

Shaun's Story

My name is Shaun, a 29-year-old adult with OA/TOF. I was born at the Royal Hampshire Hospital in Winchester; my mum was induced on 13 February due to me being two weeks late. Although the birth started well, the following hours were far from it. My lips had turned blue and I needed suction to keep my throat clear. I was seen by three consultants who eventually informed my parents that I had some complications. I was taken to the paediatric intensive care where I spent the rest of the night. The following morning, I was taken by ambulance to Southampton General Hospital. After a few hours, a consultant (Mr Burge) sat down with my parents and explained that he believed that I had the conditions TOF and VACTERL.

In the next few hours, my first operation to close the connection between my oesophagus and trachea was successfully completed. However, the repair split and a second attempt was necessary. Unfortunately, this also failed, so the decision was made to perform a gastric transposition. This is where my stomach was brought up into my chest. I had no more issues with my TOF, other than the occasional stricture. However, as I have a smaller stomach, I do suffer with dumping syndrome, which makes eating large meals difficult. A few weeks later, I had another operation to repair my bladder and bowel. I was born with a high imperforate anus (I did not have an opening), as well as having a connection between my bowel and urethra that allowed stools to enter my bladder. This was successfully repaired. Though, this meant spending a long time in intensive care without any physical contact.

During this time, I had a colostomy to allow the repairs to heal. This was reversed a few months later. It was hoped I would develop muscle control in my bladder and bowel. However, by the age of 7, I was still in nappies, which made school hard. Due to the nerves being tangled in the base of my spine, I was incontinent. This led to me having to make a difficult choice to either undergo surgery to have a permanent colostomy and mitrofanoff (a small stoma on the abdomen where a catheter can be passed through to empty the bladder) or stay as I was. I chose to have the surgery and here I am today.

How being born with TOF affected my childhood

My childhood mainly consisted of long hospital stays, outpatient appointments, unpleasant tests and procedures and a considerable number of operations. Obviously, this made socialising and developing



Shaun and his fiancée Jenny - tying the knot this September

friendships difficult. My parents managed to find a nursery who would take me one day a week. This gave them some much needed respite and allowed me to spend time doing normal childhood things like socialising, playing, team building and of course learning to share. I spent a lot of my early years being prepared for the next big operation. I know there were several operations where I wasn't expected to survive, so, I was often taken to see family and friends. As the years went on, my visits became less frequent and I spent more time at home and eventually school! My first few years were quite different for me compared to my classmates as my mum would have to come in and change my nappy. This obviously led to my friends asking questions, which I didn't want to answer. I kept my condition a secret right up until I went to college. Things got a little easier after my colostomy and mitrofanoff. However, I missed out on a lot for almost a year because of that operation. I also missed a lot of school down to the number of operations that I needed. Secondary school was definitely a lot harder; I always knew I was different but I came to understand just how much during this time. I went through a dark period and suffered from depression due to hating how I was affected by the leaks in my stoma and not being able to take part in some areas of regular childhood. However, I managed to find a friend who I could be open with, which helped.

Highlights of my life so far!

After becoming an adult, my life started to resemble something more "normal". I went to college and it was there that I met my fiancée. We are getting married in September 2023. I can't

wait! I now work full time at a golf club and have also worked in hotels. My condition still affects my day-to-day life but I have learned how to manage. I am now more open; I wouldn't have dared "go public" in my teenage years. I have been able to travel abroad, including Australia. It was complicated as I had a lot of supplies that I needed to take as well as three weeks' worth of medication.

I would hope my story reflects the difficulty some children and their parents are currently going through but shows how once you're through the harder times, you can still continue to live successful, fulfilling lives.

