

Inform Podcast  
Episode 13: Kylie Maslen's Show Me Where It Hurts Transcript

Kylie Maslen

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Kirby Fenwick

Hello and welcome to Inform, a podcast where you'll be hearing from people with disabilities, as well as industry experts, on a range of topics.

I'm your host, Kirby Fenwick.

Joining us today is Kylie Maslen, the author of *Show Me Where It Hurts: Living With Invisible Illness*, a collection of autobiographical essays that weave Kylie's personal experiences with sharp cultural criticism and explores how living with chronic pain, invisible illness and disability impacts Kylie's work, relationships and day-to-day life.

Today, we'll discuss the value of online communities, why we should be talking about sex and dating for people with disabilities and Kylie's hope that readers who are disabled or living with chronic pain and invisible illness can find a form of kinship in the pages of *Show Me Where It Hurts*.

But first, where did such a striking title come from?

Kylie Maslen

I mean, it began with the idea of being in a doctor's rooms or, in the, unfortunately many cases where I've been in emergency where that's sort of what doctors are asking you. They'll be like, where is the pain? Can you show me on your abdomen where, you know, the sharp pains are coming from, where the dull pains are, that sort of thing.

And we, you know, it's something that we hear from a very young age as well in that like, you know, you fall off your bike and mum will say, show me, show me what hurts.

But yeah, as I came to write the book, it also works on a level of the way that I use pop culture and online culture and you know quite visual mediums to try and describe what day-to-day life is with invisible illness and disability.

Kirby Fenwick

Kylie's experience of chronic pain, invisible illness and disability is felt in every facet of her life. In *Show Me Where It Hurts*, she uses music, literature, TV and film and online culture—everything from *Spongebob* to *Beyoncé* to *Frida Kahlo*—to explore those parts of her life, mixing cultural criticism with her own experiences and often using those cultural references as a way to dig deeper into a topic or idea.

Kylie Maslen

I guess I came to use those pop culture references because it was my way of understanding what was happening.

Some of the, some of the ideas, yeah really come from my own experience of coming to terms with diagnosis. So, particularly my sort of quite recent diagnosis of bipolar two, which only happened when I was 35 and I'm about to turn 38. Finding comfort in the film *Silver Linings Playbook* and, and the TV show *Lady Dynamite* really helped to break the stigmatisation that I had internalised with these labels, and really kind of helped me to see the illness framed from within and coming with humour rather than the kind of like seriousness with which it's discussed in a psychiatric setting.

There were other examples where I wanted to show what was being done wrong or in an ableist way. So, I talk about one particular episode of *Friends*, which is horrendous on a number of levels.

Yeah, I think part of my intention of using those pop culture references was to create a safe space for people on the outside. I mean, I wrote this book both for people who, like me, have needed to have their pain validated, continue to need to have their pain validated. And I knew that if I had a resource like this, at any point in the last sort of 20 years of my life, it would have made an enormous amount of difference to my mental health and to my physical health.

But a big part of my targeted audience writing this was also the people in our lives. So, by that, I mean family, friends, support groups, peers, colleagues, of people who live with invisible illness. I wanted them to be able to see and understand what we often find so difficult to communicate. And the cultural references help to make that experience more accessible, I believe and hope. And, and I was also, I mean I was also very particular with the tone in which I was writing with. But yeah, those references were a key entry point I thought for a lot of people.

Kirby Fenwick

Kylie writes that 'the very nature of chronic illness lends itself to isolation'. So, finding support and understanding in online communities becomes, as Kylie describes it, a lifeline. But more than that, Kylie says the memes and gifs she shares with these online communities help to convey 'complicated emotions and frustrations', becoming a kind of shorthand but they also help to add humour to what can be a heavy conversation.

Kylie Maslen

And I also just really wanted to give voice to online communities that are a real lifeline for people like me and people who are chronically ill or disabled in any, for any number of reasons.

Ah when I say it's a lifeline, I mean that really literally like these, these groups, and I should say that, you know, there's a group for every illness and there are, you know, a number of, for endometriosis in particular, there are a number of groups to which I just can't identify, for whatever reason, you know, like a difference of lifestyle or different use of language or a focus on fertility, sorts of things that I find are less important to me or they don't align with my values. But then there are, I've been really

fortunate to find other groups and within them some really amazing people who have become dear friends, even if we haven't met in real life, who have that understanding of, you know what the bad days are really like and they understand the grind of the constant appointments and the expense and the fatigue and the trialling new drugs constantly and what that does to your body and your mind.

So, these groups become a place where you can ask for advice. So just recently I went—I posted saying, you know, like these are the illnesses that I have, these are the current drugs that I'm on, my psychiatrist wants to trial me using this or an increased dose of this. Does anyone have experiences with this drug. And what you get is a really honest account of side effects that perhaps your doctor hasn't talked about or even just to know that there are other people out there who are using these drugs because often you know, when you're, part of my bipolar has meant that I have gone on anti-psychotics for the first time and the stigma attached to that kind of name for a drug is a lot to deal with. So, having people who can be a form of kinship and to you know help frame what that actually means and how much it's helped them has been enormously helpful in my life.

I think those, those memes as well just become part of that shorthand that we use to talk to each other. And yeah, sometimes the exhaustion means that our cognitive function can be impaired, which means that finding words is really difficult. But, you know, we might have these things saved to our phone that we look at or we might have posted something that feels a bit incoherent to us, but that other people can understand what we're trying to say and will reply with something like that. And that just makes us feel seen and validated and it's almost like a form of affection. And it is a form of affection, kind of coming through the screen.

Kirby Fenwick

Dating, sex and relationships are topics that people with disability are often dissuaded from talking about. In *Show Me Where It Hurts* Kylie writes honestly about her experiences.

Kylie Maslen

There's a quote in the, I think in the scar tissue chapter about tattoos and body image that when we talk about disabled people we often or able bodied people often do so in a way that's like, well, you know, you're alive, you're being cared for, what else could you want and in that, in that sense, they're talking about being represented in terms of, being represented in the media and seeing your face reflected back at you and in the experiences that you have every day.

But I feel like that quote also works in terms of talking about disability and sex that it's a, yeah, people just don't want to talk about it. And it's incredibly important and it's something that I'm still navigating myself and I knew if it was this important to me it would be important to other people.

It's also just something that has caused me tremendous pain. I mean, physically, I talk about that but mentally in terms of the disclosure of illness and how to navigate that.

Most of the, most of the online conversations that happen around this, presume that people are in long term relationships or are looking for a long-term relationship. And

so, the way that it's talked about, I just find really alienating. I'm yet to find a way of people talking about sex and dating for disabled people as they talk about it for able bodied people. And that is, it's 2020. So, everyone's you know, finding people on Tinder or navigating a more casual relationship to sex or you know, a lot of our communication during courtship to use an old-fashioned sounding word, is done via text or whatever.

And there's still not a lot of good writing about that just generally out in the world, let alone being disabled. So, I wanted to, it was important to me to contribute to that. And part of that was needing to be really open and raw about those experiences.

It means that this chapter where I talk about what vulvodynia looks like, what it means to be physically examined so much by doctors and then you know, have very similar experiences then happen in a bedroom in a romantic setting, you know, that's really difficult to navigate. That needed to be out there. And it's the chapter that I probably get the most feedback from from people who are chronically ill or disabled, that's the one. And prior to, prior to the book coming out the writing that I had done in a freelance capacity about dating was something that was really, really resonating with people. It's definitely the chapter that I was most nervous about extended family reading and people in my life having judgments on but also these are my choices as a grown woman with feminist principles so such is life.

Kirby Fenwick

In writing about the many parts of her life, from work, to dating, to family and friends, to her fears about what the future may look like for her, Kylie illustrates how these things intersect with being disabled or living with chronic pain and invisible illness.

Kylie Maslen

Yeah, there's no way to separate myself into a sort of disabled person and then a able-bodied person. Or I think often the expectation of like a disabled person who can pass as an able-bodied person. I think that's, I've never put it that way. But that feels right like I can be an advocate for disabled people because I am disabled but also, I can do so in a way that is palatable for able-bodied people and I think part of that comes from the privilege of having invisible illnesses but yeah, I needed to write about the broad facets of disability because that is the experience of it.

And I use the chapter where I talk about the ways that we look at Frida Kahlo to help explain this. So, there is a version of her who was disabled, relied heavily on mobility aids in order to pass as a non-disabled person. And that's kind of, that cropping of her and lack of discussion about you know what was going on under those clothes and under those shoes and all that sort of thing compared to the work that she created as an artist that was incredibly political, incredibly forthright in her discussion of disability.

You know, all of these things just, they don't quite connect. We've chosen a narrative about her in retrospect, that is incredibly ableist and doesn't represent who she was. And I, I think you know, that's a good analogy for how we quite often look at disabled people. And I talk, I talk about the term that Stella Young coined, inspiration porn in that so often disabled people are looked to as an example of strength and overcoming

adversity and as some kind of aspiration which is bizarre when you think about it. We talk about or able-bodied people talk about inspiration porn when, when disabled people are just looking to be the person.

I'm disabled, but I'm also a writer, a football fan, a daughter, a sister, a friend, you know, there's all of these different elements of who I am. And by, I think, you know, we need to break out of this form of trying to separate all of these different aspects of who I am rather than it being a collective.

I think we risk alienating both the disabled person but also people around us by oversimplifying things. And I think in the case of disability, that personal and political are always enmeshed because this is the society that we live within is one where the fault in this situation is of society rather than the person who is disabled.

And I think we're slowly kind of, slowly coming to terms with this reckoning as a society but moving a lot more slowly than it could and should be.

Kirby Fenwick

What Kylie hopes, is that writing about her own experiences offers some comfort to others living with disability or chronic pain or invisible illness. But she also hopes it creates opportunities for reflection.

Kylie Maslen

Just because people know what it is physically, doesn't mean they know what it's like to live with it and to experience it. And so that was really a key motivation of mine in writing the book was to help propel these conversations into a more empathetic one where you don't just know what the invisible illnesses that I have, you don't just know what they are, from a terminology point of view. You have a better idea of what life looks like when you have those invisible illnesses as well.

I hope, I hope if people are reading this book who also have invisible illnesses. I hope that they just, first of all, just feel seen and feel really validated that their own experience isn't a singular one. It can be really isolating and really lonely, I think being unwell of any kind. I mean like you have bad cold or the flu or something that keeps you in bed for a week and when you're finally well enough to go out it feels amazing right like to be out in the world again you know, you can imagine when you go through constant cycles of that your whole life or most of your life it's not great for your mental health and I hope that readers who are chronically ill, mentally ill, disabled can find a form of kinship in this book. I hope that, I mean, I don't hope that they see their experiences in it because some of these experiences are pretty awful. But unfortunately, I know that many people are going to see their experiences in it and I hope at least that makes them feel less alone and, and validated to keep fighting because it is a fight for treatment, unfortunately.

You know, like having myself reflected back in those online communities and having people reach out to me when I've needed it, I hope that people can hold this as a tangible object and say this is me or part of me is in this book. I wanted people to be able to pick it up if they were having a pain flare or were having a hard time with their medical care, having, you know, just going through a bad patch, whatever that might look like. I wanted them to be able to pick up this book and flick to a part that

resonates with them and that they could find some comfort in that. And I deliberately wrote the book in a accessible, I hope accessible way, in sort of plain language so that, I mean I know myself that when I am unwell I find reading really difficult, which is rough when you are a writer who loves to read so yeah, I wanted, I wanted people to be able to grab this at any time that they needed to know that it wasn't just them. And that yeah, there are people around them even if they can't see them at that point in time.

And I really hope that this book finds the people in their lives and helps to explain to them in a way that probably people like me have struggled to articulate for a long time you know what that looks like and how that feels. And almost selfishly, but I guess also not. I hope that people find this as a bit of a starting point. So, all of the pop culture stuff that I love that I've forced upon people by talking about in this book, I hope that they go out and seek that but then also think about what other media are they consuming and what does that representation look like?

Kirby Fenwick

Thank you for listening to Inform, a production of Independence Australia. Inform is hosted and produced by me, Kirby Fenwick. Our managing editor is Alison Crowe.

Our thanks to Kylie Maslen for joining us for this episode of Inform. Show Me Where It Hurts: Living With Invisible Illness is published by Text Publishing. You can find it in all good bookstores or digitally. For more information about where you can get yourself a copy, check out the show notes at [www.informonline.org.au/listen](http://www.informonline.org.au/listen)

This episode of Inform was recorded and produced on the lands of the Wurundjeri people of the Kulan nation and the Kaurna people of the Adelaide Plains. We pay our respects to elders past and present.

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