



# Patient advocacy: an antidote to loneliness and more

Sophia Walker

Sophia Walker describes her accidental pathway into patient advocacy and how finding people with shared experiences gave her a sense of community and the opportunity to influence change

I wish it was altruism—or something equally as laudable—that led me to patient advocacy. But if I am being honest, it was a much more pedestrian reason: loneliness.

The advent of social media was still a long way off in 1986 when I was diagnosed with type 1 diabetes at the age of 6 years. And I hardly knew anyone else with the condition. Type 1 diabetes is relentless with gruelling and constant self-management requirements. Although it was a huge part of my daily life, I did not feel that it was a part of me that I could share. I did not believe that people outside of my immediate family would understand and I did not want to feel any different from others than I already did. Like many children, I was under the impression that not talking about uncomfortable things would minimise them. Years later, I learnt that what I went through in those early days was similar to what many people experience after the diagnosis of a chronic, long term condition regardless of its nature.

I quietly managed the condition through adolescence but then, on a whim, in my early 20s, I signed up for the American Diabetes Association's Call to Congress. The Call to Congress brings together people affected by diabetes in the United States every year to meet with policy makers in order to advocate for increased funding and research into all types of diabetes. Again, my motivation was less than honourable—I was living in Boston (MA, USA) and I was mainly attracted by the free trip to Washington, DC (USA).

But what started as a free trip quickly morphed into something more. Surrounded by people with similar experiences to mine made me feel like part of a community. What usually made me feel alone, instantly connected me with others; my condition meant entry into a vibrant and meaningful community. I had finally found a consolation to living with a chronic condition. Talking with policy makers, I recognised my personal story helped to bring data and statistics to life and that my lived experience could help them to see things through a different lens. I also saw how parts of my experience as someone living with diabetes specifically, and as a patient more generally, were universal and that patients had a tremendous amount to bring to the table.

Shortly after, I moved to the UK to do a masters degree in Health, Community, and Development at the London School of Economics. The masters provided me with a clear understanding of the main tenets of global healthcare systems and public policy. After graduating, I embarked on a career in pharmaceutical market access and strategy consulting.

Meanwhile in my spare time, I pursued advocacy work for type 1 diabetes, such as lobbying members of parliament for increased access to treatment, participating in decisions for funding research, and attending conferences as a patient representative. Through my dual professional and personal experience, I saw that the conversations and debates that I was privy to as a patient advocate did not always play out meaningfully at the policy level. Frustratingly, I saw that the treatment and management that patients valued was rarely prioritised.

When asked to advise on the launch and running of *BMJ Medicine*, I was thrilled, but also slightly apprehensive. Would I be able to represent the patient community writ large? But then I thought back to the lessons that I started learning on that trip to Washington, DC so many years ago. The desire to be heard, to be involved in decisions that affect us—in other words, to have a seat at the table—is universal, and timeless.

I do not know what it is like to live with another condition but I do understand that, regardless of the condition, patient contributions are essential. These contributions—whether at the individual level, such as reviewing a research study, or at a broader level by speaking for a community as a whole, or anywhere in between, can and do guide healthcare improvements. Bringing this lived experience to bear in healthcare research, policy, and practice is essential to increasing the quality, safety, value, and sustainability of health systems. I will advocate for that through my role at *BMJ Medicine*. As I also understand that a diversity of voices and experiences is required to prevent bias and tunnel visions in healthcare decisions making, I will work to ensure the inclusion of those traditionally marginalised or hardly reached.

*BMJ Medicine's* commitment to partnering with patients and the public is more than making patients feel heard. It is a recognition that this involvement is the only way to ensure that medical journals are relevant, practical, and clinically impactful. Representing the patient community in my role as patient adviser to *BMJ Medicine* is the perfect antidote for loneliness and a valuable opportunity to help improve care. I hope that my experience will encourage fellow patients who are still hesitant to get involved in advocacy work to take the plunge.

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