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Transcript

(References included below)

Anna Veprinska [AV]: Because I'm using poetry to process difficult emotions and to process the emotion, like the realization that somebody can make a sound and that can hurt my body.

[Music: Ascending, bright, twinkly, uplifting, electronic]

Emilia Nielsen [EN]: This is *On Being Ill,* a show about creativity, disability and identity. I'm your host, Emilia Nielsen.

[Music rises then fades]

Today I'm excited to share a conversation I had with poet and scholar Dr. Anna Veprinska. Anna and I talked about the role that noise pollution plays on all living beings, why we need to take a more robust approach to accessibility, and about how poetry can offer a *little* quiet place to process all the *big* things going on around us.

And just a quick note before we get started: I had the privilege of sitting down with Anna in person, so you might find that the sound quality of this episode is different from our other episodes. This is the beauty and limitations of handheld recorders and those differences are indeed audible. Alright, let's get into it. I started our conversation by asking Anna to introduce herself.

AV: My name is Anna Veprinska. I'm a poet and a scholar, and many identities that I have change, but those seem to remain pretty stable. I teach here at the University of Calgary, where we're speaking from today, which is on the traditional territory of the people of the treaty seven region in southern Alberta. And I live with chronic pain, which unfortunately, doesn't seem to change, but does shift and alter. I'm a person who carries a pen with me everywhere I go, and I think those are the things that remain pretty stable. And I have, also, the privilege to teach creative writing in English here at the University of Calgary.

EN: Amazing. Thank you so much for meeting with me in person, maybe to get right into it, in thinking about your constant identities, the things that remain true as both a scholar and poet – someone who always carries a pen, I love that – I have to say, reading your book, *Bonememory*, I got the chance to read it as a manuscript, and it's going to be out spring 2025, with the University of Calgary press…that has this great series called Brave and Brilliant, which I love… sitting with your manuscript – soon to be book – was a really sort of totalizing experience for me. It was a very deeply immersive experience. And I shared with you that, you know, some of the little moments of many that stood out to me was, you know, encountering this girl on the page who can no longer remember to smile, in this highly orchestrated family portrait setting. And then moving to a woman who cannot feel pain, someone from the news. And then we have our central speaker of this book who is enduring a combination of psychological, even spiritual pain. But at the same time, we have the speaker who's a very attentive observer of the world, who's caring for, and I think even wishing for a better world, in this world that right now is quite wounded. And so I was just curious about how this project – which is also a book – *Bonememory*, came to be? What is its origin story, or its threaded origin stories? I'm sure there's…there's more than one, as with most projects.

AV: Thank you for paying such deep attention to the work. First of all, Emilia. It's a deeply personal collection of poems, and I'm so glad to be working with the University of Calgary press. It has been a real pleasure. And the book looks back, as you already touched on, at my childhood, that moment where I forgot how to smile, the kind of fabricated ways in which we interact with the world. Also about my family's immigration to Canada from Ukraine. But also it's a book that is looking, I hope, unflinchingly at the present both – my presence, so looking at my chronic pain, at the profound ways that my research on the Holocaust has affected me, but also the present moment in which we all live. So settler colonialism, the war in Ukraine, the COVID pandemic, and the sometimes devastating woundedness of being a human being. So the origin story of this book really comes from the title, bone and memory. And the book is divided into two main sections, bone and memory, with a small interlude in between. So thinking about the ways my bones have moved through the world, whether it's through illness or otherwise, and also thinking about personal, collective, and intergenerational memory informing the book. That's kind of the conceptual origin, the more mundane origin, kind of how I got to writing the book is that between 2020 and 2022 I was doing a postdoctorate at the University of Toronto, and I was…my project was watching and listening to audio/visual Holocaust testimonies and also writing poems in response to the testimonies. So it was very much a research creation project. And I think as a way, as a way to kind of extract myself from that really deeply difficult work, I began to just write for about 30 minutes a day on whatever I wanted. And the poems kind of were birthed from that time. And they were really touched by these really traumatic and difficult memories that I was encountering. And so yeah, the book came out of that, and I'm very grateful for that postdoc to have that time, to not only explore the research project that I was doing, but to also exit that project, to explore something else that's really not unrelated to that work.

EN: That's…thanks for letting us into the process. I mean, that's such a concern for me. I mean, it's an interest, to think about how when we're practicing research creation or engaging in it, that it is this connectedness between the scholarly research and the creative practice. Ideally not as two separate things, but two inextricable things. And it's interesting to me that your response, in part, to sitting with and being witness to this very difficult oral and visual testimony, that you turn to the page through poetry. Which makes a lot of sense. And maybe that's also for me in reading the book, strangely, the experience too, and kind of an affective level, was that there was this weightiness in the book, as you say, speaking to your own personal history, but also doing justice to the history of others. But then also this hopefulness as a kind of counterbalance, despite this deep woundedness that you as a poet are observing and taking to the page to also document. I'd love to ask you to read a couple of poems from the book, which will really kind of ground, I think, for our listeners, more concretely what the book is. But I was thinking about the neologism of Bonememory, and your insistence that these two words are together, and then, as you describe in the book, they're also separated. I'm just curious about that…the both, right? The and. Like these bone memories together as a new word, and it's also going to be presented in the manuscript, separated with this interlude in between. Do you remember why you decided to do that?

AV: I think I've been really influenced by the poet Paul Celan, who I've only read in English translation – he wrote in German, was a post Holocaust poet. And neologisms are kind of like his signature, and ever since I read him when I was maybe about 20 years old, I've just gravitated towards that kind of refreshing of language and that kind of newness of what happens when we have these words and then we recombine them, and what does that do to the meaning of them? And I think just experiencing illness and seeing, like, my body come up against these things that maybe I never thought about or expected, is also kind of a newness of the body and so bone and memory together and separate…in ways, sometimes I want to separate them because I don't want the memories – like the traumatic memories, the difficult memories – to affect my bones, to affect my body. But at the same time they're really inextricable. So that…I think that tension between the two is where that title came from. Thank you for that question, because I don't think I've been asked that before.

EN: No? Well, I mean, thank you for your answer. That makes sense: the insistence on the inseparability, and the wanting of the parsing apart of those two things. Could you read a couple of selections from one or two or whatever you choose, and maybe set up the poems as much as they might need to for our listeners, in terms of what they might need to know going into the poem?

AV: Yes. So I brought in one poem. It's a bit longer, so I decided on one, and it's actually the one…you helped me decide on this with your other question about the woman who cannot feel pain, and I thought it would be an appropriate one to read. So this poem, it's called “The New York Times Reports Woman Who Feels No Pain.” And it's a poem about an article I read years ago about this woman's…the condition is called congenital insensitivity to pain, and it's very rare. It's, I think, one in 125 million people. And it's actually very dangerous, because, you know, as we know, cognitively, we need pain for survival, but when you experience chronic pain, that cognitive knowledge gets diluted to like a frustration at that pain. And so the poem is very much about how reading about this woman who feels no pain, I kind of imagined, what if I don't feel pain, and what would that look like? And at the same time, I was coming to terms – in this poem, and I think it really happened in the writing of this poem – that just because someone else's story looks so different from yours, and they physically cannot feel pain, does not mean that they don't experience suffering. And I think coming to terms with that was really an important part of writing this poem. So I'll read it now: “The New York Times Reports Woman Who Feels No Pain”:

I am throbbing with envy
because she is seventy-one and has steered
her life through the snug grooves of ache-absence
sculpted by a mutated gene. Sure, she doesn’t sense
blood oozing from a cut or fingers burning
when removing baked potatoes from the oven. Sure,
these insensitivities tender their own dose
of danger. Sure, pain serves a purpose. Meanwhile

my abundantly-toothed pain gnaws
at my body like a famished god, announces
its chronic presence the way a guest who intends
to stay might announce the need for more linen, chortles
as I shift from here to there to accommodate
the burning in my colon, my eyes,
my knees, these serrated migraines. Earth-sensitive
bones, sticky with hurt. What is this bullshit

about experiencing life fully, pain and all? What kind
of naïve Red Riding Hood do you take me for? About
nine months into the year 2020 in the Gregorian calendar –
that bully of almanacs – the Ge’ez calendar marked
the beginning of the year 2013. How much
I could recover if I retraced my steps to 2013, tiptoeing
backward on an unbruising gradient until pain squatted
hushed in margins, an unborn babe: docile, toothless. Years ago

my father told me ow was my most uttered word,
courting pain like a clumsy nightingale. I wonder:
does the woman who feels no pain ever howl
ow? What syllabic gatherings of grievance
break from her lips? What could I know, really,
of the underbelly of her suffering? The same
each of us knows of each. Shadows, shadow.

EN: Thank you for that. Oh, that line about “ow” as your most repeated word, really kind of does something when you hear that, because you imagine a child right through the course of life, this being a reoccurring exclamation that is only like an approximation of pain's hold, I can imagine. I haven't lived with chronic pain. I've lived with chronic pain – I no longer live with chronic pain, is actually more of an accurate description. And I remember when that pain was gone. I felt its absence, and I didn't know what was wrong at first. And I'm just someone that happened to have a surgical intervention, that worked, that relieved, and I know so many people that it's not…that's not their story, and that's not a possibility. But I sometimes, when I move in my body, I sometimes go, there's something wrong, because the pain is not there, because it was such a constant companion. And yet it's not visible to others, and so it requires this kind of self assertion, a sort of self advocacy. And I'm thinking about something that you said after your recent talk about those pain scales, you know that they're really difficult and troubling, and that you were describing that you found them challenging to answer. Why do you think that's the case? It's a common refrain for folks that live with chronic pain, especially, and find themselves in need of medical intervention or support, that the pain scale always seems like a bit of a farce – with the little cartoon characters that you're supposed to identify with. But yet one does endure and go on in all of its cartoonish-like horror, right? Like it's not an option to not. And so what is it about the pain scale? And I'm thinking about two medical practitioners that sometimes go, what can I do differently then?

AV: I think the idea of, like – it's such a good question – I think the idea of quantifying pain is very, I think, foreign to me as somebody who just…like it's never at a zero. And other than zero and maybe 10, I don't really understand what happens in between. There's a kind of coldness to this quantifying, and I've had eye pain that's been like with me for like, the past five years now. And I remember I went to see a new ophthalmologist here in Calgary recently. I mean, he's trying to help me, so this is great. But when he asked me, what is the level of your pain, and I said, “suicidal level,” and he said, “Okay, so what is that on a scale of 1 to 10?”

EN: No, no. Oh, no!

AV: Yeah. And so I think there's a kind of, like…we want to understand, and I think, honestly, I haven't thought about this before, but my work on empathy, and the kind of concepts I theorized in the monograph I wrote on empathy, really touches on this, like wanting to express your experience and wanting others to understand, but at the same time knowing that nobody really can climb into your body and know what it feels like. And words fall short already, but numbers fall even shorter.

[Music: Quick, light, percussion, descending keyboard, minor tones, chill]

EN: You recently gave a talk at the University of Calgary, where we are right now entitled “Listening as Pain and Necessity: Hyperacusis, Noise Pollution and Auditory Accessibility.” Did I say hyperacusis correctly?

AV: You did.

EN: Yes? Ok…as the Wayne O. McCready Emerging Fellow at the Calgary Institute for the Humanities. And I got to watch a recording of that talk, it was just recently, a few weeks ago. But if I understand correctly, this talk and what you were sharing there, which was a hybrid talk, in the sense of we were reading poetry and also reflecting on the process of writing, your creative practice, but also incorporating your research under these topics: hyperacusis, noise pollution, auditory accessibility. And it seems to be gesturing towards perhaps a new avenue of research and creative activity for you, where you are really stepping in and exploring auditory pain, listening as method, and then poetry as a response, where everything is quite purposefully entangled. And so I was just wondering if you could first tell us a little bit more about what you're exploring here in this project, or how this came to be. Again, we love the backstory on this podcast, because it's so interesting for, I think, for all of us as creative people, and many of us as scholars and interested publics, how these projects come to be. And some are more rooted in experiential knowledge, and others aren't. This one, I think, though, is rooted in the experiential. I know that from listening to your talk.

AV: Yes. Thank you for that question. So I do want to preface by saying that most of my scholarly work has been in memory studies, affect studies, Holocaust studies, and so disability studies – this is, like, very new foray for me, and so I'm looking forward to learning more from scholars like you, Emilia. But at the heart of the project is really this tension between my accessibility driven reliance on listening, but at the same time my reduced tolerance to noise. So in 2023 I experienced an acoustically traumatic event, which should have been just like an everyday event, and just affected me in a way that, like, I felt physical pain in my ears, and since then, I've become extra sensitive to noise. And so I feel physical pain from things like accelerating cars or sirens or construction work, or even things like rattling dishes or too loud music or too loud crowds. And the condition, I later learned is called hyperacusis – so your heightened sense for sound. And so that is like one half of the project. And the other half is that a few years before that, as I've already mentioned, I developed this eye pain, and it makes any concentrated activity challenging, and that includes things like screens. So I've been using audio accommodations when I can, not always possible, but when I can through things like text to speech or audio books. And so there's this tension, I find, between these intersecting disabilities, really. You know, on one hand, I rely on listening, and on the other, listening is the thing that hurts me. And so that's kind of where this project was born, from this very, like, experiential knowledge, as you mentioned. And poetry seems to be my avenue into anything, and that's just part of my own sensibility. But poetry is also a very quiet art for me, and it's a place where I can go to quietly process whatever I need to. And so there's this kind of quietness that it provides. But also the poetry I'm writing is really attuned to voices of others, and so I conceptualize it as, this term that Lauren Fournier really theorized – “autotheory.” And so thinking about these personal experiences through the voices of others as well. So each poem also includes voices from disability studies, acoustic ecology, etc. And so that's…that's the origin story of the project. And I think the idea for it didn't even come up until less than a year ago, because I very much was invested in doing the testimony work. And then when all of this came up, about a year ago, with the ears and…I mean, the eye stuff is very difficult for me to write about, so it's almost like a sideways way to think about it, through listening, but it interrupted not just my life, but also my work in the sense of it. It felt like this was the work I needed to do, and I feel lucky that I have the opportunity at the Calgary Institute for the Humanities to pursue that work.

EN: It's great to hear them supporting work that's like disability-adjacent or gesturing towards or might be more deeply involved with, because, of course, the double-bind, but also the reality that you are not alone in needing auditory and visual accommodation and tools. And that these tools are imperfect, and you were describing in the talk that when you first were exploring and needing speech-to-text software so that you could have articles read…and you describe, you know, they're not always read correctly, right? So you have to…you have to be very patient with the software, as it does not pronounce words or even get the word correctly. But when that is gone, or that becomes…the listening becomes a necessity, but a source of pain – where does one go and how does one adjust? And remembering, like, you know that at the core of critical disability studies, or thinking about disability and accessibility and accommodation is that there is no one size fits all. And the reality is – and I think one of the things that disability studies does so well is point out – there is no one singular natural body. There is no one normative way of working and learning. Now there's a whole infrastructure that would like to argue that there's a standard to which we all should be comparing ourselves, and there's a standard that's the norm. But I think about the great variety of ways in which we as scholars or artists, we do our work, the different kinds of physical spaces we use, the ways we use our bodies, the ways that we even are reminded that we misuse our eyes, while reading and and, and... we get reminders from our bodies about that. But the…the fluctuation, the profound fluctuation that you're experiencing does seem to be just a really challenging double-bind as a scholar. And it's something that you are beautifully navigating through poetry and sharing, I think, with us, not just the difficulty, though, but some of the kind of strange humour of your predicament, right? The Gwyneth Paltrow AI generated voice, badly pronouncing words and getting it all wrong as she/it tries to, of all things, read Virginia Woolf's foundational essay "On Being Ill" – something that we certainly love here on the podcast. It was one of the origin stories to why this podcast is called *On Being Ill*. But also I was, you know, reflecting on how you give voice to the destruction living with higher than safe noise levels has, not just on human species, but I think you said wonderfully – more than human species, so non-human animals. That we're all putting up with, allowing for, noise that's actually not safe or good for anyone when it comes to some of those decibels that cars go now, construction noise – this will have a profound effect on people's hearing, if not in the short term, perhaps in the long term, and it's actually affecting where animals will or will not choose to live with us or in proximity to us. And I found that really powerful to think about, and even just think about when I see, you know, neighborhood construction noise go up, and I go, Okay, well, the songbirds probably won't be here right now, and maybe the coyotes won't be back. And you even describe that affects the plantosphere, that even plants are profoundly affected by our industrial noise.

AV: Yeah, it's pretty interesting. Like this…this work – I had no idea, and I think we don't usually think of noise as affecting our health – but doing this work has made me realize, like, what a profound effect it does have on our health. And even if you're, for example, sleeping, and you…there's a siren that passes by and you don't wake up, your blood pressure still spikes. And so if you think about something like that, you think about the ways that our bodies are being affected in these kind of invisible ways. They're heard, but they're not seen. And the World Health Organization says that noise is the second largest environmental cause of health problems after air pollution, right? But we don't really talk about it.

[Music: Upbeat fast-paced keyboard sounds ascending and descending, slow melodic wind instrument, resolves in a calming tone]

EN: As you think about this project, and I love the entanglement of…interconnectedness, really, of noise pollution, the experiential body accessibility – I'm wondering how you think it might…your future work, or where you're at right now might engage with some of these larger questions around critical disability studies, or even disability justice? I say this because, you know, if the World Health Organization is framing noise pollution is the number two, you know, cause for concern around human health, right behind air pollution, it feels like you know Disability Justice is justice for more than humans, right? It's justice for non-human animals and plants too. If we're thinking about the connection between the environment, or what we call the environment, and the human body. I'm just curious about like ways, maybe that theoretical terrain is coming into your consciousness or where you think it might go? I mean, I'm not asking you to be a soothsayer into the future, but the things that you know you want to explore in that…in that realm.

AV: Yeah. So again, very, very new terrain for me, but definitely thinking about intersecting disabilities. Thinking about the ways that sometimes, like, in my case, they can really like work in opposing directions. What do we do when that happens? I really like what you said about how disability justice isn't just about humans, but also about animals, plants, our larger ecological world. And so I think thinking about those things has been really a privilege, as well as something really difficult to think about the ways we're impacting…Like, one of the poems I read in the talk was about a blue whale, and thinking about whales and how, really marine animals rely on sound, and how we are disrupting that sound and causing things like decompression sickness, death, other things, with just like sonar, with our loud vessels. And so yeah, it's very painful to kind of learn the effects that we're having just with noise. And there's something that…there are these two scholars I quoted in that talk, Karen Dali and Leah K. Brochu. And they talk about how – and I think this goes towards the Disability Justice question – they talk about how this availability of audio learning, whether it's audio books or text-to-speech, should just be seen as an issue of diversity and inclusion that isn't only about people with disabilities, but also just anybody who just has a preference for audio learning. And I think addressing, and I think this goes to the social model of disability, and thinking about, like the systemic ableism in our structures, ways of learning, etc…And I think just opening up to that. I wrote some years ago, actually, I wrote an article with a friend, and it was about audiobooks and accessibility in academia. And thinking about how, you know, you can find a lot of fiction as audio books these days, and audiobooks like, we're very lucky, because audiobooks have, like, shot up in popularity and shot up in the amount of production. But it's very hard to find audio articles. So when you're in academia, you're relying on systems like speechify, for example, which is a text-to-speech system that I listen to, or even Microsoft Word has a built-in text to speech, but it sounds robotic. And that's something I find a lot, that robotic voice, and what that does to your learning to engage with a robot.

EN: Yeah, not a very good robot. Oh, I, yes, I love that article too. It made me think about that that, you know...I'm quite new to audiobooks. I've always loved radio, and then when podcasts became a thing, I really loved that. And I love the kind of conversations that were like…that you could have, you know…there could be a pop culture conversation, if that's what you were into listening to, but you could also listen to, like, something like *Ideas* on CBC Radio where, you know…a much more involved kind of learned conversation. And a friend had said, a friend that experienced acute eye pain and recovery was saying, Oh, I could only listen to audio books, but really, all that was available to your point was fiction. And I remember I said, when I was a PhD student, this would be a good 15 years ago, and I was experiencing photophobia, so extreme light sensitivity, which I also experienced from the screen and eye pain and discomfort. And I've had a couple of corrective surgeries which have helped with some of that. But at that time, it was quite acute, and I remember going to the campus accessibility office and describing this, and they were like, "We want to help you, but we're not quite sure how to help you." And it was because at that time I was done my comprehensive exams, but I was engaging in my PhD research, and I was describing exactly like you're saying, what I needed help with. And they were sort of like, “You should try it out, but again, you're going to have a kind of robotic voice read to you, it's not going to necessarily know how to pause – like the difference between a period and a comma.” And it really just makes me think about how for some of us, like yourself, – publishing…a well published academic – that part of our knowledge mobilization work could be to read in our own words, some of our own academic articles. Who would have thought right? But to think about that as being a project…that maybe it should become commonplace, because we're always challenged to think about knowledge mobilization and different ways of reaching different communities and outside of, you know, traditional scholarly publishing. Well, we haven't even got there for accessibility for traditional scholarly publishing, if we're only offering the printed monograph. And now we're starting to offer the e-book, but to think about other ways in…So I love that. Maybe we have a collaboration in the future. To think about getting university presses on board with that.

AV: I think that's wonderful, actually. And I think one of the important things when we wrote that article on audiobooks was to record it as an audio article, because that was so inherent to what we were doing…

EN: How could you not?

AV: And the work that will come out of this talk that I did, like these new poems that I'm writing in response to the auditory pain, but also auditory necessity, will be in, like, a collection of poems, but also I intend to have it as an audiobook as well. And I think poetry is very interesting with audio books. Often it's not a machine that can read that.

EN: No, well, I mean, exactly, and it's amazing. I was approached by a feminist translation group out of Poland, and they had asked to translate a couple of my poems from *Body Work*, which they did. I said, “Yes, of course. Go ahead. Try.” You know. And one of the things that was amazing is that when it was published in Pismo, which is a great Polish publication, they also hired an actor to read the poem in translation, in Polish. And you know, an actor can do that work and understands that poetry in not to be read by a robot, but that…but everything, including the line breaks, the caesuras, the punctuation, the way the line…the way the poem, the lines appear the page, the way the poem appears on the page, is so important. And trying to approximate that through… through the performance, through the voice, is so important. We should connect, then, to work that you have that is not new, which is, of course, the work that you've been doing for some time now, and culminating in this great book that came out in 2020. Which to me, feels like yesterday. Now I'm realizing was just a few years ago, but *Empathy in Contemporary Poetry After Crisis*, which came out with Palgrave Macmillan. I'm curious, this book, as you described, is focusing on memory studies, affect, Holocaust Holocaust studies – how any of that work is connecting to the work you're doing now, because there's always those threads, and sometimes they're invisible threads, or they're only apparent to ourselves, or someone points them out, but it seems to me that there would be these threads of connection to that work that you've sat with for some time, both in your PhD and in your postdoc, and then the work that you're doing now.

AV: It's such a great question, because it's not one I've considered. I really see this as a new departure in my research. But of course, there are connections. To speak to the monograph briefly…in that monograph, I looked at how empathy manifests in poetry after three different crises: the Holocaust, 911, and Hurricane Katrina. And I theorized this concept I termed "empathetic dissonance," and that concept I defined as this tension in these poems after these crises, to both invite empathy, to both want understanding from people, especially those who hadn't experienced these like, really, like limit experiences, but also this rejection of empathy, like you can't really understand, and I found that working in all these crises literatures. And so one of the things that I talked about with empathetic dissonance is it really shows this distrust of empathy in these poems, this distrust of somebody else coming in and being able to feel whatever this person, who's really – and I call these these events at the limits of empathy – because they are so hard, and it's just extremely difficult to be able to feel into, as empathy needs. And so…so that was…that was that work, and I was really invested in that work, but at the same time it was – and I felt it was really a part of me in some ways, but at the same time it was really separate from me. And so I think it's, it's not that surprising that I turned to a personal crisis, right? So it's no longer this kind of collective crisis that I was studying. It's more a personal crisis. And so I returned to crisis and to memory studies, but with the lens turned inward. So looking at myself and in terms of affect studies, which really is so much a part of this work as well, right with empathy, I think now I'm looking at different affects, although I feel like letting go of empathy has always been really hard for me, as like slippery and as complicated as that concept is, because it's not just an ethical approach to others. But in this new work on sound, there's a lot of look at kind of shock, the shock of like being in this new body with these new reactions to the world: sensorially, frustration, despair – all the fun emotions [laughing].

EN: Yes! [laughing]

AV: Yeah, and how those come up through the intersecting disabilities. So I think, um, even though in some ways this work is new, it's also like harkening back to this crisis and trauma work. And also in my postdoc, when I listened to these testimonies of Holocaust survivors and wrote my own poems in response, I think I used that project to really process a lot of the difficult emotions I was feeling, and I think I'm using that same approach in this new work, because I'm using poetry to process difficult emotions and to process the emotion, like the realization that somebody can make a sound and that can hurt my body with like, no control over it. And the realization that I rely on text to speech software that is often faulty and is just like this, like shadow of reading, right? And when it touches something you love, like what you love most, reading and writing. And that's the thing that now brings you pain. It's a very…yeah, there are, there's a lot of affect in the work I'm doing. And so same, but different, like these different pathways into crisis, memory studies, affect studies, trauma studies.

EN: That makes a lot of sense, and that particular unfairness of…and I think it's okay to give voice to the particular cruelty of pain from something you love, right? The pain…the thing that would give pleasure: the reading, the visual engagement, suddenly or all at once or in a moment, becoming kind of surrounded by pain. I think too, I was thinking about the empathetic dissonance, as you described so well in your monograph, and thinking about that dissonance of the clinical encounter we were talking about earlier and the pain scale and so many people that enter those spaces, as we do in our clinical encounters with doctors, wanting, we think, something like empathy or at least wanting understanding. We don't want to be rejected. We want…we require understanding. We require a kind of witnessing, and we also go in knowing that they're not going to get it. Like too much that ableism is threaded through medicine so much that something that can't be diagnosed and then treated really quickly kind of gets pushed to the periphery of the not knowing, and then the encounter with the doctor can become very difficult as we try to explain more, and then the divide sort of starts to grow, and we can sort of go "Agh, they'll never get it," right? That even the best-meaning, the most well-meaning doctor, the most empathetic, the one with the best bedside manner, when pushed to their limits of understanding, will kind of retreat to to medical knowledge, rather than, perhaps the experiential knowledge right in front of them, the person right in front of them, with the body in pain and telling their stories. There's a kind of, perhaps connection, the empathetic dissonance, as you spoke about in your talk, with compassion fatigue. You know that these are very real things, and we might not wish them to be so, but that doesn't get at the work actually that compassion fatigue is doing. It's presencing something that's wrong. It's presencing that something that's difficult for healthcare workers, or emotional fatigue that we experience perhaps, in working with difficult material, even if we think we shouldn't say, "Who am I to complain? I have it so much better." It doesn't make it go away.

AV: Oh, truly. And I think at the same time, as you know, that example of the doctor with the pain scale that I gave, at the same time that it's like very difficult to have that kind of response to something very painful. At the same time, I can't, you know, blame anybody for for having that response, because I just think like, if doctors had so much empathy, you know, if they didn't have a limit to their empathy, if they didn't take care of themselves, right, there would be even more burnout than there is. It would just be impossible work. Yeah, because we go to doctors and we seek medical intervention or help, but also we do sometimes seek that understanding. And I think that, you know, in some ways, rightfully, in some ways, maybe, you know, maybe there's some good balance. I mean, Leslie Jamison in *The Empathy Exams* is so great talking about that. But, yeah, it's a…I think it's a balance. And I think it's as much as, like it was a difficult experience, I can also empathize with the experience of the doctor and thinking about how…what do you say to that?

EN: They heard it, and then were like, "Must translate into a response," right? Yeah. Is there anything that we haven't talked about yet that you'd like to speak to?

AV: I wanted to say one other thing.

EN: Great.

AV: Thinking about the kinds of disclosure that creative writing might ask for, and talking specifically like about creative nonfiction and poetry, because I don't think fiction really falls into this category. But I know that one of the lessons I always try to impart to my creative writing students when they're writing, is that specificity is key to immersion, and so if we're specific in our writing, you know, we give specific details, we give the imagery, we visually imagine – visually, auditorily, tactilely – imagine the world that they're creating for the reader, that will be what immerses the reader. And so I've been thinking about that in conversation with writing about illness and how much of ourselves does that writing require us or ask us to reveal?

EN: Yeah.

AV: Like, for example, I've been much more open about my chronic illnesses in my writing about illness than I've been anywhere else in my life, really. And so…and maybe I can do it more easily in writing, because the audience is only imagined. And sometimes, like, despite what I tell my students, not even imagined, you know, just like writing. And I wondered maybe you had some thoughts on that, but just the disclosure that creative writing asks for.

EN: It's something I've thought about a lot as well, because we don't owe anyone the specifics of our diagnosis or our conditions. We don't have to sort of play into the biomedical game, you know, in the sense that there's a specificity of that latinate biomedical language that can pin us to a diagnosis. But I've really, like wrestled with, like you say, being very specific about the certain details and certain affects and certain ways that my experience is translated through poetry, but also maintaining space around that actual diagnosis and treatment. And I often tell my students – and I don't teach in a creative writing program – I teach in a very interdisciplinary Health and Society Program, and so they often are doing arts-based projects. I always say, “Keep one thing just for yourself,” like one detail, especially of a difficult or traumatic experience, even if you feel like you want to share a lot on the page, that this is the right time, this is the right audience. I always say, “Keep one thing that only you know” and it doesn't…it could be something very incidental or could be something very formative, but writing about experience does change it, and it even changes our memory of it. You know? So it's like I'm both, like, encouraging, but cautious to a certain extent.

AV: Completely, and what you say about keeping something to yourself really resonates with me. There's an essay I wrote, a creative nonfiction essay about illness and about my kind of lifelong struggle with it from like when I was a baby and I was born not too much…too long after Chernobyl, and so it was, it's about that, and moving like into chronic illness in the present moment. And I submitted that essay for a contest, and it was shortlisted, which was great, but I was like, kind of happy when it didn't win, because I'm terrified of having that published. And I haven't sent it out since because I'm a bit terrified, because it is so full of just exposure and these details that I think I've only kept to myself and it's on the page and there…there's a part of me that wants it out there and there's, I think a bigger part of me right now that doesn't.

[Music: Ascending, bright, twinkly, uplifting, electronic]

Our guest today was Dr. Anna Veprinska. You can follow Anna on Instagram and X @SplitEndedPoem

On Being Ill is researched, recorded, and produced by a team of White Settlers on the traditional, unceded and treaty lands of Indigenous Peoples across North America, specifically in Canada and the United States. We recognize that this land acknowledgement is limited in what it can accomplish, and yet still feel it's important to name the violent ongoing colonial context in which we do this work—on lands historically and presently caretaken and stewarded by Indigenous Peoples. Here at OBI, we aim to unsettle deeply rooted beliefs around ability and disability that have entwined origins and implications in colonial thinking and actions—we invite you to join us on that journey, and if this connection is new for you, we invite you to learn more on our website.

This show is produced by Emily Blyth and Coco Nielsen, and executive produced by me – Emilia Nielsen.

Prince Shima creates all of the music you hear on our show. You can find him on bandcamp at @PrinceShima.

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And be sure to check out our brand-new project, CreativeEntanglementCollaboratory.ca where you'll find this podcast and much more. The Creative Entanglement Collaboratory is a collective who works across creative activity and critical scholarship with academic affiliations at York University, Simon Fraser University, and Emily Carr University of Art and Design.

And if you'd like to get in touch with us, please write to OnBeingIllPodcast@gmail.com. We'd love to hear from you. Until next time, let's create, converse, and crip the system together!

[Music rises in crescendo then fades out]

[End of transcript]

References

Fournier, L. (2022). *Autotheory as Feminist Practice in Art, Writing, and Criticism*. MIT Press.

Jamison, L. (2015). *The Empathy Exams: Essays*. Granta.

Veprinska, A. (2025). *Bonememory*. University of Calgary Press.