

25% M.E. Group 21 Church Street, Troon, AYRSHIRE KA10 6HT TEL: 01292 318611 Email: <u>enquiry@25megroup.org</u> Website: www.25megroup.org

Charity Number: SC034265

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If you, or a loved one, has Severe M.E. (Myalgic Encephalomyelitis), Please Join us!

Who are the 25% M.E. Group?

The 25% M.E. Group is a unique nationwide community based voluntary group. We have two paid members of staff and a number of volunteers - most of whom have severe M.E. We provide a range of services to people affected by <u>severe M.E.</u> (Myalgic Encephalomyelitis) and their carers.

Because of the intensity of the symptoms and disabilities experienced by severe M.E. sufferers, we seek to alleviate the isolation which having this illness can cause.

We encourage: communication between members; participation in the Group on a number of levels via our special interests groups, members' contact list; private Facebook Group, members' Forum *etc.*

What is M.E.? (Myalgic Encephalomyelitis)

Myalgic encephalomyelitis is characterised by a combination of muscle pain (myalgia), and neurological and cognitive symptoms such as memory loss and concentration difficulties (hence 'encephalomyelitis').

Clinical symptoms have been found to be consistent in over sixty recorded epidemics of M.E. spread all over the world. Patients had disabilities due to persistent symptoms of pain, fatigue and loss of endurance to normal physical activities, with abnormal muscle fatiguability and conspicuous deterioration of symptoms after exercise (post exertional malaise). To-date there is no known specific medical diagnostic test to determine or confirm a correct diagnosis. Although the symptoms experienced by M.E. sufferers can be similar to other illnesses – such as multiple sclerosis - diagnosis can be made on the specific clinical presentation through pattern recognition of a range of characteristic symptoms and how they relate to activity.

M.E. is a very debilitating illness, with no known cure. The vast majority of severely affected sufferers are virtually housebound or bedbound.

As well as the above core features, the symptoms and disabilities which many severe M.E. sufferers experience include:

- o visual problems
- o vocal limitations,
- o chronic weakness of limbs
- o problems with balance and fine motor control
- o profound malaise
- o hypersensitivity to stimuli such as light and noise
- o sleep and temperature disturbance
- o cardiovascular symptoms
- o digestive disturbances

As with any illness, the symptoms and disability which results will be experienced differently by each individual. We need to remember that no two people are alike in every sense of the word - we are all unique individuals.

What causes M.E.?

There has been much research into this condition, using modern technical methods. Researchers have demonstrated numerous abnormalities of the immune, muscular, cardiovascular, and central nervous systems. The emerging picture is of a multi-system disease with a strong component of immune and neurological dysfunction.

Doctors and researchers throughout the world continue to search for clarification on causal factors, for diagnostic tests, and for effective treatments.

The 25% M.E. Group do not offer specific medical advice to individuals on what treatment(s) may or may not be suitable to meet individual needs. We as a Group accept and recognise that what works for some does not work for others.

We cannot stress enough how important it is that any information which we are able to help you with should not be considered or taken to mean that we support any one treatment method, nor do we advocate that it be used or seen as a substitute for information and or guidance given to you by your GP or any other medical specialist.

What Services do we offer our Members?

- Twice yearly Newsletter
- Group Library
- Practical and Emotional Support
- Welfare Advice and Assistance
- Telephone Support Helpline
- Raising Funds to Support our Services
- Various Fund Raising Initiatives
- Special Interest Groups organised by members themselves
- Private Facebook Page and Members Forum

Would you like to help? Want more information? Please phone us on 01292-318611, or send an e-mail to <u>enquiry@25megroup.org</u>, or write to us at the above address. You can also contact us via the 25% M.E. Group's website at <u>www.25megroup.org</u>

Information about our Advocacy Service for Members

This is an exclusive service available only to members of the 25% M.E. Group and their carers.

If you would like to find out more about this service and becoming a member, please email us at:

enquiry@25megroup.org

As part of this service for members, we offer help with the following:

- Assistance to apply for benefits, including help with completing forms
- Help to appeal if a benefit is refused. (However, we are unable to provide representation in person at appeal hearings.)
- Advice and information on housing issues
- Advice and information on community care
- Advice and information on the Direct Payments scheme and other ways to self-direct care
- Assistance to lodge community care complaints
- Information and advice sheets on various topics

Whilst we will endeavour to ensure that all advice offered is accurate, legislation changes frequently so clients should always, as far as possible, seek to cross-reference the information given. We do not provide legal or medical advice, so if you require this type of advice contact a solicitor or your GP as appropriate.

We aim to provide a high- quality service to our members and to provide accurate information, but we cannot guarantee that we will always be able to ensure the desired conclusion in every advocacy case.

Our Volunteer Service

We are always looking for help and support from willing volunteers. Many of our current volunteers are severely affected M.E. sufferers thus restricted in what activities they can undertake. But it is truly amazing how many different members are actively involved within the Group in one way or another.

We need volunteers to:

- set up local fund raising groups;
- distribute our publicity and promotional material;
- assist with fund raising events, gala days, fetes.

Volunteers will not be expected to operate in isolation. We will provide you with as much support, help and assistance as we can.

If you, or a loved one, is severely affected by M.E. please consider joining our Support Group to receive information, help and support.

Our Annual Membership costs just £15.00 (UK) and £20.00 (Overseas)

You can join online via our website:

Website: <u>www.25megroup.org</u>
Email : <u>enquiry@25megroup.org</u>
Tel: 01292 318611
Or write to us at
The 25% ME Group, 21 Church Street, Troon, Ayrshire, Ka10 6HT

The 25% M.E. group promote an equal opportunities policy.