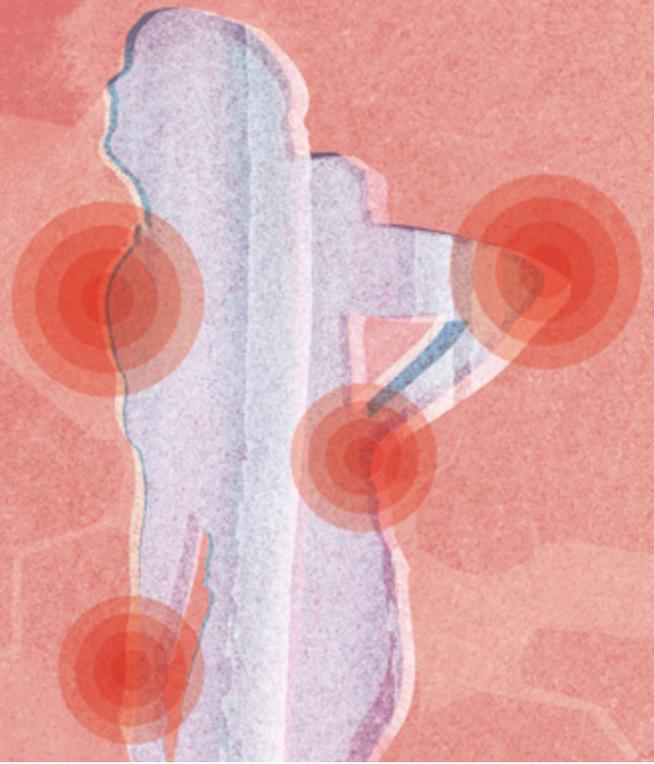


You look just fine – when pain is invisible



*Fibromyalgia is a chronic disability which manifests with aches all over the body and profound fatigue, including headaches, sleeping problems, and difficulty concentrating. **Miriam Calleja** talks to people who try to make the most of their lives while being held back by this condition.*

Have you ever stayed up studying (or partying?) for most of the night and slept just a couple of hours? You might wake up feeling not so bad, but later you notice you're tired and can't quite focus. Then perhaps some nausea sets in. You are so exhausted that you might collapse.

This is how a fibromyalgia and myalgic encephalomyelitis (also known as Chronic Fatigue Syndrome or CFS) sufferer describes her day-to-day life. You might recharge on resting, but for a person with fibromyalgia or myalgic encephalomyelitis, the battery never charges.

Christabel Cutajar (25) is studying psychology at the University of Malta (UM) and is a fibromyalgia sufferer. She struggles with accessibility and finds that current adaptations of the learning environment don't offer equity to students like her. Together with a fellow sufferer, she is working to raise awareness and achieve the crucial changes she needs.

'MY BODY JUST BROKE'

Since fibromyalgia and myalgic encephalomyelitis are diagnosed by elimination of other potential ailments, misdiagnosis is common. This means that further investigations are not made, or delayed, with detrimental and sometimes fatal consequences for the patient.

Fibromyalgia affects 10 times more women than men. It has baffled medical and health experts for

decades because it does not show up as abnormal in blood tests or scans. Due to the lack of 'evidence' some healthcare professionals do not take these ailments seriously, and diagnosis is delayed or missed.

Myalgic encephalomyelitis is a devastating multi-system illness that causes dysfunction of the neurological, energy metabolism, immune, and endocrine (hormonal) systems. It is estimated that up to 25% of patients may be housebound or bedbound. Like in fibromyalgia, there is a spectrum of severity, and sufferers may feel different daily. A single stressful experience may have an effect that lasts for days or weeks.

Although numerous UM students have researched the lived realities of fibromyalgia and myalgic encephalomyelitis, local peer-reviewed research on these conditions is scarce. Martinique D. Vella-Baldacchino, Matthew Schembri, and Mikhail Vella-Baldacchino, writing in the *Malta Medical Journal*, pointed out that Malta only recognised myalgic encephalomyelitis/CFS as a disability in 2011, although the effect on quality of life is comparable to AIDS.

The initial onset of fibromyalgia normally follows a trauma and that of myalgic encephalomyelitis often follows an infection. 'Everything was fine and suddenly my body just broke,' recounts Rebecca Camilleri (35), who suffers from both fibromyalgia and myalgic encephalomyelitis after glandular fever. ➔



As she combats the condition, she shares how ignorant onlookers have dismissed her pain: you're lazy, you're being dramatic, or you're a hypochondriac. In other words – you're faking it. But how many people would switch from having an active work and social life to depending on others constantly, physically and financially, for the sake of faking it?

In this year's budget, the government has added fibromyalgia and myalgic encephalomyelitis patients to the list of those eligible for assistance with their disability. For Rebecca and Christabel, the worry here is the mention of 'stringent testing'. With invisible disabilities such as these, the Commissioner for the Right of Persons with Disability Oliver Scicluna suggests that 'as a state, we should now assess such individuals on a social impact level [i.e. what they can and cannot do in the society] rather than just from a medical point of view. Methods such as the ICF, or International Classification of Functioning, and other assessment codes can be used.' Invisible disabilities may not have physical parameters to measure or consider, so how are authorities to test their impact and judge what these patients need? If assistance is given to those who work, what happens to those who are too unwell to have a steady job?

PAIN AND STIGMA

'I need to plan to pre-plan when and what I'm going to do,' Rebecca explains. If she is planning to wash her hair on a given day she would not have the energy to go buy bread and milk that day. Fear is a constant, a norm. 'If I overexert myself, will I wake up paralysed tomorrow?'

This is because the body of a patient with myalgic encephalomyelitis does not deal with exertion in the same way every time—numerous studies have found that blood flow to the brain and heart, and oxygen uptake by haemoglobin are reduced in these patients. The overall picture is much more complicated and involves various systems in the body.

A cold shower can cause excruciating pain. Some patients can feel a light touch to be like burning. To others, there may be days when the simple touch of clothing against their skin can be extremely uncomfortable.

In an academic setting, how, then, does a patient get from one lecture to another in a few minutes? 'If it takes the other students an hour to learn something, it may take me up to three times that much, especially if I have brain fog,' Lina, a mature student at the time, told UM Master's degree student Erika Spiteri in 2015. 'I have to produce a medical certificate every time I have a flare-up and cannot get out of the house.'

The University of Malta Access Arrangements (of October 2018) do not mention fibromyalgia specifically, but they

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mention myalgic encephalomyelitis/CFS and post-viral fatigue syndrome. Christabel believes that the University is equipped with the facilities to make life easier, yet these are still waiting to be put to good use. The option to listen to lectures online would be a game-changer, benefiting various students (e.g. single parents or primary carers). Rebecca and Christabel find a little solace in their NGO, accompanied by the 'ME, CFS and Fibromyalgia support group' on Facebook, where they share their experiences, woes, and advice.

The more I learn about fibromyalgia and myalgic encephalomyelitis patients, the more obvious it is that many problems could be reduced through simple measures and some understanding. If you want to be an ally of people with fibromyalgia or myalgic encephalomyelitis, take a few minutes to learn about these conditions. If you're an employer, try to provide opportunities for people to work from home. Keep an eye out for bullying and be active about stopping it. Understand that another person's pain doesn't always show. Recognise that people with invisible disabilities don't always look ill (actually, they try to look their best). Listen, check in, see what you can do to make your friend's life easier. Try to help sufferers who may be stuck in abusive situations because of their disabilities.

But first, stop judging and relying on assumptions. Don't say things like 'but you look fine' when someone asks for a hand, instead care and listen. **T**

Further reading

Häuser, W., & Fitzcharles, M. A. (2018). Facts and myths pertaining to fibromyalgia. *Dialogues in clinical neuroscience*, 20(1), 53–62. Available online at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6016048/>

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Vella-Baldacchino, M. D., Schembri, M., and Vella-Baldacchino (2014), M. Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). *Malta Medical Journal*. 26(1), 17-22.