



NARRATING NARCOLEPSY TOOLKIT

Created by:

projectsleep



TOOLKIT INDEX

Welcome	3
Meet the Panelists	4
Narrating Narcolepsy	5
More Tips & Takeaways	13
Resources	14



WELCOME!

We are so glad you are here. This toolkit is designed for people living with narcolepsy and their loved ones to offer new tools, tips, and perspectives on navigating narcolepsy. Project Sleep created this toolkit as part of the **Narcolepsy Nerd Alert** series.

Narcolepsy Nerd Alert is an educational series diving deeper into specific topics relevant to narcolepsy. For each episode, Project Sleep broadcasts a live event via Facebook, hosted by Julie Flygare, JD, Project Sleep's President & CEO.

After each live broadcast, we create a corresponding toolkit (like this one!) to capture our collective knowledge to help others down the road. Quotes featured throughout the toolkit are from panelists and participants who joined us for the live broadcast.

PLEASE NOTE

The **Narcolepsy Nerd Alert** series is intended for educational and awareness purposes and is not a substitute for medical attention. If anything in this toolkit sparks questions for you about your medical management, please bring those questions to your sleep doctor or narcolepsy specialist.

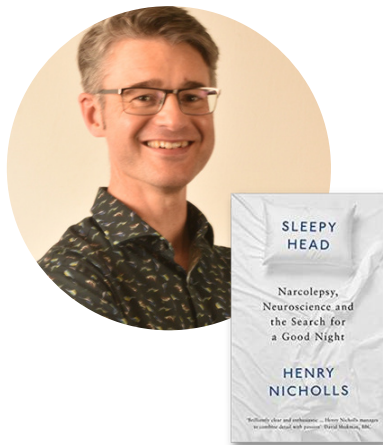


MEET THE AUTHORS



Claire Crisp is an award-winning author and advocate for children with narcolepsy. Her book, *Waking Mathilda, a Memoir of Childhood Narcolepsy*, charts her family's course from the UK to the US in search of a life-changing treatment and attempt to rescue their youngest child, Mathilda, who developed narcolepsy following the 2010 H1N1 flu vaccine. Her work has been featured in national newspapers, medical journals, and on national radio.

Claire is the co-founder and Chief Experience Officer of Sleep Consortium, a non-profit organization dedicated to accelerating research in central disorders of hypersomnolence and related diseases. In 2022 she was awarded an MFA from the University of Saint Andrews for a substantial contribution to the creative non-fiction literature titled *Belonging: A Memoir of Home, Place, and Identity*.



Henry Nicholls is a teacher, science journalist, and author specializing in evolutionary biology, conservation, and the history of biology and sleep. He developed narcolepsy when he was 21 years old and his book, *Sleepyhead, the Neuroscience of a Good Night's Rest*, explores the neuroscience of sleep and the devastating impact sleep disorders have on physical and mental health. Henry lives in London.



Julie Flygare, JD, currently serves as President & CEO of [Project Sleep](#). She was diagnosed with narcolepsy with cataplexy in 2007 while in law school. Julie is an internationally recognized patient-perspective leader, an accomplished advocate, and the award-winning author of *Wide Awake and Dreaming: A Memoir of Narcolepsy*.



NARRATING NARCOLEPSY

Would you write about your experience with narcolepsy?

On April 27, 2022, leading narcolepsy authors Claire Crisp, Henry Nicholls, and Julie Flygare came together for the first time to discuss their books, share behind-the-scenes stories from their publication process, and provide tips for aspiring writers.

Writing a book can feel like a daunting task, and narcolepsy – a complex neurological condition whose symptoms are mostly invisible – adds another layer of challenge. We hope Claire, Henry, and Julie's insights and the resources contained in this toolkit inspire and assist you in your writing journey!

- Watch the [Narrating Narcolepsy](#) Video
- Learn more about the [Narcolepsy Nerd Alert Series](#)



I've come to see living with narcolepsy as one of the best qualifications you could have to write about sleep disorders.

- Henry



The journey between narcolepsy onset and diagnosis is complex and varied. Putting it in print gives power and voice to those who remain undiagnosed and are struggling.

- Claire



My hope is that people with narcolepsy continue to find ways to bring our stories to general audiences and the medical space.

- Julie



GETTING STARTED

Writing a book requires hard work, dedication, and ambition, but it's a powerful way to share your authentic experience.



When I started to think seriously about writing, I knew I had to learn the craft of writing. For me, that meant reading. I read over 100 memoirs in the process of writing 'Waking Mathilda' and spent as much time studying the books I didn't love as I did on the ones I really liked.

- Claire

You can tell your story without formal training as a writer. There are many ways to improve your craft and prepare to write a book. Keeping a journal or posting on a blog are two good ways to develop your voice as an author and practice your writing habits.

Choose your genre. Some authors say to write in the genre you most enjoy reading. Henry had been writing science journalism for years before taking on sleep disorders as subject matter. Julie found inspiration from the works of Dr. Oliver Sacks when writing her story.



Dr. Sacks's writing brings to life something invisible – the internal experiences of people with neurological conditions. He validates his patients' perspectives. That inspired me and gave me the courage to talk about the hallucinations and sleep paralysis incidents I'd experienced.

- Julie

Hone in on your book idea. Maybe you already know what your book is about, but this may evolve during the writing process. For example, Claire initially thought she would write about her daughter's experience, but realized that her book would have to tell her family's story through her own lens.



Do your research. No matter which genre you choose, research is an important part of the writing routine. For fiction writers, research can inform decisions about the time-period, setting, and character archetypes in your book. In non-fiction genres, research is a larger part of the process. Henry conducted hundreds of interviews with scientists and people living with sleep disorders while writing *Sleepyhead*.

“ I went to Stanford for four days and knocked off about ten brilliant, amazingly efficient interviews. I would have loved to travel more and meet even more scientists.

- Henry

Plan it out. Well-structured writing creates clarity and cohesion for your readers. An outline is an essential blueprint and will help you get "unstuck" while you're writing. There are many structures to choose from, and your genre and writing style may influence your choice. Julie's memoir follows her story chronologically, whereas Claire's moves back and forth in time. Henry, a science writer, devoted roughly one chapter to discussing each sleep disorder included in his book.

“ If each chapter is isolated – not connected with the others – it's like reading a collection of disjointed stories. Weave something through that stitches them together into a satisfying whole.

- Henry

Research and planning can take a long time, years even, and should not be rushed. However if you find preparation perfectionism holding you back, at a certain point you may just need to jump into writing!

“ Writing a memoir draws on a lot of personal experience, including difficult times, but as you write, you process. It is cathartic, it is meaningful, and it is a legacy.

- Claire





WRITING

Our guests offered guidance for overcoming some of the challenges of writing about narcolepsy.

Trust what you think. You're probably more insightful than you believe, and your perspective is valuable.

Remember that narcolepsy is a complex topic. There are layers of symptoms, which can be challenging to describe independently, and sometimes it's all happening at once. Often writers are advised to "keep it simple," however more nuanced stories can more accurately depict the range of narcolepsy experiences.

If you read about other sleep disorders, you may find a lot of common ground and some significant differences. Many symptoms people with narcolepsy may experience — daytime sleepiness, restless legs, disrupted nighttime sleep — are also associated with other conditions, and to Henry "finding these connections was rather wonderful."

It's also worth noting that certain symptoms — hypnagogic & hypnopompic hallucinations and cataplexy especially — can look like symptoms of other neurological conditions. For example, cataplexy is commonly mistaken, even by medical professionals, for a type of epileptic seizure. This is a challenge that leaves many people with an incorrect diagnosis for decades, and it's one more reason more stories are needed — to illuminate this crucial difference.

Don't be afraid to slow down. Detailed descriptions of events and emotions will draw your readers in and help them understand your experience.

“ Claire's book stops time in a way, and that's the power of the story. We talk about long delays to diagnosis — often eight to fifteen years — but Claire's stories remind us that the experience of living with narcolepsy is every day.

- Julie



Use your resources. It can be helpful to go back to your outline, research notes, journals, or medical notes if you get "stuck" or feel unsure about a sequence of events. While writing her memoir, Claire reread the medical notes from before her daughter's diagnosis to be as methodical and accurate as possible. Henry included a detailed description of his first experience with sleep paralysis, which he had captured in a journal entry at age 21.

“ Authors have the privilege of writing through our own lens, but I wanted to hold intentionally to the truth. Reviewing medical notes from before Mathilda's diagnosis validated my thoughts as a parent, and also as a storyteller.

- Claire

Keep it real and just keep writing. While editing you may choose to remove or modify some scenes, but do your best to put words on the page until your first draft is done. It's natural to struggle with some parts, while others will flow more easily.

“ They say, 'Write like your mum's never going to read it.'

- Claire

Henry found that writing about sleep, specifically the disrupted sleep that often comes with narcolepsy, was harder than writing about other symptoms. Julie added a scene late in the process of writing her book about having cataplexy during sex. She says, "I spent three years with the text, and I just got more and more honest. Ultimately I'm glad those pieces made it into the final version."

“ Narcolepsy can affect people on very personal and intimate levels. What I appreciated very much while rereading 'Wide Awake and Dreaming' was how vulnerable Julie was willing to be over really personal issues.

- Claire



EDITING

Your book will probably go through several rounds of revisions and editing, looking at each sentence and the text as a whole.

You may choose to take editing on yourself, seek out a professional editor, or even ask trusted peers for feedback.

Look at the big picture (characters, plot holes, missing information) and at the specific language and sentence structure in your writing. You can look for themes that could be strengthened and consistency in your tone.

It can be helpful to develop a system to track your edits, and to save scenes that have been cut for future writing.

When your revisions are complete and you're satisfied with the text, you can look for opportunities to add meaningful final touches. In the last couple of weeks before publishing, Claire reflected on her book and picked quotations from children's literature to frame each chapter.

“ In an earlier version of 'Wide Awake and Dreaming' there were certain people in my life that hadn't been in the text, so I tried to make things like my family structure more clear. - Julie

“ My first draft was like an explosion of words on the page, and then second draft I'm pulling back, third draft I'm running it by some people and we take some parts out. - Claire



PUBLISHING

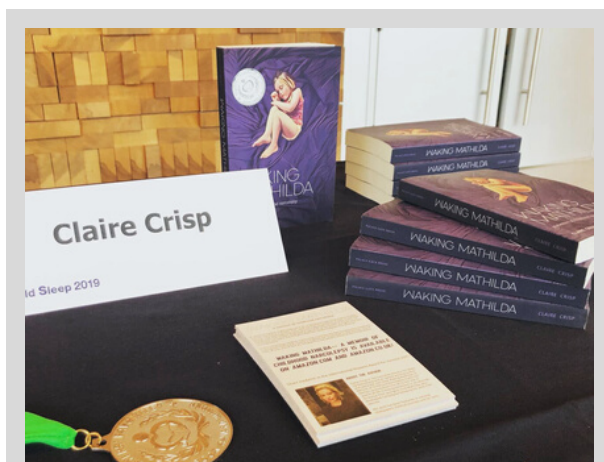
When you're ready to publish your book, you have two options: self-publish or sign a deal with a traditional publisher.

Traditional publication involves signing a deal with a publishing house and is usually facilitated by a literary agent. This deal gives the publisher exclusive rights to print and disseminate the book.

- If you're considering traditional publication, you'll need to submit a book proposal to a publishing house. Henry worked on the proposal for *Sleepyhead* for years before he even started writing the book.
- If the proposal is accepted, the author works with the publishing house to create a fixed number of drafts. After that the publishing company can decide to bring the book to the public or not.

Alternatively, there are now more ways than ever to self-publish your book: via self-printing, print-on-demand, or as an ebook or audiobook. Using any of these methods, or a combination, allows authors to get their book in front of an audience without going through a publishing company.

Self-publishing gives the author more freedom in how to promote and share their book. For example, Julie read chapters of her memoir weekly on Instagram live and discussed the writing process with viewers.



Flyers on Claire's table at a conference announce that her memoir is available to buy.



Julie and Claire are authors & publishers of impactful memoirs of narcolepsy.



POST-PUBLICATION

Celebrate! You have published your book. Take a deep breath and enjoy this moment.

You can enter **writing competitions** to find new audiences and gain recognition for your book.

Offering an **audiobook or translations** will broaden the audience your book can reach. Typically the author pays for the narrator or translator.

Don't stress too much about how your book is being received by the public. Claire rarely checks reviews, and no one has ever messaged Henry to say they hated his book.

You may find there are things you would change about your book after it's published. That's okay. Even our guests have changes they would make to their wonderful work!

“ The therapist I saw for two years after being diagnosed helped me process my narcolepsy experience, and was also a huge part of my book experience. I really wish I had included her as a character. - Julie

“ I ran out of time to do more on Kleine-Levin syndrome, so that's a gap for me. There are other sleep disorders, but that's a very interesting one that gets scant attention, and I wish I had covered it. - Henry

“ I feel like 'Waking Mathilda' is a great first attempt and I'd write it differently now. But on the other hand, I'm not the same. We're not there. And it was very much a story of its time. - Claire



MORE TIPS & TAKEAWAYS

Everyone's experience is **unique and complex**, and no single story can capture the entire scope of living with narcolepsy.

Commit to the writing process sincerely. If you know you want to work on a book eventually, write journal entries, stories, or blog posts to develop your voice as an author. Maintaining a blog is also a good way to practice editing your work and sharing it with the world.

Trust your memory and your version of reality. They're probably more accurate than you believe them to be.

If you're not ready to disclose your diagnosis publicly, you can still share your story **anonymously** or use a pen name. Graduates of Project Sleep's Rising Voices program often publish their stories using their first name only.



If you're writing about narcolepsy, then just do it. Everyone's experience is completely different, completely original, and completely valid. We need that breadth so everyone — medical professionals and the general public — can see beyond a simple, one-dimensional stereotype of narcolepsy.

- Henry



Claire signs a copy of her memoir.



Julie and Henry meet up at a conference.



RESOURCES

WRITING AND PUBLISHING

Bowerman, P. (2013). *The Well-Fed Self-Publisher: How to turn one book into a full-time living*. United States: Fanove Publishing.

Franklin, J. (1987). *Writing for Story (Mentor)*. New York: New American Library.

Greene, A. E. (2013). *Writing Science in Plain English*. United Kingdom: University of Chicago Press.

Heath, D., Heath, C. (2007). *Made to Stick: Why some ideas survive and others die*. United States: Random House Publishing Group.

Karr, M. (2015). *The Art of Memoir*. United States: HarperCollins.

Lamott, A. (1995). *Bird by Bird*. United States: Anchor Books.

Lyon, E. (1995). *Nonfiction Book Proposals Anybody Can Write: How to get a contract and an advance before writing your book*. United States: Blue Heron Pub..

Palumbo, D. (2000). *Writing from the Inside Out: Transforming your psychological blocks to release the writer within*. United Kingdom: Wiley.

OUR GUESTS' FAVORITE BOOKS

Karr, M. (2001). *Cherry*. United Kingdom: Penguin Publishing Group.

Karr, M. (2009). *Lit: A memoir*. United States: HarperCollins.

McCourt, F. (1999). *Angela's Ashes: A memoir*. United States: Scribner.

Sacks, O. (2020). *A Leg to Stand On*. United States: Knopf Doubleday Publishing Group.

Sacks, O. (2021). *The Man Who Mistook His Wife for a Hat: And other clinical tales*. United Kingdom: Knopf Doubleday Publishing Group.

Solomon, A. (2013). *Far from the Tree: Parents, children and the search for identity*. United Kingdom: Scribner.



BOOKS ABOUT NARCOLEPSY

Crisp, C. (2017). *Waking Mathilda: A memoir of childhood narcolepsy*. United States: Palace Gate Press.

Flygare, J. (2013). *Wide Awake and Dreaming: A memoir of narcolepsy*. United States: Mill Pond Swan Publishing.

Hufford, D. (1982). *The Terror That Comes in the Night: An experience-centered study of supernatural assault traditions*. United States: University of Pennsylvania Press, Incorporated.

McKay, D. B. (n.d.). *Fake Medicine: Exposing the wellness crazes, cons and quacks costing us our health*. Australia: Hachette Australia.

Moore, B. A. (2016). *40 Winks: A narcoleptic's journey through sleep, dreams & spirituality*. United States: Brenda A Moore.

Nicholls, H. (2018). *Sleepyhead: The neuroscience of a good night's rest*. United States: Basic Books.

Przekop, P. (2008). *Aberrations*. United States: Emerald Book.

Zee, G. (2017). *Natural Disaster: I cover them. I am one*. United States: Kingswell.

PATIENT ORGANIZATIONS

Major US Organizations:

- Hypersomnia Foundation www.hypersomnifoundation.org
- Narcolepsy Network www.narcolepsynetwork.org
- Project Sleep www.project-sleep.com
- Wake Up Narcolepsy www.wakeupnarcolepsy.org

International Organizations:

- Listed on Project Sleep's World Narcolepsy Day webpage www.project-sleep.com/worldnarcolepsyday.

Project Sleep's Rising Voices program trains speakers and writers to share their stories to raise awareness and decrease stigma around sleep disorders.

www.project-sleep.com/rising-voices-of-narcolepsy/



THANK YOU!

We are so grateful that you took the time to check out this toolkit!

Project Sleep is a 501(c)(3) nonprofit organization dedicated to raising awareness about sleep health and sleep disorders.

More resources at: www.project-sleep.com

