

Thank you for considering joining Action for M.E.

I joined Action for M.E. in September 2012 and am delighted to be working with a staff and volunteer team and Board of Trustees who are passionate, dedicated and determined.

We aim to meet need now to improve the lives of people with M.E. while taking action to secure change for the future.

A small organisation that regularly punches above its weight, we are leading, with others, a growing community of supporters working to create real change on the scale so urgently needed at a local, national and international level.

In April 2017, we began supporting children and young people with M.E., after joining forces with national children's charity, the Association of Young People with M.E. In January 2022, we began offering Healthcare Services following our merger with the ME Trust. This provides an exciting opportunity to raise more money to reach more people and raise much needed awareness and understanding

I believe that Action for M.E. can, and will, make a major contribution to creating the change that is so desperately needed.



Sonya Chowdhury
Chief Executive

Our values

Shared values are held with high regard in our organisation and reflect how we seek to work with our supporters, partners and other key stakeholders. They reflect the attitudes, beliefs and behaviour that we value in each other and underpin our whole approach and culture.



About us

Action for M.E. takes action to end the ignorance, injustice and neglect that people with M.E. face day-in, day-out.

The charity was founded by Sue Finlay in 1987 and since then has been working tirelessly to tackle the inequality experienced by people with M.E.

M.E. (Myalgic Encephalomyelitis) is a chronic, neurological illness affecting an estimated 250,000 adults and children in the UK. It may be diagnosed as Chronic Fatigue Syndrome (CFS, or M.E./CFS).

People with M.E. experience severe, persistent fatigue associated with post-exertional malaise, the body's inability to recover after expending even small amounts of energy, leading to a flare-up in symptoms.

Even in its so-called mildest form, M.E. can have a significant impact on an individual's life, and not just on their health. A lack of understanding and awareness about M.E. means patients can experience disbelief, and even discrimination, from friends, family, health and social care professionals, employers and teachers.

Our vision

A world without M.E.

Our purpose

We take action to end the ignorance, injustice & neglect experienced by people with M.E.

Our people

President

Clare Francis MBE

Vice President

Martin Arber

Patrons

Lord David Puttnam CBE

Lord Melvyn Bragg

Julie Christie

Alan Cook CBE

Chair of Board of Trustees

Roger Siddle

Vice Chair

Alison Deeth

Board of Trustees

We are an organisation led by people affected by M.E. for people affected by M.E. We aim to have a minimum of 51% of our Trustees who have, or have had, M.E. themselves.

Our Trustees are unpaid and meet at least four times a year and many sit on one of our four sub-committees. Board meeting location alternates between London and Keynsham.

We have a staff team of 40 (28 full-time equivalent) and approximately 70 volunteers who support our work in a number of different ways.

Our head office is in Keynsham (between Bath and Bristol) and we have colleagues all over the UK working from home.

Breakthrough-ME: driving research to end M.E.

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 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.

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 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.

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.

Healthcare Services

Following our merger with The ME Trust in February 2022, we are now able to offer Healthcare Services alongside our Information, Support and Advocacy Services.

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.

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

Our model is one of individually tailored whole-person care. That means we seek to support people with M.E. in whatever way is right for them as an individual physically, emotionally or spiritually. We also offer encouragement and support to families and carers.

What we do

At Action for M.E. we understand how difficult it can be to find good clinical advice and support. While NHS provision remains patchy across the UK, we are working to ensure that everyone affected by M.E. has access to diagnosis, treatment and care. We offer consultations with a Doctor, Physiotherapist, Counsellor, or Chaplain. In order to provide whole-person care, some people choose to access the services of more than one health professional at the same time, and the clinical team make internal referrals where appropriate.

Our services are available for people aged 13 and above, in the UK.

NB. Currently our counselling and chaplaincy services are only able to support adults (aged 18 and above).

Fees

As a charity, we charge fees only to cover our costs. We aim to keep our fees affordable, and help is available for those in financial need through a bursary scheme (for up to 50% of fees).

Job Summary

Healthcare Services: Chaplain

Spirituality and Faith

Action for M.E. Healthcare Services include spiritual and pastoral care as a resource which can be offered as part of our multi-disciplinary practice. A person's spirituality (the part of us which is beyond words and deeply who we are) plays a vital part in our ability to live well within ongoing limitations or any improvement in health. Chaplaincy support is open to those of all faiths and none, both patients and their immediate carers. Current chaplains are all trained and experienced Christian ministers, who encourage those who wish to take up this support to explore all that is spiritually lifegiving for them. (as defined by the Action for M.E. Spirituality and Faith Statement). It is therefore person-centred and, although it may involve sharing information and ideas, is not primarily didactic about the teachings of faith nor used to convert people or change their faith for covert proselytization.

Key Working Relationships

Chaplains are self-employed contractors and report to the Director of Healthcare Services

Other key working relationships:

- The Lead/co-ordinating chaplain;
- Other chaplains within the team;
- Other members of the clinical team;
- Action for ME colleagues

Job description

Key tasks

- To work within Action for M.E.'s policies and procedures, including, but not limited to, confidentiality, healthcare services recording, safeguarding and data protection
- To work by phone, zoom or skype to offer spiritual support to patients or their carers
- To assess possible new referrals to the chaplaincy service
- To set up sessions as appropriate for the person involved, e.g. monthly for 30 minutes
- To keep appointments as arranged
- To respond to each patient's spiritual journey as appropriate in a person-centred way
- To help patients identify possible spiritual resources – e.g. online or local to them
- To record the session on the shared Tracker and assess the nature of the session, using the coding agreed, eg Pastoral Support (PS), Spiritual Accompaniment (SA), Live Prayer (LP) etc
- To agree times to review, e.g. after 6 sessions

- To take part in peer supervision with the chaplaincy team, at least every 8 weeks
- To attend clinical team meetings on a regular basis and at least once per calendar year e.g. to liaise with other clinical team members about patients and issues in common, within the confidentiality guidelines of the service.
- To maintain professional insurance cover and personal tax arrangements

Person specification

E = Essential D = Desirable

Ordained or authorised minister or lay leader or spiritual director within a recognised faith community	E
Basic listening and responding skills	E
Training in counselling / spiritual direction	D
Experience of working with chronic illness	E
Knowledge and experience of ME/CFS	D
Willingness to learn	E
Experience of working by phone/ zoom/ skype	D
Sensitivity in listening and empathising with limitations and vulnerabilities, e.g. - energy levels, pace and tone of speech, brain fog, sensitivity to sounds, screens, fragrances etc.	E
Experience of multi-disciplinary working in a medical setting	D
Ability to reflect on practice within a team	E

Action for M.E.'s Spirituality and Faith Statement

“Action for M.E.’s core values of Empathy, Clarity, Courage and Collaboration are reflected in how we view matters of faith. Accordingly, Action for M.E. is open to those of all faiths and none, both patients and their immediate carers. Currently, the Chaplains are all trained and experienced Christian ministers, who encourage those who wish to take up this support, to explore all that is spiritually lifegiving for them. A person’s spirituality (the part of us which is beyond words and deeply who we are) plays a vital part in any improvement in health, or ability to live well within ongoing limitations.”

Terms and conditions

Outlined below are some of the main terms and conditions relevant to all self employed contractors providing healthcare services to Action for M.E.

1. Self Employed
Contractors are treated as self employed and must be responsible for their own tax and national insurance arrangements
2. Professional registration
Contractors must provide proof of registration with an appropriate professional body, and undertake any training to maintain that registration
3. Professional Indemnity Insurance
All contractors must provide proof of professional liability indemnity insurance

4. Contract for Services
A schedule of services to be provided and fees to be paid is attached as part of the contract
5. Payment
Contractors will invoice for services at the end of each month. Invoices will be paid within 14 days.
6. Clinical Team Meetings – Healthcare professionals are required to attend clinical team meetings on a regular basis (as often as possible and at least once a calendar year)
7. Termination
The contract may be terminated if two months' notice is given by either party

Application timetable

Deadline for applications	Tuesday 5:00pm 31 May 2022
Interviews (to be held via Zoom)	Flexible, by the end of June

How to apply

For more information, or to request an informal chat about the role prior to your application, please contact our recruitment team at Action for M.E., 42 Temple Street, Keynsham BS31 1EH. Tel: 0117 927 9551.

To apply, please submit a CV and covering letter explaining your interest in the role and how your experience will enable you to fulfil it to:
recruitment@actionforme.org.uk



Cover image shows, top left to right: Jake, Ian, Paul, Dan, Chris, Rich and Matt who ran and cycled the virtual length of America's Route 66 highway – 2,280 miles - to raise £4,500 for Action for M.E.; Christmas Angels knitted by our supporters to send to young people with the condition; the ME/CFS Priority Setting Partnership research project logo; Olivia, who has had M.E. for ten years, taking part in our 2021 #yearsinlockdown campaign.

Bottom left to right: Prof Chris Ponting, patient representative Andy Devereux-Cooke, Solve ME/CFS Chief Scientific Officer Dr Sadie Whittaker and Action for M.E. CEO Sonya Chowdhury at a webinar for DecodeME, the world's largest M.E. DNA study; the campaign banner for our Big Give Christmas Challenge; the cover of *InterAction*, our membership magazine, described by many readers as a lifeline.