Living With MYALGIC ENCEPHALOMYELITIS
An Invisible Disability
I am so pleased to have the opportunity to introduce this comic on Myalgic Encephalomyelitis, as part of an initiative promoting awareness of Fibromyalgia, Myalgic Encephalomyelitis and chronic fatigue syndrome. I wholeheartedly commend all the contributors who made the comic a reality.

I show my appreciation to Prof. Divya Jindal-Snape, Director, TCELT Research Centre at the University of Dundee, for the synergy she created and for sharing her expertise in all aspects of developing the comic.

I would like to thank Rebecca Camilleri, Ruth DeBono, and Maria Gauci, from the ME, CFS & Fibromyalgia Alliance (Malta) for sharing their real-life stories. I believe that through your openness in sharing, you are reaching people who suffer in silence, showing them that they are not alone.

This is just the beginning of a fruitful and sustainable collaboration that will raise awareness of all the invisible disabilities, not only among people living with these conditions, but also their families, carers, professionals in the field, and policymakers, in Malta, Europe and beyond. I assure you that I will continue to support this initiative in any way possible, until every person living in Malta and Gozo becomes aware of the invisible disabilities and their consequences. The invisible disabilities have been invisible for long enough. Together, we will make them truly visible.

Marie-Louise Coleiro Preca
Former President of Malta
Chair of The Malta Trust Foundation

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Living with Myalgic Encephalomyelitis (ME) and Post-exertional Malaise

Story: Rebecca Camilleri; Script: Divya Jindal-Snape; Art: Steven Affleck; Lettering: Damon Herd
You were such a hyperactive child, independent and full of ambition.

You got a job at 16!

Do you remember I dreamt of having my own business to sell my artwork? I worked 3 jobs to make my dream come true, but...

I told you, it’s just growing pains.

Nothing to worry about! They will disappear soon enough.

Stop wasting my time!

I was always in pain, suffering from headaches and constantly at the doctors due to this.

My migraines and “growing pains” never went away! They only got worse with age.

This was in fact Fibromyalgia, gone undiagnosed for years.

Worse still, at 17 I came down with glandular fever.

That was the onset of Myalgic Encephalomyelitis.

It was the end of my life as I knew it.

I had to quit two of my jobs as I physically couldn't make it to work.
I clutch onto this paper bag...

I throw up every morning as my body is too weak to get out of bed.

They said that if I kept calling in sick so often, they would have to let me go...

I have to push on.

You look like death. You are too sick to be at work!

Mum! Mum!!! Hurry up.

I can't move...

I was temporarily paralysed from my waist down. It was then that we knew it was something much worse.

You see, Myalgic Encephalomyelitis and Fibromyalgia are two conditions that still have no direct tests.

One can only get diagnosed by excluding a long list of other conditions.

I only found out because of an article I read. It took me 15 years to get diagnosed...

15 long years of fear and abuse from doctors and workmates!

She is just stressed.

She is lazy.

She just wants attention!

She is just making it all up because she is depressed.

Do you know the fear a person feels when they know there is something terribly wrong with them but no one knows what, and they actually blame you for it?

I had to give up most of my life. I am not always bed bound but I am often house bound.
Do you know what it feels like living with ME?
Waking up every morning so weak you can barely breathe or speak?
Waking up already exhausted before you even started the day?
When whatever you eat makes you sick?
When any source of light burns through your eyes and the slightest noise feels like the loudest speaker directly in your ear?
75% of ME sufferers are housebound and cannot work. From those 25% are bed bound. 3% of death rates were found, some due to suicide.
Most importantly, do you know what it feels like to lose your life but still exist?
Because I do!

I slipped through all the cracks of the system and get no financial help from the government to buy even medicines.
I live with my mother who has cancer. We both cannot work and live off her minimum pension. If one can call this living!

No one chooses to be sick, no one chooses all this!

I don’t want your pity or special treatment.
I want you to understand that I only want my dignity and a bit of my old life back.
Work is dignity and will give me that push in life to feel useful and needed.
There are schemes for disabled people to help them go to work… but what about those who can’t go out?

We are educated, you know? Our NGO campaigned for teleworking as it would help us. But we were told that wasn’t possible.

We need teleworking schemes to support us to be able to work from home, even if it is for 5 hours a week. It will give people like me a reason to live when we have none... and studies have shown that it reduces thoughts of suicide.

Lo and behold, COVID hit and half of Malta was put on teleworking!

I don’t want special treatment.
I want you to understand that I only want my dignity and a bit of my old life back.
Work is dignity and will give me that push in life to feel useful and needed.
There are schemes for disabled people to help them go to work... but what about those who can’t go out?
Working and Living with Myalgic Encephalomyelitis

Story: Maria Gauci; Script: Divya Jindal-Snape; Art: Rebecca Elysium; Lettering: Damon Herd

I work 20 hours per week.

This is very challenging because I live with Myalgic Encephalomyelitis.

I changed from clinical to administrative work.

Still 20 hours per week.

I wanted to prove to myself and others that I could do it – and I did it, with flying colours!

...but at a cost, I am physically, mentally and emotionally burnt out, barely holding myself together.

On bad days, it can take up to two hours to do jobs I could do in one hour. I have, what I call, 'dyslexia moments'.

I don’t want to be judged.

Come on Mum! You said yesterday if I let you rest, we could go to the park today.

Q: What should you do when you have a flare up and crash?

Rest for the day so you can go to work tomorrow.

Do some jobs at home so your husband doesn’t have to do everything again.

Spend quality time with your family.

Go grocery shopping, stay in bed for 2 days after that.

I feel so guilty. I can’t be the wife and Mum that I always dreamt I would be.

Some days are worse than others.

Always wondering where I will get the energy to do the next step.

Unable to hide the fatigue and pain any more... my whole body failing me.

I decided to resign to get a break before starting a new job.

But here I am 4 years later... still unable to work.

I really miss my job.
Grocery Shopping: Myalgic Encephalomyelitis and Post-exertional Malaise
Story: Rebecca Camilleri; Script: Divya Jindal-Snape; Art: Tasha Leah Santiago; Lettering: Damon Herd
It's been a long while since I felt good, 
questioning my existence, faking my mood, 
My body complains of pain and fatigue 
Searching for meaning, searching for truth.

Opinions are fired, shot, and directed 
At my aching heart being adjudicated, 
Silence kills me, yet necessary for me, 
Broken hearted, I cry myself to sleep.

My past and my present, against all odds, 
All kinds of abuses, all playing gods, 
Exclusion, conclusion, discriminatory truths, 
Brought me down on my knees, all ruined my youth.

Emotional bombardment, a storm full of pain 
Exhaustion and burn out, emotional rain, 
My tears ask me questions; “who really am I?”; 
My lips quiver answers: “traitor and lies”.

“You don’t look sick, you don’t qualify, 
Take some pain killers, get on with life.” 
“She must be lazy, a social parasite, 
Just let her be, she’s a lazy wife!”

Why is my trauma, given the side? 
My sexual and physical abuse are tied, 
My emotional storm has been my guide, 
Taught me how to keep it all inside.

Exclusion came early, since a young child. 
Hiding my pain, want to cut my vein, 
But smiling, behaving, ignoring my pain, 
Crying in silence, is warrior’s gain.

Negativity has no place in today’s world, 
Why tell them, why bother, what could I change? 
Positivity’s the new trend, makes it all blurred 
What should I do to make a change and be heard?
The ME Association Factsheet:
What you need to know about M.E.

- M.E. (myalgic encephalopathy or encephalomyelitis) is a complex multisystem disease with a wide range of disabling symptoms.
- M.E. can cause greater functional impairment and poorer quality of life than many other serious medical conditions, including multiple sclerosis and cancer.
- M.E. has a characteristic clinical feature known as post-exertional malaise – a delayed exacerbation of symptoms that can follow even minor physical or mental exertion.
- M.E. research has determined significant abnormalities in the central nervous system, immune system, endocrine (hormone-producing) system, and muscle (causing energy metabolism impairment).
- M.E. is classified by the World Health Organisation (WHO) as a neurological disease. WHO classification is recognised by the Department of Health, the Medical Research Council and NICE (National Institute for Health and Care Excellence).
- M.E. is estimated to affect around 0.2-0.4% of the population (c.265,000 people in the UK) – including children and adolescents.
- M.E. can affect some people very severely, leading to atypical seizures, speech and swallowing difficulties and extreme intolerance to light and sound. These people will be bedbound, they require continuous 24-hour care and may need tube-feeding.

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Organisations

- ME, CFS & Fibromyalgia Alliance: https://www.facebook.com/me.cfs.fm.AllianceMalta
- ME Action: https://me-pedia.org/wiki/ME_activists_and_advocates
- Millions Missing: https://millionsmissing.meaction.net/millionsmissing-2022
CONTRIBUTOR BIOGRAPHIES

**Steven Affleck**, no relation to Ben, is an illustrator/cartoonist based in Scotland.

**Rebecca Camilleri**, a sufferer of both Myalgic Encephalomyelitis and Fibromyalgia, set up a support meeting in 2013. The NGO ME, CFS & Fibromyalgia Alliance Malta was subsequently established advocating for both invisible disabilities, where she works as the Public Relations Officer and Events Manager.

**Ruth Debono** has advocated for Fibromyalgia and Myalgic Encephalomyelitis as President of ME, CFS & Fibromyalgia Alliance since its inception in 2013. She herself suffers from Fibromyalgia and chronic fatigue and other comorbidities with chronic widespread pain as her main symptom.

**Rebecca Elise** is an illustrator and comics artist based in Leeds, whose work explores articulating experiences of anxiety and re-examining mythological narratives through a modern lens.

**Maria Gauci** suffers from ME/CFS and Fibromyalgia. She has been an active board member of ME, CFS and Fibromyalgia Alliance.

**Damon Herd** is Programme Director of the MDes in Comics & Graphic Novels at Duncan of Jordanstone College of Art and Design, University of Dundee. He is also an artist, researcher, and comics maker.

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**Tasha Leah Santiago** is a digital animation student currently studying at Singapore Polytechnic, who also creates local comics for CS comics, a Singaporean superhero franchise.