

Project Sleep Narcolepsy Nerd Alert
“Narrating Narcolepsy” (Season 1, Episode 13)
Transcribed by Mirela Starlight

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Claire Crisp is a children’s advocate and award winning author of the book “[Waking Mathilda](#)” which tells the story of her family’s move from the U.K. to the U.S. in search of life-changing treatment for their youngest child, Mathilda, who developed narcolepsy at age three. Claire is also a co-founder of [Sleep Consortium](#), a non-profit organization working to advance research in central disorders of hypersomnolence.

Henry Nicholls is a science journalist, teacher, and author living in London. His book “[Sleepyhead](#)” seamlessly weaves together his own experiences of living with narcolepsy with cataplexy since the age of 21 along with the history of sleep and some of the neuroscience behind narcolepsy and other sleep disorders.

In today’s episode, Julie and two other authors of books on narcolepsy and sleep disorders come together to discuss the writing process, what they wish they had put into their books, tips for other aspiring writers and why it’s so important to get the patient and caregiver perspective out there into the world through books and other creative outlets.

The Narcolepsy Nerd Alert series invites listeners to dive deeper into specific topics relevant to living with Narcolepsy. This is a written transcription of the podcast “Narrating Narcolepsy” (Season 1, Episode 13) from Project Sleep.

Project Sleep is a 501(c)3 Nonprofit Organization, dedicated to raising awareness and advocating for sleep health, sleep equity and sleep disorders.

All guests and speakers express their own opinions. While medical diagnoses and treatment options are discussed for educational purposes, this information should not be taken as medical advice. Each person’s experience is so unique, which is why it’s so important to always consult your own medical team when making decisions about your own health.

Julie in intro: Storytelling is so powerful and in today’s podcast I had the chance to speak with two amazing fellow authors who also wrote books about narcolepsy, Claire Crisp and Henry Nichols. In this episode we share some behind the scenes stories and tips for aspiring writers. Claire Crisp is an award-winning author of “[Waking Mathilda](#), a Memoir of Childhood Narcolepsy” which charts her family’s heart wrenching journey to find an accurate diagnosis and then move from the U.K. to the U.S., in search of a life changing treatment for their youngest child, Mathilda. Henry Nicholls is a teacher, science journalist and author and his book “[Sleepyhead](#), The Neuroscience of a Good Night’s Rest” explores the neuroscience of sleep and the impact sleep disorders have on physical and mental health. And of course, I’m the author of *Wide Awake and Dreaming*, a memoir of narcolepsy which tracks my journey developing and adjusting to narcolepsy in my early 20’s while in law school.

Julie: Hello! Welcome, today we're really excited to bring all three of us authors together. So, I guess to start, where did you guys get the inspiration to write your book, what was that decision like, was it an easy decision, and— what or who inspired you, I guess.

Henry: I'd been a journalist, a science journalist from about 20 years ago. And so, from about the early 2000s until, easily 2011, I deliberately avoided writing about narcolepsy. Looking back on it I can't really believe that I made that decision. But it was partly, I just didn't— because when you do a piece of science journalism you really find out stuff. And I didn't really want to find out stuff, which— I can't believe that I'm saying that now. You know if there's one thing that you definitely have to do with something like narcolepsy it's really, really find out everything and understand your disorder as best you can. So, I mean doing the book eventually I learned a huge amount about it. But just— I think what tipped it was meeting Emanuel Mignot, who perhaps more than any other researcher on narcolepsy, and I met him in Cambridge in 2011 at the [Narcolepsy UK](#) annual meeting— and interviewed him there and then wrote a feature for [New Scientist](#) and then it sort of— it just followed from there, the idea— you know still took about another five years for me to actually put the proposal together, but— that was when it— when I decided to write it, yeah.

Julie: Yeah 'cause Henry I think I remember talking to you— I remember what apartment I was living in when we first Zoomed and you talked about—

Henry: Yeah.

Julie: So, it must've been I was— just published I think, when we first talked about you writing a book. I want to say early 2013.

Henry: Yeah, I— think that was probably one of my first interviews with you, actually. So I read your book and then knew that I wanted your voice in it, so we talked— yeah that was really early on. See that's how long it takes [laugh] if that was 2013 then there's another five years to publication, and really if I'm honest it's— I'm only writing for that last year. So you know you sort of put together interviews and start— you have to do so much reading and developing ideas and connections and mapping things out, it just takes forever with a book like this. But yeah.

Julie: Claire what about you?

Claire: Yeah it's interesting, Henry, so I sort of am tracking with what you're saying— and had a similar sort of struggle early on— although inspired by Julie— and I think we'd connected over writing, must've been about 2013, 2014. But I struggled for different reasons. Not so much with the science but more the emotional piece. So the sort of inspiration I suppose was really just the journey and the struggle. And there was one night probably in sort of early 2014 because as caregivers my husband and I were up, you know, through the night. You know monitoring, first dose Xyrem, second dose Xyrem and then— everything in between. And it was— it had been crazy for so long, like our lives just being nocturnal really, as caregivers. And there was one particular night where all of us said you know, we should write a book about this. I thought that was a great idea because he was already an author although he's a scholar not in, you know, any way near the memoir genre, but. I remember thinking, "Aw that's a really good idea— he could write the story and I could just fill him in with all of the sort of medical details and the dates," and looking through the doctor's medical notes, but— that was kind of the start of it and it soon became pretty apparent that it was my work. I had initially thought I would tell Mathilda's story— but then realized that I can't tell her story, she's four, five years— six years old. Like, she

needs to tell her own story. So to back up a little bit and then tell the family journey through my lens, really. So that's kind of how it started.

Julie: Yeah. I guess for me I wrote a big paper about the history of Xyrem and GHB in law school and my professor said it was the best paper she'd ever received in all of her time at UC Law, and so she said I should turn that into a book, and it resparked something in me because I loved creative non-fiction when I was in college and so I guess I set out to write that book—the history of GHB/Xyrem. I worked on that for a few weeks— [laughs] and I felt like I just kept finding myself going to my story. And I thought I would include myself in that story, however I just found I wanted to talk so much more about myself [laughs] —than the history of GHB, or even just realizing I wasn't really a drug expert in the way that people thought a drug expert should be writing a book or something. So I changed my idea, and if my dad wasn't upset or scared originally when I said I was going to write a book after law school instead of being a lawyer, then when I changed my idea about what I was going to write about a few weeks later he was even more scared, I think— [laughs] but I did stick with that one.

Henry: Julie I don't know what the other book would've turned out like, but I feel you made a good call there, so. [laughing]

Claire: Mm.

Julie: Well I could still write it someday, and we've talked about we could later in the conversation talk about next steps and what we still want to do and—

Claire: Perhaps Julie your decision speaks to the power of the personal narrative— and I'm sure—

Henry: Yeah, exactly, that's—

Claire: —we could be more, you know, science-y and more fact based— but what people remember is the personal experience. So you definitely made a good call. I think we all—

Henry: Yeah, that's what I meant, I think. Yeah.

Julie: Yeah. Thank you. There weren't really— there was one book about narcolepsy at the time, and it had been published in the '90s and I enjoyed reading it but I think I felt like a creative non-fiction lens could be good. Or a memoir style, although I don't really like medical memoirs, so I really drew my inspiration from people like Dr. Oliver Sacks. And I was curious if you guys have like literary inspiration— Henry I remember reading about yours— in further reading, but can you guys just describe a little bit more about where you drew from?

Henry: The book I mention at the end is— a book I never would have picked up in a bookshop, but I bought it on electronic device. And I wouldn't have picked it up because it turns out to be 1000 pages. But it should not put you off, it's called [Far From The Tree](#), by Andrew Solomon. He's a writer and writes lots of sorts of psychology and— New York based, he's really great writer, amazing writer. And his book is really about this thing of what happens when you have children who are not quite what you expected and they're different from you. Or, when you're a child and your parents are actually quite different from you. So there's this metaphor, being far from the tree. And a lot of this in there is disabilities, so there's a chapter on deafness, what's it like being a hearing child growing up to deaf parents, or vice versa. There's dwarfism and— one amazing chapter on exceptional musical talent, when you have an incredible gift as a musician

and your parents aren't obviously that great but you become this prodigy, and that's quite alienating too. It's a fabulous, fabulous book— I can't recommend it highly enough. But it brought in a lot of, I suppose science, but this very, very brilliant conversational, in depth, getting to know these characters.

Claire: Wow. So, I think I was leaning sort of when I was thinking about writing, I sort of re-wound back to, okay what did I read in memoir, you know back in the day and I sort of remembered Frank McCourt, [“Angela’s Ashes”](#), all of the real classics that were game changers in the memoir space. But that was pretty you know, dated at that point. So, when I started to think seriously about writing I knew I had to learn the craft of writing. And for me that meant— reading. So, I probably read— probably over like 100 memoirs, in the process of writing *Waking Mathilda*. But there were a few that stand out, and one of them is Mary Karr's work, 'cause she's— I always find some of the best memoirs are also parrot. And she wrote “Lit” and “Cherry” and she's written on writing, in fact I should say that as well as reading memoir and some of them I loved and I studied their prose 'cause prose was really important to me in terms of finding my voice, and that was a real struggle and a real journey— but also, whether or not I kind of loved their prose or didn't like— I feel like I studied the books that I didn't love as much as I studied the books that I did like, how I don't want to do it and how I do—

[Henry laughing]

Claire: —how I do want— you know because I have no formal training, I mean my background is in physical therapist and as an educator so I was coming at this really kind of very cold and— excited, but also very aware of the challenge because it's one thing to say, oh I'm just going to you know— isn't it something like 99% of the population want to write a book? and like 1% of them do. So I was very aware of needing to study the craft, so Mary Karr has written a not just great memoir but also the “Art of Memoir” and also Ann Lamott, on “Bird by Bird”, Steven King obviously. So, I think I studied great memoir within the genre, not so great memoir, like cannot do it but also— the craft of writing, as well.

Julie: I love the way you put that because I actually found I didn't like a whole lot of memoirs and that really discouraged me, you know, in a way— and I even remember throwing one medical memoir across the room 'cause I couldn't stand reading it and then I thought I'm going to write one of these? So finding the gems and studying the craft of writing— it is such a process, isn't it? And I love investigating so I guess that's, you know, we have to do a lot of reading— and I guess for me when I mentioned Oliver Sacks, that was I think what was so inspiring about his writing was that he brought to life things that were invisible. You know, the invisible experiences of people with neurological conditions and that somehow gave me the courage to talk especially about like the hallucinations and sleep paralysis incidences I'd experienced because even though he was often talking about his patients as a doctor, he validated like that firsthand patient perspective so much to me, so. And things that other people might think are, you know— so weird or whatever, you know he had these beautiful explanations for it, so. Yeah. So that was one of my major inspirations. And thinking about you know how you approach a book, I mean narcolepsy is so much. And there's so much to it, right, and it's all happening at once and there's just different layers of the symptoms and even as you think about narrating narcolepsy I think often, you get advice from books about like, keeping things simple— [laughs] you know or how do you— when so much is going on, how did you feel like you ended up deciding to structure your books, I guess.

Henry: With a book like mine, so I thought I've got to write a book about narcolepsy and I pitched it to my publisher and they went, "uhhhhh," [laughs] “could you write a book about all

sleep disorders, with narcolepsy as a bit of it?" I thought well I could really write about narcolepsy 'cause I actually know that and I don't know the others. And so it's going, if I tried it would be really unbalanced and it probably actually is, if I think about it, it is definitely much more about narcolepsy than any of the others, but— there's a good reason for that. And it turns out that yeah as you say, narcolepsy is so much going on, that I've come to see narcolepsy as like one of the best qualifications you could possibly have to be writing a book about sleep disorders. 'Cause it just covers— it covers everything. And I didn't realize it at the time but then you know, you're sort of trying to— I've got chapters that I've got to write about insomnia or I've got to write about restless leg syndrome— which I know nothing about! Actually, I know all about both those things. And most people with narcolepsy will too. And so finding these connections was rather wonderful. The structure then, actually the structure of this book is— relatively straight forward, in that I could almost treat a sleep disorder within one chapter as a contained thing and that obviously helps a lot when you're writing 'cause you can focus in on one thing and you know where it's going to go in the book, but. You do not want, I think, and at least my publisher's always encouraged me to try to—you know, mix it up, so that it isn't— then it's— it's not, and I might be wrong, but— then it's— if it's just one chapter that's totally isolated, not connected with the other, then it's just like reading a collection of disjointed stories. So you need to weave something through all of these that stitches them together into a more satisfying whole. The structure of a book like that is torturous. And writing the book was a completely simple, like once you've got the structure. But that is like, when you're pitching it to a publisher you've got like two pages that you're going to sell it, that's all you have to write. It sounds like really easy— that might take you four years to get those two pages good. So yeah, moving that bit around. And it is a bit organic, as it went, you know, "Ahh, there's that new connection, I can put that back in here and it'll touch with that bit I mentioned earlier," and so you've got characters weaving through, but me kind of going all the way through.

Julie: I know for me, running the marathon, I knew at that point I was writing a book and so it was kind of a strange thing to know if I don't finish the marathon I'm going to have to come up with a different ending—

[Henry laughing]

Julie: —so I was going to go with the end of law school— [laughs] —as the ending, but it did put an extra pressure on running that marathon. Just to finish, you know, I didn't think that people would care too much about the time— but it did, it was interesting to do that experience and as I was writing about my marathon journey I knew it would probably be part of the book so it was kind of a different way of thinking, whereas the beginning part of my journey with narcolepsy I didn't want to be a part of my life, I never thought I was going to write a book about it, I was like, get this narcolepsy out of my li— you know so, it's a different experience— and people have said that those sections of my book read differently and I kind of wonder if that's why, um— whereas like trying to recapture a time of my life that wasn't important to— you know at the time didn't feel significant to something that, "Ok, alright, I'm writing about this for a book." [laughs] But Claire what was your experience like?

Claire: Yeah, so relate to Henry's comment on the organic nature of structure. I think I had set out with something much more linear— you know like, I was very dependent on medical notes and my memory's a bit terrible which is a really interesting topic for memoir because how much are we dependent on our memories and therefore how much truth do we kind of weave into the narrative, but. I had certainly set out with this sort of very linear like, you know we start in 2009, when Mathilda's healthy and then we do you know the H1N1 vaccine and then everything goes south. But actually at the end I did a U-turn and I think it's 'cause I was reading, a lot— and just

felt more engaged with narratives that were a little bit more kind of jumping around in space, so I actually switched it all out at the end and I think I started with the present and then I jumped back to the past, and then I also did something else which was just a very sort of self-indulgent kind of reflective few weeks right at the end before I published where I just had this moment where I decided to— kind of frame each chapter within a child's book narrative that I had read to the children. And so you'll see in the beginning of my chapters there's a quote from real classics, you know it could be— Harry Potter or Trumpet the Swan, or whatever. And it was really interesting it was a very sort of creative experience and really sort of emotionally poignant and important to me to frame the context of what I was saying— with the past, I think. So I needed to jump around between being linear and non-linear.

Julie: I love the structure, I just love that you started with the really intense moment and then sort of back up to Mathilda's birth, and— and getting to know your family, so yeah. I thought that was a really powerful structure and the ending too, you kind of jumped around with time at the end.

Claire: I did. Yeah I think it just draws on you know a lot of personal experience and— difficult times, but also— as you write as a writer you start to process that and it is cathartic, and it is meaningful— and it is sort of a legacy. Whether we love that or not, it is you know once something's in print, that's something. But I actually feel the same way about all forms of art, you know whether we as writers put words on a page and construct paragraphs or, mentor our audience. If their gift is to create art forms that are more visual, more digital, more theatrical— you know there's all sorts of contributions, it's just, so happens that mine was with words.

Julie: We talked a little bit about memory, and I think for me I felt very similarly, especially those beginning years that I didn't want this to be part of my life and I did— forget if it was from a book or a class I took, they said to trust what you think. That you're probably more correct than you believe yourself to be, so I kind of went with that, and wrote some stuff and I eventually went back and found emails and that was very rewarding to actually see how closely the emails I'd written to a friend— like that same week of the actual thing happening, matched up so closely with my memory years later. I thought that was kind of interesting. Henry, I think you know you said that you didn't have a lot of writing but one of my favorite passages I think of your whole book is the um, your— detailed analyses of your sleep paralyses. First time you felt it you were, in India, I want to say?

Henry: Oh yeah, yeah, yeah yeah! And I've got a couple of little note books of things like that. One, which I'll come back to and then one from a meeting with a neuro— consultant neurologist where— and bear in mind this is pre-internet, 1994, no way of searching this up. I have written in this tiny notebook, the words narcolepsy and cataplexy. I'd self-diagnosed and I went to a consultant neurologist and went, "Could it be these?" [laughs] and was told, "No, it can't be these." But the— the India one, so that was around the same time, in '94, 1994— and then in the summer holiday I went sort of backpacking around India. I was really sleepy around the place, on these coaches and things, got to some hostel and just crashed out on the bed. And then woke up— but I couldn't move, and I could just hear— but this— you talk about in your book, auditory hallucinations. What I now know to be an auditory hallucination, so this kind of— quite disturbing kind of horror film-like sound coming from the overhead fan, it was just going round and round and round. And I couldn't move. And it was a bit of a battle and then eventually came out, like you do— and I was so frightened by it, and I was only 21 at the time so in that phase, that rather lovely phase of youth where you keep a diary and you write profound things in it and so I had one of those and I actually would write something every day in it. They're lovely. If a little bit embarrassing to look back at but— [laughs] I woke up and then I quickly got

the book and I wrote, I wrote exactly what it felt like. But that was— so that was the first time and the first time is pretty scary. And then when it happens like two, three, five, 10 times a night— ugh god you get bored with it. But and you kind of half know, don't you— what it is. But the other half of you is still terrified.

Julie: Were you—

Henry: —every time.

Julie: Were you surprised to rediscover that notebook? I can't remember about that part.

Henry: I kind of knew these things were there so it was like combing through for interesting stuff and yeah my medical notes when I tracked them down from a hospital that was really useful as well, to just look at the medical side of it and—! Yeah— get that verification 'cause it had the kind of, the notes from that consultant and others— and what they'd written— I had known about it at the time and they'd said no you don't have this, you've got this. And they had to write up their consultation, so you could see— [laughs] ohhhh, the things that they write about you after you self diagnose— correctly at the age of 21, from a library— thank you very much, so proud of that.

Julie: How 'bout for you Claire? I feel like the notes from appointments and everything, I bet that was probably pretty frustrating?

Claire: Oh so it was— so when I was writing I think that was the first time, and I'd brought like physically brought— Mathilda's notes over from the U.K. to the U.S. 'cause this again was sort of pre-digital really. And I had notions that when she was in hospital pre diagnoses, 'cause it was like a six month period where we were in and out of hospital and her demise was pretty dramatic. And I was really curious is like, why are they testing her? I mean we'd ruled out so many things like as you'd said Henry, epilepsy and other you know— cerebellum brain—

Henry: Brain tumors, yeah.

Claire: Like really dramatic kind of potential diagnoses, but. It was interesting re-reading the notes just because I wanted to be methodical, and as accurate as I could be, knowing that my memory was a bit sketch, and also you know I think there was a sense in which we of course as authors have the privilege of writing through our own lens, but— wanting to hold that intention with the truth as much as possible. But I did actually read in her notes— it was one I remember it, it was one morning in May sort of a year in, and I was like question mark mother and— yeah. Munchausen by proxy.

Henry: Oh, wow.

Claire: So, I mean I wasn't that surprised because we were, pre-diagnosis, both sent to psychiatry. So it's just tough to sort of read it you know when you actually see it written out in medical shorthand, but I think it did just— validate what I was thinking as a parent and also as an author and as a storyteller. So actually it was quite helpful but it was a little bit difficult— [laughs] as well— just to go to the edges of— that whole world of pre diagnosis and how difficult it is for people with narcolepsy to put their stake in the ground and kind of claim their territory, you know pre and post diagnosis but therefore— how important it is for us to augment those stories.

Henry: Yeah.

Julie: And I think Claire I mean the way that, for me, your book stops time in a way because I know we talk about these long delays to diagnosis you know eight to fifteen years and it can almost get, oh yeah you know. And mine's only six years and I'm lucky! And I know Henry you talk about that too—

[Henry laughs]

Julie: —but the way that you stop time to go through those stories and that's just the power of the story, I mean reminding that it's just every day you know some of those scenes in the hospital I'll just never forget.

Claire: It's a good point because actually Mathilda's diagnostic journey was really brief. But I think that's a comment on two things, one is that with the pediatric onset is usually very abrupt. Especially with type 1 where you know— it was basically cataplexy, a video of cataplexy that diagnosed her. Without that it doesn't matter how articulate I was, how determined I was— every time we went back to the ER room with really, really dramatic symptoms like ataxia and incontinence and visual disturb— like, nothing— nothing held. So I would really recommend getting as much video and photographic evidence as possible. So it— it was those pieces really that informed very much where I was coming from and I did lean very much on those documented pieces in her medical notes and then kind of married that with my memory. You know, I think I tried my best to chart the sort of nuances and the complexities of a diagnosis of narcolepsy and we just need more storytelling because it is so, so complex. And it is so invisible. And then you put that in a three-year-old body, and they can't even articulate what they're experiencing and it's like a totally— it's just a hot mess, really.

Henry: Your persistence as well, Claire— and just because a lot of people, that slightly terrifies me about it, is against so many obstacles, or people telling you to, ok, ok— just give you a little gentle pat, tell you to go and sniff some lavender or things. I mean most people will try twice, three times, five times. But as I've spoken to so many people who, you know, and the delay is because— this, they just got beaten and— nobody quite listened. So you do have to be, you have to have that person that you were for Mathilda and be that advocate and be dogged and persistent. Which is not how it should be, but it is the case, I think still.

Claire: I think all the narratives and— thank you, Henry, for saying that. But I think, you know we need as many narratives that feed into that journey between onset and diagnosis as possible, because it is so complex and so varied. Mathilda's story definitely was probably, fairly classic for a pediatric story— but how classic is that for a three-year-old, still not really. But we need all those narratives and perspectives to— really support people that are where you were Julie in your 20's, and Henry at 21. I think it's layering upon those different perspectives and putting it in print or— expressing it other ways. That really gives power and a voice to those that remain undiagnosed and are really struggling.

Julie: I wanted to ask you guys about— sort of how the reception has been? And were you surprised by anything, and also if there's anything you wish you would've included, I guess that's a big question 'cause I have a response to that myself, and there's something I wish I would've included, but— how's the response been and would there be anything you'd change?

Henry: Yeah, really good. No one has— No one's sent me a message saying they hated my book, so that's okay but they probably weren't going to, anyway. Kind of— ran out of time, and

there's a— you know I'd of loved to done more on Kleine Levin syndrome, and so I feel that's a gap for me, but I didn't you know, there's other sleep disorders but that's a very interesting one. That I should have covered and it gets scant attention so I feel annoyed by that. I would've loved to have been able to travel more, and meet more scientists in the research. I just went to Stanford for four days and knocked off about 10, it was brilliant, amazingly efficient bunch of interviews, but— and some brilliant people.

Julie: Claire, how about you? How do you feel the reception has been and is there anything you would change?

Claire: I think people are really generous, honestly. I've— I don't really like go on to Amazon but perhaps twice a year, one of my kids does, like, mum! you know, check this out. So that's really encouraging, but, um, would I change anything? I don't know, I— I mean, you know kind of re-reading— 'cause I read you guys' two books again recently and I was like, wait a minute, maybe I should read mine. It was a little bit, I don't want to say like a dog returning to vomit but I just feel like it was a great first attempt and I'd write it so differently. But on the other hand— I'm not the same, we're not there, and it was very much a story of its time. There is one scene that I wrote that I didn't put in and again this is the author's privilege really, to include or not include, but— yeah there was definitely, there was definitely moments where my head space went to kind of a sort of fantasy, actually. When it was really horrible in the first two years, and— I sort of had these weird daytime escapes where I would sit down and literally see myself walking away from my family and it was really strange 'cause— I was just walking with nothing other than a water bottle for, weeks and weeks and weeks in a desert somewhere. It was very odd. But it was a pleasant thought moment and I include— I did actually include it into I think the second draft and it didn't make the cut. When I was reflecting on why I didn't put that in and I think at the time of writing Waking Mathilda back in 2014, '16— I felt a lot of shame around that, and— because it sort of spoke to a mother that wanted to walk away. Which I didn't, really. I just felt I was absolutely desperate. But I wonder now, a few years down the road whether I would include it because— it was just the truth and I don't feel the sort of same amount of shame. But at the time when I wrote Waking Mathilda there is a— there is a chapter, I think it's chapter six if I remember rightly, on mother's guilt. So I was already like, loaded up with guilt and I felt like I couldn't add the shame. But maybe now I would because— I think it's all— speaks to truth and humanity and vulnerability and you know, we come out the other side but— it's really important to share that experience with others.

Julie: Yeah. That's really interesting.

Henry: It is.

Julie: I think for me the vulnerable bits got in— [laughs]

[Henry laughing]

Julie: —for the most part.

Claire: Well yeah.

Julie: But I think the thing I've look back on, that was a miss for me was that one of my big messages has been the important of social support— which I think is in there 'cause I talk about going to the Narcolepsy Network Conference and how impactful that was for me and also for my dad of course, but I actually had a therapist the first two years. You know I got a therapist before

I was— well they thought it was depression before they figured out it was narcolepsy, and so I went to a therapist for one week, and then found the word narcolepsy with cataplexy— but I forgot to cancel my appointment. So I just went back, you know and was like oh hey well it's not depression, I have narcolepsy with cataplexy and I ended up telling her about it, and really liking that, and then I kept her for the next two years and she definitely walked through that journey with me. And she's such a huge part of my experience, even in writing the book, she was the first person I told after my professor had said you should write a book, she was the first person I could say that out loud to. 'Cause I just knew my dad was not going to like it— [laughs] he was so important to me, and so— not only did she help me process my narcolepsy experience but she was a huge part of my book experience. And still to this day sends me articles about Oliver Sacks and, so— I really wish I would've included that because I think there should be no shame in getting support from different places and for me part of that was therapy, by accident, sort of. Because of the depression pre-diagnosis and so I wish I would've included that. Just sort of as another idea for people and— I don't think it was because of my feelings about stigma around therapy, at the time, 'cause I'd kind of like been in and out of therapy since I was—13, so I don't think I had— it wasn't about stigma for me, 'cause hey I put a sex scene in, I could put a therapist in, right. But I think it was a little bit of, I got tired. And I got lazy. And so of course you look back later and go, maybe I shouldn't have gotten lazy on that one. And I should've weaved it in a bit in a few places and— made her a character.

Claire: Well there is this sense in which at the end of the project that's like two, three, four years long you do need to like wrap it up— [laughs] you know and that's the difference between being a perfectionist and being like, this isn't perfect, I'm never going to get it— and just being like, I just need to wrap this up. So, you know I resonate with you on that for sure. You know it's not perfect by a long way but, it's something.

Julie: We definitely want to make sure we get to time to talk about what's next for us but also if you have any tips for people that are interested in sharing their story through writing, I think my biggest one I've already kind of mentioned which is to actually— trust your memory, and trust your version of reality because that is what you have— and not to second guess yourself, I think that would be one of my biggest tips. And I'll have to think, maybe you guys'll say some other good tips and it'll remind me of stuff. [laughs]

Claire: I think I find— commit to the writing process— sincerely, and in terms of like creating really good habits around writing, whether that's journaling or blogging. You know there's some great avenues and platforms like Medium.com where you don't even need to have your own website and you can kind of just like push the publish button, that always feels really good. So, to be committed to it and in that process be okay with like, developing your voice. And then be open to— 'cause one of the things we haven't talked about is, you know, Henry's more robust route of traditional publication and our more alternative route of self-publication and you know what those differences look like, so there's so many opportunities for people, just saying, if you can commit to it, do it.

Henry: Because I'm old—

[Julie and Claire laughing]

Henry: —ish. [laughs] I have a feeling that, I mean books is great— and if you want to write, then— yeah, definitely the thing of journaling or just keeping a diary, writing. But obviously most people are going to be doing that through some kind of blog or something, that would be great. Amazing. Not even if— if nobody responds, it doesn't really matter. The act of pressing that

button and putting it out there is very important. Because you will have gone through a perfecting, editing bit beforehand. You're going to have to have been happy with this, and then you put it out there, and then you will start— getting feedback and you will start getting more confidence. So, all of that's great. And I think if you're writing about narcolepsy, well then just do it. Because your experience is— everyone's experience is— completely different. Completely original. And completely valid, and there's Claire and— yeah, as you're both saying, we need all our— we need that breadth, so that everyone, medical professionals and all the people out there start to see beyond— a straight forward kind of stereotype, a simple one dimensional stereotype of narcolepsy. There's quite a lot of different things, there's like an infinite number of different things. Yeah but I— thinking about just when I started, books may not be it, if you're— we need more creative kind of publishing using all the incredible tools that are out there. Clever ways to get the message out that I'm— now too old to learn. [laughs]

Julie: Like TikTok?

Henry: That would be the next opportunity, I think— I mean I was thinking about blogging obviously, but that's quite old and conventional but then you know, I don't know— Someone needs to get up and make a whole TikTok thing, don't they?

Claire: I think it's you Henry, come on.

Henry: Me? Aw, yeah, right.

Claire: You're not too old, come on. You've got this, you've got this.

Julie: Yeah, I think you know too if people feel afraid to share their full name or something we've always said with Rising Voices that you can just do it with your first name or a different name and I think you can probably do something similar with Medium. And for me it was— when I put my first blog post out was the first time I said, “Hi, I'm Julie Flygare, I have narcolepsy.” On the internet. and that did feel like a big moment. I think there are ways to still share aspects of your stor— or we've published from people anonymously— a medical student with narcolepsy that really wanted to share her experience and so we were able to do that through our blog, you know, and maintain her privacy and still to this day people years later commenting back on that. So, there are definitely ways to share and maintain some privacy if you want to. So, what's next? I mean what kind of creative projects— besides Henry's TikTok channel—

[Claire laughing]

Henry: Yeah, I'm starting a TiKTok channel.

Claire: So exciting! [laughing]

Henry: That's me, I'm sorted.

Claire: Exactly!

[Henry laughs]

Claire: Um, I just finished an MFA at St. Andrew's on— it was also creative non-fiction but had a different kind of angle. I mean I think it's interesting 'cause narcolepsy's always going to be part

of you know our family's journey, so I can never really completely separate from it, and neither would I want to because it is, you know, the truth but— yeah I was writing on home and belonging and displacement and someone who's moved around a lot and what is it like, to— what is home? What does home mean to people, is that the building that you grew up in, is it your current place where you raise your children, is it your community, so— it was a really neat exploration. I'm not sure if I'll publish it but, we'll see.

Julie: I feel like your different homes in the book all very much came to life, like I'm somewhat not surprised to hear that, because— that you went in that direction 'cause I feel like, you know even the Princeton— year that you spent there, it just felt like we could really envision the different places.

Claire: Yeah. It's really interesting actually, 'cause I wasn't really built for it actually, you know. I kind of like the idea of just being you know, near my family in London. So, it's been quite a journey and then that was amplified by moving from Bristol in 2011 to California, it was really— important, because we obviously were seeking out treatment and expert care from Stanford but— so yeah, even my current writing I think is a reflection on how those experiences have informed me now as a person and— and hopefully relating to people that feel similarly displaced but also seeking to figure out identity within a broader context of community.

Julie: Henry, any other projects besides TikTok?

[Henry and Julie laughing]

Henry: No, not really. I mean not— I've got things I might write one day, and I learned to teach a few years ago so that's an ongoing project that will never stop. Trying to get better at that. Yeah.

Julie: Hmm. People have asked me if I'd write another memoir, you know it is kind of interesting I guess, especially now 10 years— have gone by. So it's interesting how close people still feel for me but from a time in my life that feels so far. [laughing] You know, my early 20s. And so I have thought about that, I don't know what the story would be, exactly, and how interesting it would be. I think it has to do a lot more with like my own character development and like leadership sort of and how you're kind of winging it and you don't really know what you're doing, but people seem to think you do.

[Henry chuckling]

Julie: And you know I still have the history of GHB or Xyrem, I could turn that into a book. But I think what I've focused on is helping other people share their stories and loving having founded the Rising Voices program and— and now Lauren is the wonderful program manager, I never thought I could even leave that program with someone else because it felt so close like, oh no one would ever be able to understand all these nuances of storytelling and it's been incredible to see how Lauren now trains these advocates so well to share their stories. Because like, I'm sick of my story. Like, you know I've heard it— and many, many times. And so it's the energy from hearing other people's is I think a big driver and so many times I hear someone sort of like, "I can't wait for everyone to hear your story!" So, I love that feeling. Thank you, guys, so much for taking this time to have this discussion, that was a dream discussion for me. To share this time with you and just thank you guys for what you've contributed to this community and continue to give back, like giving this time. And yeah, I hope the big message that everyone

takes away is of course that we need more stories! [laughing] So, hopefully there's some encouraging tips and ideas.

Henry: Yeah, but then also just you have mentioned, do you want to just, while you've got people there, the Rising Voices.

Claire: Mmm.

Henry: They should just, that would be a good place to start, wouldn't it?

Julie: Yeah, we— you know it's a nice leadership training that, right now— trains people on how to share their story via speaking, but I think there's a lot of you know— going from there, and different people are doing really different creative things, from that training. So it's a good basis I think. We have over 100 storytellers that are trained to date, across the U.S. and in the U.K. US and different places around the world, so. We just hope to find more opportunities for them and I think that's just the next step, is making sure that patient stories are more integrated with the medical system, and— more opportunities for people to share those stories.

Claire: Thank you so much Julie, for the opportunity.

Henry: Yeah.

Claire: We've got another like, 10 hours, I don't know. I love nerding out. I'm not actually a nerd but this has been fun, thank you so much.

Henry: Yeah, really fun. Thank you.

Julie: Alright, thanks everybody for tuning in.

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