

'It's such a relief to know other people have the same symptoms'

After 25 years of living with a condition causing symptoms of chronic pain and fatigue Ian Logan has his life back. During ME Awareness Week he speaks to JAMIE ROSS and says support is out there

MORE than a quarter of a century ago, Ian Logan was oblivious to the fact that a relatively harmless virus would soon be the catalyst for decades of misery.

Triggering something that to this day is still not understood by the best medical minds, the heating engineer went on to suffer for 25 years with myalgic encephalomyelitis, commonly known as ME.

Ian says: "There are so many names given to it, ME, fibromyalgia, chronic fatigue syndrome, chronic fatigue immune dysfunction syndrome, or CFIDS, but all over the world, it's now coming up to be the same thing.

"These people are all showing the same symptoms at different times."

For many years the condition was not recognised, in fact, it was a common belief that the symptoms were imagined by the patient and the course of treatment offered, if any, was a psychological one.

The 67-year-old says: "The psychology lobby keep saying it's all in your mind. I, like others, was told, 'I can find nothing wrong with you' and you find yourself left to one side."

But Ian's symptoms were all too real and they ended up robbing him of a large chunk of his life, leaving him too exhausted or in too much pain to carry out the most straightforward day-to-day tasks.

"There were five years of slow onset following a viral thing," he explains. "I never thought I would get right again. Then it went down hill.

"I couldn't even carry my tool kit, I couldn't even get down the stairs. It's like torture.

"The fibromyalgia pain is all over, you can't sleep. You go for weeks with very poor sleep, you don't even know if you slept properly at all. The symptoms are legion."

The exhaustion and pain naturally has a knock on effect to the rest of your life and with family members and friends.

Ian says: "People lose their jobs – I wouldn't have employed me, I was too unreliable. Many people are almost made to retire early.

"There's 25 years of my life gone. My wife, Karin, stuck by me. Lots of people don't because it's not the person they married anymore. There are no holidays, you loose most of your friends and social connections

ME AWARENESS DAY 2014 – SHARE THE MESSAGE

ACTION for ME strives to empower people with ME to fulfil their potential and secure the care and support they need, while working towards a greater understanding of the illness, and ultimately a cure.

ME affects an estimated 250,000 men, women and children in the UK. Symptoms can include post-exertional malaise (a period of intense exhaustion that lasts for more than 24 hours following exertion) and chronic pain. ME affects different people in

different ways and symptoms can fluctuate and change over time.

Some manage to struggle on with their lives. Others spend most of their time bed-bound or house-bound, unable to perform basic functions unaided.

Many people still believe ME to be "all in the mind", however, research has found potential biomarkers (physical evidence) for ME but much more research needs to be done to confirm the cause, or causes, and a cure.

For ME Awareness Day, Action

for ME is trying to get as many people as possible to share its message at exactly noon today using Twitter, Facebook or Tumblr.

The message is:

"Many symptoms, too little research, no proven cure. It's ME. Awareness Day: read the facts, spread the word #MECF5 <http://thndr.it/1i9ovmY>"

To join Action for ME in sharing this message together at the same time – automatically – visit actionforme.org.uk.

are all excluded.

"And they are not being unkind but you just can't keep up with the conversation."

For many, the daily torment of the condition leads to some very dark thoughts and, according to Ian, some even take their own lives to escape it.

He says: "If you're being tortured, what do you want? What you want is out.

"But you have family and you can't, and you're not allowed in this country. People I know did and it's sad.

"People who decided they had enough and they did something about it."

Thankfully, Ian has finally discovered something ridding him of the wretched symptoms.

"I'm back to normal," he says. "It's a personal triumph, nothing to do with modern medicine, it was actually Chinese herbal medicine.

"There's nothing in conventional medicine to do anything for this condition.

"Before, I wouldn't have been able to talk to you like this. When you have ME, fibromyalgia, if someone asks you a question, you can't answer, you can't access your own vocabulary."

As well as coping with his condition, for the last 25 years, Ian has been involved with the Worcestershire ME Support Group.

Now the chairman of the group, he wants to spread the word to other people trying to cope with the condition that they need not suffer alone.

"We're a self-help group, we all do it for free and we're desperate for volunteers," Ian explains.

"We can offer expenses and we do value people's energy and time.

"We need help with a newsletter, we can get it printed relatively cheaply but it's getting people to spend a bit of time at home creating it.

"Jill Pigott has been our secretary for about 12 years, she looks after her son who has ME. She has been doing the newsletter but it's a lot to do for one person and what we need is people to share the workload.

"The group is for people with ME, fibromyalgia, or people caring for people with the condition. It's people who have had the problems and sharing their experiences with people who are new to it.

"There are six meetings in the county, we don't have meetings in January or August, so we have a total of 60 meetings a year.

"We have to pay for the room in most cases which is our biggest expenditure.

"We are self raising for funds, we are lucky we have had a lot of regular supporters.

"The main reason for doing it, rather than being left in limbo, not knowing what to do, people can share their experiences, what has worked for them."

As there is currently no medical cure or relief for the condition, the group also discuss alternative therapies that they have found helpful.

Ian adds: "The best bit is the new people who come along and the difference in them from when they came in to when they leave.

"It's such a relief for them to know other people have the same symptoms as them."

Ian strongly recommends anyone currently struggling with ME or any of the other associated conditions, come along to one of the meetings.

He says: "If people can just be brave enough to come along to one of the meetings of even just pick up the phone."

Monthly informal gatherings take place in Worcester, Malvern, Pershore, Droitwich, Kidderminster and Redditch.

To highlight ME Awareness Week, the group has organised a special meeting on Saturday at Museum of Carpet in Green Street, Kidderminster.

There will be a number of DVD presentations on ME, chronic fatigue syndrome and fibromyalgia as well as information from previous ME Research UK and Invest in ME conferences.

Ian now has the rest of his life in front of him and he is determined not to waste a moment of it.

He says: "Having now got well, and having lost so many years, I don't know what to do first.

"The house was half way through being built, the motorbikes, the steam, the days out.

"But I would always say to people, don't ever take your health for granted, you miss it when it is gone."

● **Worcestershire ME Support Group** aims to raise greater public awareness of the condition and support sufferers, their carers, friends and relatives. For more information and to find out when and where the meetings take place, visit worcsme.org.uk or call Ian on 01886 888419.