note: *Congratulations on sharing your story, Lily – and also for being our Star Letter winner. An Action for M.E. goodie bag is heading your way!*

Information and Support Service user feedback

"I was overwhelmed by the support I received. I had no knowledge such support existed and it has enabled me to feel more empowered in my understanding and actions. Extremely grateful for the service."

"The communication you sent me was very comprehensive but clear and simple to understand. I had absolutely no idea prior to contacting you, about ANY of these things. I can't thank you enough."

To chat to our friendly Information and Support Service team, get in touch using the details on p 2.

We love hearing from you!

Solidarity with Ellie

I totally experience what Ellie says just as she says it: "To be chronically ill is to be lonely. This can be emotional loneliness from other people not understanding what you're going through or physical condition – isolation and not being able to participate in the world." (*InterAction* 116, p 37)

I don't find any solutions for making friends apart from to force yourself out where you pay in spoons, in energy and PEM, whatever you call it. Or you stay in and make acquaintances through the internet and the charities.

I have made a friend through ME Association penpals.

InterAction reader (name supplied)

Can't find a film? Try this, says Katherine

You can rent DVDs from **www.20thcenturyflicks.co.uk**. You can hire three films for £13 and they post them out to you. I've used them to track down some films that aren't available from streaming services like Amazon Prime and Netflix. They're a lovely small business in Bristol that also have some small private cinemas to hire.

I hired one to watch a film with some friends for my birthday a few years ago and it was brilliant. I've been afraid to go to the cinema recently because of the risk of catching Covid, so I've been thinking of doing it again. I thought that other people might like to know about it if they're in the same boat of wanting to go to the cinema but feeling like they can't risk it.

Katherine Langford

20 years of service

Sussex & Kent ME/CFS Society wrote to us to highlight the 20-year anniversary of the NHS Sussex-wide specialist ME/CFS Service (operational since 2004).

Based in Haywards Heath, this service was established following months of consultation between the Sussex & Kent ME/CFS Society and the health authorities, after hundreds of people affected by the debilitating illness, together with GPs, were surveyed. They called for a specialist service to be set up to assist with diagnosis and to run management courses.

Service staff includes a specialist physician and occupational therapists, along with physiotherapists and a psychologist. It has dealt with over 8,000 referrals during the past 20 years. (After thorough assessment nearly 40% of those referred turn out to have an alternative diagnosis, according to local NHS service management, which is consistent with other similar centres.)

"We are immensely proud to have been involved in getting the NHS centre established and continue to work collaboratively with them," says Colin Barton, chair of Sussex & Kent ME/CFS Society. "We have seen them help many people to manage their illness and a good number to significantly improve, with some able to move on to lead reasonably active lives."

We'd love to hear about your experiences of local NHS ME/CFS services. Have you found them helpful? Get in touch and let us know!

Happiness in my garden

What makes me smile and laugh? Watching the robin in my garden trying to chase off the other birds, when I have put food out.

The small things in life become a lot more important when your life is very much limited. Achieving anything lifts your spirits, ie when I grow something from seed – flowers, or fruit and veg. Even though it's often hard work! All is forgotten when I get the produce – tomatoes, potatoes, beans, etc.

A friend sent me a wall plaque that says *Gardening… it's cheaper than therapy…and you get tomatoes!* There is some truth in that, if you are up to it and if you are lucky enough to have a garden like me.

In theory there are lots of things we can do to make us happier, lots of hobbies, but often we are not well enough to do them or we are in so much pain and discomfort that we get no enjoyment from doing them.

Michael Dunn

Ellie reflects on the conundrum of not having the energy to do the things we enjoy on p 37.

Do you have hobbies that you do find manageable? Get in touch with the editor if you'd like to share them with InterAction *readers.*

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).

Impact of infection on ME

I've been suffering with a combination of chest and nose infection, and bad ear wax due to this. It has really affected my ME. My ME has got worse, my legs feel jumpy inside and I am having back-of-head aches sleeping. I feel ME symptoms whirling around inside me.

Having antibiotics has made the ME symptoms go from mild to severe. Have any others with ME had infections like this and found it has affected their ME – and having antibiotics has done the same? Would love to know and what can I do to combat it. Doctors are sympathetic but don't really understand. Any advice gratefully accepted.
Stephen, Box no. 4997

Get in touch and share your notices and tips

Reader tips

Discounts for utilities

Your local water board may provide discounts for those with certain illnesses which require more water usage, such as skin conditions, or for those on low incomes.

Scope offers some advice on this: **tinyurl.com/waterdiscounts**

Food deliveries

For those who need groceries delivering to their door but can't manage screens owing to light sensitivity, Sainsbury's accept orders by phone. You can contact their order line team on 0800 917 8557. The order line is open Monday to Friday, 9am – 5pm.

For those who can use the internet, via computer or smartphone, delivery services such as Deliveroo do groceries as well as takeaways. Good for getting easy-to-cook, last minute things for dinner if you haven't had the capacity to think about food – or forgot to get something out of the freezer! However, not all supermarkets sign up for it, so you'll need to see what is available in your area.

Change to UK landline services

The old copper phone network is being replaced, as it is becoming increasingly difficult to maintain. The transition to digital landlines (using broadband) is anticipated to be completed by the end of January 2027. Originally, this was scheduled to take place by December 2025, but the timeframe has been extended.

If you already have broadband, this should be straightforward. You can keep your current phone number. If you don't have an internet connection at home, your supplier should install one. They will contact you in advance to let you know when things are changing and what you need to do.

If you have specific requirements (for example, if you have other devices connected to your telephone line such as alarm systems or telecare devices), or have any other concerns, contact your telephone provider or equipment manufacturer directly.

Thank you!

We wanted to say a big thank you to our longstanding volunteers Tim Godsalve and Ken Manley. Tim has been editing InterAction-on-audio files since the days of cassettes. His dedication and expertise as been invaluable to our team of audio volunteers over the years. Ken has been lending his voice to us for many years and we deeply appreciate his commitment. Both are stepping down from their roles for a well-earned rest.

Listen to InterAction here: **www.tinyurl.com/audioIA**

David Hinde, one of our runners

Representing ME in Edinburgh

Despite the rain, an amazing team of six runners took part in the Edinburgh Marathon festival back in May, raising over £5000 between them! Most of our runners have family members or friends with ME. We can't thank them enough for their fundraising, which helps us provide our vital services, but also for raising awareness and showing their support for people with ME.

Back to survival

Ellie reflects on how fun and enjoyment are basic human rights but, for people with ME, these can get left behind.

SPEED READ...
Ellie has been managing a part-time job for the past three years, but this takes up all her energy. She feels like a modern-day Thomas Hardy character, toiling just to survive. How, she asks, can those with ME find energy to enjoy life, to be playful and creative? She does not have an answer, but her words convey a frustration that will resonate with many readers.

Reading about controversies surrounding Netflix series *Baby Reindeer* (a harrowing account of stalking and assault), I was struck by a legal phrase I hadn't heard before. Fiona Harvey, who the series is allegedly based on, is suing Netflix for loss of enjoyment. She's suing them for lots of other things (including loss of earnings, defamation, privacy violation) but 'loss of enjoyment' really caught my attention.

An essential part of life

It made me think about enjoyment as a basic human right, as something essential to our survival. I remember when a friend started claiming job seeker's allowance after school and lamenting that she didn't have enough money to have fun. I remember thinking, *the money's there for you to survive, not enjoy yourself*, but now I totally disagree with my 16-year-old self.

Fun is an essential part of life. It was my countryside background that made me think it wasn't. I'm from a farming community where work is God. Back in the day, there was little time to enjoy yourself, you toiled in the fields and stopped only for food, sleep and church. This all sounds like a bleak Thomas Hardy novel: how on earth can these people have been happy?

Happy or not, they were surviving, and ensuring the survival of their offspring. Fast forward 200 years and, theoretically, there's more to life.

Except when you have ME. Then it all comes back to survival again. People who experience moderate or severe ME struggle to enjoy life in the same way, often spending the little energy they have doing the things we have to do to survive.

Instead of toiling in the fields for survival, they're toiling in bed for survival.

So…how?

I have 'mild' ME and I still think managing it is a full-time job (with no paydays or annual leave).

How do you enjoy yourself when you physically don't have the energy? I know of so many creative people with ME who write poems, novels, create videos, design things, draw things, you name it. But we can only create when our bodies let us.

The first thing I did when I was moderate seeing glimpses of mild ME was get a job. It's been a zig-zagging journey, but I've been working part-time for three years now. Every time I have a setback or relapse, seeing friends and having fun are immediately off the table; work gobbles up every bit of energy I have.

I become the Thomas Hardy farmer, only I'm working on a computer screen on the desk in my spare room.

I don't have to tell you how necessary play is, how enriching it is to your life, how vital it is to your mental health. Needing to play and create are part of being human, just as much as eating and resting are, but as adults with ME it's so hard to give them the attention they deserve with the energy we have at our disposal.

We have ME. Who do we sue for loss of enjoyment?

> "we can only create when our bodies let us"

Do you use the internet for online support?

Diane Shortland is seeking volunteer participants for a study on how people with ME/CFS get support online. She explains:

If you use the internet to connect with others with ME/CFS, I would love to talk to you to learn more about these experiences and if/how online connections affect your offline life. Good or bad experiences are welcome and there are no right answers. I am looking to answer the following questions:

- How are online connections formed, in what capacity do they exist, and how are they maintained?
- Why are online connections sought and what effect do they have on people with ME?
- What, if any, is the relationship between online connections and participants' offline lives?

If you would be willing to chat about your experiences in an informal online/phone interview lasting approximately 30-60mins, please get in touch. If you require interviews of shorter durations, multiple sessions can be accommodated, as too can any other reasonable adjustments. The interviews will take place via Zoom/Teams, with camera on or off, as you prefer, or over the phone.

Everything discussed will be confidential. The interview will be recorded and transcribed; the information gathered will only ever be used anonymously to protect identity.

Full ethical approval has been gained for this study. You remain able to withdraw from the study up to four weeks after receipt of the interview transcription.

All research is transparent and you will receive information on what is being studied, the findings and impact the work will have on improving the lives of people with ME, if you would like to.

Please email Diane on ***DLS760@student.bham.ac.uk*** *and she will be in touch to arrange a convenient time to discuss things further.*

Diane is a PhD student in Applied Health Research at the University of Birmingham. Her doctoral studies are on the experiences of people with ME/CFS. You can read about Diane's preliminary findings in *InterAction* 116, p 16.

FUNDRAISING

An ocean is made up of drops

John Morsley and his wife Indira have been raising awareness and funds for those with ME.

Anna, Indira's daughter, was diagnosed with ME/CFS in 2022. "Like so many people, we knew little about the complexity of this devastating neurological condition with its wide range of fluctuating symptoms that can make it impossible to carry out even the basic activities of daily living," Indira explains. "It has been a vertical learning curve."

Anna lives in Australia. John and Indira travelled to see her, as it was difficult to grasp fully what she was going through from the other side of the world. When they arrived, it became clear that her condition was serious. They had to limit the time they had together.

"The healthy, active daughter who could open water swim for miles had disappeared," says Indira. "By the time we left, she was in total crash, lying in a dark room, barely able to lift her head and hardly able to speak. It was devastating… Living on the other side of the world where day is night and vice versa makes it impossible to do little more than give moral and monetary support. That is emotionally and mentally distressing and those things in turn have a physical impact. We knew we had to find a way to do more."

John has run three virtual London Marathons for ME charities and has explored ways to educate and raise funds through cake sales (Indira's particular forte), boot and table sales. "These have given us the opportunity to engage with many people who have shared stories, made suggestions and donated." John plans to run the 2025 London Marathon in person for Action for M.E.


John and Indira

"Our intention is to continue to advocate tirelessly for ME, raising awareness and funds for this dreadful hidden illness," says Indira. "Anna is courageous and resilient in untold measure and is forever hopeful that one day she will be better. We know that alone we cannot change the world, but an ocean is made up of many drops and we have found there are people who care. They give us hope and make it worth every moment of time and effort and doubt."

Christmas cards

As a charity we have taken the decision to **stop selling Christmas cards**. We know that this news will come as a disappointment to some of you, but due to low sales over the last few years it is no longer financially viable to continue selling Christmas cards, as it results in a financial loss for the charity.

We want to ensure that we maximise the amount of funding that can go towards our frontline services and investment in biomedical research and have taken this difficult decision with this in mind.

We will still be providing Christmas e-cards designed by members of the ME community, in exchange for a small donation.

Our 2023 winning e-card by Helen

Find the e-cards from our 2023 competition here: **tinyurl.com/AFMEecards**

Look out for the Big Give Christmas Challenge

With incredible support from members like you, last year we were able to raise £129,900 (plus gift aid) through the 2023 Big Give Christmas Challenge, both online and offline. Now we're looking ahead to this year's challenge.

Save the date

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

1. **Save the date!** This year's Big Give Christmas Challenge starts at midday on 3 December and runs for seven days. You can stick this reminder on your fridge or noticeboard.
2. **Visit the Big Give website** from midday on Tuesday 3 December until Tuesday 10 December 2024 and every donation above £1 will be doubled, at no cost to you.
3. **Tell a friend and see their gift doubled too!** We need your help to keep spreading the word.
4. **Share our Big Give posts across your social media platforms** to help us reach more people and raise more money, so we can continue to provide services and fund research.

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

Be an angel this Christmas!

Action for M.E.'s Christmas angels project – now in its 14th year – enables people with ME to send Christmas cards to each other via the Action for M.E. office.

If you would like to send or receive a card from another Action for M.E. Supporting Member this Christmas, or know someone severely affected who would appreciate a card, please get in touch. All it will cost you is the price of a card and a stamp.

If you have online access, please complete our simple and secure online form, which you can find at **www.actionforme.org.uk/christmas-angels**

You will then receive instructions by email right away about what to do next.

If you do not have online access, you can let us know you want to take part by writing a note to the editor at the address on p 2 or by calling us on 0117 927 9551 and choosing option one.

We ask that all cards arrive with us in our office by Monday 9 December.