

## Episode 3.23 Pain

March 29, 2019

Hannah (Host): [00:07](#) [Music: "Mesh Shirt" by Mom Jeans] Hi, I'm Hannah McGregor and this is *Secret Feminist Agenda*. Happy spring, everyone. It's, I mean, March 21st happened, which means it's officially spring now, whether or not the city that you live in is completely covered in snow. I guess happy autumn if you live in the bottom half of the world [laughs] Okay. Happy seasonal change, which may or may not be manifesting presently or kind of imminent, but it's one of those times of year when, at least if you work at a university, it definitely feels like a seasonal change it because spring, the spring equinox, is a couple of weeks before the end of the semester and even at the end of the best semesters and this was a good semester, but like my students, I am, I am also ready for it to be done. We're all ready, we're all ready for this 12-week period to come to its beautiful natural conclusion, and by "natural" I mean arbitrarily selected by an institution, and spend more time outside. We've got daffodils in Vancouver and when it's sunny out and the daffodils are blooming, it's awfully hard to keep students focused on the exciting history of zines. Can you believe it? I can't. I'm going to jump straight into the topic for this week's minisode, but first up I want to give you a content warning. I'm going to be talking about chronic illness and chronic pain. I'm going to be talking about drug addiction, about cancer, and about suicide. And that makes, it sounds like a really fun episode, doesn't it? But I wanted to give you a heads up that that's the kind of stuff we'll be touching on this week. So cue interstitial music. [Music: "Mesh Shirt" by Mom Jeans]

Hannah (Host): [01:58](#) Cool. This week I want to talk about pain. I mentioned, I think in last week's episode, that I was planning on undoing this episode on talking about pain and that's because of an experience that I had last week. A distressing and then ultimately ephemeral experience, I guess is the best way I can think of to put it, which is I have a, a neck injury. We don't know what caused it. Physiotherapist has told me that with necks and backs, we often don't know what originates the pain in them, they just start hurting. She has assured me that it's not serious, that really it's not an injury at all. There's nothing actually wrong with my neck. It just hurts. And the best thing to do for a neck that hurts, other than pain management, is at least in this case strengthening. So that's what we've been working on. And the other thing she warned me during that first visit was necks and backs tend to be pretty unpredictable, and so the healing for this would be less linear, less straightforward than with other

injuries. You know, I've, I've hurt joints before and usually there's a pretty, even if it takes a long time, there's a pretty straightforward movement through to, sort of, recovery. And she said with necks and backs that that's just not the case, so there were, there were likely to be setbacks in the healing process. And I had had a few setbacks. I've been dealing with us for a couple of months now, had had a few smaller scale setbacks, but last week, I think I slept on it weird and I woke up on Tuesday and it hurt more than usual, and the pain escalated throughout the day. I went to bed really thinking that I, that I'd sleep it off, that I'd wake up in the morning and I would feel better. And a couple of hours into sleeping, I woke up in what felt, at the time, like really overwhelming pain, pain that was, that was overwhelming enough that I had a pretty intense panic reaction to it because I didn't know why it hurt so much, or what to do about it, or how it could have gotten so much worse so quickly. And because it was one in the morning and I couldn't think of anyone I could call, I was alone. I texted some friends to see if they might still be up, but nobody was, and it didn't feel like enough of an emergency to justify waking somebody up. I just, I just knew that I felt really scared. Fortunately for me, I still had some codeine leftover from my wisdom tooth surgery and managed to get back to sleep, but woke up the next morning still in really debilitating pain. I managed to get myself to a walk-in clinic. It took me a really long time to get there because walking was really, really uncomfortable. And after an hour and a half wait at the walk-in clinic, a doctor asked me what was going on, I explained, and she said that there was nothing wrong. I was fine, keep going to physio and prescribed me some, some painkillers and some anti-inflammatories. And, and this is the moment that I've been, that I've been mulling over: this short interaction with this doctor. The speed with which she said, "there's nothing wrong with you, have some pain medication and go away." And all I wanted in that moment was for somebody to explain to me what was happening. I wanted somebody to say like, "this is why this feels the way that it does. You'll feel better soon." But instead I got drugs. And when she handed me the prescription, I just broke down. And I have got to tell you, I'm not a public crier. I am really not. And even in the limited public of like, me and a doctor, I don't know. It's, it's not my, my M.O. She was pretty unmoved, which is to say she told me to take my time getting myself together and left. And then I went next door to the pharmacy, continuing to cry, and let me tell you, they filled that prescription really quickly. There's nothing like crying in public to, to really escalate the speed of your customer service. I went to physiotherapy the morning after. My physiotherapist was, was much, much better about, about talking me through things and, sort of, I mean doing,

doing what she could to explain what was going on. But her explanation was the same one that she, she'd given me from the beginning, which is that there was nothing wrong with me, it was just pain. And in fact that because pain is not purely a nerve response, that pain is a really, really complex reaction to all kinds of things, including mental and emotional factors, that my pain when I woke up in the middle of the night was probably worse because I was panicking, because I didn't know what was wrong, because I was afraid that I had injured myself in some terrible way and would always be in pain. She also assured me that, that while it felt like a really significant setback that I would be feeling back to normal in a matter of days and she was right. And now what I have left is this experience that, that at the time felt so all-consuming, the experience of being inside that pain, that is also pretty fundamentally unrecalable. Which is to say that I remember that it happened. I remember the fact of it happening. I remember the events. I can't remember how it felt. I can't actually remember the physical pain. I can just remember my reaction to the physical pain and thus that the pain must have been real because I believe myself, and so I believe that what I was reacting to was actually happening. But everyone else around me was saying to me, very seriously, that nothing was happening, that it was, for better or for worse, all in my head. And that that experience, just that, that 48 hours, the kinds of interactions I had, the kinds of emotional responses that I had, had me thinking a lot about pain, about how pain affected my sense of time, my sense of self, how it felt to me like it was eating away at the edges of me. And I found myself wanting to, to think more and read more about pain.

Hannah (Host):

[08:54](#)

And as I started thinking more and reading more about pain, I realized, sort of, unbeknownst to me that there had been something else at work on me when I was having those reactions, those really panicked reactions. And I realized it in the process of, of doing some, some reading about pain. So, so there were a lots of, of aspects of this experience that I felt like I was already, sort of, equipped to think about. Like for example, the relationship between pain management and opioids, and drug prescriptions in general. You know, I thought about the fact that I could show up at a walk-in clinic and yeah, I had to wait, but ultimately they gave me prescriptions without question and that I'm certain has a lot to do with my class, my race, my presentation, despite the fact that my presentation at the time was, was highly emotional. That nonetheless I present myself as somebody who, who's not questioned in medical situations when I need help with pain. Whereas, extensive studies have shown that for example, Black women's pain tends to be disregarded in medical settings and Black women are

significantly less likely to be offered pain medication than white women are. You know, at the same time, that experience of having an emotional breakdown in a doctor's office reminded me of, of the history of, of women's hysteria and the way that women in general, our pain tends to be taken less seriously, it's often dismissed as hysterical overreaction. And my sense of, of humiliation in that moment at crying because I was in pain, was certainly wrapped up with that, that awareness of how, how likely my pain was to be dismissed. And that felt, even though my physiotherapist was, was trying to help me understand how my pain was working and what I could do to alleviate it. Her telling me it was all in my head powerfully evoked the history of women's pain being dismissed as hysteria. That narrative is, sort of, I think always there, when I think about whether or not my pain deserves to be taken seriously. But after I put out a call on Twitter for, for what people would recommend that I read and started working my way through this material, this really great material, I realized that there were other aspects of pain and of chronic pain and chronic illness that, that I hadn't been considering. You know, for one thing, I found that that things that I had experienced, during that that 48 hour period, had been beautifully expressed, beautifully articulated by people for whom this is much more a lived experience. People who have been grappling with and experiencing pain for a much longer time. For example, people recommended that I read a piece called "Pain Scale" by Eula Bliss, who at one point talks about both the intensity of isolation around pain. She writes "the reality that my nerves alone feel my pain is terrifying. I hate the knowledge that I am isolated in the skin alone with my pain and my own fallibility." And then she also, in the piece, talks about how difficult it is when we were appraising our own pain or diagnosing our own pain, how difficult it is for us to separate physical pain and our emotional reactions to it. And she uses the example of children really struggling to distinguish between the pain that they're in and things like, like fear or anxiety, which was, was ultimately exactly what my physiotherapist was trying to tell me. That, that in that moment, what's physical pain and what's anxiety at the idea of physical pain can become fundamentally inseparable. As I was reading through the various pieces people had recommended, there's one in particular that really, not only resonated with what I've been thinking, but actually transformed for me what I'd been thinking, and I want to pause here and note something about theory.

Hannah (Host):

[13:10](#)

The piece I'm about to talk about is a scholarly article, a quite theoretical article, theorizing pain from a disability studies perspective. And in reading it and feeling the deep comfort and simultaneous excitement at having something that I'd

experienced reframed for me in a way that helped it to make more sense, I was reminded of why it is that I love theoretical writing in general. For a lot of people, theory is a waste of time, or it seems like a waste of time because it's so disconnected from the real world. But I've always experienced theory really differently from that. I've always experienced theory as something that is deeply connected to the real world and that, that helps to frame and explain and make sense of the world, or to complicate the world in ways that ultimately do make it make more sense. Some of the earliest theory that I read was gender theory and it, it really helped me to understand my experiences of being a woman in the world in a way that I, that I hadn't previously. Theory for me, while it can be really a challenge to grapple with ultimately functions as a tool set to help to navigate really difficult situations, and this is a perfect for me, a perfect example. So, so the piece that I read is called "Recovering a Cripistemology of Pain" by Alyson Patsavas. It's got a great subtitle; ": Leaky Bodies, Connective Tissue, and Feeling Discourse." So the, the word there in the title, "Cripistemology of Pain," that's a a portmanteau that refers to crip studies, or the idea of crippling things, which is a, a term perhaps comparable to the idea of queer studies and queering things, but that emerges out of disability studies. So "crip" is a, a term that disabled people used to self identify. It is certainly not a word that able bodied people should ever use, but it's a word that, for example, I've been reading a lot in Leah Lakshmi Piepzna-Samarasinha work. They talk quite a lot though about crippling things, or about crip community. And so the idea of a cripistemology that this article is trying to articulate is, on the one hand, trying to draw on the wisdom that emerges from disability studies, which is believing and valuing knowledge that comes from experience. So in this case, valuing the kinds of knowledge of pain that come from people who have been in pain a lot and and recognizing that that provides forms of knowledge that people who haven't had that experience don't have. And the epistemology part is a reference to, to stand point theory, which is a really important form of feminist theory that essentially says that you can speak from your position and your perspective, but that there are limits to your knowledge that are a function of your position. So cripistemology both recognizes and values the knowledge that comes from experience while simultaneously recognizing that that knowledge has limits that need to be marked. You know that the fact for example, of having lived in your own pain, it doesn't mean you understand everybody else's or everybody else's disability. So Patsavas is talking about, in her words, "the cultural discourses that frame pain as an isolating, devastating experience. That," and this is still her words, "prevent the

exploration of alternative explanations for why chronic pain might be or seem to be unlivable" end quote. And so the argument that this article is making is that pain is not an objective experience, it's a culturally framed experience that we make sense of via the cultural scripts we have available to us, and that the current cultural scripts or discourses around pain say that it isolates you, that it ruins your life, that it is not livable. And Patsavas really wants to draw on the kinds of radical work coming out of disability studies and disability justice activist work to point out that, that in fact pain is livable for people within disabled communities, for people living with chronic pain. So she hearkens back to Elaine Scarry, who wrote some of the really foundational work on pain and conceived of pain as, as unsharable, so as this sort of deeply personal, non translatable experience, kind of what Eula Bliss says in "Pain Scale," and kind of how I felt in that, that panicked middle of the night moment, and pain as destroying language. But as Patsavas points out, there's actually a rich history of people writing about pain, which became very clear to me when I asked people for their favorite work on pain and tons of people had really incredible work to share with me. So Patsavas wants to challenge both that idea of pain as unspeakable, whereas destroying language, but also pain as unsharable, as isolating. She's thinking in the article about how much disability studies and disability justice focuses on interdependence, on this idea of building communities of care where people care for each other, and that the idea of us not as isolated subjects but as interdependent in these networks of care suggest that our experiences are also not isolated and unshareable, but that in fact there's a sort of fluidity. She uses the language of "fluidity," of "experiences between bodies," that we can in fact share our experiences with other people, or that our experiences bring us into to networks and relationships with other people in different ways, and not always in good ways. So the example she uses is of going to the doctor's office and of being a patient who recognizes the cultural history that you are bringing, for example, the history of women being locked up or thrown out for hysteria. Well, the doctor is also bringing their own personal history for example, of having seen thousands of people with pain and that, you know, in some ways that that leakiness of our understanding of pain, the way that those understandings have to do with, with relationships, and with histories, with personal narratives, and cultural narratives, that can lead to situations where we cannot communicate, where I can't tell you what my pain is. But at the same time, those personal histories and cultural narratives can also produce settings and relationships and opportunities where we can communicate what we're experiencing to each other and that

as a result become less isolated. And that that understanding of pain as fundamentally isolating, doesn't need to be true. And as I was reading this and really sort of thinking through what, what Patsavas was saying and how her thinking really challenged my sense of pain as having isolated me fully, I started also to think about, you know, what narratives were at work in that panic response that I had, in that sense 1) of, you know, almost immediately upon feeling this pain, of being convinced that it was forever, and 2) my sense of intense dismay at pain medication. And after spending some time with that article and spending some time thinking, I realized that a big part of the reaction that I'd had has to do with, with personal history, that I spent a really significant part of my childhood watching my mother who had breast cancer starting from when I was eight and died when I was 16. I spent a significant amount of those years watching her be in pain that could not be effectively treated at the pain that was caused by her cancer. There weren't medications that didn't make her sick that allowed her to still function that actually addressed the pain. And the last two years of her life she'd been diagnosed as terminally ill and the culture around her pain treatment suddenly changed because all of a sudden the doctors were saying, "actually, yes, you will be in pain for the rest of your life." And so they gave her unlimited access to painkillers. I had to text my dad to remind me what painkillers she was on because I had been reading another really great piece and excerpt from *The Opium Eater*, about the search for non-addictive pain management solutions, and I was curious if you remembered what my mom had been on and he did and I'm sure that was a thrilling text to receive. But she was, both Dilaudid and then fentanyl patches, which he's reminded me she had unlimited access to because no one was worried about ever having to wean her off them or about how addictive they were. In the moment being told by a medical professional that my pain felt worse because of my emotional reaction to it felt really undermining; it felt like my pain wasn't being taken seriously. But after reading this article and thinking about how powerfully the stories we tell ourselves a better experiences shape how we actually experience them, it became really clear to me how much my experience, in that moment, was shaped by personal histories, and how much my fear and sense of isolation were also shaped by how much those personal histories have felt unshareable and unspeakable in the same way that pain often feels unshareable and unspeakable. Especially chronic pain, especially pain that doesn't have a cleaner, straightforward reason behind it. The reading I've been doing over the past week is, for me, just beginning to scratch the surface of disability studies work and disability justice work, and I've been finding it really transformative, incredibly exciting

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work that is really shifting how I think about my body and my body's relationship to my communities, and my body's relationship to my own histories, about the link between pain and trauma, about notions of the able body as the, sort of, isolated an impermeable object and how that that cuts us off from communities of care. So I'm going to obviously give you a reading list of all of the stuff that I read and all of the stuff that was recommended to me in the show notes. If there's more work that you're aware of that you think, sort of, resonates with this, I would love to hear about it. And I hope you do go and take a look at some of this work and maybe that it, that it resonates for you as well. [Music: "Mesh Shirt" by Mom Jeans] All right. You know what time it is. It is time to hear from Kaarina. [Music: "I Will" by Mitski]

Kaarina:

[25:09](#)

Hello and welcome to Kaarina's Cozy Self Care Corner. Today I am enjoying the sun that I've been experiencing in my city. It's so nice. And I also been finally getting into owning plants and not letting them die. This is a big development in my life. I have six plants on the go right now, two in my office and four in my house. And they're just, you know, growing and stuff and I just like looking at them and seeing what they're up to and taking care of them. And it made me think lately, I really need to treat myself like I'm a plant. [Laughs] I really need sunlight and water. And when I neglect those two things, I feel pretty bad. So if be you are also experiencing the reappearance of sun and warmth in your town/city/homeplace then, here's my little, suggestion: treat yourself like a plant. Make sure you stay watered and, make sure you get that sunlight and, and to let yourself grow a little have a good weekend, my leafy friends. Bye [Music: "I Will" by Mitski]

Hannah (Host):

[26:37](#)

As always, you can find show notes and the rest of the episodes of *Secret Feminist Agenda* on [secretfeministagenda.com](http://secretfeministagenda.com). You can follow me on Twitter @hkpmcgregor. You can follow Kaarina @kaarinasaurus and you can tweet about the podcast using the hashtag #secretfeministagenda. And you can always rate and review the show. It is the best way to help other people find it. There's a new review this week from Iced 1824 who as that name, my indicate to you is from Canada. The podcast's theme song is Mesh Shirt by Mom Jeans off their album Chub Rub. You can download the entire album on [freemusicarchive.org](http://freemusicarchive.org) or follow them on Facebook. Kaarina's theme song is "I Will" by Mitski. *Secret Feminist Agenda* is recorded on the traditional and unceded territory of the Musqueam, Squamish, and Tsleil-Waututh first nations where I'm grateful to live and work. This has been *Secret Feminist Agenda*. Pass it on. [Music: "Mesh Shirt" by Mom Jeans]