

BUT YOU DON'T
LOOK SICK?!



Young Women's Experiences
with ME/CFS and Fibromyalgia

The Invisible Illness Warriors Health Collective

Acknowledgments

We would like to acknowledge that this project was conducted on Kurna land and to recognise the Kurna people as the traditional custodians of the greater Adelaide region.

We would like to graciously thank the Dulwich Centre for the generous use of their venue for our group meetings. The Dulwich Centre does great narrative therapy and community work with marginalised communities and individuals. You can check out their work at dulwichcentre.com.au

We are also most grateful for the time and energy given by our groups volunteer support person – Manja Visschedijk (aka the 'legs' of the group!). As well as providing a supportive ear, Manja provided us with many yummy snacks and countless cups of tea!

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Thank you to local artist Grace Mitchell who designed our amazing Invisible Illness Warriors logo and to graphic designer Nicole who turned our text into a beautiful booklet.

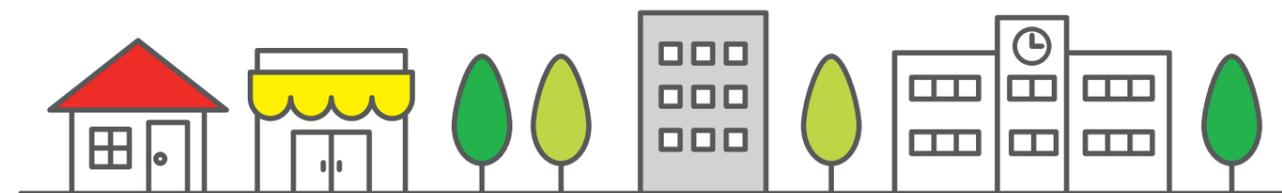
We would like to thank everyone who came to our screening of the documentary 'Unrest'. A portion of the profits from that great night were used fund the development and printing of this booklet.

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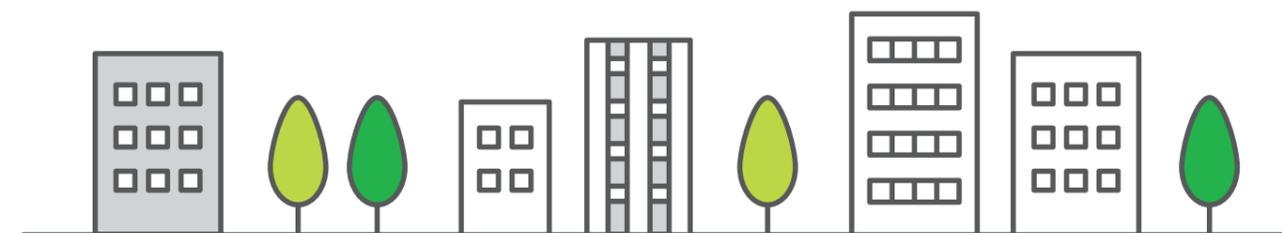
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Front & Back cover photo & design by Gipsy Hosking.

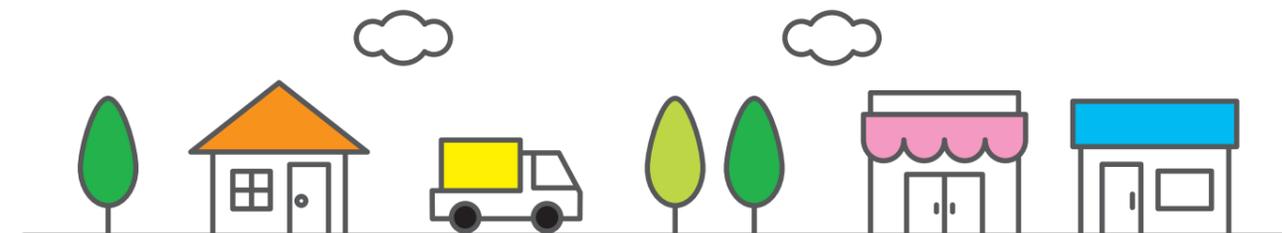
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Some Chronic Illness Sayings

Repeat after me: it's not your fault that you are sick.

"The quote, 'the only disability in life is a bad attitude', the reason that's bullshit is ... No amount of smiling at a flight of stairs has ever made it turn into a ramp. No amount of standing in the middle of a bookshelf and radiating a positive attitude is going to turn all those books into braille." - Stella Young

**Yes, hello I'd like a refund on my body?
It's kinda defective and really expensive"
- anyone with a chronic illness**

I'm too young to feel this old.

I'm too functional to be disabled and too disabled to be functional.

Other people in my age group are like 'I went to this party yesterday, it was crazy!' while I'm just like 'I got out of bed yesterday, it was crazy!'

'But you don't LOOK sick!' Oh well, please tell me, what does sick look like? I'll make sure to try and get it right next time.

"The ill person who turns illness into story transforms fate into experience; the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability... As wounded, people may be cared for, but as storytellers, they care for others. The ill, and all those who suffer, can also be healers." - Arthur Frank

hi!



We are a small group of passionate young people from Adelaide, Australia living with invisible, chronic illness.

This project arose from a distinct lack of resources, visibility and support for young people living with conditions such as ME/CFS and Fibromyalgia.

If you have these conditions we hope this booklet provides you with validation, strength and hope. Know that you are not alone and we know your struggle is real.

If you don't have one of these conditions, we thank you for taking the time to learn more about them and for reading the words of those who live with chronic illness.

This booklet is also for our family, friends and support teams, whose own experiences supporting someone with chronic illness are often invisible and silenced.

The Invisible Illness Warriors Health Collective was formed as a research group as part of Gipsy Hosking's PhD at the University of South Australia.

The group met regularly to develop this booklet and the corresponding video called 'You Can Ask That - Getting Real about ME/CFS and Fibromyalgia' which you can find on YouTube or at facebook.com/IWHCSA.

Through group discussions it emerged that one of the most significant issues facing young adults with these conditions was the lack of understanding (from friends, family, doctors and the general public). Further, the social impact of these conditions including isolation, missing out and the loss of dreams and hopes is most debilitating. The struggle of chronic illness is not just about the physical symptoms rather many hardships come from stigma and the mental and social consequences of illness.

We hope this booklet helps break the invisibility and silence surrounding these conditions and provides a means to open meaningful dialogue about what it really is like to live with ME/CFS and Fibromyalgia.

Best wishes,

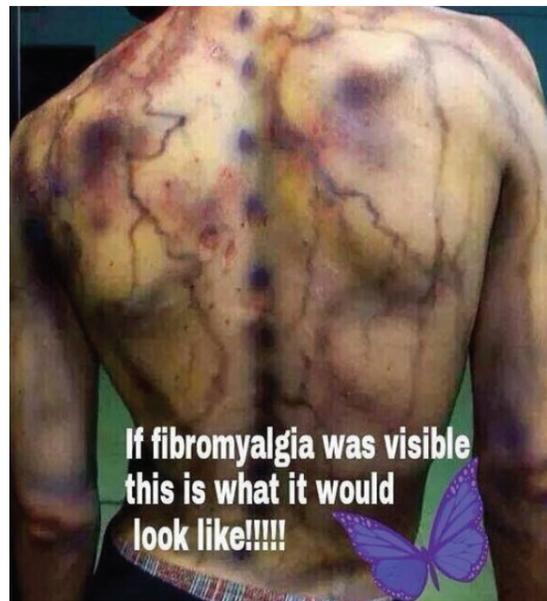
The Invisible Illness Warriors Health Collective Team

Aimee, Emily, Gipsy, Kathryn, Kirsty Maria*, Lisa, Rachel, Rita

Plus a few others who wish to remain anonymous

*Not her real name

What is ME/CFS and Fibromyalgia?



If fibromyalgia was visible this is what it would look like!!!!

Fibromyalgia, also known as Fibromyalgia Syndrome (FMS) is a chronic pain disorder with symptoms similar to ME/CFS. The two illnesses often co-exist. Although Fibromyalgia is more common than ME/CFS even less is known about its possible causes. This is again due to lack of medical research and research funding. Fibromyalgia is thought to be a dysregulation of the central nervous system resulting in widespread pain and tenderness throughout the body. This is accompanied by extreme fatigue, increased sensitivity to stimuli such as light and heat, cognitive problems, sleep disturbances and more. 9 out of 10 Fibromyalgia sufferers are women. Treatment for Fibromyalgia mainly includes pain management and trying to manage the other symptoms.

“Being a woman changes the way you’re perceived, I’ve been treated as hysterical frequently, many, many times”
 – Invisible Illness Warrior

There is no cure. Further as pain is subjective and cannot be shown on a lab test it often takes a long time to get a diagnosis and appropriate treatment.

“I’d just moved interstate to study and I got a flu like virus and one day I collapsed in a hallway and I went blind and deaf. I remember sort of panicking and screaming; I remember screaming but I couldn’t hear myself scream and that’s how it started. And I went to see a lot of doctors actually after that, they all diagnosed me with anxiety.”

– Invisible Illness Warrior

Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) is a complex multi-systemic condition that effects all body systems, but primarily the nervous, immune, cardiac, gastrointestinal and endocrine systems. It is a debilitating condition that leaves many unable to work, study or leave their homes. The main symptoms of ME/CFS are extreme fatigue, post-exertion malaise (symptoms made worse by any mental or physical exertion), muscle and joint pain, cognitive dysfunction (‘brain fog’), orthostatic intolerance (worsening of symptoms when standing or sitting up), dizziness, vertigo, gut problems, poor sleep, compromised immunity and increased sensitivity to light, sound and chemicals. There is currently no cure and limited medical treatment available. However new research from around the world is providing hope that more will soon be known about this illness. ME/CFS is conservatively estimated to affect at least 240, 000 Australians with around 75% of sufferers being women. It can strike at any age and is more debilitating than illnesses such as heart disease, kidney failure and multiple sclerosis. ME/CFS often comes on suddenly following a virus but can also develop slowly over time.



Running on empty

Original image by Gorka from Gorka Aguirre Studio see gorkaaguirre.com. Image viewed at fav.me/d748p0.

Chronic Illness Bingo!

I wish I could stay in bed all day! Lucky you!	Oh yeah, I'm so tired too	Have you tried drinking coffee?	You sleep too much	You don't look sick	I wish I could stay in bed all day! Lucky you!	Oh yeah, I'm so tired too	Have you tried drinking coffee?	You sleep too much	You don't look sick
Are you getting enough sleep?	You need to think positively	Have you tried 'this' diet?	You're just stressed	Are you better yet?	Are you getting enough sleep?	You need to think positively	Have you tried 'this' diet?	You're just stressed	Are you better yet?
If you really wanted to you would get better	You take too many medications	You should exercise more	You should stop/start	You should be grateful you are not worse	If you really wanted to you would get better	You take too many medications	You should exercise more	You should stop/start	You should be grateful you are not worse
Let God in and you will heal/ God is punishing you	I haven't heard of that, is it a real illness?	Just push through it	You need to get out more	Have you tried? (e.g. yoga, vitamins)	Let God in and you will heal/ God is punishing you	I haven't heard of that, is it a real illness?	Just push through it	You need to get out more	Have you tried? (e.g. yoga, vitamins)
My ex/friend/ cousin/co-worker had that and they did X & now they are all better	It must be nice not having to work	You complain too much, we all get tired/pain	You should eat more/ less/ better/ different	I went through a similar tough time let's talk about what a great person I am!	My ex/friend/ cousin/co-worker had that and they did X & now they are all better	It must be nice not having to work	You complain too much, we all get tired/pain	You should eat more/ less/ better/ different	I went through a similar tough time let's talk about what a great person I am!

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Resources and Links

ME/CFS Australia (SA) Inc: South Australia's state association, working to improve the quality of life and health management of people with ME/CFS (also has information on Fibromyalgia and Multiple Chemical Sensitivity)

- sacfs.asn.au, 1300 128 339

Bridges & Pathways Institute Inc: Working for solutions to improve the health and access to services for those living with complex chronic conditions such as ME/CFS and Fibromyalgia

- bridgesandpathways.org.au

Emerge: The Australia-wide organisation for information, support services, research, news about ME/CFS

- emerge.org.au

Fibromyalgia Support Australia: Information, support and community

- facebook.com/FIBROMYALGIA-SUPPORT-AUSTRALIA-364885047318/

Carer Support Network SA: Support services for unpaid family carers

- carersupportsa.org.au

Invisible Illness Warriors: Passionate SA young adults spreading awareness about ME/CFS and Fibromyalgia

- facebook.com/IIWHCSA

The Mighty: Personal stories about disability, illness and mental illness. Tips, advice, advocacy and community. Anyone can contribute a story.

- themighty.com

Facebook Groups

ME/CFS Australia: A central point for ME/CFS, Fibromyalgia (FM), Multiple Chemical Sensitivity (MCS), Lyme and associated illnesses

- facebook.com/groups/MECFSAustralia/

Good Australian Doctors for ME/CFS/FM/EDS/POTS/Hashimotos

- facebook.com/groups/287952358017187/

Young ME/CFS Australians 18-40

- facebook.com/groups/1559828907642995/

Invisible vs. Visible

Words + Photo by EMILY, 25

Having an invisible illness can be complicated. Naturally people struggle to understand what they can't visibly see. Unfortunately, I find myself constantly doing things to further hide the effect CFS/ME/FMS has on me. To avoid bringing attention to myself I hide my compression garments, strapped joints, and nausea bands. I cover my arms after intravenous medication, I take medication privately, I use make up to cover up dark rings around my eyes, and I admit I even avoid using needed mobility aids just to name a few things I do. CFS/ME/FMS being invisible can be a blessing when trying to just blend into a crowd but I find loved ones and people you need to understand such as health care professionals, do struggle to comprehend the extent of this illness when our instinct is to appear as "normal" and many visible signs of living with this illness are also covered. I hope one day to no longer instinctively want to cover up the visible effects of CFS/ME/FMS and to no longer be concerned about the response I might get from society for doing such.



Reflections on invisible illness

Words + Photo by GIPSY, 30

Visibility/ invisibility is such a crucial element in the struggle for acceptance. The invisibility of our illness increased the stigma and discrimination we face. I am always astounded in how differently I am treated when I go out in my wheelchair. Suddenly I am seen as a person with a disability rather than a young woman who doesn't look sick.



ME is real



Words + Photo by KATHRYN, 24

You know ME is real when you get admitted to hospital for a racing heart and severe nausea and dizziness, and they prescribe you a drug that was designed for severe nausea and vomiting in chemotherapy patients - but even that doesn't give you relief from ME nausea or vomiting!

Therapy pets

Words + Photo by EMILY, 25

Being bed/house ridden for a large part of the last 9 years my pets have been invaluable to me. From curling up next to me, to interrupting my yoga sessions, to entertaining me with their ridiculous behaviours, the positive impact my pets have on my life is invaluable.



back into the workforce and doing anything we can to help them get into work." Well that's great, but I can't get out of bed most days!

The Centrelink staffer looked at me and said, "well what kind of work are we going to get you into?" I stared back and said flatly "I can't work, have you even read my file? I have Chronic Fatigue Syndrome". He admitted he hadn't even looked at my file. "I've just been through tribunal" I said, and I watched his eyebrows shoot up to his hairline (which was very high by the way)! He went to his computer and literally sat there in silence for 15 minutes reading my file. Next, he got up and went to talk to someone for 5 minutes before he came back and made a phone call. Again, he went to talk to someone else, came back, made another phone call, before he went out to talk to a social worker. In the meantime, I had fallen asleep 3 or 4 times on my mum's shoulder because I was so exhausted and unwell. His eyebrows were going higher and higher and higher. Finally, he looked at me and said, "well you've been through a lot haven't you!" 'Yeah no shit!' I thought. "We are going to get you in for a medical assessment" he said. "Why?" I demanded "we've been through this, I'm bedbound, we've just been through the tribunal". He replied dispassionately "well, we will just see what the medical assessment says". I was so angry, I thought this saga was meant to be over.

Calling In The MP

We told my Dad what happened when we got home, and he was absolutely furious. Now you have to understand that my dad is not a 'get angry' person, he is a very quiet, stoic person; he just doesn't get angry. But this made him mad! Eventually, he rang our local MP's office and told them what had happened. With my permission they contacted Centrelink to find out the story.

Magically, we get a phone call the next day from Centrelink asking me to come in for an assessment. At the meeting, the first words from the Centrelink officer's mouth were "oh you've rung your MP have you". Through the course of this meeting the fact that we had rung our MP came up no less than 4 times. But they were finally taking us seriously. The lady doing the assessment actually turned out to be human and took one look at me and could see how sick I was. She had read my whole file and knew everything that had happened, and she said "look I am reclassifying you at 30 points and this means you have no forced work and no more job meetings". It was such a relief.

Never Give Up!

This whole process took 11 months and I was already relapsing from the stress and additional exertion in the first few weeks. I was so bad that I couldn't walk anymore. I am still feeling the effects of it now some 2 years later and have not got back to my 'pre-Centrelink saga' level of functioning. I remain significantly worse. I'm back to where I was when I was 14 and at my worst. Standard DSP reviews are scheduled for every 2 years and my next one is due in the coming months. I can already feel my anxiety levels increasing.

I hope you never have to go through an experience like mine. But be aware that it may happen and if it does then you must fight for yourself (even if it nearly kills you). Do your own research (or get someone to do it on your behalf) because Centrelink doesn't tell you everything that they should. I encourage you to seek support, it is difficult to be your own advocate when you are so sick. Get a friend or family member to be your support person and then find an advocacy program or someone who knows the system.

Whatever happens never give up, you know your body, you know your truth.

A note on the title: 'The 2 Yearly Struggle' reflects the fact that the DSP reviews happen every 2 years..... every 2 years the struggle to have this illness recognised begins again.

I went back to the Welfare Right's Centre and found an amazing pro-bono lawyer who challenged this ruling. In turn, my case was taken to the appeals tribunal, forcing a third assessment. In preparation for the tribunal, I had to book into all my specialists and get new letters of support and a whole new raft of tests. Centrelink demanded really specific information such as standing time, tolerances, and whether I could toilet unassisted or not. They even wanted to know how many times a day I went to the toilet, as well as other invasive questions that left me feeling violated.

"Whatever happens never give up, you know your body, you know your truth."

The whole process was not only exhausting for me, leading to an exacerbation of my symptoms; but it was also an added expense - just when my income had significantly dropped due to the loss of the DSP. Centrelink had decided to put me on Newstart Payment (an unemployment payment designed for people looking for work), which is significantly lower than the DSP rates. Further, the second review made a ruling to not accept medical certificates for me which meant I was expected to look for work and attend fortnightly meetings. While all this was all happening, I developed kidney stones and was in and out of the hospital. Centrelink continued calling me while I was in hospital as I was expected to be completing job search criteria and I had to try to talk to them while on morphine, which was great! They wouldn't give me online reporting access, so I was expected to go into the office every 2 weeks for meetings. Despite being in and out of hospital, Centrelink kept rejecting my medical certificates and forced me to go to an appointment with a job service provider who took one look at

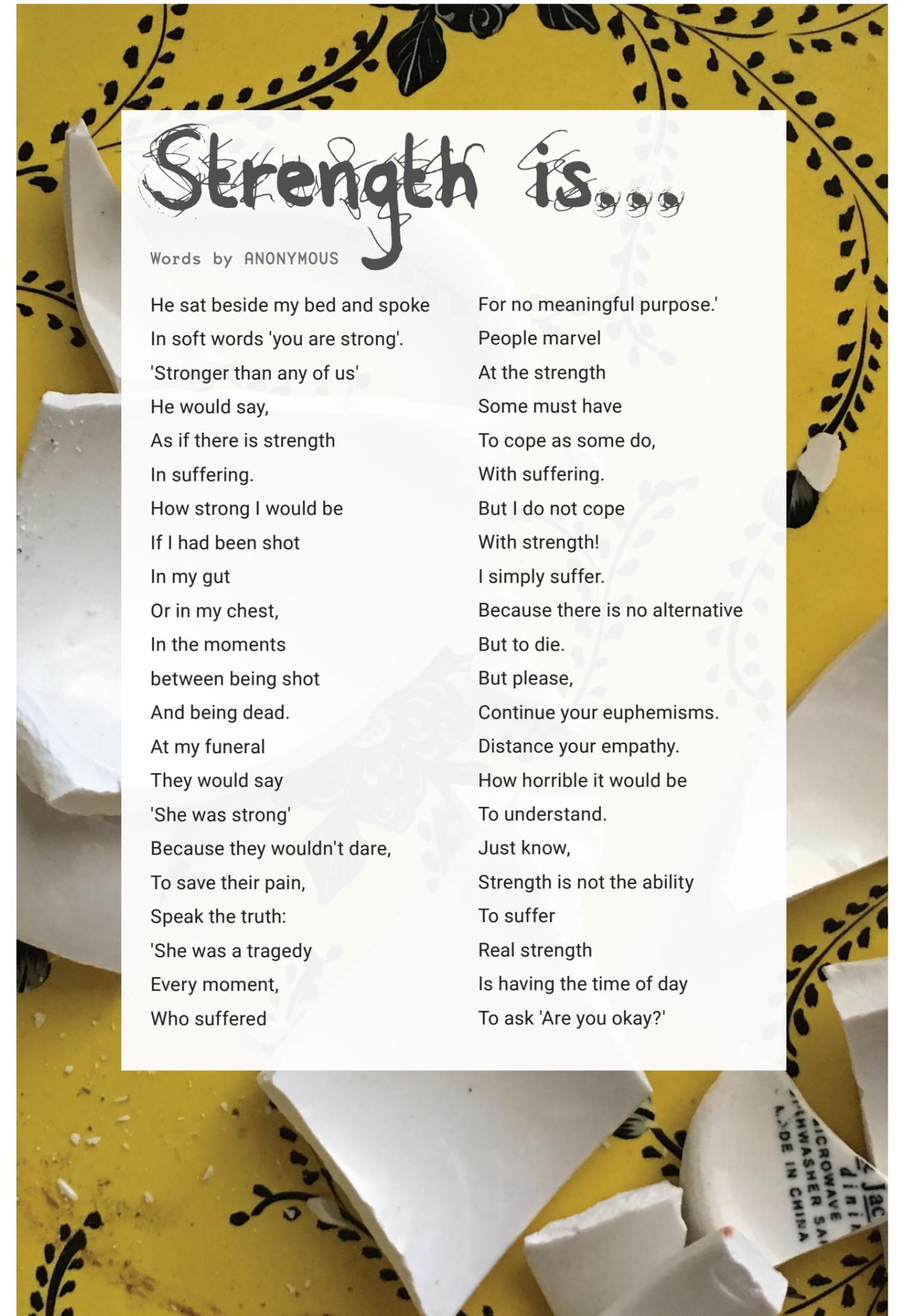
me and said "why are you here? You should be home in bed; what are they doing to you?" I told her what had been going on and what they had been making me do and she said "look we are going to help you; we are going to do everything we can to make sure you don't have to hurt yourself more". She went through all my paperwork with me and showed me the kind of information that Centrelink needed to see, which was amazing! I went back to my specialists for the third, fourth and fifth times to get more letters. My Chronic Fatigue Specialist wrote an amazing letter to the tribunal explaining that I have had no improvement since being sick in 2007, and that **all the stress of this process had made me significantly worse**

The Tribunal Hearing

The day of the tribunal finally arrived. I was meant to attend in person but by this point I had relapsed so badly that I was bedbound. We made an arrangement for the head of the tribunal to call me. Thankfully, he had obviously read my file and history thoroughly. He only asked me a few questions before saying he was going to reject all recommendations from Centrelink, and that it was ridiculous that I had been put through this. He even apologised on behalf of Centrelink. He told me not to worry and that he would sort it all out. I hung up the phone and burst into tears because the relief I felt was so overwhelming.

I thought that was the end of the saga but I was wrong!

Two days later I got another letter saying I had a job assessment appointment with Centrelink. It turned out we had only disputed the *rejection* of the DSP at the tribunal and not the *medical impairment rating* which had assessed me at being able to work 8-15 hours per week. At the jobs skills meeting, I was again given the government spiel of "our government is committed to getting young Australian's



Strength is...

Words by ANONYMOUS

He sat beside my bed and spoke In soft words 'you are strong'. 'Stronger than any of us' He would say, As if there is strength In suffering. How strong I would be If I had been shot In my gut Or in my chest, In the moments between being shot And being dead. At my funeral They would say 'She was strong' Because they wouldn't dare, To save their pain, Speak the truth: 'She was a tragedy Every moment, Who suffered	For no meaningful purpose.' People marvel At the strength Some must have To cope as some do, With suffering. But I do not cope With strength! I simply suffer. Because there is no alternative But to die. But please, Continue your euphemisms. Distance your empathy. How horrible it would be To understand. Just know, Strength is not the ability To suffer Real strength Is having the time of day To ask 'Are you okay?'
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Wings of Encouragement: SILVER LININGS AMONGST THE STORMS



A Collection (& Fragments) of Thoughts & Page Design by Kirsty Maria*, 28

Chronic illness and pain changes us. We no longer take the smallest things for granted. Every small step, every minute, every hour and every day is a victory for us. We appreciate the smallest and most pure elements in life. We do not want others to experience the suffering we have and continue to endure on a daily basis.

Courage, strength, the unknown, fear regarding all aspects of future, vulnerability, ongoing medical appointments, lack of answers, lack of understanding, isolation, invisibility, lack of belief.

"It's just a constant battle: me against my body; my passions and my dreams and what I want to do with my life, against what I'm physically able to do."

-Austin Carlie

We are still the same people we were pre-diagnosis. External facets like the ability (or lack thereof) to work, study, enjoy a healthy social life, travel near or far are stripped away or at best, partially limited. We are forced to dig deep inside and discover our core values when our independence and previous identity have been stripped away, and/or limited. We are still worthy of love and acceptance, we are not just our monetary or work-related achievements!

We are warriors! We battle everyday yet no one sees it. We appear healthy, but inside we are trapped, we are caged, we are broken. We are stronger than we think we are because everyday we fight, we keep going, we put one foot in front of the other and we never give up.

No matter how intense the pain is, it's beautiful isn't it – how we never give up?

MJ Fox has Parkinson's disease. Some diseases get recognition and proper labels, they also have clear pathological evidence in medical tests and scans.

"Acceptance doesn't mean resignation. It means understanding that something is what it is and there's got to be a way through that."

-Michael J. Fox

Chronic illness does not, this is why there is a lack of awareness and understanding on a global scale. MJ's statement really resonates with me – we have to accept that we have a permanent disability. Our lives will never be what they once were, despite how bleak that may sound - we have to accept and create a new "me". This will take time.

Bad days will pass, and we will come out stronger on the other end of the storm. Have faith and hope, these are both paramount.



*Not her real name

need any. I continued to believe I was just there for a standard meeting (they still hadn't told me it was a review), but then the questions the Centrelink officer asked got weird and I began to feel confused and uncomfortable.

The interviewer asked a lot of leading questions; She would keep asking variations of the same question and getting me to speak until I said what she wanted to hear and then cutting me off. I'd say something and it would be interpreted as, 'well I can do it, I just choose not to', instead of 'I actually can't do it and if I did I would probably have a horrendous relapse'. She asked me "do you take public transport?". I said "no, mum drives me everywhere". That was taken as 'Aimee does not choose to take public transport', rather than what I meant, which was 'I can't take public transport because it involves too much walking and standing and strain on my body and causes my symptoms to flare'. She didn't ask me anything about my illness but rather asked if I could fold laundry, as well as could I cook and could I garden?

I have trouble doing all of those things. Most of the time I can't do them at all. Perhaps when I'm having a particularly good day I could do something, but it would take me way longer than a healthy person – I'm talking ten months to fold one basket of laundry!

These questions were directed by the new legislation and the tables of impairment that rated your ability function. However, the problem with conditions such as Chronic Fatigue Syndrome and Fibromyalgia is that maybe some days we can fold laundry or get our own dinner but what you don't ask is what impact do these activities have on your symptoms?

These conditions are characterised by Post-Exertion Malaise (PEM) – a significant worsening of symptoms after any kind of physical or mental exertion.

DSP Rejection: Effective Immediately

We left the meeting feeling confused but still thinking it had been alright. We still didn't know that it was a review. But the

next I got a call and was told that I had been rejected from the DSP - effective immediately. I was in shock. I didn't know what to say. I asked "Is there anything we can do about it? Is there a review process? Is there someone we can get in touch with? What can I do?" She said, "look I'll get a social worker to call you but other than that you are off the DSP as of today" and hung up. A few days after the meeting I received the information letter about the meeting (that we'd had a few days ago) saying that I needed to bring doctors certificates, and outlining a requirement to bring all x-rays, films, reports, test results, relevant medical documentation etc. so that my claim could be backed up. Of course at the time of the review meeting a few days prior, we had no idea because we hadn't yet received this letter! Trust me if I had known, I would have brought a truck load of letters, reports, scans and tests. Centrelink users are supposed to be given three weeks notice to prepare for a medical review but clearly this was never adhered to.

The social worker who called me was lovely and got me in touch with some advocacy programs. I contacted the Welfare Rights Centre and they too were really helpful in providing me ample information about the review process and the kinds of medical documentation that I needed to present. Consequently, I disputed the ruling that kicked me off the DSP, and was able to schedule a second review meeting.

The Second Meeting: Can Things Get Any Worse?

The second review meeting consisted of a phone call where I was asked the same leading questions and not given an opportunity to provide any medical documentation. When I was originally assessed for the DSP back in 2011, I was rated as a 30, in the first review meeting they rated me as a 10, and after this ridiculous phone call - that rating was dropped to 5! Recall that the higher the rating, the more disabled you are considered. So according to the second review I was quite well, and didn't qualify for anything, not even a medical certificate.

THE 2 YEARLY STRUGGLE



Words by AIMEE, 24

I wish to tell you a cautionary tale. I hope with all my heart that this never happens to you but if it does perhaps you can learn something from my experience. I was shocked that this happened to me. I had such good experiences with Centrelink up until this point. They had been lovely so to be attacked like this was very overwhelming.

I also want to expose the problems that people with disabilities or complex medical problems encounter within the systems that are supposed to support us. Often when you have a disabling chronic illness, your ability to advocate for yourself is severely compromised by the symptoms of your illness. But I'm getting ahead of myself, let me take you back to the start.

I fell sick in 2007 when I was 13. It was March 2nd 2007 to be exact. I was at the Clipsal event with my Dad and I fell on the floor and fell asleep and that was it. It just spiralled from there, my official diagnosis happened in August, six months after. It's not fun...I don't recommend it!

I was in my first year of high school and excited for the adventures ahead. However, I spent the majority of the next few years bedbound. I don't remember much of that time. I spent so much time confined to my darkened room that for 2 years most of my memories are just of darkness. I never got to finish school.

"I spent so much time confined to my darkened room... I never got to finish school."

I was granted the Disability Support Pension (DSP) in 2011 when I was 18. I didn't particularly want to be on the DSP but I was too sick to even consider working. My doctors also encouraged it saying it was what I needed. Under the DSP assessment, people are given a number rating that indicates their impairment of functioning. The higher

the number, the more 'disabled' you are considered. I was rated at 30 and this meant that I was considered unable to work at all. For the next few years I lived off the DSP and worked hard to manage my multiple medical conditions.

The DSP Crackdown

In 2015, the new Liberal government introduced legislation changing the DSP and other welfare payments with the expressed aim of getting people off welfare and into the workforce. In other words, their intent was to catch the so-called 'dole cheats' and 'bludgers'. This crackdown targeted young people (under 35) who were on the DSP, with the intention of re-assessing every application under the new tighter rules.

One otherwise ordinary day in 2015, I got a phone call from Centrelink asking me to come in for an appointment just 2 days later. I had no idea what the appointment was for, I assumed it was just a meeting, I'd had lots of meetings with Centrelink so I wasn't concerned. I asked what the appointment was for and what I needed to bring and was told it was just a chat and I didn't need to bring anything. The appointment was scheduled for 9am which was a problem for me because I have trouble sleeping and then waking because of the nature of my condition. I asked if the appointment could be later in the day when I am more functional, but my request was denied 'oh no we can't do that, we can only do appointments at 9'.

So I dragged myself out of bed, barely functional and mum drives us in. When I first walked into that meeting I felt safe, Centrelink staff had always been lovely to me and looked after me, but then it was like we were cannonballed. She asked me if I had any medical documentation and I said "no, I didn't know I needed to bring any". She said that was fine and I didn't

"The most beautiful people we have known are those who have known defeat, known suffering, known struggle, known loss, and have found their way out of the depths. These persons have an appreciation, a sensitivity, and an understanding of life that fills them with compassion, gentleness, and a deep loving concern. Beautiful people do not just happen."

-Elisabeth Kubler-Ross

In saying this, please note that I do not mean to downplay or compare "invisible" illness to other diagnoses like cancer and parkinsons, multiple sclerosis etc.

I am, however, pointing out the common theme that many people do not believe our illness is 'real', and also mock it or make quite hurtful comments like "I get tired too", or "it's all in your head". I can guarantee no one would say this to someone who has had/has cancer/in remission stage. When someone cares enough to ask what your condition is, it is so sad that the vast majority of the population has no clue what the illness even is! How can we expect one to understand or empathise such a complex, hidden, debilitating illness...?

We have a depth and richness because of the ongoing insurmountable suffering (both physical and emotional/mental) that gives us a complexity yet softness. I truly believe that this brings out positive qualities in all spoonies – primarily, we can really empathise and connect with others on a richer level.

If we are going to survive with dignity in this world, we need to have compassion and empathy towards others (including our own) suffering.

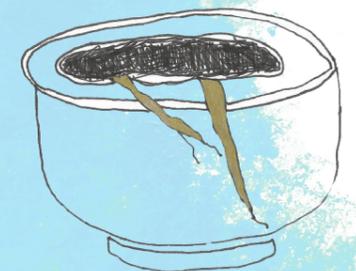
Some issues we face include: financial expenses, side effects of medication – not just physical but also on cognition. Unpredictability of how we will feel one day to the next and trying to explain this to friends, family, colleagues etc. Constantly being guinea pigs/trial and error of medicines and treatments (also psychological, not just allied health or medical professionals).

Chronic pain changes everything – the grief and loss is insurmountable. You only

see the tip of the iceberg, even when we try to express one of our "bad days" to our loved ones. We also feel guilt and sorrow for our loved ones who have to care and see us suffer every minute of every day. We don't wish this upon you or anyone, and we thank you more than anything for still loving and wanting to care for us. Mum – this statement is especially for you. You are my rock and advocate through it all. I love you so much.

The butterfly is symbolic in that it represents transformation. The different sizes and shades represent all of us with chronic illness – we come in all shapes and sizes! Although we may appear healthy or look healthy and "glowy" on the outside, really we are hiding behind a mask.

Hope is key. Without hope us spoonies have nothing. Hope of better pain days. Hope of new medicines or treatment. Hope of more understanding and less isolation. Hope that EVERYTHING will improve. Without hope, you give up on yourself. A single thread of hope is a powerful thing.



"When the Japanese mend broken objects, they aggrandise the damage by filling the cracks with gold. They believe that when something's suffered damage and has a history, it becomes more beautiful."

-Barbara Bloom

Perspective of circumstance



Words + Photos by EMILY, 25

I had been bed ridden for a few weeks when I saw this sunset out my window. I pushed myself to grab my walking stick and my camera and stumble outside and take a few shots. Instantly I felt calmed and at peace with my circumstances and the sunset reminded me tomorrow is a fresh start and even if my symptoms

are still flaring there is still beauty all around me, I just have to be willing to see it. On social media people saw a pretty sunset but to me the photos I took represent a lot more than that and I still have one framed to remind me to appreciate the small things. With ME/CFS/FMS I can rarely control my circumstances but I can control my perspective of my circumstances.

Loss of self

Words + Photo by ANONYMOUS



Before I got sick my greatest passions included hiking, adventure travel, and playing tennis. The bottom left picture of me climbing out of an underground cave was taken just days before I suffered sudden onset ME/CFS with glandular fever. I collapsed in a hallway one night, went temporarily blind and deaf and after that my life was never the same. I was forced to drop out of a Medical Science degree, quit various sports and repeatedly turn down parties. I am naturally extroverted and driven to always be doing things so no longer being able to dance or socialise or even walk became it's own kind of prison.

It's having to juggle the stigma from an illness that is both invisible and contested.

The loss and grief are always a heavy burden. Grief for the life lived and lost. Was that really me? Running around on the soccer field? Chatting and dancing and carefree? Unaware that my body had limitations.

It's the grief for the imagined life that is no longer possible. Will I be able to have the baby that I have always wanted? Will I be able to travel and live overseas? Will I be able to write that book I've wanted? Will I be able to be there for my mums as they age as they have been here for me while I am sick.

Then there is the constant stress about the more mundane. I haven't worked in 5 years. I have no savings left. I'm not well enough to work. I'll probably never be well enough to work. You can't save on the pension and I am bloody lucky that I get that. So many others don't. There is that discrimination in the health care system. If you can't find a doctor who believes in ME/CFS and is actually willing to diagnose it (far rarer) then you have no hope of getting on welfare. What about housing?

The struggle is personal, its political, its social and it is so often invisible.

As your body stops functioning as it should you watch your life crumble away piece by piece until it feels like there is nothing left of you except pain and exhaustion. Too many people still ask if this is a real illness, or respond to us with scepticism. I'd love to be able to lie around all day. Really? Try it for a week, a month, a year. Don't leave your bed except for food or to go to toilet. You have two hours of screen time a day because that is all that your brain can process without crashing. Use it wisely. One hour of tv and one hour of computer perhaps? No talking on the phone, you can only read for 10 minutes at a time. Is it really as fun as you thought it would be?

We have too few allies. Our support and advocacy organisations are all run by volunteers who themselves have this illness. There is so little funding for research or support services. Male pattern baldness got 6x more federal research funding than ME/CFS last year in America. Baldness – when suicide is the leading cause of death in ME/CFS. But we suffer in silence no longer.

We are the #MillionsMissing from schools, from workplaces, from sports teams and shops. Please hear us, see us, talk to us and most importantly take the time to listen to us.

Afterword

I feel compelled to write a short follow up a year after I wrote the above piece. I believe this piece captures the hardships of living with ME/CFS but as with all things, there is no single story. There are always multiple stories and while sometimes the above is my truth, it also misses out on other stories. Stories of strength and resilience, acceptance and adjustment.

While my life isn't what I expected or perhaps hoped for, it still brings me many moments of fulfilment and joy and has opened up unexpected pathways such as a move to Adelaide, this PhD and a love for bunnies as a companion animal! I now have new chronic illness friendly plans and dream. I've learnt strength, resilience, patience, courage and mindfulness. I've learnt to appreciate the little things, to be flexible, to go slow, to find creative solutions, to listen to my body, to advocate for myself and to nurture empathy. There are good moments as well as really hard moments. The nature of chronic illness is that it is always changing and we can only ever capture a fragment of experience on paper.

The Burden of ME/CFS

Words + Photo by GIPSY, 30

It's not just the pain and the exhaustion. The feeling that your muscles are filled with lead and your legs can no longer support you. It's not just the relentless fatigue. Exhaustion so complete that you wonder if it's possible to die from it. You no longer remember what it felt like to be free of fatigue all you know now is degrees of exhaustion. Its not just the dizziness or the nausea. Eyes that can no longer deal with light and ears that have become so sensitive to everyday sounds. It's not just that your brain no longer works properly, that you can't find the words and your thoughts and memories are fuzzy. It's not just screaming inside a broken shell, having to push through layers of exhaustion and brain fog to get your words out.

It's the restrictions, the loss of activities once enjoyed. The loss of opportunities and of friends. It's the hopelessness and despair. The grief. The isolation. The knowledge that this prison is most likely to last forever.

It's having to say no over and over again until people stop asking you and you feel even more alone. It's watching friends disappear and move on. Seeing your friends and your peers have adventures, both good and bad and the complicated mix of the two. Listening to a friend's woes about their latest breakup and that treacherous little voice inside you snipes at your friends *well at least you got to go out and date, you should be happy that you can date and breakup... unlike me who can't leave the house and who nobody will ever want to be with.*



There is always the despair lurking. Always waiting over your shoulder for you to stumble. Is this all there is you ask? Yes whispers despair. There is no cure, there is no recovery. The pain will not stop.

But you shouldn't complain since it's not as if you have a real illness. You are just not trying hard enough to get better. The doctor told you he could find nothing wrong. You test results are fine, perfect in fact. It's probably just depression. You need to get out more. Have you tried exercising? If you are having trouble getting started in the morning just drink coffee.

Chronic Illness Bingo

I wish I could stay in bed all day! Lucky you!	Oh yeah, I'm so tired too	Have you tried drinking coffee?	You sleep too much	You don't look sick
Are you getting enough sleep?	You need to think positively	Have you tried 'this' diet?	You're just stressed	Are you better yet?
If you really wanted to you would get better	You take too many medications	You should exercise more	You should stop/start	You should be grateful you are not worse
Let God in and you will heal/ God is punishing you	I haven't heard of that, is it a real illness?	Just push through it	You need to get out more	Have you tried? (e.g. yoga, vitamins)
My ex/friend/ cousin/co-worker had that and they did X & now they are all better	It must be nice not having to work	You complain too much, we all get tired/pain	You should eat more/ less/ better/ different	I went through a similar tough time let's talk about what a great person I am!



How to Play!

1. Photocopy this page or turn to page 29 for a tear out – every player needs a sheet plus one extra sheet.
2. Cut the extra sheet into individual squares then fold them and place into a container.
3. Draw out one square at a time and read aloud.
4. If you have had this comment (or a variation) said to you mark the square on your sheet.



First person to get a 5 in a line (vertical, horizontal or diagonal) wins!!

Note - Carers/parents/partners can play too, just mentally modify the squares from 'you' to 'they' e.g. 'you' need to get out more becomes 'they' need to get out more.

This idea was adapted from a blog post by Annaham from FWD/Forward, you can read it here @ disabledfeminists.com/2009/11/02invisible-illness-and-disability-bingo-1-0/

The view from my bed

Words + Photo by AIMEE, 24

Day after day. Week after week. Month after month. Year after year. This is my reality. So when I open up to you and tell you what my life is like please think before you speak. "Oh I wish I didn't have to work" is not appropriate neither is, "I'd love to be able to sleep all day." Because I'd love to have been healthy, active and have completed high school, been to uni and had a job in the real world.



As the years go by



Words + Photo by KATHRYN, 24

I couldn't think of anything that would show what this illness is like, since it's invisible, but Aimee and one of my best friends gave me the idea of taking a photo of my room every day when I wake up.

It shows how much of life I've missed out over the past three years - you can clearly see through the blinds the sun is well and truly high in the sky, because lately I have not been able to drag myself out of bed earlier than lunch time. If my mum had not been bringing breakfast into my room before she leaves for work in the mornings, I wouldn't be eating three meals a day, either.

My self-confidence increased significantly over this period.

I was exposed to role models going through significant struggles but still living the kinds of lives they wanted to live. I began to adjust to the impact my illness had on my life and found that I was able to achieve things I never considered possible when I first got sick. For example I never imagined, after the terrible struggle of finishing my secondary education, that I would be able to succeed at university. Fortunately my university was much better equipped at dealing with my chronic illness than my high school was. Special considerations were made to help minimise the impact my chronic illness had on my ability to study, and I was able to graduate from my Bachelor of Arts with first class honours and go on to a PhD. One of the biggest reasons behind my success was accepting my limits and doing my degree part time, which required accepting that it was ok to do things slowly! One of the ways I found to deal with my illness and the fact I didn't know anyone else with a chronic illness like mine was seeking out others like me online.

"If I could go back to when I was younger, I would explain to myself that things do in fact get better, that some problems don't last forever and that I am actually capable of achieving some pretty cool goals."

I joined online communities and discussion groups centred on illness and disability. The relief I felt at finding other people like myself was palpable. It was like the weight I carried on my shoulders suddenly wasn't just mine anymore; others were carrying it with me and that made it lighter. There were people I could engage in gallows humour with, share tips with, complain to and know they truly understood, rather than just feeling sorry for me. A doctor can know all there is to know about a medication or a disease symptom, but speaking to someone who has been through it, who can tell you how they personally dealt with it, to say "hey it's not so bad, I got through this, this is how, you can too!" is invaluable. It also helped me

to know that other people were sick too, that it was OK for me to be sick and not something shameful to be hidden, and also that it was something I could have more control over.

A huge aspect of my illness was the experience of disempowerment. Control was taken from me in a number of ways: I didn't have control of what was happening within my body, the disease took over; I also didn't have any control of what happened to my body, how my disease was dealt with. At 14 I was put on a plethora of medications without a whole lot of explanation from doctors. It was my job to comply with instructions and take the pills. **At times, I often felt like a walking illness, rather than a person: it consumed my identity.** All the doctors seemed to care about were my test results or symptoms. This somewhat dehumanising dynamic between doctor and patient was described by French academic Michel Foucault as "the medical gaze"; I became the subject of this medical gaze and was seen by doctors as the sum of my illness, rather

than a person and an active agent. Now that I am older I have learned to take a more active role in my treatment, to speak up with my doctors and demand to be involved in decision making. I can say "hey I really don't like how this medication is making

me feel" or "I do not wish to do this" and they have to listen to me, because we are dealing with my body and the choices belong to me. I didn't know that was possible, and a huge part of me developing those skills and developing the confidence to exercise my autonomy was my exposure to others with chronic illnesses, and their input. If I had not read about other people doing such things, being exposed to people with such a mindset, I would never have considered it a possibility. I can only imagine how much more enriching it would have been for my younger self to actually interact with people like myself in real life, to be able to sit down face-to-face and speak about things, just to have someone "like me" in my life.

My Story

Words by ANONYMOUS

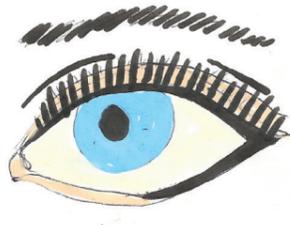
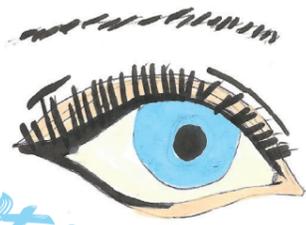
As a young teenager I was diagnosed with an auto-immune disease, as well as Fibromyalgia and Chronic Fatigue Syndrome. It came on very suddenly and I went from being outgoing, confident and highly social to spending the majority of my time at home, usually in bed. This happened almost overnight. The nature of my disability is invisible which creates some unique challenges. Nobody can look inside me to see that I have this disease. There are some physical cues but they are very subtle and won't be picked up by anybody who doesn't know me well. When I became ill at 14, my friends thought I disappeared seemingly without reason. Suddenly I was absent from school more days than I attended and I wasn't participating in social events like sleepovers or trips to the movies. **I tried my best to explain what it was like for me but the fact that I "didn't look sick" made it difficult for my peers to fully comprehend.**

They didn't understand why I couldn't just keep up with them, they would forget I couldn't walk very fast or far before needing a break, or that I had to go to bed early. The variability of my illness also confused my peers; why could I do certain tasks one day but not on another? I gave up constantly reminding them. I felt embarrassed about being sick. I wouldn't talk about it and spent all my energy trying to hide it instead. Nobody else I knew was sick; sitting in the specialist waiting room I was surrounded by older people. I felt alienated and alone. Sometimes comments my friends made about my illness would amplify these feelings. I recall a friend telling me they were jealous I was on the disability support pension; they wished they could get money for sitting around doing nothing.

I was crushed and didn't bother explaining how badly I wished I had the ability to take on a part-time job, how much I just wanted to be normal. I didn't have the vocabulary to explain to them how ignorant and hurtful such comments were.

It wasn't just my peers who had trouble understanding I was sick. The adults in my life could be just as guilty of making thoughtless assumptions based on how I looked, even when they had been apprised of my illness. **Teachers operating on the "but you don't look sick" principle would accuse me of wagging school or "taking advantage" of my illness.** I had trouble concentrating on my school work and was away sick frequently which meant missing out on entire topics or subjects. Nobody thought to say "hey, let's modify this curriculum for you, let's adjust the way we assess your learning". When my teachers noticed how withdrawn I was at school one of the counsellors thought it would be helpful to buddy me up with an older student, essentially creating a mentor relationship for me. Unfortunately, the mentor I was paired with was not someone who lived with chronic illness or had knowledge of any kind of disability. I experienced the same road blocks with them as I did with my peers, my teachers and the other adults in my life. There was a fundamental lack of understanding between myself and others who have not lived through a chronic disabling illness.

A really positive change in my life came about when I was 20, when I joined a group of young people living with a varied range of disabilities who work together on initiatives aimed at empowering young people with disabilities. Not only was I able to discuss life and all the things that matter to me with a group of people who understand what it is like to live with disability, I was also making positive contributions to the community and developing a range of new skills.



Thoughts on Hope

You are sick for a week and it feels so gross you just want it to end, and it usually does. But then you're sick for a month, then a season, then a year. After a year I still had it in my head that this illness was temporary. I think it's a part of the human condition. Every day I would wake up hoping that today would be the day I could get out of bed. And every day I would be disappointed, and I would suffer with a fever and pain and the distress of not knowing what is wrong. It's been two and a half years now, hope is getting harder. Hope isn't something I make an effort to feel, it is something that comes naturally or not at all. It is still there, but it is faint. I don't think it will ever go away.

LOSS OF FREEDOM

The loss of freedom is something a lot of people don't really understand. I am genuinely grateful that I can walk short distances and breathe and think. They are freedoms I have lost in the past. The pain of living in a prison of my own body is the greatest horror I've ever known. It's probably a horror many people will know before they die but most people our age haven't experienced. It's something that changes the way you see the world. I think it's kind of like going to war and coming home with an entirely different outlook on life and then trying to take part in the superficial habits and customs of society. It seems like people who have never been to war spend their entire lives trying to ignore or deny their own mortality. Or avoid reality. But there's a moment when you're forced to face it and afterwards you can never look away.

"I recently switched specialists so I can totally relate to this picture."

GATHERING YOUR MEDICAL RECORDS

@chronicillnessmemes



From [instagram.com/chronicillnessmemes/](https://www.instagram.com/chronicillnessmemes/)
Original still from 2016 film Zootopia directed by Byron Howard and Rich Moore



Words by RACHEL, 26

Today is all I have. It is all you have. It may not be the best today I've experienced but it is far from the worst.

Today I can walk, it hurts but it is easy compared to a week ago.

Today I can sing, even if it is not with as much gusto as I would like.

Today I can breathe easily in my warm house, even if I am breathing alone.

Today I can eat food from my fridge, pantry or fruit bowl, the nausea which intermittently affects me is very limited today.

Today I can read, even if only for 10 minutes before my eyes begin to fail.

Today I can tell those I care about how much I love and appreciate them, even if it is only through text as I'm not well enough for a phone call.

Today I can smile, or I can frown. Yes today I choose to smile, even if it's just for the expensive braces smile that it is.

Today I can be grateful for all that I have.

Today I can be grateful for all that I do not have.

Today I can love myself simply because I am.

Today I can connect with myself and with the spirit within me, this never changes.

Today is all I have.

I seriously overdid it yesterday... so much so that I'm finding it really hard to get my body to move, feel like Pinocchio learning how to walk. Shakes and stiff knees. Moving my fingers hurts. Speaking is too hard. I barely made it to the loo in time having held on for soo long. I'm having trouble understanding things my concentration is non existent. Overwhelming body pain, my muscles are complaining like I ran a 10k yesterday. Not go to our group and to a BBQ. Head hurts, really light sensitive feeling dopey from pain meds. Hungry but too woozy to eat. Hungry but too tired to move. Hungry but to tired to ask for help.

There is so much grief and loss when you have a chronic illness. I feel my identity has gone (or have felt this in the past). You have to dig deep to find your core values outside of factors like work, study, attending social events, travel, freedom. There is so much anger, bitterness. You need to reinvent yourself as a new you! I feel much more vulnerable and have even clung onto so many people because I'm scared to lose more, which was not like me at all in the past. Chronic illness and perfection do not go hand in hand!

I feel an overwhelming sense of embarrassment and shame as I step out of my car, parked in a disability parking permit space. Is anyone watching? Do they think I look sick enough to park here?

I'm tired having trouble thinking
Having trouble holding my head up
Worn out
In my almost jarmies
Can't be bothered
But I'm here
Pain in my leg, new meds not working well.

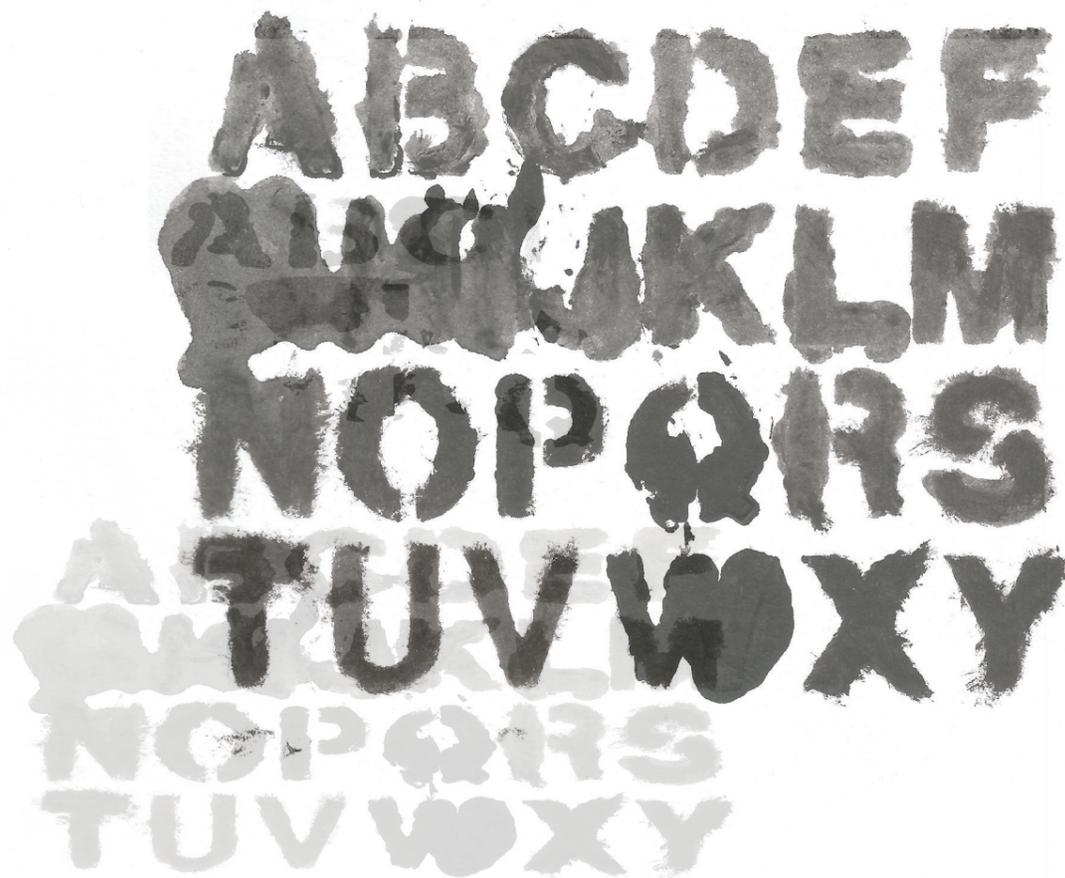
My personality has changed
Not the same person anymore
Can't be the same hardworking person anymore
Missing out on work or study, career
Missing out on independence
See friends less

You can have a go too!

- Set a timer for 2 minutes or 5 minutes. Write (or get your carer/helper to write) about how an issue affects you in your day to day life.
- You could write about what you do, what you feel, what you think, what you experience.
- You could write in the first or third person
- You can write anything – just write!
- Don't censor, don't edit, don't overthink, just write continuously– let the words flow and see what happens.



**Chronically Waiting:
So much time spent
in waiting rooms**



Free Writing

What is a significant issue for young adult's with ME/CFS and Fibromyalgia?

Lack of understanding as a result of problematic social misconceptions, in combination with a broken political and medical system, results in an entirely preventable addition to the multitudes of suffering we already go through on a daily basis. Why are people unable to look at suffering? Or ask questions when they don't understand?

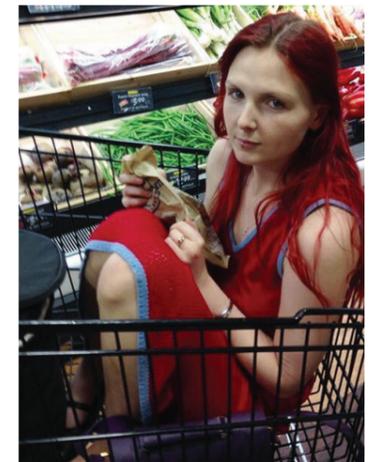
I feel like in becoming sick I've lost who I am. But at the same time, I like the person I've become through my illness. Sometimes I feel like I wasn't worth sticking around for because all my friends bailed when I wasn't able to do the things they could. I lost my teenage years and I will never get them back, and because of this I feel like I am not as developed emotionally as 'normal' people my age.

Isolation
Not wanting to talk about my pain, hiding it means experiencing it alone but it's easier that way. Dealing with others feelings without my illness – Emotional labour – difficult.

Making the best of it

Words + Photo by ANONYMOUS

I wanted to go shopping, I wanted to pick something nice for dinner and also get out of the house. So I went with my mum to Foodland. After a few minutes walking around the supermarket I was exhausted. Rather than abandon the shop I hopped in the trolley and used a packet of zooper doopers as a cushion. It worked quite well I just pointed to what I wanted and which aisle to go down. This isn't the first time I've hopped in a trolley with my mum.



A weeks worth of meds

Words + Photo by AIMEE, 24

This is my weekly medication. Excluding pain killers. It takes a ridiculous amount of energy/time/effort/money to get this together and then sorted every week. It's just too much some days. But if I don't take it I can't function. Ahhh such is life.



(Possibly antiquated) rackets

Words + Photo by RITA

Here is a photo of my rackets, taken today. Pulled from the depths of my wardrobe. They have not been out of their cases in 5 years. I played tennis for 11 years from the age of 7 to 18. I often still have dreams that I am playing.

A quote I often say to healthy people is: Health is the greatest possession you don't even know you have.



A Letter To The Lady Who Said ...
"Chronic Fatigue, isn't that
another word for lazy?"

Words by EMILY, 25

I was in a vulnerable state when I met you.
I was at breaking point and I'd fought my instinct to suffer
in silence and went out that day in a desperate pursuit of support.
Your words were ignorant and kept coming ...
"I was up all night I feel like I have Chronic Fatigue today"
followed by laughter of how funny you thought you were.
I fought every fibre in my body to not cause a scene and
give you a mouthful of exactly what I thought of your words.
I went bright red with anger. I'm sure you noticed.
Your words were hurtful. Your words were ignorant.
Your words were stigmatising.
I still remember that day vividly even though it was six years ago.
At the time I wanted to say ...
"I hope you get this illness so you can realise how wrong you are".
But I knew I didn't mean it.
I wouldn't wish this disease upon my worst enemy.
I can tell you if you said those things to me today I would educate you.
I would explain to you just what its like living with this disease.
I would describe to you every single symptom this disease can give a person.
I would enlighten you to the life I am actively fighting for, every single day.
I would highlight to you how strong, motivated and the polar-opposite
of lazy, every single person still fighting this disease is.
I would make it crystal clear this disease is far from a punch line.
Dear 'The lady who thinks Chronic Fatigue Syndrome is a joke',
Please educate yourself.
I forgive your ignorance. I forgive your derogatory behaviour.
But I truly hope you are educated about Chronic Fatigue Syndrome.
I was unable to educate you at that time but I hope somehow your life
experiences have helped you to understand this illness.
If not I hope to see you on the street one day, when I'm physically
strong enough so I can help you to understand this disease.
I went out that day in desperate seek of help, but looking back on it now,
you were and may still be the one who needed help.

WHAT GETS YOU THROUGH THE TOUGH TIMES?

- Remember you are not alone
- Social media and positive online communities
- Support (family, friends, online)
- Hope
- Give yourself permission to feel the emotions
- Try and get outside
- Pets and animals
- Remember you don't know what tomorrow will bring, it's a new day and it might be easier
- Take it one day at a time, or one hour
- Listen to your body and what it's telling you
- Don't push through – if your body is saying stop, then stop
- Practicing gratitude – writing a list of things you are grateful for
- Nature and fresh air
- The beach
- Set (very) small goals
- Don't blame yourself for your ill health – it's not your fault
- Don't define yourself by your illness
- Be mindful of your mindset (you may not be able to change the physical experience but you can affect the mental experience)
- Have empathy and compassion for yourself
- Just focus on what you need right now to get through
- Be present in the moment – don't fixate on the future
- Find a positive, supportive community
- Your illness is real – never doubt that
- It will get better – it won't always be this hard
- Celebrate the little victories
- Stay hydrated
- Try and eat regularly (even if you don't feel like it)
- Use distraction – tv, books, audiobooks, radio, music, podcasts, hobbies

"I only get one life, and I will
not let Fibromyalgia take
the joy from living it"

–Morgan Freeman