How I balance my nursing degree with a long-term condition

Implications such as a feeding tube have an undeniable impact on my studies and placements, but also enhance my self-awareness and ability to show empathy towards patients

I was diagnosed with the connective tissue disorder Ehlers Danlos syndrome (EDS), a long-term condition that affects the joints, skin and tissues, in 2020.

As a result of my condition, I have multiple co-morbidities, including digestive problems, and in April 2022 I had a nasojejunal (NJ) tube fitted for all my nutritional requirements. This was during the first year of my degree in children’s nursing, and despite having completed eight months of my programme while managing my long-term health conditions, adjusting to nursing with a nasal feeding tube was an entirely new challenge.

When I was diagnosed with EDS I had to come to terms with the fact that I would never be as healthy as my peers. I was determined to pursue a career in nursing, but I did not know anyone who was living with a long-term disability and able to work as a nurse.

I had heard accounts from people who had a history of ill health and were now nurses, but I did not think I could be a nurse while having a number of physical health conditions.

EDS causes me to have multiple joint dislocations and subluxations every day, which means I have a lot of pain and may not be able to do the ‘heavy lifting’ that sometimes comes with the job.

Before I had a feeding tube – which made my health needs more visible – I had experienced stigma from colleagues who had perhaps not seen my workplace risk assessment. My conditions are invisible, so when I said I was unable to do something it was often met with an eye roll, but since having my feeding tube fitted I no longer get this response from colleagues.

The biggest impact on my work life now is that in a post-pandemic NHS I am unable to work in certain environments because of the personal protective equipment (PPE) required.

How I perceive my abilities as a nurse

The main thing I have experienced since having my tube fitted is internalised ableism – when disabled stereotypes become misconstrued and the person believes they are inferior to their non-disabled peers, or they are not really that sick and others have it much worse than them.

I have spent most of my life trying to prove I am capable of achieving things despite my health conditions, and my automatic response is that I need to fight to earn my place.

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My university and placement areas have been accommodating of my needs, ensuring any support I need is always in place. At first this meant doing half days on placements and easing back in gently. But I am now able to adapt my practice to my needs, and support is in place if I become unwell or need to work from home occasionally.

This has only been possible by being honest about what I was going through. It is difficult to raise a health condition with an employer or educator – it puts you in a vulnerable position where you have...
to talk about aspects of your life that you would often rather block out. It also causes worry that you may be removed from your post and deemed unfit to practise. But as a worker, you have rights to reasonable adjustments and a right not to be treated unfairly as a result of a physical or mental health condition.

By not reaching out to the appropriate people, you may not receive the support you deserve and need in the workplace. It can also put you or your patients at risk if your ability to work is compromised.

**Self-awareness and coping under pressure**

When you have a disability or chronic illness you become more in tune with your body. This has definitely helped me manage university and placements, as I am very aware of what my ‘normal’ is like.

I know when I am able to push through or when I need to take extra care of myself, although I have had to learn to give myself permission to rest and recover, especially in the age of ‘hustle culture’ with the constant pressure to do more.

While being successful in my studies is always going to be important to me, I have learned that my health must take priority and that I am going to be a nurse no matter what grade I qualify with.

Adjusting to working with children with a feeding tube on my face was a huge emotional challenge for me. I was worried that parents would think I was not capable of caring for their child, but on one of my first shifts back a child pointed to me and said: ‘Mummy, that nurse looks like me.’

I spent a lot of time in hospital as a teenager and this encounter reminded me of when I was admitted to an adult ward at the age of 17. I was unaware at the time that I was going to be unwell for the rest of my life – I was undiagnosed so still had hope that I was going to get better.

I was looked after by a doctor’s assistant and a nurse, both of whom had been in hospital when they were my age. The care they gave me was exceptional, coming from a place of true empathy because they understood what I was going through.

They were both a signal of hope in what was a difficult time in my life, and the desire to have such a positive effect on others is what led me down the path of children’s nursing.

**Tips for nursing while managing your own condition or disability**

» Be honest with those around you and find out what support is available, including on social media. A group on Facebook called ‘wonky teacups’, set up for healthcare professionals and students who have a long-term health condition, is a great place to ask questions and seek advice

» Be self-aware, give yourself regular breaks and stay hydrated, and take rest days when you need them. You can always make up hours or pay but you cannot get back life

» Allow yourself some reserve energy – don’t go full throttle with your studies and placements. If you consistently give 100% of your energy in your professional life, you come home and have zero left to function in your daily life. You need to allow yourself energy to cook food (or in my case, set up feeds), get some fresh air and care for your personal needs

» Don’t underestimate how much of a difference you can make to your patients and colleagues

**Being a patient is no barrier to being a healthcare professional**

Diversity and inclusivity in the NHS is so important. We need to show young people that being a patient does not have to stop you being a nurse, doctor, physiotherapist or any other health and social care professional, and that there is a place for everyone in the health service.

I am privileged to know a lot of other students and registered nurses with conditions similar to mine, and am proud to stand alongside them to collectively show that having a long-term condition is no barrier to a career in nursing.