

Fighting chronic fatigue

Christina McDonald Legg talks to ME sufferer Orla Ní Chomhraí about the condition that affects 140 Galway City people

Imagine you have a severe hang-over, your muscles ache like you've been on horseback for a week, your vision is blurred and your head is pounding severely. Now combine that with extreme exhaustion like you have run a marathon and an inability to concentrate. This is what it is like to have ME, a severely disabling and painful neurological disease.

Also called Chronic Fatigue Syndrome, ME (Myalgic Enccephalomyelitis) can take a healthy, active person and lay them in bed in one fell swoop. It can incapacitate a runner's legs; it can debilitate a swimmer's arms. For many, the symptoms of ME can last months or even years and can vary from day to day and person to person.

Over 140 people are suffering from this incurable disease in Galway City, with around 10,000 people suffering in Ireland. Orla Ní Chomhraí, Volunteer and Coordinator with the Galway ME Support Group, was diagnosed with ME in the summer of 1998 after a bout of illnesses.

After months of various tests and a process of elimination, the fight began to overcome the illness. Ní Chomhraí is forced to use a mobility scooter because of the chronic exhaustion and pain that plagues her. After a few relapses and continuous illness, Ní Chomhraí doesn't know what will happen from one day to the next.

"It's been an up and down course," she says. "The last few years have been an awful lot worse. I can't work; I don't have a social life. I only get out very rarely and then only to the cinema or to meet a friend for a cup of tea, basically where I can sit down."

Since ME usually starts after a viral illness and is mostly an invisible illness, it is often difficult for sufferers to get appropriate support and treatment. According to Ní Chomhraí, treatment, basically, is just the management of the symptoms, making it difficult to plan for the future.

"I don't really know what the prognosis is, so that's frustrating." "It's hard for me to know what the future holds; I can't really think beyond the week."

In an effort to raise awareness and funds, the Irish ME/CFS Support Group held its annual Blue Ribbon ME Awareness Week last week, sending information leaflets and posters to citizen's information centres, youth centres and third level institutions around the country.

"We concentrate a lot of our efforts on raising awareness, as an early diagnosis improves the prognosis. As there are no simple diagnostic tests, it can be a difficult illness to diagnose," Vera Kindlon, Chairperson of the Irish ME/CFS Support Group says.

The Galway ME Support Group has also organised a free talk in Galway at the Courtyard Merriott Hotel on the Headford Road at 3pm on Saturday, 20 May with Dr Charles Shepherd, author of 'Living with ME' and Medical Advisor to the ME Association in Britain.

Dr Shepherd first became interested in ME over 20 years ago when he developed ME following a viral infection. As well as talking about illness management, Dr Shepherd will be reviewing the latest research findings on this illness. He will also explain how these advances in knowledge may be leading to the development of treatments aimed at the underlying problems, rather than



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just alleviating symptoms.

Dr Shepherd will also discuss the new initiatives taking place in Great Britain and how it might be worth trying to obtain similar government action in Ireland.

"Despite all the clinical and research evidence, there is still a great reluctance on the part of government departments, the medical establishment and research funders to accept that ME has a neurological basis," Doctor Shepherd says in a

report he submitted to the Gibson (UK Parliamentary Inquiry) a couple of weeks ago. "Consequently, there is not a climate of confidence or support for neurological research into either the cause or management of ME in the UK. Without support, encouragement and funding, we are not going to find the underlying cause of this illness and develop successful forms of treatment."

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