

## Introduction

Hello, my name is Ciara Leahy. I am 18 years old, and currently a leaving cert student, in St Mary's High school, I in Midleton.

I am the eldest, of 3 children , I have two younger brothers aged 15 and 10.

I was asked, to come here today, to speak to you about my journey with scoliosis, over the last, 4 ½ years.

Growing up, I was always the sporty girl. Mam struggled to put a dress on me, as I would much prefer, to be in a tracksuit or a pair of shorts, and a jersey and be outside kicking a football , or holding a hurley in my hand.

There weren't enough days in the week, for me to fit in all the sports, that I wanted to participate in, from, horse riding, to swimming, running, camogie, ladies football, to name a few . We were always, on the road with one thing or another.

## Discovery

At the age of 14, I was on the floor one night making a jigsaw, with my brother, when Mam noticed a hump on my back.

The following day, I was taken to our G.P. , and referred for some x-rays. It was at this point that I was diagnosed, with adolescent idiopathic scoliosis.

AIS is an abnormal curvature of the spine, usually caused by a rapid growth spurt, during the teenage years. However, the definite cause is unknown.

It affects more girls than boys. At this stage I had an 18 degree curve, which wasn't huge but needed monitoring.

Scoliosis, is one of the very few orthopaedic conditions that can be life threatening, as the curve gets worse . It can affect the ability of the child's heart, and lungs to function, and, their ability to grow. Fortunately, scoliosis can be fixed.

This is the one thing, my parents kept repeating to me over and over in the beginning. "**This can be fixed**"

They left no stone unturned, to make sure that I got the best treatment pre, and post op so, that I would have the best possible outcome.

I was monitored in Cork, for the first 6 months, however as my curve started to progress, my consultant said I need referral, to Dublin, as he thought I may need surgery down the line, scoliosis surgery, is not performed in Cork. We choose to attend Dr. Pat Kiely, at the Sports Surgery Clinic in Santry.

## Managing

The most important thing for any boy or girl heading into scoliosis surgery, is to be fit and healthy. I was already very fit, and healthy, and was determined to keep myself in good shape.

It was then that one of my teachers, introduced me to '**Straight2Swimming**'.

Straight2 Swimming, launched in Belfast in 2014, is now operating in Kildare, since 2015, and Cork, since 2017. It provides swim therapy, for patients up to the age of 18, for pre and post scoliosis surgery.

The initiative which is the **first of its kind in the world** is free of charge to participants was kindly **sponsored by K2M.**

To say, Straight2swimming was invaluable, to me as a scoliosis patient, and to my parents is an understatement.

Initially, we travelled weekly, to Kildare. From the very the first meeting with course co-ordinator, Eimear Browne, we felt very welcome. The pool, was closed to members of the general public, during our swim lesson.

Many scoliosis patients have body issues, and will not go into a public pool, for fear of being singled out, for looking different, for having a curved spine.

Straight to swimming, gave the kids a chance to swim together, to talk about their individual struggles, teenager to teenager. It gave our parents, a chance to meet other parents, who were on the same journey, in particular, it was great to meet people who were out the other side of it. Straight to swimming, held conferences, for the parents, where they brought the surgeons, anaesthetist, physios, psychologists all together in one room to speak to parents, about what to expect, when your child is facing surgery.

### **Pre Operation**

Finally, in July of 2017, I got news that I would be having my surgery at the end of September.

#### **I could not wait!**

We spent the next couple of months, preparing for my big trip to Dublin. It was expected, that I would stay in hospital for 7-10 days, following my surgery. There were a lot of logistics, to sort out beforehand. Both my parents, were coming to Dublin with me, leaving my two brothers at home, to be cared for by family members. A bed was provided for one of my parents, to stay with me at night in the hospital, while, the other stayed with relatives in Dublin. (Dad was not the best babysitter in the hospital, as he kept falling asleep)

I travelled to Dublin, twice in early September, as I had to have a series of pre-op tests, before my surgery could proceed.

### **D-DAY**

I was woken around 6am, on the morning of my surgery and prepped for theatre. My parents came with me, to the operating theatre. I was put to sleep around 7.30am. The operation, was expected to take anything from 8-10 hours. The anaesthetist phoned my mam two hours in, to say all was going as expected, and not to be worried.

At around 4.30pm, my parents got a call from Pat Kiely, to say that he was finished, they were just finishing up in theatre and to meet him in ICU at 6pm. He told them that I was fused, from T4 to L2.

Initially, he thought I might need to be fused to L4, but was delighted that he only had to go to L2, as that would leave me with more flexibility long term.

## Post Operation

Two titanium rods, and 22 screws were inserted into my spine.

I had internal stitches, and 58 staples on the outside of my back holding the wound together. It looked like I had a train track running down my back.

## First steps

The morning after my surgery, at 11am, two physios came into ICU and informed my parents, that they were going to get me to sit at the side of the bed. My parents later told me, they were very nervous, and didn't think I would be able to do this, as I was so tubed up, and in obvious pain. I managed to do as they asked, and told them that when they come back in the afternoon, I wanted to walk over to the door, to see the trees outside. To everyone's surprise I managed to do this too.

The days that followed, were difficult at times. There was lots of pain, and discomfort as I tried to walk a little bit further, every day. One of the challenges, you must overcome, before discharge is to walk a lap of the floor, and climb a set of steps. On the Monday, 5 days, after surgery, I completed two full laps of the floor, and climbed the set of steps, twice. At that point, my surgeon said, I would be allowed to go home on the Wednesday. Exactly one week, after my surge

## Getting Home

The journey home was to bring its own challenges. Going into surgery I was 5' 7", the same height as my Mom. After surgery, I was measured at 5'11". I was physically too tall, to get into our family car comfortably. I couldn't bend my back, plus, my tolerance for sitting on a chair, was only 1 minute. Friends offered us their jeeps, and vans, anything, we needed to get me home. My parents even looked, at hiring some sort of vehicle for me.....

Then, my Mam read somewhere, about Bumbleance, and how they brought children to, and from, hospital. My Mam made a phone call to Bumbleance, they could not have been, more helpful. From the first phonecall, they were **amazing**. They said that they would take care, of bringing me home. It was such a relief, to all of us. The ambulance, pulled up outside Blackrock clinic, and drove me all the way, to home my in East Cork. I was able to lie flat, the whole way home. My Dad, travelled with me, as my Mam, went on ahead to get things ready for our arrival.

## Recovery

- It was so good to get home, but frightening, at the same time. We got no sleep at all, the first night.
- The staples were removed 14 days after surgery.
- I was on lots of morphine and other meds for the first couple of weeks. it was said I ran the chemist nearly dry of all their meds
- I don't remember too much of this.
- My Mom had to set alarms on her phone as I needed meds almost every hour.
- One of my Parents slept on the floor of my bedroom by night for the first couple of weeks after I came home.
- Gradually, every day got easier, I got stronger and stronger. The hospital gave me an exercise target, for the first few weeks, we followed it religiously.

I went back to straight2swimming, 6 weeks after my surgery. Eimear, had a recovery programme made out , specifically for me. As luck would have it, there just happened to be a parents forum, organised by the Straight2 Swimming team, the same night. My parents attended this, while I was in the pool. One of the physios from the Mardyke, Roisin was there, she spoke about a new post op programme, that she had developed, for scoliosis patients. We made enquiries about it, and I started the programme the following week.

To the naked eye, I looked perfect , and I thought I was well recovered. In a sense, I was, but when I was asked to stand on one leg, I was unable to do so. My balance , was completely off.

For the next few months, I worked with the physio, to strengthen my body, to get 'match fit' again.

For me, the proof was when I had my 1 year post op appointment, with my surgeon. In his report , he said, that I had the “ **best range of motion, and function**, that he has seen, in someone, who had scoliosis correction, for years”

### **Today**

Today, here I am standing straight and tall, pain free, with the world at my finger tips, excited to see, what is in store in the next few years, with college, and travel.

My scar is totally healed, barely visible. One of the things that initially freaked me out, was having a big track line down my back. Being a girl, I thought I'd never be able to wear a bikini again.

Every scar tells a story. This is mine. At 14, I thought having a scar down the length of my back was the end of the world.

After I was diagnosed, I found a quote online, which really inspired me, I had it printed out over my desk. It reads:

**“A scar is a tattoo with a better story”**

Last summer, not only did I cut my hair shoulder length, which I wouldn't have dreamt of before hand, I wore my bikini with pride in France.

### **The Future**

This June, I will sit my leaving cert. One of the things scoliosis has taught me, to **fight your battles and come out on top.**

I hope to attend UCC next year, to study Commerce international with French.

Academics aside, in the long run, I have many plans to travel, and experience lots of different countries, also to complete an ironman. I will complete all of these, with my head held high, standing tall, with a straight back.

**Thank You all for listening to my story**