

Essay

Not growing out of it



As a child, I always looked forward to going to school. I would arrive at school early, stay late for extra classes, and use my free time completing further reading. Then, when I turned 14 years old, something changed. I started feeling tired in a way sleep could not touch, and some days my body ached so much I would struggle to put one foot in front of the other. For the first couple of years, I was able to keep a handle on these symptoms. Painkillers and excessive consumption of energy drinks got me through most days, and when they didn't, I would just take some sick leave. But this was not sustainable, and by the time I was 17 years old, I was running on empty. In my final year of high school, I was missing weeks of school each term, severely fatigued, sick with pain, and behind in my studies. I no longer looked forward to going to school. Fast forward another 8 years, multiple hospitalisations, and countless medical investigations, at age 25 years, I was diagnosed with fibromyalgia.

That was last year.

Long diagnosis times are a common occurrence for people living with chronic health conditions, and many will cite the primary reason for this delay as the reluctance of health-care providers to believe their symptoms. Moreover, the majority of chronic health conditions, fibromyalgia included, are non-visible. This means that the condition might not be immediately apparent from the outside, but still severely restricts an individual's ability to carry out daily activities. For example, fibromyalgia is a condition commonly characterised by extreme fatigue, widespread pain, and cognitive difficulties (often referred to as fibro fog). Unfortunately, this lack of visibility only compounds the tendency of health-care providers to disbelieve symptoms experienced by their patients.

Such an attitude is particularly exaggerated towards children and adolescents, and this is hard to challenge at an age where you might not yet have learned the language or confidence to advocate for yourself. Growing up, all-too-common responses from clinicians we visit tend to range from attempts to minimise our suffering by telling us we "just need to toughen up a bit" to outright dismissal in the suggestion that we are "just faking to get out of school" to the final condescension of "you'll grow out of it". In fact, most young people with a chronic health condition will survive to adulthood, and the reality is, we very rarely grow out of it.

Recently, through the honesty of either a select few clinicians or my friends in medical school, it has become apparent that this approach is largely due to a lack of understanding surrounding chronic illness. Many chronic health conditions have limited research when it comes

to the cause of the condition or the long-term outlook, and even fewer studies have looked at discovery and testing of safe and effective pharmaceutical and non-pharmaceutical treatments for these conditions. However, from a socioeconomic standpoint alone, it seems illogical, let alone immoral, to ask young people to cling to the falsehood that they might get better, only to later be told, that there is no light at the end of the tunnel. A lack of proactive care only places a greater burden on the health-care system further down the road. The prolonged, untreated physical stress of a condition will often result in further deterioration, as well as an increased risk of developing additional medical conditions, and this, in turn, can have a devastating impact on mental health and wellbeing.

Outside of health-care settings, whenever chronic health conditions are talked about in the public domain, it is generally done in reference to adults, particularly in countries with an ageing population. What is not discussed is the high prevalence of these conditions in children and adolescents, and when we do hear about young people with chronic health conditions, the suggestion is that such an event is rare, negating society's responsibility to respond to the call for substantial and long-term change in our stance towards chronic illness.

I stopped looking forward to school, not because of my health condition, but because I wasn't allowed to be ill. Non-attendance was penalised and taking more than a few days off would have us labelled as bad students. Asking for help was considered a weakness, and for those few wonderful teachers who did try to provide support, there was little to no infrastructure in place by which to enact reasonable adjustments, let alone physical adjustments to make buildings accessible. Over a decade later, and I see the same ritualistic humiliation and discrimination being repeated throughout the education system with a younger generation. Students who are chronically ill continue to experience a lack of support, particularly when it comes to attendance. During the COVID-19 pandemic lock-down periods, we quickly and quite successfully introduced the option of remote working and schooling. However, despite there now being more people and, by extension, more young people living with chronic health conditions than ever before, we have backtracked from remote alternatives and continue to push for in-person attendance. By failing to make education accessible, society fails to provide equitable opportunities for students who are chronically ill to equip themselves with the knowledge and tools to fulfil their full potential, compounding the barriers young people face as they grow up.

Growing up with a chronic health condition can be an incredibly lonely experience. Not only do you miss out on education, but you also miss out on making friends. Young people living with chronic health conditions already have an increased risk for suicidal behaviours, and this risk will only be exacerbated by isolation. If we want to build an equal and inclusive society, we must first ensure that people start off on an equal footing. Governments should focus on promoting awareness and improving the provision of resources allocated to advancing our understanding of chronic illness and the impact it has on the lives of young people with these conditions. Likewise, politicians should make it a priority to listen and respond to concerns and

requests surrounding equitable opportunities at every level of health and social care policy making, and they should place particular importance on ensuring the development of more comprehensive guidance for educational institutions to provide accessible education. Finally, health-care providers should focus on transparent communication and involving young people in the decision-making process surrounding their treatment.

Young people depend on society to guide and support them, and we must show them we care.

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