InterAction

Tis the season…

for the Big Give! p 4

Dealing with disbelief p 13

The gift of song p 24

ISSUE 118
WINTER 2024

Our vision is a world without ME

action for m·e

Time to believe

Welcome to your winter issue of *InterAction*, our magazine for Supporting Members. As we move forward towards another year, we are reminded of the longstanding need for recognition, research and education about ME.

We continue to provide vital support and care to people with ME today, whilst driving positive change for the future. "Help for today, hope for tomorrow" is the theme our of Big Give Christmas Challenge campaign (3 – 10 December, see p 4 for details). This year, we have a unique opportunity to double our target to £200,000, helping us raise even more funds for vital services, research and education.

Despite the biological nature of the illness, we know that many of you still face misconceptions about the nature of ME. Our Information and Support team share some tips on handling dismissal and disbelief from loved ones (p 13).

New guidelines are also being drawn up for the British Psychological Society, with a working group comprised of those with lived experience of ME (p 14). These aim to educate psychologists about ME as a physical (*not* psychological) illness, address misconceptions and enable some rebuilding of trust.

We are disappointed about ongoing delays to the Government's delivery plan on ME/CFS, continuing to leave people without appropriate support. The landmark report into the tragic death of Maeve Boothby O'Neill highlights the need for swift action after so many years of neglect and misinformation about ME (p 7 – contains distressing content).

"Please believe ME," says Roberta, in her poem (p 21). It's time to believe. This belief needs to be followed up by determined action to change the lives and to renew hope for all those living with ME and ME-like symptoms.

Thank you so much for all your support and encouragement, and for your kindness to one another.

On behalf of all of us at Action for ME, I wish you a peaceful Christmas and hopeful new year.

Sonya

Sonya Chowdhury
Chief Executive

Contacting Action for ME

Information and Support service

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

Call **0117 927 9551**
Email **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**

If your prefer to send by post, please write to us at our new address
(please note postal enquiries take longer to process).
Action for ME, Unit 2.2 Streamline, 436-441 Paintworks, Bristol BS4 3AS
Post sent to our 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 ME. We strongly advise people to examine with scepticism any treatment, therapy or other approach which claims to offer a cure, has not been subject to research published in respected peer-reviewed journals and requires the payment of large sums of money.

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

Contents

Hot topics

- Our **winter raffle** is back! Find details on p 11.

- Our (rescheduled) **AGM** took place on Wednesday 30 October 2024. Find details of our Annual Report on p 8.

- **NHS England** is asking staff, patients and organisations to input into its 10-year plan, sharing your ideas about how to make the NHS fit for the future. We will respond to this request organisationally; you can also take part individually at **www.change.nhs.uk**

- As we went to press, our **Learn about ME** webinar for GPs (see p 9 for full story) had already been viewed more than 1,600 times in barely a month. You can signpost this great resource to any health professional supporting you.

- Action for ME is one of 60 organisations who signed **Turn2Us'** open letter to the Chancellor ahead of the autumn budget, calling for a more compassionate and just narrative around social security. Read the letter at **tinyurl.com/Turn2Usletter**

- Action for ME staff, volunteers and contributors share their songs for the season throughout this issue. You can listen to them all on our free spotify playlist at **tinyurl.com/IA118songs**

- If you still want to be a **Christmas Angel**, check out p 38.

Help for today, hope for tomorrow…

with the Big Give Christmas Challenge!

This December, the Big Give is back, and it's bigger than ever! From noon on Tuesday 3 December to noon on Tuesday 10 December, you can make one donation, with twice the impact – thanks to our Big Give Christmas Challenge.

This year, we have been given the exciting opportunity to significantly increase the amount we can raise, creating the potential for an even bigger impact on the lives of people with ME.

Last year's Big Give

In 2023, our amazing supporters donated more than £58,000 during the campaign week, which was doubled to an incredible **£135,703**, including Gift Aid. This funded our much-valued Information and Support Service, and our Healthcare Services (see p 16 to hear from one of our physios).

It also funded our young people's Breaking Isolation workshops, where children and young people with ME have a chance to connect, learn skills, play games and take part in creative activities together.

These workshops have made a huge difference to Sophia, who formed a beautiful and supportive friendship with another workshop participant. With lots of careful planning and support from their mums, they were able to meet in person halfway between their homes. Sophia even started to facilitate some workshops!

Thanks to the success of last year's campaign, we can continue to reduce the isolation experienced by young people with ME. You can find out more information about these workshops here: **www.actionforme.org.uk/breaking-isolation**

This wouldn't have been possible without your support last year. This year, we can create an even bigger impact.

Each donation made between noon on Tuesday 3 December 2024 and noon on Tuesday 10 December 2024 will be doubled using our even bigger £100,000 match pot*, bringing us to a total campaign target of £200,000 plus Gift Aid!

With an **estimated 1.3 million people** in the UK with ME or ME-like symptoms, this year we have an opportunity to make an even bigger impact and keep up with the increasing demand for our services.

**Donations between £1 and £25,000 made through the Big Give website will be doubled immediately, providing there's money in our £100,000 match pot.*

Christmas Challenge
BigGive

The money raised this year will allow us to:

Continue providing information, support and resources to over 2,000 people affected by ME each year

Reduce the isolation experienced by young people with ME through access to our young person's community (we work with at least 400 children and young people each year)

Offer healthcare bursaries to people with ME so that they can continue to access ME-informed doctors, physiotherapists and counsellors

Accelerate much-needed breakthrough ME research through our Research Fellowship

Inspire the next generation of ME researchers through our Future Leaders Network

Educate the next generation of doctors on the patient realities of living with ME through a medical student essay competition, inspired by the successful competition we ran earlier this year as part of our Learn about ME project.

Taking part in the Big Give is easy!

Step one

Between noon on Tuesday 3 December 2024 and noon on Tuesday 10 December 2024, go to **tinyurl.com/afme-bgcc24**

Step two

Click on the **double your donation** button to be taken to our page on the Big Give Christmas Challenge website

Step three

Make your donation by credit or debit card. Donations between £1 and £25,000 will be doubled immediately, as long as there is money left in our £100,000 match-pot. The Big Give Christmas Challenge website will confirm that your gift will be doubled when you start the process, and allow you up to 10 minutes to complete your donation

Step four

Tell your family and friends how easy it is to give, and see their donation doubled too! If you're online, click 'Share' on our social media posts on Facebook, Instagram, X (formerly Twitter) or LinkedIn to help spread the word

Not online?

Thanks to a generous supporter, we have a separate, dedicated, telephone match-pot. So even if you're unable to use a computer, you can still see your gift doubled.

The telephone match-pot will be available from noon on Tuesday 3 December and noon on Tuesday 10 December on 0117 927 9551.

Your donation can only be doubled during the campaign

Call on the Government to 'Act for ME'

We have reviewed and renamed our manifesto for ME, calling it Act for ME.

We have shared it with all MPs, asking them to pledge support for our three key actions:

1. **Launch and full implementation of the Government's Delivery Plan:** Following multiple delays, we are calling for its immediate release and for its recommendations to be enacted in full
2. **Equitable research funding:** Funding must be proportionate to the prevalence of post-viral diseases
3. **Amend the Severe Disability Group criteria:** Given the lack of specialist ME clinicians across the country, the Severe Disability Group criteria* must be amended to ensure that people with ME can access the care and support they need and deserve.

**The Severe Disability Group is used to identify claimants with the most severe and permanently disabling conditions, to fast track them to the higher rate of disability benefit without having to go through the usual application and assessment process.*

You can use our template letter to ask your MP for support in ensuring that the Government works to achieve our three key actions, and/or to meet with us to discuss how they can better advocate for people with ME/CFS.

The letter gives you space to provide your own experience of ME, and we encourage you to make your letter as personal as you feel comfortable doing.

To see the Act for ME call in full, and download the template letter, go to **www.actionforme.org.uk/news/act-for-me** or contact us for a paper copy (see p 2).

Re-establishing the APPG for ME

Since the general election in May, Action for ME has been engaging with new and continuing MPs to raise understanding of ME. This work includes increasing our number of Parliamentary Champions.

We have also been working to secure commitment from parliamentarians to take on one of the four officer roles needed to establish an All-Party Parliamentary Group (APPG) on ME.

These are dissolved at each general election and so must be set up again afterwards, with a minimum of 20 members.

Once we are confident that these can be secured, a date will be identified for an inaugural meeting. We hope to resume our role of joint secretariat with the ME Association in taking this forward.

Assuming appointments of the officers and membership requirements are met, the APPG can then be formally registered.

We know many of you may already have met or had conversations with your local MP. If so, please do contact them to invite them to join the APPG or enquire whether they would take on an officer role. You can direct your MP or send any information to **policy@actionforme.org.uk**

Thank you for your support.

An urgent and immediate need

In October, the coroner of the inquest held into Maeve Boothby O'Neill's death issued a Regulation 28 Report to Prevent Future Deaths (PFD).

Trigger warning – upsetting content

SPEED READ...
This PFD report was sent to a number of recipients, including the Department of Health and Social Care. It outlines four concerns: the lack of specialist healthcare provision for those with ME; the lack of available funding for research and learning; the limited training for doctors on ME (especially severe) and the lack of detail in the NICE guideline on how to manage severe ME at home or in the community. Recipients have a statutory obligation to respond by 3 December 2024.

Following an inquest, coroners may issue a PFD report when they believe that action to address some of the identified concerns should be taken to prevent future deaths. Receiving individuals or organisations are obliged to respond to the coroner's PFD report within 56 days (in this case, by 3 December 2024). Extensions may be requested but are not always granted.

Deborah Archer, Assistant Coroner for the area of the County of Devon, Plymouth and Torbay sent the report to:

- **Andrew Gwynne MP** (Parliamentary Under-Secretary, Department of Health and Social Care) and **Rt Hon Wes Streeting** (Secretary of State for Health and Social Care)
- **NHS England** (NHSE)
- **National Institute for Health and Care Excellence** (NICE)
- **Medical Research Council** (MRC)
- **National Institute for Health and Care Research** (NIHR)
- **Medical Schools Council**.

Archer highlighted her findings that Maeve Boothby O'Neill died of "natural causes and…that she died at home after three admissions to hospital were unable to treat the consequences of her severe ME".

She went on to say that "during the course of the inquest the evidence revealed matters giving rise to concern". In her opinion, "there is a risk that future deaths could occur unless action is taken."

Matters of concern

The coroner identified four concerns:

1. The lack of specialist hospitals or hospices, beds, wards or other healthcare provision in England for people with ME, which meant that the Royal Devon and Exeter Hospital where Maeve was treated had no commissioned service to treat her or others like her
2. No current available funding for the research and development of treatment and further learning for understanding the causes of ME
3. Extremely limited training for doctors on ME and how to treat it, especially in relation to severe ME
4. The NICE Guideline on ME (2021) does not provide detailed guidance on how severe ME should be managed at home or in the community and, in particular, whether adaptation is required to the 2017 guidance on nutrition support for adults.

Longstanding issues

The matters of concern that Deborah Archer raised are nothing new to us at Action for ME. However, we are grateful that issues around specialist provision, research funding availability, training for doctors and issues with the NICE guideline have all been singled out. We hope that the response will be substantive and focused on addressing these longstanding issues.

Several similar cases to Maeve's are currently ongoing. It is so important that Maeve's death need not be in vain and these organisations have power to create change for the future.

This includes those with the power to launch the long-awaited Delivery Plan on ME and ensure that it is now also informed by the report.

Alongside the immediate need to improve services and support for people with ME, especially those with severe and very severe ME, we urgently need a strategic approach to funding for ME research and call on the Government to ensure that this happens.

Courts and Tribunals Judiciary

Time for change

In a column in the Guardian in October, George Monbiot responded to the case of Maeve, describing it as "a terrible result of the most remarkable situation I've ever encountered in either medicine or journalism."
Read the article here: **tinyurl.com/GuardianMaeve**

Also in October, on BBC Radio 4, our CEO Sonya reflected on the lack of care for those with ME. "The most severely affected are often the most severely neglected," she said. "To have a report of this nature that requires response from the recipients is certainly a first… it's about time things change."

Listen (from 26 mins) here: **tinyurl.com/Radio4PFD**

Action for ME Annual Report

Our Annual General Meeting took place in October 2024.

"Sadly, the impact of Long Covid continues to grow, with ever increasing numbers of people reporting symptoms that mirror those of ME and demand for our services remaining high," writes Roger Siddle, Chair of our Board of Trustees, in our Annual Report. "The world, for people with ME, is often beset by enormous challenges and frustrations, and I would like to thank my colleagues for their vital contributions, most of all, for their dedication to supporting and improving the lives of people with ME."

We continue to use client feedback to improve our services, and we are exploring more accessible ways to ensure those with severe ME and from underserved communities have access to resources and information. We have relaunched our independent Adults Advocacy Service.

Read our Annual Report: **tinyurl.com/AFMEAnnualReport24**

Doctor joins team

We're delighted that Dr Sarah Williams is joining our Healthcare Services team.

Sarah is a GP who graduated in medicine from Cardiff University in 2011. She has spent time working in the NHS in all countries of the UK. She has an interest in integrated whole-person care and is passionate about partnering with patients to improve their health.

Sarah has also developed an interest in ME, gaining a deeper understanding of the limitations and frustrations of trying to navigate the health system with a complex illness. She is committed to providing a service and care that offers an alternative opportunity where patients are heard compassionately and responded to using the available evidence.

www.actionforme.org.uk/healthcare-services

Breaking isolation for young people

In our Breaking Isolation series of online workshops, young people with ME can make friends and share how they live with the condition. In the October 2024 workshop, young people shared experiences of accessing healthcare. Dr Robin Kerr attended to help share tips for pacing and energy management, as well as explaining some of the science of ME. **www.actionforme.org.uk/breaking-isolation**

ME is a biological illness, says Miranda

Comedian Miranda Hart has responded to criticism of her recently published book *I haven't been entirely honest with you*. "The book is about all the teeny tiny ways I reduced stress in my life to help living with a stressful illness," she shared on social media. "It's not a recovery story, but a story to become at home in myself to bring a life of joy and meaning." Her experience of chronic illness began with Lyme Disease, a bacterial infection spread by tick bites. She believes this was contracted when she was a teenager. The diagnosis was confirmed three decades later.

Miranda describes ME as "a ghastly misunderstood condition and many don't get any alleviation, which hurts my heart. I just believe reducing any fear when living with an illness can but help our quality of life. But it's very hard and I can only speak from my experience." She asserts that ME is a "physical, biological illness that needs to be recognised and treated as so."

Learn about ME webinar for GPs

Dr Nina Muirhead and Dr Robin Kerr led a free Learn about ME webinar for GPs on Thursday 26 September.

Around 50 health professionals registered to take part and/or have access to the materials following the webinar. All attendees who responded to the webinar poll agreed they felt more confident to support patients with ME/CFS as a result.

About Nina

Nina is a Dermatology Surgeon in Buckinghamshire, with a personal and professional interest in ME. Nina has firsthand experience of ME after contracting Epstein Barr virus in 2016. She has done research on quality of life for patients with ME and their family members, and qualitative research interviewing patients on their experiences with GPs. She was an expert witness for the 2021 NICE guideline on ME/CFS and is the author of Learna's free online ME/CFS learning module.

About Robin

Robin was a fulltime GP partner in the Scottish Borders for over a decade. He now continues to work in General Practice, but also leads his local Rapid Cancer Diagnostic Service and offers UK-wide online consultations for patients with ME and Long Covid (via Action for ME). Amongst other things, this allows him to offer ME patients options based on applying evidence from medical research, in which mainstream medical practice currently lags behind. He contributes to the Scottish EAVE-II and international TeamClot groups researching ME and Long Covid.

Nina and Robin's presentation covered up-to-date research and practical guidance on diagnosis, pathophysiology and symptom management. To watch the recording, see the accompanying slides, and/or read a two-page summary and full-transcript, visit **www.actionforme.org.uk/news/learn-about-ME**

The Learn about ME project is supported by the Scottish Government and delivered by Action for ME in partnership with the ME Association and #MEAction Scotland. We are funded to promote Nina's online learning module to GPs and other health professionals in Scotland, as well as producing webinars like this one, and a series of podcasts. Our final podcast for the project will focus on severe ME.

Genetics Centre of Excellence update

Over 100 people registered to attend our Genetics Centre of Excellence webinar in October.

This virtual network of ME researchers, set up and coordinated by Action for ME, work with the ME community to drive ME/CFS genetic research forward and build on the insights gained through DecodeME and other studies.

The agenda included an update from our CEO, Sonya Chowdhury, on the centre's main activities since its launch, including grant applications and new partnerships. It also included a presentation by Prof Chris Ponting, University of Edinburgh, about a recent Medical Research Council grant application for a ME genetic research partnership, and his vision for what the Genetics Centre of Excellence hopes to achieve.

There were also presentations from Prof Simon Carding, Norwich Medical School, on research and partnerships there; and from Research Fellow Audrey Ryback about her research on biomarkers for ME/CFS. As you may know from previous issues of InterAction, Audrey has been working under Prof Ponting since October 2023 (part of the first Clare Francis Postdoctoral Fellowship awarded by Action for ME).

Presentations and a recording of the webinar will be added to our YouTube channel: **www.youtube.com/@ActionForMEcharity**

My song for the season

"I love having Christmas tunes playing whilst my wee ones decorate the tree, particularly *It's Beginning to Look a Lot like Christmas.*"

Dr Robin Kerr

A biological disease

A research paper highlights how psychosomatic views of ME are harmful and inconsistent with research.

This article is abridged from ME Research UK original content.
The full article can be read on ME Research UK's website at **tinyurl.com/ye7tjnrh**

SPEED READ...
ME is a biological disease. A research paper has looked specifically at why the 'psychosomatic' view is inconsistent with biomedical research. This view has impeded research and caused harm to people with ME. Understanding ME correctly is essential to providing adequate care. High-quality biomedical research needs funding, and health professionals need up-to-date and accurate evidence-based training on ME.

Although research has shown that people with ME have biological abnormalities that are associated with disease severity and symptoms, and most researchers consider ME as a biological disease, there is still a misconception amongst many people – worryingly, including health professionals – that the disease is psychological in nature (psychosomatic) rather than biological.

One article by a team of researchers in Germany and the USA – including Manuel Thoma, Leonard Jason and Carmen Scheibenbogen – provides a clear summary of why the view that ME is a psychosomatic illness is inconsistent with results from biomedical research.

Not only this, but the article highlights that the continuing perception of ME being psychosomatic amongst health professionals, and those funding research, has impeded biomedical research and understanding of the disease, and led to potential harm to people with ME – including misdiagnosis, delays in diagnosis and treatment, and dismissal of symptoms (medical gaslighting).

Summary of the article

The research team provide a summary of why psychosomatic models of ME are inconsistent with evidence of biological abnormalities in individuals with the disease. The authors discuss that research has shown that the use of psychosomatic models can lead to potential harm to people with ME.

Not only does the misconception that ME is psychological in nature increase the stigma experienced by patients, but Thoma and colleagues state that it also worsens symptoms and quality of life through the impact on social relationships. It may also make people with ME less likely to seek mental health support – for example, should they experience low mood as a result of living with the disease.

Health professionals who dismiss ME as psychosomatic risk causing harm to people with ME – from telling them their illness is not serious, or that they are making symptoms up, to recommending potentially harmful therapies.

The research concludes that a correct biomedical understanding of ME – in line with current evidence – is essential to providing adequate care for people with the disease.

Therefore, it is crucial that more high-quality biomedical research is funded, and that health professionals are provided with, and supported in completing, up-to-date and accurate evidence-based training on ME, which reflects that it is a biological disease.

Resources that better educate the wider population may also help to reduce stigma, and promote understanding that research shows ME is a biological illness.

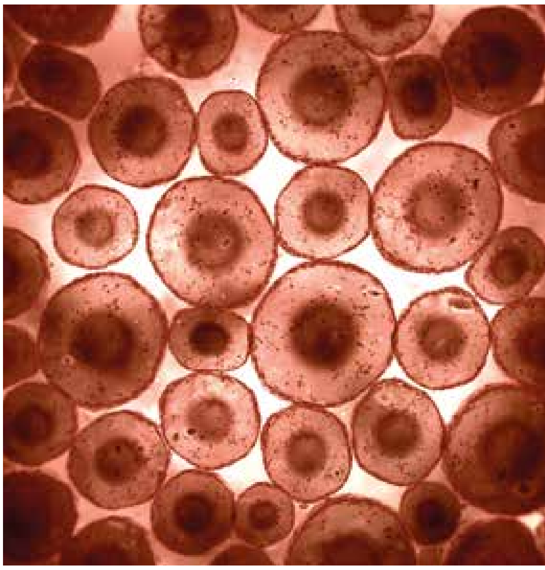
Takeaway messages

Current evidence shows that there are biological abnormalities in people with ME. Most researchers consider ME as a biological illness. Despite this, there is still a misconception amongst many people – including health professionals – that the disease is psychological in nature (psychosomatic).

The continuing misconception that ME is psychosomatic has increased delays in research and understanding of the disease, and led to potential harm to people with ME – including misdiagnosis, delays in diagnosis and treatment, and dismissal of symptoms.

Thoma and colleagues summarised that, to date, research has consistently shown that people with ME have abnormalities in the immune and circulatory systems, and in energy metabolism. Importantly these abnormalities can be seen across multiple studies. Findings often correlate with disease severity, suggesting that they play a role in mechanisms involved in the disease, and explain why symptoms of ME persist.

More high-quality biomedical research must be funded to replicate findings, and further understanding of disease mechanisms in ME.



Health professionals need to be provided with, and supported in completing, up-to date and accurate evidence-based training on ME, which reflects that ME is a biological disease.

Resources which educate the wider population may also help to reduce stigma, and promote understanding that research shows ME is a biological disease.

Why the Psychosomatic View on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Is Inconsistent with Current Evidence and Harmful to Patients by Thoma et al. was published on 31 December 2023 and can be viewed here: **www.mdpi.com/1648-9144/60/1/83**

Action for ME's winter raffle is here!

We have cash prizes to be won, for up to six of our wonderful supporters. **Our first prize winner receives £1,000!** Five more lucky winners all receive **£100**.

The funds raised from each raffle helps us to provide our vital support and healthcare services, campaign for change, and invest in much needed research.

How to enter

Enter online at tinyurl.com/Winterraf24 or **scan the QR code below**. Tickets are £1 each.
You can buy as many tickets as you like and share the link with family and friends.
Enter by post by returning your paper stubs with a cheque using the freepost envelope enclosed (or by using the address on the back of the tickets). Tickets are £1 each or £20 for a whole book. You can buy tickets yourself or sell them to family and friends.

Last date to return paper ticket stubs or buy tickets online is **Friday 7 March 2025**.
Winners will be drawn on Wednesday 12 March 2025.

To request paper raffle tickets, or to opt out of receiving them:
- email fundraising@actionforme.org.uk
- call 0117 927 9551 (choose option for fundraising)
- write to us at Action for ME, Unit 2.2, 436-441 Paintworks, Bristol BS4 3AS.

18+

An evening with Stuart

You may remember we interviewed Stuart Murdoch in our last issue of *InterAction*. Our CEO, Sonya Chowdhury, was delighted to be invited to host the Bristol-based event for the launch of his autobiographical novel, *Nobody's Empire*.

In discussion with Sonya, Stuart likened his early years of having ME to having to "step out of a river", with the river representing the energy levels that young people without ME have.

He referenced the memories of slowly having to give things up when he first became ill, losing friends and hobbies as his health worsened, something sadly familiar to so many people with ME.

Stuart also discussed some of the reasons behind writing *Nobody's Empire*, expressing his desire for readers without an experience of ME to understand more about the condition. For those who have experience of ME, he would love them to feel a sense of hope and belief that things can improve.

Juliet Gilchrist, one of our Information and Support Services team, also attended the event.

"It was a privilege to hear Stuart's experience of ME manifested as autobiographical fiction, music and reflection," she says. "It will hopefully inspire many people to use their own unique skills and creativity to express the way in which they are affected by a little-understood condition."

The InterAction interview is also online: **tinyurl.com/IAStuartMurdoch**

My song for the season

"My favourite Christmas song is *Step into Christmas* by Elton John. I think it perfectly captures how frantic and fun Christmas Day feels – it is frenetic and gorgeous and over much too quickly! It always gets me up and singing off key, just as I'd like to think Elton intended when he wrote it."

Leah Martindale, Fundraising and Membership Officer

Throughout this issue, we'll be sharing a medley of musical favourites from Action for ME volunteers and staff. We hope you enjoy reading these! Feel free to tag us on social media with your own #songfortheseason

My song for the season

"My favourite Christmas carol is *In the Bleak Midwinter*. I sang this as a solo in my very first UK primary school, during a very bleak and cruel winter, newly arrived from the heat of Guyana in February 1961. It had a huge impact on me as I sang to baby Jesus, 'What can I give Him, poor as I am?', who seemed very real, and here was the starting point of my Christian faith. It still takes me back, often bringing tears whenever I hear it."

Ann French, *InterAction-on-Audio* volunteer reader

Ann's cherished stable ornament

Dear team

Our Information and Support team answer your questions.

Q. I am due to stay with family over the Christmas period. Some of my relatives are very dismissive of my ME. I'm not sure I want to go, but it's the one time of year I see them. How do I manage their disbelief?

A. This is a difficult subject and, sadly, impacts many in the ME community. Doubt and lack of understanding in any situation is hard. When it comes from loved ones, it causes extra hurt.

The festive period can be such a muddle of feelings – loud and quiet, joy and sadness. Many people with ME find it a lonely time. This not always being alone physically, but of not feeling seen, heard or understood.

Making the best decision for you

There can be pressure at Christmas to be with family or friends, to be jolly and bright. If you are unsure you want to stay with relatives, it's important to listen to your gut. Weigh up the pros and cons of the benefits versus the impact on your symptoms and wellbeing.

If you do decide not to go, feel reassured that you have made the best decision for yourself.

Coping with disbelief when staying with relatives

It could be helpful to have an ME ally or friend who you can contact whilst away. You might wish to connect with others on our ME Friends Online forum. You can reach out to a helpline such as Samaritans on 116 123 (available 24 hours) or SHOUT, via text, on 85258.

It can be very hard to navigate explaining ME to people. It may be best to stick with some key phrases which you can repeat when needed.

"I need to manage my energy to help me be as well as possible, so I'm going to rest now but I look forward to seeing you later."

"I need to rest somewhere quiet, so I'm going to spend some time in my room."

"My earplugs help me when I'm finding the television too loud. I'm happy for you to watch a film whilst I sit here, they just filter some of the sound to prevent me feeling unwell."

"Don't worry that I'm missing out. I'm very glad of the time I'm getting to spend with you by putting things in place to help me do so."

"When you dismiss my ME, I find it really hard. It's a real illness. I didn't choose it and it's very hard to live with. I hope that you respect me enough to try and accept this."

It's important to remember you are not responsible for other people's behaviour. Other people's lack of belief is not a reflection of your truth. If you don't have energy to explain, don't feel compelled to do so.

Being prepared

Are there portable aids which help you to manage your energy in a potentially challenging environment? If so, it could be worth making a list of any everyday items you use so that you remember to pack them.

You could find out where you will be sleeping/staying at your host's house so that you can guarantee a 'safe space' to escape to when required. You could also ask if there are any events or meals they are planning in the time you are staying. This will allow you to work out whether you are able to attend these (and whether you want to!) and also to factor in rest before and after as needed.

Once you have a rough idea, it is worth letting family know that you will be attending certain events and not others, so that they are aware in advance.

> "Other people's lack of belief is not a reflection of your truth"

Permission to care for yourself

Allow yourself permission to leave the room as needed, even if others don't understand. You are allowed to prioritise your health and wellbeing.

Put yourself first as best you can over the festive period. ME is real. You live it every day and you are an expert in your own condition. People with ME face so much doubt in general, but you can go forward with integrity.

Remind yourself what it's taken you to be there. Allow space to nourish your wellbeing on your return home.

Further help

- More tips on staying with family or friends on p 36
- List of support organisations on inside back cover
- Our online forum: **www.actionforme.org.uk/MEFO**

A step in the right direction

Katherine Langford tells us about new guidelines in development to update and inform psychologists on the nature and impact of ME.

SPEED READ...
ME is not a psychological illness. It can't be cured with psychological treatment. Katherine Langford knows this from personal experience, after receiving harmful advice when she was first ill. What psychologists can do is help people cope with and come to terms with their illness. It is imperative that these professionals follow up-to-date medical advice or the consequences can be catastrophic. Therefore, the British Psychological Society is developing guidelines on ME/CFS.

I've had ME for 23 years. When I was first ill, I saw a paediatrician who clearly thought my illness was psychological and all in my head. He basically told me to get over myself and go back to school.

I naively trusted him, but following his advice caused my health to rapidly deteriorate to the point I couldn't get off the sofa or have a conversation more than a few sentences long. He also made things very difficult with my school as he told them that I could get better if I wanted to. My parents wanted to make a complaint about him, but they were afraid that he would contact Social Services.

My mum contacted ME charities, including Action for ME, and found out about pacing. I've gradually been improving ever since, but I'm still not as well as when I first went to see that paediatrician.

I know from first-hand experience how much damage incorrect medical advice can do, so I'm keen to ensure that others get the support and information that I wish I had had when I was first diagnosed.

I'm really disappointed that so little has changed since I was first ill.

ME is not psychological

ME is not a psychological condition. There is significant evidence which proves that it is physical.

For example, blood samples collected as part of the Biobank study have revealed 116 biomarkers that differed in comparison to samples from people without ME **(tinyurl.com/UKMEbiobank)**. This could lead to a blood test to diagnose ME/CFS.

While it is not possible to cure ME with psychological methods, psychology can help to improve the lives of people with ME. This is why I'm really excited to announce that the British Psychological Society (BPS) are working with Action for ME and the ME Association to create good practice guidelines for psychologists working with people with ME, based on the 2021 NICE guideline for ME/CFS. I am working on these guidelines in my role as an Action for ME volunteer.

What the guidelines will achieve

I think these guidelines will have four main benefits.

1. Well-informed support

ME has a significant and devastating impact on people's lives. As with other long-term illnesses, the limitations that come with it cause difficulties and frustration. Psychologists cannot cure ME, but they can help people adjust and try to manage the impact of this debilitating illness. The BPS have guidelines on other non-psychological conditions, such as care for stroke survivors, dementia, brain injury, dyslexia and autism. Psychologists can help those with a physical condition by providing support and listening, especially when people with ME frequently battle disbelief from friends, family, co-workers and doctors.

2. Basis for better practice

Psychologists need to know current, up-to-date best practice when offering advice to people with ME. Giving the wrong advice can have catastrophic consequences. These guidelines will provide psychologists with the information they need on topics like pacing, resting and symptom management. This is especially important for people with ME who are not receiving the help they need from other medical professionals, such as their GP.

3. Addressing misconceptions

It's important for professionals and the public to have access to reliable and reputable information. The BPS is the UK's leading psychological institution, so these guidelines will carry weight. We intend for the guidelines to include information on those who are severely affected by ME and the crisis cases which end up in the media.

4. Rebuilding trust

It's hardly surprising that some people find the mere mention of ME and psychology in the same sentence triggering. There has been a history of people being dismissed as being able to get better if they wanted to or their illness being all in their head.

Despite the many people affected by ME, very little money has been spent on researching it and, in the past, there has been a focus on psychological treatments rather than biomedical research. Trust needs to be rebuilt between people with ME and the medical profession, psychologists included.

The first step is for professionals to listen to the ME community and these guidelines provide a platform for that to happen. These guidelines are being written by people with ME and/or people who work in ME/CFS services and are having input from other people with ME.

Alongside myself (Action for ME) and Russell Fleming (ME Association), this working group includes Joan Crawford, Sara Meddings, Louise Kenward and Nita Baker. The group brings experiences from clinical, counselling, occupational and educational psychology backgrounds.

As Joan Crawford has explained, "There are several psychologists with ME involved in leading this project. It is not about promoting treating people with ME with psychotherapy. That has zero evidence base. It is about ensuring psychologists know this and have information about ME to support them appropriately."

Those with lived experience of ME are being fully involved right from the start. "People with ME/CFS are the experts by experience of their own condition and will greatly enhance the work we do," says Sara Meddings.

These guidelines intend to give people with ME a voice, to explain to professionals what it is like to have this illness and help them to understand. I think they will be a huge step in the right direction towards ME being treated as the biological and physical condition that it is.

Have your say!

It's really important that these guidelines contain the experiences of people with ME. I don't think that you can understand what this illness is like just from a list of symptoms, so we're looking for direct quotes from you that we can share.

At the time of writing, we're in the process of conducting an initial survey asking people with ME and their friends, relatives and carers for their opinions about what should be included in the guidelines. We've had over 850 responses so far.

By the time you read this, we should have finished processing the results. We are going to have further input from people with ME via focus groups and other online platforms.

If you haven't had a chance to contribute, but feel strongly that you would like to, then don't worry, we'd love to hear from you. In particular, we don't have much feedback from people under 18, as well as black or Asian people (particularly men). Carers and family members are also welcome to get in touch.

If you'd like to join the mailing list for news or details of further opportunities, you can complete this survey: **tinyurl.com/BPSMEguidelines-stayupdated**. (If you can't access the online link, please write or call Action for ME using the contact details on p 2, and we will add your details for you.)

I'm planning to write a report for the next edition of *InterAction*, so watch this space for future updates.

Supporting people on their journey

Melanie De Luca, physiotherapist in our Healthcare Services team, talks to us about her work helping people with ME.

How would you introduce yourself to our readers?

My name is Melanie De Luca (Mel) and I am one of the physiotherapists working within the Healthcare Services team for Action for ME. I qualified as a physiotherapist in 2008. I have been on the team since February 2022, previously working for the ME Trust (from July 2020).

What help do you offer as an Action for ME physio?

There is a wide range of things we can help clients with. Mostly, we help with pacing and management of energy limitations, finding baseline daily routines, pain management, strengthening ranges of movement, and rest.

We are able to provide education to help those just starting out on their journey about the importance of pacing and rest in recovery and can give different ideas around how this can work for each individual.

Melanie and her son Max

How do the sessions work?

I receive referral forms via our Healthcare Service Admin team from those clients that request physiotherapy support. I then make contact initially via email to introduce myself and offer to arrange an initial session.

All of our sessions are virtual – over the phone or by video call. Sessions vary in length, depending on how long each client is able to spend talking.

During the session, we document everything we discuss and write up a summary report, which is sent directly to the client so that they can look back over what we discussed and see the advice offered.

All follow-up sessions are arranged directly with each client at the end of each session.

What do you find most inspiring about the role?

I love being able to help and support people as much as possible and it is why I chose my career as a physiotherapist. I am honoured to be a part of my clients' journey with ME and to give as much information and advice that I can, to help improve their quality of life.

I am inspired by the strength, bravery and perseverance that the clients have and their openness to receiving advice, even when it can be challenging. I learn so much from the clients, from the experiences they have had with their illness and new ideas that are discussed amongst the ME/CFS communities.

What about the most challenging?

The most challenging part is wishing that I could do more! I wish I had all the answers, but am very aware it is a teamwork approach with the client, other healthcare professionals, family and friends.

Everyone's journey with this condition is individual, so requires an individual physiotherapy approach. What may work for one client may not work for another, so I am constantly learning.

This year, funds raised from our Big Give Christmas Challenge (see p 4) will help fund our healthcare bursaries. What would you say to someone considering giving to the Big Give campaign? Why do you feel it is important?

Being able to help fund our healthcare bursaries will allow those that are finding it financially difficult to self-fund healthcare services privately. This will allow them access at a reduced fee to access healthcare services that can be so beneficial.

A lot of people with ME have had to stop working or reduce work due to their symptoms, therefore may not have the funds to access support.

What are your hopes for people with ME?

I hope that all people with ME are listened to and understood, from those who are mild, moderate to severe. I hope that, by raising awareness, we can help to improve the quality of healthcare services that this client group deserves and needs.

You are the expert

Mel took part in Learn about ME podcast episode 7, together with fellow physiotherapist Gina Wall. In this podcast, they discussed what physiotherapists need to consider when working with someone with ME.

This podcast highlighted that being person-centred and client-led is essential, as people with ME present very differently, with varied personal circumstances. The person with ME is always the expert. Any physiotherapy needs to fit in with the ME, not the other way round.

Physiotherapists can offer clarification and reassurance to help people work with their ME, identify their own baseline and how they can work with this – plus help them not doubt themselves or their condition.

Find this and other Learn about ME podcasts here: **www.buzzsprout.com/1717775**

My song for the season

"My favourite Christmas song is *Driving Home for Christmas* by Chris Rea. It always reminds me of driving home for Christmas when I was at university and the first year I drove home, I got in the car and this was the first song that came on the radio! Since then, when I travel to my Mum's house for Christmas with my family, it's the first song I put on in the car."

Mel De Luca

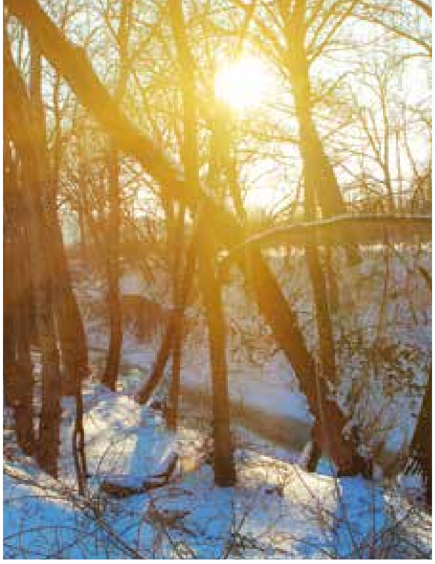
Our Heathcare Services team includes doctors, counsellors and chaplains, as well as physiotherapists like Mel. Details can be found on our website: **www.actionforme.org.uk/healthcare-services**

You can make a self-referral by completing our Healthcare Services self-referral form, which also has a bursary section for those seeking help with fees: **www.actionforme.org.uk/self-refer**

FUNDRAISING

Mel and Max take on the inflatables!

Melanie and her son Max raised £320 for Action for ME by taking part in the 'Inflatable 5k' – a 5,000-metre run over an inflatable obstacle course. We're so grateful that Melanie was able to use her passion for supporting people with ME to raise much-needed funds to help us provide vital support and healthcare services.



Reset your circadian rhythm

Sally Ulph reflects on how natural light can be a foundation for health.

SPEED READ...
Light has an impact on our 'circadian clock', which controls various biological processes. Adjustments in how we are exposed to light can benefit health. This article explains more and highlights suggestions from circadian health professionals, on aspects such as natural light exposure, limiting artificial light and 'grounding'.

Important: People with severe ME or light sensitivities may be unable to do many of these things or need to adapt their approach. This is not intended to be medical advice.

People with ME frequently struggle with disrupted sleep/wake cycles, temperature dysregulation, immune and hormonal dysregulation, and energy production issues. These all relate to circadian rhythms, bodily processes triggered within the 24-hour cycle.

Understanding circadian health

Our circadian clock is coordinated by what is called the suprachiasmatic nucleus (SCN) of the brain. It controls processes such as sleep/wake cycles, hormone release, temperature, and metabolism. It is controlled by external cues, particularly light, but also by external temperature, social interactions and food timing.

The SCN is primarily set environmentally by light. Light exposure (particularly to blue light) helps it reset each morning, ensuring proper synchronisation with sleep/wake cycles.

For people with ME, disruption to circadian rhythms can make symptoms worse. Circadian disruption is associated with impaired immune function, reduced mitochondrial activity (mitochondria are the energy factories of the cells), and increased inflammation, all of which may be problematic in ME.

The right type of light

Light exposure is key to managing circadian rhythms. The right type of light, at the right times, can help reset and regulate these rhythms.

Morning sunlight, which is rich in blue and UV light, is essential for regulating the circadian rhythm. Exposure to natural morning light tells the brain it's daytime, triggering the release of cortisol, which increases energy and alertness, and suppresses melatonin, the sleep hormone. Regular exposure to morning sunlight can help synchronise the body's circadian clock, improving sleep quality, mood, and daytime energy levels.

Improper light exposure, such as excessive artificial blue light from screens in the evening, can lead to disruption – falsely signalling to the brain that it is still daytime.

People with ME suffer from sleep disturbances, non-restorative sleep, and daytime fatigue. Incorporating regular morning sunlight exposure may help restore circadian rhythms and improve sleep quality, which may alleviate some fatigue and other symptoms associated with the condition.

Recommendations from experts

Carrie Bennett (MSc Nutrition) specialises in circadian biology and mitochondrial function. Professor Russell Foster is Director of the Sleep and Circadian Neuroscience Institute at the University of Oxford.

They recommend lifestyle habits to support people with chronic illness and overall health:

Morning sunlight exposure

Morning light not only signals to the body that it is daytime; it also stimulates energy production and helps hormonal balance. Both Bennett and Foster recommend getting outside in the early morning in natural light (20-30 minutes is ideal).

If this is beyond your capacity, perhaps first try being on your doorstep with the door open for one minute (but only if you are able). Foster and others suggest using a high lux (minimal 2,000, but preferably 10,000) SAD light box in the morning, if you cannot get outside.

Limiting artificial light at night

It's important to reduce exposure to artificial blue light in the evening, as it can disrupt melatonin production and circadian rhythms. Bennett recommends using blue-light blocking glasses and using dim, warm lighting in the evening to support the body's natural transition to night-time. This promotes better sleep. Foster is less dogmatic, suggesting dimmer lighting two hours before sleep and stopping using devices half an hour before sleep.

Grounding and nature

Bennett also stresses the benefits of grounding (walking barefoot on the earth) in combination with natural sunlight exposure. Some research suggests that grounding can reduce inflammation and improve mitochondrial function and general resilience. (It may be wise to wait for a warmer time of year to try this!)

A piece of the puzzle?

Scientists like Bennett and Foster argue that circadian biology is foundational to health, and hence could be an important piece of the jigsaw puzzle to benefit overall health – including for those with chronic illness. Perhaps these habits sound too simple to be effective, but evolutionarily they make sense.

Have you found changing your light environment helpful? Has your sleep or energy been improved? Let us know – see p 2 for how to get in touch.

Key terms at a glance

Circadian: biological processes recurring on a 24-hour cycle

Melatonin: the sleep hormone, produced by the pineal gland in the brain, supporting sleep/wake cycles

Mitochondria: the energy factories of our bodies' cells

Suprachiasmatic nucleus (SCN): part of the hypothalamus; the central pacemaker of the circadian timing system; regulates most circadian rhythms in the body

If you are sensitive to light

We acknowledge that, depending on the severity of your symptoms, you may be extremely light sensitive. If this is you, these tips may currently be unhelpful or even make things much worse for you. Please listen to your body and do what works for you at this moment.

It's important to remember that ME is known to be a fluctuating condition. If another piece of your ME jigsaw puzzle is resolved, you may find that your light sensitivity shifts over time, meaning that you may be able to take on board some circadian health principles later.

For further information and support about light sensitivities, including different types of light bulbs, see **www.lightaware.org**

Resources

Website with mobile app and various blogposts: **www.circadian.life**

Article from the Sleep Foundation: **tinyurl.com/SFcircadianrhythm**

Please note that Action for ME does not endorse specific management approaches or external links.

Creative corner

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

A way to observe the world for Alexis

"Having severe ME and POTs means a lot of the time I can't even get out of bed or have the curtains open or talk to anyone," says Alexis. "Photography has given me a way to observe the world around me – even when that world is really small and limited – to find something beautiful and joyful in it each day helps a little to keep me going."

Alexis is on Instagram as **@a_x_lense**

Kim's winning design

Kim's eye-catching crafts

Kim Rowland has had severe ME for over 40 years. "I made this Christmas card for a special member of my family," she says. "As I have very limited mental and physical energy it took some time. I started in the summer, and went back to it intermittently adding a little at a time. It always leaves me with a sense of satisfaction and pride when I finally complete the project," she explains.

Earlier this year, Kim won first prize for her entry in the craft section at her local village show – for a 'Seaside Scene on a Plate'.

"It took me several weeks to make on and off, as energy permitted," she explains. Well done, Kim – your prize is well deserved!

Hold on to hope, says Roberta

"I consider myself lucky," says Roberta. "You may think that is a strange thing to say about having ME, which is now severe. I feel that I am lucky because I didn't become ill until I was 72, which is very old compared to a lot of people and I feel very sad hearing about younger people who are so ill."

Here, Roberta shares her poem *Please Believe ME* with *InterAction* readers. "I'm just coming up to 83 now, so have had 11 years of going through what I'm sure most of you have in terms of illness, but [also] in terms of disbelief and lack of knowledge from others," she explains.

"I had a happy life bringing up a family and now seeing grandchildren growing up and doing well. I got to go to lovely places and have fun. I am lucky because for the last five years my husband has tirelessly looked after me since I became bedbound.

"Being lucky doesn't mean that I don't curse this illness every day of my life. I feel the pain of losing those years that I had so many plans for. I'm hoping that someone is going to come up with answers. I do feel it is more likely now that those answers will be found, so I urge anyone reading this to hang on to hope."

Please believe ME

You look at me, what do you see
You see a well person, you don't see ME
I talk for a while then run out of steam
But you think I am bored or just rude
If I say I have no energy to do
You think well we all feel like that too
Nothing new there, we all feel like that
But you don't.

Your body's not failing, not holding you up
Your mind's not a muddle of things you forgot
You don't have ME, you are just a bit tired
That's what you think I am,
I'm not!

You don't have the crushing unending pain
That pummels your body again and again
The flu like sickness that won't go away
The loss and sadness that is here to stay
You think I exaggerate looking for love
But I don't.

It's exhausting, degrading to always be told
Well if you tried harder then things would be fine
You just need to pick up and smile
I once was a person respected and whole
Who always helped others and lived by my soul
My freedom to be who I wanted to be, not a
Broken ghost who is haunted by
ME.

Our Information and Support team reflect on dealing with disbelief on p 13 of this issue of InterAction.

Creativity helps Charlotte feel happy

"I am a professional painter with ME, diagnosed aged 28 back in 2014," says Charlotte. "I also have several other conditions which interfere and overlap with ME. I find abstract painting, singing and also writing poetry very therapeutic. It helps me to stay happy when it can sometimes feel like everything is working against my body. It also helps with relaxation."

This is a photo collage of some paintings Charlotte did for different projects. "Some were made into bookmarks for a Buddhist event and they allowed me to just 'play' with the paint and mark making. Other ones I framed and put in my lounge to make the room feel freshened up for spring. I hope that your readers feel the healing properties of the work as much as I do making them."

Charlotte wanted to give a mention to Kara Jane Spencer, who passed away in 2023 at just 32 years old. "Kara Jane inspired me a lot to keep going and reach creative goals when circumstances make it feel impossible. She created an album called 'It's Still ME' and it's really soothing to listen to."

Find Charlotte on **www.cltabstracts.co.uk**
Find Kara Jane's music at **lnk.to/KaraJane**

For more creativity, check out Rose's Christmas story on p 32!

My song for the season

"My favourite Christmas song is *Last Christmas* by Wham! I play a game called Whamageddon each year with my friends, but there are Facebook groups for it too. The aim is to see how long you can go through December without hearing the original song. When you do, you are deemed to have been sent to 'Whamhalla' and you have to declare where and when you hear it. It's completely ridiculous, but it's a great way to interact with friends/the Whamageddon community across the world! I'm most often caught out in a pub or supermarket."

Joanna Pickering, *InterAction* audio volunteer

My song for the season

"My favourite Christmas song is *O Holy Night*. No other carol gets close, in my mind, to intimating the majesty of the Nativity, in all its soaring promise."

Josie, *InterAction* proofreader and audio volunteer

My song for the season

"Few would agree that Joy Division are the most festive or jolly of bands – but Sufjan Stevens sampling them in them in his song, *Christmas Unicorn*, just works somehow. It's a relatively recent addition to my festive playlist and a real earworm. It starts with the lyrics: 'I'm a Christmas unicorn in a uniform made of gold / With a billy-goat beard and a sorcerer's shield and mistletoe on my nose' and then gets progressively, delightfully more odd."

Clare Ogden, Head of Support Services at Action for ME

FUNDRAISING

Raising awareness of the impact of ME

Mike Cooper's daughter-in-law was diagnosed with ME in 2020. In May 2024, the Barratt and Cooper families decided to organise a fundraising event.

Mike said they hope to "raise people's awareness of ME and its impact, and to raise money towards further research into the causes of ME and, hopefully, an eventual cure for it."

The families raised an incredible £4,675 for Action for ME by completing a 12-mile walk. Each family started from a separate side of the Yorkshire Wolds and met at the halfway point.

We are so grateful to Mike, and both families, for their dedication to people with ME and for supporting our work.

Take a mindful moment

Alice Muskett suggests some ways to be mindful this winter.

Get cosy. Think blanket forts on the sofa, a scented candle and a mug of your favourite hot drink.

Look inwards. Check in daily by asking how you feel physically, mentally and emotionally. Try not to judge the answers and listen to your body, giving it what it needs this winter. You are the expert when it comes to your own mind and body. Listen to its messages.

Give yourself permission to rest. Rest is necessary, so try to remove any guilt around taking naps or quiet time during these colder, tiring and often busier months. Animals hibernate over winter, so why can't we?

Be gentle. If you notice difficult emotions that often come with the busier festive period, such as feelings of loneliness or isolation, be kind and remind yourself that many others feel the same way at this time of year. This too shall pass.

Let go of 'shoulds' and 'musts' in the busy festive period. It's easy to get caught up in an idea of what we think the festive season 'should' look like and this creates unnecessary stress and pressure. Mindfulness encourages kindness towards oneself, so if you need to wrap up in a duvet, watch films and eat chocolate – then do it! Let's remove rules on what winter and the festive period 'should' look like. Let's focus instead on what feels right for us.

Prioritise your own joy. We're often told this is the season of joy. But joy looks different for all of us. So spend time doing what really brings you joy this winter, not what you think *should* spark joy. If this means saying no to certain visitors or activities, then that's okay.

Take a mindful moment outside. If you have the energy, take a very gentle stroll or spend a minute in your garden. Bring yourself into the present moment by focusing on the senses. Notice what you see, feel, smell and hear in the crisp winter air.

Alice runs monthly public mindfulness meditation sessions on behalf of Action for ME over Zoom. You can find out more by contacting **avril.mclean@actionforme.org.uk**
To listen to one of her guided meditation sessions in your own time, visit **tinyurl.com/MindfulMomentAFME**

We reflected on making the season more ME-friendly in our winter issue last year. Remind yourself of some of our suggestions here: **www.actionforme.org.uk/reinvent-the-season**

"Joy looks different for all of us"

The gift of song

Jill Rakusen reflects on how living with ME drew her into a new relationship with music.

I had no idea about the profound impact a song could have. The sheer power of it to effect such significant change within me; the possibility of being able to 'meet', and draw on, this power; to grow into becoming 'one' with it.

The reason I discovered it? I became ill. My world changed beyond recognition. It was bewildering, shattering, challenging beyond measure. A familiar story, eh?

My ability to cope with all this was pretty limited. I kept trying, and failing, to get back to work. My employers were very understanding, but ultimately I had to leave my job.

Living with the possibility, and then the actuality, of long-term illness can lead to a huge sense of loss, including a kind of loss of identity. This often involves a journey. Was mine a journey into becoming someone else? Or was it a journey towards a truer me? I eventually felt just brave enough to gravitate towards the latter. Because of ME.

Jill Rakusen with her book

Being with a song

ME propelled me towards a new relationship with music, and with song in particular. While I'd already rediscovered singing, and I was fortunate that it was still possible (at times), this was something else. For instance, I came to know how I could be with a song: 'just' me and 'just' the song, without others, or even a recording (so often, sensitivity to sound made listening to anything out of the question).

In this way, I could have all-consuming musical experiences, even when my world was limited by illness. Invariably the most profound experiences occurred when I wasn't singing at all – exhaustion could easily make singing too demanding to contemplate.

I found these discoveries revelatory as well as astonishing. They helped me grow. I could find buoyancy even whilst exhausted, and deeply nourish myself – thereby helping to rebuild my 'energy bank account' .

Songs I engaged with came from many parts of the world. Soon I amazed myself by starting to create songs. And I was equally astonished at others' responses once I dared to share my first.

My songs quickly became trusty companions. They came not as succour, or hope for happier days, but rather to illuminate a deeper reality and help me open up to it, find compassion for the faltering self, build strength, and embrace as much ease as possible.

As I engaged with a song, new facets might be revealed – of the song, of myself, of the world. I discovered the power that I had – to find peace within. Joy, too. And I didn't need to sing, or listen to, a note! It was gratifying and humbling to discover such possibilities.

Yet at times I could easily feel abandoned, including by song. This meant I could forget its enormous power (and that of myself). However, I was acutely aware how negativity flourishing within me fuels misery and even exhaustion, and this could provide the impetus needed to look beyond it, often prompting the emergence of new songs, such as one called I *See Beauty*.

Sharing my discoveries

After a while I tentatively began to explore if others might be interested in this way of being-with-song. To cut a long story short, it became known as *Giving Voice (GV)* and the *GV Process*. An early group I ran was called the *GV Experiential Research Group*. What a mouthful! To my initial amazement, people began to make discoveries themselves, largely on their own between the sessions.

Often, like it was for me, their most significant experiences occurred in silence.

GV has continued ever since, appealing to a range of people – some who sing, some who believe they can't; some who are unwell, or their carers; some who simply wish to learn, to grow, to 'become'. Eventually I produced a book to help others 'unlock' the power of song. Since Covid, I run occasional events online.

While I've gained enormously through the personal gift of song, being able to introduce this approach to others has itself been a huge gift: hearing how people have used it in their lives – even when exhausted (so important!), or witnessing others' depth of experience, particularly when they have not 'known' themselves as musical beings.

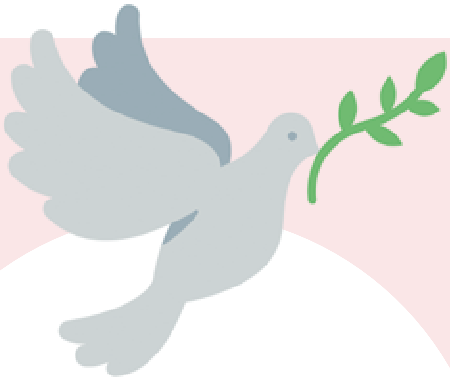
Of course, because of my ongoing condition, it can be challenging to run events, but I've been fortunate to have assistance, in all sorts of ways. I'm eternally grateful to the many organisations and countless people who've helped over the years.

I've been spurred on by all who've shared the benefits of the process including members and trustees of the National Foundation for Giving Voice, a charity that was set up to take this work forward, and my dear colleagues, Rachel Healey and Caroline Thorpe, who sought to learn from me how to facilitate this process. Doing it is a labour of love for the three of us.

Action for ME was particularly helpful to me in the early days. It would so warm my heart if any readers were to find my experiences helpful too.

The Giving Voice Foundation aims to illuminate the relationship between music and health and wellbeing. The charity is very kindly giving away five copies of Jill's book, *Unlocking the Power of Song: A Companion for Challenging Times*, to *InterAction* readers. The book shares more about her journey and how her approach can be drawn on by others.

To be in with a chance to receive a copy please email **interaction@actionforme.org.uk**, or write to the address on p 2, with the title 'Gift of Song' by **Monday 6 January 2025**. More information can be found at **www.givingvoicefoundation.org.uk**



Jill's song for the season

I've chosen *Silent Night* for several reasons: because of the profound nurturing restfulness it can engender (which all of us touched by ME probably need in spades), because of its history, and because it touches on something deeply universal.

By Joseph Mohr and Franz Gruber, *Silent Night* was born in Austria out of immense suffering, after 12 gruelling years of war in Europe which ended in 1818. Almost a century later, near the beginning of World War I, a German officer began singing it on Christmas Eve, first in German, then in English, leading to 'enemy' soldiers joining in and sharing other carols.

Given our present-day wars, including in Europe, and in the Middle East, 'cradle' of the world's three Abrahamic religions, I feel it's a song so needed now: not a saccharine version that can appear on the airwaves, rather a version that can be deeply held in the intimacy of our hearts, as we link with all who've suffered in the past, through to the present day.

I was moved to tears recently on coming across a video of some Muslim girls singing it in Arabic – in Beirut – in 2017. I pray that they and their loved ones have found safety, and can take succour from it amidst the current ongoing destruction … And I trust that holding them in our awareness, and all who are suffering, will support them, and contribute to peace throughout the world as we connect with it deeply in our hearts.

The video mentioned above can be found here:
tinyurl.com/SilentNightBeirut

Other renditions of *Silent Night* that Jill holds dear will be listed on **www.givingvoicefoundation.org.uk**, together with additional links. Contact Jill at the Foundation if you want to join her online as she shares *Silent Night* during the Christmas period.

Making all feel welcome

Maggie Aherne tells us about the SS Great Britain and why she loves volunteering on the team.

SPEED READ...
Maggie volunteers at Brunel's SS Great Britain, a museum and visitor attraction in Bristol. A member of Action for ME, Maggie shares how volunteering has helped her regain her 'spark' after a tremendously difficult time. Living with the challenge of ME provides her with an insight into what museums and visitor attractions can do to help meet that challenge. She gives us a flavour of the SS Great Britain, as well as some of the things they are doing to make it accessible to visitors with additional needs.

When ME/CFS first hit me in 2003, it took away everything that made life worth living. People thought that if I was simply at home lying on the sofa instead of being at work, I could at least be catching up on reading or watching movies: no, because my brain couldn't retain what I'd just read or seen. Nothing worked.

I was in physical pain, and seriously worried about how long I'd be out of action. It was a long, slow haul out of that pit. A few years later, when I was well again, an early breast cancer was caught; as I was recovering from the surgery and radiotherapy, my husband had the first of the strokes that eventually took him. I don't need to describe the exhaustion, physical and mental, of living through those years.


Maggie

A new chapter

After my husband died and I was able to build my energy back up, I looked for a new activity that would help me regain the spark I'd lost. We had been members of the SS Great Britain for many years (big Brunel fans!) and so I applied to volunteer there. What a good move it was.

I've now been wearing the uniform for 12 years and loving every minute. My supervisors and colleagues know that I'm liable to flare-ups of ME. They're generosity itself in the allowances they make and the kindness with which they treat me. That attitude is reflected across the museum in the care that's taken of visitors.

There are many things that can impact a person living with ME: crowds, noise, bright light, nowhere to rest. It's a welcome change to find a first-class museum and visitor attraction that understands our challenges.

The SS Great Britain story

This was a revolutionary ship: the first ocean-going passenger liner to be built of iron, powered by steam and driven by a screw propeller. These technologies transformed the number and demographics of people who travelled around the world on a scale only seen again with the arrival of air travel – and revolutionised the speed that information and cargo moved around, reshaping global trade and empires.

The ship was designed by Isambard Kingdom Brunel as the second of three record-breaking steam ships and was launched in Bristol in 1843, first as a luxury liner crossing the Atlantic to New York, then as an emigrant ship taking people back and forth to the British colony in Australia, and finally as a cargo ship taking coal from South Wales to San Francisco. Altogether, it encircled the planet 32 times in its long working life.

After sustaining severe damage in a storm off the Falkland Islands it was written off as a working vessel. The SS Great Britain was used for many decades as a floating warehouse before being towed to a remote cove, scuttled and abandoned for the sea to break up. But the ship survived, and in 1970 an audacious rescue saw it towed 8,000 miles across the Atlantic back to the very dock in Bristol in which it was built.

And so began the next stage of the ship's life as a museum and visitor attraction. Brunel's SS Great Britain has won countless awards, both for the quality of the refurbishment and recreation, inside and out, as well as for the friendliness of the staff and volunteers.

So, what's it like to visit?

Credit: Adam Gasson & SS Great Britain Trust

An accessible experience

The SSGB team recognise that not all visitors are equally able to cope with the rigours of navigating a large site, especially on busy days. They've worked hard to make the experience more accessible.

- All the museum buildings, plus the dry dock and the ship itself, are **equipped with lifts that reach every level**. A visitor with mobility issues need not miss out on anything.
- **Wheelchairs** are available for hire at the admission desk. If you bring your own wheelchair, there's an information sheet giving the dimensions of corridors and passageways on board the ship, and weight limitations for each of the lifts.
- There is an **accessible toilet** in every building and on the ship.
- **An access map** shows the ship and the museum buildings, listing points of potential difficulty such as narrow doorways and areas of reduced headroom, cobbled surfaces, trip hazards and the like, as well as the location of seating, step-free access routes, the lifts and the accessible toilets.
- Other information guides cover items that some people might find **triggering**, such as the mannequins that demonstrate life as a passenger or member of crew. There are downloadable guides on where all the mannequins are located, and where the sounds and smells (there are a lot!) can be found, so that nobody need be taken by surprise with any sensory triggers.
- **There is free admission for companions** accompanying disabled visitors.

Help for people with ME

There are aids and initiatives originally designed for neurodivergent people, which can also be a boon to people living with ME.

- If a noisy environment is a problem, you can **borrow ear defenders** at the main desk when you check in.
- If you are feeling overwhelmed by crowds and bustle, there's **a quiet room that you can ask to rest in**, for as long as you like. (As admission to this room is via the staff, you can be assured that you won't be disturbed by other visitors popping their heads around the door!)
- One of the greatest initiatives, though, is the **'Calm Sessions'**. In these sessions, capacity is limited, so that the site is quiet and calm. These sessions are scheduled on days that are typically the quietest for the time of year. The audio, visual and smell effects will be turned off, or at least reduced as far as possible.

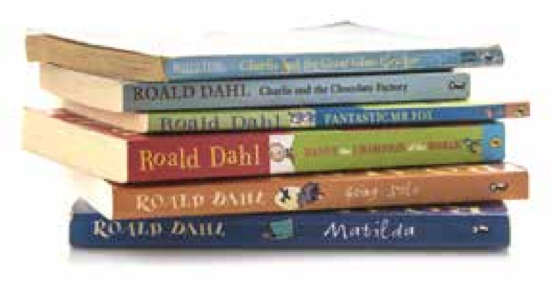
  If you book ahead but can't make it on the day, you will be offered an alternative day or given a refund. Sessions operate on certain days throughout the year rather than on a fixed schedule, so you'll need to check the website for the dates: **tinyurl.com/SSGBcalm**

Anything else?

My own personal recommendation, for when you are out and about is this: equip yourself with a stool rucksack. These are usually aimed at people going fishing: the rucksack has an integral fold-out stool that allows you to sit anywhere you need to. (They aren't the most comfortable, but sometimes there's no alternative!) The mere fact of knowing that I could sit and rest whenever the fatigue hit was an enormous help in getting through the challenge of a day out.

The team at SSGB is working hard to help visitors of all kinds to have a great day out. I'm so proud to be part of the team!

For more information on visiting the SSGB as a disabled person (including downloadable guides), see: ***www.ssgreatbritain.org/access-for-all***



Accessible ways to explore

Emma Baker, volunteer member of *InterAction's* Editorial Board, works part time (around her health needs and university studies) at the Roald Dahl Museum and Story Centre. Their accessibility initiatives are tailored towards children.

"As part of their SEND programme, they have visual stories and accessibility guides, as well as 'Explorer Bags' which can be requested at the ticket desk," explains Emma. "They are basically a different way of exploring the museum (in them they have fidget toys, ear defenders, laminated sheets with information and activities on, sunglasses, magnifying glasses, etc)."

The museum also has dedicated SEND days which are specifically tailored towards people with additional needs – so the sounds are turned down and artificial smells are turned off as much as possible. There are reduced visitor numbers, more staff on hand and different trails to suit different learning styles.

"There seems to be a wider movement of museums trying to cater for different needs and experiences," says Emma. For example, the National History Museum provides explorer bags and sensory bags.

Find out more about the Roald Dahl Museum SEND programme: **tinyurl.com/RoaldDahlSEND**

Take a 360-degree virtual tour: **tinyurl.com/RoaldDahlTour**

Go on a virtual tour of the National History Museum: **tinyurl.com/VirtualNHM**

We shared some other ideas for virtual visiting in InterAction *issue 114 (p 26) – scroll down this page:* ***www.actionforme.org.uk/ways-to-see-the-world***

Have you had a good experience of a museum or visitor attraction as a person with ME? Get in touch and let us know! Contact details on p 2.

My song for the season

"The Christmas song that I probably listen to the most is *Carol of the Bells*. I really enjoy Christmas songs, but since my ME relapsed I sometimes find them a bit draining, so can't listen for long. *Carol of the Bells* instantly makes me feel Christmassy without being too tiring. Plus it's in Home Alone, which has got to be one of the best Christmas films of all time!"

Katherine Langford, *InterAction* Editorial Board volunteer

My song for the season

"I quite like *The Power of Love*. It's not a Christmas song per se, but John Lewis used it in one of their Christmas adverts. The reason I like it is because for a long time I thought the lyrics said, 'love is like a manatee' (they actually say 'love is like an energy') and I liked the image of a manatee because apparently they're very gentle animals!"

Emma Baker, *InterAction* Editorial Board volunteer

Escaping into a fantasy world

Jordan Dove shares her love for anime art.

I initially became ill in March 2020 after a severe case of Covid. Over the course of a year, I visited several doctors and specialists, but struggled to access support without an official Covid diagnosis.

I finally received my diagnosis in January 2021, and it turns out I have mild to moderate ME and hypermobility, along with ongoing pain and sensation issues that have been under investigation for over four years!

Dealing with ME has completely altered my life. I had to resign from my job of nine years after a year of sick leave. I then decided to pursue a degree at my local university. I will be graduating this October with a First-Class Honours degree in Applied Psychology. I consider myself fortunate to have such a strong support system comprising my husband, family, and friends, many of whom I connected with in the chronic illness community (shout out to the spoonies!).

After my diagnosis, I started drawing as a hobby, focusing on anime art. Anime originates from Japan and encompasses various styles. Anime art is characterised by large eyes, disproportionate bodies, and expressive facial features. From an early age, I loved cartoons such as Pokémon and Sailor Moon, but anime exploded into my life during lockdown, and the long hours of acute illness quickly became full of Studio Ghibli movies, Little Witch Academia and Sword Art Online.

When I'm drawing, I slip away into this fantasy world; it really is true escapism. Drawing doesn't require much energy from me. I can do it from the sofa or bed.

The only thing it really affects is my eyesight. I have to take breaks when my vision blurs. I can use aids such as a pen grip, a lap desk to balance my tablet on, a contour mouse, and a wrist rest to keep my arms from becoming sore.

Despite the limitations it can present, creativity in any form is very soothing. It speaks to our inner child, helps us to process events/emotions, and allows us to live vicariously through our characters.

When I submitted my last drawing to Action for ME (featured in Creative Corner, *InterAction* 117, p 32) I hadn't been drawing for very long. It isn't reflective of where I am now with my abilities. The message I wanted to convey still stands though – radical rest is important, and you don't need permission to give yourself that grace.

Action for ME has kindly allowed me to share another piece to update you on my progress (left). I've now been drawing for over four years, and I plan to create a webcomic of my own, using my principal character and mascot, Kibo.

Brain fog by Jordan

InterAction

The magazine for Supporting and Lifelong Members of Action for ME

Please note that Supporting and Lifelong Members of Action for ME are not members of Action for ME 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 ME. The Trustees are the members of Action for ME 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 ME).

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**).

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

Copyright
Unless otherwise stated, permission is granted to copy or quote articles from *InterAction* for non-commercial purposes, provided appropriate credit is given to the author and *InterAction*, including Action for ME's website address. Note that this does not apply to photos or cartoons for which permission must be sought prior to reproduction.

Editorial board
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.

Design and print
Designed by Ninepoint www.ninepoint.co.uk
Printed by Warners Midlands Plc www.warners.co.uk
Library photographs (posed by models) from www.shutterstock.com or www.canva.com

Registered office
Unit 2.2 Streamline, 436-441 Paintworks,
Bristol BS4 3AS
Registered charity in England and Wales
no. 1036419.
Registered in Scotland no. SC040452
Company limited by guarantee, registered in England
no. 2906840

President: Clare Francis MBE
Vice-President: Martin Arber
Founder: Sue Finlay
Patrons: Lord Bragg, Julie Christie, Sarah Dorin, Philip Mould OBE, Professor Anthony J Pinching, Lord Puttnam CBE and Alan Cook CBE
Honorary Patron: Ondine Upton

Ninepoint

This publication is printed by Warners 01778 395111

Giveaway

Win this luscious giftbox!

For the winter season, we're giving away a mindful letterbox gift, which includes a mindful colouring book, a pack of colouring pencils, a bar of chocolate, a face mask and other treats.

The perfect de-stress, unwind and relaxation box!

How to enter

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

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

The deadline for entries is Monday 6 January 2025.
Good luck!

Terms and conditions
The Promoter is Action for ME, Unit 2.2 Streamline, 436-441 Paintworks, Bristol BS4 3AS.
Draw closes at midnight on Monday 6 January 2025. The winner will be notified via telephone or email.
Please note contents of the gift box may vary from what is pictured above.
The sending of the prize will be confirmed by Action for ME.
Entrants must be 18 or over.
Winners may be required to take part in or co-operate with publicity. Winners agree to keep confidential any knowledge about Action for ME charity, its organisation and its personnel received by them as a result of the free prize draw.
No cash alternative is available and all prizes are non-transferable and non-refundable. Prizes are not for resale and cannot be used for commercial use or use in further promotions.
The prize winner will be selected at random by Action for ME. Their decision is final in every situation and no correspondence will be entered into.
Action for ME will not pass your personal details to any other organisation without your permission, except for the purpose of awarding your prize if necessary.
Use of false name or address, ie. name by which the entrant is not usually known, will disqualify them from receiving any prize.
Action for ME reserves the right to amend these rules at any time.
Entering implies acceptance of these rules.

“I am not defined by ME”

Christmas is a very difficult time for Rose. Using her imagination helps her to cope with isolation during this period.

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.*

Finding distractions

Writing for me is a great distraction, especially when I use my imagination. I use the ME Friends Online Forum to express myself through ‘silly’ threads. I write scripts as they are cathartic and hopefully make others smile. I plan on another festive forum itinerary this year and, with help from the Forum Friends, I hope we have some Christmas fun.

My ambition is to write children’s books as I want to use creative writing to teach children. I have other books that I want to write as well. I am working on a novel about the neighbours – I am adding humour to my work, and it is therapeutic for me. Ultimately, I want to raise awareness on being bullied in the neighbourhood and living with an invisible disability.

Christmas Angels

The Christmas Angels project (p 38) is something I participate in every year. I think it is a wonderful project. Knowing you are connecting with others with ME is heartwarming.

Facing Christmas alone

I long for the day when I can say, “I am now with my partner, and he is making me Christmas dinner!” It is tough being alone. My ex left in November 2005. He said he left due to his depression about me having severe ME. We were so young.

Nonetheless, the past is gone, and I am welcoming a time when I can have a partner again. Not to be my caregiver; I will continue to have Personal Assistants (PAs) as they enable my independence. In hindsight, if I had PAs when I was with my ex then it would have taken the stress off our relationship. I am glad he is in the past.

I have evolved through the illness, the struggles, the constant challenges and I feel ready to share my life with a partner. I pray that will happen soon, as I have a lot to offer.

I am not defined by ME. I have worked hard to let go of all the emotional baggage from the past.

Christmas at Rose Cottage

The other day I thought “why bother?”, but today I received a parcel containing a Christmas robin that I ordered, and it cheered me up! Even though I have a heavy heart and long for my new family, I am not a bah-humbug kind of girl! I still love the sparkles – the decorations! So, with new Pixies (PAs) being recruited, I am hoping that I will achieve a cosy Christmas with some nice treats. I pray that my beautiful 20-year-old cat, Jera, will be well, and we can enjoy some special moments.

Being thankful

Being thankful is so important. Society takes so much for granted. Living with ME teaches us to focus on the small appreciations, because we have lost so much. It is through suffering and loss that we find such appreciation.

Thinking of others

I always think of the homeless and elderly people at Christmas and try to donate to their charities. There is a homeless charity in my area, and I plan on gifting them some Christmas decorations I no longer want. I also buy a homeless person a Christmas dinner every year online with the charity Crisis. I have no family to buy for, so this is my way of giving.

I wish you all a lovely, comfy Christmas. Remember to gift yourself with kindness and know it is okay not to feel okay – even on Christmas Day. Get comfy and focus on something that brings you joy, however small. Wrap yourself up in a cosy blanket and watch something nice on TV eating yummy treats!

Special thoughts to all who are very severely impacted with ME and bedridden. Love to you and your carers. You are all doing so amazingly well – stay strong.

If you want to make new friends with ME, please join me and the ME Friends Online forum at **www.actionforme.org.uk/MEFO** for some festive fun threads and support.

If you cannot get online, please know we are thinking of you.

Love, Rose x

Read Rose’s Christmas story overleaf

My song for the season

“My favourite carol at Christmas is *O Holy Night*. Every Christmas Eve I watch the version by Kristin Amarie on YouTube, as it is so beautiful and heartfelt.”

Rose

Elvis the elf

A Christmas story by Rose, dedicated to all those with ME and Long Covid.

It was December in Lapland. Year 2024.

All the Elves were extremely busy making and packing up the toys for all the children across the world.

Eric the senior Elf noticed that the young Elf Elvis was slacking and, he thought, not pulling his weight.

"Come on Elf, you need to get a wriggle on!" He pointed his fat finger to 24 December on the calendar, rolling his eyes in disapproval. "At this rate your shipment won't be ready until 2026!"

Elvis nodded weakly and muttered to his Elf-Self, "What on Elf is wrong with me?"

Suddenly he noticed his hands were trembling, as he tried to use the packing tape. He then felt too exhausted to lift the small box into the crate.

"Are you okay, Elvis?" asked Edna.

"No, I'm not," whispered Elvis. Suddenly he collapsed and landed among a heap of toy penguins singing *Jingle Bells*.

"Help!" said Edna. "Elvis has collapsed."

Eric and the Packing Elves rushed over and circled Elvis.

"Stop that noise, please…I cannot bear the noise. Please!" cried Elvis.

Santa was alerted and rushed over from his grotto. He picked up Elvis in his arms and took him to the ward on Sleepy Dust Corner, where the poorly Elves would stay to recover. "It's okay Elvis, I will make sure you get the best Sleepy Dust treatment there is!"

The Elf Doctor Ernest was very concerned about Elvis. "He caught the flu last month, Santa, the Real Elf Flu – not just a sniffle! He might have Post Viral Elf Flu."

Santa nodded from left to right and right to left and right again.

"I cannot let him get sicker. We need to find a cure," said Santa. He marched off to find Mrs Claus.

"But there is no cure… no cure for PVEF," muttered Elf Doctor Ernest.

Elvis cried, "The room is spinning, and Rudolph's nose is too bright for my eyes. I cannot stand it. My ears are burning and I feel as if I have bugs crawling on me. I am hot and cold at the same time. My body feels like lead. My thoughts are racing. My arms and legs keep twitching. I feel scared; I am too Elf-exhausted to sit up…what is wrong with me?"

Rudolph was very sad, because he could not shine his nose so bright as it would hurt Elvis. All the Elves had to tip toe, so the noise of their bells did not make a sound. Santa could only mime "Ho-Ho-Ho" and Mrs Claus could not wear her mince-pie perfume, as Elvis had sensitivity to smells.

It was very sad in Lapland.

The days, weeks, months and years went by, and Elf Elvis was still bedridden in Sleepy Dust Corner. "I may as well give up, Santa, feed me to the reindeer."

"I will not do any such thing, Elvis! The reindeer are vegan and besides, you must BELIEVE."

One magical moment, Santa felt some magic in his belly and the beautiful aurora borealis beamed down. The phone rang in the Grotto. It was from Professor Elf Heineken, who had been studying the DNA in Elves and why their bodies shut down after contracting Elf Flu.

"I cannot promise my remedy will work, Santa. So far it has only been clinically tried on Dutch Elves, but they have improved enough to wear their clogs again."

Santa jumped up from his chair in glee – with his bottom still stuck in the chair! He thought to himself, *Goodness, I need to tell Mrs Claus to not feed me too much. I am now stuck!*

"Yes, do come with this medicine, Professor," he said. "Elvis needs it as it is the first of December, and I know he would love to feel better for Christmas!"

Professor Elf Heineken arrived by Reindeer flight the very next day.

He gave Elf Elvis the medicine, which was to decode the impact of Elf Flu and recover from PVEF. Elvis coughed and spluttered on the first sip and then he slept for five days and had the medicine by intravenous Elf Drip.

By 10 December, Elf Elvis managed to sit up in bed; then he could clean his own teeth. He managed to eat some Elf Porridge and, on Christmas Day, he could manage a mince pie.

Elf Elvis continued to recover and that was because he had lots of support, love, rest and, of course, the medicine.

Rudolph could finally shine his nose bright again. The Elves danced around Elf kitchen in celebration, whilst Santa ate more mince pies!

As the Elf clock ticked, and time went by, Elvis recovered enough to go ice skating at Elf-Rink and met his future wife, Elf Elaine, on the ice.

They then had Elf-Twins, Esa and Eetu. And lived a very Elfie life together.

Believe!

My song for the season

"There are two songs which, when I first hear them as the autumn passes by, always say to me that Christmas is fast approaching. One is *Fairytale of New York* by the Pogues and Kirsty McColl. The other is *Jingle Bells* which always takes me back to my years teaching young children – they always loved shouting the 'Hey!' bit at the end of each verse!

"But my favourite Christmas song, one I'd always stop to listen to, is *River* by Joni Mitchell. Not a traditional Christmas song but a beautiful one."

Tracey Taylor, *InterAction* volunteer proofreader

"My favourite piece of Christmas music is *River* by Joni Mitchell. Not the cheeriest, but in with all the cheesy, jolly tunes I like a little melancholy! I get so stressed and tired at Christmas. I often wish I did have a river I could skate away on…"

Sam Priestley, *InterAction*-on-audio volunteer reader

Reaction

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

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

Star letter

Using language to describe ME

I think Helen explained severe ME very well with the description "Severe ME is like dragging around a dead body and I'm both the dead body and the person dragging it around" (*Interaction* 117, p 21).

I often use the phrase "dragging myself round like a corpse" when asked how I'm doing. I also use the analogy, "Someone turned up the gravity!"

I like to stay positive and not feel like I'm moaning all the time, so I find dark humour and descriptive language (and swear words!) very useful to describe how I'm feeling without seeming too negative.

I also find it useful to have shorthand to use with close friends and family to communicate easily which state I'm currently in. For example, "struggling" means I'm able to get out of bed, but even the slightest activity is incredibly difficult, and "wrecked" roughly translates as "Don't expect me to be able to move much or string together a coherent sentence." They also understand that when I say I'm "good", "okay" or "not bad" I mean it in a purely comparative sense!

Nikki Pope
Age 46, ME for over 30 years

Editor's note: *Nikki receives an Action for ME goodie bag. Congratulations, Nikki!*

Getting help for co-existing conditions

Most patients living with long-term ME have multiple other undiagnosed conditions. These are often serious and ignored, or are just part of ME – or so we are often misled to believe.

I know this from my own experience to be true and many others know it as well.

Many are suffering for years or decades with conditions or symptoms that are often very treatable, but no one is really bothered as it's not them in serious discomfort or pain and it's "all in the mind" anyway.

If patients were properly investigated (most are not!) then these other co-existing conditions could be addressed and could make quite a big difference to many patients' standard and quality of life!

Most are left to rot and suffer often because of a faulty mindset or wrong belief, that it's all 'psychological'… and they can't be wrong (can they?)

Michael Dunn

Editor's note: *They indeed can be wrong and this is a big focus of this issue of* InterAction. *It is, as our CEO states on p 2, "time to believe". ME is a biological illness with devastating impact, affecting every individual differently, which is why it is so important for individual cases (including those with co-existing conditions) to be looked into with care.*

Lee Colligan, who walked the coast of Ireland in memory of his brother Josh, has raised over £26,000 for people with ME (see *InterAction* 117, p 33). Thank you so much, Lee!

Trouble tolerating medication and supplements

Thank you for highlighting osteoporosis in your magazine (letter from Rose Swales, *InterAction* 116, p 35). So many of us who are long-term severely affected with ME are potentially vulnerable to the condition. I first asked my GP about a DEXA scan (measures bone density) about 15 years ago. His reply was "I'll refer you for one if you want one but, if the test is positive, you'll never be able to tolerate any of the medication. If the test is negative, then it will be a very long and exhausting day for you to go to the hospital." At the time I felt he was right, so I didn't have one.

Fast forward 15 years: an X-ray for a very painful foot showed signs of osteopenia, so the young female GP encouraged me to be tested for osteoporosis. Now I have stronger help (to drive me to hospital and to push a wheelchair), I agreed to go for a DEXA scan and spine X-ray. The treatment is medication called bi-phosphates, which can have nasty side effects even for well people. [This includes] acid reflux.

My digestion is already poor and it has taken years to build up to eating as much as I'm currently eating. It is also necessary to have all dental work done before starting the medication as it can cause complications when having dental treatment. As I've been too ill to get to the dentist for years, apart from emergency appointments, and react badly to anaesthetics, then that is a no-go area. I'm sure there are many others in my situation with long-term severe ME and unable to tolerate any medication or supplements (even vitamins and minerals). Vitamin D and calcium are important for strong bones.

I was tested for vitamin D back in 2019 as I'd lost four teeth during the previous seven years. No one had ever thought to test my vitamin D levels, despite being bedbound/housebound for many years with little exposure to sunshine. My levels were very low, but the vitamin D capsules I was given caused such severe chest pains that my GP surgery told me to call an ambulance.

At A&E, when I told the young female doctor that I had long-term severe ME, she started on a rant: "My friend has ME. He is so ill now he can barely eat. It's appalling the way the NHS is treating ME patients. It's disgusting that my friend is so desperate for help that he is having to pay for help."

My cardiac tests were normal and, even though she was unable to give me any help or advice, I'm so grateful to her for that rant.

Kate Johnson

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).

This is CFS Art has launched an online exhibit showcasing artists living with ME.

The exhibit, founded by Zoe Wright, who lives with ME herself, aims to highlight the resilience and creativity of artists with ME, and seeks to change the invisibility that many people with ME experience.

To view art or submit your own work, visit the exhibit website: **www.thisiscfs.art**

The right to record

Guidance from the Department of Work and Pensions states claimants now have the right to audio record their work capability assessment for Universal Credit or Employment and Support Allowance (ESA) using their phone or other device (rather than sophisticated recording equipment). Claimants are required to advise the assessor, in advance of the consultation, that they will be making an audio recording.

Music making

"I play the piano when I'm up to it," says Action for ME volunteer Katherine Langford. "I used to play the violin, but had to give it up after I came down with ME as supporting the violin exhausts me quickly. I kept finding that by the time I'd tuned it and tightened the bow so I was ready to start playing, I had to stop as I needed to rest. Being able to just sit down at the piano and start playing instantly suited me much better. When I'm not up to sitting at the piano then sometimes I'll use an app to practice my sight reading or play music games on my iPad or phone."

It may be someone else in your life who likes to make music – and found it addictive! "During the first Covid lockdown my partner took up learning to play the ukulele," says Imogen Ward, our Information and Support Supervisor. "While I'm very glad he had something to focus on during that unsettling period, it's possible the situation is now getting slightly out of hand! The ukuleles in our house just seem to be prolifically reproducing. We now have six (I'm not entirely sure why one person needs six ukuleles).

"I'm proud of him, though, for having success with a musical instrument in contrast to my pretty abysmal track record. His dad (who plays the organ for his local church) always said my partner has a pianist's long fingers, and was a little disappointed that he didn't take to the piano. I'm glad he's found a musical outlet that he enjoys."

Do you manage to play an instrument – or enjoy listening to someone who does? Have you found other ways to enjoy music when ME makes it hard?

What Make Visible is making visible to me about ME

In a future issue of *InterAction*, Emily Skye will be sharing details about her relationship with the Make Visible app, designed as a patient research-led pacing tool to help conditions like ME.

Here she shares some initial thoughts about what she's learned so far.

It's been two months since I plugged myself in to find out how I am. It's been ten months since I ceased to be the 'me' I recognised.

I've learned that when I think something is too much for me, it is, but slightly more too much than I thought it was.

I've learned that pacing works for me.

I've learned that when I feel like I'm resting well, I am.

I've learned that what I think helps me to rest, does help.

I've learned that when I do too much so that my heart rate goes above 94, it's hard for my system to recover and PEM may strike.

I've learned that my symptoms and capacity fluctuate a lot during any day, week and month. This can confuse me and make it difficult to recognise when I'm declining and need to dial down, and difficult to recognise when I'm inclining and need to stabilise.

I've learned that my Action for ME physio does not find this so difficult to discern.

I've learned that if I do anything for too long, even if it's only slightly active, like sitting up watching TV, it's hard for my system to recover and PEM may strike.

I've learned that this is probably a long haul.

I've learned to listen much better to myself and to err on the side of caution, whilst enjoying what I can.

visible.

Staying in someone else's home

On p 13, our Information and Support team reflect on managing disbelief from loved ones over the festive season.

However, the act of staying in someone else's home is challenging enough in itself. Do you have any advice or tips on managing this that you are happy to share with readers? Please get in touch and let us know.

Here are some of our initial questions to consider:

- Do you have any special dietary requirements which you need to make your hosts aware of? Are there key foods and drinks that you'd like to take with you (especially if someone else will be doing the shopping)?
- Do you have sensitivities to particular types of toiletries, eg soap? If so, make sure you have your own supply.
- Do you have difficulty with light, noise or smells or any other allergies which you need to speak to your family about ahead of time? Are there key things such as black-out blinds, headphones, eye mask or ear plugs which could be of benefit to you?
- Have you ensured you have enough supply of medicines you need? Make sure that you pack these to take. You could use a pill box (with sections for days) if it would be helpful.

Some of the tips from our travel article in *InterAction* 114 may also be of interest: **www.actionforme.org.uk/ways-to-see-the-world**

How are you feeling?

Ellie Finney considers why this question makes her feel cross.

SPEED READ…
Ellie shares her experience of being asked how she is feeling – and how to manage this question. Sometimes it feels like she is having to reassure others rather than be honest about her own situation. She is determined to be more vulnerable in answering it over the festive season and to resist telling people she is 'fine'.

How can four words and a question mark be simultaneously the right thing and the wrong thing to ask someone with ME?

I think we can all agree that pretending someone isn't ill and never asking after their health is the wrong way to behave with a chronically ill person.

I get it. People don't know what to do or say, so they say nothing. But that doesn't make it okay.

It's a very real, very big part of my life and that should be acknowledged by those around me, but the gateway to talking about it is "how are you feeling?" and that question can make me very cross.

Talking to your inner circle

Parents can be tricky. They grew up in a different world, a much more silent one. Talking about issues can be seen as indulgent or even damaging. They can think bottling things up is best. I keep this in mind and tell myself they're doing the best they can. My mum goes heavy on the sympathy. My dad says, "it is what it is, just get on with it." Then they start talking about their own health issues. And people they know who've had a heart attack, even if you've never met or heard of them before. Cool.

My partner gets very sad when I'm ill. Recently, I had a horrible bout of vertigo and he kept saying, "are you okay?" while I was throwing up. I could not have been more visibly not okay. What he was really saying was: *can you comfort me? I'm upset that you're ill and I can't do anything to help you.* Which is the opposite to helpful because now I have to be sick every time I move *and* reassure my healthy boyfriend about it.

We discussed it (when the three-day vertigo circus was over) and decided on different language. Instead of asking me if I'm okay when I'm particularly bad, he now says, "I care about you." Because who can get annoyed at that?

Talking to your outer circle

My trick with people in my outer circle is to use rehearsed responses and metaphors. My favourite at the minute is, "Oh, you know, up and down. Like a rollercoaster I didn't want to get on and can't get off." I tend to make light of it, probably to soothe the listener and make myself look hard as nails, but that's not always helpful. Vulnerability is better, but harder. I can put on a good show of being fine and telling everyone I'm fine, then they're very surprised to hear the next day I'm so ill that I physically can't turn over in bed.

So, with the festive season upon us, I'm going to take my own advice and be more vulnerable answering questions about my health. The word 'fine' will not escape my lips, no matter how uncomfortable it makes people.

After all, it's more uncomfortable for me to be chronically ill than it is for them to hear about it.

My song for the season
"My favourite Christmas song is *A Spaceman Came Travelling* by Chris de Burgh. It's hard to say why I like it so much, I think because it's so random. It's an alternative telling of the nativity but with aliens – what's not to love?"

Ellie Finney

My song for the season

"My favourite line in a Christmas Carol is from *O Little Town of Bethlehem*:

How silently, how silently the wondrous
gift is giv'n!
So God imparts to human hearts the
blessings of His heav'n

"This speaks to me of the deep love of God for all people and the quiet work of the divine in the midst of our busy, noisy and, for so many, dangerous world. The vital importance of the inner life can get submerged, and silence can be isolating and lonely, but it's the life of the heart, the inner spirit, and all that feeds it which sustains everything else."

Ruth Lampard, chaplain

"As editor of this magazine, I'm the one who asked contributors, volunteers and other Action for ME team members to share their favourite seasonal songs – so it's only fair I should do it too. However, I am immediately challenged by which to choose! Like Katherine (p 28), I love *Carol of the Bells*. I've always had a soft spot for *God Rest ye Merry Gentleman*, especially mellow cover versions, such as the one by Aimee Mann.

"However, I also want to mention *Mary, Did You Know?* It gives me tingles. The lyrics were written in 1984 by Mark Lowry and the evocative, soaring tune by Buddy Green in 1991. I was chuffed that the acapella community choir I attend learned it for last Christmas, adapted from the version sung by Pentatonix. It was challenging to learn the parts, but being part of the gorgeous harmonies made it worth it!"

Lucy Cheesman,
InterAction editor

Have you enjoyed reading about people's festive favourites in this issue?

Find a compilation of the songs shared here: **tinyurl.com/IA118songs**

Angels make us feel included

There's still time to participate in our Christmas Angels project if you can get cards to us by **Monday 9 December**.

"It is a lovely idea to send and receive an actual physical Christmas card which can be viewed and enjoyed at any time," says one regular participant. "Through the sending of physical cards, [those with] severe ME are not excluded from receiving a card. Accessing a card on screen may exacerbate symptoms."

Other comments include:

"It really makes me smile each year and helps make me feel less alone on Christmas Day."

"It's a great initiative and I look forward to it every year. It's special to receive a card from a fellow ME patient and be able to spread some Christmas cheer myself by sending cards."

"It's wonderful – a lifeline if you're on your own, especially if you can't access screens."

Find the sign-up form on **www.actionforme.org.uk/christmas-angels** or contact us by post or phone, letting us know you want to take part, using the details on p 2.

Support at Christmas

Where to get information, advice and support over the festive season.

Mental health support

Mind
Information, signposting and support for anyone experiencing a mental health problem.
Open weekdays 9am to 6pm, except bank holidays.
Support line: 0300 102 1234
Email: info@mind.org.uk
www.mind.org.uk

Samaritans
24 hours a day, 365 days a year, whatever you're going through.
Freephone: 116 123
Email: jo@samaritans.org
Online chat also available.
www.samaritans.org

Sane
Emotional support and information for families, friends and carers over 16. Offers a textcare service to send messages of support.
Helpline open daily 4pm-10pm.
Tel: 0300 304 7000 (UK/NI)
Email: support@sane.org.uk
www.sane.org.uk

Shout
Free, confidential, anonymous service for anyone in the UK, via text.
24 hours a day, 365 days a year.
Text SHOUT to 85258
www.giveusashout.org

Campaign against living miserably (CALM)
Suicide prevention helpline.
365 days a year, 5pm-midnight.
Tel: 0800 58 58 58
Live webchat and WhatsApp also available.
www.thecalmzone.net

Breathing Space
For people in Scotland experiencing low mood, depression or anxiety.
Webchat also available.
Monday to Thursday 6pm to 2am, then Friday 6pm to Monday 6am.
Tel: 0800 838587
Textphone: 18001 0800 838587
www.breathingspace.scot

C.A.L.L
Listening line for Wales.
24 hours a day, 365 days a year.
Freephone: 0800 132 737
Or text HELP to 81066
www.callhelpline.org.uk

Lifeline
Northern Ireland crisis response helpline for people in distress.
24 hours a day, 365 days a year.
Tel: 0808 808 8000
Textphone: 18001 0808 808 8000
www.lifelinehelpline.info

Switchboard
Listening service for LGBTQ+ people via phone, email and instant messaging.
Helpline open daily 10am–10pm.
Tel: 0800 0119 100
Email: hello@switchboard.lgbt
www.switchboard.lgbt

Carers

Carers UK
Free advice, information and support for carers, including an online forum.
Helpline open weekdays 9am–6pm.
Tel: 0808 808 7777
Email: advice@carersuk.org
www.carersuk.org

Older people

Age UK
Free, confidential information and advice for older people, their families, friends, carers and professionals.
365 days a year, 8am–7pm.
Tel: 0800 678 1602
www.ageuk.org.uk

The Silver Line
Free confidential support for older people, run by Age UK.
24 hours a day, 365 days a year.
Tel: 0800 470 8090
www.silverline.org.uk

Cost of living

Money Helper
Money advice provided by the UK Government's Money and Pensions Service.
www.moneyhelper.org.uk

The Trussell Trust
Support with essentials like food, heating and toiletries.
Helpline open weekdays 9am–5pm, except public holidays.
Tel: 0808 208 2138
www.trusselltrust.org

Help for households
Government-led sites with cost of living advice.
tinyurl.com/H4HEngland
tinyurl.com/H4HScotland
tinyurl.com/H4HWales
tinyurl.com/H4HNorthernIreland

Young people

Childline
Free support for children and young people by phone and online.
24 hours a day, 365 days a year.
Tel: 0800 1111
www.childline.org.uk

Papyrus
Support and advice for under 35s having thoughts of suicide; and anyone concerned about a young person feeling suicidal.
24 hours a day, 365 days a year.
HOPELINE247: 0800 068 4141
Text: 88247
Email: pat@papyrus-uk.org
www.papyrus-uk.org

The Mix
Essential support for 11-25 year olds by phone and online.
Text THEMIX to 85258 (anytime)
www.themix.org.uk

Kooth
Online support for young people, including 1:1 live chat or message support with mental health professionals.
www.kooth.com

All of us at Action for ME wish you a Christmas and New Year filled with hope and kindness.

**Our last working day before Christmas will be Friday 20 December 2024.
The Action for ME office will reopen on Monday 6 January 2025.**

The Big Give Christmas Challenge 2024

Donate online between noon on Tuesday 3 December and noon on Tuesday 10 December and see your donation doubled!

See p 4 for details.

Still want to be an angel?

You can still take part in our Christmas Angels project if you get cards to us by Monday 9 December.

See p 38 for more.