Issue 121 • Winter 2025

Our vision is a world without ME

# InterAction

## You can make a difference

...with this year's Big Give p 4

ACTION FOR M.E.

Plus

Exploring the treasure map of DecodeME p 10
Have your say in our Big Survey p 20
Low-energy crafting ideas p 22

# Making an impact

Welcome to your new issue of *InterAction*, our magazine for Supporting Members. If you have recently joined us, welcome! If you are a long-time member, thank you for all your support.

At this time of year, we aim to make an impact with our annual Big Give Christmas Challenge campaign, where your donations are doubled between 2 December and 9 December (p 4). Please note these dates and spread the word! It's a fantastic opportunity to raise funds and awareness.

In this issue, you'll find our Big Survey. Our last Big Survey was completed in 2019 by over 4,000 people of all ages. Information from the survey will be instrumental in furthering awareness of ME. It has been designed to maximise the impact made by our fundraising, policy work and much-valued services. There is no obligation to complete every question. We can provide telephone support to people with severe ME (see p 20).

We know that research is important to our members. We've taken a look at the implications of the initial findings of DecodeME (p 10). The findings from the study provide a treasure map for researchers and scientists, telling them where to start looking in the quest to make a real impact for those living with ME.

Dr Audrey Ryback, now a familiar face in InterAction, shares information on her new study (p 14) and explains why replication studies are so important. Through PRIME (p 15) we'll be looking to build more research capacity for ME in the UK, forming partnerships and networks to enable this.

Alongside all this, there is a cosy feel to many of our features. We recognise that this festive period is difficult for many of you; we hope that these pages can act as winter warmers during this time.

With best wishes for the season from all of us at Action for ME. We look forward to the New Year and exploring new opportunities, together, to make an impact for all those affected by ME.

Sonya

Sonya Chowdhury
Chief Executive

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## 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. Please see back cover for festive opening times.

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

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

***InterAction* editorial enquiries only** (for membership please call number above)
To submit a letter or notice, give feedback or reply to a box number
Call **0117 937 6620** Email **interaction@actionforme.org.uk**

**If your prefer to send by post, please write to us at**
Action for ME, Unit 2.2 Streamline, 436-441 Paintworks, Bristol BS4 3AS
*(please note postal enquiries take longer to process).*

## Medical advice

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

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

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

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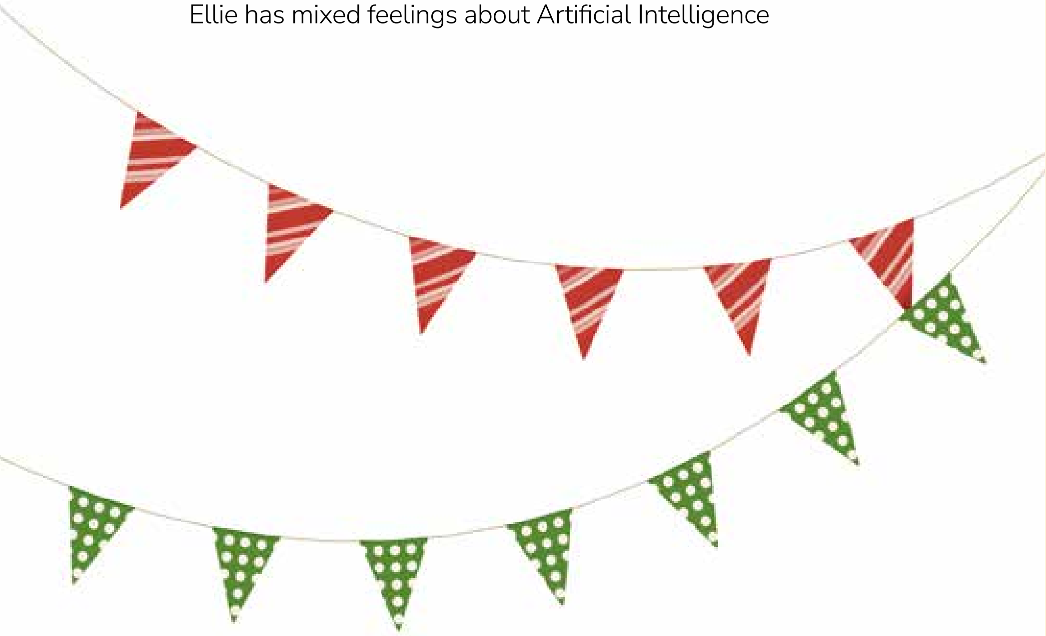


## Hot topics

- Your **Big Survey** is inserted into this magazine. Find instructions and information on how your data is used on p 20. Every little piece of information is valuable to us – please just do what you can.

- It's time for our **Winter Raffle**! Enter for a chance of winning £1000. See p 9 for entry details.

*Note: there is one freepost envelope in this issue. You can use it for both your Big Survey and your raffle entry, but please note the deadlines are different: the Big Survey needs to get back to us by 16 January 2026 and the raffle entry by 6 March 2026. Both can also be submitted online.*

- Researchers at the University of East Anglia say they have developed an accurate blood test to diagnose ME.

  This study could prove to be a useful starting point for future research into blood-based diagnostic biomarkers. However, there are limitations to what the researchers have called a "proof of concept" study, including its very small sample size.

  Professor Chris Ponting has pointed out that some claims made were "premature" and that the test needs to be fully validated by better-designed studies. Further research into this area of diagnostics is required before we can conclusively say that we do have an accurate blood test for diagnosing ME.

  Read more on our response and the study's limitations here: **bit.ly/news-UEA-test**

- There's still time to send and receive cards in our **Christmas Angels** project, as long as cards get to our office by Monday 8 December. See p 9 for how to register.

# Double your impact

## Help us improve lives and accelerate understanding with the Big Give.

It's that time of year again! The Big Give Christmas Challenge returns to Action for ME for another year.

Last year, your generosity blew us away. It helped us provide information and support, reduce the isolation experienced by young people with ME, educate healthcare professionals and accelerate research.

### Julie's story

It was especially meaningful to Julie. Julie became severely affected by ME in March 2016 following a nasty bout of flu. When her daughter sadly started struggling with debilitating post-viral symptoms mirroring ME, Julie reached out to us for specialist advice.

"I was overwhelmed by the advice and support I received. It makes all the difference when you know there is someone who understands and is fighting your corner."

This year, every donation made during the campaign will be doubled*, using our £67,500 match pot. Help us reach our target and raise a total of £135,000 to improve lives and accelerate understanding of ME.

Christmas Challenge

BigGive

### The money raised will:

- provide information, support and healthcare services to improve the lives of those affected by ME
- build on the success of DecodeME and drive further research to accelerate understanding of ME
- ensure the voices of people with ME are heard by Government.

**Give now and make double the difference.**

## How to donate and share

### Midday on Tuesday 2 to midday on Tuesday 9 December

### Online

Donate online at:
**bit.ly/big-give-25**

### By post

Send cheques made out to **Action for ME** to the address on p 2.

Write 'Big Give' on the back of the cheque.

### By phone

Call us on **0117 927 9551**

Choose the option for the Big Give Christmas Challenge.

### Spread the word!

**Tell your family, friends, neighbours or anyone who wants to see change for people with ME**. If you are online, **share our social media posts** and see your impact reach even further.

**Donate between Tuesday 2 December and Tuesday 9 December 2025 and your gift will be doubled!**

*Donations between £1 and £25,000 made through the Big Give website will be doubled immediately, providing there's money in our £67,500 match pot.

Donations received by phone and post will be doubled as long as funds remain in our £5,000 offline match pot. We encourage you to give online if you are able.

# "I felt heard, understood and validated"

## Francis found help thanks to donations from Action for ME supporters.

Before becoming ill with ME, Frances had never taken a sick day. She led a busy life as a secondary school headteacher, local Guide leader and mother of three. She was physically fit and took an active role in her local church and community.

Everything changed when she became ill, and Frances is now predominantly housebound and often bedbound.

"The effects of ME are profound – both physically and cognitively – and reach well beyond the person with ME, affecting family, colleagues and friends," says Frances.

Living with severe ME means that Frances now needs 1:1 support to carry out activities of daily living. She uses a powerchair and has had her house adapted to meet her physical needs. She had to take ill-health retirement from the job she loved.

In 2024, Frances discovered the Action for ME website. "The information and resources helped my understanding of my symptoms. I then contacted the Information and Support Service by telephone," she says. "When I received a call back, I immediately felt listened to."

Frances was able to access financial support to see our doctor with a bursary provided by donations from Action for ME supporters. The Action for ME doctor confirmed a diagnosis of severe ME. "This appointment was so important – although it left me exhausted, I was buzzing with positivity. I felt heard, understood and validated," says Frances. "I cannot understate how important this appointment was, giving me clear direction and hope."

With our doctor's help, she was able to make a successful pension application. "My initial pension appeal was unsuccessful," Frances explains. "Email correspondence with the Healthcare team was a massive support as I prepared to appeal the decision. I was successful on my second appeal, no doubt in part due to the detailed and thorough emails that I received from the team."

"Support from your services has given me time, understanding, current thinking and invaluable guidance in navigating the very unfamiliar situation that I found myself in," Frances told us. "ME threatened everything about me that made me *me* – my body, my mind, my relationships and my career. Action for ME has been there throughout, supporting me to hold these pieces together and to find myself again."

**Donating to the Big Give Christmas Challenge will allow us to help more people like Frances.**

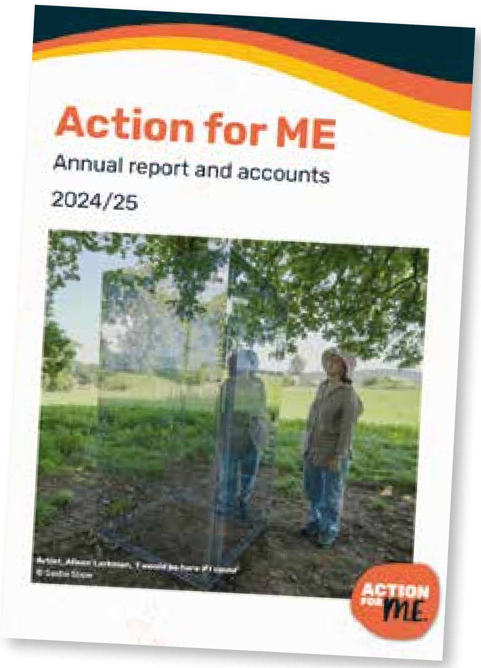
# Sharing news at our AGM

## Thank you to everyone who attended our Annual General Meeting (AGM) on Wednesday 17 September 2025.

The meeting was held online via Zoom with presentations from colleagues, plus a Q&A where we answered questions about our membership, services, research and campaigning work, as well as the wider ME landscape and our plans for the future.

Our team shared updates on the progress we have made on our strategy, in which we set out our ambitions as follows:

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



Action for ME
Annual report and accounts
2024/25

You can watch the recording of our AGM and find the link to our most recent Annual Reports and Accounts here: **bit.ly/AfME-AGM25-recording**

# APPG on ME

At the September 2025 meeting of the All-Party Parliamentary Group (APPG) on ME, the group heard directly from three people with lived experience as part of the Severe ME Inquiry.

Whilst attendance at the meeting was heavily impacted by TFL strikes and other parliamentary activity, all members of the APPG received an evidence pack containing a variety of recorded and written contributions from people with severe ME and/or their carers.

The APPG is very grateful for the people with lived experience who provided evidence as part of the Severe ME Inquiry. They, and we, recognise the importance of their voices being heard, but are also mindful of the post-exertional impact that likely followed.

For information and minutes from APPG meetings please go to: **appgme.co.uk**

> **"I'm committed to working cross-party to push for fairer policies and ensure the voices of people with ME are heard in Westminster."**
> **Siân Berry MP**

# A growing network

Our network of Parliamentary Champions keeps on growing! They are our 'go-to' individuals when engaging with Government and building support for our campaigns more broadly in Parliament and beyond.

### What do they do?

One of the most common ways Parliamentary Champions support our work is through tabling written or oral questions. We regularly share topical questions with them to ask, which are then responded to by the Government, placing their response on formal record and raising awareness of a specific issue.

They also support us in engaging with other parliamentarians and raising awareness of ME by sharing the briefings we provide them with and attending relevant debates.

### A broad church of Champions

At the time of going to print, we had a total of 21 parliamentarians from across the spectrum of political parties in our network, with Cat Smith MP, Sir Jeremy Hunt MP and Siân Berry MP joining most recently.

We will continue to ensure that parliamentarians from all political parties do more to support their constituents affected by ME, recognising the importance of cross-party support if we are to create positive change at policy level.

Tom Morrison MP

# Early Day Motion tabled for Delivery Plan

In September, Tom Morrison MP tabled an Early Day Motion (EDM) to discuss the final Delivery Plan on ME/CFS. EDMs are used to express opinions, raise awareness of issues or support specific causes.

The motion references the need for the Plan (and the work of everyone involved in its publication) to be welcomed by the House, but also to recognise that the Plan falls short in a number of areas, including:

- the omission of a dedicated ME research hub and strategic funding
- the lack of sufficient accountability for implementing services and updating medical education in line with the NICE guideline
- the limited attention given to severe ME and the absence of guarantees on specialist care provision
- the overall lack of robust accountability for the Plan's implementation, and provision of necessary resources to improve care, support, and outcomes for people living with ME.

Thank you to Tom and his office for working with us to bring these concerns to the House of Commons' attention.

Find the official text of the motion here: **bit.ly/EDM-Delivery-Plan**

Read our response to the final Delivery Plan on our website **bit.ly/afme-delivery-plan** or see *InterAction* issue 120, p 4.

# A new charity partnership

## Action for ME has joined as an affiliate charity partner of Our Future Health, the UK's largest health research programme.

As an affiliate charity, we'll support Our Future Health to shape their programme to ensure it serves the research needs of a range of health conditions and diseases, including ME.

"We're really pleased to welcome Action for ME as our newest affiliate charity partner," says Dr Raghib Ali, CEO and Chief Medical Officer of Our Future Health.

"We want our programme to benefit research into all health conditions, and with this new partnership, we can ensure ME is represented. Action for ME's expertise in supporting health research will help Our Future Health achieve our aims of helping people live longer, healthier lives."

"Our Future Health are revolutionising the battle against disease through their extensive and innovative volunteer network across the UK," says Sonya Chowdhury, our CEO. "We're delighted to be announced as an affiliate charity partner and look forward to advocating for people affected by ME, whilst supporting Our Future Health achieve their aims of helping people live longer, healthier lives."

*Our Future Health is a collaboration between the public, charity and private sectors, bringing people together to develop new ways to prevent, detect and treat disease. It is run in partnership with the NHS.* ***www.ourfuturehealth.org.uk***

\+
Our
Future
Health

## Action for ME's Advocacy Service

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

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

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

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

# Learn about ME project to continue

Our Learn about ME project has been awarded £33,366 of funding from the Scottish government to continue for another year.

Since 2020, Learn about ME has helped healthcare professionals in Scotland build confidence in recognising and supporting people with ME, signposting to Learna's free CPD-accredited learning module on ME, developed by Dr Nina Muirhead. Over 1,600 professionals have completed the module so far, and thousands more have engaged with Learn about ME podcasts and webinars.

**With this new funding we will:**

- Work with Dr Nina Muirhead, the ME Association and ME Action Scotland to update the CPD module with the latest research and information
- Create new podcasts and webinars
- Develop resources on ME and related conditions.

Our aim is to help more professionals understand ME, improving early recognition, treatment and care.

Listen to podcasts here: **www.buzzsprout.com/1717775**

# Medical Education Hub

Did you know that the World ME Alliance has launched a Medical Education Hub? It's designed to guide healthcare professionals to reliable, evidence-based resources on ME.

The aim is for the Hub to further develop and expand over time, making it as clear, user-friendly and accessible as possible across different languages and levels of cognitive impairment.

The pilot version of the Hub can be found here: **bit.ly/ME-Hub**

World ME Alliance

# Our UK-wide medical essay competition

## In 2025, we hosted an essay competition open to medical students at any Medical School in the UK. We were pleased to receive over 50 entries.

Last year's competition was open to students in Scotland only, as part of our Learn about ME project. Now, inspired by this and thanks to funds raised by our 2024 Big Give Christmas Challenge campaign, we have expanded the competition UK-wide. The aim is to increase knowledge and confidence in supporting patients with ME.

The essay title remained as: *What is your most important learning point about ME/CFS?*

We looked for essays that offered insight into what healthcare professionals should consider when supporting a patient who may have ME, with reference to its impact on their quality of life and level of functioning, and emerging biomedical evidence on post-viral illnesses.

The competition closed on 5 November 2025. The winner will be announced in the first week of December. We aim to publish the winning 500-word essay in a healthcare journal. We will also share the second and third placed essays on our website and in *InterAction* in 2026.

All students who entered were required to complete Learna's free StudyPRN CPD module, developed by Dr Nina Muirhead, to inform their submission.

# Still time to put on your wings!

## There's still time to participate in our Christmas Angels project, if you can get cards to our office by Monday 8 December.

Sign up here: **bit.ly/ChristmasAngels25** or contact us by post or phone, letting us know you want to take part, using the details on p 2.

"Christmas wouldn't feel right if I didn't send a Christmas Angel card as I've been involved in this project from the very beginning," says one participant.

We ask for people's date of birth on the form in order to ensure that all those aged 18 and under only send/receive cards from other young people.

"This is a great idea," says one younger participant. "I know people in my school give cards, but since I'm not well enough to be in school I never receive any or get to give any, so this is amazing."

# Enter our Winter Raffle

## ... to be in with a chance of winning £1000!

17 November 2025 – 6 March 2026

**Plus, five more prizes of £100 to be won!**

**£1 per entry.**

The money raised helps our work to secure meaningful change for people affected by ME. Help us increase our impact by sending the link or selling tickets to friends and family.

Enter online by scanning the QR code or visiting **bit.ly/winter-raffle-2025**

Or return paper ticket stubs by **Friday 6 March 2026** (you can use the same envelope as for your Big Survey response).

If you want to opt in / opt out of receiving ticket books in future issues of *InterAction*:

**Email:** fundraising@actionforme.org.uk
**Phone:** 0117 927 9551 (choose the fundraising option)
**Post:** Action for ME, Unit 2.2 Streamline, 436-441 Paintworks, Bristol BS4 3AS

**The draw will take place on Tuesday 17 March 2026.**

Hear from our Spring Raffle winner on p 35!

# X marks the spot

Decode ME
The ME/CFS Study

## …on the treasure map discovered by DecodeME.

**Speed read…**
DecodeME's landmark study has discovered genetic signals associated with ME. Finding genetic differences gives indicators of the biology of the disease. This shows scientists where to look when researching ME, its causes and, down the line, any future treatments. It also validates the experiences of those living with ME and aligns with how you describe your symptoms.

**DecodeME**
Co-produced by a dedicated team of researchers at University of Edinburgh, Action for ME and people with lived experience of ME/CFS, DecodeME was the world's largest biological study into ME/CFS. The study brought together scientific expertise and the voices of the ME community to ensure the research was relevant, inclusive and held to the highest standards throughout.

The success of the study shows what is possible with funding, collaboration and patient involvement. Its findings have had extensive coverage in the media in the UK and worldwide.

> "DecodeME is about you as a community"

In August 2025, the DecodeME team announced the first findings from their groundbreaking study. After years of preparation for the study, sourcing samples and then analysing results, the study's findings validate the experiences of the ME community.

Eight places in our genomes have been found where people with ME have genetic differences more often than the general population. (A genome is the set of DNA 'instructions' found in a cell.) These highlight specific areas to explore when researching ME – indicating biological drivers of the disease.

### The recipes in our genes

As DNA doesn't change with the onset of ME, the differences found across the genome reflect causes, not effects.

As a genome-wide association study (GWAS), DecodeME looked at nearly nine million of the DNA letters in their samples. This kind of study looks in those places where people often have different letters from each other (each different letter at a particular location is a 'variant').

A DNA letter is one of the four chemical 'building blocks' that make up DNA. Letters are written as A, T, C, and G – the alphabet of DNA. Just like words are made from letters in English, your genes are made from these DNA letters in different sequences.

Humans have three billion DNA letters!

The DecodeME study indicates that the genetic differences they found contribute to the risk of developing ME. (The increased risk is still statistically small and doesn't mean that family members will necessarily develop ME.)

DNA acts a bit like a recipe book, containing all the instructions needed for our cells to make proteins, which are critical for our bodies to function. Therefore, if we pinpoint genes where differences occur, we can also pinpoint proteins. These proteins generally do something specific. Hence, the study's findings point to the biology of ME. **It shows where causes of ME may be found.**

For example, results show that people with ME have subtle genetic differences in how their bodies detect and respond to infection – pinpointing **the immune system** as a place to look. This doesn't mean that the infection itself causes ME. However, it could mean that the way their immune system reacts to infection increases the risk of developing the condition.

They also found a genetic signal which has already been linked to chronic pain, reinforcing neurological contributions to ME – ie. the involvement of the **nervous system**.

This aligns with the experiences of those living with ME.

The genetic signals identified in this study were not the same as genetic signals that have been found to be associated with depression and anxiety.

### A foundation for future research

More needs to be done before these findings can lead to diagnostics and treatments. The signals cannot tell us whether someone has ME or not. ME has lots of genetic signals of small effect; these cannot be used to diagnose individuals.

"The genetic variants that have been identified in association with ME appear to increase the risk of developing the condition, but only to a modest degree," explains Action for ME's Research Manager, Daphne Lamirel. "The GWAS method only allows us to uncover common variants that occur widely within the general population, rather than a single rare mutation. This is very different from a single rare, deterministic mutation that almost guarantees the development of a disease."

In other words, each common variant on its own does not determine whether someone will develop ME. Neither does it mean that everyone with ME will have these genetic differences.

"Instead, these variants contribute to a slightly elevated susceptibility," says Daphne. "It is likely that these genetic risk factors interact with other influences, such as environmental exposures, to shape an individual's overall likelihood of developing ME."

Professor Chris Ponting explains that the chances of getting ME are affected by four things:

1) Genetic signals discovered by DecodeME
2) Genetic signals still to be discovered (in future research)
3) Non-genetic influences that exist in the environment (eg. exposure to infection)
4) How genes and environment interact with each other.

"Genetic signals are not perfect predictors of disease or non-disease," Chris explains. Neither does the DecodeME study tell us about whether people can or will recover – a further study would be needed for this.

The findings don't immediately impact treatment and testing of/for ME. DecodeME is about "establishing a firm foundation of evidence upon which we and others can build", says Chris.

DecodeME marks the spots where evidence needs to be found for future treatment and testing. Now what we need is for scientists all over the world to dig for this treasure.

The findings from the study are based on large-scale patterns across thousands of people with ME. They show that, on average, people with ME are more likely to have these differences than people without ME. These signals are about what we can see across populations, not individuals.

"DecodeME is not about the genetics of one person but of you all together," says Chris. "It's about you as a community. It's about everyone who shares your genetic variants and has ME."

### The start of the journey

For years, people with ME have been maligned and disbelieved. These findings provide credibility and validation for so many.

There is so much more to find. These results are just the start of a journey of discovery. Highly targeted studies are needed by scientists around the world.

"We need researchers whose expertise is relevant to these eight genetic signals to come forward and help us explain more precisely what DecodeME's signals mean," says Chris.

Genetic research is important because it gives insight into the causes of a disease and not the downstream consequences of the illness. Genetic evidence also increases the chance of successful treatments being taken up and developed in due course, because it shows us where to look.

Targeted intervention based on this evidence can make a big difference even when the target area itself is small. "The genetics tweak things," explains Chris. "They tell us where to go in and intervene. A drug will [then] go in like a hammer on a nut."

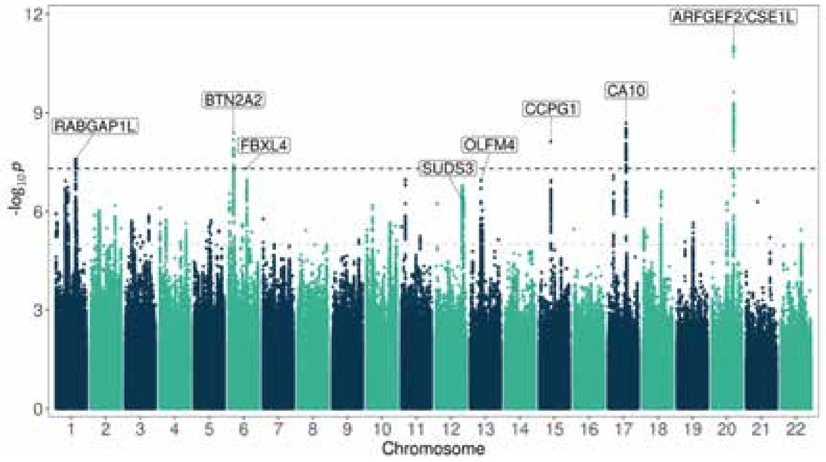
The ME community wants research. They want to understand and be understood – and they want this research to have an impact on their lives. They want hope. Although DecodeME is just a first step, it has provided a host of biological clues for researchers to follow up.

X marks the spot. It's time to dig for treasure.

*Professor Chris Ponting shared this as part of the DecodeME results webinar – see box on p 13 for link to the recording.*

"If I had enough spoons, I'd be sobbing. A thousand thanks to everyone on the DecodeME team who worked so hard for so long and so little to make this happen." Instagram user

For more community responses to the findings, see p 36



## Finding the plot

DecodeME looked at the DNA of 15,579 people with an ME/CFS diagnosis who met the study's tight research criteria. They compared it with the DNA of nearly 260,000 controls without ME/CFS. The analysis revealed eight genetic 'signals' for ME/CFS from the nine million variants studied. You can see these signals as the peaks ('skyscrapers') that stick up above the dotted line in what is called a 'Manhattan plot' above.

They show where there are groups of variants that are significantly different in people with ME compared to healthy people. These peaks, or signals, are each flagged with the name of the gene that could explain them. These signals will help to reveal the biology of the disease.

## Key terms

**DNA** – a molecule that contains your unique genetic code and instructions for making proteins

- Common DNA variant – a difference in DNA lettering that a number of people have in the general population (for example, 10 in 100 people might have the letter 'A' instead of 'G' in one place)
- Rare DNA variant – a difference only found in a few people in the population (for example, out of 100 people, perhaps only one has a 'T' at one spot, where most people have 'A')

**Genome** – the entire set of DNA instructions found in a cell

**GWAS / Genome-wide association study** – a study that looks at places in the genome where differences are expected/commonly found

**Proteins** – large, complex molecules that play a critical role in the body and how cells work

### Help boost ME research

Find out how to support future research by visiting **bit.ly/AfME-boost-research**

# FAQs

### What does this mean for my family?

Findings suggest that there are differences in risk for ME depending on the genes inherited. We know that ME sometimes runs in families, which suggests that genetics can play a role, but it's just one piece of a much bigger picture that includes things like infections and other environmental factors.

Having these genetic differences doesn't mean that someone will definitely develop ME, it just means their risk might be slightly higher.

### Does having these differences mean I will never improve or recover?

No. Having these genetic differences does not mean someone with ME will never recover or improve. These genetic differences may influence someone's risk of developing ME or how their body responds to certain triggers, but they don't forecast someone's future.

Many other factors also shape how ME affects a person over time, including biology, environment, support and treatment.

### What happens next with DecodeME?

Although the initial results of DecodeME are now available, we are not finished. We'll continue to analyse the genetic data, and we will update our scientific paper as needed before it is peer reviewed and published. We also have a detailed and valuable dataset from the second questionnaire that focused on symptoms, quality of life, treatments and therapies. We will be analysing and reporting on this in due course.

Our work doesn't end there. Approved researchers will be able to use the data of those who consented through our data access process, helping to catalyse new studies and discoveries.

Find these and other frequently asked questions at **bit.ly/DecodeME-FAQs**

## Lived experience at its heart

The Patient and Public Involvement (PPI) DecodeME Steering Group was made up of people representing groups or networks from the ME community.

They worked with the study's Management Group to put public involvement at the heart of the research project from start to finish, and to ensure the National Standards for Public Involvement were met. Members were embedded in every workstream of DecodeME.

Sian Leary has been on the PPI Steering Group for the past five years. "I am proud that this study was run differently, with lived experience at its heart," she says. "Proud that our community stepped up en-masse to participate, enabling this study to identify the genetic differences we have. Proud that we are at the forefront of scientific research into this debilitating illness. And proud that we are changing hearts and minds about this disease along the way."

Alongside celebrating the moment, Sian wants to acknowledge the intense suffering that people with ME continue to endure. "This study gives each of us validation that has too often been missing from healthcare professionals and those close to us."

"For DecodeME to show evidence validating ME as a physiological disease is enormously satisfying," says Claire Tripp, another PPI member. "My sense of pride and achievement at being part of this groundbreaking study is immeasurable. This solid scientific data from DecodeME brings new hope. I look forward to seeing where these discoveries lead for people with ME, and their families and carers."


Sian Leary

### Time to build

"It is essential that we capitalise on the momentum the study's successes have created. We aim to achieve this through prioritising fundraising efforts for studies such as Sequence ME & Long Covid, whilst also building on the improved collaboration that now exists within the ME and overlapping illness research fields, thanks to initiatives such as the Genetics Centre of Excellence."
**Roger Siddle, Chair of Trustees, Action for ME**

Read more about DecodeME and find blog posts here: **bit.ly/decodeme-study**

Watch the initial DNA results webinar here: **youtu.be/rsvr2e5N2tM**

## The treasure hunt continues

**We are still seeking substantial funding for an exciting new study, Sequence ME & Long Covid, which will look to find more of the genetic clues beyond what has been found by DecodeME.**

Genetic disease is inherently complex. To see the whole picture requires us to read the whole genome – in other words, the full recipe book!

DecodeME focused on parts of the genome where we most suspected we'd see differences but, should our quest for funding be successful, Sequence ME & Long Covid aims to look at the entire genetic code, using advanced whole-genome sequencing technology.

Where DecodeME looked at common DNA variation, Sequence ME & Long Covid will also look for rare variants. Common variants can collectively impact disease traits; rare variants are more likely to have significant impact on traits as individual variants.

There are also large changes in our genomes called structural variations, which cannot be seen in the DecodeME study method, but are visible to the sequencing method.

Through DecodeME, we have learned a lot about the genetic areas involved in the disease. If funded, Sequence ME & Long Covid will provide far more precision about which genes contribute to the risk of developing ME.

Read more: **bit.ly/Sequence-ME-LC**

# Looking for solid ground

## Seeking a starting point

### Dr Audrey Ryback tells us about her new replication study looking at blood markers.

Once again, I am performing a replication study of a previously published result. This time, I am working with Dr Ava Khamseh and Dr Sjoerd Beentjes to try and replicate their published findings of blood markers that were different in people with ME/CFS in the UK Biobank.

A blood marker is a molecule you can measure in the blood (such as a protein or a hormone). We are trying to find ones that might be different in people who have ME, that might one day help us develop a blood test to diagnose ME or tell us something about the biological processes of ME.

We are going to test whether the same markers are different between ME and controls on a completely different cohort of 88 people with ME (who have well-characterised ME) and 73 controls. We want to see which, if any, of the blood markers replicate. If some of the markers replicate, we want to understand how well they can predict whether someone has ME.

If we replicate and validate markers that can predict ME well, this could be a starting point for developing a blood test for ME.

*Audrey's study is part of the first Clare Francis Postdoctoral Research Fellowship awarded by Action for ME. The study is also being funded by ME Research UK.*

Audrey Ryback

## The value of replication

### We asked Audrey to tell us more about replication studies and why they are a core part of the scientific process.

**What is a replication study?**

A replication study is a study where we are testing whether we get the same result as a previously published or reported finding on a new set of samples or data. They are so important, and such an over-looked part of science!

**Why do we need to do the same thing again – shouldn't we be looking at new things?**

You should only ever believe a scientific finding if you see the same result more than once.

We absolutely need to look at new things ('discoveries'), but it is also essential that we replicate any studies that look like they show promising biological differences in ME.

A standard way to establish whether a new discovery is true is to ask the same question again, on a new set of samples.

If you see the same result again in the new study, you can be much more certain that the original finding is really true. This is because you are very unlikely to see the same result by chance more than once.

Replication is a core part of the scientific process. As scientists, we want to establish the facts, and replication gives us confidence that a discovery is true and generalisable. It puts us on solid ground to plan follow-up work.

Replication studies are especially important in ME research because ME does not receive enough research funding. This means that many studies have very small sample sizes. Small sample sizes make the scientific findings less reliable.

In studies with small sample sizes:

1) We are less likely to discover true differences

2) The results are more prone to random fluctuations (eg. seeing differences by chance, or over-estimating the magnitude of differences)

3) The results might not reflect results from the broader population, which make them less generalisable. This is an important limitation, because we are most interested in discovering biological differences that are true for the majority of people who have ME (and not just a small group of them).

> "Replication gives us confidence that a discovery is true"

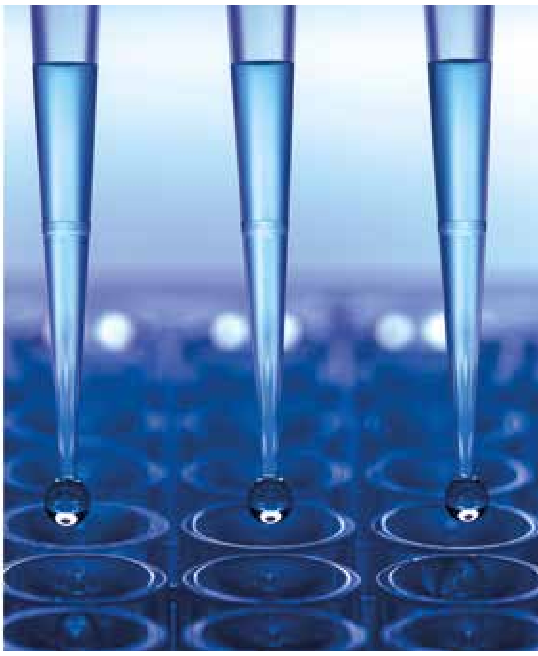
### What does it mean when a result is not replicated?

A result that is not replicated means that the original result is not very robust. It doesn't necessarily mean it is not true (eg. it was seen by chance), but it does suggest that it may not be generalisable or that the result is only seen sometimes, or under certain conditions.

### Why is a 'null result' still important in the world of research?

Null results tell us which research avenues are unlikely to help answer our biological questions. They help us rule out hypotheses (eg. statements predicting the outcome of a study), which is just as important as discovering new things.

It is especially important that null results are published and communicated to the research community, so other researchers do not put time and resources into following a hypothesis that is unlikely to lead us to strong answers, because the results do not replicate.



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# PRIME kicks off

The PRIME project started with a kick-off meeting with the academic co-leads, the Action for ME team and Patient and Public Involvement (PPI) members.

The group started discussing ideas for the three pillars of:

1) 15 new study partnerships
2) research networks
3) and a PPI pool.

They talked about the symposiums and workshops that will be organised as part of the project (topics, audience, etc.), strategies to grow the PRIME network and what might there be in terms of 'easy wins' (eg. for collaboration and funding).

They also talked about the current needs of researchers/academic co-leads (such as when developing applications), and the need to ensure the PPI pool is accessible and inclusive for people from different demographics and levels of severity.

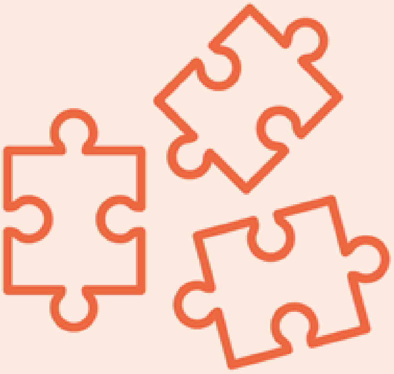
This is just the beginning of the project. Work will continue on the PPI pool (development of the platform, dissemination strategy, training) in collaboration with the prime PPI partners. We expect to start recruiting members of the public by Spring 2026.

Updates on key developments will be shared with the community via our website and newsletter.

*Sign up for our e-newsletter here:* ***www.actionforme.org.uk/#newsletter***

### What is PRIME?

PRIME (building infrastructure for Patients, Researchers and Industry for ME/CFS) aims to build research capacity for ME in the UK. Read more about its aims at **bit.ly/AfME-news-PRIME** or see *InterAction* issue 120, p 13.



### Correction

In our *Pieces of the puzzle* research article in the print edition of issue 120 (p 14), we wrongly attributed the wording to Katharine Cheston, when it should have been **Kate Firth** – apologies to Kate and thank you for providing us with such a helpful commentary on recent research papers. This has been corrected on the PDF version, which is available to members.

View recent PDFs of *InterAction* at **bit.ly/AfME-InterAction-online**

# Proper understanding is essential

## Katherine Langford provides an update on the ME Guidelines for the British Psychological Society.

**Speed read...**
ME is not psychological, but therapy can be helpful in processing and adjusting to the impact of life-altering illness. It's important to ensure that psychologists understand, among other things, that ME is a biological condition. Katherine is a volunteer working on guidelines for psychologists working with people with ME. She's recently been working on the young people's section of the guidelines. Her next job is organising feedback groups for other sections – including on severe ME.

The British Psychological Society (BPS) is collaborating with Action for ME and the ME Association to produce guidelines for psychologists working with people who have ME. I am a volunteer working on the guidelines as Action for ME's representative. It's my role, along with Russell from the ME Association, to ensure that people with ME have an input into these guidelines. We both have had ME ourselves for over 20 years.

ME is a biological condition. While we don't know the exact causes yet, we know that it has a physical origin, not a psychological one. Research such as DecodeME (see p 10) proves this.

It can, however, be beneficial to speak with a psychological professional for help processing the significant change brought on by a life-altering illness, addressing common emotions such as grief, loss and anger.

It is essential that psychologists have a proper understanding of ME, particularly that it is a physical condition. Treating ME as though it is psychological is extremely damaging.

### Unfounded accusations

Recently, I have been working on the young people's section of the guidelines with a team of psychologists.

This section will include topics such as families being accused of Fabricated or Induced Illness (FII), where a parent or carer exaggerates or deliberately causes their child's symptoms. This can result in Social Services being called in inappropriately and the family having to deal with the threat of the child being taken into care on top of having to already deal with a debilitating illness.

A survey by Action for ME (2017) found that one in five families of young people with ME have faced unfounded accusations of FII, abuse or neglect, leading to child protection referrals. This figure is considered to be much higher for those who have severe or very severe ME. Psychologists should be well placed to help families in these circumstances by helping to educate other professionals that ME is not a psychological condition.

### Organising feedback

My next job is organising feedback groups for different sections from other people who have ME.

We are looking first at the section on severe ME, so that we can give a group of people with severe ME as much time as possible to give their feedback. We'll also be providing an audio version of the section. We're doing our best to make it as accessible as possible.

An exciting development is that we now have an assistant psychologist, Sophie-Anne, to help process more of the survey that asked what you want included in the guidelines. We had an overwhelming response.

Our survey showed that there was a relatively even spilt between people finding seeing a psychologist helpful or unhelpful. Sophie-Anne has been looking at why that is. Helpful psychologists listened without judgement, validated the person with ME, believed them and taught practical tools and coping strategies.

Unhelpful psychologists treated ME as a psychological condition, used inappropriate assessments and had a lack of understanding and condition-specific knowledge.

### Future involvement

We've also been having meetings about what future Expert by Experience (people who have ME or their carers) involvement will look like. We're organising groups to feedback via email and are planning to arrange more focus groups (we've had two so far). When the guidelines are nearer completion, we're going to have a webinar sharing what's going in them, before they're published.

We want the process to be as transparent as possible, so if you have any questions then you can get in touch with me: **katherine.volunteer@actionforme.org.uk**

*The guidelines will be published in 2026. Watch this space for updates.*

## The impact of ME

Feedback from the survey for the guidelines shows the impact of ME on people's mental health.

"We feel robbed of our careers, relationships, mobility and generally of a normal life. Of course, we have difficulty in adjusting to our 'new normal'. We grieve for our former selves and we need people to acknowledge and understand that loss."

"As ME patients we already encounter disbelief from people in general, even from our own family and friends. To have anyone in healthcare then treat you with suspicion further lowers your sense of self worth. Creating an environment of trust is paramount. As ME patients we are aware that it is 'passed off' as a psychological condition and so we often hide the mental impact of the condition."

"I am actually too unwell for any sort of therapy, I don't have the energy to spare to try and feel better… I wish that something could have helped me before I got to this stage."

"Most of us have gone from being very active, hard-working people with busy working lives to a shadow of ourselves. We are filled with feelings of guilt and failure because we believe we have let down our loved ones, friends and work life. From my experience in dealing with professionals, they don't recognise the severity of the impact that this has on us."

"There is a huge amount of grief of losing the life and person you used to be. There is anger at the medical community for its dismissal of the condition and lack of research into its cause. There is very little hope for complete recovery and years before any treatment may be found. All we can do is do our best to focus on any positives in our lives and be grateful, as best we can, for little things. We may never be able to accept our condition fully but having tools to try and focus on positives is the only antidote to this I have found. It needs to be ongoing and sometimes we may be more successful than others in doing this."

We'll be reflecting further on the impact of ME on our mental health in a later issue of *InterAction*. Do write in and share your thoughts using the contact details on p 2.

# Collaborating to campaign

**Action for ME is collaborating with other charities and alliances who represent people living with a neurological condition.**

### Speed read...

Anyone can be affected by a neurological condition. This was emphasised by an awareness campaign in March. Neurological alliances in the UK and Ireland, with their respective charity members, also took part in 2024's *My Neuro Survey*. ME was a frequently reported condition. The survey showed how difficult it is to live with a neurological condition and access help. It also highlighted the economic impact and the burden on carers.

Around 1 in 6 people in the UK are living with a neurological condition, yet only 8.9% of healthcare research expenditure is investing in research in neurological conditions.

Although there are over 600 known conditions, there is much that we don't know about neurological conditions and how they affect the people who experience them.

This certainly reflects the situation faced by people with ME.

The UK neurological alliances, representing the four nations, came together in March 2025 to campaign for increased funding for research in neurological conditions as part of Brain Awareness Week, an annual event.

The campaign offered member charities resources to raise awareness and call on the UK governments to invest in research into neurological conditions. It highlighted that anyone can be affected, at any age or time, by a neurological condition.

## My Neuro Survey

In 2024, neurological alliances in the UK and Ireland, with their respective charity members (including Action for ME), took part in a patient experience survey of people affected by neurological conditions: *My Neuro Survey.*

Over 10,000 people including adults, children and carers took part. It included a specific survey aimed at carers.

Many of the alliances produced their own report based on their national responses. In two of these reports, ME was the most frequently reported condition. In England, people with ME made up 17% of the survey and in Scotland, 20%.

The survey covered a range of different topics, including diagnosis, treatment, day-to-day life, hospital care, mental health, financial support, social care access and more.

This spread of conditions and topics offers useful insight into understanding the impact of living with different neurological conditions and how well services are working to support people and reduce the impact of their condition.

## Key findings

The findings varied slightly from nation to nation but generally the key findings were:

1. Most adults say day-to-day life is difficult to cope with and their condition has an impact on their mental health
2. Adults find it difficult to navigate systems and get support; many feel unsupported by the healthcare system
3. The economic impact of neurological conditions is substantial
4. Carers find daily life challenging and many are at breaking point.

All the alliances and individual members will use the results of the survey to advocate and influence governments and services to act to address the key priorities identified by the survey.

### Individual reports

Read the reports produced by the different alliances:

The Neurological Alliance (England): **bit.ly/NS-England**

The Neurological Alliance of Scotland: **bit.ly/NS-Scotland**

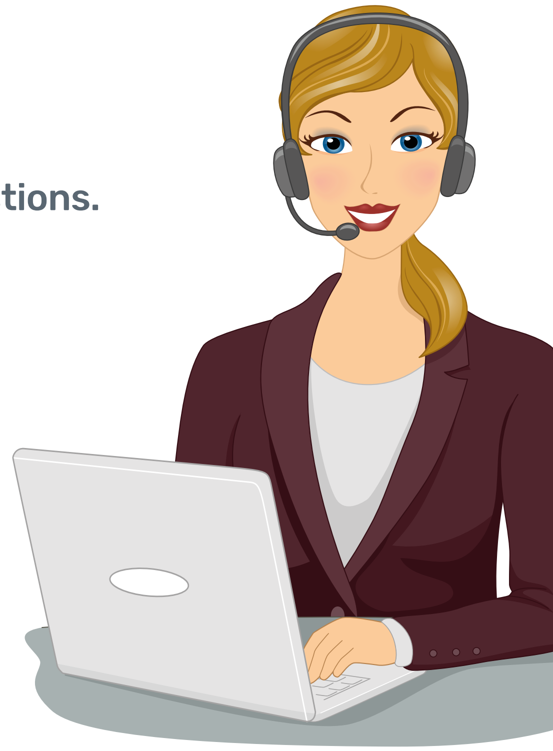
Neurological Charities Alliance (Northern Ireland): **bit.ly/NS-NorthernIreland**

Neurological Alliance of Ireland: **bit.ly/NS-Ireland**

Wales Neurological Alliance also took part in the survey.

# Dear team

## Our Information and Support team answer your questions.



**Q.** I am housebound with ME and feel extremely lonely. I don't have any local family to support me and friends have drifted away since I got unwell. I have carers come in but am too unwell to hold a conversation or small talk, as I might have done in the past. It sometimes feels like the 'real me' is locked away and my world can feel really small. Have you got any ideas on how to feel less alone?

**A.** This is huge part of having a chronic illness and something people without one find very difficult to understand. Whilst I have a few suggestions on how you might connect with others/the outside world, these will depend on your individual symptoms and what feels manageable without causing those symptoms to increase.

It's hard to get the balance between seeking an emotional boost for your wellbeing and knowing the impact that will come after. I've included some ideas below, with the caveat that these will depend on how your ME impacts you and what you are able to do/access:

- Connecting with others with ME. Some options might be to join our ME Friends Online forum (depending if you are able to use computers/screens) or to listen to some of our previous *InterAction* articles on our Action for ME SoundCloud site.
- Getting involved in projects such as Christmas Angels (see p 9).
- Requesting a penpal via our *InterAction* noticeboard. This could require as much or little correspondence as you feel able to do, but it may help to know you have an ME ally out there.
- Connecting with nature – can you see nature from your window? A little time each day to sit near sunlight and take in the outside/spot for nature, if able, may give some respite from feeling that your world is within four walls. Dependent on what you are able to do, if you have a garden you could ask your carers to help you out to spend a little time seated there once a week, or however often you can manage.
- Finding out if there are local befriending services you could connect with. This is something our Information and Support team could help you research.
- Listening to a podcast or music.
- Accessing one of our mindfulness sessions for people with ME. Ask our team if you would like further information on these.
- Reach out to services such as Samaritans and Shout for 24/7 support (find a full list on p 39, the inside back cover).
- You may be interested in accessing counselling or chaplaincy via our Healthcare Services. These are paid-for services, but they can offer bursaries where appropriate.
- Remember the little things that make you feel something. This can be extremely difficult when the things you used to enjoy feel out of reach and this will very much depend on what impacts your individual symptoms. For some, it might be a cup of tea and a favourite treat, for others, a favourite TV series under a blanket or listening to favourite music. For those who cannot access any of these things, this is incredibly hard and there isn't, at the moment, a solution.

These are only words, but know that there is a huge ME community who sees you, understands and longs for better support and better outcomes for people with ME. Many felt that the recent initial results from DecodeME offered some validation and hope for further research and possible answers (see p 10).

Please do reach out to our Information and Support team for more specific information or to help look at local support services in your area.

### Signposts

Get in touch with our Information and Support team using the contact details on p 2.

Our healthcare services:
**bit.ly/AfME-healthcare**

ME Friends Online forum:
**bit.ly/AfME-MEFO**

*InterAction* online (includes link to SoundCloud):
**bit.ly/AfME-InterAction-online**

# Welcome to our Big Survey

**This page explains what the survey is, why it's important and how we will use the thousands of responses to inform our work and services.**

Action for ME runs its Big Survey every five years. The data produced informs all aspects of the charity's work to improve the lives of people with ME. The aim of the 2025 Big Survey is to illustrate the impact of ME and the current challenges faced by people with ME.

**If you are willing and able to complete the survey online, we'd be very grateful as this would help us save time and resources. You can find a link at bit.ly/AfME-BigSurvey-2025**

We have a separate survey for children and young people with ME, which can be accessed online via the link above.

If you prefer to use a paper version, please complete the questions on the following pages and send it back to us by **Friday 16 January 2026**. You can use the freepost envelope included in the magazine for this. *Note: this deadline is for responses sent by post. If you complete the survey online, you have until 27 January 2026.*

## About the survey

This year, the survey is being produced in collaboration with Durham University's Institute for Medical Humanities. Postdoctoral researcher Dr Katharine Cheston will work with Action for ME's research team to analyse the survey data.

The version included with your magazine is for adults in the UK who live with ME or who live with long Covid and experience ME symptoms (debilitating fatigue, post-exertional malaise, sleep disturbance, cognitive difficulties), whether or not they have a diagnosis of ME.

**If you are unable to fill out the survey, a carer is welcome to fill it out on your behalf.**

## The questions

The survey has 46 questions, but not all may apply to you.

We know that this is a huge undertaking for people with ME and long Covid. Each question has been carefully designed to give us meaningful data that strengthens our advocacy. The survey has also been co-produced with a Patient and Public Involvement (PPI) group drawn from the wider ME and long Covid communities (including, but not limited to, members of Action for ME).

**Every question on this survey is optional**. You can skip questions and whole sections. Every piece of information you give us is valuable and is hugely appreciated.

Please note that the survey asks about topics that may be upsetting, such as experiences of healthcare.

## Your data

By completing the survey, you are giving your consent for your anonymised responses to be used by Action for ME, and its research collaborators, in their work. This includes using anonymised quotations from the text shared in the survey, in which any identifying information will be removed. Survey data will be used in outputs, which may include (for example) policy reports, publications, briefings, presentations and factsheets.

**For more information on how we will use your data, see p 21.**

No identifying information will be shared, at any point, and all data will be handled in line with data protection best practices. See our privacy policy at **www.actionforme.org.uk/privacy-policy** for more information on how we handle your personal data.

We understand that recalling your experiences may bring up some strong emotions and/or difficult memories. If you need support, please reach out – you can find a list of organisations on page 21.

Thank you so much for your time and energy.

**Every question is optional. Every piece of information you give us is valuable.**

If you need support filling in the survey, or if you have any questions about the survey and how your data will be used, please contact Action for ME's Research Team: **research@actionforme.org.uk**

If you have severe or very severe ME and cannot fill out the survey, we can provide telephone support. This would involve completing the survey with a member of our team, over the phone. To arrange this, please email us using the email address above or phone **07548 558 921** – we will get back to you as soon as we can.

# Thank you so much for taking part in Action for ME's Big Survey 2025.

We are very grateful to you for spending your time and energy in this way. The information you have provided will inform our work to improve the lives of people with ME.

Paper versions of the survey need to be sent back to us by **Friday 16 January 2026**. You can use the freepost envelope included in the magazine for this.

We look forward to sharing the results of our Big Survey with you in Spring 2026, online and in *InterAction*. You can also receive updates by subscribing to our free email newsletter. The form to complete is at the bottom of every page on our website. This link will take you to the form: **www.actionforme.org.uk/#newsletter**

## How will we use your data?

Data from the Big Survey will support and inform Action for ME's research and influencing work, our fundraising, and our support and healthcare services.

It will help us better understand the challenges faced by the community, raise awareness of the impact of ME and call for urgent change.

Anonymised survey data will be shared with Dr Audrey Ryback, University of Edinburgh, who will use the data to study the age of ME onset, triggers and heritability.

If you provide additional consent and opt in, your anonymised survey data may later be shared with other researchers studying the impact of ME and with other organisations working with people with ME and long Covid.

Applications to access the anonymised Big Survey data, of those who provided their additional consent, will be reviewed by Action for ME's Research Subcommittee.

## Managing emotions

If taking part in this survey has raised any issues for you, and you feel that you need to talk to someone about how you are feeling, please contact one of following organisations, by phone, email or text. You are not alone.

**NHS 111**
Call 111 and choose option 2 for a trained mental health professional to assess your needs, provide advice and self-care tips, or signpost you to other local services.

**Samaritans**
Call **116 123**, at any time to talk to someone about how you are feeling. Trained volunteers listen without judgement, without giving advice.
Email **jo@samaritans.org**
**www.samaritans.org**

**Campaign Against Living Miserably (CALM)**
Call **0800 58 58 58**, 5pm to midnight every day.
You can use a Live Chat service via the website.
**www.thecalmzone.net**

**Shout**
For urgent mental health support, text SHOUT to **85258**.
This service is open 24 hours a day, every day.
**www.giveusashout.org**

*These, together with more support organisations, are also listed on p 39 (inside back cover).*

For information, support, resources and signposting to help you navigate life with ME, you can contact Action for ME's Information and Support Service. See p 2 for contact details.

If you have any questions about the survey itself or how we will use your data, please contact **research@actionforme.org.uk**

**Data from the survey will help us better understand the challenges faced by the community, raise awareness of the impact of ME and call for urgent change.**

# Exploring creative play

## Germaine Hypher shares low-energy ideas for expressive arts and crafts.

**Speed read...**
Germaine uses artistic expression and useful crafts to give her a sense of comfort and wellbeing while living with ME. She enjoys tangible crafts such as knitting and patchwork; playing with colour with various media; doodling and collage – among other things! She also finds expressive writing helpful. Her creative play enables her to explore her feelings and identity.

Having lived with ME since young childhood, I have often felt isolated, frustrated and bored. Days drag when having to rest and endure, while slipping through empty seasons at a remarkable rate. I've had to teach myself how best to pass this time, comfort myself and create a fulfilled life. Whenever possible, I've done this through arts and crafts.

### Playing with texture, colour and shape

Chronic illness can bring grief, anxiety, depression and loss of personal identity, but some relief can be found in the varying elements of different arts and crafts.

Occupying myself with the gently repetitive actions and soft textures of knitting, crochet, cross-stitch, embroidery and English paper piecing patchwork, I have felt calmed. Indeed, crafts like these have been demonstrated to affect the body in a way similar to meditation.


Germaine Hypher

I have also felt time and symptoms temporarily slip away when playing for a few minutes with soothing or uplifting colours via pens, pencils, pastels or watercolours.

The emphasis here is on playing, rather than pushing towards any goal, and staying within my safe energy limit.

Manual dexterity or stamina aren't vital, just the desire to express myself through colour and/or loose mark-making. Watercolour pencils, or brushes with an inbuilt water reservoir, can make such activities easier to navigate when propped up in bed or on a sofa.

Meanwhile, a pile of magazines and scrap papers for collaging can provide both inspiration and materials for a lap-based craft that takes very little cognitive effort when I'm happy just to see where the pictures take me. When a touchscreen has been easier, I've enjoyed using a digital collage-making app, like Dada.

Simply a pen and a desire to doodle can lead into the world of zentangling (doodling with intricate patterns, many of which can be sourced online for ideas) or reverse colouring books (these contain pages of colourful abstract images on which to draw original outlines and designs).

Then there are the possibilities to be had with flower arranging, origami, polymer clay that hardens in a kitchen oven, and so much more.


*The Nature of My Wheelchair*, pen and pencil drawing by Germaine Hypher

Through expressive arts and useful crafts, I find myself exploring my feelings and identity as a disabled person. By making tangible items, I affirm my existence and my intrinsic value even amidst layers of symptoms. I can even feel closer to activities I long to partake in by depicting them creatively, and nurture connections with others through homemade gifts and cards.

### When crafting feels too much

Some crafts have proven too much for my body, but there is a plethora of creative pursuits to choose from as well as disability aids, craft tools and hacks that can make a previously inaccessible activity more approachable. Primarily, I aim to stay within my energy envelope. A few minutes of creative exploration can be the foundation of a sustainable routine that builds to a completed project or sense of satisfaction over time.

When too unwell physically to play, I have found my creativity focusing on problem-solving, alternative speech (the word substitutions that appear when brain fog thickens can epitomise creativity!) and imagined adventures.

Creativity is an abundant tool when met with curiosity and enthusiasm.

*To see more of Germaine's creations and find out about her new book, visit* ***www.germainehypher.weebly.com***

*This collage is created from an old calendar picture, scraps of a map, torn sections of a vintage magazine, tissue paper, and a watercolour attempt at a flower and leaves that didn't work on the page – so I tore it up to see how it might like to develop. I played with the collage in short sessions, paced over a couple of weeks, finally adding some pastel to help the different elements link together.*

*My first go at a zentangle mandala*

## Creative Writing

Expressive writing is one way of releasing and sharing emotion-laden experiences, helping me to feel seen. Speech-to text functions on my phone and laptop have sometimes helped me with this.

Poetry is a particularly valuable outlet for me because of its shortform nature. Blackout poetry (taking an existing page of text and blacking out all the unwanted words, just leaving those that form a unique miniature poem) even provides the topics and words to choose from. Flash fiction, brief journal entries, and stick person cartoons are other ways of embracing creative writing without having to expend energy on reams of cognitively demanding text.

## Not into art or crafts?

See overleaf for some non-crafty low-energy ideas.

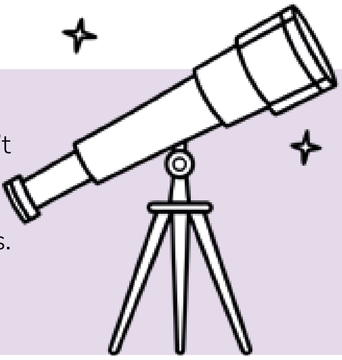
**Chance to win**

You can win a copy of Germaine's book, *Crafting a Path Through Illness: exploring creativity while chronically ill* in our giveaway on p 34! The book is full of ideas, suggestions, solidarity and inspiration.

# Making activities manageable

*Note: we are aware that for some even the smallest activities feel unmanageable. We see you. You know yourself best – only do what you can.*

**We've brain-stormed some gentle activity ideas for those who don't see themselves as arty-crafty. We'd love to hear yours.**



## Out-of-this-world photography

'Astrophotography' is photographing the stars and planets. Thanks to NASA, you don't need any of your own fancy equipment. You don't need to stay up late. You can borrow one of NASA's telescopes here: **bit.ly/NASAphotography**.

Tell it what you would like to photograph and select the desired exposure and filters. Enter your email address – you'll receive a link to download your free photo once it's been taken. You can also use the website to edit your image.

## DIY and repairs

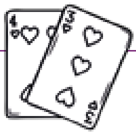
Do you enjoy tinkering with things? There may be a small item that needs fixing, or a job that is easily broken up into chunks and doesn't require much cleaning up. (If you have a small space where you can take your time without clearing up too frequently, great!) Completing that small task – however many steps it takes – can give a real sense of satisfaction.

## Making things homey

For some, housework is not a chore but a therapeutic outlet they miss. Clean the sink, not the whole bathroom. Making just a tap or small mirror shiny lifts the feel of the room. Look into pleasant-smelling products, which make you – and your living space – feel nice, without aggravating your symptoms.

Don't sort an entire chest of drawers; do one drawer, or half a drawer, or just get rid of one thing from a drawer! Put a cheerful coaster or seasonal decoration on your bedside table.

*Thanks to our editorial board members for contributing ideas to this page.*



## Other ideas

**Card games:** there are plenty of one-player games to play on a tray on your lap.

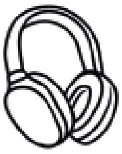
**Cloud spotting:** look for different types of clouds and see what shapes they make.

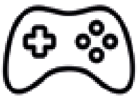
**Collecting:** stamps, buttons, favourite quotations or your own little curiosity cabinet – there are so many possibilities.

**Daydreaming:** let your mind relax and find its own stories or pictures.

**Jigsaw puzzles:** they are designed to do in pieces!

**Meditations, podcasts and audio books:** you can listen while wearing a comfy eye mask.





**Online gaming:** this ranges from simple puzzles to multiplayer community games and can be on your phone, a console or computer.

**Puzzle books:** words, numbers, pictures or logic, the choice is yours.

**Reading:** choose books or magazines that suit your preferences and energy levels.

**Study:** if there's a topic you've always found fascinating, a flexible course might be of interest. Or tailor your own study with slow, gentle research.

**Taking pictures:** no need to go far; everyday objects can make great photos and most phones have a built-in camera.

**Watching sports or listening to sporting commentaries:** prioritise favourites as your energy allows.

# Shiatsu is his favourite word

## Emily Skye tells us how she, her wife and her dog have grown and adapted together in the face of ME.

**Speed read...**
Emily was worried about the impact her illness would have on rescue dog Ollie. Support was found through *Borrow my Doggy* and befrienders. Emily's wife, Beth, grew in fitness and confidence as she walked their beloved dog. As Ollie adjusted, he became a healer and a mediator for both.

When I became ill with ME, my biggest heartache was the impact on our Ollie.

Ollie is a lively and sensitive four-year-old Kelpie x Border Collie, whom we had adopted from a shelter two-and-a-half years prior. Some days he has been fed up or distressed by my distress. What I couldn't have known, though, was how much he – and we – would gain.

### Finding ways to manage

I was the planner and muscle in our family. These capabilities were suddenly lost. No more long hikes. No more tug-dance. We needed solutions, fast.

We found someone experienced with rescue dogs who could take him for a long walk once a week. It took many weeks to communicate the nuances of his stressors. It was going well, but then she was no longer available.

Action for ME told us about *Borrow my Doggy* (**borrowmydoggy.com**). I was cautious, but we met a young couple who were brilliant with him. They took him weekly for many months, before getting a beautiful puppy of their own.

Before I was ill, I was involved with building a community garden across the carpark from our back gate. When being upright and moving around started leading to PEM, they created access through a gate for me a few paces from our front door. My carer's son's girlfriend turned out to be our near neighbour. Sometimes she accompanied Ollie and me to the garden, where I could sit while she walked him around.

### Growing in confidence

My wife Beth worked on increasing her fitness and confidence in walking Ollie. Like his befrienders, she would take him to the quiet vineyard and to paid dog parks for exclusive use, to avoid stressors.

Ollie has become an old hand at greeting visitors: carer; cleaner; odd jobs people; friends and neighbours helping in multiple ways. He thinks everyone comes to entertain him and, usually, they comply.

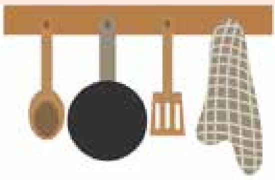
Ollie learned how to place his ball directly in my hand on the sofa. He learned all my guided rests and hops off the sofa into his bed to give me space to stretch out. He also coaxes me to sit in the yard with him.

Our most beautiful moment was when I had my first shiatsu session at home (a kind of physical therapy involving targeting pressure points, gentle manipulation and stretching). Ollie went to pick up my special stone and place it carefully on the mat where I would have the treatment. He gently took the blanket in his teeth and smoothed it out. He proceeded to work in partnership with my friend, the shiatsu practitioner, as a co-healer. To this day, 'shiatsu' is his favourite word.

Now he is six. He has grown in confidence. He is sociable. His relationship with Beth has deepened. She is delighted with her much-improved fitness. He is proud to be a healer. He is also an effective mediator when we're stressed with each other.

We have all grown and adapted together. Thank you, Ollie Collie, we love you so much.

**We'd love to hear about your pets and how you manage pet ownership with ME. See p 2 for our contact details.**



# Tips for the home cook with ME

## Leah Martindale shares tips for low-energy cooking, plus one of her soup recipes, perfect for the winter season.

For those of us who love to cook, but feel restricted by what our pacing allows, it can feel like cheating to adjust how we cook.

However, remember: the best thing to eat is what you can eat. The best thing to cook is what you can cook. An intricate, more complex meal might seem 'better' for you, but be worse in the long run.

When I am cooking something that requires a few stages (like a good soup) I break these tasks up over days. Today, I might chop, and tomorrow I bake, then the day after, I fry and add the stock. Most cooked food will keep for a good while in the fridge, and working at my own pace not only makes cooking more manageable, but it makes cleaning up easier too.

Many supermarkets sell bags of frozen chopped onions, and jars of chopped garlic and chillis which can go in the fridge once opened. These alternatives are just as good for you as freshly chopped vegetables and can alleviate a lot of chopping work.

### Leah's simple soup

I love soups! They are hearty and warm and pair well with a lovely, buttered bread. Soups can also be a great way to get in lots of good nutrients, fibre and vitamins.

My recipe uses chopped tomatoes, as these are a cheap and easy cupboard staple. You can also use fresh tomatoes – I would recommend chopping them into cubes about an inch square, and don't bother draining off that lovely liquid!

### Ingredients

1 tin chopped tomatoes

1 stock cube

½ a medium sized brown onion, diced (or 100g of pre-chopped onions)

2 garlic cloves, diced (or 1 teaspoon of pre-chopped garlic)

Optional: 1 stick of celery, thinly chopped

Optional: 2 finely chopped finger chillis

Dried basil, oregano, rosemary, smoked paprika.

*My herb selection is just a suggestion based on my tastes. A pre-made Italian herb mix will give your soup a hearty, bold flavour, without having to open or buy lots of different herbs.*

### Requires:

A hob
A blender (a hand blender is fine)

### Step 1:

Add your onion, garlic, and optional celery and chilli to a pan to sauté on a medium heat in shallow oil/fat. Add a pinch of salt to draw the water out of the onion.

### Step 2:

Once your onions are translucent (slightly see-through) and starting to brown, add a pinch of each of your dried herbs and spices of choice. Stir until the herbs are spread out.

### Step 3:

Add in your tin of chopped tomatoes, stock cube and about 200ml of water. Leave to simmer on a low heat.

### Step 4:

Stir your soup after 10 minutes to test the consistency. If you like a thicker soup, let it simmer until your spoon touches the tomatoes as soon as you dip it in. If you like it a little thinner, you can take it off the heat sooner, or add some water back in if it has cooked too quickly.

Once you have it how you like it, give it a good blend, add some cream if you like, salt and pepper to taste, and enjoy!

# Winter warmers

**Winter doesn't have to be grim, says Rose. Focus on winter warmers to replenish.**

**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.

## Loneliness

We all feel lonely at times, especially when we live with a life-changing chronic illness. I enjoy my own company and appreciate the stillness. However, I really miss my feline Jera. This is the first time I have been alone since becoming unwell with severe ME in 1999. I feel lonely.

The carers are on shifts. It's chaotic when they are here, but the contrast of the quiet when they have gone is unsettling. Jera was very vocal, so she broke up the isolation and was great company.

## Losses

Jera was by my side for over 20 years, so I feel alone and vulnerable. Christmas without Jera will be incredibly difficult, but I know she will be watching over me, with my friend Jazzy. My Christmas story (p 30) is dedicated to Jazzy, and I hope one day to be able to write a novel about Lady Booja in Jazzy's honour.

## Bounce back like Tigger

I need to dig deep into my inner strength and befriend myself. I do not have best friends or family to lean on. I come from a traumatic upbringing. Friends disappeared when ME was so badly misunderstood – to the degree that it was judged as psychological and Yuppie Flu.

Thankfully, times are changing. If my 11-year-old self had been diagnosed with ME in current times, then I would have known that each 'viral flare' was the condition, not constant viruses and that my low energy levels were not because I was weak. I have struggled for so long, but I must tell myself that I survived, and I will keep going, because I am strong.

I no longer grieve the old life path with the toxic relationships. Losing Jera proved to me that she was a gorgeous, loving soul who loved me unconditionally. The grief I have for her is because she showed me so much joy. I want to experience more joy in my life, and it starts with how I feel emotionally and mentally. I need to shift my focus, as I do not want to feel this low. I feel I have fallen into a void of low mood and need to bounce back like Tigger!

## Time to replenish

I want to focus on the season of winter as a time to replenish. A time to be gentle and nurture. The noise of summer disturbances has dimmed like the sunlight. I can gain comfort from closing my curtains and feeling cocooned in my home.

## Winter warmers

Winter warmers can be something as simple as a hot drink in your favourite mug, a heartwarming Christmas card or a comfy blanket. Try and think of your winter warmer blessings, as they are comforting when your symptoms flare and you feel low. You could also make a Winter Warmer Sparkle Jar or Box and write yourself little notes to boost your morale and ask loved ones to participate.

Another thing I try to do is think of three good things about my day. Perhaps over winter you can think of three good things each day: how warm the blanket is, how tasty the food is or how something made you smile.

## Christmas

Christmas almost fills me with dread, being alone. The festive season is so commercialised with so much pressure to have 'fun with the family' and extends into the new year. That is not always possible when you are so unwell and for those who have no family (or those too unwell to join family gatherings). I hope that I have carers to support me, as that is always a worry. I will take enjoyment from my Christmas decorations, fairy lights and some Christmas TV whilst eating Booja-Booja chocolate!

## Forum

I will miss virtual panto with Jazzy on the ME Friends Online forum. We like to remember her. We have archived posts of hers, which are so special. The forum is always a great place to connect with others, join in fun and games or seek out support (**www.actionforme.org.uk/forum**).

Whatever you do, try and give yourself time to breathe and enjoy some moments of peace and joy. Wishing you all a good winter, with some warming moments.

*Love, Rose x*

# 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.**

## Andrea's creative expression

"I still have a couple of quilts I made when I was 'only' severe," says Andrea Redmond Hind. "I was engrossed in that hobby from 1983-1993."

Now Andrea is very severe and visually impaired. However, she sometimes take photos with her phone. "Mostly flowers in my garden because nature changes all the time. And lots of photos of my nursing team – my three cats."

Andrea's quilts were recently featured in ME Advocates Ireland's craft exhibition for Severe ME Day.

Milo, one of Andrea's nursing team

## An Ode to DecodeME

Jo shares her poetic response to the findings of DecodeME.

*I woke up today and heard the news*
*They've proved ME isn't just 'the blues'.*

*It's in the brain and in the spine*
*Even though we look just fine.*

*DecodeME solved the enigma*
*And set us free at last from stigma.*

*Hats off to Chris Ponting and his team*
*Thanks to you we might yet live the dream.*

## Cosy crafts by Shortbread

Shortbread is well known on our ME Friends Online forum for her knitted and crocheted items. She shares more:

"I taught myself to crochet and knit from online videos about nine years ago, when my ME meant I could no longer work. I needed something to keep me occupied and to give a bit of purpose to the day, but also something that I could just put down when I started to crash, and not worry about needing to tidy away. Everything I make gets donated to charity. I'm currently enjoying making baby blankets and clothes for my local baby bank. "

## Kim's recent makes

Kim Rowland has made this lovely Christmas card for her mum. "It took me a while to make as I can only do it sporadically, but does bring me some joy." She also made a harvest wreath, bit by bit, for the autumn village show.

# Christmas at Booja Manor

### A story by Rose

"Booja-Booja vegan chocolate is delicious. Merry Christmas!"

Cook was busy hand whisking up a mixture for Lady Booja. The more she whisked, the more her bottom swung back and forth. Cook had a rather large bottom because she indulged in eating leftovers at midnight. "Waste not, want not," was her motto.

Lady Booja required Cook to savour her food. However, Cook's palate was not acquired to Booja tasting, because she drunk too much cider. Every Friday evening at 18:01 Lady Booja's pet owl, Orla, would taste and spit the Booja to ensure they were exquisite.

Cook was very busy. Lady Booja had instructed a new recipe for this Christmas Luncheon.

"You okay, Cook?" asked Barnes the Butler.

"No! I'm all in a custard. Milady wants me to make Turnip Trifle, and the mixture is too dense." Cook wedged her wooden spoon in the large ceramic bowl of mixture and the spoon stuck to the bottom. "I've whisked and whisked and swung my bottom, but I can't do it." Cook wept and tears fell down her floured, rosy cheeks.

"Oh Cook, don't get upset, luv. Let me text Paulette and see what she can do."

Paulette was Lady Booja's lady's maid. Only Paulette was allowed access to Lady Booja's wardrobe, because it was magical. Paulette wore a very prestigious uniform, and the wardrobe key hung around her neck for safe keeping.

Paulette had her daily routine of accessing the wardrobe to check there were no meeces – who were after the Booja. The wardrobe magically extended every time Paulette took a step inside. She reached her arms open wide and touched all the glorious gowns with her white gloves.

Paulette dreamt she could wear a beautiful gown to a posh manor ball. She admired the sparkling tiara nestling on a blue velvet cushion and was tempted to try it on, but was interrupted by a text from Barnes which read, "Cook in a custard. Turnip Trifle. Urgent!"

Paulette rushed downstairs to Cook, forgetting she had left the wardrobe door open...

"Quick!" squealed Rose."Lady Booja is snoring poshly, and Orla is eating a tub of Christmas twiglets."

Bambi followed Rose. They tiptoed into the wardrobe carrying sparkle jars. Rose was known for being a mischievous maid, whilst Bambi always liked to follow etiquette, except on Tuesdays. Today was indeed Tuesday.

Meanwhile Cook had cried so much that Paulette had to mop the kitchen floor.

"Come on, me duck, no more tears. We can order in Turnip Trifle from Just Eat. Lady Booja will not know."

Cook was relieved and gulped her cider and burped.

"It will be a lovely Christmas, Cook. Upstairs will all be fancy and posh, but downstairs we will have more fun."

Bambi and Rose rushed to the back of the wardrobe, where a magical door led to the village. It was snowing and cold. The villagers were not all wealthy like Lady Booja. Some struggled to even buy a mere sprout, let alone a turnip. The girls giggled and opened the sparkle jars. The jars contained fairy dust and magical messages for everyone who was sad and lonely at Christmas.

The golden fairy dust weaved into the snow showers and landed on every doorstep of every house in the village, forming a beautiful hamper that contained lots of goodies including turnips and Booja-Booja cholcolates.

"Bravo!" said Lady Booja, smiling brighter than her tiara. "The truest gift is thinking of others. Now let's go inside and have some yummy Turnip Trifle with Booja sprinkles."

# Colourful memories

## Finn2, one of our ME Friends Online forum members, shares her easy-to-make tree decorations – and some of her story.

I was first ill with ME in my student days. Life became more limited than I could have imagined, but I feel fortunate that I was eventually able to have a family and mostly be able to work.

About 10 years ago, I relapsed after a thyroid infection. I struggled increasingly despite support. A further relapse at the end of 2021 (another infection!) meant having to retire early from a job I enjoyed.

My life has become smaller in many ways but larger in others – Action for ME's ME Friends Online forum has introduced me to many new friends who always understand and, this year, I've become a grandmother with another grandchild due soon, so my family is expanding!

I'm finding ways to be a different kind of grandparent than the one I might have imagined years ago. I'm hoping that I'll be making decorations with my grandchildren a few Christmases from now.

### Finn2's easy-to-make decorations

One reason I like making these is that I can stop and start again later, depending on energy levels. They don't have to be completed in one go. They don't cost a lot and the variety of paper cases available means that there should be a colour scheme/ pattern to suit all tastes.

Every Christmas, I think I'm going to go for a more sophisticated theme for my tree and every year I bring out the decorations my children made, decorations my grandmother had and decorations from days when I was able to travel. The colourful memories always win out over sophistication!

### What you'll need

- 12 paper cupcake cases for each decoration
- Glue – I use a 'Pritt Stick'
- Short strands of wool, ribbon or string to hang the decorations.

### Step-by-step

1. Flatten 12 cupcake cases then fold in half
2. Glue one outer side of a folded case
3. Attach another folded cupcake case to the glued case and press firmly
4. Apply glue to the 'unattached' side the attached next case and press firmly
5. Repeat steps 3-4
6. Before gluing the last case, insert the strand of ribbon, string or wool, apply glue and stick the unglued side of first case to the glued side of the last case. All cases are now attached and a sphere is created.
7. Hang on the tree and enjoy!

Step 1

Step 2

Step 6

**When storing for next Christmas, I flatten the decoration and hold in place with a paperclip.**

# Will we climb the big hill?

## Mair Squire reflects on talking about chronic illness to children.

**Speed read...**
Mair Squire responds to a concern about how to communicate the fluctuations of chronic and invisible illness to young children – by creating a book as a resource for families. Here she shares some of her inspiration, as well as some tips.

Mair Squire has had long Covid for four years. It changed her life, leaving her unable to work or participate in the world around her.

"I went from having two active jobs (as an early-years teaching assistant and a sports massage therapist) and enjoying exercising three to four times a week to needing to lie down after dressing," she says.

### Food for thought

Mair joined an online community, which has been a lifeline for her in the past two years. In one online group session, a parent asked for advice on communicating her long Covid to her young children. "She was concerned about how her health limitations would be impacting them," Mair explains. "The older child would be visibly afraid to see her so incapable." The younger child was having angry outbursts, "finding it difficult to understand why mummy couldn't walk up their hill today when it was always an option in the past".

Although Mair's own children are now young adults, the question hit a nerve. She tried to find a book or resource to recommend – but drew a blank. "So I decided to give it a go myself."

### A lotus from the mud

Cara Smart, Mair's co-author, later volunteered her help. "Between us we have created something very special, I think," says Mair. "Not having any experience of this world of writing or publishing, I can say it has been a steep old learning curve and often impacted my health. But I've been so determined to make something positive from this circumstance – my 'lotus from the mud'."

Mair hopes that the book will be a valuable resource for families grappling with the fluctuating nature of chronic and invisible illnesses, including ME. She uses it to address emotions such as anger, frustration, resentment, sadness, grief, fear, confusion and loss – "as well as showing that positive emotions like happiness, love and compassion can co-exist and help to process the trickier emotions."

These emotions are real for the parent or carer too. They can experience "grief for what they 'could' be for their child and knowing that their child may never have that from them".

"Guilt is a large part of my experience of being a parent to teenage girls," Mair says. "Overwhelming guilt can cloud any rational response to an unrealistic request from the child. Brain fog can make any conversation extremely difficult and tiring. It really does take an awful lot of mental strength to get through this – not so easy when the brain decides not to work!"

Illustrated by Beth Pawlin, the book uses the challenge of whether or not the adult can manage to "climb the big hill" today, and how to manage the emotions that come from not having the energy to do this. Mair hopes the little book can help support parents who have energy-limiting illnesses.

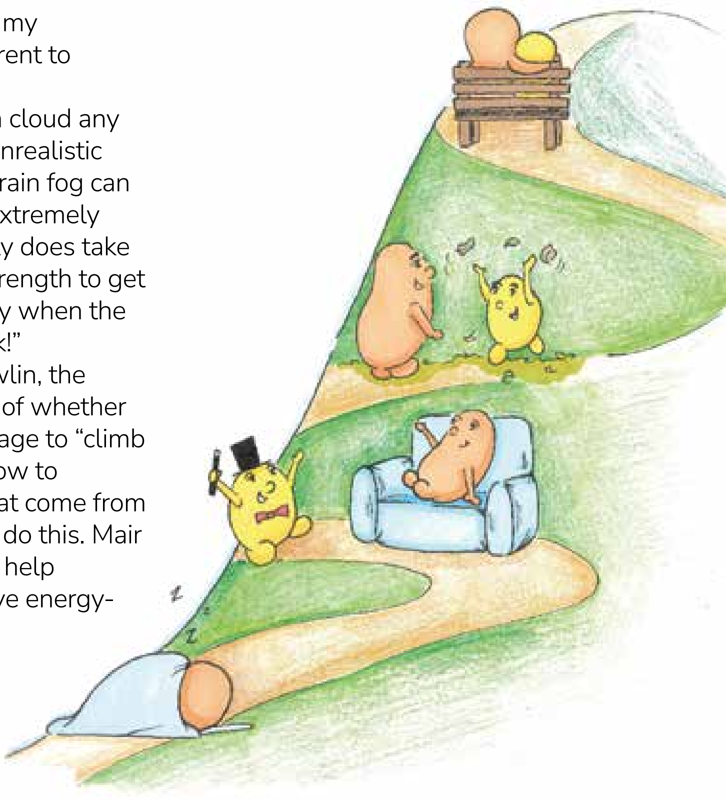
### Mair's tips

Draw your own big hill together and fill it with ideas of activities, so you have a visual aid to show your child what you're capable of on any given day. This will show the relevant activities you've chosen and give your child clear parameters at any given time.

Often a stock answer is helpful when cognition is impacted. This visual aid will act as your stock answer and give you both ideas of what to do together.

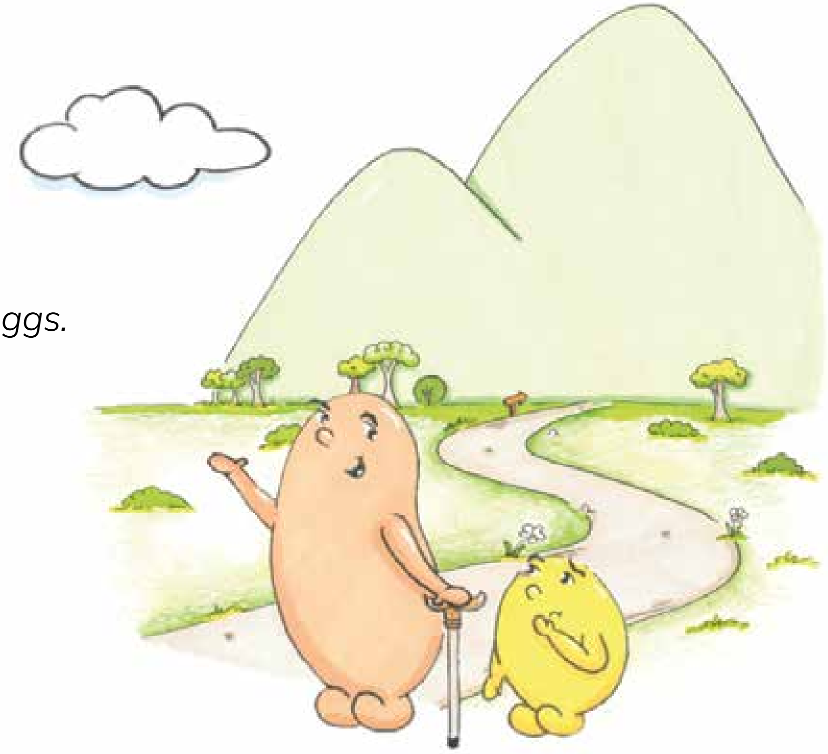
Keep talking and letting them know how loved they are.

Keep looking for even the tiniest glimmers of joy and of course take as much help as you can get!



*The thing with this illness*
*You can't always see*
*Is outside I'm OK, but inside of me,*
*I feel like I have concrete legs*
*And my brain is full of scrambled eggs.*

from *Will We Climb the Big Hill today?*
by Mair Squire and Cara Smart



Illustrations by Beth Pawlin

**Mair has kindly provided five copies of the book for our readers! For a chance to win, email interaction@actionforme.org.uk with the subject heading BIG HILL by Friday 16 January 2026.**

# Red's community makes a difference

## People are using online gaming and livestreaming to fundraise for charities, including Action for ME.

Red and her online community – #vTuberswithDisabilities – used Twitch (an online livestreaming platform) to build community, raise awareness and fundraise for Action for ME throughout August this year, raising an amazing £400 – more than double their target!

"I've been ill since I was 10 years old. Just over 15 years now," says Red. "It was places like Action for ME that made a lot of change and helped throughout my life."

Red uses pre-recorded video, live Q&As and the group chat to talk about ME. Those on the stream play games and host giveaways to raise money.

### A way to send support

"We thought it would be great to use this as a way to send support to others with the condition. We have handmade charms and 3D-printed rewards for donors and made new items every day of August to show off during our streams!" Red explains. "Making these has always been a hobby to help manage my condition, so adding them to our event has been a great feeling."

We're constantly inspired by the creativity and passion of our fundraisers. Every idea, every effort – big or small – makes a real difference.

"Not only can we help raise funds to support others, but we can teach others about the condition in some more depth and show others where to find help from places like Action for ME," Red adds.

We're truly grateful for the energy and dedication our fundraisers bring – in all its wonderful forms.

### What is livestreaming?

**Livestreaming is when someone shares a video of what is happening on their screen with others. In the case of gaming, viewers can watch the gamer playing and listen to them commentating on what they are doing. They can chat and share tips. Communities are formed around this shared experience.**

## *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).

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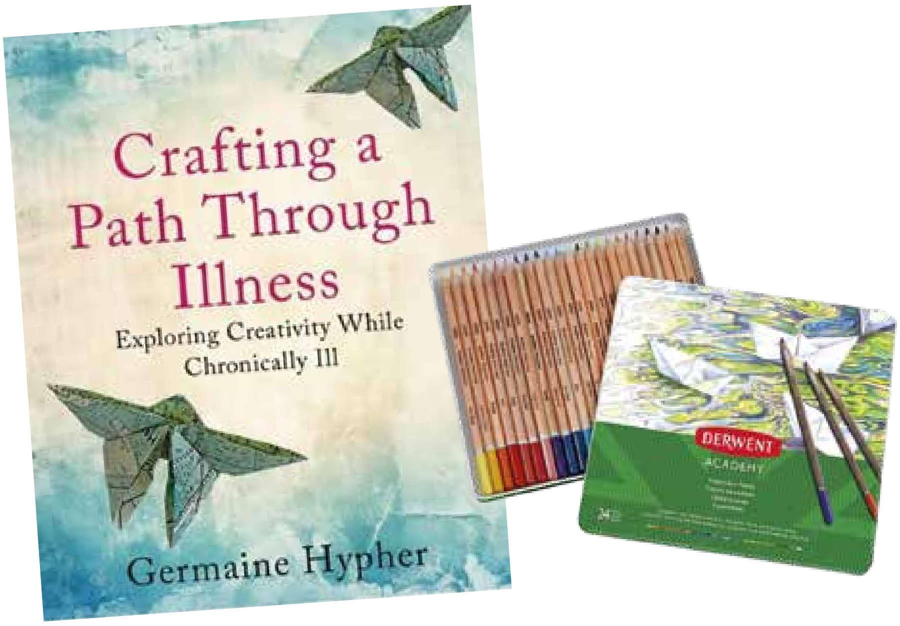
# Giveaway

## Win this lovely prize!

For this issue, we have a copy of Germaine Hypher's book, *Crafting a Path Through Illness: exploring creativity while chronically ill*, to give away to a lucky reader (Germaine writes for us on p 22). The winner will also receive a set of watercolour pencils to fuel their own creative play.



### 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,
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**The deadline for entries is Friday 16 January 2026.**
**Good luck!**

#### Terms and Conditions

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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. Watercolour pencils may vary from those pictured above.

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.

# 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

## Nature is good for us

As I flicked through the pages of my new *InterAction* magazine (issue 120) I stopped at page 29. May I congratulate Samuel for his interesting photographs.

Photography is one of my hobbies. I spend a great deal of time at home and always have the camera nearby. I enjoy watching the birds. Three years ago, beautiful doves started visiting the garden and I throw out food for them. Naturally they have increased in number. They wait on the roof and when they see the goldfinches arrive at the birdfeeders they fly down to the ground and pick up many seeds that the goldfinches drop (sunflower hearts).

The photos in Nic's article are very good and I agree with her – nature is good for us all.

These photos are taken through my kitchen and dining room windows.

With best wishes to the *InterAction* team and all its readers.
**Jeanne Rushby**

**Editor's note:** *Congratulations to Jeanne for her star letter. An Action for ME goodie bag is on the way!*

## Feline friendship

I've had ME for 30 years. I live on my own and spend 99.99% of my time alone. The main thing that keeps me going is my little black cat Ellie No-tail. I couldn't manage without her.

I understand completely the emotions of Rose in telling of her loss of her cats Jera and Vespie (*InterAction* 120, p 25)... thanks to her for telling us about them and my deepest condolences for her loss.
**Adrian**

## First-time prize winner

Can I just say how much I've appreciated Action for ME... I've belonged to the group for well over 20 years. I've often done raffles but never ever won a prize – this is so unexpected! Some of the money will go to my great-grandchildren for summer holiday spending, which will make them happy, I'm sure.

I've had some fantastic support from Action for ME, particularly in my early days of having ME, when it was not as recognised as it is now.
**Pam**
**(Winner of our Spring Raffle)**

*You can enter our Winter Raffle on p 9 for a chance to win £1000!*

## The struggle to find the balance

I was interested to read of Ellie's experience of trying to track her symptoms ['The Mystery of ME' – *InterAction* 120, p 38].

I have had ME for over 40 years and it will be of no surprise to most suffering from it that one can make neither head nor tail of why it decides to be bad sometimes and less bad at others. Like Ellie, I kept a chart, only mine was for the five years from 1998 when I was ill-health retired with ME. It made absolutely no sense at all. The only pattern of any sort was – and still is – a very subjective one: that at any time I am feeling confident of my health, it will soon go down.

My ME is much less frequent now. I have just come back for a wonderful family holiday where I have swum, run and walked. Naturally, I have ME symptoms this week! Post exertion, you will say. Yes – but there is no given amount of exertion that will produce the symptoms. Should I just sit around in case? After all these years, I still don't have the balance right!

**Martin Earl**

## Tears of relief

**The announcement of the early findings of DecodeME (p 10) had a lot of feedback from the ME community. These were comments shared on social media:**

"I didn't realise how much I desperately needed hope from being a part of this study. I got overwhelmed and cried because potentially future sufferers and tomorrow's children will have treatments and not be left to rot away being neglected and abused by medicine, society and others. ME took away my ability to have a family and I desperately don't want others to suffer in the way my peers and I have. I hope that we are finally heard... what you have done has the potential to save many lives. Not just through treatments, but by giving some hope for people struggling to continue to fight."

"Finally, some proof and validation. And a great start to hopefully much more study and investigation. And hopefully one day, a test and treatment options."

"Thank you, tears of relief. ME has destroyed my life and that of my family but knowing there are people like yourselves out there who believe us and are doing so much to help has kept me going through very dark times."

## Christmas just rubs it in

Please don't assume all of us are necessarily looking forward to Christmas. There are:

- Those whose have family who live too far away, or are too ill to travel, or who don't get on with our families and are losing touch with our friends
- Those too ill to even unwrap presents on Christmas Day and then remember what we've been given by whom
- Those who do not see Christ's birth, and the subsequent impacts of Christianism on the world, as something to be celebrated.

Saying a few times, "it's okay to not be okay," isn't really helpful, in my view, when what's making people like me feel not okay is the feeling of being left out, being excluded. So the more "oh good, look, Christmas is coming and we're all excited" stuff you see, the more it rubs it in quite how left out you actually are because of your ME.

For what it's worth, my favourite Yuletide song is Charlie Murphy's *Light is Returning*, which celebrates not Christmas but the Winter Solstice and the return of the light – which makes much more sense to me.

**Sylvia Rose**

**Editor's note:** This was written in response to our Winter 2024 issue of *InterAction* (where we featured people's favourite "Songs for the Season"). We are very much aware that this complex season means different things to different people – in terms of beliefs and also personal circumstances. We try and get the balance right in *InterAction* as much as we can. This issue is not just for Christmas and is read over the wintry months following, too!

Our wonderful, diverse membership will naturally respond differently to various content and find some things more helpful than others. We work hard to be as inclusive as possible and are grateful for all your thoughts and feedback.

# 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).**

## Resources for pacing

Sue Lorkins has recently updated her website and wants to share it with readers. "I live in the UK and have had ME/CFS since 1998. When I first developed the illness, I wish I had been given some (sensible!) practical advice on how to manage ME/CFS, but it was several years before I had an appointment with a specialist. "

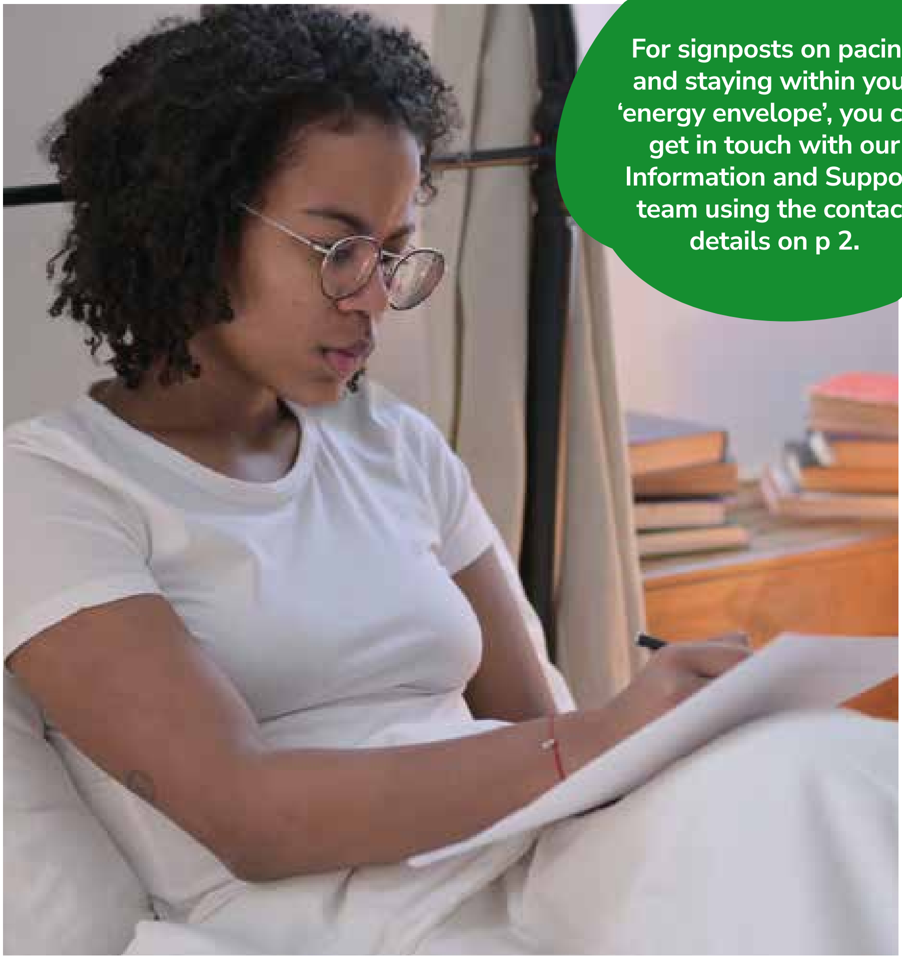
The website is a series of blank forms, charts and diary sheets that are free to download and can be edited to suit individual needs. They can be used to monitor routines, energy levels and what people find helpful – or not. Examples of filled-out templates are provided [see editor's note below].

Sue has benefited from careful, gentle pacing. "It is people like me in those early months/years I am trying to help, together with those who are longer-term patients – or indeed anyone who would benefit from an objective and practical approach to managing the illness," Sue explains.

Download the free resources here: **www.meforms.org**

**Editor's note:** Every person with ME will have different levels of what they can manage and what qualifies as a high- or low-energy activity. Please be aware that, when looking at examples of what one person can manage, it won't necessarily be what works for you. What is a low- or medium-level activity to one person will be high for someone else!

**Get in touch to share your notices and tips!**



**For signposts on pacing and staying within your 'energy envelope', you can get in touch with our Information and Support team using the contact details on p 2.**

## RADAR keys for accessible toilets

Did you know that RADAR keys are available for those with disabilities and not just for wheelchair users?

A RADAR key means you can use accessible public toilets that have a RADAR lock.

It's worth checking if you can get a RADAR key from your local authority, either for free or at a low cost. You can also get them online.
**www.disabilityrightsuk.org/radar-keys**

## Have you had thyroid surgery?

I'd be interested to hear from any members who have had thyroid surgery and have then started taking thyroxine. I'm keen to find out if this has been challenging or reasonably straightforward.
**Anna**
**Box number 4999**

# AI doesn’t call in sick

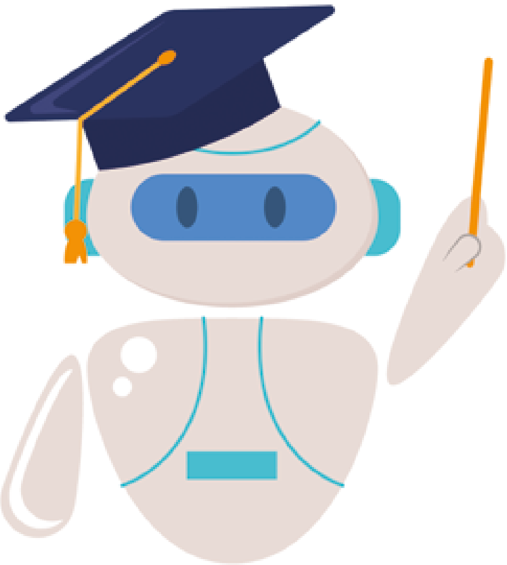
## Ellie Finney can’t avoid Artificial Intelligence.

**Speed read...**
Ellie isn’t particularly keen on Artificial Intelligence. She believes part of being human is critical reasoning, not relying on instant answers. However, she asks the question: are there ways it could be helpful to those with ME?

Try as I might, there’s no avoiding Artificial Intelligence (AI).

Even my mum knows what it is (although claims to have seen “an AI” on *This Morning* and wouldn’t back down when I told her that’s like saying she’s seen “a biology” because it’s a branch of science). I’m sick of people telling me to “ask ChatGPT” (a language model that’s been trained to generate human-like text) about anything from work, travel planning and even interpreting dreams.

On the face of it, it’s a more efficient way of Googling something or using a calculator, things I regularly do. Except the results may or may not be true. I did a quiz at work recently where I pointed out that one of the answers was wrong and the quiz master admitted they’d asked ChatGPT to write it, five minutes prior to the meeting.



### Generating content

AI is efficient but not always correct. It hoards the information people put in it to continue its training. It’s learning things about us and how we behave. We don’t know who else can see this data and what nefarious purposes billionaire companies could be using it for. On the whole people don’t mind, because it gives instant answers. It makes our lives that bit easier and makes us rely less on our own brains.

To me, part of being human is that critical reasoning. ChatGPT is giving everyone the same answers: if you ask several humans, it’s unlikely they’ll give you the same response. We’re inherently individual and different from one another.

But another part of being human, as we all know so well, is being ill.

AI can churn things out in milliseconds without needing a break and doesn’t call in sick. I work in a creative industry, one where redundancies are happening and work is drying up as companies move towards using AI-generated content. The quality is poor, but no-one seems to care about that, or people argue that it will only improve.

### Other industries

It’s scary for my industry, but could it help other industries – ones where human error and bias lead to misdiagnosis and harm? Would I be better off with a robot doctor? The NHS is already testing AI tools that can spot cancer missed by doctors.

Could anything be developed to help us? Could AI be used to help diagnose ME? Could it provide us with personalised recovery plans based on the prompts we give it? Could it crunch the data and find out why some people get worse over time and some get better [see editor’s note]?

Could it alleviate loneliness? I listened to a podcast series recently called *Flesh and Code*, about people developing relationships with AI chatbots. It seemed a lot of the people who sought this type of companionship out were people who struggled with human-human relationships for all kinds of reasons. Either they’d been badly hurt (or abused) in the past and wanted to talk to someone safe or they were used to the humans around them having a lot of problems, and wanted to talk to someone uncomplicated and always there for them.

I wonder if there’s a glimmer of hope there. There’s currently too much of a dark side (there are cases of chatbots encouraging people to do dangerous and harmful things to themselves and others), but I feel like these technological advancements could surely be used for good, as well as profit.

Do you feel like the development of artificial intelligence is hopeful or harmful? Could AI be used to help people with ME?

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**Editor’s note:** There are many forms of AI, some of which are being used in health research. PrecisionLife, for instance, uses AI tools as part of their combinatorial approach to clustering ME data into sub-groups, such as in the LOCOME project. We’ll be featuring an update from LOCOME in issue 122.

# Finding support

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

## Mental health support

**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**

**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**

**Mind**
Signposting and support for mental health. Weekdays 9am-6pm, except Bank Holidays. Closed 25 December to 1 January.
Support line: 0300 102 1234
Email: info@mind.org.uk
**www.mind.org.uk**

**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**

**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-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 season filled with hope, peace and replenishment.

Our last working day before Christmas will be Friday 19 December 2025.

The Action for ME office will reopen on Monday 5 January 2026.

## The Big Give 2025

Donate between noon on Tuesday 2 December and noon on Tuesday 9 December and see your donation doubled!

See p 4 for details.

## Be an angel

It's not too late to take part in our Christmas Angels project, if you get cards to us by Monday 8 December.

See p 9 for how to register.