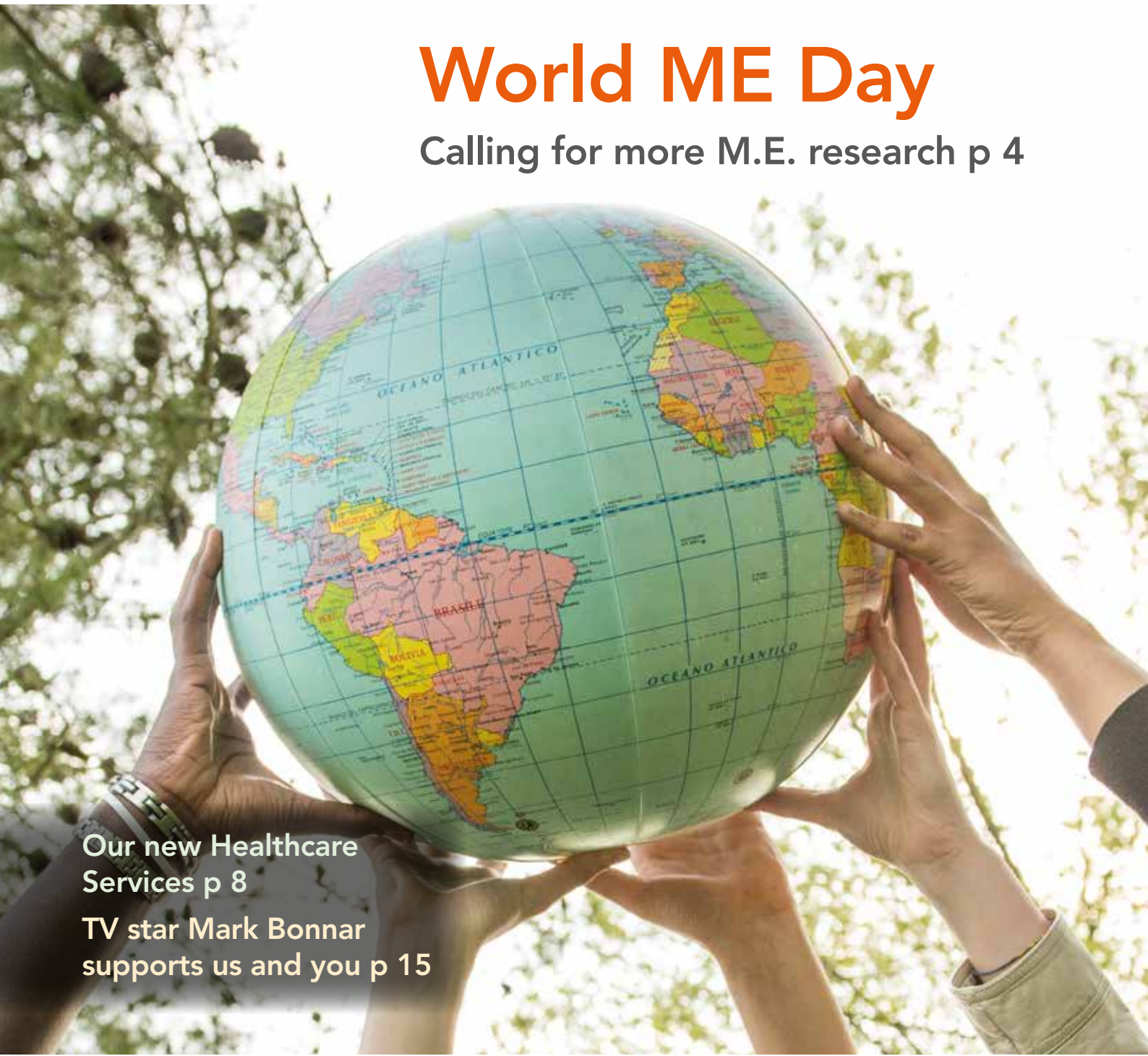




InterAction

World ME Day

Calling for more M.E. research p 4



Our new Healthcare
Services p 8

TV star Mark Bonnar
supports us and you p 15

ISSUE 110
SPRING 2022

OUR VISION IS A WORLD WITHOUT M.E.



Research focus

They say time flies when you're busy, and that's never been truer for the team at Action for M.E. After living with the uncertainty the pandemic brought during the past two years, the charity is emerging stronger than ever, continuing its mission to put men, women and children with M.E. at the forefront of all we do.

And those aren't idle words – the association with M.E. and Long Covid has made M.E. a very topical and much discussed illness. This has led to more interest, more funding and more collaboration. Some of our plans are ambitious – and why not? We aren't going to defeat this life-zapping illness without being forward thinking and determined.

Our new five-year strategy, which we are almost ready to launch, sets out three outcomes: improving lives through ensuring access to information, support and advocacy; improving health through delivering holistic healthcare services; and developing effective treatments via

Breakthrough-ME, our exciting plan to rapidly grow research.

As part of this project we will host a genetics research summit this year and also plan to open the first Genetics Centre of Excellence to build upon knowledge gained from DecodeME and other studies (see p 12).

May is M.E. Awareness Month and this year taking centre stage will be World ME Day on 12 May. Hosted by World ME Alliance, a collaborative of organisations from across the globe, it will use collective action to bring about change, particularly as the world tries to understand and tackle the post-viral illness Long Covid (see p 4).

I'm sure you will be pleased to hear that our merger with the ME Trust is complete and Action for M.E. now offers doctor, physiotherapy, counselling and multi-faith chaplaincy services alongside its support, information, signposting and advocacy services (see p 8).



Finally, it was fantastic to see the popular actor Mark Bonnar champion M.E. when he took part in ITV's Celebrity Catchphrase (see p 15). Winning more than £17,000 for Action for M.E. was brilliant enough (it will be spent directly on improving the lives of people living with M.E.), but what Mark did was priceless – he shone the light on this illness on primetime national television. For that we, and the M.E. community, are very grateful indeed.

Sonya Chowdhury
Chief Executive

Contacting Action for M.E.

Information, Support and Advocacy Service and Healthcare Services

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

Call **0117 927 9551**

Email questions@actionforme.org.uk

Visit us at www.actionforme.org.uk

Find us on social media

www.facebook.com/actionforme

www.twitter.com/actionforme

www.instagram.com/actionform.e

InterAction enquiries

To submit a letter or notice, give feedback or reply to a box number

Call **0117 927 9551**

Email interaction@actionforme.org.uk

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

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

Medical advice

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

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Hot topics

- Dr David Strain, Action for M.E.'s Medical Advisor, featured on **BBC Radio 4's Inside Health** programme on 15 March talking about the similarities between M.E./CFS and Long Covid, including post-exertional malaise. You can listen to the programme by visiting tinyurl.com/bbcMEandLongCovid

- Turn to the back cover to find out how you can support our **Walk with M.E.** fundraiser. The sponsored walk with a twist aims to be as inclusive as possible.

- Poet Stuart Bryan (featured in *InterAction* 109) has teamed up with pal Lindsay Vine, who has been living with M.E. for the past six years, to launch a podcast dubbed 'a recovery podcast for fellow CFS/ME/Covid Warriors'. Each episode looks to cover a different aspect of recovery. Check the duo out on Instagram [@postviralpodcast](https://www.instagram.com/postviralpodcast). Their podcasts are available on Spotify and Apple Music.

- Tickets for our **Summer raffle** are enclosed in this edition of *InterAction*. Please fill in your tickets and return them to us using the Freepost envelope also enclosed. Tickets cost £1 and people will have the chance to win up to £750. Proceeds will help fund our work with people with M.E. Tickets must be returned by 25 July 2022.

United we stand

proudly supporting
World ME Day

The World ME Alliance, a collaborative of organisations from across the globe founded by Action for M.E., is launching the first ever World ME Day on 12 May this year.

This new initiative aims to bring together organisations and unify efforts to raise awareness and campaign together on M.E. Through collective action, we will step closer to our goal of a world without M.E.

The theme for the first year of World ME Day is #LearnFromME. This campaign will work to bring the knowledge people with M.E. and health professionals working in this field have to the wider world.

#LearnFromME will also highlight the woeful lack of investment in M.E.

research across the globe. It is only through research, and by choosing to #LearnFromME, that we can find treatments and one day a cure for this disease and related illnesses like Long Covid.

Action for M.E. Chief Executive Sonya Chowdhury is also Chair of the World ME Alliance. She said: "Many people with M.E. know all about post-viral illness. So much could be learnt about Long Covid if this knowledge and experience is recognised.

"We want to see more research funding which enables people with M.E. to have a platform to share this knowledge in the hope more will be discovered about all post-viral illnesses, which in turn could lead to improved treatments."

Find out more about the campaign by visiting the homepage for World ME Day <https://worldmealliance.org/worldmeday/>

What the campaign is highlighting

People with M.E. are the experts in their own illness.

Listen – Believe – Learn

Become a better healthcare professional.



Learn about post-viral illness, like Long Covid.

People with M.E. and experts can provide advice on pacing and managing long term illness.



Study M.E. and you will find out more about post-viral illness generally. People with M.E. desperately want to be part of research, even if it may not lead to treatments in their lifetime, they want to stop M.E. for future generations

Some of the learning which will be shared

WORLD ME DAY

I learnt that...
Pacing your energy day to day takes incredible will power.
Will you #LearnFromME?
World ME Day

I learnt that...
Research into ME is underfunded compared to other diseases across the globe.
Will you #LearnFromME?
World ME Day

I learnt that...
Fatigue could feel more crushing and be more debilitating than I ever knew.
Will you #LearnFromME?
World ME Day

proudly supporting
World ME Day

action for me

WORLD ME DAY

- The World ME Alliance, a collaborative of organisations from across the globe, is launching the first ever World ME Day on **12th May** this year.
- This new initiative aims to bring together organisations and unify efforts to raise awareness and campaign together on ME. Through collective action, we will step closer to our goal of a world without ME.
- The theme for the first year of World ME Day is **#LearnFromME**. This campaign will work to bring the knowledge people with ME and health professionals working in this field have to the wider world.
- #LearnFromME will also highlight the woeful lack of investment in ME research across the globe. It is only through research, by choosing to #LearnFromME, that we can find treatments and one day a cure for this disease and related illnesses like Long COVID.

proudly supporting
World ME Day

action for me

Why 12 May?

12 May honours the birthday of Florence Nightingale, founder of modern nursing. She established the Nightingale Training School, despite being virtually bedridden with an illness resembling M.E./CFS.





Working with you

Action for M.E. will be working alongside the World M.E. Alliance using the theme of **Learn from M.E. for M.E. Awareness Month** this May.

We have been asking our community to be part of the work to mark M.E. Awareness Month by sharing what they feel the world could learn from their experiences. These learnings will form a video highlighting the cross over between M.E. and other health conditions.

Radio 4: Listening Project

On Sunday 17 April, the Radio 4 'The Listening Project' put the spotlight on the M.E. community. The insightful discussion featured Jay, who was diagnosed with M.E. in the 80s, and Joanna, who has been diagnosed with Long Covid.

The conversation explored some of the challenges both Jay and Joanna face living with their conditions. They touched on their experiences with healthcare professionals, the impact their condition has on their day-to-day life and their frustration at the fact that traditional medicine is unable to provide them with any answers.

A comparison has been made between the symptoms of Long Covid and other post-viral illnesses

like M.E., and we are now seeing many Long Covid patients and doctors turning to those who have lived with these types of debilitating conditions for years for help.

The episode is available to download now: tinyurl.com/bbc-thelisteningproject

M.E. in Parliament

Do you follow us on social media? If you do, you will have seen the MPs who featured M.E. within their debates over the last month or two.

We saw Fleur Anderson, who represents Putney, Southfields and Roehampton for the Labour Party, speak passionately of the struggles those with M.E. deal with on a regular basis.

Elsewhere we saw Labour MP Paul Scully mentioning the gap of knowledge for employers and healthcare professionals who are working and supporting those with M.E.

Lighting up for M.E.

Back in January, a guest who featured on our Learn about M.E. podcast got in touch about marking M.E. Awareness Month with a twist. This year's twist will be to light up the Maryhill Burgh Halls in Glasgow in blue, the colour of M.E. awareness.

We will use this opportunity to pay tribute to 25% of people with M.E. who become housebound because of the devastating effects of the condition.

Learn about M.E.

We were delighted to see that our podcast, Learn about M.E., had surpassed 1,500 downloads. To mark M.E. Awareness Month, we will launch an episode to complement the webinar hosted in March with Dr Nina Muirhead.

The episode will discuss how social care professionals can better support those living with M.E. who are trying to access social care services that were thought out of reach for the community.

The podcast series is available to stream at your podcast provider.

Join the Blue Sunday Tea Party!



After an amazing year in 2021, raising over £20,000 for M.E. charities across the world, champion fundraiser Anna Redshaw is inviting you to take part in her Blue Sunday Tea Party once again, to raise vital funds for people living with M.E.

What is Blue Sunday?

Anna's Blue Sunday Tea Party is a chance for people with M.E. and their loved ones across the globe to come together and connect, as well as to fundraise for M.E. charities. After years of feeling isolated due to M.E., Anna was desperate to get behind M.E. Awareness Week, but being housebound, she was unsure how. She couldn't run a marathon, but she could have a small party with tea and cake.

For her birthday in November 2012, Anna and her family asked her friends to post a photo of themselves raising a cup of tea to celebrate her birthday.

"It felt wonderful to see their faces and feel a connection during a time when I couldn't have visitors because of sensory overload and generally

being too unwell. That virtual birthday party became the inspiration for the first Tea Party for M.E. in the following May."

Since 2013, Anna's Blue Sunday Tea Party has raised more than £40,000 for a number of M.E. charities.

How you can take part

Once again, Anna will be having her tea party virtually. She is encouraging readers of InterAction to join in by hosting their own Blue Sunday Tea Party on **Sunday 15 May**. To join in, all you need to do is:

- Wear something blue (pyjamas count!)
- Dig out your best cups and saucers to make an occasion of it
- Bake or buy your favourite cake
- If you can, post a photo of your little tea party set-up to social media
- Invite your family and friends to enjoy tea and cake with you, in person or via video call
- Ask everyone to donate the price you'd pay in a café for tea and cake if they can – some of us haven't been in a café for years so aren't sure what this is! But anything from a couple of pounds upwards is much appreciated
- The idea is people can connect with others online who are doing the same, by commenting on their photos and posts. New friends are made and recipes are swapped.

You can join the Facebook event here: tinyurl.com/BlueSunday22FB

And use/follow these hashtags on Twitter or Instagram:

#TeaPartyForME2022

#BlueSunday2022

The event runs all day, but Anna aims to be most active online between 12-3pm.

Not online?

If you don't have social media, or can't go online, you can still join in! Anna says: "Many people invite a small number of their own family or friends round for afternoon tea and make an occasion of it. My own health doesn't allow me to host a video call with everyone but some people organise their own and enjoy tea and cake and a chat that way."

We are so grateful to Anna for choosing to fundraise for Action for M.E. again this year, amongst a range of other M.E. charities. Anna said:

"I've chosen Action for M.E. again this year as I continue to be incredibly impressed by the work and dedication of the team. Having had the pleasure of working with some of the Action for M.E. team through the DecodeME DNA study, it is clear how passionate every member of the team is, not only about supporting people with M.E. but also about furthering research, changing attitudes, and bettering the lives of M.E. sufferers and their families. For many of us a change feels so slow (too slow) but it has been uplifting to see a snippet of how hard and how unwavering the support and work of Action for M.E. is."



Anna Redshaw pictured at last year's event

Her Action for M.E. fundraising link is: www.justgiving.com/fundraising/bluesundayaforme22

Twitter @theslowlane_ME

Instagram @teapartyform.e

Facebook @theslowlaneME

With huge thanks to Anna for bringing the community together and supporting Action for M.E.



Ev's Cinnamon Rolls

The team at Action for M.E. all have their own favourite recipe whether that's sweet or savoury. Our Communications Manager Ev shares her recipe on making cinnamon rolls with a vanilla icing. Please note, this recipe has been tested to be replicated with gluten free flour if this is more suited to your dietary requirements.

Ev says: "Cinnamon rolls are one of my favourite things to bake. Not only does everyone around me love eating them but the smell of cinnamon in my kitchen is just a warming smell to tease your taste buds. These can be served as a treat or even part of an afternoon tea, delicious served either warm or cold. I love them warm with vanilla ice cream and a sprinkle of cinnamon."



Ingredients:

- 300g self-rising flour (GF self-raising flours are available)
- 2 tbsp caster sugar
- 1 tsp ground cinnamon
- 70g butter, melted, plus extra for greasing
- 2 egg yolks
- 130ml milk, plus extra for glazing

For the filling:

- 1 tsp ground cinnamon
- 55g light brown soft sugar
- 2 tbsp caster sugar
- 40g butter, melted

For the icing:

- 125g Icing sugar
- 15ml warm water

How to make:

Step 1

Heat oven to 180C/fan 160C/gas 4. Grease a 20cm loose-bottomed cake tin and line the bottom with baking parchment.

Mix the flour, caster sugar and cinnamon together with a pinch of salt in a bowl. Whisk the butter, egg yolks and milk together and combine with the dry ingredients to make a soft dough.

Step 2

Then turn out onto a floured surface and roll out to a rectangle, about 30 x 25cm.

Mix the filling ingredients together. Spread evenly over the dough then roll it up lengthways, like a Swiss roll, to form a log. Using a sharp knife, cut the dough into 8 even-sized slices and pack into the prepared tin. Brush gently with extra milk and bake for 30-35 mins or until golden brown.

Remove from the oven and cool for 5 mins before removing from the tin.

Step 3

Sift the icing sugar into a large bowl pouring the warm water into make a simple thin consistency glaze. The icing sugar should glaze across your buns.

Step 4

Enjoy the buns. Happy baking!

Stronger together

Action for M.E. has now completed its merger with The ME Trust, offering Healthcare Services in addition to Information, Support and Advocacy Services.

SPEED READ...

Action for M.E. has now merged with the ME Trust and is offering Healthcare Services including access to a doctor, physiotherapist, counsellor and chaplain. To cover costs charges are applicable but people can apply for a bursary towards the cost.

By combining the power of our organisations, we aim to ensure that all adults and children with M.E. can access the care and support they need. Our friendly and experienced services team are contactable by phone and email (see p 2) and offer the following services to people with M.E. and their families, friends and carers:

- **Free Information, Support and Advocacy Services**, including peer support services to reduce isolation
- **Healthcare Services** including a Doctor, Physiotherapy, Multi-Faith Chaplaincy and Counselling.

As a combined team we are already looking at how we can scale up the existing holistic support available to people with M.E. in the UK and expand our services to reach more people. We will continue to post updates on our website and social media channels.



All healthcare services previously delivered by The ME Trust will continue in the merged organisation.

Helen Winning, Director, Healthcare Services, Action for M.E., said: "The merger with Action for M.E. means that we have the opportunity to expand the healthcare services previously offered by The ME Trust and to reach more people with M.E. and their families.

"We will continue to adopt a whole-person-approach, supporting people in whatever way suits them best, helping them to manage their symptoms and improve their quality of life."

How we can support you

We offer individually-tailored, whole-person care. That means we seek to support you in whatever way is right for you as an individual physically, emotionally or spiritually. As well as listening and caring for the needs of the whole person, we offer encouragement and support to families and the immediate community of carers.

Our approach

Action for M.E. is committed to patient-led care, supported by robust biomedical evidence. We recognise that people with M.E. may have experienced stigma and disbelief about their health. We fully support research into the biological causes of the illness and are currently encouraging our patients to sign up

for the DecodeME research study (see p 12).

We support people to manage the physical symptoms of M.E. with medical advice and intervention, and physiotherapy. We also acknowledge that any long term illness can have psychological effects, and we therefore offer counselling, emotional support and spiritual direction for people who find that helpful.

This is the model of whole-person care which is fundamental to the activities of Action for M.E.

M.E. has a wide spectrum of severity and symptoms, and there is no one size fits all.

What we do

At Action for M.E., we understand how difficult it can be to find good clinical advice and support. We are working to ensure that everyone affected by M.E./CFS has access to diagnosis, treatment and care.

Doctor

Our doctor gives an individual, personal, clinical assessment of the biological aspects of the whole person, noting that M.E./CFS affects most systems in the body and is an illness resulting in much more than 'chronic fatigue'.

Reviewing the information provided regarding the past medical history, medication, investigation and interventions tried elsewhere, they give their medical opinion. Our doctor provides individual clinical advice but does not offer the issuing of prescriptions. However, medication advice can be sent to your GP.

Physiotherapy

Our physiotherapist's expertise and advice helps to improve quality of

life, working gently, step by step towards increasing levels of activity and function. She often begins with a questionnaire about baseline function and together works out with her patient what are their own priorities and aims. This may also involve family and carers.

Coming up with a plan gives the patient a sense of control and hope. Reviews allow for adjustments and take into account the variable nature of M.E., which is not expected just to steadily improve day by day.

Our physio can also help with pacing (learning to work within one's 'energy envelope'), learning to relax in a planned way, and can give advice about resting positions and pain management.

Counselling

We offer both counselling and emotional support.

Sessions are both supportive and therapeutic in nature: they may include strategies and goals on how to deal with depression and anxiety or manage difficult emotions and behaviours

Each session is weekly or fortnightly and is booked into the diary on a regular basis. Counselling may be time-limited or ongoing.

Emotional support sessions are by definition supportive in nature and the emphasis is on listening and offering emotional and practical support. Our counselling and emotional support services focus on M.E.-related support, i.e. living with or coping with M.E. Broader mental health issues, including historical trauma, or other defined conditions, must be addressed by local services. Our services are provided via telephone or Skype and so there are limitations to what we can offer effectively, safely and ethically.

Multi-Faith Chaplaincy

Our team of chaplains offer spiritual accompaniment to people of all faiths, and to those who are uncertain or have none.

Multi-faith chaplaincy, like counselling, takes place within a supportive listening relationship. The pastoral support felt by this is similar to emotional support from a

counsellor, except that the patient/client knows their listener has a faith perspective which may come into the conversation if the patient wishes it to.

The focus of multi-faith chaplaincy work is not so much on resolving specific problems/issues as working towards personal and spiritual growth. Multi-faith chaplaincy sessions may comprise pastoral support, or they may move into spiritual accompaniment, or they can be a mixture of both.

Our clinical team

We offer support in a variety of ways:

- consultations by phone, Skype, Zoom and email
- home visits (depending on location) CURRENTLY SUSPENDED.

We can also offer support to carers and family members affected by your illness.

You can find more details about the services we offer and profiles of our team of clinicians by visiting www.actionforme.org.uk/healthcare-services

How do I access services?

The referral is simple, just contact our Information and Support Team via webform, phone or email (see p 2 for contact details and opening hours). They can send you a Healthcare Services self-referral form, which includes application for a bursary if you need it.



Do you charge for Healthcare Services?

It is our dream to offer all our Healthcare Services for free but until we are in a position to do so, we charge fees only to cover costs. As a charity, we aim to keep our charges as low as possible. Full details of charges and what you can expect to receive are available on our website or by calling our helpline.

Bursary

We want to do everything we can to help those who can't afford to pay the full amount. In most cases, we offer either a 25% or 50% reduction on our charges.

If you have been awarded a financially assessed benefit, you will be eligible for bursary support. If you are not in receipt of benefits, you may still be awarded a bursary after a confidential discussion of your individual financial situation with a member of our team.

You will receive confirmation of your award by email. Your bursary allocation is valid for 12 months from the date of the confirmation email. Any sessions remaining at the end of this period will not be carried forward.

Further bursary support may be available if your financial circumstances are unchanged and after consultation with the appropriate member of the Action for M.E. clinical team.

Support for severe M.E.

Do you have severe M.E. or care for someone who does?

SPEED READ...

A book providing guidance for people with severe M.E. has been updated. Written by the late Emily Collingridge and first published in 2010, the book, *Severe ME/CFS: A Guide to Living*, has been brought in line with the 2021 NICE guideline and contains revised information about welfare benefits. It can be ordered at www.actionforme.org.uk/shop

The latest edition of *Severe ME/CFS: A Guide to Living* is now available.

Published in 2010, this invaluable book was written by the late Emily Collingridge, a patient with more than 12 years' experience of severe M.E., in consultation with more than 30 patients, carers, friends, relatives and health professionals.

"Emily's book is the legacy she left behind to support us all. I don't know how I'd have coped without it. It has been my M.E. bible. I wish I could thank her, but no thanks could ever convey the depth of my gratitude." Kara, severe M.E. patient

The book's 144 pages offer guidance on every conceivable area of life with severe M.E. at any age, as well as specific help for carers, loved ones, health and social care professionals and home tutors. It sets out to answer questions like:

- "Washing makes me feel ill; what should I do?"
- "I'm struggling to eat; how can I avoid malnutrition?"
- "My medical team doesn't know anything about severe M.E.; how can I get them to understand?"
- "Some of my symptoms are very frightening; what can I do about them?"
- "I'm finding basic daily activities really difficult; is there any equipment that could help me?"

Over the past few months Action for M.E. has been honoured to work with Emily's mother, Jane, and her friends, Naomi and Victoria, to update *Severe ME/CFS: A Guide to Living* in line with the 2021 NICE guideline for M.E. and revised information about welfare benefits. Jane is also responsible for the www.severeme.info website while Naomi

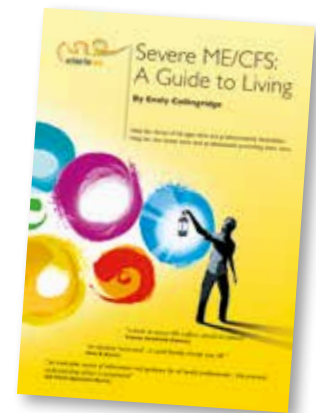
and Victoria manage the guide's Facebook page.

We have chosen a printing company which uses only vegetable-based inks, water-based chemistry and FSC accredited paper and board, and a sample has been tested for smell-sensitivity.

In accordance with Emily's wishes, we sell the book at cost price. Increased paper/printing charges mean that this has risen to £9.25, which includes postage to anywhere in the UK. Extra postage will be added to international orders.

You can:

- read more about Emily at www.severeme.info/about-emily.html
- order the book at www.actionforme.org.uk/shop



M.E. on the agenda

All-Party Parliamentary Groups (APPGs) are informal cross-party groups of MPs and members of the House of Lords. They meet regularly to discuss, campaign, and promote certain issues, in this case M.E. When effective, they are a great means of spreading awareness of an issue within Parliament and the media.

The Annual General Meeting (AGM) of the All-Parliamentary Party Group (APPG) on M.E. took place via

zoom on 29 March, chaired by Carol Monaghan MP.

We encouraged our community to invite their MP to attend by sharing our APPG tweet and tagging their MP's Twitter handle. We also shared a template email on our website.

In addition to reconstituting the APPG, the AGM included a discussion on our work plan for the next year in relation to the APPG purpose: to seek to improve health,

social care, education, and employment opportunities for M.E. sufferers and encourage biomedical research into the cause and treatment of M.E.



Listening to you

Feeling lonely? Listen to M.E. launches soon

According to Age UK's Campaign to End Loneliness, the effect of loneliness and isolation can be as harmful to health as smoking 15 cigarettes a day.

We are launching a new project in May called Listen to M.E., which aims to help people with M.E. feel less lonely.

You will be able to call our Listen to M.E. volunteers for a chat about anything – it doesn't have to be directly related to M.E. – and they will listen with empathy and understanding. Whether you want to talk through something on your mind, or just make a connection with a friendly volunteer, Listen to M.E. is here for you.

We are aiming to launch the project in May, with volunteers ready

to take calls for two hours a day (exact hours TBC), every week day. You don't need to make an appointment.

Our volunteers will have had training on understanding M.E., its impact and active listening and communication skills. They will be well supported and supervised.

Listen to M.E. will run alongside our other free services, including Information and Support (for information, resources and signposting) and Advocacy (for one-to-one support to get access to services that meet your needs).

This work has been made possible by an award from Postcode Local Trust, a grant-giving charity funded entirely by players of People's Postcode Lottery.



Would you like to be notified when the Listen to M.E. project launches? Please get in touch (our contact details are on p 2) and we will let you know.

Please note, Listen to M.E. is not a mental health support service, and does not offer advice – none of our free services do. If you think you would benefit from counselling, with planned therapeutic sessions, we now offer this as part of our holistic Healthcare Services, alongside multi-faith chaplaincy, physiotherapy and appointments with our doctor – see p 8.

Improving your experience in hospital

A 'patient passport' which will let clinicians know about your illness is set to be launched by Action for M.E.

The A5 document can be used by people to make their in-patient appointments or stay in hospital less stressful. It can also be used when visiting a GP who is unfamiliar with your medical history.

It will contain a passport-sized head and shoulders photograph of the patient as well as essential information such as name, address, date of birth and NHS number. It will also include any allergies you might have, any medication you are taking

and your medical diagnosis.

The passport will have a section for requesting any reasonable adjustments you may require during your visit/stay.

The passport has been devised in collaboration with Dr Nina Muirhead and A&E nurse Mark Jeffers, both of whom live with M.E. Mark is also a member of our Nurses for M.E. group.

It is hoped these passports will be available for use later this year.

Sonya Chowdhury, Chief Executive, Action for M.E., said: "Many people with M.E. have told us that

appointments with clinicians can be extremely stressful particularly as they use up so many 'spoons'.

"The aim of the patient passport is to support the patient in communicating with medical staff and thus help conserve precious energy. It will also ensure that nothing important gets forgotten.

"We will be including a QR code on the passport which, when scanned, will link to Action for M.E.'s website where it is hoped clinicians can learn more about this illness and the devastating impact it has on lives."

DecodeME launches testing phase

In January DecodeME, the world's largest genetic M.E./CFS study, invited a small number of people to take part in a testing phase. This testing phase focused on people who would find filling out an online questionnaire challenging and would therefore require a paper version.

Participants who were invited to take part in this phase were asked to complete the questionnaire, answering various questions on their symptoms and experience of their M.E./CFS. They were also encouraged to provide feedback on

how they found the process – whether they found particular questions confusing or more challenging.

The project will look at saliva samples from 20,000 people with M.E./CFS in the hope that the knowledge discovered will aid development of diagnostic tests and targeted treatments.

The questionnaire portion of the study collects information on each person's M.E./CFS as well as determining if they meet the study criteria. If they do, they will be sent a spit kit to provide a saliva sample so their DNA can be studied.

This testing phase is such an important stage in the project and the feedback we have received has been incredibly valuable. It has allowed us to identify aspects of the questionnaire that can be enhanced. DecodeME strives to ensure that people with all severities of M.E./CFS and different requirements can take part in a straightforward manner. Therefore, the team is applying the feedback received and



making the necessary changes to the questionnaire.

The majority of people who take part in the study will use the online questionnaire when we launch wider recruitment. We encourage anyone who can take this route, as this will help us reach our goal of 25,000 participants as fast as possible. The team is working to finalise the online questionnaire before it can also enter a testing phase, before full recruitment.

If you would like to take part or know someone who may be interested, then you can 'register your interest' on the DecodeME website (www.decode-me.org.uk) and be notified when wider recruitment begins.



FUNDRAISING

Cambridgeshire Relay: Michele and Chrissie run to work

Michele and Chrissie, colleagues at Barratt and David Wilson Homes, challenged each other to run from their head office in Peterborough to their new work site in Cambridge.

One of them will be running the 27.5 miles there, and tagging the other, who will be running the same distance back, hopefully all in one day's work.

They said: "To make it worthwhile, we have decided to raise money for a charity close to Michele's heart, Action for M.E.

"Michele's mum has been quite heavily affected with M.E. over the last 10 years, so we've decided to try and raise money and awareness so other people can get better help and support than she did."

So far, Chrissie and Michele have raised an amazing £1,840. The relay was due to take place as *InterAction* went to print – we wish them both huge good luck and a heartfelt thank you for raising vital funds for us. You can see their fundraising page at www.justgiving.com/fundraising/cambsrelay



Chrissie



Michele

Research to improve lives

Despite the devastating impact of M.E., understanding of the disease is still woeful. While at least 250,000 people live with M.E., and even more are now experiencing overlapping symptoms with M.E. following Covid, we have no treatments and little understanding of its causes. Significant investment in high-quality research is critical.

Action for M.E. has worked hard to improve the lives of children and adults with M.E., but this is not enough. To end the neglect of M.E. we need a national strategy that includes a focus on research.

Research

Now the charity is launching Breakthrough-ME: our plan to rapidly grow research and funding.

Our goal is to achieve a breakthrough in M.E. research that will provide the scientific knowledge required to deliver the diagnostics, treatments and eventually cures that we so desperately need.

Partnering with Prof Chris Ponting

(Medical Research Council's Human Genetics Unit and Principal Investigator on DecodeME), Action for M.E. will:

- Host a genetics research summit to stimulate new studies. We will bring together leading biomedical researchers and people with lived experience of M.E. this year. The summit will focus on genetic research and knowledge gained from other post-infectious diseases including Long Covid
- Establish the first Genetics Centre of Excellence. We will establish a virtual network of M.E. researchers to work with the M.E. community, to build on the genetic insights gained through DecodeME (see p 12) and other studies. We will establish a programme of high-quality research, supported by the Centre of Excellence.

Breakthrough-ME will ensure that people with lived experience are at the heart of all research delivered

through the Centre of Excellence.

We will build on the patient and public involvement that is driving the DecodeME study and the M.E./CFS Priority Setting Partnership.

We want to see the same level of funding and high-quality research as in other severe diseases. We will work across other scientific disciplines to accelerate our ability to pursue research leads as they emerge.

Investment

We will invest in a Future Leaders programme to create a pathway for early-stage career researchers to secure funding and stay in the field.

Prof Ponting said: "DecodeME cannot be the last M.E./CFS research project funded by taxpayers. Currently, low-level funding is yielding low-level evidence that fails to reach the high level of evidence required for competitive funding. Funders should act now and break this vicious cycle."

FUNDRAISING

Danny goes above and beyond

A huge congratulations and thank you to our champion fundraiser, Danny Redhead, who has, to date, raised more than £11,000 for Action for M.E.

Danny became unwell with M.E. in 2014 and in 2019 suffered a relapse after an emergency appendectomy. He began fundraising for Action for M.E., doing what he could within the limits of his health.

Danny says: "I want nothing more than to be well again. I spend every day trying to find improvement, and I have tried many things, but

ultimately I know that what I need is a proper medical treatment which is what has inspired me to do what I can, within my limitations, to raise funds for Action for M.E. to help drive research forward through their exciting and ambitious Breakthrough-ME strategy.

"Due to the severity of my health, most of my fundraising is very simple, often done laid on the sofa via my phone, and with the support of my family and friends."

Through a number of creative fundraising efforts, including the Movember challenge,

AmazonSmile, recycling ink cartridges and contacting local businesses and schemes for

donations, Danny has gone above and beyond to help support others who are living with M.E.

We are so grateful for his unwavering commitment and determination to raise funds to drive M.E. research forward – thank you Danny.



Learn about M.E.

Action for ME has been working in partnership with other M.E. charities in Scotland (#MEAAction Scotland, ME Association, 25% ME group) since November 2020 to inform and educate healthcare professionals on M.E./CFS.

This has been incredibly successful with more than 1,000 professionals in Scotland accessing and completing the training module on M.E./CFS we promoted (tinyurl.com/MEstudy module). From the professionals who provided feedback, the impact was:

- 76.4% felt more confident in diagnosing M.E./CFS
- 76.6% felt more confident in treating and managing M.E./CFS
- 96.5% felt that more formal education and training for medical professionals is needed on M.E./CFS.

We also recorded and promoted a series of podcast episodes (tinyurl.com/buzzsproutpodcast) to accompany the training module. We made sure that these included the voices of lived experiences.

We have now widened this work to

include social care and social work professionals. We kicked this off with a webinar on 17 March this year. Promoted throughout Scotland, this has received a very good response from a wide range of services and supporters. More than 30 people came along to the webinar and a further 20, who were not able to attend, wanted to receive a recording of the session.

Poll

A poll after the webinar found that 88% felt more confident now that they understood what care and management strategies people with M.E./CFS and Long Covid might need. A total of 12% felt that they needed more information to feel confident. We had some really good feedback on the day that it would 'improve people's practice' and that they found it 'very informative and helpful to better understand people living with M.E./CFS, their abilities/needs and also their limitations.'

We will make sure that the webinar is able to be shared with professionals in the future and will be

recording a podcast based on the webinar that can also be shared. Both of these and other information will be available on our website. This way we hope to inform more professionals about the needs of people with M.E. when they access and use social care or social work. It is important that they know about the advice for social care that is within the new NICE guideline on M.E./CFS. We also followed up with information on all of the M.E. charities' contact details, and further information and resources for services to use and to signpost others to in the future.

You can watch the webinar by visiting tinyurl.com/youtubeMEwebinar

Find out more

If you would like to find out more about our Learn about M.E. project and access a template letter about the training module and the latest advice from the updated NICE guideline, visit www.actionforme.org.uk/learn-about-me/



We are pleased to announce that thanks to more than 440 wonderful supporters, our Big Give Christmas Challenge 2021 raised an astonishing £133,804 both online and offline. The money raised will go towards funding our vital services and improving access to support, as well as campaigning for change and investing in biomedical research.

"A BIG thank you for donating to the Big Give Christmas Challenge. It is hard to live with M.E./CFS as a child but I have been able to make positive changes to my life by accessing services at Action for M.E. Your generosity helps children like me with M.E./CFS live a happier life."

Emma, 10 years old

A huge thank you to everyone who shared or donated.



Thank you Mark

Scottish actor Mark Bonnar has won more than £17,000 for Action for M.E. after appearing on ITV's *Celebrity Catchphrase*.

Mark, 53, is best known for his roles as Max in *Guilt*, Duncan Hunter in *Shetland*, Bruno Jenkins in *Casualty* and DCC Mike Dryden in *Line of Duty*.

Celebrity Catchphrase, hosted by presenter Stephen Mulhern, sees contestants attempting to identify the right catchphrase by viewing a short comical animated scene normally starring a golden robot called Mr Chips.

Mark, who played alongside singer Alexandra Burke and actress Claire Sweeney, scooped an incredible £17,200 that will improve the lives of children and adults living with M.E. If you missed the original airing on Saturday 15 January 2022, you can watch or replay the episode via the ITV Hub free of charge.

Sonya Chowdhury, Action for M.E.

Chief Executive, said: "I am ecstatic that Mark chose to represent Action for M.E. and won such a fantastic amount of money. I am sure that viewers of the show living with M.E. will feel validated after years of feeling unheard and invisible to the broader population."

"Mark's fantastic total will help us to deliver our one-to-one support services for adults, young people, and families with M.E. and support our collaboration in biomedical research."

Mark's appearance on the show had an amazing reaction across social media channels. One Facebook user said: "Well done...I was so overwhelmed that he did this for M.E." Another person took to Twitter to say: "I started crying immediately for reasons I cannot even put into words. I have suffered from this disgusting illness for 23 years."

"I didn't know you 30 minutes ago



Mark (far right) pictured with presenter Stephen Mulhern, singer Alexandra Burke and actress Claire Sweeney

but trust me, your name is now forever branded in my heart."

Someone else tagged Mark, commenting: "You've raised so much awareness of ME, spoken about the condition to a big audience and supported so many people that feel forgotten. Thank you."

Following the episode, LGBTQ e-magazine *Forever with Pride* reached out to inform us that Action for M.E. had been chosen as their charity of the year; their mailing list will encourage people to donate to us.

Jennie is our new ambassador

We are delighted to welcome actress Jennie Jacques as an Action for M.E. Ambassador.

The British actress rose to fame in the drama *Desperate Romantics*, which aired on BBC Two in 2009. She then went on to star in the hit period drama *Vikings* that streamed on Amazon Prime Video from 2015 – 2019. Jennie played the recurring character of Saxon Queen, Judith.

Jennie was diagnosed with M.E./CFS following a severe viral infection. She said: "I was hospitalised twice in 2019 with an acute severe Epstein-Barr virus infection complicated by severe viral hepatitis, amongst other nasties."

"It has been a painful and tumultuous time, and an eye-opener on many levels. Long Covid patients will likely be able to empathise."

Although CFS stands for Chronic Fatigue Syndrome, this illness is a lot more than feeling 'fatigued'."

Jennie was approached by Action for M.E. in 2021 to see if she would be willing to do an interview for *The Times* about her M.E.

She had been debating how to talk publicly about her personal connection with the illness, so Jennie decided to take up the opportunity.

Jennie, who describes M.E. as a "Rubik's cube of an illness", said: "I agreed to do the interview with Sean O'Neil, Chief Reporter at *The Times*, who put together a very well-executed piece. I'll always be grateful for this. We then kept in touch with Sonya, CEO at Action for M.E. My instinct was that I should be an Ambassador for a U.K. charity for M.E. Sonya's work ethic and

communication skills sealed the deal. I'm excited to join forces with Action for M.E."

"Moving forward, I endeavour to continue raising awareness for virus-initiated illness, utilising my platform."



"It's been the most painful project I have ever worked on"

An internationally renowned artist and poet has spoken of his emotional journey after leading a project based on the experiences of people living with M.E.

Alec Finlay, who became ill with M.E. when he was 21, worked with Action for M.E. to set up a questionnaire asking for people with M.E. to share their experiences.

More than 200 people responded to the project – called descriptions – and Alec used their words, anonymously, to create a collective patient-led description of the illness. The results will be published as a book, launched by Action for M.E. this June.

Response

Alec, the son of Sue Finlay who founded Action for M.E. in 1987 when she received 15,000 letters in response to her Observer article about the difficulties of living with M.E., said:

"Descriptions has been the most painful project I have worked on, and also one of the most important. The pain came in reading so many accounts of loss, anguish, and experiences of prejudice, but that is also what makes this work so important.

"I was humbled by the length and depth of the responses, and aware of the energy this will have cost. It was a reminder that this community has felt so erased for so long.

"The poem itself is, I believe, a model of patient-led medicine and collective memory. It makes the reality of M.E. impossible not to grasp. It may even bring a sense of shame to those who denied people's experiences for so long, and pressured them to follow regimes of care that, in some cases, did active harm."

Alec continued:

"I am convinced that this project will further the need for an enquiry

into how people could be disbelieved and ignored for so long. It is one of the scandals of medical science that a community of people with such serious symptoms, described with such consistency, should have been subject to the fantasy that their illness was a product of their own mind.

Lessons

"We all know that Long Covid has already acted as a judgement on such a speculative stance, but reading descriptions it was brought home to me, forcefully, as it will be to anyone, that the real mystery is not this disease, but the reasons why its treatment was allowed to spiral into such a caricature of medical care. It is urgent that these lessons are learned.

There should be no "controversy" about M.E.: there should simply be biomedical medical research, adequate care, and support.

"I was a child when my mother and her friends established Action for M.E. I feel a sense of pride to have made a small contribution to that legacy, and I commend Action for M.E. for supporting an innovative creative approach, but most of all I think of the four decades of my life in which so many people were left alone and ignored."

Physical copies of the book will be on sale but people will be able to download a free PDF copy or listen to an audio recording.

For further information please get in touch with us (see p 2 for contact details).

An extract from the book:

"you don't look ill"

"there is nothing physically wrong with people with ME"

"get on your bike and go for a ride, that will fix all your problems"

"if you really wanted to get well, you would"

"must be nice to get to lie down so often"

"you're just tired because you sleep all the time"

"I wonder if your symptoms have become self-reinforcing?"

"your thoughts are wrong, that's why you're ill"

"your brain is just imagining you are in pain"

("joke" message written on the black-board by my teacher and class)

"you are not ill, you are skiving"

"that's the lazy illness isn't it?"

"you're just scared of getting a job"

"does having ME actually affect your life?"

"ME, that stands for Medical Excuse"

"I can't see what else we can do, short of committing you"

"do cardio workouts three times a week, come back to me if you are really ill"



Living with M.E., a photographic study

Would you like to share your story for a series of photographic portraits about living with M.E.?

Photographer Jeremy Jeffs is looking for people who'd like to be photographed in their own homes for a new project that aims to show what life is really like for people with M.E.

For Jeremy, this is a deeply personal project as he's lived and worked with M.E. since he was diagnosed in 1987, at the age of 19.

He is creating a series of environmental portraits, with pictures of people at home, in the places they're confined to by illness, or the spaces they find peace and relaxation. The portraits will become a book and exhibition, with a permanent online display on a dedicated website.

Jeremy has the unique experience of not only having lived with M.E. for more than 30 years but also being a professional photographer and documentary maker. He said: "I've filmed and photographed so many people who are coming to terms with profound illnesses, but I've never had the chance to investigate the illness that has shaped my life."

Jeremy would like to hear from anyone who has M.E., whether they're recently diagnosed or have had it for many years, whether they're working, housebound or more active: "We have such a range of abilities, including people who are confined to their homes or beds. I'd love to show a full range of how it affects us."

You can also take part if you are a carer, friend or family member of someone with M.E.

As a photographer and film maker,

Jeremy specialises in working with people who have severe or long term illnesses, and works extensively with charities such as Anthony Nolan (the blood cancer charity), Dementia UK, and Muscular Dystrophy UK. You can see some of his latest work on the Anthony Nolan website or on company website

www.magnetofilms.com

This is an independent project and is self-funded by Jeremy.

You can contact Jeremy by emailing jeremy@magnetofilms.com



Jeremy's work includes this image of ceramic artist Lubna Chowdhary

FUNDRAISING

Father and son take on the Cardiff Half

A huge thanks to father-son running duo, Colin and Matt. The pair ran the Cardiff Half Marathon on 27 March 2022 in honour of Liz, Colin's wife and Matt's mother. Matt said:

"M.E. is a condition that has always had a big impact on our lives. Liz has lived with the condition for almost all of my life, nearly 30 years now. Although Liz suffers very severely, it doesn't affect her day-to-day positivity and she remains an inspirational mother,

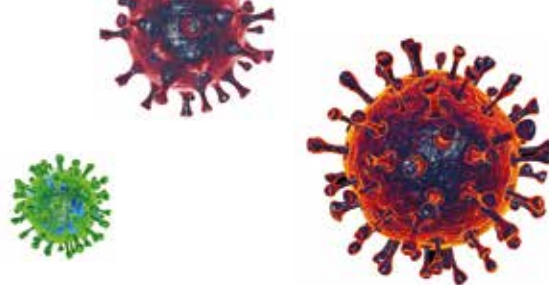
grandmother and wife who will always be the head of the family. Liz's determination to not let the condition dictate who she is and her outlook on life has inspired us to raise funds for this brilliant charity."

Matt has fundraised for Action for M.E. before, but this was his and his Pop's first half marathon. They raised a brilliant £1,225 to help us to fund our vital support services.



Matt and Colin

Every cloud?



It's taken a pandemic for clinicians and Government to wake up to post-viral illnesses like M.E. Diane Shortland lives in hope that the tide is finally turning for people living with this debilitating condition.

When Covid-19 struck in 2020, it was assumed to be an entirely respiratory disease that acutely affected a minority, with the majority experiencing only short-lived mild symptoms. As the months rolled on however a different picture began to emerge which was all too familiar to the M.E. community. As well as lung damage, patients were often left experiencing severe fatigue, muscle pain, and cognitive problems. An article in the *New York Times* written by Sarah Mervosh reported that patients were receiving little support for their ongoing symptoms and were dismissed by their GPs and not believed by family and friends ('It's not all in my head: They survived the Coronavirus but they never got well' ([tinyurl.com/nytimes-coronavirus](https://www.tinyurl.com/nytimes-coronavirus))). In many ways the story of Long Covid is a mirror to that of M.E./CFS but of speeded up progression and hopefully a resulting eventual outcome that will benefit not only Covid sufferers but M.E. and all viral illnesses.

Research

The term 'Long Covid' is in actual fact an entirely patient-made name, first used on Twitter and shared as a hashtag experience whereby other sufferers could find each other for mutual support. This label expanded to other areas very quickly appearing in scientific journals and within three months the World Health Organisation referred to it directly as a disease entity in its own right. The growing online Long Covid community took action quickly and independent of any medical or scientific knowledge base. The Body Politics Covid-19 Support Group (www.wearebodypolitic.com) conducted their own survey of 640

patients with prolonged symptom experience, providing an initial invaluable snapshot of this emerging worrying illness course. In November 2020 the Government announced that they would be investing £10 million to set up Long Covid clinics across the UK, and the National Institute of Health Research pledged £18.5 million into Long Covid research. As researcher Nisreen Alwan rightfully states: "We cannot fight what we do not measure" ([tinyurl.com/Alwan-Nature](https://www.tinyurl.com/Alwan-Nature)). This is an argument M.E. patients and patient organisations have been stressing for decades. The million-dollar question is will people with M.E. benefit from this research push though or will they again go unrecognised?

To look at the differences and similarities of Long Covid and M.E., firstly and significantly there is a biological test for Covid providing objective confirmation of the disease, unlike M.E. yet, but many early sufferers of Covid weren't able to be initially tested. For these patients, a battle for legitimisation is created just as with M.E. A study in December 2020 reported Long Covid patients feeling stigmatised and not taken seriously, this uncertainty resulting in additional stress ([tinyurl.com/pubmed-stigma](https://www.tinyurl.com/pubmed-stigma)). Many people experiencing Long Covid had only initial mild symptoms which makes it hard for friends and family to fully grasp the extent of their condition since mild should mean an ease of recovery in their rationale. The Government also failed to see Long Covid coming despite repeated warnings, including from doctor Nina Muirhead who has M.E. and Professor Chris Whitty, back in March

2020. Dr Muirhead said: "Because M.E. is so misunderstood by the medical profession, they didn't have the same end of the binoculars as I do. They didn't see it coming in the same way." ([tinyurl.com/bma-newsandopinion](https://www.tinyurl.com/bma-newsandopinion))

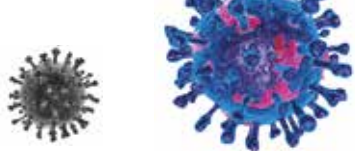
Injustice

The overlapping symptomatology of fatigue, post-exertional malaise and cognitive problems of Long Covid and M.E. began to be recognised first by patients, as people with Long Covid began to look to the M.E. community for advice. Essentially both Long Covid and M.E. are post-viral illnesses, after all. But other Long Covid sufferers were not so keen to be associated with the history of trivialisation that M.E. has been tarnished with. In a ripple effect now though, as health correspondent Jamie Ducharme points out: "Belief in long-haul Covid could translate to belief in other contested illnesses" ([tinyurl.com/time-longhaulcoronavirus](https://www.tinyurl.com/time-longhaulcoronavirus)).

To me, it looks like progress for M.E. appears to hinge on whether the medical profession continues to define Long Covid as a separate diagnosis or if it's viewed as something that turns into M.E. if symptoms persist over a period of months. But it seems likely that the public may find it difficult to grasp how a new virus can lead to an old illness.

With similar symptoms however, is it an ethical injustice to attempt to treat one illness and not the other? As a member of the M.E. community myself, I certainly believe so. Many people with M.E. are indeed angry and, as a Facebook post I spotted from the mother of a girl with M.E. expressed, it has taken a pandemic





for medical professionals and the Government to wake up to an illness that has been around for years. She also expressed high hopes though, that in making Long Covid a mainstream viral illness, people with M.E. will hopefully no longer be invisible.

In terms of research there has certainly been a surge in trend towards studying viral causes of fatigue. Another hot research topic is currently immune system and immune response investigation. The pandemic has undeniably spurred a new wave of interest in what the M.E. community have been saying for a long time. Health writer Lucia Osborne-Crowley sums it up: "There's a phenomenon whereby humans contract viruses from which they never recover." ([tinyurl.com/refinery-longcovidCFS](https://www.tinyurl.com/refinery-longcovidCFS)) Had this been given attention when it was needed, the global impact of Long Covid could have been somewhat lessened.

Fatigue is a difficult concept to understand in general, since in both Long Covid and M.E., it is a subjective experience that is not easy to measure or comprehend. Without any biomarker, patients rely on health professionals for authentication of their suffering. Family and friends tend to interpret fatigue in terms of their own experience of it and so fail to grasp its severity in chronic illness. The pandemic has brought chronic fatigue into mainstream viewing and this will hopefully lead to it being a

better understood and more accepted concept in everyday life. The researcher Julia Puauschunder highlights an already greater obligation by employers to be attuned to the current situation where rest and relaxation needs to be appreciated more in working life ([tinyurl.com/Covid19-longhaulers](https://www.tinyurl.com/Covid19-longhaulers)).

United

National Institute for Clinical Excellence (NICE) rapid guidelines on Long Covid were criticised by Dr Charles Shepherd for not drawing on knowledge of M.E. and post-exertional malaise. In a letter to the *British Medical Journal*, Shepherd said: "I was disappointed to find no recognition of the important clinical and pathological overlaps between Long Covid and M.E., along with a failure to make use of the detailed guidance on energy and activity management in the draft of the new NICE guideline on M.E." ([tinyurl.com/BMJ-letter](https://www.tinyurl.com/BMJ-letter)). Patients writing in *The Lancet* about their experiences of Long Covid clinics reported misguided assessment and treatment in some of its Long Covid centres ([tinyurl.com/pubmed-livedexperience](https://www.tinyurl.com/pubmed-livedexperience)).

The experiences of many people living with Long Covid are being shared by thousands of sufferers across social media platforms, linking themselves to M.E. patients, since Joanna Herman, a consultant in infectious diseases, states, they "remain in a post-viral sea looking for a mooring" (*People with Long*

Covid urgently need help. Why can't we access it?) ([tinyurl.com/TheGuardian-Herman](https://www.tinyurl.com/TheGuardian-Herman)). The Long Covid clinics have also been criticised for not opening their doors to M.E. patients so that both groups can gain benefit of the service that is essentially treating much of the same symptomatology. The key to any mutual benefit in terms of biomedical understanding and treatment options currently firmly rests on how Long Covid is classified, as either M.E. or as both diseases linking together as post-viral illness. This will allow for the increasing interest of researchers, scientists, health professionals, patients and society as a whole, to aspire to work as a united front in tackling what has been a major obstacle in disease knowledge for decades but is now of mainstream concern. With continuing patient advocacy online in both Long Covid and M.E. camps, this could indeed be an exciting and hopeful time for the M.E. community, finally and justifiably so.

Is the future looking brighter for people with M.E.? Do you think the pandemic will lead to a better understanding of the condition which in turn will result in effective treatments and even a cure? We'd love to hear your thoughts. Please write to us at *InterAction*, Action for M.E., 42 Temple Street, Keynsham, BS31 1EH or email interaction@actionforme.org.uk



About the author:

Diane Shortland is a PhD student at the University of Birmingham studying for a doctorate in Applied Health Research. Diane, who has M.E., is investigating the social implications of long-term illness focussing on how people with M.E. build and maintain social support both online and offline in their daily lives. The viral pandemic has proved an interesting comparable point of study and is currently giving greater depth to ongoing research. If you'd like to know more of Diane's work, she can be contacted on DLS760@student.bham.ac.uk



Living with tinnitus

People with M.E. face a myriad of health conditions and wonder if they are connected. In this issue we look at tinnitus with Nic Wray from the British Tinnitus Association.

"A mosquito"; "reminds me of a steam train"; "it's hard to describe, it's not like anything I've heard before". These people are talking about their tinnitus, a condition often described as "ringing in the ears" but which can appear as almost any type of noise, or mixture of noises. Some people, such as comedian and naturalist Bill Oddie, even hear snatches of music. Whilst musical tinnitus such as Bill's is fairly rare, tinnitus is a very common condition.

What is tinnitus?

Tinnitus is the perception of noises in the head and/or the ears which have no external source. Tinnitus is not a disease or illness; it is a symptom generated within the brain's auditory system.

The noise may appear to be in one or both ears, or in the head, or it may be difficult to pinpoint its exact location. The noise may be low, medium or high pitched. There may be a single noise, or more. The noise may be continuous, or it may come and go.



About one in eight adults (7.1 million people) in the UK have persistent tinnitus, and of those, about 1 in 10 find it affects their quality of life. This means it can cause distress, anxiety, sleeplessness and lack of concentration – familiar symptoms for those living with M.E.

Causes of tinnitus

The causes of tinnitus are still not fully understood, but it is generally thought to be related to change in physical or mental wellbeing, and that these changes aren't necessarily related to the ear.

Some of the more common causes associated with tinnitus are:

Hearing loss – the delicate hair cells in the inner ear may reduce in number due to 'wear and tear' as we age. This gradual change can cause hearing loss, which makes tinnitus more noticeable as it is not masked by external sound

Exposure to loud noise – hair cells can also be damaged by loud noise, which could generate tinnitus

Stress and anxiety – it's not always clear whether stress causes the onset of tinnitus. However, tinnitus may be more noticeable if you are anxious or stressed

Ear infections or ear wax build up – middle ear infections or impacted ear wax can cause hearing loss and tinnitus. This is normally temporary, but it is important to get treatment from your GP

Although not an illness, it is wise to see your doctor if you think you have tinnitus. Your GP will be able to refer you to specialist Ear, Nose and Throat (ENT) and Audiology services.

M.E. and tinnitus

There's very little information about living with M.E. and tinnitus, but a

poll conducted on the Science for ME forum suggests that about 80% of people living with ME have experienced tinnitus¹. In a 2001 Belgian study of 2073 CFS patients, 48.5% of patients meeting the Fukuda criteria and 52.1% of patients meeting the Holmes (CDC) criteria reported tinnitus² – in the general population, this figure is around 30%³.

A more recent study from the Netherlands, looking at over 167,000 people, has identified associations between tinnitus and a number of functional somatic syndromes, including fibromyalgia and chronic fatigue syndrome⁴. People with CFS were 22% more likely to experience tinnitus than those without. More research is needed to identify if tinnitus and these syndromes have underlying mechanisms in common.

Treatment options

Sadly, many people believe that 'nothing can be done' for tinnitus and that they just have to 'learn to live with it.' Whilst it's true that there is currently no cure for tinnitus, there are management tools and methods available to ensure that if you have tinnitus, you don't have to 'suffer' from it.

The British Tinnitus Association's (BTA) booklet "Living with Tinnitus" outlines five top techniques for learning to live well with tinnitus:

Information – you will probably feel better when you find out more about the condition, that it is very common, and that you are not alone.

Correcting any hearing loss – if your tinnitus is accompanied by any hearing loss, then trying to correct this loss with hearing aids is often very helpful.

Sound therapy – if the noises seem louder at quiet times, particularly during the night, it may help to have some environmental or natural sound from a CD, a sound generator, or even a fan or ticking clock in the background. Some people use in-ear sound generators.

Relaxation – learning to relax is probably one of the most useful things you can do to help yourself. Those who practice relaxation techniques say they reduce the loudness of their tinnitus and help them become indifferent to it.

Counselling – techniques such as Cognitive Behavioural Therapy (CBT) can be helpful, either as a standalone therapy or combined with sound therapy.

Tinnitus support

Tinnitus can make people feel isolated and trying to tackle it alone can sometimes feel like a challenge. There is support out there to help you to feel less alone.

The BTA can offer support through their freephone helpline, email, SMS/text and web chat services. Their tinnitus support team has many

years of experience supporting people with tinnitus.

Freephone helpline: 0800 018 0527

Web chat: www.tinnitus.org.uk

Email: helpline@tinnitus.org.uk

Text/SMS: 07537 416841

Take on tinnitus

The BTA has developed a free online learning resource 'Take on tinnitus', designed primarily for people who have just begun to experience tinnitus. However, it is also a valuable resource for those who have experienced the condition long term.

The site, which is designed so it can be used on mobile phones, tablets or computers, includes an initial taster session followed by seven 10–15-minute learning modules covering the fundamentals of tinnitus, hearing and tinnitus, benefits of using sound, the link between tinnitus and relaxation, sleep and tinnitus, the benefits of talking about it and living your life with tinnitus.

www.takeontinnitus.co.uk

Tinnitus support groups

Members of tinnitus support groups often share experiences and advice. It can be helpful just getting to talk with other people who have tinnitus.

Support groups may be facilitated by audiologists or hearing therapists, volunteers with the condition or, in some cases, by staff from local charities working in the area.

If you would like to find out more about your nearest tinnitus support group, call the BTA on 0800 018 0527 or visit www.tinnitus.org.uk

1 Science for ME. Tinnitus poll: Do you experience it? (2018) Available from <https://www.s4me.info/threads/tinnitus-poll-do-you-experience-it.3158/> [accessed 23 February 2022]

2 De Becker P, McGregor N, De Meirleir K. A definition-based analysis of symptoms in a large cohort of patients with chronic fatigue syndrome. (2001). *Journal of Internal Medicine* 250(3) 234-240. <https://doi.org/10.1046/j.1365-2796.2001.00890.x>

3 Schubert NMA, Rosmalen JGM, van Dijk P, Pyott SJ. A retrospective cross-sectional study on tinnitus prevalence and disease associations in the Dutch population-based cohort Lifelines. (2021). *Hearing Research* 411: 108355. <https://doi.org/10.1016/j.heares.2021.108355>

4 *ibid*

Jules' story

My first symptoms of M.E. appeared after I had glandular fever and whooping cough one after the other in 1982. I also suffered an extreme emotional trauma that year and I think my body just couldn't cope and was overwhelmed.

In 1999 I had a knee op that caused nerve damage and that was the real beginning of my more severe M.E. I was finally diagnosed in 2014. I cried when the specialist gave me the diagnosis because I was relieved to finally have a label.

I now have moderate to severe M.E. where even the simplest task can leave me bedbound for days.

I honestly can't recall when I first noticed the tinnitus. I know I used to visit clubs and concerts in the

1980s and often had sporadic tinnitus but that was "normal" back then.

It only really became a problem in the last five years with a constant ringing/whistle that drives me insane. I have always suffered with ear infections and my hearing is now affected when I am in a busy location.

I have found Audible (online audiobook service from Amazon) really helpful at night for tinnitus. I have "sleep headphones" that allow me to fall asleep whilst listening. I can't fall asleep in silence as my brain is never silent.

Being in lockdown and totally isolated I figured my symptoms would ease. However, that wasn't the case and not having contact

with friends and family made my mental health worse which in turn exacerbated my M.E. Now I try to limit stress and physical exertion but balance that with living my life as well as I can.





A dream come true

When James Wythe was so ill with M.E. he couldn't get out of bed, never in his wildest dreams did he think he would one day be author of a best-selling recipe book. But that's exactly what happened. Melanie Hawley reports.

Just over 10 years ago James Wythe couldn't talk, eat, drink, or even stand up. He lost three stone in weight and was rushed to hospital with a suspected brain tumour.

After numerous tests, James was diagnosed with M.E., believed to have developed after a viral infection, and told there was no 'cure' – all he could do was rest and wait.

His mum refused to believe there was nothing that could be done to help her son so threw her weight into finding answers to her many questions.

She arranged for a nutritionist to visit James who advised him to cut dairy and gluten from his diet, which he did straight away. It took a while for James to see an improvement in his energy levels.

James, 31, said: "It was a very gradual process where I improved a little bit each month and still have continued this progression over the

10 years to the point now where I would say I am around 90-95% recovered.

"Having made these first adjustments to the way I ate, over the next 12 months I slowly began to see improvements in my health. I was at last able to get out of bed and walk to the window (a mere 2 metres away) and I could finally hold a conversation that lasted longer than five minutes. For me, these were huge achievements.

"During the two long years of being confined to my bed, the one thing that kept me going was telling myself that I would get better and that as soon as I did, I would help inspire others in similar health situations. I could not accept that this was it for me, and I knew that someday I would get to share my story to support and motivate other people."

Love

It was during this time James fell in love with a girl called Luise. They had met through mutual friends previously and when she found out James was ill, she asked if she could visit him. It was a 90-minute round trip but that didn't deter Luise from dropping by again and again just to sit on the end of his bed and talk to him. Their relationship blossomed and they eventually moved into a flat together.

With Luise at uni and holding down a part-time job, James had to make sure he was able to cook and take care of himself.

"I taught myself how to cook from scratch with the precious five or 10 minutes of energy I had. I took a chair into the kitchen so that I could sit down and rest whilst making my food."

Seeing the positive benefits his recipes were having on his health and mental well-being, James's passion for food grew.

Website

Family and friends were fascinated by James's easy and quick recipes, which were all gluten-free, dairy-free, egg-free and mostly plant-based, and persuaded him to share them with the wider world. Encouraged by such support, in 2016 James launched his website *Healthy Living James* and hasn't looked back.

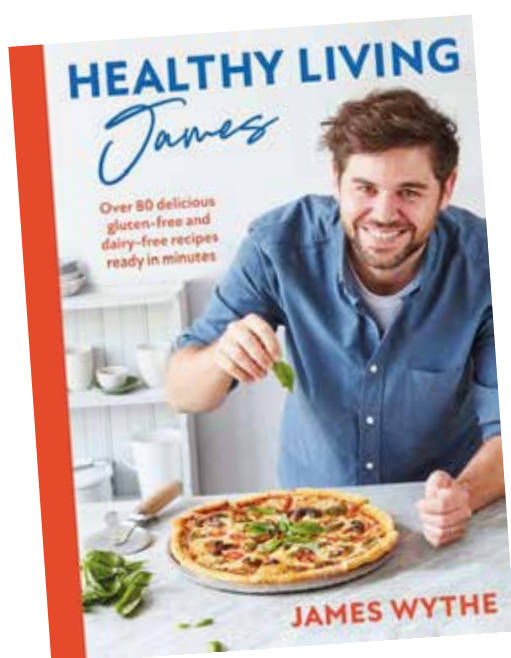
His blog on the website attracts 300,000 page views a month and he has nearly 200k followers on Instagram, where he also shares recipes. His biggest dream – to publish a recipe book – came true this March when *Healthy Living James* hit the bookshelves. The book showcases some of James's best recipes which also include easy options to add in meat or fish should you wish. Using affordable supermarket ingredients, his recipes are also suitable for people with allergies.

James, who is now married to Luise, said: "Cooking became an escape for me, and still is. When I cook, I forget about everything else going on around me and just focus on what I am making. This especially helped in the worst parts of my illness because it switched my mindset from what I couldn't achieve anymore to what I could. And then came the health benefits that also kept me motivated to keep going."

Website: www.healthylivingjames.co.uk

Instagram: @healthylivingjames

Twitter: @HealthyLivingJW





One-bowl 3 bean salad

A gluten free, vegan plant-based and protein-packed summer salad that's simple to make and ready in just 10 minutes. It can be stored in the fridge for up to 3 days. This recipe will serve 6 side serving size portions.

Ingredients

- Black Beans
- Cannellini beans
- Kidney beans

But you can use whatever beans you have in the cupboard. You can add olive oil for the salad dressing. James loves to add cider vinegar and maple syrup as well as olive oil for the salad dressing.

Add the following chopped vegetables (or the vegetables of your choice):

- Red pepper
- Carrot
- Celery
- Cucumber

You may also want to add in some freshly chopped coriander.

Alternatives

Beans can be swapped for chickpeas/lentils

Veg – use what you have

Coriander can be swapped for parsley

You can try adding in chopped onion, crushed garlic and smoked paprika, but these are not essential.

Method

1. Chop your chosen vegetables.
2. Add your drained and rinsed beans to a large mixing bowl along with your chopped vegetables.
3. Finally add the salad dressing ingredients and stir until well combined.

Now you may enjoy your freshly prepared salad or store it in the fridge for later.



10 minute creamy tomato soup

This is a creamy tomato soup that's gluten-free and dairy-free, suitable for both vegetarians and vegans.

Ingredients

- Glug olive oil
- 1 red onion roughly sliced
- 2 garlic cloves roughly sliced
- 1 tbsp dried basil
- 690 g jar tomato passata (or swap for 2 x cans chopped tomatoes)
- 1 heaped tsp veg stock powder (or 1/2 veg stock cube)
- 2 heaped tbsp coconut yoghurt (swap for other yoghurt or leave it out)

Method

1. First slice your onion and garlic
2. Heat your pan on a medium heat, add in a glug of olive oil, the chopped onion and garlic along with 1 tbsp dried basil and fry until the onion softens (2 minutes)
3. Now pour in your passata, 1 heaped tsp veg stock powder and 2 heaped tbsp coconut yoghurt and stir
4. Simmer for a few minutes so the flavours combine
5. If you prefer a chunkier texture, the soup is ready. For a smooth soup, whizz with a hand blender or transfer to large food blender and blend until smooth. Season to taste!

Now you may enjoy your freshly made soup. It can be kept in a sealed container in the fridge for a couple of days or allowed to cool and freeze for another day.



These recipes can be found in *Healthy Living James*, published by Headline Home and available in bookshops and online, RRP of £20.

Win a copy of
*Healthy Living
James*
See our Giveaway
on p 30

A jazz CD?

Music to Tim's ears



We continue our series about people with M.E. and their hobbies and how their favourite pastime is helping them manage their condition.

Tim Martin, buyer and seller of CDs

I've learned a lot about managing M.E. since the nineties, mainly through pacing myself. Fortunately, my interest in sport was always minimal so I lost nothing there but managing work and a small child took its toll. Fast forward to the 2010s. By now, regular employment was a thing of the past. I became self-employed in 2014 as a consultant and copywriter, mainly because it meant that I dictated when I worked, not the other way around.

Marketplace

Music has always been a key part of my life and I long ago discovered the various places where cheap CDs were to be found. Over the course of a year or so I built up a small pile of discs that had been played once and were unlikely to be played again.

With domestic pressure to free up some space becoming intense, I decided to try selling them on Discogs rather than simply ditch them. Originally created as a hobby project in 2000 by Kevin Lewandowski, Discogs has grown to become a definitive resource for vinyl and CD recordings. It is a huge site that started life as a database of music. They claim to have nearly 15 million albums, EPs and singles catalogued. Alongside this, a marketplace has grown up connecting buyers and sellers around the world. With millions of discs for sale and thousands of sellers, it is the largest music market on the planet, catering for everything from a cheap chart hit to obscurities worth hundreds of pounds.

So, what do I sell? Mostly jazz, because this is what I like best, but also classic and progressive rock, folk, blues, pretty much anything except "Now" CDs and pop from the last 25 years or so. Why CDs? Because they are easy to post, convenient to store, and because I don't like vinyl. I remember the days when the clicky poppy cheaply produced vinyl was so awful that it made me switch to cassettes, despite them being nearly as fragile. While we are on the subject, I don't like the term "vinyl," particularly when it is made into a plural. They are LPs or albums, singles or 7 inches. If you were to apply the same logic to CDs, you would call them polycarbonates... But I digress. The vinyl revival may be headline news, but CDs are where the collector who is interested in music still lives, especially in jazz which ideally suits the extended play time of the discs. An artist's whole career can often be squeezed into a double-disc set.

Flexibility

What are the advantages of an online CD shop as a hobby, or for me over lockdown, a valuable source of income? It can be done sitting down. If I feel like a bit of time out, I can go for a gentle wander round the charity shops or to the second-hand record shops that I've made friends with. If I don't fancy a walk, then scouring the various places I've found to buy discs from online, or checking my adverts, can be done at my desk, on the sofa with the dog, or even in bed on a bad day. It connects me to people, through the Discogs forum, on Facebook, and by

Messenger. There is always someone to talk to and it never requires much effort.

Where do I buy discs? Mostly from people clearing houses or downsizing. If you have a collection of my sort of music, please get in touch: I'd love to hear about it. My best buy? I was away for a few days and in a charity shop in Chipping Norton, I picked up a CD. "What's that?" asked my non-jazz loving friend dubiously. "Just a jazz disc," I said. The man in the queue in front of us turned round and asked; "I don't suppose you know anyone who wants to buy lots of them, I've been trying to get rid of my Dad's for a year..."

Shopfront link

www.discogs.com/seller/Selling-Songs/profile

To sell me your CD collection get in touch tim@sellingsongs.co.uk



Bio

Tim Martin is 58 and lives in Clevedon, Somerset. He has had M.E. since contracting glandular fever in 1995. He spends most days in his shed, writing blogs and websites. For fun he writes about and listens to music and tracks down strange jazz CDs.

Dear team

In the first of a series, our friendly Information and Support team answer questions on different aspects of living with M.E.



Q: My health has not been good for at least six years. My GP finally diagnosed me with M.E./CFS after what seemed like a long process of testing. I am not sure that she understands the condition very well. During my last appointment she has suggested I try anti-depressants. My mental health has definitely gone downhill as a result of being unwell for so long and the isolation of being stuck on my sofa for so much of the time; however my priority is improving my M.E. symptoms. How can I get my GP to listen to what I'm saying so that I can get the right care and support?

A: I'm sorry to hear that it took you so long to get a diagnosis, and that you continue to struggle to get the care and support you need. Unfortunately you are not alone in this; we know that many GPs feel under-confident in diagnosing M.E. and supporting patients with the condition. A minority also report facing disbelief from their doctor.

If you decide that you'd like to 'reset' your relationship with your GP, or if they are not a good fit for you, we have some guidance on our website. This looks at education of health professionals, communicating with your GP, how to have your voice heard or changing GPs.

Advocacy Service

Additionally, our newly re-launched Advocacy Service can help to ensure your voice is heard and your rights and wishes are upheld. You can find copies of these documents on our website, or you can contact us to request either a printed version of these documents or a referral to our advocacy service).

You could ask your GP to refer you to an NHS specialist M.E. clinic. These exist in some areas of the country for people who have mild-moderate M.E., although unfortunately the vast majority are in England. These centres have multi-disciplinary teams, and aim to teach patients about the illness, living with the condition, and how to manage and improve their symptoms.

Another option is to self-refer to Action for M.E.'s Healthcare Services (see p 8). We have a doctor, counsellors, physiotherapist and multi-faith chaplains, who can all offer remote appointments by phone or video call. At the moment we are unable to provide these services for free, and so charge to cover costs. Bursary support is often available for those on low incomes.

Pacing

You might also benefit from self-management strategies. For example, 'pacing' looks at establishing your 'energy envelope' and working within that envelope in order to try to avoid crashing. Our pacing booklet is online or available in paper copy on request.

Isolation can be a huge issue for people with M.E., particularly those who are more severely affected. Our M.E. Friends Online forum is a place for shared experience. Moderated by Action for M.E., you just need to register online, send a message and see if there's someone out there who would like to make contact. Connecting with someone who can

say "I know how you feel" can be a powerful thing.

M.E. shouldn't be treated with antidepressants. As you highlight however, many people with M.E. can experience poor mental health as a result of living with the condition (in line with many other physical conditions). It's worth talking with a doctor about what options you have for improving your mental health, alongside options for healthcare for M.E. This discussion with a doctor should be respectful and collaborative, and you should not feel pressured into taking any approach that doesn't feel right for you.

Action for M.E. is working hard to develop and promote education resources for healthcare professionals. It's not your responsibility to educate your GP but if you feel empowered to do so, you can signpost them to our free online learning module on the diagnosis and management of M.E. It also links to the recently updated NICE guidance on M.E./CFS. It's professionally accredited so hopefully a win-win for both you and your GP.

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

"I see this tale as one of neglect"

Jill East has consulted dozens of GPs but her health continues to deteriorate.



Content warning This article contains frank descriptions of symptoms of M.E. and other conditions that some readers may find upsetting. We appreciate that different people will experience different symptoms of M.E. however we want to ensure that the voices of people with severe M.E. are heard. If you are affected by any of the issues raised in Jill's story, please contact us for information, support and signposting (see p 2 for contact details).

My motive in writing is to leave a record of my thoughts. I am 84-years-old. In August 2021 I was given a multiple diagnosis:

1. two compressed vertebrae – cause 'lifestyle'
2. crumbling of entire skeleton – cause 'old age'
3. acute diverticulitis due to a lifetime of constipation
4. cancer of the left ovary.

In May the same year I had sought help believing I had a kidney infection, which had resulted in a series of tests and this compound diagnosis. During the intervening ten weeks I had lost 7kg in weight and two inches in height.

Painful

In the months since I have lost a further 4kg but have regained the ability to stand a little straighter. My back is still too painful to allow me to leave the warden-assisted block where I now live.

I call the condition "Total Erosion" and feel it has to two causes, the first of which is M.E. It began when I was fifty and half my adult life has been governed by the condition. Until that time I had enjoyed excellent health and was strong. I was politely asked to retire, and since then I have had no caring, informed or interested help from the medical profession, although I have sought it. Any help at all came in the guise of GET, CBT

etc., normally preceded by the words: "The only thing I can offer you is..." (Due to several moves I have consulted more than 30 GPs.)

The second cause of my being now in this rapid decline is a series of events which began when I moved house from Banbury to Worthing in July of 2019. Aside from M.E., I was reasonably healthy at that point. One day I suffered dreadful back pains, even when in bed. I went to the local A&E that night in a taxi and was treated carelessly and perfunctorily. The next day I was unable to cope and in such dreadful pain I called 111 and was fortunate enough to speak with a doctor who called ahead and sent me to spend another couple of night hours. There was an improvement in attitude, but still I was told to take only paracetamol – codeine would encourage the constipation. I took a lot as the pains were similar to birth pains – waves of scream-level pulses up my back.

Bedbound

I moved house to Worthing in great pain, my son being kind enough to drive me. The back pains diminished over the next weeks, then suddenly returned, leaving me bedbound. This was diagnosed as kidney infection and I was given antibiotics, which appeared to bring about a cure but two weeks later it returned, meaning more antibiotics. At this stage I began to wonder whether

the pains on moving house weren't muscle strain as we had all assumed, but a kidney infection from the start.

I confess I see this tale as one of neglect, the final stage beginning at the end of May when despite my very clear requests/descriptions to 111 it took five days and five atrocious nights of screaming pain to get more antibiotics to me. Since then I have found life extremely difficult, but have engaged a carer for three hours a week. I could not possibly cope without her.

I am pleased to be able to add that during the last few weeks I have been astounded to find the pains lessening and needing fewer pills. During the entire time, I was never given strong pain killers although after the 20 minute phone call from the doctor I was prescribed codeine. The dose given was 15mg and I had to take four to make a difference.

Deterioration

Blame is useless, but this string of incidents have been the cause of the rapid deterioration I am now suffering. GPs down the years persistently groaned and looked at the ceiling at mention of M.E. Now I am fighting tooth and nail for an MRI scan (privately – Benenden is paying) – this being the only test left which might reveal something helpful.

I am certain the cause of all this is rooted in the thirty-year neglect of M.E. and is far from being the expected deterioration of old age.

"Vitamin D3 worked for me"

Peter Buchan credits vitamin D3 and healthy eating for his return to health.

I was diagnosed with M.E. in 2000, eventually having to give up work – effectively being retired aged 45.

Early on I discovered that eating sugary foods such as cakes and biscuits made me feel better, but only for a while. This was not a healthy diet, so with my wife's help I explored low GI foods that release their energy slowly over a long period. So now my regular diet is to avoid processed food, and when I'm hungry I eat home-made muesli or home-made wholemeal bread.

It was not perfect, and there were times, particularly in the winter, when it hardly helped at all, but in the summer I had enough energy to go with my wife on cycle camping holidays. Some of these were in bright clear sunshine for maybe two weeks, and I did not have any M.E./CFS symptoms. In fact it felt like I had never had M.E.

When I discovered that the cause of this energy was vitamin D3 (the only vitamin D that we make from sunshine, and technically a hormone), which our body makes when our

unprotected skin (not even sun screen) is exposed to direct sunlight, I started to experiment with vitamin D3 supplements to try and re-create that energy, eventually taking 100 micrograms (mcg) twice an hour (mimicking being out in the sunshine), about 11 or 12 times a day.

The effect was just what I hoped for, and my energy levels rose to those I have experienced when in the summer sunshine. Taking one tablet at a time became too confusing, and I always forgot when I had taken the last tablet, so I started taking two at a time every hour, and that was noticeably more reliable and efficacious. This meant that I was able to walk briskly when before I could only manage a leisurely stroll, and keep up with my wife on our walks; drive and do the shopping by myself, sharper thinking – being able to make decisions quickly and decisively; more confidence generally – being able to plan for tomorrow.

This January, we had to drive 250 miles to my Mother's funeral. Because I was feeling so full of

energy I said I would drive. I took my first 200mcg vitamin D3 as usual, but noticed that my head was a lot clearer than it has ever been. I decided that I wouldn't take any more vitamin D3, and see what happened.

At lunch time my wife asked me if I was OK and would I like her to do some driving. I said 'No, I was enjoying it', in fact I felt I could keep going all day. And I haven't had to take any vitamin D3 since, in fact I feel as if I am going from strength to strength, and I am amazed what I can achieve. But if the M.E. symptoms ever return I now know what to do.

Action for M.E. does not recommend any individual treatments or management approaches. Because we don't yet understand the biology of M.E., there are no targeted treatments that work for the majority. A treatment approach that you find effective may or may not have a different impact on someone else with the illness, and vice versa.

The October 2021 NICE guideline for M.E./CFS advises health professionals to "be aware that people with ME/CFS may be at risk of vitamin D deficiency, especially those who are housebound or bedbound. For advice on vitamin D supplementation, see the NICE guideline on vitamin D."

While NICE also advises that "there is not enough evidence to support routinely taking vitamin and mineral supplements as a cure for ME/CFS or for managing symptoms," we hear from many people with M.E. like Peter who

report some benefit, alongside others who experience no noticeable effect. ME Research UK reports (tinyurl.com/MERUK-vitD) that M.E./CFS, as "a chronic illness with immune, infectious and cardiovascular aspects, there is at least a possibility that vitamin D deficiency/insufficiency could be involved in the development or maintenance of the condition or its specific symptoms [...] vitamin D inadequacy has been linked with impaired neuromuscular functioning and chronic pain, two important facets of the day-to-day experience of ME/

CFS patients."

Regarding supplements, the British Dietetic Association (BDA) (tinyurl.com/BDA-MECFS) advises: "You may be at risk of side effects if you take doses above the recommended daily amount. However, people with ME/CFS may be at risk of Vitamin D deficiency, particularly those who are bedbound or do not go outside. It is recommended to take a daily supplement containing 10µg (micrograms) or 400IU (international units) vitamin D."

Would you like to share your story? Please email interaction@actionforme.org.uk or write to *InterAction*, Action for M.E., 42 Temple Street, Keynsham, BS31 1EH telling us in no more than 700 words about your journey with M.E.

"You can turn the bad things from your life into good things"

Emma Calder, 21, found chronicling her devastating M.E./CFS journey through poetry to be cathartic. Now her first book has been published and she couldn't be prouder.

SPEED READ...

Emma Calder used her experience of having M.E. to write a collection of poetry describing the trials and tribulations of living with the illness. Called *Off My Chest*, Emma's book has now been published by Olympia Publishing. Emma, 21, said: "*Off My Chest* proves to me that you can turn the bad things from your life into good things... I can be a writer and having chronic illnesses will not stop me."

I began having symptoms of Chronic Fatigue Syndrome before my fifteenth birthday when I was overworking myself during mock exams. I kept working and working until I was burnt out. I thought that meant I had worked hard, that I had given it my all. I thought I had the flu (which made sense since it was Christmas time), but a month went by and the symptoms stayed.

I kept going to doctors, getting blood test after blood test, X-ray after X-ray and they all came back normal. I was 'fine'. I wasn't fine. After persisting for six gruelling, confusing and frustrating months, I was diagnosed with M.E. I had a diagnosis. Everything was going to get better now. It didn't. My specialist and I didn't work on how to manage my fatigue. We had to throw all of their methods out of the window. It was the year I took my GCSEs, my school was exceptionally unwilling to help.

Unaccommodating

I was taking an extra GCSE which I was forced to drop and I was advised that I should drop another subject; I chose history. My workload dropped, which did help, but I was nowhere near having a fair playing field. I needed rest breaks during exams, I needed longer doing the exams, I needed shorter school days, I needed to take my exams at home. It felt like pulling teeth to get those things.

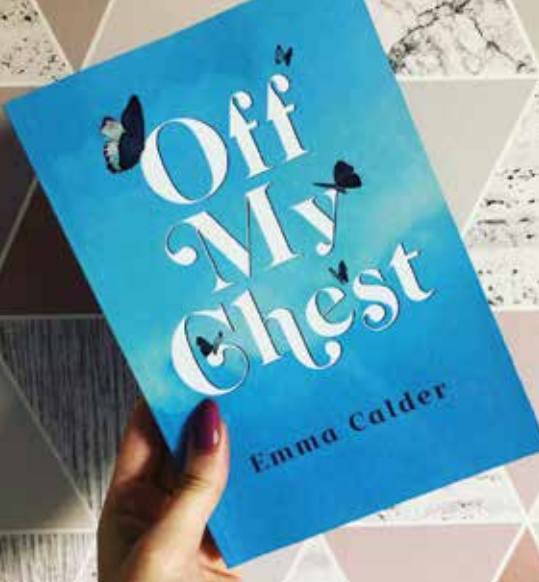


My exams were nearing closer and closer and I couldn't have felt any less prepared. By February, my M.E. specialist had arranged a meeting at the school. It didn't go very well. She told me that she had never dealt with a school so unaccommodating. I did my exams at home with rest breaks, no extra time. I had to do boom and bust to survive. I passed. I genuinely don't know how, but I managed to pass.

Confusing

College was a fresh start for me. High school is over, all of the bad things have stopped. I wanted to leave all of my CFS struggles in high school. It can't be that simple though, can it? History repeated itself. Differently, mind you. The college was more willing to help in some ways, unyielding in others. Communication was lacking. I was allowed to go to student support to rest when I needed but I was scolded by my teacher when I missed a lesson. Told I had to come in early to make up for what I missed. I was told the work I had missed would be sent to me via email so I didn't fall behind.

It was so confusing; a game of 'he said, she said'. I couldn't do that. I could barely do the school days I was attending. I couldn't do it anymore. I barely survived my GCSEs: A-levels are significantly tougher. I'm not well enough. Doing



exams like this again would break me. And it's a real shame because I love learning. I hate exams, though. College wasn't the fresh start I wanted, after all.

Dual-diagnosis

Everything got worse, so much worse. I had stomach pain and back pain added to the fatigue. I started losing sleep. Throughout the entire month of November, I didn't sleep a wink. I was given medication, after much reluctance, and it helped. For a bit. The pain still was there. The sleep was better but not good. I went to a therapist to try and help. Everyone told me I wasn't sleeping because of my mind. "Your mind keeps you awake", is what they'd say. I went and I quickly ran out of things to say. The therapist stopped the sessions and concluded, once again, that I was fine.

I was moved from the children's hospital M.E. department to an adult clinic. There I was diagnosed with a Dual-diagnosis of Chronic Fatigue Syndrome and Fibromyalgia. I had learnt all of the techniques to cope with M.E. (boom and bust, etc.). Now, I had to find help for my pain.

Expressing myself

That was a long journey. Doctors injecting me with steroids, making the pain worse. Surgeons telling me I was lying, making me cry in front of my mum and dad. More mindful exercises that I could never take seriously – I can't do meditation, I'll just laugh; it's not for me. I was trying so hard to get better and nothing was working. I couldn't cope. That's

when I started writing. I was just doing it as a way to express myself. Writing notes on my phone, getting everything I was feeling off my chest.

Before I knew it, I had so many notes on my phone. Enough to write a book. I have always loved writing. During my GCSEs, in an attempt to keep myself sane, I wrote a book. Probably an incoherent book that was poorly structured but it was helping me keep sane. This time, I had no exams to focus on. I didn't have to sacrifice my creativity anymore. I put all of the poems from my notes into a Word document and sent it to my dad. I was nervous, letting someone read how I was truly feeling. I didn't need to be. My dad is fantastic.

Disbelief

Over the months, my fatigue and pain were relentless. I was working so hard, doing everything I was told yet I seemed to keep getting worse and worse. I added more poems. If I'm being honest, it took the pandemic for me to structure the book. I had all of the poems that could tell a story, I just hadn't found the time to do so.

I submitted my book to be published numerous times and with each rejection, I changed the book to be more accessible. Even though I wrote this book with invisible illnesses in mind, I wanted it to reach everyone. I wanted my book to be a tool for learning. I must have done something right because I received an email from Olympia Publishing saying they wanted to publish my book. I stared at my phone in disbelief. I was so happy, so shocked. It didn't feel real but it was. I did it. I wrote my first book.

Powerful

It took me around four years to write a coherent book, in total. I jumped (and sometimes tripped) over hurdle after hurdle. My book is finally in print. This is something I have always wanted. I could cry with joy. *Off My Chest* proves to me that you can turn the bad things from your life into good things. From the darkness

comes light. With the sadness, I can appreciate the joy. I can be a writer and having chronic illnesses will not stop me. If anything, it makes me better. I have a different perspective and that is a powerful thing.

Dedication

My support system is amazing. My parents are so understanding, my family and friends are patient. My grandma gave me a great source of joy and I'm sad that she'll never know that I've written a book. So, to combat that, I dedicated the book to her. My family is small but we are very close. There is more love than anyone could ever need. At this point, I count my close friends as family. My chosen family. They continue to stick up for me, laugh with me and are patient with me. They understand. I don't know what I would've done if they didn't.

Biological Clock by Emma Calder

The clock is ticking,
All the time I'm killing,
I'm petrified of the future,
Rely heavily on humour,
Get lost in my books,
Reorganise my room; every nook.
I get excited when I have a hospital appointment,
Get sad when they're cancelled; all the prevailing disappointment.
I'm young, that's all I hear them say.
But, if they don't help me, I'll have the same problems when I'm not young, someday.

I have chosen this poem because I think so many people with M.E./CFS can relate to the feeling of helplessness, of being brushed off. I hope this poem helps those people feel seen and heard.

Off My Chest by Emma Calder is published by Olympia Publishers at the RRP of £8.99. It is available from book shops as well as online outlets.

You can win a copy of Emma's book as part of *InterAction's* Giveaway competition on p 30.

InterAction

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

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

Box numbers

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

InterAction audio version

With the help of a team of volunteers, we are able to provide an audio version of each issue of the magazine via Soundcloud (www.soundcloud.com/actionformeaudio). For Members who are unable to get online, we also offer the audio version on CD (this is a free service but donations are welcome). To add your name to the CD distribution list, please get in touch (see p 2).

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The *InterAction* editorial board is Dr Katrina Pears, Carina Norris, Clare Ogden, Jayne Taylor, Sonya Chowdhury and Tilly Creighton. Thanks to proofreaders Michael Campbell, Rebecca Young, Jamie Crummy, Nina Crummy, Sherry Brown, Vicky Anderson, Ruth Hobart, Dr Katrina Pears, Tracey Taylor, David Burton, Josie Huntley, Karen Jones, Katherine Langford and Simon Everitt.

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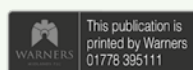
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Giveaway

Win these great prizes

We are giving away **James Wythe's Healthy Living James** book which contains 80 gluten-free and dairy-free recipes, along with **Emma Calder's Off My Chest** poetry book which chronicles her six year-long journey with M.E. For good measure we will throw in a 'Poetry Lover' mug featuring poetry quotes in a distressed typewriter-style font and some herbal tea.



How to enter

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

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

The deadline for entries is Monday 13 June 2022.

Good luck!

Terms and conditions

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

Draw closes at midnight on Monday 13 June 2022. The winner will be notified via telephone or email. The prize consists of *Healthy Living James* by James Wythe RRP £20; *Off My Chest* by Emma Calder RRP £8.99; one poetry mug from Etsy RRP £15; and a box of herbal tea to the value of £4.

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

Entrants must be 18 or over.

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

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

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

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

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

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

Entering implies acceptance of these rules.

Rose's diary

It is dark outside... but the fairy lights on the garden arch remind me that despite the darkness there are still sparkles of hope...

My tiny garden is my creative outlet – I am very fortunate to have a weekly gardener who has been with me for many years; she is more than happy to act out my creativity.

My garden is adorned with daffodils dancing in the breeze and tulips are coming up through the earth to mark a new beginning. Spring is always a good reminder to hold onto hope's hand.

Hidden Warriors

Living day to day with M.E. is so very hard. From the young age of eleven I had mild M.E. but it was undiagnosed. I struggled for years with fatigue and flu flare-ups. It is unfair that I was not diagnosed because it meant I carried on "pushing" until I became severe after a virus. I know so many are in the same situation: my advice would be "do not push".

I often wonder how many 'Hidden Warriors' there are behind closed doors living with a chronic illness. The outside world judging because they cannot see the invisible disability. Judging the brave face but not knowing the physical or emotional challenges. Warriors put on an armour, but they are often crying inside. We all need nurturing and kindness. I spend SO much time in isolation and the smallest gesture of kindness torches the darkness. People can be so very cruel because they do not understand you or your situation. I just wish everyone could take a day in our pyjamas and feel

what it is like – really live it. Not all of us are hardy, many of us are sensitive and we are doing our best to navigate the illness and life stressors. 'Hidden Warriors' deserve a medal.

Reliant on paid help

When I am bedbound no one sees me. I am far too ill for the carers to call before 12pm so my routine is to stay in bed, to rest before they attend but I am always overdrawn in spoon energy and running on adrenaline.

I honestly wish that I had a partner to balance out having paid help. I find being solely reliant on paid help incredibly stressful. I signed with a care company before Christmas in hope a managed service would be a good option as well as having private carers. Finding the right match is not always easy for the care company and some of the attitudes of their carers have been terrible. Some carers prefer clients they can control, but I am trying to teach a different perspective – which is exhausting. However, I have given constructive feedback and the Care Manager has stated that my carers will now be given training on M.E. and they have asked for my input on this training, which is very encouraging.

Boundaries

The neighbour has caused me more issues. I do not understand when I am bedbound/housebound and they do not even see me. In the New

Year she planted in a green space which is my boundary, and she even revved her car and parked in my bay outside my lounge window which caused me so much upset. However, I will not let her bully me and the housing association are now dealing with the matter.

Being bullied with severe M.E. is horrendous. I was bullied at school and even in the workplace but never spoke out as I was too shy. I was mistreated by my family and ex-partner. I have worked so hard to remove negative people from my life for my own self-care and self-worth. Along this journey I have grown and empowered myself with the understanding that not everyone will align with you but that does not give them the right to mistreat you.

Voice for the vulnerable

I never had a voice when I was young. Too shy to hold my hand up in class. Too scared to stand up to the bullies. Every time I stand up for myself, I am standing up for someone who is vulnerable. Not everyone likes a voice, but I will not be silenced. Voicing in a constructive way enables you to be heard. It is exhausting and it requires you to sit on your emotions but with the support of my admin carer, I am voicing to those I never would have imagined. Voicing for positive change...

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



Creative corner

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

These three poems were posted on our Friends Online forum, showing just how talented our wonderful forum members are. If you would like to join and meet like-minded people for friendship and support, you can register by visiting www.actionforme.org.uk/forum

Unexpected angels

For every tear you cry
And every struggle that you face
You are so loved and thought of
often
and angels drape you in white lace.
Their gentle hands will soothe you
Letting you know you're not alone
And your forum family are waiting
near
on computer or through your phone.
To you who may be reading this
In the darkness of the night
Hold on for sunbeams are on their
way
To guide you into daylight.
In the darkness and the silence
Things can seem so very tough
But you are tougher despite your
strife
And will get through these times so
rough.

Take heart my darling
For you aren't alone
Even when you're by yourself
For you are held in friendship dear
And that is life's true wealth.

If it weren't for this cursed illness
We perhaps would never have met
Let's polish that silver lining
So its shine we'll never forget.

Bambi

Harmony

Volumes scattered on the timber
floor, half read, discarded
A piano with the lid shut, untuned,
unpolished
An overgrown garden spilling into
the next house, sharp raps on my
front door in the evening
Grime on the kitchen sink, blocked
drains, a musty stench
Cat fur of a distant memory, felt on
my bare feet twice

But a book imagined, a tune
refrained, a friend discovered
The air breathes a spring morning
The wine bottle casts the sunlight
The garden flows into itself
The front door is open

So keep looking

Apple Crumble

Oh, Ukraine

No birds fly
Just screaming metal
In our sky

No grass left
Just mangled fragments
Animals bereft

No trees stand
Just barricades
Arranged as planned

No laughter now
Just sighs and tears
As our beaten bodies bow

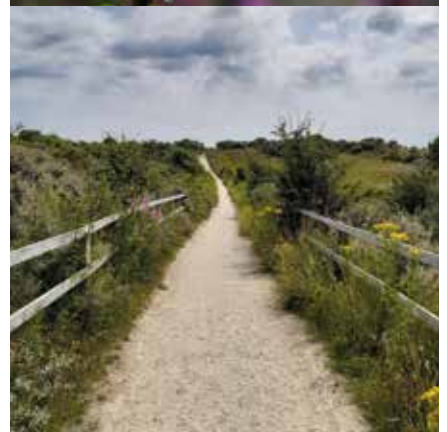
No buildings tall
Just burnt out wrecks
Someone please just end it all...

tedious webs

Reflecting the natural world

"During lockdown I practised photography with a DSLR camera my brother-in-law lent me. I love being able to capture the beauty of nature. Instagram has given me an outlet to share this with others, as well as to get inspiration. Here are a few of my favourite pictures." (below and opposite)

Anna, @acheshire1





FUNDRAISING

Flat Tyres for M.E.

On 12 April, James and his friends took part in an online gaming fundraiser on the streaming platform, Twitch.

James has had M.E. for 10 years, since he was 17. He went from being incredibly active to bedbound and struggling to be awake for more than four hours a day. James turned to Twitch, where he found friends and an interest in gaming. James said:

"I've always been very open online about how my health is and how it affects me. YouTube and Twitch are what has kept me sane during all of this. It has even led me to talking to a bunch of people, becoming close friends and playing some games with them. I have featured in a lot of their videos

where my health often crops up explaining why I had to miss a session or something. I have always wanted to do more to try to help get word out about this awful condition that so little is known about."

During their fundraiser, which they named 'Flat Tyres for M.E.', they raced difficult cars in a simulated racing game, whilst completing challenges and answering quiz questions about M.E., designed to raise awareness. There were also donation 'penalties' for mistakes made on the course, and the team streamed their gameplay on Twitch, to ask their followers for donations. After a very chaotic but fun-filled race, the team had raised an amazing £1,185.



You can watch their action-packed race, and listen to them answering M.E. quiz questions at www.twitch.tv/jameskn and www.twitch.tv/izzi280

Thank you so much to James and his friends for fundraising an incredible amount for Action for M.E. and for raising awareness about the illness.

Reaction

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

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

Star letter

Speed read will help those with brain fog

In *InterAction* 109, there was a request for précis of articles to help those of us with brain fog. You might like to know that our local paper, the excellent Maidenhead Advertiser, has been providing, in the print edition rather than its online edition, a "speed read" block for most medium and long news items. They are useful and could be a valuable asset to *InterAction*.

Ken Manley

Editor: Ken followed up his letter by sending us examples from his local paper (see photo) and we really appreciate his efforts. We took his prompt and as a result readers may have noticed a "Speed read" box on several of the articles in *InterAction*. This idea is in response to Sandra Putnam's letter in *InterAction* 109 where she said she would like to see summaries of articles for people who aren't able to read an entire story.

What do you think of this idea? Has it helped you? We'd love to hear your thoughts. If readers are in favour, we will look at extending it throughout the magazine.

Please get in touch by emailing interaction@actionforme.org.uk or writing to us at *InterAction*, Action for M.E., 42 Temple Street, Keynsham, BS31 1EH.

As author of our Star Letter, Ken receives an Action for M.E. goodie bag.



Good idea, Sandra

I've finally got round to flicking through the Christmas 2021 magazine and totally agree with Sandra Putnam's letter on page 34.

With moderate to severe M.E. I struggle to read long and/or in-depth text. I often flick through magazines reading the headlines and looking at the photos so a summary of the key topics contained would be very helpful.

Hope this helps to shape the magazine going forward. Keep up the good work!

Samantha Wilkinson

CBD oil: my experience

I have been using CBD oil now for some 18 months (*InterAction* 107). It had no effect whatsoever for three months, but then I noticed that my energy levels were improving slightly.

I think I have fewer relapses after overdoing thing too and I have definitely needed to take propranolol less frequently. I take it when my heart goes into 'overdrive' when I have overdone it yet persist with activities. I often used to get tachycardia and ventricular ectopics, which propranolol cured. However, I have seen no effect on back/joint pain or insomnia. My fibromyalgia remains as it was.

Carol Geddes



Festive connection

Christmas Angels is an excellent project. I received some lovely cards, which, as a housebound, severe M.E. sufferer, made me feel like I'm not alone in this illness. Some cards were from others in the same position as me and it made me feel like I'd made new friends, friends who understand me.

Andrea

Editor: This was one of many lovely comments received by Action for M.E. in response to last year's Christmas Angels project. We will publish more feedback in the Autumn edition where we will give information about how to take part in this year's initiative.



Get in touch
and share
your views

Help from your council

When I moved to my new home I contacted my local council to ask what help they could offer a disabled person. I was told they offer an assisted bin collection, which means all I now have to do is put my rubbish outside my front door and they collect it from there.

I was also told that as I am disabled I could apply for a reduction in council tax as my property is disabled-friendly. I needed to fill out a form and, after a month, I was told I was successful and my council tax band would be reduced to the band below.

If you live alone, you can also get a single person reduction of 25% off your council tax.

Different councils may have different rules but it is worth looking into, or, if you aren't well enough, asking someone else to apply for you.

Miriam

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).

Support for children

My name is Sam Mincher and I'm in the early stages of research for a children's book with the intention of helping parents with M.E. communicate the impact of the illness to their children. I'd also like to help children process the difficult emotions that will arise during this process. My Mum has had M.E. for more than 25 years so I want to create a resource that would have been helpful for when I was younger. At this stage, I'm looking for input from parents who have had M.E. If you are able to help, please complete the following survey: <https://form.jotform.com/220582671574056>.

Alternatively you can email sammincher@hotmail.com

I will also be looking for an illustrator in the future, so please let me know if you or anyone you know have any relevant skills and would be willing to contribute to the project.

Sam

Help needed for extreme sensitivity

I am posting the following message on behalf of Alison from Oxon.

Does anyone know of an air purifier which is effective for removing smoke (not cigarette smoke) from wood, possibly coal fires? My neighbours have a lot of fires and despite closed windows I am plagued by it. It would be useful if it was effective for hydrogen sulphide. I am considering the BluAir range and, or possibly the IQ ones but I think they are expensive.

Also, I am urgently looking for a holistic/alternative-type doctor who would treat adrenals (and thyroid) in the context of M.E. and extreme sensitivity. As the adrenal situation is severe I need someone who would consider prescribing Prednisolone (I can't tolerate hydrocortisone). I would be very grateful for any suggestions of who might help (or who to avoid). I would be consulting at a distance unless they were able to visit Oxfordshire. Is anyone consulting Dr Hemby, Dr Kenya, Dr Eric Ashes or Dr Econs for similar?

If you are an Action for M.E. Friends Online forum user please leave any messages in the forum (my user name is KACATAA). They can be printed off and posted to me or call and leave a message for Alison on my landline – 01608 810188. I can ring back, preferably to a landline number.

Kathy

Tips

Magnetic help

I find a magnetic 'To do' list and calendar to be an invaluable help. They stick to the fridge so are in a prominent position to remind me of the things I need to do. These are available in many shops and online and seem to be much more widely available than they used to be.

Charlie

Colour

As I spend so much time in bed, I was fed up of looking at the same boring pillowcases so I ordered some colourful ones online. Sometimes the small things do make a difference.

Charlotte

InterAction needs you!

We would love to hear from more people who are currently underrepresented within the pages of InterAction including those with severe M.E., men and those from Black, Asian and Minority Ethnic backgrounds.

M.E. affects all members of the community and we would love to be able to reflect this in the magazine.

There are numerous ways you can play a part – from joining our editorial board to suggesting ideas for articles, to telling your M.E. story, to taking part in fundraising events we can report on – so please do get in touch by emailing interaction@actionforme.org.uk or writing to us at Action for M.E., 42 Temple Street, Keynsham, BS31 1EH.

Get in
touch and
share your
notices
and tips

Book time

Ellie Finney is surprised to find she enjoyed reading a romance novel and discovers an author whose sentences take her breath away.

The Matzah Ball by Jean Meltzer

I wasn't expecting to enjoy *The Matzah Ball* as much as I did. I don't read romance novels, let alone Christmas romance novels, but the lure of a protagonist with M.E. was too tempting. I'm glad I picked it up: it was a rich, addictive tale that was funny, relatable and very well plotted.

The story follows Jacob and Rachel, who first met at Camp Ahava (which means love in Hebrew, I googled it) as pre-teens and soon fall in love, until a misunderstanding leaves them holding a grudge against one another into their thirties. They're invited to the same Shabbat dinner in New York and what happens next is comfortingly predictable.

It surprised me that a Christmas romance made the perfect vehicle for a story about M.E. This book is

about the fantasy of an escape and Christmas movies are the embodiment of that. Rachel, who has M.E., says it herself, "It brought her to this place of unapologetic joy, where nothing bad ever happened and everyone found their happy ending (p15)." For people with M.E., reality isn't the best place to be, so fantasy becomes an outlet, a place where you have control.

Rachel describes her M.E. as moderate to severe, which I took exception to because I'd describe mine as mild and could never chase around Manhattan like she does. Several times I wanted to scream don't do it, go home and rest! through the pages. But I suppose for the narrative to work, she must have some exploits, and she always suffers for them. Meltzer describes crashes and PEM really well, weaving in

complaints about how stupid the name CFS is and giving plenty of airtime to the unique challenges of this illness.

Overall, the book stays on the right side of sickly sweet. I loved learning about Jewish traditions but found the perfection of the handsome, rich Jacob a little too unrealistic. To give you an example, he has a near-perfect understanding of M.E. (his mother had M.S.) and says, "...while people wore ribbons for cancer or marched for heart disease, they hid chronic illness" (p197). Maybe I'm just jealous.



The Hut by Zeeba Ansari

The Hut follows protagonist Arun Persaba in a quest to resolve a trauma that happened to him in his early teens. This physical and metaphorical journey starts and ends with two different huts, and between takes him from a remote village to a bustling merchant port, a camp of thieves in the desert, library caves, and a peaceful sanctuary. Thankfully it has a happy ending, but expect it to rip your heart out in between.

Arun is referred to as 'the boy' throughout the novel, long into his adulthood. I read this as his inability to grow up because of his trauma. He's stayed the age he was when all he ever knew was taken from him. By going on his quest to get it all back, he only compacts the trauma. Although his life is damaged, difficult

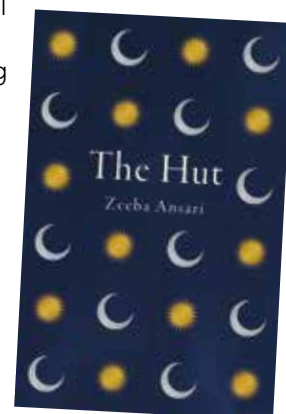
and unpredictable, there are moments of joy, beauty and happiness. Knowing Ansari has M.E. makes me wonder if this is an allegory.

This novel is clever, celestial, atmospheric, and poetic. The descriptions of food, furniture and flowers are so lush that you'll wish it didn't end at page 681. Often, it's a tale within a tale within a tale. It's clear that Ansari is a poet; some of her sentences take your breath away. On page 271, Arun "wonders why no-one has advised him to dip his heart in wax, to stop it splitting." On page 166 the carpets are "soft as spice."

It transcends reality, not only with Arun's conversations with Night but with the fact that he never seems to

run out of food or money and finds kind and welcoming strangers in every port. We're given no time or place to orient ourselves: the story could take place a thousand years ago or today; it could be set in Morocco or China or The Middle East. We're not supposed to know and the story is all the richer for it.

This astonishing novel invites you to settle down with a cup of herbal tea and join Arun on his journey. You won't regret it.



Supporting you



Organising member John Lane talks about how the ME/CFS Friendship Group in Gloucestershire helps people with M.E. to manage their daily lives.

Our Origins

The ME/CFS Friendship Group in Gloucestershire was founded in 2018 following a screening of the film 'Unrest' at the University of Gloucestershire. Afterwards, several people present discussed the idea of setting up a local support group following the very moving screening.

One of them, Chantelle, launched the group on Facebook. Membership increased very quickly. We currently have 476 members on our Facebook group and have recruited 163 since 1 April 2021. Some of these new members have Long Covid or have received an additional diagnosis of M.E./CFS. We also have 17 members on WhatsApp.

Our online presence

The (private) Facebook group is the main means of keeping in touch, plus a WhatsApp group for those who don't use Facebook. Now that Covid is less of a risk to our vulnerable members (*all of us!*) we have restarted our coffee mornings/lunches at various pubs in the Cheltenham, Gloucester, and Stroud areas. The dates, times and locations vary but are always posted on Facebook and WhatsApp well in advance.

John is pictured bottom right raising a glass of cola to toast the group. Group founder Chantelle is pictured below the advertising sign.



Our community presence

A few of the organising members pop up in various groups – we don't have a committee as this would use up a lot of our precious 'spoons' to maintain. By participating in these groups, we gain not only valuable free publicity, but also, we are now recognised for our work on improving M.E./CFS, fibromyalgia and Long Covid support locally.

We have representation on some key committees and steering groups run by the local NHS trusts, Gloucestershire Clinical Commissioning Group (CCG), Gloucestershire County Council, local voluntary sector groups, and local community groups. As examples, our group is linked in with the CCG commissioning team for the Gloucestershire ME/CFS Support Service and the new Long Covid services. We are also active with the newly formed ME Local Network alliance of groups spread across the UK.

Funding

We are not funded in any way at present, we rely on the generosity of members to pay for any essentials (thankfully limited amounts). We did receive a one-off grant pre-Covid that allowed us to hire a room in a village hall to run craft, tea and chat sessions, but sadly that is all spent.

Our local 'presence' is rather limited though by this lack of funding, for advertising for instance. We do try to run 'Millions Missing'

events if we can and last year our founder Chantelle even arranged for Gloucester Cathedral to be lit up in blue for us in M.E. Week!

Our support

We support people with M.E./CFS, fibromyalgia, Long Covid and similar fatigue-related conditions. We have a 'hive mind' among our members. This hive mind helps members with all sorts of life issues, not limited to M.E./CFS but covering a wide range of other comorbidities that a lot of us have to deal with on top of the M.E./CFS. We always make it clear that any advice we give is from a fellow member and not given from any medical/clinical perspective. Action for M.E. publications are very helpful, especially for newly diagnosed members and those still in work.

Campaigning

We campaign for service improvement and development whenever we are able. Sadly, we are seeing an increasing membership with Long Covid, support for this in the county is limited at present, but we have contacted the key 'movers and shakers' with a view to helping them to develop their services. Initial responses are very encouraging as they are planning a major reorganisation of health and care services under the forthcoming 'Integrated Care System', to be launched by the Government in July.

Contact details

Facebook: tinyurl.com/MEgroupgloucestershire

Email: mecfsfriendship@outlook.com

WhatsApp: Send mobile number via email to be added to WhatsApp



Call 0117 927 9551

Email questions@actionforme.org.uk

Web www.actionforme.org.uk

Find us on social media

 www.facebook.com/actionforme

 www.twitter.com/actionforme

 www.instagram.com/actionform.e

Walk with M.E. is back

From 31 May to 7 September 2022, join us to Walk with M.E.

Walk with M.E. is a sponsored walk with a twist – everything is done as a team. Team members count their steps for 100 days and add them together to make one grand team total, aiming to reach 1 million steps between them.

Walk together

If you have moderate or mild M.E., having a team around you means there's no pressure to do more than you can. Whether you can walk one step or 100 steps, they all count towards the total. Pace yourself and do no more than your health will allow. If you use a wheelchair, you can take part by recording distance travelled.

Walk in honour

One in four people with M.E. are so severely ill they are house or bed-bound, too ill to take a step. Could a friend or relative get involved on your behalf? In 2021, friends Emily, Emily and Sian walked in honour of their friend Hannah.

"We are completing 'Walk with M.E.' on behalf of our special friend, Hannah. Hannah has lived with M.E. for a number of years now. Although she is unable to participate herself, Hannah's resilience continues to amaze us, so we are walking for you Han, keep going, stay strong and we hope we can all see you again soon."



Walk with M.E.

So far, Walk with M.E. has raised more than £25,000 for Action for M.E., helping us to reach even more people with M.E. who need information, support and advice.

Can you help us make Walk with M.E. 2022 our best yet? This year, Walk with M.E. starts on 31 May and ends on 7 September. During this time, you'll have the full support of the Action for M.E. fundraising team, as well as regular newsletters, fun competitions and fundraising materials. It's quick and simple to get involved:

1. Put together your team, and get in touch to sign up and let us know your team name. We'll send you a welcome pack with more information.
2. Set up an online fundraising page, or use offline sponsorship forms that we can send you.
3. Decide how to record your steps. Our guide to pedometers and apps, plus Walk with M.E. step charts, are sent with the welcome pack.
4. Share your story with Action for M.E. to help us raise awareness and encourage others to get involved.
5. Start your steps, and asking for sponsorships. We'll stay in touch throughout the campaign with fundraising tips and ideas.

Even better, every penny you raise will be doubled.

We are delighted to announce that every penny raised in this year's Walk with M.E. will be doubled, thanks to a long-standing, generous family trust. This means your brilliant fundraising efforts will have double the impact for children, adults and families affected by M.E.

To sign up for Walk with M.E. or if you have any questions, contact the fundraising team at fundraising@actionforme.org.uk or call 0117 927 9551 and choose the option for fundraising. Lines are open 10am – 4pm Monday to Friday.