



**Learn About M.E.**  
**Informing professional practice in Scotland**  
**Final report November 2023**

The Learn about M.E. project was [funded by the Scottish Government](#) through the *Neurological Care and Support: Framework for Action 2020 to 2025*, under the [Staff capacity building](#) heading. The framework aims to ensure people can access personalised care and support, regardless of their condition or where in Scotland they live.

The aim of the project, which ran from October 2020 to September 2023, was to increase knowledge and confidence in healthcare professionals in Scotland on the diagnosis and management of Myalgic Encephalomyelitis (M.E.)/Chronic Fatigue Syndrome (CFS).

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## What is M.E./CFS?

M.E./CFS is a multisystem disease which is exacerbated by exertion. It is estimated that about 20,000 people in Scotland have M.E., although this is likely to be an underestimate given that many people do not get a diagnosis. Many people with M.E./CFS face disbelief and stigma around their illness and do not receive the appropriate care and support they need.

As a result of the lack of understanding of the latest biomedical evidence on M.E., diagnosis remains very slow and management and treatment can be disjointed and ineffectual. Online professional education can make a big difference in effective practice and so ease the burden of illness for this condition.

The M.E. community has historically experienced prejudice and disbelief and could feel stigmatised by people (including family, friends, health and social care professionals, and teachers) who do not understand their illness, as noted in the 2021 NICE guideline for M.E./CFS [\[NG206\]](#).

This project aimed to address these challenges.

## What was funded?

Four charities that operate in Scotland formed a partnership to realise this project. Action for M.E., The M.E. Association, #MEAction Scotland and The 25% ME Group also collaborated with Dr Nina Muirhead, a specialist doctor in dermatology who has personal experience of M.E.

Funding from the Neurological Framework supported the dissemination of an [online learning module](#) for primary care professionals, developed by Dr Muirhead, to improve knowledge relating to diagnosis and management of M.E./CFS. It also supported development of other resources, such as podcast episodes and webinars that offered supplementary and complementary knowledge.

*“Only after I developed M.E. myself did I realise that I had not understood the illness. Feeling the devastating impact of M.E. on myself and my life, I felt determined to offer something that changed that experience for other people.”*

Dr Muirhead

The module aims to improve knowledge of the illness, reducing delays in diagnosis, and focusing on good practice, thereby reducing the potential for harm for people with M.E./CFS, whether through delays in accessing care or through inappropriate advice.

Hosted on Learna’s StudyPRN platform, which has over 40,000 subscribers, the module is based around 10 clinical case studies which aim to typify patients who may or may not display signs and symptoms of this illness. It reflects evolving biomedical findings alongside lived experience. Dr Muirhead and Helen Brownlie (of The 25% ME Group) updated the module in January 2023 to reflect the increasing amount of research around post-viral diseases, including Long Covid.

The GMC recommend that GPs participate in 50 hours of CPD-related activity a year, to be able to demonstrate their approach fits with good medical practice and that they are updating their knowledge in order to revalidate their licence to practice. Health professionals received one hour's Continuing Professional Development (CPD) accreditation upon successful completion of the module.

### Breakdown of expenditure

Staff costs (including include employer NI & pension contributions )	£12,021
Podcast creation & editing (three episodes)	£2,775
CPD module consultancy	£900
Learning events	£1,000
Comms and marketing	£2,000
Overheads @ 15%	£2,804
<b>Total</b>	<b>£21,500</b>

### What were the project objectives?

In order to improve the experiences of people with M.E. accessing healthcare services, three objectives were identified:

1. Health professionals report increased confidence in diagnosis of M.E./CFS.
2. Health professionals report increased confidence in treatment and management of M.E./CFS, including improved understanding of the main diagnostic features of M.E./CFS and recognition of the importance of early and accurate diagnosis.
3. Health professionals report improvements in patient-centred care and patient pathways, including an improved ability to judge the impact on quality of life and appreciation of the importance of providing patients with relevant documentation and information in connection with applications for benefits, social and community care, and third sector support.

### What has changed as a result of the project?

As of April 2022, 1,065 people in Scotland had accessed the module. This exceeded our target of 500. Since then, we estimate that at least 376 further professionals in Scotland (up to September 2023) have accessed the module.

We worked with Learna Study PRN to develop pre and post survey questionnaires for everyone who accessed the CPD module, collecting quantitative and qualitative data.

- Results of the survey consistently show that more than 75% of people who completed the survey feel more confident in diagnosing and managing M.E./CFS.
- More than 96% thought that more training was needed for medical professionals on M.E./CFS.
- More than 99% understood how central the patient was to care in M.E./CFS.

Learna agreed to share a survey with people who had previously completed the survey to gauge the longer-term impact of what they had learnt. This was sent to over 1,500 people, with 105 responses received.

- Over 70% of respondents agreed that they were more confident in the diagnosis of M.E./CFS.
- Over 70% agreed they were more confident in managing and treating M.E.
- Over 65% agreed they had put the knowledge gained from the module into their practice with their patients.

*“For those coming into the field it is excellent, for those want to brush up, it is also excellent. And for those of longstanding, it is an excellent refresher, not only for the physician, but for the physician-patient relationship.”*

Module feedback

Further positive feedback on the module from health professionals who have taken it includes:

- The module is excellent and up to date.
- It is informative and relevant to clinical practice.
- It is important that all medical staff have mandatory training for M.E.
- It is a good introduction to the condition, even for those who already know something about it.
- It is particularly useful to get more information on the physical and pharmacological aspects of intervention.

More than 90% of the people who completed the post-questionnaire said that they would recommend the resource to others.

For 2023’s Severe ME Day (8 August), a Question of the Day was sent to over 40,000 healthcare professionals who had subscribed to Learna’s StudyPRN platform. Over five days, daily questions were posed about one case study on severe M.E. Explanations, further information and references were sent to those who completed the assessment.

The most common reason that health professionals gave as to why they chose to complete the CPD module was they wanted to gain more knowledge and understanding of M.E. so that they could better support their patients. Others wanted to improve their clinical practice or had a personal interest in learning more about the condition.

### **How did we extend the reach of the project?**

We aimed to hold focus groups with GPs to secure feedback on the CPD module, but struggled to make contact due to the impact of Covid-19. One GP told us: *“I don’t know of any specific practice that could do it. My own practice is drowning in the workload at the moment and I can’t ask my colleagues to take on anything extra.”*

Instead, we had feedback on the module from the NHS services in Scotland that offer support to people with M.E., the Centre for Integrated Care, Glasgow and Astley Ainslie M.E./CFS, Edinburgh. We also approached patients through M.E. support groups in Scotland to help them contact their GP about the CPD module and then try and gauge the impact of the module. Many patients reported that they struggled to access their GP and so we were unable to secure any feedback.

### **Podcasts featuring patients and professionals**

We developed a series of podcast episodes to make clinical and patient knowledge and experience available to a wider audience in an accessible format. There are now 10 episodes available.

- Episode 1: Learn about M.E.
- Episode 2: Learn about M.E. and long COVID
- Episode 3: Learn about M.E. and the new NICE Guideline
- Episode 4: Learn about M.E. in Medical Schools
- Episode 5: Learn about M.E. and Social Care
- Episode 6: Learn about M.E. and Nursing
- Episode 7: Learn about M.E. and Physiotherapy
- Episode 8: Learn about M.E. and DecodeME
- Episode 9: Learn about M.E. and GP Prescribing
- Episode 10: Learn about M.E. and Paediatrics

All of these episodes are available to listen to via [Buzzsprout](#). At the end of October 2023, the podcasts had been listened to over 4,000 times.

### **Bringing in social care**

In the second phase of the project, we widened the remit to include professionals working in Social Care, as each charity partner regularly receive requests for support with this from people with M.E. and their carers and supporters. Through creation and delivery of a webinar and further podcast episode, we transferred the knowledge and learning from the CPD module into a format accessible to Social Care and Social Work professionals.

We approached a number of Social Care organisations to secure their oversight with the content of a webinar for Social Care professionals. We used their feedback to shape the content of the webinar, [still available to watch on YouTube](#).

We had a good response, with 80 people registering their interest in the session and receiving a recording of the webinar, and 30 people attending the webinar on the 17 March 2022. It has now been viewed 665 times, and we recorded a podcast episode to supplement this resource.

Building on our promotion of the project to other professions in Social Care, we made contact with Social Work teams and Community Link Worker teams and offered

presentations on the project and its resources that could support them in their role to offer more targeted support to people with M.E. and their carers.

### **Considering the role of technology**

We offered a webinar through Pogo Digital Healthcare during M.E. Awareness week in 2023. The subject of the webinar was, *'What can we learn from M.E. when it comes to treating other long-term conditions and what is the role that technology can play?'* We used this opportunity to promote Learn About M.E. resources to a wider audience.

### **Attending conferences and events**

Our poster was accepted by Voluntary Health Scotland for its annual conference, *Fair Health- Who gets it?* in October 2022. This meant we were able to pitch to delegates on the purpose of the project and the poster, and share a blog with them.

We had a stall at a neurology conference at the Royal College of Physicians and Surgeons of Glasgow on 31 March 2023. We followed this up by attending the college's event to prepare PACE Neurology candidates. At this event we spoke to 23 people and got a positive response with all of the candidates taking a leaflet on the project. We followed this up with an advert on the project in the Royal College of Physicians and Surgeons of Glasgow member's magazine. This was available in the paper and online editions.

We attended the RCGP's annual conference each year of the project to target our core audience, GPs. For this year's event in Glasgow, we used the conference poster and other Learn About M.E. resources such as the post cards and business cards. We felt there was a difference in the level of engagement and interest in our resources. At this conference, we spoke to hundreds of delegates. There was a definite change in attitude in delegates from previous conferences. Many stepped forward and were keen to hear more about the resources available, as they wanted to support their patients more effectively.

We handed out more than 500 leaflets to GPs and offered a QR code that signposted to the CPD module and other resources to help their practice. The week following the conference, the series of podcast episodes was listened to 40 times. This is much higher than normal and hopefully reflects that GPs did follow up on our contact and access the project resources.

### **What did we learn from engaging with professionals?**

There is a significant gap in knowledge on this condition and its impact on quality of life and functioning.

Feedback shows that many people have an interest in finding out more about M.E. However, it is people who don't feel that they need to find out more who are probably the most important audience for the CPD module and podcasts. The results of the questionnaire consistently show that people overestimate their knowledge and understanding of M.E. before completing the module. Support to address this audience, who may unintentionally do harm through lack of appropriate knowledge and understanding, would be beneficial.

We learned that good communication and flexibility was key to continuing in a partnership. Much of our learning came from the feedback we received through the questionnaire and conversations at events.

We streamlined the process for accessing resources by using QR codes, as GPs have limited time and want quick access. We also became aware of how difficult GPs' work was and that they now faced more challenging situations, with increasing complexity of cases and safeguarding, as well as a lack of capacity. We are now mindful of these issues and will continue to simplify and refine our resources and approach keeping these issues in mind.

We learned that support to engage with Social Care and Social Work services was required in the pre-assessment stage. Without this flexibility and adjustment in pace, communication and engagement, people may be dis-engaged with by services due to a lack of understanding. The other key learning was the need for personalisation and co-production of care plans and that 'reablement' was contraindicated for people with M.E. Having information in care plans that could be shared amongst staff meant that there was no need for the person to repeat the same information, thus conserving energy and possibly helping to stabilise their condition.

### How are we using our learning to inform future work?

We discerned a number of areas where more information and clarity is needed for GPs, including the following.

- Concise one- or two-page description of the features and symptoms of M.E., with further reading and references to aid diagnosis and management. Information on how other professionals such as OTs can assist with this condition.
- Patient information that enables people to better understand and manage their symptoms. Pacing and energy management is a specialist area and requires that people get support to enact this in their life.
- Signposting information for patients and their families. M.E. can impact people's finances, employment, caring responsibilities and housing. They may need support with understanding how to turn to for help with the wider aspects of managing their health and lifestyle.

We are grateful to have been successful in our funding application to extend the Learn about M.E. project to March 2025.

We will explore how to directly engage more effectively with GPs, being mindful of the existing pressures they face. We will also benefit from making contacts at a strategic level within NHS Education for Scotland to cascade information and resources to people who would be able to support its further dissemination.

## Information and support about M.E./CFS

Each charity involved in the Learn about M.E. project offers information, resources and support services for people with M.E. and healthcare professionals working with them.

### **Action for M.E.**

Tel: 0117 927 9551

Email: [questions@actionforme.org.uk](mailto:questions@actionforme.org.uk)

For patients: [www.actionforme.org.uk/info-support](http://www.actionforme.org.uk/info-support)

For professionals: [www.actionforme.org.uk/medical-professionals](http://www.actionforme.org.uk/medical-professionals)

### **The ME Association**

Tel: 0344 576 5326

Email: [meconnect@meassociation.org.uk](mailto:meconnect@meassociation.org.uk)

For patients: [www.meassociation.org.uk/contact-me-association/](http://www.meassociation.org.uk/contact-me-association/)

For professionals: [www.meassociation.org.uk/health-care-professionals/](http://www.meassociation.org.uk/health-care-professionals/)

### **#MEAction Scotland**

Email: [scotland@meaction.net](mailto:scotland@meaction.net)

For patients: [www.meaction.net/countries/scotland](http://www.meaction.net/countries/scotland)

For professionals: [www.meaction.net/countries/scotland/medical-education/](http://www.meaction.net/countries/scotland/medical-education/)

### **25% ME Group**

Support for people with severe ME and professionals caring for them: 01292 318611

Email: [enquiry@25megroup.org](mailto:enquiry@25megroup.org)

For patients: [www.25megroup.org/me/living-with-severe-me](http://www.25megroup.org/me/living-with-severe-me)

For professionals: [www.25megroup.org/me/for-professionals-2/](http://www.25megroup.org/me/for-professionals-2/)