

► 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 tingling 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

“Prioritization is absolutely critical when one is in a diminished state. If it’s trivial, let it go.”

to work with me. It made me feel he had confidence in me.”

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 over-tax 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.**