

Hidden illness: one patient's story

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I was diagnosed with lupus at the age of 14 following symptoms of joint pain, muscle weakness, fatigue and more. I received a quick diagnosis, but the years since have been bumpy to say the least! After countless medications, flares and hospital stays, I am now 20, have transitioned to adult services, am in my final year of university and run a charity dedicated to supporting young people with 'invisible illnesses'. Through my own experience and those of other young people, I have found that while living with chronic illness is different for each person, many issues we face are the same. For many, the hidden nature of illness can be the most challenging part. Similarly, being a young person with a chronic illness brings a unique experience, as young people try to navigate all the ordinary challenges of growing up, with added stress, difficulties and responsibilities.

HIDDEN SYMPTOMS

One way in which a condition may be a 'hidden' struggle is through the simple fact that many symptoms cannot be observed. While I've struggled with inflamed joints and breathing difficulties, often the most debilitating symptom is fatigue. It impacts my ability to work, to focus on my studies and socialise with friends but it is often glossed over. While my other symptoms can be measured in blood tests and scans, fatigue is more difficult to pin down or quantify, but this does not mean it causes me any less difficulty. These struggles can have a big impact on someone's mental health and quality of life as it brings everything to a halt, which other symptoms might not. For example, if my knees hurt, I take painkillers and limit walking, but if I have fatigue, I am unable to do anything. I think it is important that clinicians are aware of this so that they can provide advice and support. Furthermore, it would be great to see more research being done in the area to improve treatment.

FULL PICTURE

The importance of the psychosocial aspects of chronic health conditions in young people cannot be overlooked. In my case, my treatment plan was handled incredibly well by my hospital, but a lot of the problems I had in relation to lupus were elsewhere, in particular at school. I struggled to get the

support I needed and my teachers did not seem to understand the impact of my condition. I was seen as lazy and was criticised on my attendance when I had to miss school for appointments. The constant struggles to get understanding was a huge factor in making the already stressful situation of being ill even worse.

This experience led me to set up a charity which aims to educate teachers on how to support students with chronic or invisible illnesses. At this time, the support of my hospital team was invaluable. My consultant phoned the school to have a conversation about lupus and how it might impact my school life. Similarly, after an incident with the attendance officer, my specialist nurse spoke with her and organised that she become the first port of contact should the attendance officer have any questions about why I was missing school. This took a huge weight of both my mind and my parent's minds, so that we were able to focus on my health and treatment.

One of the biggest struggles I have had since transitioning to adult services is navigating conversations between my hospital, general practitioner (GP) and pharmacist. I often feel as though I have to be the go-between in discussions but often forget, or do not fully understand, the details. Similarly, when my consultant and GP have different opinions on something, I can struggle to get the treatments or tests. This is stressful and takes up a lot of time and energy. I think it is important that all parties communicate better, so that everyone is on the same page. Ultimately, it is important to see the full picture of a patient's story, not just the clinic appointment.

UNDERSTAND MISTAKES

While I have talked a lot about the difficulties of having an illness which is invisible, it is worth noting that sometimes this is a good thing. I, like most young people with a chronic illness, want to lead a normal life. While this is possible, it can sometimes be difficult to find a balance as being ill inevitably changes things. I can still achieve my goals and live a good life, but there will always be differences in how I do this in comparison to my peers who do not need to consider appointments and treatments as I do. This can be difficult as managing a chronic illness is not something most young people have to deal with. An area which I feel

Takeaway messages

- ▶ Sometimes the most difficult symptoms are the ones which cannot be seen, measured or tested. Try to put as much time and discussion into treating these symptoms as those which may be more straightforward.
- ▶ Try to offer support in all aspects of a patient's life, including communicating with school; communicate well with general practitioners and pharmacists to make accessing treatment easier. Ensure everyone is on the same page.
- ▶ Try not to judge young people for making mistakes in how they manage their condition. Try to avoid using language/tone which creates feelings of guilt for the patient. Reassure them that being a young adult with a chronic illness is difficult and comes with unique challenges and help come up with solutions to guide them through this.

needs more discussion is the support which young people get as they transition into adult services in terms of self-management, as managing a chronic illness is no easy feat! One issue may be ensuring that young people are taking their medication, which I know is something I have struggled with. Similarly, I have always struggled with 'pacing' to manage my fatigue. Between university, running a charity, starting my career and spending time with friends, my life is very busy. I often forget to take time to rest and burn myself out. Needless to say, I am not always the perfect patient. It is difficult to say 'no' to things and adjust my life to fit the needs of my health, but I'm learning! With the help of my doctors and support system, my ability to manage my health is constantly improving. I think this comes with getting older, but it is also hugely important to have never been judged or made to feel guilty. My doctors have always aimed to help me find solutions and to incorporate healthy practices into my life while still allowing me to do all the things I love. Rather than making me feel guilty about pushing myself too far or not managing my medication properly, they listened to, understood and tried to help me overcome my problem.

CONCLUSION

The most important thing is that every person is different. The key is to make sure that you are constantly asking the person his or her opinion and feelings on his or her care and, crucially, to do this

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repeatedly throughout treatment as things may change. Good communication is the best way to develop a positive relationship with a patient. The trust and understanding which comes from this can have a huge impact on the individuals' management of their health.

For more information about Sophie's organisation, RAiISE, visit the website (<https://raise.co.uk/>).

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