

# Action for M.E. Family Support Officer Application Pack



## 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

### 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.

## Job summary

<b>Job title</b>	Family Support Officer
<b>Responsible to</b>	Information and Support Senior Practitioner
<b>Responsible for</b>	Line management of volunteers
<b>Salary</b>	£26,082 pro rata (£18,257.40 actual)
<b>Hours of work</b>	Part-time (24.5 hours a week)
<b>Annual leave</b>	30 days + 8 bank holidays per year pro rata
<b>Office Base</b>	Home-based anywhere in the UK

## Job purpose

As part of our busy Information and Support Service, you will share information and support to primarily parents but also family members of children and young people with M.E., and lead projects as part of our peer-support offer for parents, and young people with M.E. You will also increase understanding of M.E. and its impact among the professionals you meet as part of this work.

## Key duties

- 1. Share information and support with families with M.E.**
  - Create and maintain a supportive and professional relationship with children and their parents, carers and family members approaching the charity for help, by demonstrating empathy and an understanding of how M.E. can affect people's lives, and by managing clients' expectations and ensuring commitments to them are met
  - Give emotional support to parents/family members who may be in distress, using active listening skills via phone, email, Skype or similar.
  - Share reliable, up-to date information and useful resources via phone, email, Skype or similar.
  - Support parents/family members to access other support/services available to them.
  - Input into developing and updating information/support content for our website and resources, informed by service users.
  - Work with colleagues in our Information and Support and Advocacy Services to ensure that children, parents and families access support needed.
- 2. Facilitate peer-support**
  - Be proactive in ensuring the child/young person with M.E. in the family you're working with is referred to appropriate advocacy and peer-support.

- Set up and lead peer-support projects to reduce isolation and offer opportunities to develop coping skills and strategies; specifically, a peer-support forum for parents, and online workshops for young people.
- Undertake all required monitoring, reporting and evaluation activities for peer-support projects
- Coordinate participation of service users in service design, delivery and evaluation.

### 3. **Working with others**

- Where appropriate, and as directed by parents/family members, work with other professionals including teachers and healthcare professionals.
- Where appropriate, provide information and support to other professionals to assist them in better understand the impact of M.E., and support families affected.
- Work as part of the wider Action for M.E. services team in an integrated and supportive manner, providing cover and support when required.

### 4. **Other responsibilities and accountabilities**

- Maintain records to enable effective service provision, support the collation of key information for reporting purposes, both internally and externally, to funders and others.
- Collect and collate output and outcomes data, feedback and case studies to demonstrate the impact of the service and support continual improvement.
- Work within organisational policies and procedures, including confidentiality, safeguarding, and services recording.
- Be proactive in keeping up to date with developments affecting service provision and improve personal competence through continuous professional development.
- Ensure best practice and value in all aspects of work.
- Undertake any other duty within your ability and within reason, as may be required from time to time, at the direction of your line manager or a member of the senior leadership team (SLT).
- Act as an advocate for the charity and its work and contribute to raising the profile of M.E.

## Person specification

### Qualifications

- None specifically required

### Experience and Knowledge

- Proven experience in delivering information and support services preferably with experience in a support or helpline role for parents/families and/or carers.
- Demonstrate a sound understanding of safeguarding children and vulnerable adults.
- Knowledge of UK services and support systems available to children and young people with M.E., and their families, and the processes by which these are navigated. Knowledge of variations across the four nations is desirable but not essential.
- Detailed and up-to-date knowledge of educational rights, especially of children with SEND.
- Robust insight and understanding of the impact of M.E. on families living with M.E. or other complex, long-term health conditions.
- Experience of facilitating service-user participation in service design and delivery
- Experience of small-scale project design and delivery.

### Skills and Behaviours

- Excellent communication, engagement and interpersonal skills with an ability to build and maintain rapport with people of all ages and backgrounds.
- Strong organisational skills and ability to work on own initiative, taking a solution-focused approach.
- Computer literate in MS Office.
- Ability to work methodically, managing and prioritising a varied and fluctuating workload.
- Resilient and self-aware, with the ability to cope with emotionally-draining situations.
- Commitment to making a positive difference to the lives of service users.
- Effective team working skills.
- Ability to reflect on and evaluate own work.
- Ability to travel and work flexibly including some evenings and weekends.

## **Attitudes**

- A positive, non-judgemental, empathetic and sensitive approach
- Proactive
- Enthusiastic
- Inclusive
- Acts with integrity
- Flexible and adaptable
- Calm and compassionate
- Resilient and resourceful

## **Key Competencies**

- Collaborative
- Empowering
- Values-based approach
- Outcomes-focused
- Organised
- Confident communicator

## Terms and conditions

### 1. Probation

All posts are subject to three months' probation. During this probationary period, either party may give the other one week's notice in writing to terminate the employment. After successful completion of the probationary period, the notice stated on your contract of employment will apply.

### 2. Annual leave

The holiday year runs from 1 April to 31 March. In each holiday year in addition to bank and statutory holidays the holiday entitlement for a full time employee is 30 days (includes 3-4 days to be taken at Christmas as directed when the office is shut).

### 3. Pension scheme

Action for M.E. operates a group pension scheme on an auto-enrolment basis. All employees will join the scheme on the completion of three month's service unless they choose to opt-out. Action for M.E. will pay a pension contribution which is currently 4% of salary. Action for M.E. will not pay into a personal pension scheme

### 4. Salary payment

Salaries are paid in arrears on the last working day of each month, by direct credit transfer into a bank or building society.

### 5. Flexibility

This post may require working outside of normal office hours and travel to attend meetings and events within the UK, including occasional overnight stays.

## Application timetable

Deadline for applications	9am Friday 17 June
Short list meeting	Monday 20 and Tuesday 21 June
Interviews (to be held via Zoom)	Tuesday 28 June and Wednesday 29 June

## How to apply

To apply, please send a CV and covering letter to [recruitment@actionforme.org.uk](mailto:recruitment@actionforme.org.uk)

Your cover letter should, in no more than three pages, explain why you want this role and how you fit all aspects of the person specification set out in the application pack. Strong applications will list each person specification bullet point related to experience, knowledge, skills and behaviours individually, and provide evidence of how they meet each of these criteria.

For more information please contact the recruitment team at Action for M.E.,  
42 Temple Street, Keynsham BS31 1EH. Tel: 0117 927 9551.  
Email: [recruitment@actionforme.org.uk](mailto: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.*