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A system that must be gamed or learnt: a patient’s perspective

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It’s easy to complain about disappointing experiences while receiving healthcare. Indeed, discussion of the ways that healthcare can ignore, dehumanise, and generally grind patients to a pulp can reach fever pitch among those of us with chronic medical conditions. There’s a lot of hot air and hyperbole in this talk, but there’s just as much truth; patients are fatigued for good reason.

As someone with type 1 diabetes, I don’t really have a choice about interacting with the healthcare system. Whether I’m in my adopted country, the UK, or my birth country, the US, this interaction can be gruelling. I’ve missed so much work time travelling across London to medical appointments and waiting in crowded rooms—with limited wi-fi—to spend mere minutes with a healthcare provider, that it has affected my career. In the US, I’m haunted by the uncertainty about whether my insulin, which I need to survive, will be funded.

Despite these problems, there are moments of humanity when I feel seen and cared for. That I’m still thriving after 36 years with a chronic health condition is testament to this care. I think of my appointment at the diabetes clinic shortly after giving birth: the receptionist, nurses, and doctors full of congratulations as they crowded around me, admiring my baby. Even the harried and overworked nursing assistant who took our vitals stopped in her busy tracks and smiled. She and her colleagues in the clinic saw me at least every week as I lumbered awkwardly through a high risk pregnancy. I’m so grateful to that team; they made it bearable and much less frightening. More recently, a nurse in Massachusetts was firing through routine questions for new patient intake when she noticed that we have the same birthday, looked up from the computer screen, and asked me what I did to celebrate mine. It was the first time we had the chance to look each other in the eyes. We even laughed, and I finally let out my breath. These are the moments that sustain me and allow me to weather the harder parts of the system.

I sometimes wonder if it’s sheer luck that I’ve received so much succour from these overburdened systems. Perhaps, instead, it’s because I became deeply enmeshed in healthcare systems from an early age, which taught me how to game them. Moreover, I have the resources and privilege to know where and how to seek help, such as tapping (either online or in person) into a network of peers with diabetes and other chronic conditions to seek both practical advice and emotional support, and to quickly recover, or at least manage, when the system gets me down. This is not the case for everyone. A system that must be gamed or learnt in order to feel cared for is not a system that works.

Care may not be built into the system, but is often found in the stolen moments. It can take skill to find it, but humanity is usually there, hidden by data hungry systems and the pursuit of efficiency. It’s the small, fragile but determined bud growing out of the crack in the concrete. As we imagine a better way forward, care needs to be the foundation on which the system stands, not an unexpected discovery or chance encounter.

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