Action for M.E.
Information and Support Officer
(12-months Maternity Cover)

Thank you for considering joining Action for M.E.

Myalgic Encephalomyelitis (M.E.) has been neglected and stigmatised for decades. It affects hundreds of thousands of adults and children in the UK alone but the continued lack of investment means there is no cure and no effective treatments.

For the first time there is an increased awareness of post viral illness because of the Covid -19 pandemic. After decades of neglect this offers Action for M.E. an opportunity to accelerate our work for people with M.E. in a way we have never been able to do before.

There are at least 250,000 people currently known to be diagnosed with M.E. The life-changing symptoms experienced by people with M.E. are being mirrored by more than half of those with Long Covid, now an estimated 2 million people in the UK alone.

We have identified areas where there is a critical lack of understanding and a severe unmet need and we have taken the decision to make a significantly increased investment in our work; to accelerate the M.E research agenda; to increase the support in the healthcare and advocacy services we offer; and to do all we can to ensure the government address the neglect and health inequity faced by people with M.E.

Our 2022 – 2027 strategy Shaping our future together sets out our ambition to end the ignorance, injustice and neglect of children and adults with M.E. By working together with the M.E. community and focusing on the most urgent and important challenges, we will accelerate change for people with M.E. on a greater scale than has been know before.

We have a talented and committed team at Action for M.E. where we encourage collaboration and support development and growth. I am delighted that you are considering this role and I hope this pack shows you the part that you can play in ending the neglect of M.E. for good.

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

We believe every child and adult with M.E. (sometimes also called Chronic Fatigue Syndrome or CFS) and their families should have access to the care and support they need at the time they need it.

We are a fast-paced organisation that provides support to people with M.E., carers and professionals while working to secure change for the future.

Our vision

A world without M.E.

Our mission

Our mission is empowering people with M.E. to fulfil their potential and secure the care and support they need, while working towards a greater understanding of the illness and ultimately a cure.

We are the only M.E. charity that provides direct support services for children and adults in the UK as well as their families and professionals working with them; alongside funding ground-breaking research and working to change the policies and investment that will result in meaningful change.

For decades people with M.E. have been neglected due to stigma and a lack of investment. This has led to damaging medical guidelines in the treatment of M.E., minimal services to support people with M.E., and a catastrophic lack of research investment.

Our strategy

People with M.E. are at the heart of everything we do.

In our 2022 – 2027 strategy, we set out four ambitious outcomes which we believe will help us end the decades of ignorance, injustice and neglect faced by people with M.E.

Underpinning each ambition is our focus on ensuring we reach underserved communities, so they have better access to healthcare, information and services.

1. The lives of people with M.E. are improved by effective access to the information, support and advocacy they need.

2. The health of people with M.E. is improved via access to our holistic Healthcare Services, and the National Institute for Health and Care Excellence guideline for M.E. being effectively implemented across NHS services.

3. Increased funding for high-quality research by more researchers leads to effective treatments for M.E.

4. The UK Government establishes and leads a national strategy for M.E.

Our people

President	**Chair of Board of Trustees**
Clare Francis MBE	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.

Our team

We have a staff team of 40 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 members of the team located across the UK, including Scotland, working remotely.

Our services

We provide free Information and Support, Advocacy, Family Support and range of peer-support services for adults, children and young people with M.E. and their loved ones. Our Healthcare Services clinical team includes a doctor, physiotherapists, counsellors and chaplains, offering individually tailored whole-person care.

While our Information and Support team does not recommend any specific treatments or management approaches, our Healthcare Services team works with individual patients to offer personalised advice, care and support. We are not able to offer specialist legal, employment or medical advice, or specialist mental health support; instead, we signpost to specialist organisations that do.

Our resources and peer-support

We have lots of information and support on all aspects of living with M.E. Our booklets and factsheets are available for free online, or we can be sent by post or email, on topics including but not limited to:

- symptom management and accessing health services
- welfare benefits processes, rights and entitlements
- accessing social care
- liaising with your child's school
- getting reasonable adjustments at work.

Our peer-support forums for adults with M.E. and 18s and under with M.E. are free to join and users tell us they feel better supported, and less isolated.

Job description

Job title	Information and Support Officer (12 months maternity cover)
Contract type	Maternity cover fixed term for 12 months with the possibility of extending some or all hours on a permanent basis if funding allows
Responsible to	Information and Support Supervisor
Responsible for	Not applicable
Salary	Up to £22,559.89 pro rata (£20,303.90 actual) depending on experience
Hours of work	Part-time 31.5 hours/week as part of a rota, to include Mondays and Wednesdays. We consider job-share and flexible working requests
Annual leave	30 days pro rata + 8 bank holidays per year
Location	You can choose to be home-based anywhere in the UK, work from our Bristol office, or a hybrid of the two

Please note, this role was originally advertised on 24 July as fixed term for 12 months at 21 hours/week. As a result of a change in circumstances, it was revised on Thursday 1 August to 31.5 hours/week, fixed term for 12 months with the possibility of extending some or all hours on a permanent basis if funding allows.

Job Purpose

The purpose of this role is to provide a holistic, client-centred, effective and efficient Information and Support Service to people affected by M.E. We do this primarily via outgoing calls made in response to triaged voicemail messages, and also via email.

You will join a welcoming and friendly team of three existing part-time (two home-based, one hybrid) Information and Support Officers and an Information and Support Supervisor (home-based) with a strong team culture of collaboration and peer support.

We support clients to:
- break issues down so they feel less overwhelming
- explore priorities and possible next steps
- frame questions to ask professionals
- feel heard and understood
- request information and useful resources which we can send by post or email
- understand what other Action for M.E. and external services are available to them.

The Information & Support team do not:

- give advice on any topic
- provide a casework service.

Some of our clients are distressed, and a small number have suicidal thoughts. We have robust internal systems in place to ensure both clients and colleagues are well supported. We measure (via a feedback survey) how our Information and Support Service helps people:

- understand their rights and options
- feel less isolated
- increase their knowledge of other services
- communicate more effectively with professionals.

From April 2023 to March 2024, more than 95% of our clients say they were satisfied or very satisfied with the service they received.

Some examples of typical enquiries include:

- “I have just been diagnosed with M.E./CFS and I don’t know where to turn for support.”
- “I’ve had M.E. for 30 years, but a recent viral infection has made my symptoms worse and I don’t know if I can cope anymore.”
- “My son has been off school for two months now and his GP thinks it might be M.E. He remains too ill to attend school but his teachers are putting pressure on us over his attendance.”
- “I’ve received my Personal Independence Payment application form through the post and I don’t know how to fill it in.”
- “I think I might have M.E. and my employer is being unsupportive.”

Feedback from recent clients includes:

- *Lovely and friendly response, very detailed and personalised which I really appreciated. It's given me some new avenues to go and explore at a point where I was struggling to know where to go next.*
- *I felt we had at last spoken to someone who understood and was able to offer a professional service which we couldn't find anywhere else.*
- *Very detailed and thorough response to a question I asked, going above and beyond to answer it in full - thank you.*

Information and Support is one of Action for M.E.’s range of free Support Services that work with adults, young people, and/or families living with M.E. The charity support colleagues across the team to take part in and share reflective practice, self-care, peer-support and training.

Please note that an enhanced DBS check will be sought for the successful candidate.

Key duties

Service delivery

- Creating and maintaining a supportive and professional relationship with adults (and on rare occasions children and young people) approaching the charity for help via email, telephone and occasionally social media, by demonstrating empathy and an understanding of how M.E. can affect people's lives.
- Offering emotional support via active, empathic listening, including to people in significant distress.
- Setting and maintaining boundaries; managing clients' expectations and ensuring commitments to them are met.
- Helping clients unpick a situation which seems overwhelming and break down complex situations into discrete issues which can then be progressed.
- Working with the client to understand their needs and wishes, empowering them to make informed choices and to take action to achieve their self-identified goals.
- Providing information and support on a wide range of issues in areas such as welfare benefits, health and social care, and including on sensitive and confidential matters, in a way that is tailored and appropriate to the individual.
- On occasion offering single, one-off pieces of advocacy, ie. taking one action with an external agency on behalf of a client.
- Referring internally to other Action for M.E. services where appropriate; and signposting to other external sources of support.
- Working flexibly and collaboratively within the team to provide a resilient and responsive service.
- Taking steps to manage your own wellbeing in work, with support from Action for M.E., your line manager and peers, and supporting colleagues to do the same.

Safeguarding and record keeping

- Identifying safeguarding concerns as they arise from contact with clients and escalating these to a manager, in line with our organisational Safeguarding Policies.
- Making safeguarding referrals where directed to by the Information and Support Supervisor or other manager.
- Keeping case notes that are appropriate, clear, up-to-date and in line with our policy and procedure.

Evaluation and improvement

- Gathering outcomes and satisfaction data from clients to enable service evaluation and improvement.
- Identify opportunities for service improvement, and work with the Information and Support Supervisor to implement these.

Other key accountabilities

- Attending Action for M.E. meetings and courses as required.
- Working co-operatively within the Action for M.E. team structure, supporting the work of other teams when appropriate and agreed with the Information and Support Supervisor.
- Working within the charity's policies and procedures, including safeguarding and data protection.
- If possible, contributing to printing and posting information resources to clients from our office.
- Keeping up-to-date with best practice and comply with relevant legislation and regulatory requirements, working within the organisation's policies and procedures and ensuring that good practice is observed.
- Positively promote the work and activities of Action for M.E. at all times.
- Ensuring that internal and external communications are consistent with Action for M.E.'s brand and position on key issues.
- Undertaking travel for occasional face-to-face meetings with colleagues.
- Undertaking any other reasonable activity in line with the responsibilities of the post as requested by your Supervisor or any member of the Leadership or Management Teams.

Person specification

All criteria are essential unless otherwise specified.

Qualifications

1. Educated to A level standard or equivalent experience in a similar role is preferred, however no one specific qualification is required.

Experience and Knowledge

2. Experience working on a helpline as part of an information, support, navigator or advocacy service, supporting clients to identify options and services available to them.
3. An understanding of the challenges facing people with a long-term health conditions, physical impairments or disabilities, such as M.E.
4. Demonstrable experience of working in a person-centred, needs-led way.
5. Experience identifying and escalating safeguarding concerns, working strictly within organisational policies and procedures.
6. Experience of working with people in distress, including people who disclose suicidal thoughts.

Skills and Behaviours

7. Ability to communicate complex concepts clearly, systematically and with nuance, both verbally and in writing.
8. Ability to demonstrate empathy while setting boundaries; emotionally resilient and resourceful, with ability to adapt in the face of challenging circumstances to maintain your wellbeing.
9. Strong team player and also able to work on own initiative; ability to work remotely while building strong relationships with your manager and peers.
10. Ability to analyse complex situations, identify options available to clients and signpost appropriately.
11. MS Office skills including Outlook, Teams, Word and Excel, and proficiency with web-related programmes and software.

Terms and conditions

Outlined below are some of the main terms and conditions of employment relevant to all employees of Action for M.E.

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 a month in arrears on the 24th day of each month, by direct credit transfer into a bank or building society.

5. Flexibility & Wellbeing

This post may require occasional working outside of normal office hours and travel to attend internal meetings/events within the UK (eg. team meetings, staff away days) including overnight stays. We offer a flexible working model, in accordance with six working principles developed by the team. We provide access to an Employment Assistance Programme and an optional monthly wellbeing session for all colleagues, regardless of hours worked with sessions determined by the team.

How to apply

Please visit https://actionforme.recruitee.com/o/info-support-officer-mat-cover-2024 and click on the **"apply"** button to submit your CV and cover letter. Please note, only applications received via the Recruitee site will be considered.

Along with your CV your cover letter should, in no more than two A4 pages, explain your reason(s) for applying for this role and how you fit **all aspects** of the person specification set out on page 9 in this Information and Support Officer Recruitment Pack.

Strong applicants will list each person specification bullet point related to experience, skills and behaviours, and provide evidence of how they meet each of these criteria.

Should you have any questions about the role, or require any reasonable adjustments to the recruitment process, please don't hesitate to email the recruitment team for this role at job.hmwfe@actionforme.recruitee.com

Application timetable

Deadline for applications	9am Monday 19 August 2024
Shortlisting	Monday 19 August to Monday 2 September
Invitations to interview	These will be sent by Tuesday 3 September
Interviews (held online)	Tuesday 10 and Thursday 12 September

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; *InterAction*, our membership magazine, described by many readers as a lifeline.