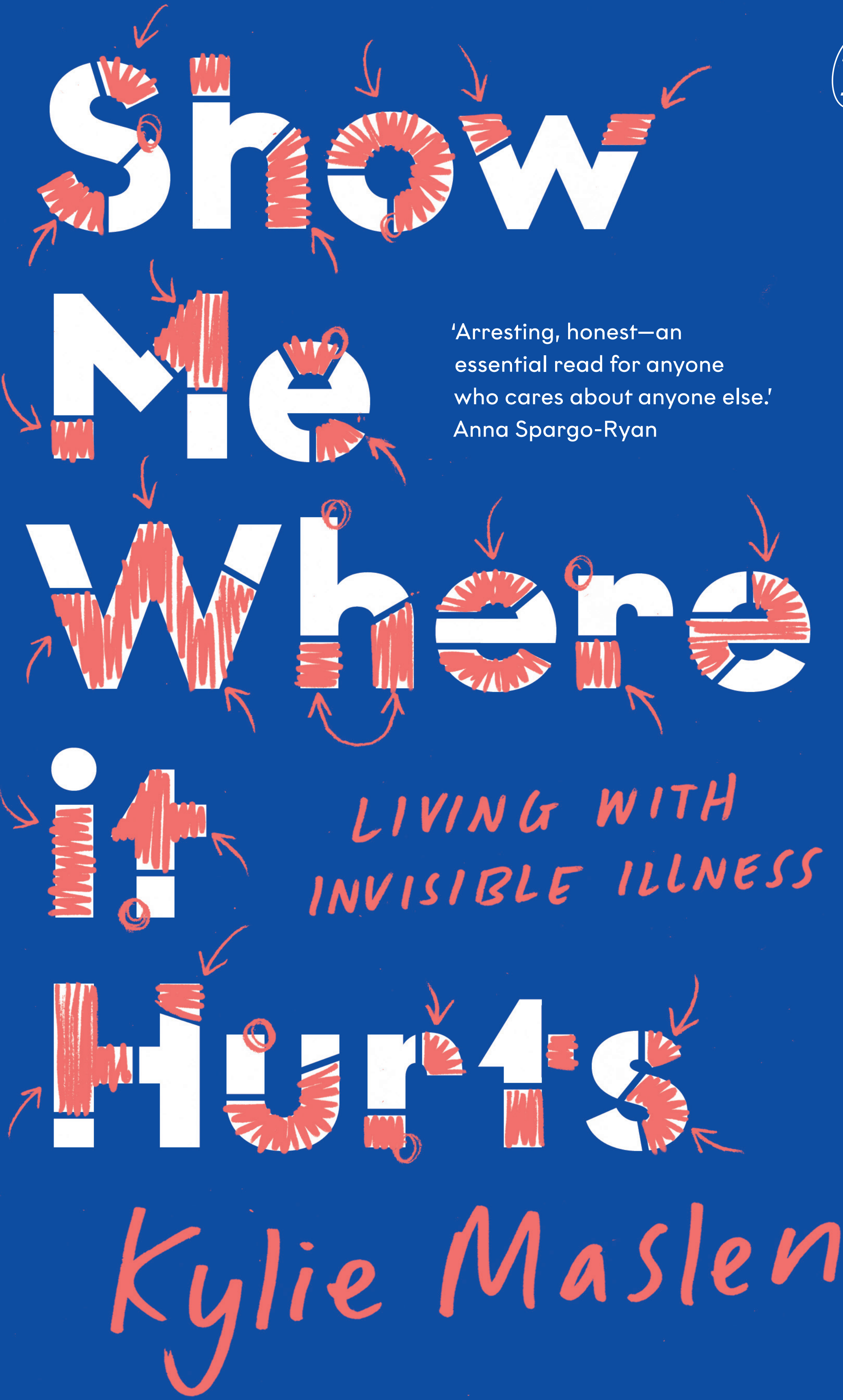

Show Me Where it Hurts

LIVING WITH INVISIBLE ILLNESS

'Arresting, honest—an essential read for anyone who cares about anyone else.'
Anna Spargo-Ryan

Kylie Maslen

I'm Trying to Tell You I'm Not Okay

CONTENT WARNING
Discussion of mental health treatment and suicidal ideation.

People ask, ‘How are you?’

What I want to say:

Do you ever feel like this? Because I don’t think this should be happening.

Do you ever start to cross the road too late to make it to the other side without running, knowing that you’re not going to run?

Do you ever have days when you’re not in pain? What does that feel like?

What I actually say:

'I'm okay.'

'I'm tired, but okay.'

'I'm tired.'

Doctors ask, 'When did the pain start?'

What I want to say:

I don't remember a time without it.

What I actually say:

'Twenty years ago.'

Doctors then ask, 'What about this level of pain?'

What I want to say:

Twenty years ago.

Fuck, I'm tired.

What I actually say:

'It's been this acute for four days.'

Doctors ask, 'How have you been feeling since I saw you last?'

What I want to say:

I'm running out of words.

What I actually say:

'About the same.'

Doctors: 'Give that to me as a number from one to ten.'

* * *

My life of chronic illness and chronic pain is one of resting for hours and hours.

I feel guilty for all the times I'm forced to cancel plans because I don't have the energy to socialise after work, or it's raining and humidity increases my pain, or the pain has been so intense for days on end that I can't get rid of the dark cloud above my head.

It's not just that I feel bad for missing the parties, dinners, dates and coffees. It's also that I second-guess my relationships because of all of the special occasions I wasn't part of.

Does she believe me?

Do they think I don't like them?

Is he angry I missed his wedding?

I think of all the children in my life whose growth I track only in pictures, the precious hours not spent with ageing relatives, the quality time that passes me by that could see acquaintances become close friends.

Some days the pain leaves me without the energy to do anything but eat, stay upright and think clearly about the meds I need to take. Then my need to rest becomes unavoidable. My body is a car trying to run on empty.

Other days I find myself with a quarter of a tank.

I feel the pain always, but I have been granted the freedom—albeit a temporary one—to rejoin my friends and loved ones.

Though, inevitably, that freedom is taken away.

I can picture the two of us in Mum's living room. That house, that couch, means I was seventeen and my brother fifteen. We had recently been uprooted by our parents' difficult separation. That house, that couch, signified a physical settling-down. Emotionally, however, we were still shaken. We were arguably too old for cartoons, but considered ourselves connoisseurs of them anyway. We needed comfort, we needed simplicity and we needed to laugh. So whenever my brother and I could, we sat down and watched cartoons together for an hour or two, relaxing into the silly but heartwarming stories that wrapped up neatly in twenty-two minutes—the inverse of the family drama still playing out in the shadows.

The '90s felt like a golden age of animation: technology leapt ahead and, suddenly, what had looked like jolting sketches across a screen seemed warm and flowing. *Blue's Clues* and *Rugrats* were made for small children, but we loved them all the same. *Arthur* was pitched slightly older, but its earnest sincerity kept it wholesome. *Pinky and the Brain* and *Daria* were our favourites, taking their audiences to darker and more sarcastic places. *Rocko's Modern Life* and *SpongeBob SquarePants* made us laugh out loud. *The Simpsons*, *Futurama* and *South Park* would screen later in the evening, but our time together was cemented in the hours between coming home from school and dinner. That was our chance to laugh and relax before homework inevitably took us to our separate rooms. The memory of those hours spent with my brother is a precious part of my life: here we were laughing and being juvenile, unintentionally making up for lost time.

Things people say:

'You must be so on top of all the good shows!'

'I wish I had that much time to watch TV!'

'So do you have book recommendations for me? I would love to read more.'

There are times when I can concentrate enough to read. Other times I'm not able to focus on the page, and all I have the energy for is binge-watching an entire television series.

But when I can't sleep, or I'm numb from meds, or I'm doubled over in pain and need a distraction, I find myself looking to Nickelodeon or Cartoon Network for comfort. During daytime hours the channels program contemporary cartoons, with slicker graphics and less familiar storylines. I enjoy some of them, but it's the evening programming of the cartoons from my teenage years that takes me back to that warm and cosy place. *Arthur* is still on earlier than *Futurama*, but now *SpongeBob* seems to run reliably in those long dark hours after 10 p.m.

When I tell people that I watch *SpongeBob* a lot, the response is generally something along the lines of 'they had to be really high to make that show', or 'that's so fun to watch when you're stoned'. I cringe a little: the effects of a couple of Endone might not be that far from smoking a joint, but I bristle at the association with stoner culture. I am not the American college student with the munchies, covered in fluorescent yellow dust and laughing hysterically. I am not actively seeking this high. Cartoons, specifically *SpongeBob*, are a refuge amid a longing for a life without drugs and pain. Again I am unwittingly trying to wind back the clock.

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SpongeBob SquarePants, or SpongeBob for short, is a delightfully kind-hearted sea sponge who—as his name suggests—wears square pants. He lives in Bikini Bottom, an underwater village, in a house shaped like a pineapple along with his pet snail named Gary. SpongeBob is a cook at a burger restaurant where he remains perennially calm and cheerful. He is naive but never stupid, and has an (almost) boundless generosity towards others, particularly his best friend, Patrick.

SpongeBob SquarePants was first broadcast on 1 May 1999. The show is in its twelfth season, with 267 episodes to date. It is Nickelodeon's longest running series, and a franchise containing video games, comic books, multiple films, a Broadway musical and, as of 2017, reported merchandise sales of US$13 billion.

SpongeBob SquarePants first aired when I was seventeen. Since then I have tried endless forms of hormonal treatments to quell the periods that wreaked havoc on my body from my early teens. I was finally diagnosed with chronic pelvic pain as a result of dysmenorrhea (painful periods) and menorrhagia (long and heavy periods), as well as polycystic ovary syndrome (a chronic condition causing irregular periods and hormonal imbalances) and endometriosis (where lesions that are similar to uterine lining grow outside the uterus, causing pain, fertility issues and potential organ dysfunction) at twenty-eight. My chronic pain formally became a disability at the age of thirty-four.

Particularly on bad days, the familiarity of the characters and plot lines of older *SpongeBob* episodes is soothing. The predictability of a resolution, and the gentle kindness displayed by SpongeBob, helps to ease the hurt of being dismissed by doctors and specialists, of being questioned by nurses and pharmacists, of the raised eyebrows that convey the disbelief of colleagues and acquaintances.

SpongeBob SquarePants has undeniable staying power. So does my pain.

The very nature of chronic illness lends itself to isolation. Time spent at home resting, time spent in waiting rooms, time spent in hospital, time spent recovering.

Things I want to say:

I don't know how long I can keep doing this.

I can't do anything nice for myself because I spend so much money on staying alive.

Instead I post a meme of SpongeBob walking into a room with an exaggerated swagger. The caption reads ‘walking into your doctor’s office’.

The receptionist at my GP’s rooms says, ‘Take a seat, Kylie’ when I walk in the door. The frequency of my visits spares me the time it takes for him to look me up on the system and confirm my appointment; he no longer asks, ‘Is this still your current address?’ before letting me sit down. I’m grateful that he can see my exhaustion and helps me in this small but not insignificant way, but I’m saddened that my life looks like this at such a young age.

A key theme in chronic-illness memes is conversations with ‘normies’ (those who are not chronically ill or disabled). Specifically, about their refusal to listen, their inability to empathise with our pain, or their quickness to dispense unsolicited advice about symptoms and illnesses of which they have no lived experience.

Things people say:

‘You don’t look sick.’

‘You look much better than last time I saw you.’

‘It’s good to see you with some colour back in your face at least.’

Many of us with chronic illnesses are often housebound. Unable to socialise with family, friends or colleagues we go online to interact with others. We are also searching for people who understand.

Peer support through social media offers a source of experiential knowledge about illness. It gives us a way to normalise pain and a life lived with chronic illness. That can take the form of sharing stories and asking questions, but often we communicate through chronic-illness memes, which are a simple visual means of conveying complicated emotions and frustrations, as well as a way to add humour to a heavy conversation. Using memes—images or videos that are already widely shared—with context tailored to illness communities allows those of us who feel socially isolated by circumstances beyond our control to connect with the broader zeitgeist.

A comparable network exists around mental-health memes. In an article for *VICE*, writer Anna Iovine notes the use of the 'Is This a Pigeon?' meme in particular. Based on a deliberate misquote in the anime TV series *The Brave Fighter of Sun Fighbird* (the character points to a butterfly), 'Is This a Pigeon?' is used widely on social media to denote confusion. That confusion can be experienced either by the creator or the subject of the meme. Iovine points to a version created by Twitter user @kokoronis where the butterfly represents 'new hobbies, useless purchases, food cravings, nostalgia, promises to myself that I will inevitably break'—'Is this a cure to my lifelong depression?'

Iovine spoke to psychologist Schekeva Hall about why the meme resonates so deeply. Hall suggested 'that a lot of people struggle to express their feelings in words'. Using memes, Hall says, is 'kind of like a way to get around that…I think it makes people understand emotion and mental health in a more accessible way.'

Memes are a form of communication, one that does not rely on face-to-face contact. Chronically ill peers can use them to let each other know they're not alone, to convey a complex empathy that is nonetheless accessible and simple to comprehend.

Doctors say: 'Where is the pain?'

On hospital beds or examination tables they ask me to point. I flinch from their touch.

Across bulky oak desks they pass me a pain chart. A blank image of a human form front and back, with faint lines delineating areas, such as shoulders from upper arms.

They say: ‘Here is a pen. Can you colour in the areas that cause you the most amount of pain?’

Like I am a child.

Then they say: ‘What types of pain do you get? Stabbing pains? Sharp pains? Dull aches? Pins and needles?’

They draw and scribble on the chart. You are the chart, the chart is you. You are one-dimensional. Your pain has sites, it has types, it has numbers. Your pain is data.

The chart has no genitalia, like an androgynous doll. How do I account for the pain my illnesses cause me when there are no reproductive organs on the chart? How do I talk about pain during sex, the tight pelvic floor muscles that make urinating sting, or the pressure my bowels place on my uterus, when my body has been reduced to a polite children’s toy?

Social anthropologist Dr Elena Gonzalez-Polledo conducted a study on social media and how it is used to communicate pain. She cites examples from microblogging site Tumblr as ‘pain worlds’: corners of social media where those of us suffering from invisible illnesses are able to express ourselves through means more creative than a number. Selfies, status updates and memes on personal or awareness accounts, Gonzalez-Polledo reports, help to make the pain feel observable, and its chronic nature and symptoms tangible. Building an album or stream of images draws a parallel to the time passing in a way that few other modes of expression can capture.

People say:

'I'm sorry.'

'Can you rest?'

'Get a good sleep. See how you feel tomorrow.'

Things I want to say:

What if I feel like this forever?

I haven't eaten in twenty-four hours, can you bring some food? But just leave it outside the door like I'm in a hotel. I don't want you to see me like this.

It is tomorrow.

Things I actually say:

'Thanks.'

'Yeah, I'm resting.'

Sometimes I can't fake a response so I don't reply at all.

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I become obsessive about tracking my sleep using an app on my phone. If I'm in acute pain, I can't sleep. If I'm simply existing with the pain, I sleep a lot.

The graph for a bad week looks like a city skyline, columns of varying and sporadic lengths.

The graph for a better week shows uniformity, a row of straight lines.

When I tell my GP I'm not sleeping well because of the pain she thinks it's just a way of soliciting for tranquillisers. She asks: 'Are you stressed? How's everything at work? Have you tried meditation?'

Many studies have found that doctors have an ingrained bias against women when treating pain. Diane E. Hoffmann and Anita J. Tarzian reported in their seminal 2001 paper 'The Girl Who Cried Pain' that doctors widely—incorrectly—hold the belief that because of a biological make-up designed to withstand childbirth, women have a natural capacity to endure pain. As a result, women wait sixteen minutes longer than men to receive pain relief in an emergency, and when they do receive pain medication it is 13 to 25 per cent less likely to be an opioid.

My GP says she needs me to try a bit harder to get to sleep on my own before she would be willing to prescribe anything to help. We talk about 'sleep hygiene', which basically means 'don't use your phone in bed'.

In 'The Age of Post-Authenticity and the Ironic Truths of Meme Culture', media and technology writer Jay Owens explains that '[t]he formal properties of the meme make it a particularly effective format for delivering an indirect payload of empathy'.

The image and its inherent wit create a comfortable distance between the person speaking and their audience, giving the sender the space to share intimate emotional information and protecting the receiver from feeling overwhelmed by its disclosure. Memes grant permission to speak about the private, the painful and the seemingly impossible. And the emotional range offered by different formats—from the innocence of *SpongeBob SquarePants* to the darker *American Chopper*—makes it easier to communicate our pain and the state of mind the pain leaves us in to others. Meme formats such as 'tag yourself' or 'distracted boyfriend' are 'by their nature iterative and quotable', Owens writes. 'Each new instance of a meme is thereby automatically familiar and recognisable. The format carries a meta-message to the audience: "This is familiar, not weird."'

I connect with the playfulness of *SpongeBob SquarePants*. When I am in pain I become childlike—I reach for comforting foods, I curl myself into a ball. I have no control over my body so I have no choice but to surrender to it. Seeing familiar images from a cartoon I first began to watch twenty years ago seems to ease the loss of agency my pain and illness cause. Perhaps, more simply, just as much now as I did at seventeen I want—and need—to laugh.

When I search #chronicillnessmemes I find an endless stream of visual gags that represent all the gaps in my life: the time waiting for my body to recharge, the weeks for the side effects of new medications to pass, the months on waiting lists for specialists who—I'm told—will be more understanding than those I've seen before, and all the heaviness that I feel on my shoulders from carrying decades of information, sadness and pain with me every day.

'And so a space is created,' Owens writes, 'to talk about being stressed and overwhelmed and unsure of the meaning of anything we do—a space which is, I believe, more open than it has been in the past.'

Memes see me, curled up in the foetal position, too tired to cry.

Memes articulate what's going on in my head better than my abrupt and stuttering text messages to loved ones. I don't have to find the words. Memes have them for me.

They speak for the anger that the doctors don't see, the jealousy I hold for people who are well, the exhaustion I feel at every new appointment and every new symptom and every new dismissal by someone who doesn't understand. They allow me to convey my body language and facial expressions when I'm reaching out to friends during a period of pain-induced isolation.

Memes are simultaneously distant and close.

Writer Emma Marie Jones says that because words are inherently tied to order and structure, they are inadequate when it comes to talking about bodies. 'We are adapting,' she says, 'language is adapting, our desires are adapting to fit into the spaces we create with text.' By combining words with images to make memes, we place less strain on the text to convey emotion as well as the statement. The importance of the visual language in memes is not to be underestimated. Pain is visceral; it is innately difficult to describe.

Words cannot properly express my pain. Charts and data cannot properly express my pain. A physical examination cannot properly express my pain. Nothing in the diagnostic toolbox used by doctors and specialists and surgeons is enough. And all of them require so much energy.

Every time I give my story to a new doctor. Every time I need to educate someone about what one of my conditions actually is, as opposed to what they think it is. Every time I try to tell someone I'm not okay, and my experience is reduced to data.

Pain—both physical and mental—is more than a number or shaded area on a chart.

Journalist Amanda Hess writes in her paper 'The Social Media Cure' that when patients with chronic illnesses are asked to describe their pain as a number between one and ten, 'they may report higher levels of pain in an attempt to communicate [the] "helplessness and hopelessness"' that the chronic nature of their pain carries. 'The problem is not that it hurts more,' Hess writes, 'it's that it just never stops hurting. For some patients, Instagram and Tumblr are better places to express that feeling than the doctor's office.'

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People ask:
'When will you be better?'
'Are you better yet?'
People say:
'She's battling through.'
'She's winning the fight.'
In fact:
There is no winner; the battle never ends.
This is it.
I'm trying my best.

Within chronic-illness circles memes often act as a wry smile. They become shorthand for 'I understand'. Away from normies and doctors, in moderated private groups on Facebook, through anonymous accounts on Tumblr or in the ephemerality of short-lived snaps (Snapchat) or stories (Instagram) is the freedom to express the warts-and-all reality of chronic illness.

In these small, regulated groups—Gonzalez-Polledo's 'pain worlds'—memes become a vehicle for jokes about loneliness, living in pyjamas, reliance on medications and annoyance at their side effects. In pain worlds, normies and health-care professionals are the ‘other’. Gonzalez-Polledo writes that pain worlds flip the social network on its head: hospital visits, isolation and poor hygiene become the normal everyday experience. Using visual cues and imagination, social networks transform lived experience of illness into the default.

Doctors start to worry that my pain is making me depressed.

They ask, ‘How’s your mental health?’ as if it’s a simple question.

I keep saying:

‘It’s fine.’

Until eventually I admit:

‘I’m struggling.’

They say: ‘Can you give each of these questions a number between one and five?’

> During the last 30 days, about how often did you feel tired out for no good reason?
>
> 1. None of the time
> 2. A little of the time
> 3. Some of the time
> 4. Most of the time
> 5. All of the time

I choose:

5. All of the time

During the last 30 days, about how often did you feel hopeless?

1. None of the time
2. A little of the time
3. Some of the time
4. Most of the time
5. All of the time

I choose:

4. Most of the time

During the last 30 days, about how often did you feel so sad that nothing could cheer you up?

1. None of the time
2. A little of the time
3. Some of the time
4. Most of the time
5. All of the time

I choose:

4. Most of the time

Then I cross it out and choose:

5. All of the time

After I finish filling out what I will come to know as the K10 form with circled fours and fives, the doctor shows me a piece of paper titled ‘Scoring. FOR DOCTOR’S EYES ONLY’:

> This is a questionnaire for patients to complete. It is a measure of psychological distress. The numbers attached to the patient’s 10 responses are added up and the total score is the score on the Kessler Psychological Distress Scale (K10). Scores will range from 10 to 50. People seen in primary care who
>
> - score under 20 are likely to be well
> - score 20-24 are likely to have a mild mental disorder
> - score 25-29 are likely to have a moderate mental disorder
> - score 30 and over are likely to have a severe mental disorder.

People ask: ‘How are you feeling about the diagnosis?’

What I want to say:

I’m sad and relieved and overwhelmed and grateful and I want to cry.

What I actually say:

‘I feel extremely *SpongeBob leaning on a wall exhaling meme*.’

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Doctors like to push chronic illnesses into moulds. Medical sociologist Arthur Frank writes of these moulds in his book *The Wounded Storyteller*. Frank identifies three types of what he calls 'illness narratives': restitution narratives, quest narratives and chaos narratives. 'People tell their own stories about illness,' Frank writes, 'but what seems worth telling, how to format the story, and how others make sense of the story all depend on shared ways of narrating illness.'

The restitution narrative relies on 'a movement toward recovery of health'.

She beat cancer.

He won the fight.

A quest narrative is one of acceptance: first of the diagnosis, and then of its ramifications for treatment and recovery (or lack thereof).

You are so brave.

They've worked so hard to be well.

Chaos is messy, interwoven, difficult.

Chaos is all that cannot be tamed.

Chaos narratives ignore simple statements. They are, by their very definition, difficult to define.

Chronic illness is chaos.

Memes, however, offer a medium that can cope with complexities despite appearing to be simple. Humour, empathy and social criticism come together in a captioned image. The format is reliable and easy to manipulate using a phone's default software. It gives those of us living a life of chronic illness a vehicle for voicing the indignities and injustices, the frustrations and the exhaustion, of chaos.

An aesthetic representation of pain is often more useful for a patient.

What colour is your pain today?

Blue: cold, crisp, tight.

Red: hot, burning, pulsing.

Grey: dull, aching, endless.

Elena Gonzalez-Polledo and Jen Tarr write in their joint paper 'The Thing about Pain' that, although it is widely understood that pain is multidimensional, most clinical trials still oversimplify measurements into quantitative data. Therefore, they report, 'it is worth paying attention to how people with pain express their condition, not only through words in clinical context, but also through other media and to other audiences.'

There is no simple reading of chronic illness and chronic pain. They result in a life lived beyond the confines of restitution and quest narratives, yet the story of that life needs to be told. It is a rejection of language: it makes the task of communicating the truth of the pain seem impossible.

There is, Gonzalez-Polledo and Tarr write, 'abundant research on the chasm between patients and doctors in the clinical management of chronic pain'. One is quantitative, based on numbers and facts and sites of pain and prescriptions; the other is qualitative, based on feeling and inability and frustration and sadness.

What if, then, doctors and patients used memes to help communicate the gaps? Rather than doctors asking how long pain has been at what number, they might turn to pain worlds to help find ways to understand and empathise with the impact of chronic pain. Recording a number as they would a blood-pressure result only leaves the patient feeling dismissed and hurt, and does not treat the cause at hand.

Pain is difficult to communicate, but it's not impossible. It does, however, rely on the use of more complex language than the current normative means of diagnosis and tracking. Chronic pain and chronic illness do not fit into neat narratives—either personally or medically—but they have found a new way to be shared. In posting chronic illness memes on social media, Gonzalez-Polledo and Tarr write, the ill ‘become witnesses whose testimony contains clues of the politics of chronic pain, [and of] the values that “should” sustain the community’.

Patients are writing their own case studies, collating their own textbooks. By turning to microblogging sites and social media, doctors have an opportunity to open themselves up to the realities of living with chronic pain. The narratives may be written in new ways, but it is this evolution that has allowed the chaotic nature of chronic pain and illness to finally be expressed.

We know that words are not enough. Visualising experience helps not only to communicate the pain but also to bridge the isolation it brings. Closing the gaps in language between doctors and patients will help in the treatment of chronic illness and the management of chronic pain. After years of fighting for diagnoses, treatments and pain relief, the reblogs, likes, reposts, comments and shares are validation; they tell us that we are seen. In this instance, social media engagement doesn’t feel shallow; rather it’s a rare but important example of a person who is ill and in pain feeling understood.

I'm sent a cartoon of SpongeBob, misshapen and sitting on the floor. One arm holds out an empty plate, the other is bent back awkwardly. He looks extremely nOt FiNe, but the subtitle reads 'I'm ok, honest'. The caption to the meme reads: 'When you try to hide being sick but it's not working.'

People say:

'I saw this and I thought of you (lol). Always here for you, no matter what. x'

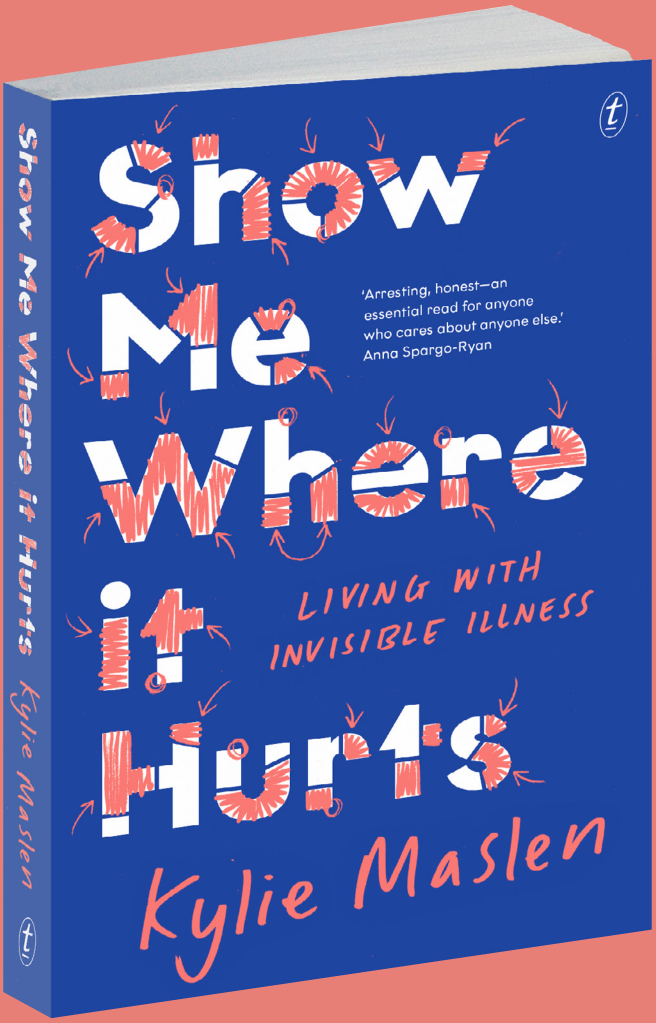
What I want to say:

Thank you for seeing me.

I never knew you understood like this.

What I actually say:

'It's me. x'



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