

Patient perspectives

Living with severe asthma since childhood



Olivia Fulton, from Edinburgh, UK, aged 35 years at the time of writing (June, 2021), has spent her entire life battling severe asthma. On occasions, she has won that battle, but most of the time, the asthma comes out on top. Describing herself as “always a wheezy baby and toddler”, her official diagnosis of asthma came at aged 4 years. “There is a lot of asthma, eczema, and allergies in the family, so I’m sure there’s a genetic element to it”, Olivia tells *The Lancet Respiratory Medicine*.

She can clearly remember the day-to-day struggles to manage symptoms and feeling different from other children. For example, she couldn’t do art classes as the classroom was too dusty, and she would often sit out physical education lessons. “When the weather got bad outside, which was a trigger, I’d be kept indoors during breaktime”, she says. There were only two other children with asthma in Olivia’s year group, as it was in the era before incidence of asthma sharply increased in the UK. “Despite my condition, my parents were relatively relaxed and didn’t try to overprotect me”, Olivia explains. “Because my grandmother had bad asthma, my family kind of knew what to expect, but also wanted me to live my life.”

Personal responsibility was again emphasised when Olivia went away to boarding school at St Andrews, 1-h drive from her parents’ Edinburgh home. “My parents reminded me to always carry my inhalers, and I cannot remember an occasion when I didn’t”, she explains. “But they weren’t constantly checking up on me.”

Olivia’s love of taking part in sport would soon clash with her condition. Her love of lacrosse and being part of the school team meant she had to take part in long distance training runs, and when she reached aged 13 years, she began to have serious asthma attacks. “I would have a serious attack twice a term on average and end up being taken by ambulance to hospital twice each year”, she explains. “But the school didn’t want me to miss out due to my condition”, she explains. “For less serious attacks, the nurses would put me on a nebuliser in their office to calm my symptoms. Today, I wonder whether more intensive management then could have avoided the more serious attacks both back then and right up to today”, Olivia reflects.

Since her parents were not seeing these serious asthma attacks with their own eyes (they would just visit in hospital after), Olivia is not sure if they grasped that the attacks were becoming more severe. “Although my medication was increased, there was no long-term input like there would be today”, she says. The attacks ended up impacting her high school exams, with stress a frequent trigger for attacks. “I was not very academic anyway and

trying to concentrate on studying when not feeling great was hard work”, she explains.

It was once Olivia left school things began to go downhill, during a stay in Canada while training to be a ski instructor. She suffered a severe attack that put her in the local hospital. “While admitted, I developed an unusual pneumonia that really attacked my lungs, and I had to be airlifted to another hospital in Canada”, Olivia explains.

That incident was the catalyst for everything getting worse. “On returning home, I found I was symptomatic most days, relying on nebulisers and oral steroids a lot”, Olivia recalls. But again, she would not be held back. She coached at a summer sports camp before heading to Winchester University to study sports science. “This was just before the indoor smoking ban in the UK, so smoking was still allowed in bars and nightclubs”, Olivia explains. “At a night out in my first week, the passive smoking prompted a very severe attack that left me in intensive care in hospital.” She was to endure several other hospitalisations in her first year, before the smoking ban made it much easier to go out and socialise in her second year.

And she continued to do what was for her, too much sport. “I just kept pushing myself, even when I knew I wasn’t feeling great”, she recalls. Finally, in that second year, Olivia’s body broke down completely, and the next asthma attack would see her admitted to hospital for 5 months. “The doctors just couldn’t get my asthma under control, despite trying various options, such as a subcutaneous infusion of terbutaline. Consultants were coming from other hospitals to give their opinion week after week.”

After her discharge, she spent long periods hooked up to the terbutaline infusion device, carried in a pack around her waist. Yet even that did not stop her. “Friends would invite me to some sport or other, and I would disconnect the device, then end up collapsing again”, she says. She had to repeat her second year of university and was treated with long term steroids on top of her inhalers. After another asthma attack landed her in intensive care again, the respiratory consultant who had treated her before gave her a stark warning. “If you cannot care for yourself, I cannot continue to make the effort to keep you well”, he told her. For Olivia, it was a wake-up call about her own behaviour.

“I ended up moving back to my parents in Edinburgh, determined to keep studying my degree using distance learning. But it was too much for me”, she recalls. “I took a step back, started concentrating on my health and got involved in volunteering, for organisations like Asthma UK. I looked at career options and decided on nursing after my positive experiences with nurses and experience of living with a chronic condition.”



Olivia Fulton

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During her studies, Olivia's hospital consultant warned her that she would always experience a background level of serious attacks—whereas before, they had always been prompted by sport. But her improved focus on her own health led to a long period of stability, with fewer serious attacks. She was able to complete her nursing studies and took up a position as a renal nurse. She had given full details of her condition to her managers, who said they would accommodate it as best they could.

However, patients Olivia was caring for began to comment that she herself looked unwell, and she struggled with the workload. Even ward work was too intense, so she was transferred to community nursing. But the same problem occurred—her patients being more worried about her than she was about them. "I started missing more and more shifts. Attacks were becoming more frequent again, and in 2015, every attack I had ended in an intensive care admission."

Although Olivia battled on with this pattern of attacks, recovery (that was not really recovery), and then returning to work, she was, in reality, getting weaker each time it happened. Finally, in April, 2019, she took a year of unpaid leave, to manage her health and decide once and for all if she would have to stop nursing. However, the decision was made for her when the COVID-19 pandemic struck in early 2020. "I had actually already decided that I could not return to work in January, 2020, but as the pandemic developed, it was obvious I couldn't", Olivia explains. She was medically retired from her post in April, 2020, as COVID-19 swept through the UK. "I had already taken the decision to start shielding myself in February, before the first lockdown", she recalls. "I drove up to my parents' holiday home in the Highlands with my assistance dog Ghillie, and spent almost a year there, visited only by my mum. I was totally alone most of the time. It almost drove me crazy, in the end!"

Olivia put the time to good use, learning as much as she could about asthma research, and taking part in many calls with many organisations, including Asthma UK. She could go out for walks without fear, and again enjoyed a stable period with her asthma not suffering many serious

attacks. "Tragically, a young friend of mine suffered an asthma attack and while in hospital, contracted COVID-19 and died", she recalls. "I was desperate to avoid any hospitalisations in case that happened to me. I increased my medication to reduce the chances of that happening. However, I did have to go into hospital in August, 2020, but thankfully I was put straight into a "clean" ward after being tested, avoiding the general busy areas of the hospital."

Although worried about potential side effects of vaccination against COVID-19 (she had a bad reaction to the H1N1 influenza vaccine), Olivia was keen to be vaccinated and has now had both doses of the Oxford–AstraZeneca vaccine. The first dose left her feverish, but she recovered after a couple of days. The second dose caused no side effects. Thanks to the UK's new year 2021 lockdown and successful vaccine rollout, incidence of COVID-19 has plummeted, and Olivia has now returned to Edinburgh. She has dedicated herself to asthma research, and is part of various committees for different organisations, including the European Lung Foundation, the European Respiratory Society, and pharmaceutical companies. She has also just joined the editorial board for the journal *BMJ Open Respiratory Research*. She brings to these roles the unique perspective of someone who has lived the rollercoaster of severe asthma and repeated attacks.

"With asthma research, I can dedicate myself to something that I can do sitting, and still make a contribution and be a positive force for patients", explains Olivia. "I do teaching, run courses on patient involvement, and, once the pandemic is brought under control, I hope to travel to conferences again. Finally, this research work is something positive out of having rubbish lungs!"

She concludes: "I want to live, despite the challenges of my asthma, and now COVID. It's not going away, we have to live with it. Having a severe respiratory illness complicates things, but I'll get on with my life. Everyone is going to have to find their own way to feel safe in the COVID era. I'll take all the sensible precautions, but I can't hide away forever."

Tony Kirby