



University of Dundee

Living With MYALGIC ENCEPHALOMYELITIS

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Living With
MYALGIC ENCEPHALOMYELITIS
An Invisible Disability



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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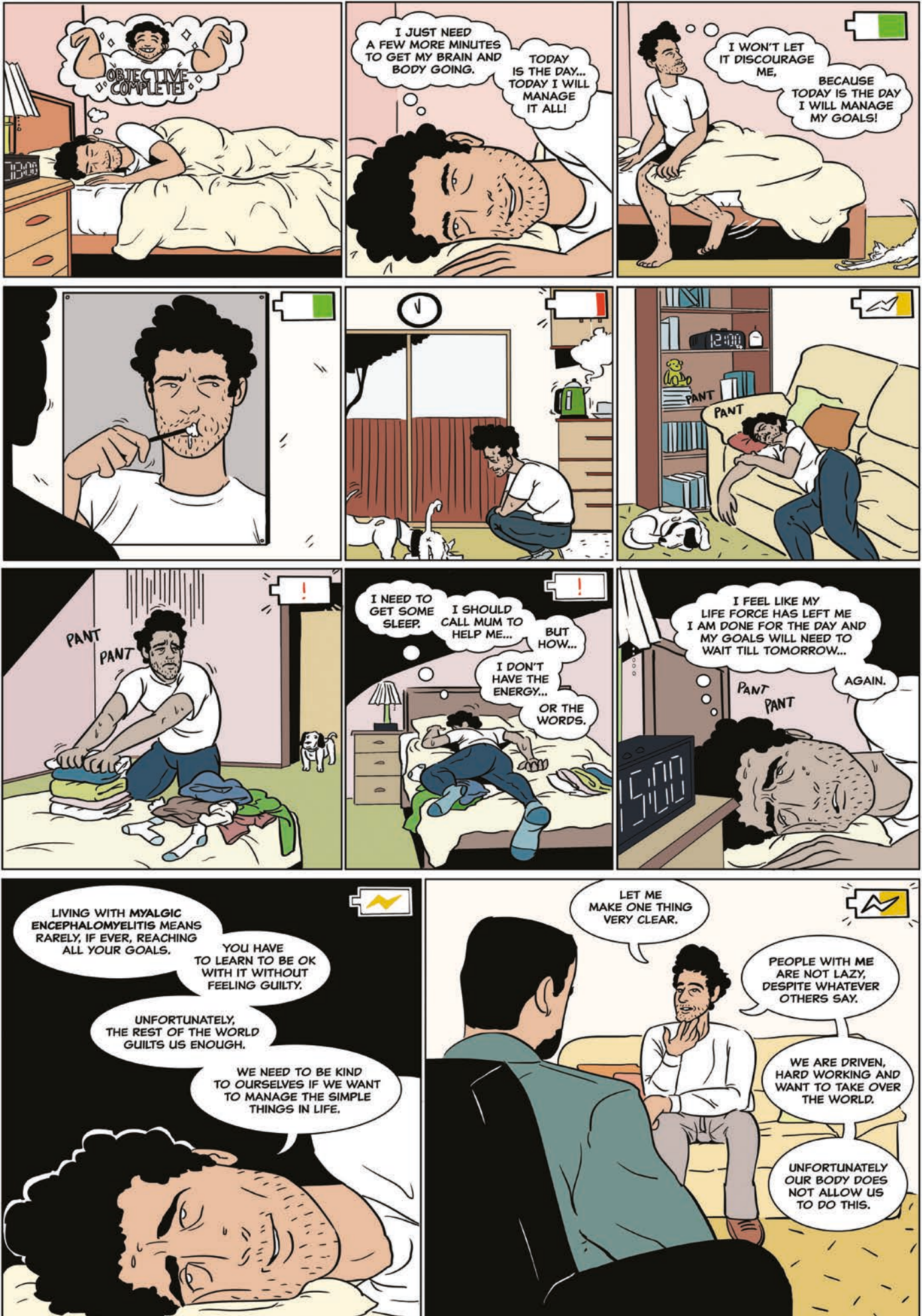
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Editors: Divya Jindal-Snape and Chris Murray
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Lettering and Production: Damon Herd

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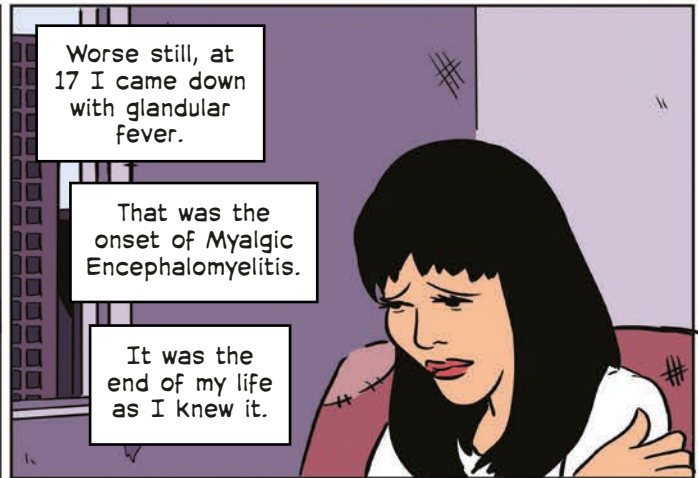
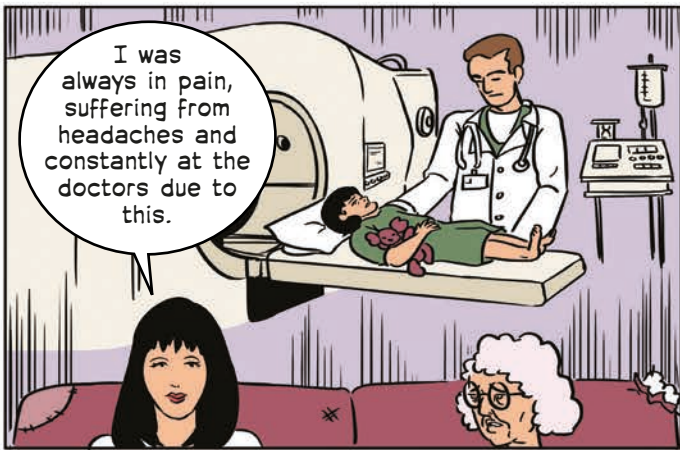
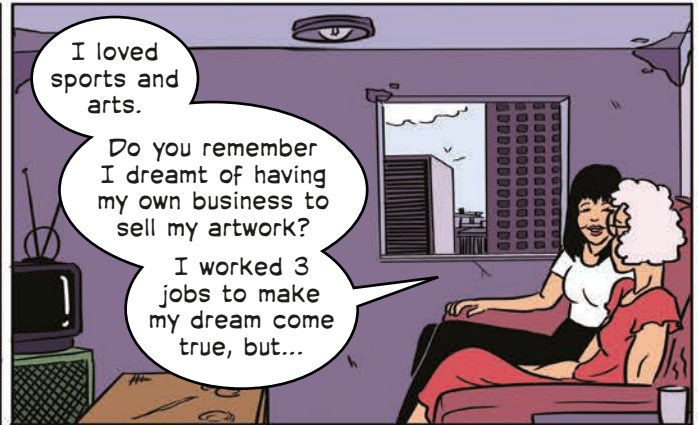
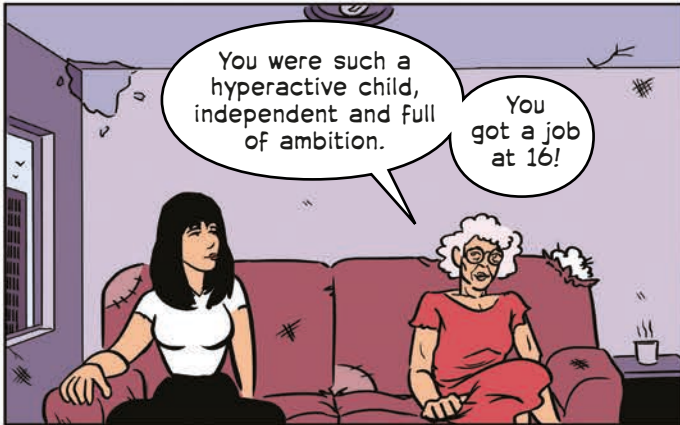
Living with Myalgic Encephalomyelitis (ME) and Post-exertional Malaise

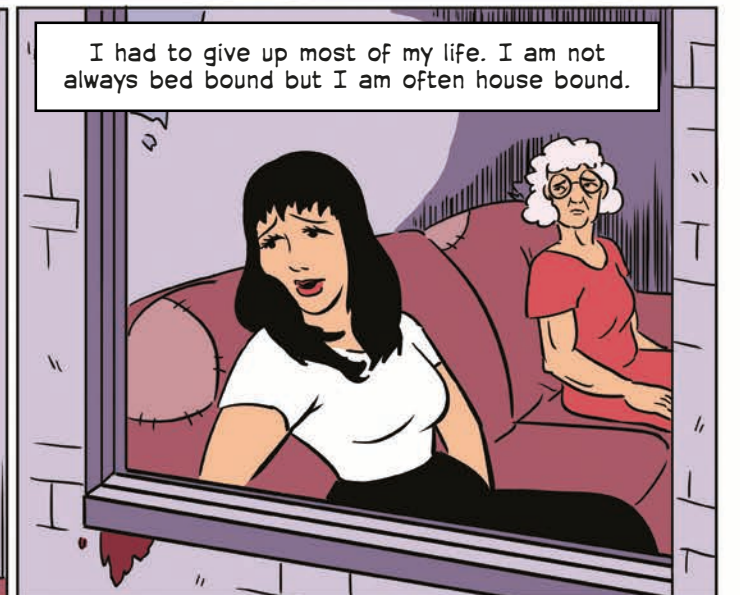
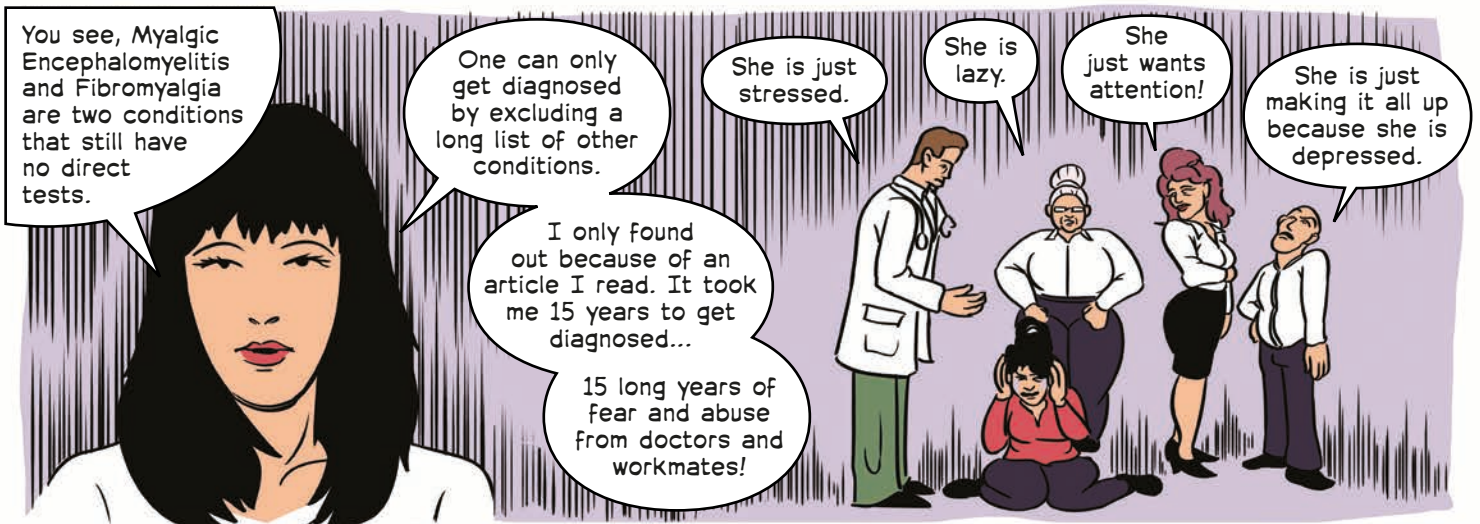
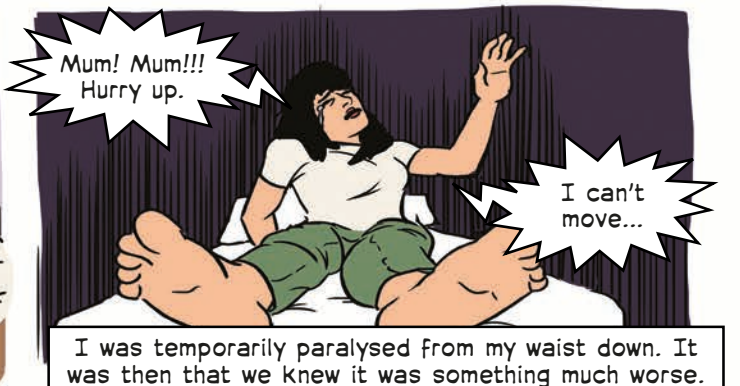
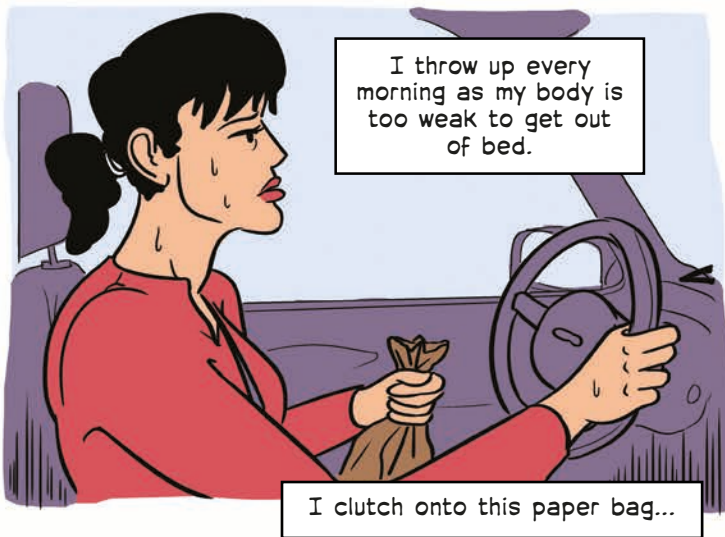
Story: Rebecca Camilleri; Script: Divya Jindal-Snape; Art: Steven Affleck; Lettering: Damon Herd



Living With ME: A New Reality

Story: Rebecca Camilleri; Script: Divya Jindal-Snape; Art: Steven Affleck; Lettering: Damon Herd







Do you know what it feels like living with **ME**?

Waking up every morning so weak you can barely breathe or speak?

Do you know what it feels like when the clothes on your skin burn and bruise you?

Waking up already exhausted before you even started the day?

When you can barely walk to the bathroom because your legs give way?

What it feels like when your brain just cannot do the simplest of tasks, like open a door or remember a word?

When you suffer from a cluster headache and just wish for someone to cut half of your head off due to the pain?

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?

Most importantly, do you know what it feels like to lose your life but still exist?

Because I do!



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

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!



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.

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

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.

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.

To Do:
 • Admin ✓
 • Ward round ✓
 • cleaning ✓
 • making ✓
 • consult ✓

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.

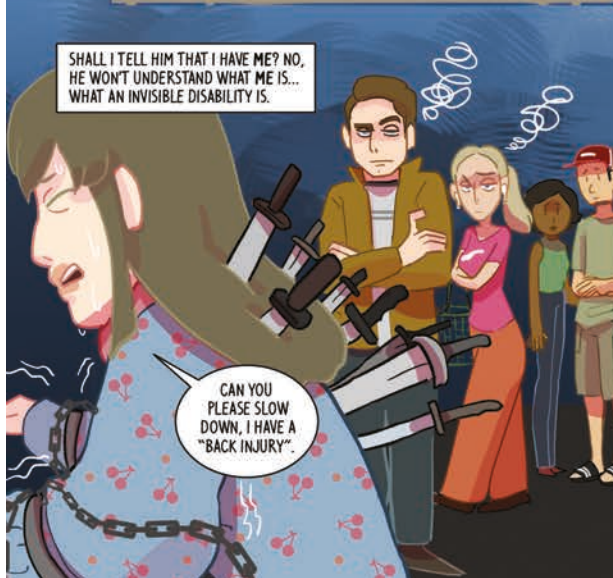
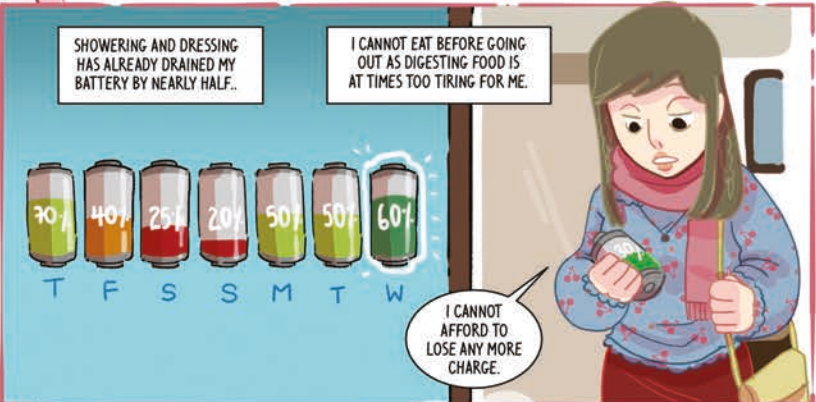
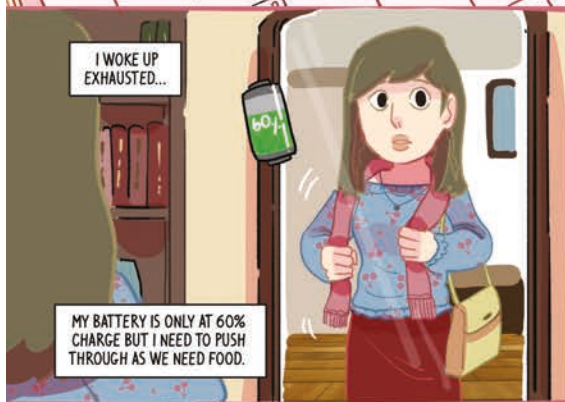
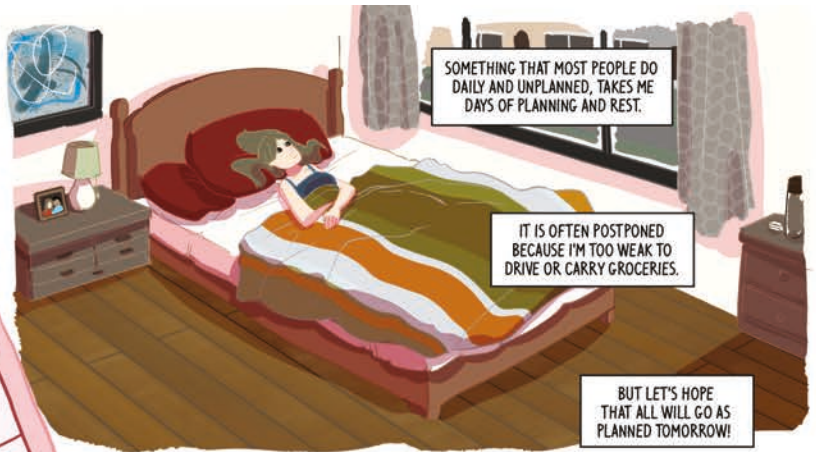
I DECIDED TO RESIGN TO GET A BREAK BEFORE STARTING A NEW JOB.

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





Mysterious Pain - Invisible Disability

Author: Ruth DeBono; Art: Tasha Leah Santiago

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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source: <https://meassociation.org.uk/wp-content/uploads/ME-Factsheet-What-you-need-to-know.pdf>

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.

Divya Jindal-Snape is Professor and Personal Chair of Education, Inclusion and Life Transitions in the School of Education and Social Work, and the Director of the Transformative Change: Educational and Life Transitions (TCELT) Research Centre at the University of Dundee.

Chris Murray is Professor of Comics Studies at the University of Dundee. He is also Director of the Scottish Centre for Comics Studies and Dundee Comics Creative Space.

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.

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