



PROVIDING SUPPORT AND CARE
TO PEOPLE WITH ME/CFS

THE ME TRUST

**Vision into Action
2020 – 21
An Interim Strategy**

Inspected and rated

Outstanding 



Transforming care and treatment for people with ME/CFS

Circumstances change, and the best laid plans must change and adapt. We have come a long way since 2017. Our ambition remains bold and wide reaching, but some things may not be achieved as quickly as we had hoped. The Coronavirus pandemic of 2020 has affected everyone and combined with other internal factors, we have not been able to meet all the aims of our original 2018-21 Strategy in the original timescale.

We are issuing this interim strategy to cover our plans up to the end of our current financial year (31st May 2021). During this year we will work on a new three-year strategy for the future.

Around 17 million people globally are thought to be affected by ME/CFS. Only now is the potential of ME/CFS to destroy so many lives being recognised. At last, research is beginning to give clues to the nature of the neuro-immune pathology behind this grossly misunderstood illness, and significant research into genetic predisposition – DecodeME was announced in June 2020.

Until there is a cure, The ME Trust is determined to deliver on a strategy that enables people with ME/CFS across the UK to receive appropriate, skilled and individualised care, enabling tangible steps towards greater health.

We are privileged to have some of the most experienced healthcare professionals in the field of ME/CFS working with us. Since December 2016 we have been offering a telephone consultation and home visit service through a multi-disciplinary team approach. In 2018 we expanded the service by opening an outpatient clinic, and in 2019 were rated Outstanding by the CQC.

In the longer term, our ambition is to develop inpatient services, which experience tells us are important not only for assessment but also to enable some people's recovery. There is currently a shocking lack of provision, with only a handful of beds in the UK specifically designated for people with ME/CFS. New services are desperately needed to care for people who have been bedbound for years.

Alongside offering clinical care, we are committed to training healthcare professionals, and to working in partnership with all those who share a common purpose in this field.

For too long, people with ME/CFS have been side-lined, thought to be hysterical, and blamed for not being able to get well again. We are working to ensure that as many people with ME/CFS as possible find a measure of health and a life worth living through transformational care.

Helen Winning
Chief Executive

Rollo Hope
Chair of ME Trust

The M.E. Trust

The M.E. Trust's distinctive purpose is to provide care, treatment and support for people affected by ME/CFS. We are the only UK charity focused on developing clinical services for people living with this illness. Our work also contributes to other important goals such as raising awareness and supporting research.

Our vision

To bring hope and transformational care to all affected by ME/CFS

Too often, people with ME/CFS struggle to find appropriate care and support. We are working 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, shaped around the needs of each person with ME/CFS and their community of carers

Our care is provided in a variety of ways, for example, home visits, outpatient clinics and telephone consultations, by a team who all have extensive experience of supporting people with ME/CFS. The team provides whole-person care i.e. meeting physical, emotional and spiritual needs. Currently, this comprises a doctor, a nurse, two physiotherapists, four counsellors and three chaplains.

Our values

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



Why our services are desperately needed

1 in 250 people in the UK are diagnosed with ME/CFS

1 in 100 11-16 year olds have ME/CFS. It is a major cause of long-term school absence

25% of people with ME/CFS are severely affected, housebound or bedbound

The physical symptoms of ME/CFS 'can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, and congestive heart failure....It can cause **profound, prolonged illness and disability**, which has a substantial impact on people with CFS/ME and their carers....' (NICE Clinical Guideline CG53, 2007). For some, it can make everyday activities impossible.

*"The exhaustion and weakness make the little things, like texting a friend, a challenge."
Jo, Home Counties*

Despite the prevalence and seriousness of this illness, healthcare services are often lacking. NICE recognised that the impact of the illness is exacerbated by 'uncertainties about diagnosis and management, and a lack of clinical guidance for healthcare professionals' (2007).

- GPs identify ME/CFS as one of the 3 most challenging illnesses they deal with
- On average people wait 3-4 years for a diagnosis in the NHS
- Less than half the Clinical Commissioning Groups, Health Boards and Trusts contacted in a 2017 survey have commissioned a specialist service in their area
- Some parts of the UK, such as Wales, have no specialist services
- More than one third of specialist adult ME/CFS services in the NHS provide no support for people who are severely affected

The consequences are devastating. *"I had been bedbound at home with ME/CFS for 18 years. After pleading with my doctor for hospital care, I was told there was nothing available to help me."* K. West Country

The lack of services, and difficulties with obtaining a social care assessment, can mean that even the most basic care needs are not being met for many people severely affected by ME/CFS. *"I was bedbound at home, unable to bath or wash myself for 18 months, desperately asking for help with personal care..."* H. Surrey

Kent University researchers found the isolation of people with ME was more acute than in any other social group they had studied (<https://kar.kent.ac.uk/52772/>).

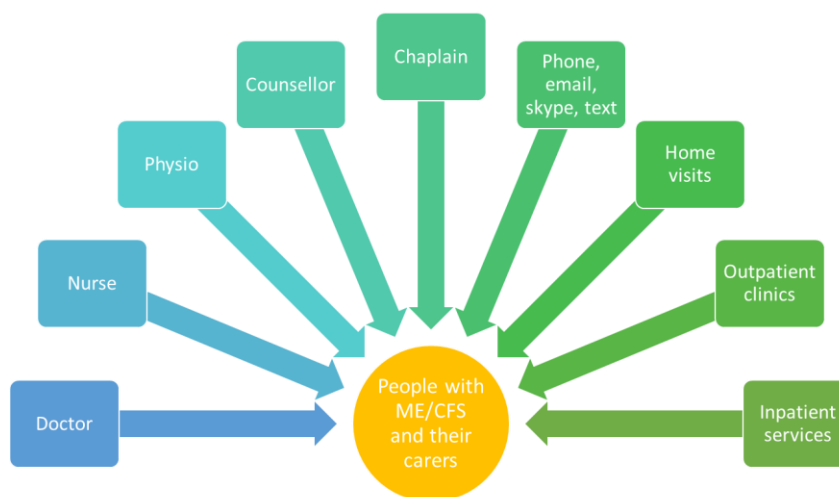
Crawley et al, *Unidentified CFS/M.E. is a cause of school absence*, BMJ Open (2011); Action for M.E., *Close to Collapse* (2016); *Health of the Nation Report*, Aviva, (2013); Collin et al. *The impact of CFS/ME on employment and productivity in the UK*, BMC Health Services Research 2011, 11:217; *Spotlight on Specialist Services: UK Healthcare for People with M.E.*, Action for M.E. (2017); 2020Health, *Counting the Cost of CFS/ME* (2017); McDermott et al, *What is the current NHS service provision for patients severely affected by chronic fatigue syndrome/myalgic encephalomyelitis? A national scoping exercise*, (2014); <http://www.forward-e.org.uk/22nd%20June%202017.htm>.

A force for change

Our Founder, Hannah Clifton, had severe ME. Despite many years bedbound and in great pain she was advised by her GPs that no hospital bed or home-based services were available for her. After 12 years, she finally found a group of clinicians with rare expertise and understanding. They were 'a revelation' to her - facilitating change in her own life, and her perception of what could be done to help people with ME. She founded The ME Trust to bring hope and life-transforming care and support to others.

Our unique model of care

Drawing on the depth of experience of the professionals working with us, we offer an individually-tailored range of services so that our whole-person model of care enables us to help people physically, emotionally or spiritually, in accordance with each person's individual needs.



ME has a wide spectrum of severity and symptoms, and there is no 'one size fits all' solution. We offer a variety of services through different communication channels to ensure we can reach people nationwide, whatever the level of severity of their illness.

We are committed to using our experience and expertise to work with, and support, other healthcare professionals to develop services for people with ME/CFS. Crucially we are providing support to GPs and other clinicians so they are better equipped to help their ME/CFS patients. The ME Trust model of care can be replicated and used to meet the needs of many more people suffering with this terrible illness.

Changing Lives

Our pioneering work is bringing real change to people's lives in the following ways:

- ✓ ***People with ME are able to access support from clinicians with expertise in ME***
 - In 2019 our team carried out over 1,000 consultations, providing clinical support through the telephone consultation service; many of these had waited years to find specialist help.
 - Our clinical support is available to people with all levels of severity of ME/CFS, including those who are bedbound.
 - Diagnosis is made, or confirmed, without lengthy delays.
 - Regular communication with our clinical team builds relationships and trust with our patients and provides a surer foundation upon which to develop and agree strategies for managing their illness.

- ✓ **People with ME/CFS manage their illness more effectively**
 - Practical guidance from our clinical team on a range of topics, including medication, pain management, sleep, rest and pacing, helps people to cope better with the physical challenges of living with ME/CFS on a daily basis.
 - Home visits to bedbound people facilitate improvements in care and management
 - Counselling and chaplaincy services provide a confidential space for the emotional and spiritual needs of each individual to be heard and honoured

- ✓ **The isolation experienced by people with ME/CFS is reduced**
 - By communicating in via different channels, e.g. by phone, home visits, and online, people who are housebound, bedbound, or unable to speak can access our support.
 - People express a new found 'hope', knowing that they are no longer alone or 'abandoned'.
 - The rare experience and expertise of our clinical team means that they can offer empathy and understanding that has often been unavailable to people with ME/CFS - "someone finally gets it!"

- ✓ **Healthcare professionals are supported to provide appropriate care**
 - Our work facilitates greater understanding of ME/CFS amongst GPs and clinicians and fosters stronger links between the patient and their GP.
 - The ME Trust is able to highlight the specific needs of individuals and provide advice for NHS doctors, on request, on potential, appropriate medication and care; this has led to improved care plans for patients.

- ✓ **Families and carers are supported**
 - The ME Trust is also able to provide information and support to family members and carers of ME/CFS patients to increase their understanding and help them provide the necessary care, when they are unable to access support services from other agencies.
 - Counselling and chaplaincy services are also available to family members and carers who are often isolated and may need to talk.

"The ME Trust has provided me with ongoing expert support with managing my ME where the NHS has been unable to. I've had regular access to an understanding GP who has given me sensible and helpful advice covering medication, pacing and symptom management.This has helped me to cope on a day to day basis and has helped reduce the anxiety I have surrounding this condition. I've not had a miracle recovery (yet) but thanks to the ME Trust I now feel hopeful for the future where I had once only felt despair." J. (East of England)

"The ME Trust has changed my life. I was at my lowest, felt life had no meaning and there was no end to the misery. I get up in the morning glad to be alive again." S. (Wales)

"The telephone support feels like a buoyancy aid when my world has been flooded. I have felt cut adrift and it did frighten me. It is a comfort to be properly heard and given wise counsel as I learn a different approach to my life with ME/CFS." F (Scotland)

“My son has severe M.E. and has been in hospital for almost a year. The ME Trust has been invaluable - kind, compassionate, understanding and most helpful. Dr Paul has visited my son, attended an MDT (Multi- Disciplinary Team] meeting at the hospital, offering his advice and knowledge, to both us and the medical team, which has helped enormously. The medics valued his input and have acted on his experience and expertise. The ME Trust is doing such valuable work to a community poorly understood and in dire need of help and support.” D. (South of England)

A pivotal moment

We are part of a growing movement for change. In a landmark development, the NICE Guideline on the Diagnosis and Management of CFS/ME is being reviewed and although delayed by the Coronavirus pandemic, will now be reissued in 2021.

The increase in cases of post viral fatigue reported by many who are recovering from the effects of CV19 make it likely that more people will develop ME/CFS over the coming months and will need help from an NHS stretched to capacity.

We expect the need for our services to grow and we will harness this momentum to initiate, inspire and enable new developments in service provision.

Progress towards our bold ambition: 2018-2021

We are passionately committed to helping people with ME/CFS through expanding our clinical services. In its first two years, our ambitious three-year plan has already made a real difference to people’s lives, enabling us to bring the best of whole-person care to more people in more places.

Increasing the service

In 2018-20 we have:

- Extended the telephone consultation and home visiting service in 2018 and 2019
- Provided monthly outpatient clinics from summer 2018 (suspended due to CV19 in March 2020)
- Rated as Outstanding by the CQC on first inspection in 2019
- Undertaken contracts with CCGs within the NHS

In 2020-21 we will

- Continue to expand the service – using Skype and Zoom to reach people who are severely affected and/or unable to attend clinics
- Resume face to face clinics when possible
- Engage with the bidding process for NHS contracts
- Offer more bursaries to make our services accessible regardless of financial need

Expanding the clinical team

In 2018 -20 we have:

- Recruited our first ME Trust nurse in 2019 to provide specialist care and advice
- Expanded our team to include a doctor, two physiotherapists, four counsellors and three chaplains

In 2020-21 we will

- Continue to expand the team – focussing on recruitment of new doctors

Training and supporting health professionals

In 2018-20 we have:

- Continued providing advice to health professionals on request e.g. Clinical Commissioning Groups, Trusts, GPs
- Made information for healthcare professionals, including carers, available through leaflets, YouTube, and our website

In 2020-21 we will

- Ensure we create training opportunities for healthcare professionals to develop their knowledge, thus enabling better care for people with ME/CFS
- Develop video-based training modules for clinicians

Working with others to change the landscape of service provision

In 2018-20 we have

- Provided expertise and consultancy to enable and support healthcare providers in establishing new services for people with ME/CFS
- Been an active member of the Forward ME group and the UK ME/CFS Biobank steering group, bringing a distinctive focus on clinical services and patient perspectives to collaborative working and research
- Actively engaged with people with ME/CFS, and other ME charities, to increase understanding of the illness amongst the public, health professionals and researchers.
- Highlighted the need for increased NHS training and funding with CCGs.

We will continue to do these things in 2020 – 21

To achieve these goals we will continue developing our organisational capacity.

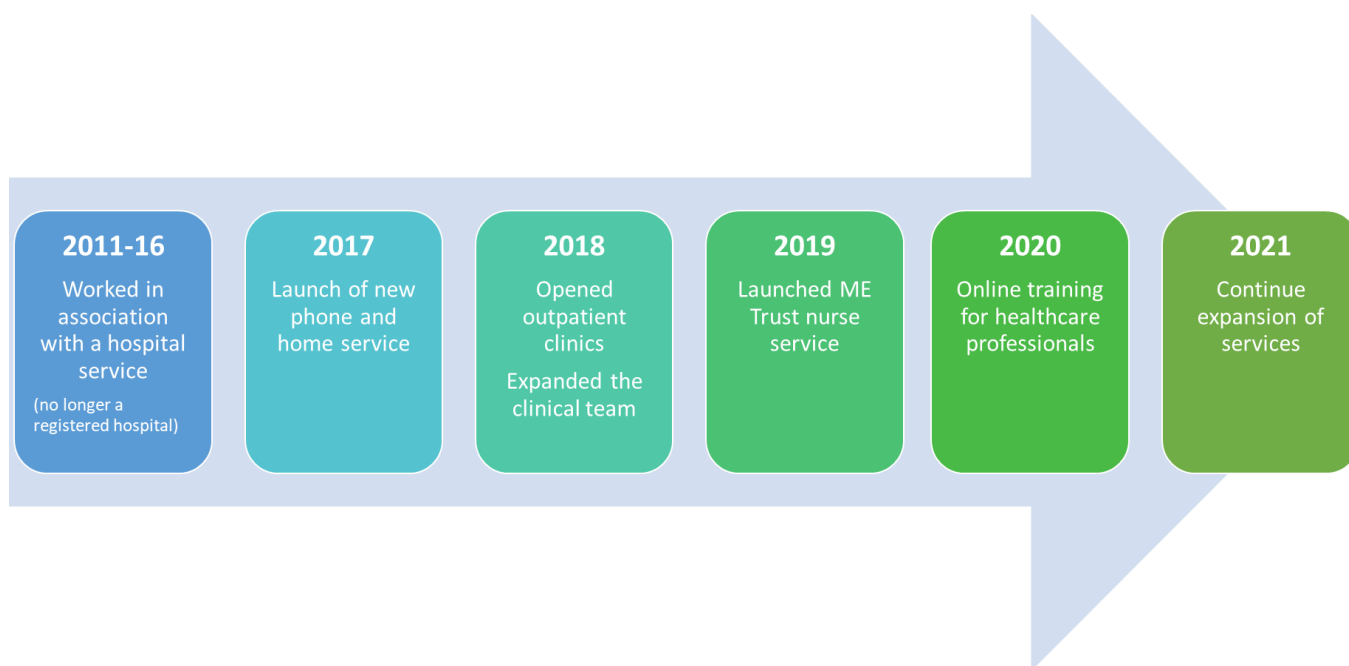
Organisational development

In 2019 -20 we have:

- appointed a paid Chief Executive
- launched a new website
- engaged regularly on social media
- changed the way we report our financial results to bring clarity to our levels of activity
- developed a fundraising strategy and increased our online fundraising

In 2020-21 our plan is still to:

- *Finance:* diversify and expand our income streams and make our services more accessible
- *Staffing:* increase our levels of staffing in line with our planned growth in service provision
- *Clinical governance:* ensure best practice and high quality care
- *Evaluation:* Collect qualitative and quantitative data to measure the impact of our work
- *Communications:* strengthen our organisational profile and give a clearer picture of the services we provide and evidence of their positive impact
- *Stakeholder engagement:* strengthen relationships with supporters and those we help



Our longer-term commitment to people with ME/CFS

Our commitment is to provide care, treatment and support, as long as it needed, whatever the level of severity of illness and wherever people live in the UK. We will keep listening to the experiences of people with ME/CFS, their families and carers, to ensure that their voices are heard and that we work to provide the services that are most helpful for them.

Beyond 2021

This current plan is the first stage in achieving our vision of bringing hope and transformational care to all affected by ME/CFS. In the longer term, our aims are to:

- Ensure specialist outpatient services are available across the country
- Ensure those who are housebound or bedbound with ME/CFS have access to specialist domiciliary care
- Ensure specialist inpatient services are available for all those who need them
- Support healthcare professionals and providers to develop our model of care in new services
- Increase support for families and carers of people with ME/CFS

Measuring impact

We are committed to evaluating our services to measure impact and to enable us to identify goals for improvement. We have put in place systems to collect and analyse data on: user feedback; outcomes; measures of impact.

As the services expand and more data becomes available, we will make information available through our website and other publications to share evidence of the impact of our work.

Partnership

To achieve our goals, we will work with local self-help or support groups, charities, researchers and other individuals or organisations committed to providing whole-person and individually tailored clinical care.

Thank you

Many people contact us for help following a personal recommendation. We would like to express our thanks to them, and to the other ME charities who have publicised and recommended our services.

We highly value and thank each volunteer, organisation, campaigner, supporter and donor partnering with us to bring about transformational change for people with ME/CFS.

Further information

For more details about our work, contact Charity Administrator at admin@metrust.org.uk or visit www.metrust.org.uk