



PROVIDING SUPPORT AND CARE  
TO PEOPLE WITH ME/CFS

Thank you for your enquiry about working as a Doctor with the ME Trust.

ME/CFS is a much misunderstood condition and is challenging for patients and clinicians alike. Reasons for this include tensions around the complexity of making an accurate diagnosis in the absence of a biomarker, the debate about the effectiveness of the few available treatments, and the very real stigma associated with the diagnosis. There are estimated to be between 150 and 250,000 people in the UK with ME/CFS, of which about a quarter are house- and/or bed-bound. Few services exist to help them manage their illness. The Doctor we seek will need to demonstrate their understanding that this is a complex biomedical condition. They will need to demonstrate compassion and patience, and to have a real desire to help individuals manage their disease - as part of a wider team.

Support and training will be offered to any Doctor who is interested in this role, working in clinic alongside Dr Paul Worthley, our current Clinical Lead and a pioneer in this field.

Please read through the information pack. If you have any questions please contact our Charity Administrator at [h.hall@metrust.org.uk](mailto:h.hall@metrust.org.uk), and you will be put in contact with either myself or Dr Paul Worthley, and we would be very happy to talk to you.

If you would like to apply please send your CV and a covering letter to [h.hall@metrust.org.uk](mailto:h.hall@metrust.org.uk).

Yours sincerely

Helen Winning  
Chief Executive

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*'We seek to bring hope and transformational care to all affected by ME/CFS'*

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## Job Description

**Role:** Doctor and Clinical Lead

**Reporting to:** CEO

**Contract:** Self-employed contractor – minimum 2 sessions per week plus 1 session a month for meetings/leadership role

**Remuneration** – negotiable. Doctor will provide their own medical indemnity cover.

### Summary:

- Lead in diagnosis and treatment of patients with ME/CFS and related conditions, working with a whole person approach, and involving colleagues where appropriate
- Act as Clinical Lead within the organisation, supporting colleagues to provide a whole person approach through 6-8 weekly Clinical Team meeting and individual support
- Provide a report to the Board of Trustees quarterly meeting
- Represent the ME Trust as appropriate on relevant forums and committees, internal and external

### Main tasks:

- Undertake consultations in the most appropriate manner for the patient- whether in the monthly face to face clinic, home visit, telephone, skype, or by email
- Establish or confirm diagnosis and suggest treatment/support plan
- Offer follow-up consultations with patients by phone/skype
- Refer patients, as appropriate, for ongoing treatment and support to team colleagues – including nurse, physiotherapist, counsellors and chaplains.

### Person Specification

#### Essential

- Be registered with the GMC
- Be registered with a Medical Defence Organisation
- Be eligible to work in the UK
- Have UK work experience
- Team worker with leadership skills
- Excellent communication skills, in both active listening and careful word usage

#### Experience

This is not a role for which there is any one set of experience, but is likely to include:

- General Practice and/or General Medicine
- Experience in Pain Management and/or Palliative Care would be useful
- More important is the belief in ME as a real biological illness, a desire to help people holistically with ME/CFS and a willingness to think outside established protocols

## The ME Trust Approach

### **A real biological illness**

The ME Trust is committed to a belief in ME as a very real biological illness. We fully support research into the biological causes of the illness and are currently encouraging our patients to sign up to the new BioBank research study.

We aim to treat the physical symptoms of ME with medical advice and intervention, nursing care 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.

### **Whole person care**

The ME Trust model of whole person care is fundamental to the activities of the ME Trust. Our Clinical Team is led by a Doctor, and for many patients, a consultation with a Doctor who listens and understands their condition is a real breakthrough. The ME Trust Doctor will always liaise with the patient's GP to help the patient access NHS services and prescribe appropriate medication. A large number of our existing patients also receive follow up calls from the Doctor.

Importantly, we also offer input from other members of the clinical team. The Nurse, who has had special training, is able to follow up an initial Doctor led consultation and offer on-going support, referring to the Doctor for guidance where necessary.

The Physiotherapist can offer practical down to earth advice and action to make daily life more manageable - for example helping the patient to find a suitable resting or sleeping position and offer advice on pacing and gentle physical activity. This is definitely not the Graded Exercise Therapy which was for a time promoted by NICE but a much more patient led and patient centred approach.

Our Counsellors can offer a range of therapeutic input: from emotional support for those who are fragile, to counselling for those that are well enough to commit to it. They can help many patients to deal with the complex psychological effects of living with long term illness.

Some people find it helpful to talk to someone who can offer spiritual support. Our Chaplains work with people of all faiths or none, and can be alongside them during their journey with ME.

Many of our patients choose to access the services of more than one therapist: seeing a Doctor in the first instance with regular follow ups from a Nurse, and with input from a physiotherapist and a counsellor or chaplain. It is up to the individual, in consultation with the Doctor to work out what is best for them. People are treated as individuals, and we offer long term support. There is no quick fix, and many people have complex needs. Our approach is to offer them the care and support that they need, in a timescale that works for them.

## Consultations

### **Within a Consultation:**

#### Take the History

- Listen and affirm. Hear the story and get to understand how the ME affects the patient
- Get a sense of their daily structure
- Document their symptoms and prioritise them
- Document any medications/supplements they may be taking
- What has helped, what hasn't helped.
- Any specialist input? If so when...
- Family history, Social history and past Medical History
- Record degree of ME according to the MEA Disability Scale

#### Offer Understanding

- Look at a possible bio-medical models underlying ME/CFS
- Help give physiological understanding causing the symptoms.
- Use Metaphors to help give insight into ME

#### Give Advice and Practical Help to include

- Advice on structuring their daily life
- Advice on balancing activity with rest periods.
- Teaching how to properly rest
- Help with relaxation techniques and resting positions
- Discuss and advice re sleep hygiene
- Consider diet/nutrition
- Give advice on medication and supplements
- Manage expectations

### **Following a Consultation:**

- Email the patient following each consultation, summarising the consultation.
- Write to the patient's GP if needed with patient's permission. The letter would normally be written to the patient, copying in the GP. A draft is sent to the patient giving opportunity for alterations. Once agreed, it can then be posted/emailed to the GP.
- Write a supportive letter for PIP/ESA if needed.
- If Nimodipine or LDN is recommended, and despite a letter to the patient's GP requesting a trial of Nimodipine or LDN, the GP is unable to prescribe, then to offer a private prescription for these off-licence medications.
- Enter appointment details on the ME Trust Tracker

## About the ME Trust

The ME Trust is the UK's only charity dedicated to providing whole person care and treatment for people with ME/CFS, and encouragement and support for families and carers.

**Our Vision** - To bring hope and transformational care to all affected by ME/CFS.

We aim to transform the landscape of service provision so that accessible, expert, patient-led care is available across the UK for all those who need it.

**Our Mission** - To provide multi-disciplinary care and support based on a person's individual needs.

We focus on delivering services directly to people with ME/CFS, their carers and family. We do this in a variety of ways to in order to reach people with all levels of severity of ME nationwide.

### Our Values

All our work is shaped and characterised by these core values:

**Respect** – We make time to listen carefully, to honour everyone's story and to build relationships of trust, working within agreed boundaries of confidentiality.

**Dignity** – We value each individual person for who they are, not for what they can or cannot do.

**Determination** – We never give up. We will keep working until people with ME/CFS have access to appropriate diagnosis, treatment and care across the UK.

**Openness** – We are keen to learn, to share and to develop new knowledge and understanding

**Choice** – We never impose solutions but aim to empower people to make their own decisions

**Compassion** – We will stay alongside and offer support for as long as is needed.

### The Story So Far

The ME Trust was founded in 2011 by Hannah Clifton, following her own recovery from ME, with the aim of bringing life transforming treatment, care and support to people with ME/CFS.

Initially the Trust focussed on raising money to support in-patient care at Burrswood Hospital, where a specialist service had been developed. The team at Burrswood, led by Dr Paul Worthley, pioneered a whole person approach to the treatment of ME. People were treated as individuals, with equal regard given to their medical, physical, emotional and spiritual needs.

In 2015, when Burrswood changed its priorities and was no longer able to accept patients with ME/CFS, the Trust was forced to consider how best to help people with this condition, especially the most severely affected cases. A new model of care was developed based on home visits and telephone consultations. At first Doctor Worthley worked alone, but understanding the value of whole person care, he quickly gathered a team around him to replicate the team approach at Burrswood.

Today the team consists of a Doctor, a Nurse, a Physiotherapist, four Counsellors and three Chaplains.

In 2018 the Trust opened a Clinic in Crowborough, East Sussex, offering face to face consultations to patients well enough to travel to see the Doctor and/or Physio. Follow up appointments are arranged, and usually conducted by telephone and/or skype. The Clinic has also enabled the training of our first

ME Nurse who can continue to support patients after an initial consultation through home visits and phone calls. There is potential to change the location of the Clinic depending on the location of our Doctors.

With the opening of the Clinic, the ME Trust registered as a Healthcare Provider with the Care Quality Commission. At first inspection in 2019, the Trust was given an Outstanding rating. The full report is available via our website - [www.metrust.org.uk](http://www.metrust.org.uk)

Looking to the future, the ME Trust intends to build on this model. We are recruiting more Doctors, Physiotherapists and Nurses so that we can offer our services to more people. We aim to grow a network of Doctors and specialist Nurses throughout the country. We will continue to offer whole person care to support more people with ME/CFS.