

Action for M.E. works to improve the lives of children, young people and adults living with M.E. in Scotland, and collaborates with professionals and policy-makers to increase access to appropriate care and support.

We are currently working on the projects and partnerships outlined below, and are happy to work in partnership with anyone looking to improve the lives of people living with M.E. in Scotland – our door is always open, so please get in touch.

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Mentor M.E. peer-mentoring

Our <u>peer-mentoring project</u> for adults living in Scotland with M.E. is going from strength to strength, and we're delighted that the value of our mentors' work has been recognised through a Quality Award from the <u>Scottish Mentoring Network</u>. We are now extending our reach to carers of people with M.E. and can train mentors online via Zoom. Our next training session for mentors will be 4pm to 6pm, Wednesday 29 May.

Educate M.E.

We worked in partnership with parents of young people with M.E. and closely with one young student to uncover the needs of young people with M.E. in education, 20 of whom responded to our survey asking what might support them to manage more effectively in school. An in-depth case study provided material for an artist to develop a mind-map of what worked, and all of this fed into a new resource for teachers, How can I help?, available on our website from Friday 17 May at www.actionforme.org.uk/teachers

Meet M.E. in Inverness in June

A new partnership with M.E. Highland & Islands Network is underway. We want people to feel empowered to fulfil their potential and secure the care and support they need, and will work together towards a greater understanding of the illness and ultimately a cure. Together we are hosting Meet M.E., a drop-in day on Saturday 8 June at The Oxygen Works in Inverness. All are welcome: please book your free place online.



Networking

We regularly participate in the Alliance's <u>Self-Management Network in Scotland</u> to share best practice, and <u>Scottish Mentoring Network</u> regional network events to support the development of our work in all areas of Scotland. We've also met with potential volunteers across Argyll and the Islands, as well as throughout the central belt, thanks to the new <u>Highland Self-Management Forum</u>, whose meetings we've enjoyed attending.

What next?

We are keen to continue working with health and social care professionals (statutory or third sector), support groups and individuals, anywhere in Scotland, to improve the lives of people living with M.E. We aim to respond flexibly and would be happy to discuss your thoughts, interests or concerns. Please drop us an email today.



What have we been up to? Some key events over the past year...

We held an event at the Scottish Parliament in May 2018, hosted by Gail Ross MSP, allowing patients and professionals to show MSPs their experiences of living with M.E. Gail also tabled a motion for the parliament to debate to raise awareness of M.E during M.E. Awareness Week. Also in May, we announced joint funding with the Scottish Government's Chief Scientist Office for a new biomedical research PhD, supervised by Prof Chris Ponting, University of Edinburgh.

In June, we presented to the ME-CFS Network Meeting for Scottish Government staff at St Andrew's House in Edinburgh to raise awareness of our Mentor M.E. project and how it can support people in work.

September was a busy month. Action for M.E. staff and volunteers hosted an information stand at the Scottish Liberal Democrats conference, where delegates voted in favour of a motion for a number of actions including the removal of Graded Exercise Therapy (GET) from the Scottish Good Practice Statement.

Working with other Forward M.E. charities, we hosted a busy information stand and sold-out workshop at the Royal College of General Practitioners conference, and will return to this event in September this year. We also led a health and well-being information session in Glasgow, offering one-to-one welfare advice, drop in art and relaxation session, and the opportunity to meet other people living and caring for people with M.E.

In **November**, we met people with M.E. and professionals at Action for M.E.'s AGM and conference in London, to share updates on the progress of our <u>ambitious five-year strategy</u> to end the ignorance, injustice and neglect.

In January 2019, we were part of a short-life working group, led by the Alliance, to engage with a wide range of people living with a neurological conditions, and to develop recommendations and priorities that would feed into the Scottish Government's National Action Plan on Neurological Conditions.

We are disappointed that the aspects of the report pertinent to people with M.E. are not reflected in the draft plan. This was fed back in our formal response to the public consultation. When the final action plan is published, we will decide upon the next appropriate steps.

Also in January, we submitted evidence in advance of the Scottish Petitions Committee debate on M.E., in response to <u>a petition from #MEAction Scotland's Emma Shorter</u>, and continue engage with policy-makers on key issues facing people with M.E. in Scotland.

In **February**, we piloted an awareness session for eight Principal Teachers and Inclusion Coordinators in South Ayrshire, whose feedback shaped the development of our new Educate M.E. resource.

We held a Reflection and Development session for the Educate M.E. partnership in March, including the artist and young person involved in the development of our new resource. We learned what worked well and how the group wanted to take this work forward in the future.

April saw us busy preparing for M.E. Awareness Month. We will attend the Missing Millions event in Glasgow on M.E. Awareness Day, and look forward to highlighting M.E. to professionals, planners and policy-makers at the Alliance conference on Monday 20 May.

We want to work with others and respond to identified needs to develop Action for M.E.'s work in Scotland so please get in touch if you want to volunteer, be mentored or work in partnership with us. Please get in touch for a chat, we are keen to hear from you.