

# *Living with ME...*

One of the biggest frustrations expressed by people with ME is that family, friends, work colleagues, the media and even doctors don't believe their illness is real, or fail to understand how debilitating it can be. Trying to explain can be exhausting, so perhaps this article can help others to understand.

ME is not "all in the mind" – it is a real physical and very debilitating illness which can affect people of any age from infants upwards, and currently affects 1 in 250 people in the UK alone. In Staffordshire there is no specific funding for ME and in most cases it is still treated as a psychological or mental illness, leading to patients being passed around from psychiatrists to psychoneurologists to psychotherapists, none of whom are relevant. Referral for CBT (cognitive behavioural therapy) or physiotherapy can even make the condition worse by pushing the patient too quickly and not allowing sufficient resting time.

The degree of physical illness varies greatly, but common symptoms include pain – both muscular and internal; sheer exhaustion; poor concentration; 'brain fog'; balance problems; difficulties with walking and other kinds of physical exertion; eating and digestive problems; and difficulties coping with mental activities such as reading, watching TV or socialising. Symptoms can vary from day to day and even from hour to hour, and patients have no idea when they wake in the morning how they are going to feel, or even if they will be able to get up at all. Making definite plans for the next day is often impossible.

ME patients only have a fraction of the energy that a well person has, so if there is something they have to do or something they really want to do, it has to be carefully planned so that they rest as much as possible before the event and can also rest fully afterwards, when they are likely to be shattered. 'Resting' usually involves lying down in a quiet, darkened room and becomes frustratingly 'dead' time wasted from the day, rather than the enjoyable scenario of sitting with feet up, a magazine and a drink

that well people imagine when they make thoughtless comments like "Oooh, I'd love to have a rest for three or four hours every day."

Sleep does not always help as sleeping patterns can often be very irregular and affected by pain and discomfort. ME patients can also be extra sensitive to sound, light, movement, heat and cold, and so are more easily disturbed.

Having ME has been described as 'like trying to drag yourself through porridge or treacle all of the time, every day' and even as 'a living death'. An estimated 25% of sufferers are housebound or bedbound – at its worst, severe ME can involve being bedbound for years and totally dependent on carers.

There are probably many more people with ME than are actually diagnosed with the illness. The symptoms can be so varied that GPs may class patients as suffering from hypochondria, depression, anxiety or IBS (irritable bowel syndrome) rather than recognising their illness as ME. Most ME patients do not suffer from depression but from TFU (Thoroughly Fed Up) syndrome, as they dearly want to do so many things and maintain their interests but they do not have the energy to do them. Relationships and social life can dwindle away to nothing, leaving sufferers isolated and lonely. Wouldn't you be fed up if it was you?

Just imagine how you feel when you have a bad dose of the flu, when you can't get up and do anything, everything aches, your head is muzzy and your legs feel like cotton wool – and then imagine how you would feel if that flu never left you, ever....

*That's what living with ME is like*