CAREERS

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HERIOT-WATT UNIVERSITY

Geologist Stephanie Zihms, who has multiple sclerosis, urges researchers to keep copies of all their medical records, especially if moving internationally.

HEALTH

Science and sickness

How to cope with a chronic condition while pursuing a research career.

BY EMILY SOHN

Jennifer Mankoff was a mid-career researcher in 2006 when she started to experience extreme fatigue. Her condition worsened during the following year with frequent flu-like attacks, a frozen jaw, hearing loss, memory trouble and problems with fine motor control.

In 2007, Mankoff was diagnosed with Lyme disease — a tick-borne illness that can be difficult to manage, thanks to disagreements in the medical community about how to test for, diagnose and treat it. She struggled to find medical solutions, but continued to publish, teach and win grants and tenure. But it took her a while to come to terms with her physical limitations.

"My image of who I could or should be didn't match up with reality in terms of my productivity," she says. "I would go back and forth between frustration and pride over what I had accomplished." Today, as an endowed professor at the University of Washington in Seattle, she studies human–computer interactions and accessible technology for those with chronic illnesses or disabilities.

Mankoff is one of many scientists worldwide who face emotional and practical challenges in their work as a result of long-lasting or recurrent medical conditions. Working as a scientist can be physically and mentally demanding, in the laboratory and in the field. It can be even harder for those with physical limitations, who might need extra rest or days off work.

Researchers who are chronically but not terminally ill might also fear bias and stigma (see 'Know your rights' for a summary of protections available under the law) if they leave work early or ask for extra help. This is particularly true if they have an illness that's 'invisible' to others, such as arthritis or diabetes.

Selective disclosure about a condition can help to foster understanding, and an acceptance of the need to accommodate physical fatigue or weakness, or additional time away from the lab, say some who have chronic maladies. They add that it can also be useful to focus on crucial tasks — such as completing a manuscript — when energy levels are highest. Ultimately, say scientists with long-standing medical conditions, perseverance is essential to success. Sticking with a research programme also signals to superiors and colleagues, ▶

and to others with chronic illnesses, that a diagnosis need not stymie a research career.

No firm statistics are available on how many scientists worldwide have chronic illnesses, syndromes, conditions or diseases; and definitions of these differ from nation to nation. The US Centers for Disease Control and Prevention estimates that around half of all adults in the United States have at least one chronic condition. Although it does not define such conditions, it lists diabetes and arthritis as examples. The World Health Organization defines chronic conditions as being "of long duration and generally slow progression"; its examples include cardiovascular diseases, cancers, chronic pain and diabetes.

A NEGLECTED PROBLEM

The experience of balancing an academic career with a chronic health condition has been under-studied and its effects underestimated, says Kate Sang, a sociologist at Heriot-Watt University in Edinburgh, UK, who has been working on a study on illness and disability in academia.

Sang, who has degenerative nerve damage in her arm, was told that she would have trouble finding even 10 or 15 subjects, but since launching the study, she has communicated with more than 70 researchers.

In interviews, a number of those scientists said that their chronic conditions make it difficult to write enough grants and publish often enough to advance their careers. Some scientists reported that they had switched fields to reduce the load on their bodies. Attending conferences was physically difficult for many: those who use wheelchairs said that meeting rooms and other facilities were often hard to access. One study subject could not get into a room to give her own talk.

Many subjects thanked Sang for listening to them. "I found that quite upsetting, to think that this is a very articulate, very privileged group of people — academics, people with PhDs — who still felt they didn't have a voice in academia," Sang says.

Getting accurate diagnoses can be difficult for scientists, who often need to move from lab to lab and nation to nation, and so have to continually find new physicians. For years, geoscientist Stephanie Zihms was told that her tingly limbs, blurry vision, fatigue and other symptoms were caused by benign cysts, carpal tunnel syndrome or stress. She has moved from Germany to Scotland to England, and is now back in Scotland, at Heriot-Watt University (where she knows Sang), but her health records haven't always been transferred. At some point, they went missing altogether. Short appointments with new doctors in each new location hadn't given her enough time to explain her history.

She finally learnt from a doctor that she might have multiple sclerosis, but it was another ten months before she got a definitive diagnosis, in autumn 2016. Zihms says that she received no advice on where to seek support or more information, and she wept in her car for 15 minutes before she could drive home. "I think having the same doctor would have led to an earlier re-check," she says. She recommends keeping a copy of all medical records, including communications from providers, hospitals and other facilities, even if that means requesting them under freedom-of-information laws.

TO TELL, OR NOT TO TELL

Many scientists grapple with the question of whether to disclose their condition and, if so, when and to whom. The timing of a condition's onset can influence those decisions. Madison Snider, a master's student in environmental science, was diagnosed aged two with juvenile rheumatoid arthritis. As an undergraduate, she found it best to tell professors early on about her illness, to avoid having to explain it to them when she most needed help.

She adopted the same strategy in 2016 while being interviewed for her current programme during a two-day visit to North Dakota State University in Fargo. She learnt that she would need to move, fill and drain large tanks of water. Snider told her potential superior that she experiences pain daily and that on some days she cannot walk. He told her that he would make sure that assistants were available to help her with the tanks. "It's an awkward conversation because when you look at me you don't necessarily see my arthritis," she says. "It was really nice that he was willing to work with me. It made me feel he had confidence in me."

> *"Prioritization is absolutely critical when one is in a diminished state. If it's trivial, let it go."*

Yet some opt to conceal their condition for fear of damaging their career. There's a fine line, Mankoff adds, between advocating for oneself and coming across as a problem, and staying on the right side of that line requires constant vigilance. Even now, she is willing to ask for a classroom close to her office or a chair to sit on during lectures, but she hesitates to request extra staff, for example, because she doesn't want to argue about whether the funding should come out of her research budget.

Zihms opted to disclose her condition to her supervisor, who was sympathetic and told her to e-mail any time she needed to stay at home. But she didn't tell her colleagues at first, and worried that they would think she was lazy on days when she could barely move and didn't come in.

Ultimately, she says, she decided to be open, mentioning her illness in tweets and in a blog, and she has received much support. During a weekend when she guest-tweeted for Shift.ms, a UK-based social network for people with multiple sclerosis, a college student expressed gratitude on learning from her that a research career was still possible. "Younger scientists told me it took someone to be open about their disabilities for them to become suddenly aware that there was a career out there for them," she says.

FOCUS ON THE ESSENTIALS

Navigating a research career along with a chronic illness, say many researchers, requires zeroing in on what is most essential. Leonard Jason, a psychologist who was diagnosed in 1989 with myalgic encephalopathy/chronic fatigue syndrome (ME/CFS), realized that he needed to be strategic about his work and careful not to overtax himself. His approach has led to recognition,

KNOW YOUR RIGHTS

What you're entitled to at work

Legal protections exist in the workplace for people with chronic conditions, and support is available, although details vary from country to country.

European Union

- The European Union follows the UN Convention on the Rights of Persons with Disabilities (see go.nature.com/2bmhlhu).
- The Academic Network of European Disability Experts evaluates EU laws and policies that affect disabled people (see go.nature.com/2or5iku).

In the United Kingdom, specifically:

- The National Health Service offers advice for employees with long-term medical conditions (see go.nature.com/2yyvez9).
- The Equality Act 2010 protects those who have certain conditions, including multiple sclerosis, against discrimination (see go.nature.com/2klipz4).

United States

- Federal laws include the Americans with Disabilities Act (see go.nature.com/2oli8zl) and Section 504 of the Rehabilitation Act of 1973.
- The American Association of University Professors offers guidelines for accommodating disabilities and explores legal implications in academia (see go.nature.com/2yyjdap).

Canada

- Legal protections include the Canadian Charter of Rights and Freedoms and the Canadian Human Rights Act. **E.S.**


DENNIS WISE/UNIVERSITY OF WASHINGTON

Jennifer Mankoff, who experiences extreme fatigue, studies technologies for people with disabilities.

including awards for excellence in research and, at one point, a position on a US federal panel advising about research on ME/CFS. He recommends that scientists pursue the work that matters most to them. "The reality is that you can't do it all," says Jason, of DePaul University in Chicago, Illinois. "Prioritization is absolutely critical when one is in a diminished state. If it's trivial and you don't care about it, let it go."

Overdoing it on good days can end up backfiring. Zihms was recently laid low with exhaustion for two days after spending six hours outside on a cold, windy day doing fieldwork in Brazil. She now prepares carefully before doing fieldwork in the depths of winter and sets aside time to recover afterwards. At conferences, she saves energy by resting between sessions and staying in a hotel nearby. And because her diet affects her fatigue levels, she makes her own breakfasts and lunches.

Mankoff finds it useful to break down large tasks into smaller ones of varying lengths so that if she has, say, two good hours or ten good minutes in a day, she can accomplish at least something that day. She honed that skill in her first year as a computer-science PhD student in 1996, when she developed a repetitive strain injury after using a poorly designed keyboard. She switched to voice-recognition software, but that led to a vocal-cord injury.

Although frustrated, she realized that she had learned how to prioritize tasks and to focus on her work when she was feeling well. Today, she limits Facebook and other social-media time to avoid distraction. She also recommends a blog community called Chronically Academic.

Therapy can be useful, Zihms adds. And self-care is important, too, says Snider. Adopting a kitten has helped to fend off the anxiety and depression that are common companions to arthritis. "No matter how down I get or how much my knees hurt," Snider says, the kitten relies on her, and caring for it is not too strenuous a task.

Coping with a chronic illness requires planning for the unexpected, and could require a job change. Julia Hubbard, a biophysicist who has type 1 diabetes and the autoimmune disease lupus, packs suitcases two weeks before trips in case she lacks the energy to pack nearer the time.

Shifting the focus of her work has also helped her to accommodate her condition. When she first became ill in the early 1990s, frequent hospital appointments and sick days made it hard for her to conduct protein-chemistry experiments as part of her job at a pharmaceutical company. She switched to a data-focused position that allowed her to work remotely when she needed to. In 2001, she retrained as a protein crystallographer and is now a research scientist at the Francis Crick Institute in London, where her manager is sympathetic to her needs, and where working remotely is an option if she needs it.

Looking back, she says, she wishes that she had been gentler with herself when she first got sick. "You've got to adapt to it. It's a loss and there's a grief cycle."

Learning to adapt can build confidence in a researcher's ability to handle setbacks, Mankoff adds. In the past couple of years, she has been feeling well enough to increase her publication rate and to feel excited about the future work ahead. But she also knows that she could relapse at any time. Still, with a battery of well-honed coping skills, she feels optimistic about the future.

"Even though I'm a full professor, I feel like I'm just getting started in an exciting way," she says. "I'll accept it if I relapse or go back to doing less. I'm just having fun digging in and solving problems." ■

Emily Sohn *is a freelance journalist in Minneapolis, Minnesota.*

GENDER

Pay differential

Pay disparities between female and male PhD holders in the United States exist across almost all fields of science and engineering, according to a report from the US National Science Foundation (NSF). The report examines annual salaries for those who earned their doctorate in 2016 and had confirmed permanent employment in the life sciences, physical sciences, mathematics and computer sciences, psychology and social sciences, or engineering. Across all fields, the median salary of US$92,000 for men was 24% higher than the $74,000 median salary for women. In biomedical and biological sciences, women earned $67,500 to men's $77,000; in geosciences, atmospheric and ocean sciences, the figures were $65,500 for women and $71,000 for men; in physics and astronomy, women earned $89,000 to men's $100,000; and in engineering, women earned $92,000 to their male counterparts' $100,000. Women had lower salaries in all fields of social sciences, including psychology and economics. In health sciences, women and men disclosed equal salaries of $80,000. The NSF report did not indicate whether the salaries reported were within or outside academia.

COLLOQUIA

Men get more invites

Female scientists give fewer colloquium talks than do their male counterparts, reports a study published in December (C. L. Nittrouer *et al. Proc. Natl Acad. Sci. USA* http://doi.org/chm6; 2017). The study authors analysed the gender differences among 3,652 colloquium speakers at 50 prestigious US research institutions in the 2013–14 academic year. They found that male speakers gave more than twice as many colloquium talks during the year as did women (2,519 compared with 1,133). The study dismantles several commonly accepted explanations for the disparity: that there are more men than women in science; that men hold higher ranks in science than do women; and that women decline talk invitations at greater rates. In talks presided over by women, women represented 49% of speakers. When men oversaw talks, only 30% of speakers were women. Colloquium talks allow researchers to publicize their research and increase their national and international reputation. Without those opportunities, women can miss out on job offers and research collaborations.