

Joe's IA/ARM Story

We all know how tough living with OA/TOF can be at times. But due to a range of complex, medical issues, some in our community face an even more challenging journey through life. Not that those added struggles have stopped one member from speaking out in a mission to help raise awareness of a little known and even less understood condition.

IA/ARM: My journey with an imperforate anus and faecal incontinence

Hi there, my name is Joe and I was born with an imperforate anus, a medical condition that affects about 1 in every 5,000 births. The condition required surgery to create an opening so that waste could be eliminated from my body. As a result, I had a colostomy and one of my kidneys removed as well as having a winged scapula on my right shoulder blade. I also suffer from faecal incontinence, which can make it difficult to participate in everyday activities.

To manage my condition, I must self-catheterise daily to wash my bowels out using my antegrade continence enema.

Growing up with faecal incontinence

Growing up with faecal incontinence was not easy. As a child, I was not aware of the severity of my condition and my parents did a great job of shielding me from it. However, as I grew older and became more aware of my body and the way it worked, I realised that I was different from other kids. I became self-conscious and embarrassed and I did everything I could to keep my condition a secret.

This was especially difficult during my teenage years. Adolescence is a time when kids are figuring out who they are and where they fit in the world. For me, it was a time when I was trying to keep my medical condition a secret from my friends. I was afraid of being judged, teased or bullied. I avoided sleepovers, trips and social events where my condition might become apparent. It was a lonely and isolating time and I often felt like I was the only person in the world who had this problem.

But I was not alone. I eventually learned that there are many people with faecal incontinence and other medical conditions that affect their bowel control. However, because of the stigma and shame that surrounds these conditions, they are often kept hidden from view. This can lead to feelings of isolation and shame as well as a lack of awareness and understanding among the general public.

Lifelong care

Unfortunately, many children who are born with imperforate anus are left with long-term complications, including faecal incontinence, which require lifelong care.

The importance of lifelong care for people with imperforate anus cannot be overstated. Faecal incontinence is a challenging and often stigmatised condition that can significantly impact a person's quality of life. It can lead to social isolation, anxiety and depression and can make it difficult to participate in everyday activities. It can also lead to other health issues such as skin irritation and infection, which require ongoing medical care.

People with faecal incontinence require ongoing support and care to manage their condition. This includes access to specialist medical care such as colostomy care, bowel management programmes

and continence clinics. It also includes access to medical supplies such as incontinence pads and skin care products, which can be expensive and difficult to obtain.

Lifelong care for people with imperforate anus should also include education and support for families and caregivers. Many families are unaware of the long-term implications of imperforate anus and may struggle to provide the support and care their loved ones need. Education and support can help families better understand the condition and its management and can help them feel more confident in their ability to provide care.

"Coming out" on social media and TV

As I got older, I realised that I wanted to do something to help break down the barriers of silence and shame that surround faecal incontinence and other medical conditions. I began to speak out about my experiences; first to my family and friends and then to a wider audience on social media, which led me appearing live on national TV.

Going live on Channel 4 was both exciting and daunting. I had the opportunity to share my story and raise awareness about imperforate anus and faecal incontinence to a wide audience, which was a fantastic experience. However, it was also nerve-wracking to be on camera and to know that so many people would be watching. Despite my nerves, I was determined to share my story in the hope of inspiring others to do the same. By speaking out about my experiences, I hope to encourage greater understanding and acceptance of medical conditions and disabilities and to empower others to speak out about their own stories.



Joe, who featured on Steph McGovern's Packed Lunch show

Raising awareness

The response I have received from social media and my TV appearance has been overwhelming. I received messages from people all over the world who have had similar experiences and were grateful to know that they were not alone. I also received messages from people who had never heard of imperforate anus before and were amazed at what I had been through. By sharing my story, I was able to raise awareness and start a conversation about a subject that is often taboo.

In addition to raising awareness, I also wanted to inspire and encourage others who are living with medical conditions or disabilities. I wanted to show that it is possible to live a full and meaningful life despite the challenges we may face.

Over time, I have come to embrace my IA, my faecal incontinence, and my antegrade continence enema as part of who I am. It is not something that defines me but it is a part of my story. My mission is to help others who are struggling with similar issues to feel less alone and more empowered. I also hope to encourage greater understanding and acceptance of medical conditions and disabilities in general.

Joe's story featured in Spring 2023 edition of TOFS Chew Magazine.

TOFS is a UK charity working towards a world in which those born with OA/TOF live long and healthy lives, unconstrained by the impact of being born with these conditions.

Find out more at tofs.org.uk