

cognitive-conversations-2-under-the-microscope-art-and-science-as-intervention

Bianca

Welcome to the Science Write Now podcast. Science Write Now is a free online magazine featuring essays, fiction, poetry and artwork by Australian writers, scientists and artists. Check out our current edition, the Underground, if you haven't already. If you're listening to this episode in future, be sure to follow our Substack and socials for updates. This week on the podcast, we're bringing you another instalment in the Cognitive Conversation series, where we tackle the big questions in creativity and neuroscience. These conversations delve into the creative process, brain science, the medical humanities, narrative medicine and other cutting-edge topics, and each episode, you'll hear from a range of experts across the arts and sciences. Please join me now for the next episode of Cognitive Conversations under the Art and Science as Intervention.

I'm your host, Bianca Milroy, an emerging science writer, editor and PhD student based in British Brisbane Meanjin on the beautiful Mewar River, and I'd like to acknowledge the Yuggera and Turrbal people and pay my deep respects to elders past and present. I'd also like to extend that acknowledgement of the traditional owners of the lands on which my guests live, write and create.

We have a fabulous lineup for you today. Firstly, I'd like to introduce Dr. Katharina Bryant. Katharina is a writer based on Kaurna land in Adelaide. Her first book, a Memoir of Illness, Strength and Women's Stories Throughout History, was published in 2020. Katharina completed her PhD, a Hybrid Memoir biography of the first woman clown in America. She is currently a South Australian Literary Fellow at the State Library of South Australia, working on a manuscript about women and chess.

Our second guest is Ashley Kalagian Blunt. Ashley is a writer, speaker and podcaster based in Sydney on Gadigal, Land of the EORA Nation. Her bestselling psychological thriller, *Dark Mode*, was shortlisted for the 2024 Ned Kelly Award and the ABIA General Fiction Book of the Year.

She is the author of two previous books, *How to Be Australian*, *A Memoir*, and *My Name Is Revenge*, a thriller novella and collected essays. Ashley is a frequent speaker and panel moderator and co-hosts a podcast on *Writing, Creativity and Health*, which I highly recommend.

And finally, Chelsea Hopkins Allen is a visual artist based in Western Australia on Minang Noongaland. Chelsea started painting at 24 when she became unwell with a rare neurological and metabolic condition that went undiagnosed for the next 12 years. Her paintings began as something purely personal and functional in a difficult time when she could no longer work as an environmental scientist, her artistic practice began exploring the microscopic scales of butterfly wings, which evolved into an in-depth investigation of the great southern moth species found in her local region. Chelsea lives in Albany with her small rescue parrot, Opal and dog, Jango, who keep her company while she paints. It is an absolute delight to have each of you on the podcast today. And I'm really excited to be bringing us together over the airwaves to discuss art and science as intervention. Although they appear to be in opposition, have more in common than you might think, and they are both powerful interventions when it comes to the body and mind.

So, my first question to each of you is, why? Why do you create art or tell stories? What does it mean to you personally that drives your creative impulse?

Ashley, could you start us off?

Ashley

Oh, that's a great question. Thank you so much, Bianca. For me, writing and creativity are about connection. So, it's kind of an inverse way of thinking about connection because most of the time, what I'm doing is sitting alone in this room with my computer or my notebook. But what I'm doing is putting ideas together and putting them out into the world.

And that's been. That's been really, really wonderful because it has brought so many amazing people into my life like. Like yourselves today. So, I've had opportunities like this that I wouldn't have otherwise had if I. If I weren't pursuing my creative impulses. So, I love talking about how writing builds connection between people, and I think, particularly readers, I think are amazing people, and I love, I love meeting readers of any type of book of any genre.

Bianca

That's wonderful. Yeah, I can definitely agree in terms of writing, thinking it's such a solitary act, but it is all about people and all about community and the connections we make. Katarina, how does making art and writing resonate with you?

Katarina

I think it's such a difficult question, especially in the context of Ashley's fantastic answer. For me, I often write about things I encounter. So, in the sense looking at history and kind of looking into those stories, it's an act of writing back to dominant narratives of history and dominant narratives around health. But then also, it's really placing myself within that and making it personal because it is very much personal. It's very much lived for me. So, writing is my way of making sense of those things I'm encountering and looking for. And in that same way, I've been really privileged to be connected to the disability community through writing.

Bianca

Yeah, thank you so much for that. And a really different answer, too. Chelsea, what do you have in terms of your visual art and your artwork? I know there's a big story behind why you started. I wonder if you could tell us a little bit about why. What keeps you painting now?

Chelsea

Yeah, so when I started, I definitely didn't intend to become an artist. I was just making art as a tool at a difficult point to try and remind me of a feeling to stay positive. So, my first artwork I came up with inside an MRI machine. I was trying to remember all the things that made me feel positive because I was really sick and, you know, you've got to lie still in this big banging machine for an hour. They were looking for something pretty bad. And so, I was just trying to remember all the things that made me feel really positive and inspired and uplifted and just consciously choosing to focus on those. And I remember the time I saw a butterfly wings scales because the butterfly wing is covered in tiny little, microscopic scales, and it just looks like this incredible abstract textile artwork in its own right.

And I remembered that, and then I felt just this total like awe and joy and wonder wash over me in spite of how sick I felt. And so that night, with some childhood paints that my grandma had dug out, I just. I just created that, like a very rough image. Not trying to make art, just trying to make something just to be like, I'll stick that up on the wall, you know, with a bit of sticky tape, and I'll look at that, and I'll try and hold onto that feeling. And then I was sick for a very long time, and that really, that really helped me. I really wanted to consciously choose to focus on what made me feel inspired and uplifted and reminded me that the world is a magical place. And so, I just kept painting to hold onto that feeling.

And then, obviously, my experience has evolved, but I really think it really comes back to that awe and wonder. Like Ashley was saying, further down the line, being able to share that with people and with the community and that crossover between art and science, that, that. I guess that's why I've continued to. For my mental wellbeing and then discovering something in. In that by accident.

Bianca

Wow. Thank you for sharing that story as well because it's such a powerful image. Something I've learned along my own journey of becoming a writer is that the creative process is. It's very personal and highly individual. I wonder if each of you could describe your process and perhaps how you've refined elements as you've grown in your practice.

Katerina, could you describe your creative writing process? I'm interested in maybe how it was different before you wrote *Hysteria* to now.

Katarina

Yeah, I definitely think *Hysteria* Was quite different for me in terms of my process because I was writing about my lived experience of illness as it was happening to me. So, a lot of the book became. I didn't even think of it really as a book as I was writing it, which opened me up in a lot of ways as well in that I wrote exactly what I was feeling and didn't self-censor because I didn't think it was going to be seen by anyone else. And then, in the end I pretty much kept it exactly as it was in terms of. I didn't really remove much because it felt. Felt like a really true capsule of that time for me. But yeah, so in saying that, I. It was a very intensive process because I was writing it as I was going to different medical appointments and as I was researching and encountering the stories of other women who've been kind of caught up in this term of hysteria.

That was a privilege in a way. I. I see it mixed when I look back at that time because I was very unwell, and I had to limit the amount of hours I could work so I could just survive financially. I am able to look back on it and see it as a privilege where when I was in the most distress, I could focus on my writing in a way and process through writing. Which was really helpful in saying that I do generally push back on the idea as writing about disability and illness as therapeutic. Because in writing and then publishing and doing publicity for *Hysteria*, those things are not therapeutic. They're very much work and take a toll on the individual. But often, when we write about ourselves and our own bodies, people can use the nature of it being therapeutic is very as condescending and dismissive.

But yeah, that was a very unique time and process for me. Now, it's a little bit more piecemeal, and I really cherishing those small moments in the day when I get to write.

Bianca

I guess there is that common thread of. Of writing about women, writing about the female experience. Is that how you would describe, I guess if you were to describe your style in a align, how would you describe what you focus on in your writing?

Katarina

Yeah, I think that idea of being an outlier is definitely there, and I think it kind of shows, you know, that feeling of being an outlier comes out in my work. It is Also, in my PhD, I was really fascinated with clowns and how they use their bodies to work. And as somebody whose body does not always listen to their mind, I was really compelled by that. And with Chess, I'm really interested with the kind of crossover with mental processes, mental illness, and chess. So, there is always that thread of disability, too.

Bianca

Yeah, definitely. No. Thank you for that generous response. I wonder, in terms of creative process and, how it's maybe been refined or changed. Chelsea, did you have anything to add from there?

Chelsea

I think it's really interesting what Katarina said because, for me, I was going through it, but my creativity was like an escape from the reality of what I was going through. And I was kind of getting to. I was very cut off because my symptoms were so significant. I was very foggy mentally and very physically. I get often very severe muscle weakness and fatigue, I think.

Katarina

Yeah.

Chelsea

My art, my creativity, was this escape from reality that started with the butterfly scales and those artworks, and they look almost abstract, and that process was very mindful. And even the fact that I use oil pastels, I was able. Like, I actually didn't have that much good movement in my hand. The more I used my muscles, the weaker they'd get. And I didn't know why because I didn't have a diagnosis. Yeah. So, for me, the art was really an escape. And it started with these big pieces based on the butterfly scales and really focusing on that sense of awe and wonder. And the creation of those pieces is very mindful because they look like big abstracts.

And as part of the process, the materials that I used also, I was able to use those materials at that point with my health condition, being with what it was, because if I repeatedly use my muscles, my muscles would get weaker. So, I used paints and brushes, which doesn't require a lot of pressure, and oil pastels, which are, you know, easy to hold and use.

And that focus evolved when I was very cut off from the world. And a lot of things that I enjoyed because, you know, when your health goes downhill unless you've got, like, a really good support network and a lot of other factors, you. You lose your job, your hobbies, your, you know, it's very hard to have a social network if you don't have family around.

You know, it hits you financially. It, you know, limits you physically. And so, I really felt trapped in this house. And my biggest passion is being out in nature and having adventures and wildlife. This one night, I noticed this big moth banging against the door. It would be attracted by the lights at the back door. And I opened it up, and I picked it up, and it had these completely shredded wings, but it was so beautiful, and I felt like it was really courageous in spite of how shredded its wings were. It was just flying out into the night, and I think I was so grateful for this interaction with this wildlife, even though it's a tiny little creature. And I was, like, appreciating and looking at so closely. And I think it really hit me emotionally because I was often struggling to walk. I would get very severe muscle weakness. My legs would buckle, or I wouldn't even be able to walk. I would get paralysed just hours at a time.

And so, this moth that. Its wings were really damaged, and it was still trying to fly, you know, using its moth senses to fly out into the night. But to me, that was like intuition and sort of faith. And I didn't have an answer to my health at the time, even though this is five years from when I started making those butterfly scale pieces. And it just felt like a symbol and a totem for me. And then I decided I wanted to paint these moths, and I wanted to paint them big enough so I could paint the scales. But I think I also. I think I felt so invisible and so trapped as well. On some level, I wanted to make something that couldn't be overlooked. And so. And I wanted to make them, like, as bigger than me, like, almost like if they were angels. And also, I thought, you know, if that moth was the size of a lion or a tiger, an elephant, people would just be, like, in awe and celebrating it. And no one's noticing these creatures. And the more I. Because I realised they were coming to the door, the more I. I was aware of them, the more I saw them and, the more they captivated me. And so, I ended up starting to paint these moths, which is absolutely ridiculous because my health was really bad. But I was painting them at, like, two meters across, these massive moths.

And I ended up getting to have an exhibition with them. And, you know, it'd be to the point where, like, I would literally collapse on the ground, and my partner at the time would come out and have to, like, pick me up off the ground and take me inside. But I dead set on creating these big moths.

Bianca

Yeah, it is just like this creation, creating art, but then at the expense of your health in a way, but feeling like you. You're driven to it as the moth is sort of to the light. And it's instinctive. It also reminded me of how much art, in whatever form we create it, it's. And putting it out there through exhibitions or through publication. It's also raising awareness of this moth species, of, you know, the small things that we don't, and bringing that to people's attention. Ashley, we'd love to hear from you in terms of your creative process going across so many different genres.

Ashley

Yeah. Thank you. And I can completely relate to so much of what you both are saying about illness and symptoms and how it affects everything in life because I think all of us have similar experiences in certain ways. When I talk about writing, I like to use the metaphor of a. Of a vehicle. And I think when people start writing, they think it's kind of like, well, I know how to read. And often, people who write are avid readers, and it's like, oh, I know how to drive a car, so therefore, I can build the car. And I think that's where, like, our thinking goes wrong right from the start, is that those two things are not equivalent, but because we know how to write, we think that that translates to the equivalent of building the car.

And so, when I first started writing, which was years and years before, you know, I wrote for years before I got sick in 2017, what. What I did and what a lot of early writers do is we build all the parts of the car that we're familiar with that we can see. So, we build, you know, the body of the car and the wheels and the steering wheel and the seats, and we work on, like, the paint, and we make sure the car, like, looks really beautiful or really dynamic or really unique or whatever it is. Right. But the problem is that we don't know how to build the engine because that's the part we're not familiar with, and that's the part that no one's ever taught us, and that's the part that's invisible to us as the reader. And so, I was lucky that I had four unpublished manuscripts before I got sick, and then I was working on two more.

In the process of working on those two more is when I started to finally learn about the components of the engineering. So, when I had little pockets of mental clarity and energy, you know, and we're talking, like, at first, it was, like, 15 minutes. I had these two projects that I was already quite deep into and I could work on. And I had. I had really started learning the tools that I needed to make them work. So that's how *My Name Is Revenge*, which was my first book. And *How to Be Australian* came out in 2019 and 2020 because I had written the bulk of those before I got sick. And everyone said to me, like, oh, you're doing so amazing.

But then my next book didn't come out till 2023. And that that gap really reflects the time I lost to, like, really intensive illness. Every manuscript I've written since then has been published. And with each one, I have refined my understanding of the components of the engine and how they work. And I'm really passionate about teaching those to writers as well. And so that's really the key way that my process has changed. I'd like to describe my life as sort of like. It's like living in a. In a tumble dryer. Like, I kind of get everything organised and like make, and I think I have everything under control, and then the dryer rotates, and everything just gets flipped upside down again. But that's, you know, regardless of writing, that's just life in general. My process, obviously, I've refined over time, but I think that encapsulates that. Encapsulates that. The biggest change.

Bianca

Oh, that's such a fantastic metaphor. That's going to stay with me in terms of the vehicle. In the coming year, we're going to see your second psychological thriller.

Ashley

Cold Truth. Yes

Bianca

Cold Truth.

Ashley

February 25.

Bianca

To follow Dark Mode. And I can only imagine the amount of, I guess, engine work in terms of plotting for that. So, does that mean you are plotting an outline before you even start the drafting process?

Ashley

Oh, so. So, how my current process works now that I know what I'm doing sort of loosely in quotes, right? Because we never really know when it comes to a creative project. But what what my process looks like now is I make a big mess. Like, I make a big mess, and I get lots of ideas down, and I start to see how pieces might fit together.

And with Cold Truth especially, like, Dark Mode came together fairly well. And when I say that I wrote 40,000 words, got kind of to the halfway point and then sort of realised all of the things that weren't working, scrapped most of it, started over, then wrote an 80,000-word draft. With Cold Truth, I wrote a full draft. I reworked the first act about three times, and I threw the entire thing out in kind of a panic after working out for 18 months because it just. It just did not work. It just did not work. And then through that process of making that big mess, so I took the ideas I could kind of salvage, rework them into a whole new plot, and that then became Cold Truth.

Ashley

And so, this is sort of the process. How I think about it is I make a big mess. I take the pieces that kind of work from that and. And I see what I can build. And then once I've got that big picture, then it's refining all of the engine parts at more of a scene-by-scene level.

Bianca

We're often Told as writers that there's plotters and pantsers and. And now there's that in between where it's like you're. You're a plantser.

Ashley

Oh, yeah. I think it's always on. Where are you on the spectrum of that? More. More than anything.

Bianca

And Katharina, I think. I mean, I'm writing memoir as a creative nonfiction, and I know you're familiar with that genre, too. Writing from life and from experience. Think that is very different

again, in terms of how we approach that and approach the engine of that work. I'm not sure if you had any comments on writing memoir.

Katarina

I think just thinking about it, too, in that sense of when you're writing, experiences that come along and feel quite profound to you. For me, I often go through phases of reading a lot and then writing a lot, so I'm never kind of mixing them too much. It's like I'm filling up my cup, and then I'm able to kind of write. So, when I'm in that state of writing, I think I'm more attuned to those little experiences around me. And it really kind of connects to what Chelsea was saying before about. And I. I think sometimes this is missed a little bit when we write about ourselves in the context of difficult experiences like illness.

But there's so much joy the. Every day. And I think we can be. When we're in that writing, creating space, we can be so attuned to those little pockets of joy. And that's just such a pleasure of having the space and time to write.

Bianca

Yeah, definitely. And sort of space to play on the page and to experiment a bit. Chelsea, I just wanted to bring you into this thread for a moment here and just sort of responding in terms of your process before you might start one of your big moth artworks or butterfly wing scales or something like that. Are you. Do you sort of sketch out or do any drafting?

Chelsea

I really was just following. Being super mindful and following my urges. But later on, I realised that I was kind of responding to the science of colour because even the outlines of the. The scales are sort of outlined in one colour, and then there's infill in another colour. And as you step back, it all kind of comes together.

But those colours are complementary, and that actually does a certain thing in the brain where it intensifies the other colour and can even create an illusion of movement with how the brain and the eyes work. And so, I'd just be responding in the moment to the outlines and then what colours go there and what Colours are placed next to it.

And that was just really intuitive. My first big moth, I just. I just launched into it. I was basing it on the real species. But since then, I definitely I developed my art techniques more as obvious as I learn more because I wasn't trained as an artist. And now I definitely try and be less impulsive because that's like a personality quality and flaw. And I try and do more studies, and really, I want to develop those techniques to really show what I'm seeing to other people. Because I'm not going for absolute realism. What I'm trying to do is find the things that I'm really noticing and that I'm feeling that wonder and getting a real visual kick out of and trying to find how I can translate them to make them obvious to the viewer or like represent how I'm seeing them.

So, I think I naturally tend to hyperfixate. So, I want to be able to use my techniques to show how I see the world to other people.

Bianca

I love that reframing and that use of how you've described the science of colour. But then, coming from enabling others to see the world, this butterfly wing scale or this giant moth through your eyes and through what you know, how you pay attention to detail. I'd like to switch gears a bit and discuss the topics and themes in your work. Each of you have such diverse entry points as we've been discussing. Ashley, you write across genres and have delved into memoir and now crime thrillers. Katerina, your debut was a memoir, and you're now working in the area of women's biography and nonfiction. And Chelsea, your artistic style is inspired by the microscopic details in nature, particularly environmental science and mindfulness.

Talking about those connections between art and science and how the act of creating, whether writing, in your case, painting, has influenced your state of mind or health more broadly.

Chelsea

I really, really like this question, and it's. To me, it's got two parts, so I hope you don't mind if I address the broader picture and then the more personal aspect.

Bianca

Go for it.

Chelsea

Something that I've learned along the journey of learning about art and having that science background is I believe that art is a really incredible tool that can be used in science. And I see a really powerful connection between, yeah, art and science as a tool. So, if, for example, my interest is of environmental science, and if you look at environmental issues, they're not specifically a problem with a tree or water or air.

I mean, that's how it manifests, but really, it's how humans have impacted these systems and the consequences it's having for the environment, it often comes back to how it's affecting us. And so, if you want to address these problems, it's not about fixing the thing in the environment. It's really about addressing our interaction with the environment and the systems and processes and beliefs and culture that we have and the repercussions that it has.

So, I feel like it's been a hidden blessing to now experience both fields because I think there's a really important interdisciplinary role there. Because to really enact change in environmental issues, art doesn't in any way replace the science. But we need to engage people, and we need to engage them emotionally and engage them culturally and to create shifts in what we're doing and how it's impacting the planet. And it's been really cool. I've actually started to like, dive into the research now. My brain's more cooperative, my health's better, and I can really read and research more. And there's, like, a whole lot of science that can really inform art and vice versa and help to bridge the gap and any complex problems.

You know, we usually need to act in an interdisciplinary way and approach it from all angles. And I feel really excited, and I feel that, yeah, that art and science have a lot to contribute. A lot of environmental problems are not visible. You know, we're living in cities or towns, and it's happening out there in the forest or in the ocean, or it's tiny, microscopic chemicals or microplastics and greenhouse gases. These things aren't, like, directly visible to us. And so, it's hard for us to feel emotionally engaged with them, or it's just depressing and disempowering. And so, I feel like, through art, it's a really great opportunity to help empower and teach people in a way that can be meaningful and even uplifting and enjoyable and inspiring.

And I think it's like a human right to know what's going on in the environment. But if it's all really overwhelming and difficult to process and we're all very busy, like, you know, if we're not getting that information in a way that we can engage with, it's. It's not really working. And for me, personally, when I started out, and my initial interests were very much, you know, in science, I was really interested in water and air and ecosystems and also, like, how different cultures survive and just human survival in general as a kid. I love National Geographic, and I like to read the SAS Handbook because I liked all those, like, really practical life, survival skill things really interested me. And then when I got sick, it really taught me that the most critical component of survival, really the mental and the emotional aspect, if you don't have that, you don't survive.

What I learned about creativity is that I think it's really an expression of human resilience and courage and just their attempt, like humanity's attempt, to make sense of the world and sense of what they're accepting experiencing. I just feel really grateful that I had. I found creativity. And I really try and encourage people, especially like anyone, you know, just to deal with the stresses of life, but especially people if they're going through something difficult, like, I don't care what it is if you're crocheting or making music or writing or painting or, you know, doing a bloody colouring book, as long as you do something that helps you process your emotions or express, Express your creativity or find a spark of joy somewhere.

I think that's. I think that's the power of creativity and, science and art.

Bianca

Oh, that's such a brilliant response. Thank you so much. I think that's all given us so much to think about. I want that kind of above my desk now. A big sign that says creativity is a survival skill. Thank you, Chelsea. Moving on to Ashley, Katarina, whoever wants to go next, if you have a burning response, please go ahead.

Ashley

Well, I'm building on that. So, one of the things that's come out of doing our podcast about writing creativity and health for the past four years is this concept that both creativity, particularly if you have creative ambitions in terms of putting your work out into the world and coping with chronic health issues are both things that require vast stores of resilience. We've interviewed so many people who have, you know, experience in both, whether it's a mental health condition or a physical health condition or both, and then creative work. And there is this interplay between the creative resilience that you build up in one area and that you use in the other, and that, you know, that may be why there's.

There are so many people who have various chronic health issues that. That are creatives. I think there's other factors that play there as well. But I know for me, what I was saying before about when I got so sick that every other aspect of my life shut down and I literally home alone, having my writing there, like having this thing that I could mentally escape into, was such a relief.

It was the. It was one of the only times where I wasn't thinking about. About the illness and how changed my life was so. For me, it was brought so much relief to be. To be able to have that creative practice to escape into.

Bianca

Absolutely. It's about that flow state and really engaging in it in a personal level and then the connections it brings in with other outside who are interacting and then engaging with what you've. What you've created. Also, I think what you've been able to bring to us through James and Ashley's Stay at Home the podcast it's been incredibly valuable.

Ashley

In one of our early episodes with art therapist Karen Foxwell, I believe it's episode seven, she. She talks about her work as an art therapist and really addresses this area as well in terms of how art therapy, you know, is not for people who have any kind of artistic practice, but she works with first responders and military personnel who have PTSD and how just by the act of making art, allows them to access parts of their subconscious that. That they were completely unable to access. It's a fascinating episode. So, I think it's. I think it's one of the ones that really speaks to this question.

Bianca

Fantastic. Thank you, Ashley. Katharina, what are your sort of reflections on this?

Katarina

It was so interesting hearing Ashley and Chelsea's understanding of the mix of art and science because I feel as though my experience is a little bit more troubled. So, I think it's a really good comparison for me looking at science in my kind of own sense of medical science. I've seen art and really story as a way to trouble some of those ideas around how we write about people experiencing illness. Something. When I was just reading a lot about my own illness, functional neurological disorder, I was really trying to find the people and the stories underneath that. When looking at medical journals, people, there wasn't that sense of the individual because also the illness is such a messy constellation of symptoms that so individualised.

And that's probably true of all illnesses, really. I was looking for that viewpoint of that art can bring of telling people's stories into the medical science space. And I think while medical science hasn't been built on the idea of the individual, I think art can contribute that viewpoint of humanising people and giving patients kind of power and sense of self.

At the same time, though, I've kind of experienced, while that's been so much of my work for such a long time, I haven't experienced any change in how I'm treated as an individual. So, it can be sometimes when I'm spending my days thinking about, you know, and talking with other disabled people about these ideas and Being really hopeful about the combination of art and science and how that can make people's lived experience better in encountering medical institutions, then it can be quite a shock. Or, like you get a real sense of backlash. Then, when you're in that space again and all of your thoughts and kind of careful conceptualising of how can these two things interact, you're just back at square one.

Bianca

Yeah, definitely. My personal experience and from experiences of stories I've read, I think there is more awareness out there now for FND or functional neurological disorder. But sometimes, it does come down to forging on despite the attitudes and the stigma that exists within the medical system and actually just sort of going by instinct. The way I found my way to a diagnosis of FND was actually through reading Katarina's book and seeing myself in the description on the first page and just feeling absolutely flawed. It was like a mirror, and that was what enabled me to keep going and to not take no for an answer. There's still a lot of work to be done in that area and finding community and really being. Staying resilient with that is crucial. I hope that we are seeing more progress, though, even if it is incremental. I would like to move on to the second part of the episode.

Art and science as intervention. While each of you have distinct creative styles that produce very different outcomes, you each have come to your craft through or alongside a chronic illness, a diagnosis. Maybe you've had the diagnosis alongside the creative practice. Maybe one came before the other. Ashley, I wonder if you could start off by telling us about your experience with chronic fatigue syndrome. Maybe tell us a little bit more about what it is, how it manifests and your take on creativity and health.

Ashley

So chronic fatigue syndrome, the core of it basically is post exertion exacerbation. So, like. Or post-exertion malaise. So, which basically, like in simple terms, is fatigue. But fatigue caused from doing just ordinary everyday things for some reason have an extreme impact on the body. And I had what's called insidious onset. So chronic fatigue syndrome, while it's not fully understood, can manifest after someone has cancer, after someone has a concussion, or most commonly after someone has a virus, even if that virus is asymptomatic, so they believe mine was post viral. But then it can manifest quite quickly, like, basically comes on like a. Any illness, or it can do this thing called insidious onset, where it comes on very, very, very slowly. And mine was the latter. And it. I started having symptoms, but because they were so vague and fairly mild, I was able to sort of write them off. And there was a lot of things that I was having that were symptoms that I didn't even realise were symptoms. Like, I would have one glass of wine. You know, when I was in my early 30s, I would have one glass of wine, and it would be like I'd had a glass of sand, and I would drink, like, a litre of water, and I would still feel so parched.

And I kind of thought, oh, I guess this is what drinking is like in your 30s. But then later, I learned that there's a symptom called alcohol intolerance, and that's what I was experiencing. So, over the year, the symptoms got worse and worse until they became acute. And I ended up in bed, and I couldn't get out of bed for a couple of months.

And so, within that time, the first six months, I was sort of convinced that it was just fighting germs or whatever. And then, within six months, the pattern was very clear, that I kept having these days, a day or two days where I couldn't get out of bed, really. So, I started to go to the doctor. And it's a diagnosis by exclusion, so I had to be tested for everything, which took six months, and then saw a series of specialists. And then finally, I had the diagnosis around the same time that the symptoms came on full-time. And it was pretty indisputable that that's what it was. What it did for me was convince me that my pursuit of writing was one of the most important things to me. Like, I had been writing for quite a while, six or seven years, and as an adult, before I got sick and not having a lot of success with it, like, I couldn't get any of my books published, for example. And now, looking back, I understand why, because. Because those engine parts that we talked about, like, just weren't there.

So, it looked, you know, it looked like a car from the outside. But it just. When you tried to have the experience of what you wanted the car to do, it wouldn't do it. So, I had, you know, invested all this time, and there was part of me that thought like, oh, is this a waste of time? Should I just not even bother? And when I got sick, I, you know, couldn't do almost anything. But the writing was so meaningful to me that I really realised, you know, even if I. If I never get published, and even if I can't do anything else, this is something that is meaningful to me, and I am going to continue to invest time in this and do this.

So that was one of the things, things that came out, you look for the little positive things because overall, I've lost years of my life, and there's nothing that can be done about that. But you know, you try and take some positives where you can.

Bianca

Yeah, yeah, definitely. That keeps coming back, I think, in terms of those pockets of joy, those moments, and just really prioritising the creativity and what we can do. Ashley, you mentioned a diagnosis by exclusion. I know that talking from experience, like FND, is seen as very much the same sort of thing, even though research, research shows that it's not and that there are positive indicators. And I'm not saying positive as in, you know, good, but positive as in that's what we're looking for. Like really distinct signs that, when they know what they're looking for, that that will indicate a diagnosis of FND. Katerina, I wonder if you could speak to a bit about if you're comfortable sharing how FND manifests for you how you came to your diagnosis. Yeah.

Anything you want to share sort of along that that thread?

Katarina

Sure. So, I experienced a series of different things with FND, and it's something that has changed over time for me now that I've been post-diagnosis for some years. When it first came on, it was very acute, and I would experience things like like visual hallucinations, Dissociation was a big one, loss of sensation in parts of the body.

So, quite a wide-ranging of experiences. I think the most distressing experience of illness for me because they came on quite suddenly. I didn't understand why. And like you said, that diagnosis of exclusion idea, for me, it came to the point of where it was functional neurological disorder. Right. In that, the idea is that your brain is functioning as it should in so much as what the scans can tell you.

But you were still experiencing these things. For me, though, I think that experience and time of diagnosis, when I was going through it, it very much felt like a before and after, like a segment of my life. But now, looking back upon it, I. And especially with the context now of since being diagnosed with celiac disease and endometriosis.

After living with FND for a while, I've been able to kind of look at my life not as a before and after FND but as a series of kind of interwoven different bodily experiences. And that has kind of changed my view, I suppose, of illness. It's something that's just ever present in my life, intersecting and collecting at this point.

I think that's also such an interesting thing to have published a book about a pinpoint in time to go back. It gives you a real gift to be able to look at it with some distance after times progress and see, at that time, it felt like this would always be my life. And my life is still similar in some ways, but you can really see how things change.

And that's such a gift to when you're. It helps you navigate illness, I think.

Bianca

Absolutely, yeah. And it's a big thing about what I've learned, too, is about expectations and reality and my expectation going into, okay, I've got a diagnosis now. I'm going through the process of accessing treatment and specialists and, you know, seeing outcomes and some progress. My most recent neurology appointment, they just said these symptoms aren't going to go away.

I still am taking this with a grain of salt, but they essentially told me that it's ongoing management and it will always be there, always be part of your life. You're not going to be able to drive again. Like, it just sorts of really hit me that, yeah, it is. It is a constant presence.

Chelsea, I'd love to hear your perspective now because when we started discussing functional and organic or structural within the brain. So, I wanted to hear more about yours, and could you describe how that affects you?

Chelsea

A big part of my medical experience was actually being undiagnosed. So, it's really only this year that I'm actually getting the full picture of what's been happening to me. And so, I feel like oftentimes, your experience of your health or having a medical condition it's not even considered valid until you get a label for it.

And so, just before I even launch into my thoughts, I'd just like to acknowledge that being undiagnosed is a legitimate experience. You can get really fobbed off and treated like a troublemaker or a time waster when you don't have these labels. And then the other thing that's really interesting to me that meant a lot was that I was misdiagnosed with FND and chronic fatigue.

But. And I, like, I saw like 40 doctors. Like, I was relentless. I was, you know, really trying to find answers because I knew for me that they weren't the right labels. I knew that there was like a chemical, biochemical type of cause. And so, I've known for other people that have had FND or chronic fatigue when they get that explanation, there's a great sense of relief to like. I mean, it's, I imagine it's very nuanced, and I'm not trying to put words on your experience. But they know that there's truth there for them, and it gives them something to work towards. And I mean, correct me if, you know, if that's not your experience. But I knew that it wasn't accurate for me and that it.

They were giving me this diagnosis by exclusion. But I knew that they hadn't figured out what was going on for me. And it was really interesting because I really felt like even before I read your book, Katerina, I was. I was like, this is like the 1800s. I mean, treated like I've got a wandering uterus or like I felt like I was being treated like it was hysteria.

And I'm like, this is Australia, you know, first world country, modern medical facilities, very well-educated doctors and scientists. It felt like the twilight zone. It was really disturbing for me psychologically. I'd like. That was one of the hardest things was just to. Because it wasn't just one or two doctors. It was like when you're going up against 30 or 40 doctors, and you're going, no, this is real. And they're going, no, it's not. You know, you start to think, is there something wrong with me? And so, for me, actually, there was a physiological, chemical reason. And so, three years ago, I got diagnosed with hypokalemic periodic paralysis. So, I would get severe muscle weakness to the point of sometimes total paralysis, where I could not move a muscle.

I could not move my pinky, I could not speak. But I was like conscious. I just go floppy like a rag. Don't look like I fainted. But it was so hypocalymic periodic paralysis just means your potassium drops too low. And potassium sends the electrical signals in your muscles. So, a lot of stuff that was, you know, the terrible fatigue, like if you had a terrible hangover or gastro, you know, like if your electrolytes out of whack, you just feel terrible and you zombie.

So, I was waking up like every day and then, you know, having all these. These like crazy muscle symptoms. And the more I tried to do the, you know, the weaker my muscles would get. You know, I'd be trying to paint, and I couldn't lift my arms or, you know, my legs would buckle. And then I found out, like, it's. It's something as simple as potassium, you know. But in, in my case, it was just dropping really rapidly. And when I actually found that out, I had an experience where I just took a bunch of hydrolyte because that had been recommended to me. And it felt really good.

And then it brought on the symptoms, and it was because it's got glucose in it, and that can spike your insulin and drops your potassium. And then I obviously pursued the right specialist and got a diagnosis. But then I thought that maybe I had completely lost my mind, and I was delusional, was inventing this crazy disease, and I was like, I need to see a psychologist or something.

Like it's so weird that actually getting verification of my experience being real made me question whether I was completely losing touch with reality like that. That's, I think, that just shows like how difficult navigating these chronic conditions can be, especially I think as a, like a woman or a young, younger woman. And then I got a lot better when I got treatment for that.

And then the next thing was I was still struggling, and someone convinced me to get a CGM, a constant glucose monitor, one of those little things you can buy, and it will tell you your blood sugar. Because I was doing really well managing that potassium thing. And you know, I could get, get fast-acting potassium and potassium medication. You you manage your diet to deal with that. So, I wasn't really having too much trouble with that. Like as long as I managed it. And then getting this constant glucose monitor, like I thought it was broken. So, I went and got a fingerprint test, and it confirmed it. And then I, like, I got more of them, and I kept going to the doctors and being like, my blood sugar is really not right.

And I kept being told, I'll just eat a snack. And I'm like, no, like it's really bad. Like it's really unmanageable. I'm doing all the things. And then this year, I was admitted into the hospital for tests. It was supposed to be three days. It blew out to nine days because, obviously, things were not right.

I just was supposed to fast for a couple of days, and obviously didn't go well. So now I have this explanation for all these like difficult myriad of symptoms that, in many ways, are similar to a lot of the symptoms that you guys deal with. But I have a a biochemical explanation. And obviously, now my health's like a lot better because I can now do something about all of this and manage it.

And my potassium issues are probably affected a lot by my blood sugar issues because the two are linked, they affect each other. But what was really massive for me was the difference in how you get treated when they think you have a psychological or FND or chronic fatigue or like one of these, you know, I know they're not vague, but they can be perceived as vague or not life-threatening. It's so massive. Like the. The difference in. Yeah. In how you're treated and in the medical care you get. And I'm not saying all medical professionals, but, you know, I'm not bashing medical professionals. There are some great ones. But it is actually, it's really shocking to me, the difference in how I experienced being treated when I had these very biochemical specific labels versus not.

And that gave me massive compassion for your experiences because it's not a nice feeling. And some of it's like you're just picking up on it, but, you know, you can't. They're not overtly doing anything. They can just be quite dismissive. And so, if. If that ties back to art because through art, you can kind of show your internal experience through different ways. And that really gave me a sense of the weight and the value and the validity understanding people's internal, like, world and experiences and what they're going through. Because, yeah, I. I really don't think you can understand a lot of this stuff purely from the outside in with science. Like, I really think you need to understand it from the inside out with art. And I think that's part of understanding yourself and your own experience of the world when other people can. You can feel that connection and see that other people are experiencing things or even notice that something's different. Like, you know, I noticed a lot of differences of what I was experiencing between myself and yourself, Katerina, and also Bianca, reading your writing, and that was even before I had a diagnosis.

And that really helped me to kind of understand what I was going through, even if I didn't have a label. Yeah, I think it's really powerful, and I think it's really important.

Bianca

Thank you very much, Chelsea, for sharing that. I'm really glad that we were able to include all of the voices here today in this conversation. We might finish off on any last comments or reflections on what Chelsea's just said.

Ashley

Yeah, can I. Chelsea, I'm so sorry that you were treated that way. That's just so upsetting. And yeah, as you said, it's shocking that that is still the treatment that people are experiencing. Especially, like I read recently, there's 10,000 rare medical conditions. Like, what are the odds that you have one of those 10,000 things?

Ashley

As opposed to just, oh, it's hysteria or whatever. But I did want to contrast that with my experience. I started seeing my doctor in early 2017, and I had a really wonderful GP, and she very explicitly said to me, this is not in your head. You're not making this up. And was really supportive through my whole process. But also all the specialists I saw like, no one treated me dismissively. So, I've read a lot of accounts of women who have been treated exactly as you just described, Chelsea. But I did just want to highlight that there. There are good doctors out there, and hopefully, more and more will start to take that same attitude that I was greeted with.

Chelsea

I'm so glad I should have also said that, basically, rare diseases as a whole are not rare. So, I actually don't know off the top of my head what the numbers are, but they're not actually a. They're very easy things to actually measure if you listen to the person. But, you know, the conditions themselves are rare. But, yeah, rare diseases are not rare. And that used to really frustrate me when they'd be like, oh, you can't have that. It's not rare. And I'm like, well, you checked everything else and, you know, like, you haven't found it. And. Yeah, and that's some. That's something that I think people really need to know is.

Yeah, rare diseases as a whole are really actually quite common. I wish I had the number off the top of my head. Maybe you can find it.

Ashley

I've heard it's 1 in 100 people.

Chelsea

Yeah. Something crazy like that. Yeah.

Bianca

Is it 1 in 100 have a specific rare condition or have a rare condition?

Ashley

Exactly.

Bianca

Okay. Well, yeah, Katerina, I just wanted to open up as well if you had any responses there.

Katarina

Yeah. I think it's so interesting and really touches on that idea of what is rare. Right. Like, I think scientists would be the first to admit how little they understand about how the brain works. But then, when it's in practice of a person explaining their lived experience of symptoms that do not fit in certain ways, and suddenly it becomes that person who is the problem. So, I think, for me, in terms of just thinking about science and art, in reading about science and the kind of constellation of all different experiences people have had, it's been really helpful to understand how almost nobody does fit into those neat boxes. Perfectly said, Chelsea, that there is no such thing as a rare illness or disease.

I suppose it's how we are seen. And I think it's easier to be considered rare because then you can be categorised as a little bit too difficult and needing to move on to the next specialist rather than taking time to explore how to help an individual. I think sometimes when we talk about, we're not advocating for ourselves or how we're being treated and all those things because we're experiencing it.

It's easy to forget to say that, like, this is times where people are at their most vulnerable, they are at their most distress. And it's really important to think about how those people can be looked after and cared for and specifically thinking about how gender, class and race interacts with those things too and massively impacts the care people receive.

Bianca

I'm so glad you brought this in. Thank you. It's such a privilege to be in the space speaking to you all and hearing these stories and sort of feeling like I, I know you all already through, through your words and your art, but just getting to have this conversation has just been such a, an absolute pleasure and, and a delight. And I just wanted to end on my gratitude for knowing you all and for being able to be in this space and talk about creativity and health and the brain and the mysteries that are still yet to be solved, if, you know, if ever really. There are so many questions there, and I think we're doing so much in this space to contribute through our art and through our knowledge as well in the way we practice that.

Ashley

Thank you for bringing us together for this conversation. It's been really wonderful speaking with both yourself and, Katerina, and Chelsea.

Bianca

Thanks, Ashley.

Chelsea

Thanks so much, Bianca and all of you, Ashley and Katarina.

Katarina

Yeah, it's been so wonderful hearing everyone's experience. I'm gonna tilt down so you can see my little sleeping puppy.

Bianca

Thank you all so much for joining me today. It's been a fascinating conversation. For those tuning in, I encourage you to check out the show notes, where I'll link each of my guest's websites and social media pages and, of course, where you can purchase their books and or artwork. There are an abundance of interviews and online workshops and events as well.

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