

The ME Show Special by Gary Burgess in association with the ME Association

Podcast transcript 9th May 2019

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Hello, my name is Jo... My name is Naomi... My name is Emily... My name is Louise... And this is the Real M.E... The Real M.E... The Real M.E...

“Hello, this is Gary Burgess and welcome to this Special Edition of The ME Show supported by the ME Association to mark ME Awareness Week.”

“This week is all about shining a light on the Real M.E. And that’s what this episode sets out to do. Real People in their own words, telling their own story.”

“You are about to hear a selection of them. Each is only a couple of minutes long, so you can pause as you go if you don’t have the energy to listen in one go. And I suspect, like me, you’ll be moved by what you are about to hear...”

Hello, my name is Jo, and this is the Real M.E.

Before I became sick, I had a full-time job and a very active social life. I loved going to gigs with friends and I loved to travel. But I’m not able to do any of those things I loved now since developing M.E. thirteen years ago. I now live my life from one darkened room, and I rely on carers for even my basic needs. I’m confined to my bed due to severe weakness, fatigue and chronic pain. I am alone for long periods of time because social interaction is so exhausting and painful. Some days I struggle to even communicate. I only leave my home for hospital visits and it takes me weeks to recover. Even the slightest activity causes my symptoms to worsen – this means if I choose to spend a few minutes talking to a friend I am likely to pay for it for days afterwards. M.E. doesn’t just affect me. It also has a huge impact on my husband’s life. Not only does he care for me, but he also has to put up with strangers – care workers and medical professionals – coming into our home. He has to be quiet all the time and physical contact is limited. His life has to revolve around me and my poor health. He married an able-bodied, active woman and has had to make a lot of adjustments because of M.E. Noise and light cause me pain, so I am forced to wear sunglasses and earplugs. I am also hyper-sensitive to touch, smells, vibration, chemicals, food and medicine. They all make me ill, so I spend most of life in isolation. Imagine a life spent avoiding human contact because you are too scared of the consequences. A life where the softest touch from your partner causes you to flinch with pain; or where your care-workers perfume makes you so ill you are unable to function for hours. Where you fear sunlight and spend your days hiding in a dark room. A life where you can’t watch TV or listen to your favourite music because it’s too painfully exhausting. Imagine how isolating this life is. This is The Real M.E. The Real M.E. is a life filled with pain, frustration and isolation.

03.33

My name is Naomi, and this is The Real M.E.

My day starts off with a bad night’s sleep. I wake up feeling more tired than when I went to bed. It usually takes me about an hour from waking up to getting out of bed. I then have a rest, have breakfast and then my medication. Then another rest before getting dressed. I am usually dressed by midday. My afternoon is then spent between doing twenty-minutes of activity and ten-minute rests. On bad days I switch it around and do twenty-minutes of rest and ten-minutes of activity. I

struggle to concentrate on things, so I switch between activities quite frequently. I do things like, watch television, listen to podcasts or audiobooks, write letters, arts and crafts – anything to distract me from the symptoms that I am feeling, especially the pain. But sometimes I am too ‘brain-fogged’ and all I can do is lie in the darkness in the quiet of my bedroom and listen to something on the lowest volume possible. Energy has to be used sparingly. You have to think a lot about what you will do with the energy that you have. Do you spend it on getting a wash or do you spend it on trying to distract yourself from the pain? It’s really difficult to decide what to do with the precious energy that you have – and the energy is precious because you have so little in reserve. You don’t have the bountiful energy that most other people without M.E. have. A lot of plans get cancelled. I’m mostly housebound with M.E. which is very difficult. I’ve gone from a life of being at university studying to be a nurse, to being housebound, struggling to do the most basic tasks, reliant upon people to help me do simple things. This is The Real M.E.

06.00

Hello, my name is Emily, and this is The Real M.E.

I’ve had M.E. for a decade now, since I was twelve. That first year was the worst for me – I went from excelling at school to barely being able to move. My grandma was essentially my daytime carer. She showered me with her love and care, and I drew comfort from her strength. I lived for two things at that point: the next round of painkillers and our daily crossword ritual. Ten years on and I am finishing my undergraduate degree which is amazing. I came to university four years ago, thinking I wouldn’t be able to make it past two months. So, I threw myself into everything because I thought it was my once-in-a-lifetime chance, my one chance to experience what everyone else had before the M.E. took it away from me again. But here I am, six weeks away from finishing my degree having spent an extra year last year researching in South Africa. It’s certainly not been easy to get here. It’s been a rocky road but it’s one I am grateful I have travelled. People used to talk to me about ‘magic wands’ that could take it all away – I am not sure I’d want that because the M.E. is part of me: it’s shaped who I am today. I’ve come to realise that the best thing about M.E. is that it makes you appreciate the moment you are in. It’s made me stronger and much-more empathetic to people’s struggles than I would have been. And it means I celebrate the good things in my life: having a shower, having clean socks, baking a cake or going for a walk. These are little things for most people, but to me they are moments of joy. These past few years I have been lucky enough to be supported by my partner Matt. He is a well of strength and support that I can draw from when I need to. Sometimes we both struggle with my M.E., but we pick each other up and when the next obstacle comes from around the corner, we’re always ready to face it: hand in hand. One of the things we’ve been talking about for the future is creating an M.E.-respite centre. A place where people with M.E. – their partners, children, carers and friends – could come and leave behind all the everyday worries of life – and just be in the moment. There would be activities for all levels: yoga, crafts, walking or just sitting in the sunshine. And at the end of the day, everyone would have some good food. People could stay as long as they wanted – two days, two weeks, two months – if it helped just one person, that would be amazing. I think it’s all about focusing on who you are – not about who you were before M.E., not the person you want to be in the future – but who you are in this moment. We are all shaped by M.E., but it doesn’t define us. I really do believe, I am not M.E., I am me.

08.38

Hello, my name is Louise, and this is The Real M.E.

I went from being an active person – a teacher – sixteen hours a day perhaps of activity, to today where I can maybe manage four hours a day (sometimes more, sometimes less). I still do a little bit of part-time work – seven and a half hours a week – I think I'd go mad if I didn't, but I feel like I have flu all of the time; I feel like I have run a marathon. Every day I am having to make a decision about what I do and don't do. I've lost everything or nearly everything. I've lost my career; I've lost my friends. I've lost family members who have just retreated into the background. I don't think I know anybody really that understands what I am going through, and that's the hardest part. Just feeling so isolated. Feeling that I have to put a face on, so that other people feel more comfortable around me. I struggle going to family events and parties. I have extreme noise sensitivity and not only that, when I listen to a conversation everyone's talking about work. Our family is full of teachers and it is so painful listening to what could have been; that I could have been in that conversation but now I don't feel that I am relevant.

10.30

My name is Tina and I am the mother of an ME Hero and this is The Real M.E.

Thank you Gary for all the work you are doing and enabling us to have a voice; it's vital I think.

Angus was eight when he was first ill. He is now fourteen. I would like people to understand that every day joys are taken away because of the effect any activity has on the increase of new symptoms while driving the severity down to a new low. This is called PEM and it goes hand-in-hand with M.E. This means everything my son does impacts on his heartrate and blood pressure. So, sitting-up in bed is the same as intensive training. He has to do this at a steady increase from raising his head off the pillow to sitting up, as he reaches his anaerobic threshold at a low impact movement. This means his body is always in intensive training; going to the bathroom is like going on a ten-mile jog for him. On a bright May-day – if we have one – it is so hard to cope with; for him and for us as a family. When everyone is out and having fun on a bank holiday, spontaneously enjoying time, this is something we can't do. You see, when Angus's older brother and sister come home and mess about like siblings do, sitting-down dodgeball, this has a dramatic effect on Angus's heartrate and blood pressure and his brother and sister have a double-guilt-trip. We all get that. We thought just pacing activities would enable some life, but for Angus that doesn't happen. You see the delayed onset of PEM when even laughing comes at a price. Learning to live with M.E. and PEM is so very difficult and it's indescribable to people when they laugh freely and heartily with no consequences. To explain that this has major consequences for my son, is very, very difficult.

13.08

Hi, my name is Marian-Michelle, and this is The Real M.E.

M.E. is like a burglar who steals from you, every minute of every day. Its booty is your energy, half a sack full of cognitive functions and whatever else it can find. Out goes your profession, your social life, your mobility, vision, memory, your ability to look after yourself without help, your idiosyncratic vitality – in short the way you were in the world. Hardest though your intelligence curls up in a ball and rolls out of reach and you lie in wait for those rare instance when you can seize it by the scruff of its scrawny neck and pull it from under the bed for a wee while.

14.20

My name is Stephanie, and this is The Real M.E.

Sometimes I feel like M.E. is all I am. But I am also a sister, a friend, a daughter, a partner, a colleague, a graduate and a police officer. Everything is more difficult now like trying to get through life while balancing a very heavy weight on my head. I am on a perpetual tight-rope juggling what I want versus what my body needs; and my body usually wins. With this comes a lot of anxiety, ranging from; how am I going to keep my job and pay my mortgage? to a small matter but just as emotional – how am I going to eat today when I am too exhausted to cook anything? Small things have become mountains that seem insurmountable most of the time. Prior to becoming ill, I worked so hard to get my dream job of becoming a police officer. I've had a lot of support, but my bright future is unclear, and I have had to change roles and reduce hours. I see friends and family less, and sometimes live the life of a social hermit. It's really tough when you want so much to join in, and it can be a very lonely situation despite all the support. With all this uncertainty, I've learned to enjoy the little things I can which I've probably overlooked previously. I've also learned how to actually rest – although I'm still not very good at this. More than anything, I'd like research into M.E. to continue. We need to know more in order to help people. There are so many others like me who feel that M.E. is all that they are when actually they have so much to offer.

15.56

Hello, my name is Katie, and this is The Real M.E.

I've been suffering with M.E. for about twenty-five years now, but only got a diagnosis about four years ago. And I still only have a CFS diagnosis. So, I am trying to go back to the place in Hull and find out if I can have an actual M.E. diagnosis because in all the research I've done over the years I feel that there are a lot of conditions that create 'chronic fatigue' but I definitely have the symptoms of M.E. I spent the last twenty-five years trying to cure myself. I've learned loads of different complementary therapies and I've had even more than that. I was told a lot of times that it was 'all in my head' and I still am by some people. So, I actually learnt counselling and went for counselling and I've done NLP and CBT and everything in-between; and after fifteen years of trying everything I can genuinely say – it is not in my head! Anyway, a daily life for me differs drastically from day-to-day. Today, I couldn't get out of bed until after midday. I've done virtually nothing today, but now I am recording this because I feel a little bit better. I get it in waves throughout the day, I can feel OK for about five minutes and then feel like death again. Basically, I say it feels like flu without snot because I just ache all over so much. Some days I am too stiff to even put my socks on. I spent two years solid in bed from 2012 to 2014. I've had quite a few relapses throughout my life, but I've always pretended I didn't have a problem and tried to live an ordinary life – which just doesn't work. Love to everyone suffering with M.E. and to everyone who is trying to help us. And, I really do hope and pray that very soon we will find the reason for the disease and find a cure; and we can be released from the prison that is our bodies. And to everyone out there: it is NOT in your head. It is a genuine illness and we've just got to keep going and pray that a scientist somewhere in the world, very soon, comes up with some answers.

18.27

Hello, my name is Karen, and this is The Real M.E.

Ben's health deteriorated after chickenpox in 2012. After about three years he was very, very, ill. Totally fatigued with unrelenting pain in his stomach and legs. Every time he exerted himself physically or mentally, he would collapse in sheer exhaustion and pain. Some days he could barely speak. No-one could figure out what was going wrong with him. We thought it was cancer and that he was going to die. We were terrified. He was eventually diagnosed with CFS. I was expecting him

to be given a course of tablets and some medical treatment, but the paediatrician told me to do research on the internet and join a support group. She referred Ben to CAMS and a physio – which was weird. Naively I thought the psychologist would at least give him some pain-distraction techniques, instead he was assessed for anxiety, depression and school-refusal; and discharged with no mental health issues. The physio wanted him to walk around the block every day and increase each week – he couldn't sit up in a chair at this point! I phoned, told them he'd made a full recovery and got him discharged. The best advice I never had from a doctor was to let him rest, rest, rest. Thanks heavens for the M.E. support groups and M.E. charities. With their advice, Ben is now having four hours home-tutoring a week and we're mostly avoiding the awful 'boom-bust' pattern. But he isn't recovering. We're managing. He's still in constant pain and is very foggy and exhausted most of the time. This isn't good enough. This isn't the life he should be leading.

20.00

Hello, my name is Jackie, and this is The Real M.E.

I've spent the last ten minutes trying to figure out how I am going to word this and how I am going to organise it. And I think the easiest way to do it is to break it down into sections. So, I am going to it as: emotional difficulties, physical difficulties, and then the techniques I use to try and help in my day-to-day life. OK so the emotional difficulties I find with M.E. since I've had my diagnosis is accepting it really. That I am not able to do the things I was able to do before – I used to be quite fit, I used to run, I used to walk a lot – and while I still do some walking, it is definitely restricted and more difficult to do. So, the acceptance of M.E. is pretty tough I find. I also feel that I am looking for validation from friends and family and from the wider community really. Needing that validation to help me accept it. Physical difficulties, I get a lot of muscle-weakness, so for me getting up from the ground – from kneeling or sitting – I find is very difficult. My legs don't seem to have the strength, again that's the same for my arms really. I get numerous aches and pains. The pains can be in my legs, arms, neck, pretty-much anywhere really but those are the most significant places I get the pain. I get fatigue to the extent that I have to have rests pretty regularly, and/or sleep during the day sometimes. I get headaches. I get cognitive difficulties – mental blocks, difficult concentrating for example trying to do this recording and just not being able to think about what it is I am trying to say – difficulty trying to find the right words or forgetting what it is I am trying to say or losing my train of thought. Other difficulties I get are sleeplessness – so I get off to sleep generally OK but find I am awake in the night, sometimes with pain, sometimes just unexplained, and then it's difficult to get back off to sleep. And, finally, ending on positive things, coping techniques that I find help me are:

- Resting – before the point of exhaustion really which is something that is difficult to do but is key I've learned so it's really trying to figure in, OK let's stop before I go too far.
- Deep breathing – I find that helps me and counting my breaths, so, concentrating on counting my breaths in and out and occasionally then taking deep breaths tends to just calm me down and relax me.
- The Headspace App – I have found it helpful. It gives you visual prompts which I find really useful so I can imagine, I can picture putting my troubled thoughts or things that I am concentrating on when I'm trying to relax; I can put them aside a bit easier.
- My garden is really one of my key therapy tools if you like. I am out in my garden as much as I can be – even if I am not doing anything – I'll sit out there in a comfortable chair or fall sleep and listen to the birds and watch the wildlife. I find that really lovely.

So, I hope that's been of some help, to share very briefly about how M.E. affects me and what I try and do to live with it and cope with it as best I can.

23.45

Hello, my name is Jenny, and this is The Real M.E.

Today, is the thirty-seventh anniversary of my coming down with M.E. I had hoped to record something about my life for you, but I am not well enough to say any more than this today. Right now, I need to rest for an hour just after taking just a few steps. This is a particularly bad period. I have good-days and bad-days. Good months and bad months. Good years and bad years.

24.37

Hello, my name is Anil, and this is The Real M.E.

I used to be a professional ballet-dancer. The first years of my illness, I was moderately affected by M.E. but these days I spend my days chiefly in a bedridden state. I don't tolerate light, so the curtains are always closed. And I always wear earplugs and earmuffs you know – the big ones for construction-workers – to avoid any post-exertional malaise crash. Because of my orthostatic-intolerance I am only up for about half-a-minute per day, just to get from one room to the other. These are just twelve steps and then my autonomic nervous system or blood-flow needs to recover for about two and a half hours, to do the same a few hours later. There's an extra bed in the kitchen and in the bathroom, so I can recover there and get my necessary things done. I can't read much, write, or even have interactive conversations as everything will make me more ill. Even recording this will give me a post-exertional malaise crash for a few days. I can't listen to music, watch videos, or have visitors – so it is a very isolated life that I am living and a great contrast to my once active lifestyle and dynamic social life. While this is The Real M.E. it is really not me. I would love to have my life back.

26.06

Hello, my name is Amy-Jane, and this is The Real M.E.

I wish, every single morning, that my first thought could simply be, hey what might today bring and what am I going to do? But instead, it's am I able to get out of bed today and do I need painkillers before I can do so? It is not pessimism, it is reality. I was diagnosed with M.E. in 2004 and have been severely affected since 2014. Over the years, I've learned to lower my expectations to absolute zero. If I expect to be bedbound and in too much pain and exhaustion to move, then on those days when I can get out of bed it's a bonus. And I use that to try and stay positive. When I do get up, I rarely brush my teeth on a morning because my arms are so heavy, and it takes time to regain some strength. I haven't been able to wash my own hair in years. Baby-wipes are a bit of a saviour, but they're also a shame. Then I get dressed in house-clothes, make it to the couch with my iPad and that's my day. If I can, I'll wash the pots and try to be happy that my productivity is instantly more than the average day. Bedbound days are horrific. Left in bed surrounded by small, easy to chew, snacks. Sports water-bottles that my partner's left for me. Dim light, ear defender's, a t-shirt over my eyes, and a timetable of who will be calling in and when. And I'll only be sipping the water because I don't have the energy to make it to the toilet. It feels like being a mathematical genius and being forced to sit an exam paper on simple two plus two sums that may take until the end of your life to finish. You're never able – ever – to utilise your full potential, show your worth, or be yourself. And there's nothing you can do about it except stay positive and be grateful that at least you know what two plus two is. Thank you.

29.54

Hi, from New Zealand, this is Ann for the Real M.E. Show.

I am one of the unusual people to fully recover from M.E. after thirteen years only to become very ill again, ten years later. During my well period I was able to return to work as a mid-wife, ski, kayak, mountain-bike – so you can see that I really was well. My whole world fell apart, ten years later and now I am housebound, and bedbound a lot of the time. When I look back the only thing that helped me was pacing and time and trying not to get deconditioned. But as we all know there is a fine line between doing too much and not doing enough. Use your energy wisely. Get a wheelchair for trips outside of the house. That's what I do.

29.54

“The Real M.E. as told by Real People on this special edition of The ME Show. And thanks to all who contributed. If you want to know more about M.E., check out the ME Association's brilliant website at www.meassociation.org.uk where you can also join as a member to show your support and join a community of people working to help each other. Until next time, as always, thank you for listening.”