



Action for M.E. Statement of Strategic Intent



2013–2016



Foreword

This Statement of Strategic Intent sets out a bold and ambitious agenda for change and reflects our willingness to engage with local and national challenges and make a difference to the lives of people with M.E. This document will set out our aspirations and agenda for the next three years.

The world we live in is changing continually and we must change too if we are to make the most of the opportunities and challenges that we face. We are living in unprecedented times with an economic climate that has led to significant changes in public, health & social care services and the welfare benefits system.

The impact for people affected by M.E., a hidden illness with significant lack of awareness and understanding of the condition and the devastating effects it can have, has grown. As a result transformational change is needed now, more than ever. We believe that Action for M.E. has the people and passion to make a major contribution. We are ambitious for our organisation and for the level of change that can be achieved for people affected by M.E.

We will increase awareness and understanding of M.E. with the public, with health and social care practitioners, with senior decision-makers and with government. We will also seek to enhance the support we provide, especially to those that most need it.

It is an exciting time in the research world with modern technology, insight and collaboration creating more opportunities than ever before. We will increase our research work, to play our part in learning more about the illness, treatments and ultimately finding a cure.

We have big aspirations. These will only be achieved through working collaboratively with others from a range of backgrounds, with a range of views and with a range of skills and experience. Our plans will take time, patience and determination and we will seek active partners to work with and alongside us. Growing our resources and increasing our funding is critical if we are to fulfil our ambitions.

We are an organisation led by people with M.E. for people with M.E. People with M.E. are at the heart of everything we do. We will increase our consultation and engagement with the many people who are affected by this devastating illness. We will ensure that for every pound we spend, for every activity we undertake, we ask the question: how will this benefit people affected by M.E.?

“Together, we can make a real difference for everyone affected by M.E.”



Sonya Chowdhury,
Chief Executive



Alan Cook CBE,
Chairman

Our context and challenges

It is estimated that 250,000 people have M.E. in the UK; that equates to 1 in 250¹ people suffering with this debilitating, fluctuating illness. The prevalence rises to 1 in 100 young people² aged 11–16 years and M.E. has been identified as the biggest cause of long-term school absence³. M.E. devastates lives and has a huge impact on the families, children, friends and employers of people with M.E.

M.E. is defined by the World Health Organisation as a neurological condition. We refer to the illness Myalgic Encephalomyelitis (M.E.) but it is also called other things and can be confused with other illnesses and sometimes misdiagnosed. Within the NHS, it is commonly called Chronic Fatigue Syndrome (CFS or CFS/M.E.); this should not be confused with Chronic Fatigue which is a different illness. Sometimes it is known as Myalgic Encephalopathy or diagnosed as Post Viral Fatigue Syndrome (PVFS).

There are a wide range of symptoms that include post-exertional malaise (a period of intense exhaustion that lasts for more than 24 hours following physical exertion), chronic pain, chemical and temperature sensitivities, sleep and concentration difficulties. M.E. affects different people in different ways and symptoms can fluctuate and change over time.



For GPs, M.E. and CFS have been the number one conditions that GPs find most challenging to refer for specialist attention. Alarming, also in the Aviva: Health of the Nation Report 2013⁴, 42% of GPs thought that the NHS would no longer provide specialist services for M.E. and CFS by 2015. 25% of GPs also reported an increase in the number of patients with M.E. in the last year.

There remains a lack of awareness of M.E. and the significant effect it has on people. One of our membership surveys⁵ found that of the 2,338 surveyed, 51% said that they had felt suicidal as a result of the illness. In another study⁶, suicide was in the top three most prevalent causes of death for people with Chronic Fatigue Syndrome (CFS). In 2006, the estimated financial impact of M.E. on the UK was £6.4 billion⁷.

People with M.E. often become isolated and the 25% who are most severely affected¹, can often be bed and housebound for many years. Services for people with M.E. vary significantly across the UK and coupled with a lack of understanding of the illness, many people face ignorance, injustice and neglect.

Alongside this, the needs of the most vulnerable continue to grow and many services, including those in social and health care, have seen an increase in demand. There are many changes to the way in which health, social care and welfare benefits are provided and this has, in places, exacerbated the difficulties faced by people with M.E.

To meet these many challenges, we need to raise additional funds to ensure that we can achieve our ambitious plans to improve life for people with M.E. We can demonstrate great need, and inspiring solutions, but recognise that this is a challenging time financially for all. There are substantial reductions in the public and voluntary sectors and this is likely to continue for the foreseeable future.

“There is still much to do but there are also opportunities that we must seize”

Our vision...

A world without M.E.

...Our mission

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.



Our three strategic touchstones...

Our promise to people affected by M.E.

Inform and Influence

We will increase awareness and understanding of the illness and its impact alongside working to influence policy-makers and others to increase investment in research and improve the services, care and support for people affected by M.E.

Empower and Support

We will empower and support people affected by M.E. to live life to their full potential, while providing them with a wide range of up-to-date information about M.E. and resources available to them.

Research

We will support high quality, evidenced-based medical and social policy research and invest in pilot research projects to help us learn more and to stimulate greater mainstream funding of M.E. research.

"ensuring impact from all our work"

Redefining our priorities...

There is much to do. We have pulled together the voices, views and opinions from a number of our key stakeholders to help us identify what we should focus on for the next three years.

We have identified five key priorities that will shape our current and future activities:

- Awareness and understanding
- Health
- Welfare
- Research
- Employment



Our promises

Inform and influence

We will:

- Raise public awareness and understanding of M.E. and its impact through building stronger coverage in the media, facilitating events and working with our Ambassadors to raise the profile of the illness.
- Work with policy-makers and senior decision-makers to ensure that the needs and voices of people affected by M.E. are heard and acted upon.
- Work collaboratively with other organisations to challenge inequalities and injustice within the welfare benefits system.
- Establish the M.E. Inform programme to improve understanding and awareness of M.E. with health & social care practitioners.
- Raise awareness and understanding of M.E. with employers, other support organisations and government departments.
- Increase our welfare rights support and provision.
- Establish a pilot Welfare Rights Advice & Advocacy Service providing casework and tribunal support to individuals.
- Establish a pilot project to help people with M.E., where possible and appropriate, to stay in work and/or access employment in partnership with health and employment services.

Research

We will:

- Work strategically with others, including the UK CFS/ME Research Collaborative and international researchers to help achieve our mission and vision.
- Develop a programme of work with others, including universities, to initiate and support social policy research projects to enhance insight of the illness and its impact.
- Fund medical research pilot studies to expand knowledge and attract mainstream funding with an additional focus on under-researched areas.
- Partner with at least three research projects to support patient participation at all levels.
- Keep patient voice at the heart of our research work and will ensure representation from a minimum of three people with M.E. on our Research Panel to oversee and steer our research work.

Empower and support

We will:

- Provide up-to-date and accurate information, support and access to services for people affected by M.E. especially through our Online M.E. Centre, Services Directory and publications.
- Evaluate and review our services on an ongoing basis to know what difference we make for people affected by M.E. and ensure continuous improvement and development of our work.
- Work with the health service to ensure that patients receive improved information and support at the point of diagnosis.
- Create an information resource for people who are newly diagnosed with M.E. to pass on to family/friends to help them better understand the illness and its impact.
- Assess what support local M.E. Support Groups want from us and what we can do to provide this.

Delivering our promises

Collaboration

Stronger collaboration is fundamental; we cannot deliver our ambitious plans alone. We aim to select and work with partners who share our ethos, values and commitment to the highest standards. We recognise and value the different views, opinions and beliefs that others bring. To enrich our work, we will seek to include, rather than exclude. We will work with others to find common goals while recognising differences we might have.

We will:

- Work strategically with others to create and increase capacity to achieve our vision.
- Consult with people affected by M.E. in identified priority areas to better inform and influence policy-makers.
- Engage with the media, Government, professionals and the public to grow awareness and understanding of M.E.
- Collaborate with patients, other M.E. charities, clinicians, policy-makers and others to identify common goals and make the most of limited resources available in delivering and developing services.

Resources

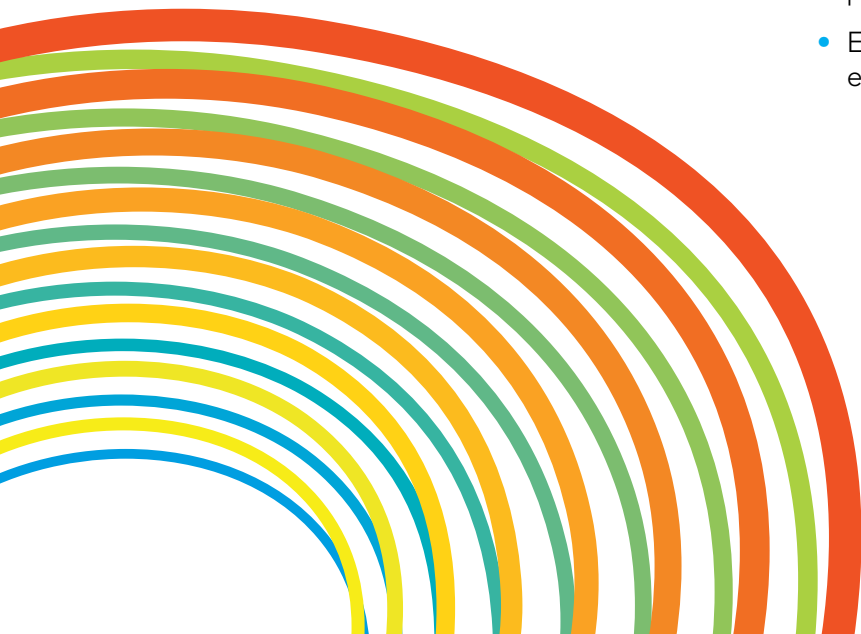
Increasing our income and resources is a priority to ensure that we can deliver on our promises. The current financial climate is challenging but the case for supporting work with people affected by M.E. is a compelling one. We must build on this and engage with both current and potential funders to maximise support for our work.

We recognise that people are our biggest asset. We will work in a way which values everyone's contribution; where everyone can see how their work contributes to achieving our strategic intent; working together to achieve a world without M.E.

We will be creative and use our insight to both seize and create new opportunities. Alongside this, we will continue to develop our systems, processes and procedures to become even more effective and efficient to ensure that valuable resources are released to invest in our ambitious plans.

We will:

- Develop a sustainable income generation strategy which delivers rapid growth to empower and support people affected by M.E.
- Ensure legacies, which fund long-term developments for people with M.E., are a core part of our fundraising work.
- Create a culture where good ideas, innovation and leadership can come from anyone in the organisation.
- Ensure our team of staff, volunteers and trustees have the skill, capabilities, insight and creativity required to deliver our promises to people affected by M.E.
- Ensure that our work is both efficient and effective.



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.

Empathy

The majority of our Trustees have direct experience of M.E. themselves. Their strategic leadership will set the parameters that reflect this intrinsic empathy and instil this value into all staff and volunteers who do not have such direct experience.

Clarity

We will be clear and transparent about what we're doing, why we're doing it and how we're doing it.

Courage

We will have the moral courage to campaign openly on behalf of people affected by M.E. and to state our evidence-based policies regardless of how unpopular this may make us.

Collaboration

We will work collaboratively and inclusively with others to create capacity and achieve the level of transformation needed.

"Action for M.E. is a transforming organisation"

References

- 1 National Health Service. Chronic Fatigue Syndrome (2009)
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- 3 Dowsett EG & Colby J. Long Term Sickness Absence due to ME/CFS in UK Schools: An Epidemiological Study with Medical and Educational Implications (1997)
- 4 Aviva: Health of the Nation Report 2013
- 5 Action for M.E., *M.E. in the UK: Severley Neglected*, a membership study (2011)
- 6 Jason *et al*, Causes of Death Among Patients with Chronic Fatigue Syndrome (2006) in *Health Care for Women International*, 27:7
- 7 Bibby J & Kershaw A. How much is M.E. costing the country? Report prepared by the survey & Statistical Research Centre. Sheffield, England: Sheffield Hallam University (2006)



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