FOR IMMEDIATE RELEASE

HEALTH Learn about M.E. - free CPD training for health professionals in Scotland
GENERAL New support for professionals on managing ME-CFS and Long Covid

GPs, medical students and allied health professionals in Scotland can now access free online training on the diagnosis and management of ME-CFS.

At present 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.

Against this background, the Scottish Government are supporting dissemination of a learning module through ***Learn about M.E. – the ME-CFS Professional Development Project in Scotland***, a project led by Action for M.E. and funded through the Health Department's Neurological Framework to improve knowledge relating to diagnosis and management of ME-CFS.

This free online learning 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. Health professionals will receive one hour Continuing Professional Development-accreditation upon successful completion of the module.

It has been developed by Dr Nina Muirhead in partnership with the UK CFS/M.E. Research Collaborative, to reflect the emerging biomedical evidence, evolving international discussions and the patient perspective of this disease.

Dr. Muirhead says, "*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*."

ME-CFS is a multisystem disease which is exacerbated by exertion. It is estimated to affect up to four patients per 1,000. Many people with ME-CFS face disbelief and stigma around their illness and do not receive the appropriate care and support they need.

This project provides vital information to assist with the diagnosis and management of patients with ME-CFS. It includes a focus on post-exertional malaise, a key feature of ME-CFS, which is also being observed in a subset of patients with Long Covid.

For these patients, inappropriate advice to exercise could be harmful, as acknowledged by NHS Scotland's recent update on the Scottish Good Practice Statement (SGPS). Scottish Ministers have committed to reviewing the SGPS, now more then 10 years old, following the publication of the new National Institute for Health and Care Excellence (NICE) guideline for ME-CFS expected in April.

The draft NICE guideline version now advises healthcare professionals: "*Do not offer people any therapy based on physical activity or exercise as a treatment or cure for ME-CFS including any programme based on fixed incremental increases in physical activity or exercise, for example, graded exercise therapy."*

The module also looks at diagnosis. The SGPS advises: *"Speedy diagnosis of ME-CFS is important to allay fears of other serious illness, to protect the patient from undue pressure and to allow symptoms control and appropriate management to begin."*

Yet Action for M.E.'s 2019 Big Survey found that only 7% of children and young people and 16% of adults are obtaining a diagnosis within the timescale recommended in the SGPS of three to four months. Almost one in five adults (18%) waited more than six years for a diagnosis.

Dr Muirhead's learning module on ME-CFS aims to address this by improving knowledge of the illness, reducing delays to diagnosis, and focusing on good practice, thereby reducing the potential for harm for people with ME-CFS whether through delays in accessing care or through inappropriate advice.

It will be complemented by a podcast exploring these themes, with input from people with ME-CFS about the positive difference that good care and support has made for them.

ENDS

For more information, or to request an interview, contact Ruth Richardson, Operations Director, Action for M.E. on 07719 305217; or email ruth@actionforme.org.uk

NOTES TO EDITORS

Key information on module and dissemination

The module can be found on the Study PRN website at https://www.studyprn.com/p/chronic-fatigue-syndrome

The Scottish Government's Neurological Framework funding is supporting the project to improve knowledge relating to diagnosis and management of ME-CFS. Dr Nina Muirhead is developing a complementary podcast and short opinion pieces to support dissemination and take up in Scotland.

Key information on ME-CFS

There are estimated to be around 20,000 adults and children living with ME-CFS in Scotland. ME-CFS is a multisystem disease which is exacerbated by exertion. The condition affects up to four patients per 1,000.

Children, young people and adults with ME-CFS experience severe, persistent fatigue associated with post-exertional malaise, the body and brain's inability to recover after expending even small amounts of physical and mental energy, leading to a flare-up in symptoms. Commonly these include chronic pain, sleep disturbance, cognitive difficulties, digestive problems, sensitivity to light and sound; inflammation and autonomic dysfunction.

ME-CFS is the most common cause of health-related long-term school absence. ME-CFS costs the UK economy at least £3.3 billion each year; this figure accounts for healthcare costs, disability-related welfare payments, productivity losses and unpaid informal care. Yet research funding into the condition represents less than 1% of all active grants given by UK mainstream funding agencies.

Published research on the impact of ill health on quality of life highlights how much lower the quality of life is for ME-CFS patients compared with other chronic diseases and cancer. Research demonstrates that people with ME-CFS have a consistently lower quality of life, particularly in relation to their physical health.

The Scottish Good Practice Statement on ME-CFS was published in November 2010. Scottish Ministers have given a commitment to review the content of this Statement when the National Institute for Health and Care Excellence (NICE) publishes its revised guideline on ME-CFS in April 2021. The draft version, published November 2020 (https://www.nice.org.uk/guidance/GID-NG10091/documents/draft-guideline), notes two major differences relating to treatments for ME-CFS:

- Do not offer people any therapy based on physical activity or exercise as a treatment or cure for ME-CFS including any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy.
- Cognitive Behavioural Therapy is not a treatment or cure for the condition and should not be offered in this context. It may be useful though in supporting people who live with ME-CFS to manage their symptoms and to improve wellbeing and quality of life.

NICE has also made a statement cautioning against assumption that ME-CFS recommendations apply to people with fatigue following Covid-19.

Key information on project partners

Dr Nina Muirhead, who developed the module, is a dermatologist specialising in dermatologic surgery and oncology based at Buckinghamshire Healthcare NHS Trust. She chairs the Medical Education Group of the UK CFS/M.E. Research Collaborative (https://www.actionforme.org.uk/research-and-campaigns/research-we-fund/cmrc/ and has worked to ensure that education reflects both the patient perspective and up-to date biomedical evidence.

Action for M.E. takes action to end the ignorance, injustice and neglect faced by people with the chronic, neurological condition Myalgic Encephalomyelitis (M.E., sometimes diagnosed as chronic fatigue syndrome or M.E./CFS). Because we don't yet understand the biology of M.E., there are no targeted treatments that work for the majority. This differentiates M.E. from other conditions where better understood biomarkers can offer clearer treatment pathways and protocols. Action for M.E. does not recommend any individual treatments or management approaches. Instead, it offers key information to support informed decision-making. Every five years, we consult with people with M.E. in our Big Survey, to gather their experiences of, and insight into, living with M.E. in the UK. We most recently did this in May 2019, consulting with more than 4,000 young people and adults over three months. See more at https://www.actionforme.org.uk/research-and-campaigns/five-year-big-survey

#MEAction Scotland is a volunteer-led group determined to raise awareness of ME in Scotland and campaign for health equality for the patient community. We are an affiliate of #MEAction UK. Being Scotland specific, #MEAction Scotland can engage directly with MSPs and NHS Scotland health boards.

The ME Association supports people with ME/CFS through all stages of their illness. We provide information, support and practical advice for people, families and carers affected by M.E. (Myalgic Encephalopathy), Chronic Fatigue Syndrome (CFS) and Post Viral Fatigue Syndrome (PVFS). We also fund and support research, and offer education and training.

The 25% ME Group represents people who are severely affected by Myalgic Encephalomyelitis (ME) and their carers throughout the UK. We are called the 25% ME Group because is estimated that one in four people with M.E. are severely affected. Based in Troon, Ayrshire, we provide a range of services to members, including a dedicated members' advocacy service, and participate in relevant consultations including from the Health and Social Care Directorate in Scotland.