



PROVIDING SUPPORT AND CARE
TO PEOPLE WITH ME/CFS

Thank you for your enquiry about working as a Physiotherapist 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.

The publication of the updated NICE Clinical Guideline for ME/CFS diagnosis and management in August 2021, giving an overview of reliable research and a consensus on best practice, is expected to improve understanding and delivery of care. The Coronavirus pandemic has resulted in a significant subgroup of Long Covid patients experiencing symptoms which fit the NICE diagnostic criteria for ME/CFS.

There are estimated to be 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 ME Trust is the only charity providing clinical services.

The Physiotherapist we seek will understand 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 Physiotherapist who is interested in this role.

Please read through the information pack. If you have any questions, I would be very happy to talk to you, so please contact our Charity Administrator at h.hall@metrust.org.uk to arrange a time.

If you would like to apply, please send your CV and a covering letter to h.hall@metrust.org.uk.

Yours sincerely

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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: Physiotherapist

Reporting to: Clinical Lead

Contract: Self-employed contractor – 2 sessions per week (negotiable) plus 1 session a month for meetings/admin.

Remuneration – negotiable, on a fee per case basis. Physiotherapists will provide their own professional indemnity cover.

Summary:

- To provide a Physiotherapy service as part of a multi-disciplinary team, for the ME Trust, on a part time basis
- Respond to specific or general Physiotherapy referrals
- Carry out assessments, provide advice and recommend interventions to manage the symptoms in patients with ME/CFS and related conditions, working with a whole person approach, and involving family/carers where appropriate
- Provide written reports for the person with ME and others involved in their care with consent of the patient
- Participate in 6-8 weekly Clinical Team meetings

Main tasks:

- Arrange and undertake consultations in the most appropriate manner for the patient- whether remotely, by telephone, skype, zoom or email or by home visit (according to geographical location)
- Carry out an assessment
- Consider choices and in collaboration with the person with ME, agree attainable and realistic goals, however small
- Offer a selection of gentle progressive interventions to facilitate an improvement in their quality of life
- Seek to reduce fear associated with the illness and to create an environment for healing
- Offer follow-up consultations with patients by phone, skype, zoom or by email
- Offer clear and consistent information and advice to people with ME and their family/carers

Working Practices:

Approach - To take a holistic, person-centred, flexible approach when assessing and considering the following:

- Priorities
- Pain
- Pacing
- Planning
- Problem solving
- Psychological wellbeing

- Energy conservation
- Environment
- Encouragement
- Empathy

Interventions - To include giving advice and looking at the impact/management of ME for the individual, including:

- Identifying potential for change
- All aspects of personal care and Activities of Daily Living
- Management of symptoms
- Mood and Motivation
- Support to family/carer

Policies - To work within the policies as set out by the ME Trust, ensuring privacy and dignity including:

- Awareness of environmental triggers for those with ME such as light, noise, perfumes etc. and consideration for people's homes and personal environment
- Ensuring there is another person in the house who is involved with the life/care of the person with ME on home visits
- Dealing sensitively with people who may be experiencing distressing or emotional circumstances
- Following the core values of the ME Trust which are Respect, Dignity, Choice, Compassion, Openness and Determination

Safeguarding - To feed back any concerns to colleagues within the ME Trust.

Person Specification

Essential

- Be registered with the HCPC and or Chartered Society of Physiotherapy
- Have up to date professional indemnity insurance
- Be eligible to work in the UK
- Have UK work experience
- Team worker
- Excellent communication skills, in both active listening and careful word usage
- Be familiar with the NICE guidelines for ME management (revised guidelines due to be published August 2021)

Experience

May be varied but would typically include:

- Several years of post-graduate experience in different aspects of the profession
- Management of long-term conditions
- Working in a multi-disciplinary team
- Experience in the management of chronic pain and its impact on the quality of life.
- Most 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 includes 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.

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, five Counsellors and three Chaplains.

From 2018 to 2020 the Trust ran a Clinic in Crowborough, East Sussex, offering face to face consultations to patients well enough to travel to see the Doctor and/or Physio.

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. With the Covid pandemic, the clinic ceased, and home visits have been suspended until further notice.

Looking to the future, the ME Trust intends to build on this model. We are recruiting more Doctors, Physiotherapists and Nurses to grow a network of Regional Hubs, in due course offering home visits, throughout the country. We will continue to offer whole person care to support more people with ME/CFS, collaborating with the NHS and other ME charities to encourage education and research, helping to deliver the standard of care outlined in the 2021 NICE guidelines. This means high quality Chronic Disease Management by a Multi-disciplinary Team, with our service working where there are currently gaps in access and provision of care