Patient Report

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My experience of life with Juvenile Idiopathic Arthritis and transitioning from paediatric care to adult services

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My name is Niamh Costello. I am 20 years old and I was diagnosed with Juvenile Idiopathic Arthritis when I was 3. I sometimes think that being diagnosed at such a young age was a blessing in disguise, as I have grown up with JIA. It has been a part of my life for as long as I can remember and it will always be this crutch that I have to carry. Because of this, I have had to adapt my life to suit my needs and also learn to know my limits. Whereas I know lots of young people who lived a healthy, sporty and energetic lifestyle until they suddenly got diagnosed in their teenage years. This must be hard to accept as their lives have now become completely different.

I also count my blessings that I do not remember much of my diagnosis, as I was so young. My poor parents had to take the brunt of it. They tell me that one morning I crawled into their bedroom on my hands and knees screaming that I could not walk with the pain in my knee. They looked down to see my whole left leg swollen up like a balloon. My knee was red and hot to touch and I was clearly in a lot of pain as they could not stop me crying. They brought me straight to my GP who brushed it off as a virus or growing pains. I soon turned from this happy, energetic 3 year old to a whiney, tiresome one who had to be carried everywhere.

This persisted for a number of weeks until my parents brought me back up to the GP as they knew it clearly was not a virus. I was admitted to hospital with a rash and a temperature and this swollen knee that was getting bigger by the day. Lots of tests and scans were done and

1 day, a doctor who had done some of his training under Paediatric Rheumatology, recognised my symptoms and referred me straight to Our Lady's Children's Hospital in Crumlin, Dublin. That is where my lifelong journey of JIA began.

I was diagnosed a couple of weeks later and was put on a high course of steroids. At the time there was no paediatric rheumatologist in Ireland so little was known about JIA and its prognosis. It was going to be a case of trial and error with my treatment. The oral steroids did not work so I was given a steroid injection directly into the knee joint and the fluid was drained. And believe it or not that was it for 4 years! I went into remission and I thought I would never have to see a hospital again. Unfortunately I was wrong.

When I was 7, the trips to hospitals started again and this time I would not get a 4 year break.

My JIA resurfaced and soon spread to other joints which made my day to day life that bit harder. Getting up for school every morning was a struggle. I needed help with things like brushing my hair and teeth, getting in and out of bed, showering etc. I had little independence and always wanted to be near my Mum for reassurance. I had to miss out on lots of things growing up as some days I physically could not get out of bed due to the pain, swelling and stiffness of my joints. I felt like I missed out on a normal childhood. Instead of birthday parties, sleepovers, school trips and running around with my friends my childhood consisted of weekly injections, trips to hospitals, blood tests, scans, needles, fatigue, side effects and a whole lot of pain.

I was always told when I was younger that I could possibly grow out of JIA, so my family lived in hope. We did everything we could to try and keep my JIA at bay but when I was 12 I remember my consultant telling me that I will probably have this for the rest of my life. When you are 12 that is a shock to the system. All these thoughts were

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running through my head, how can I deal with this pain for the rest of my life, will I have to take injections forever, will I be able to have children?! I hit a slump and I was very down in myself for a couple of years after that.

I worked my way through various biologic injections until the options started to get less and less and they soon stopped working for me. I had to start on infusions in my teenage years which meant I had to travel to hospital once a week to be hooked up to an IV drip. The infusions made me quite sick and extremely tired. I missed a lot of school throughout this time which was hard academically and socially.

When I was around 13/14, I started to go to teen clinics in Crumlin children's hospital. I would go in to clinic and see my nurse and consultant first on my own. This was daunting at first because my parents would do all the talking for me at my appointments and tell my doctors my issues and worries, I would just smile and nod. So the thoughts of having to speak to doctors on my own scared me. It turned out to be a good thing though because if I had any worries or concerns that I did not want to discuss in front of my parents I could discuss it with my consultant during this time. It also gave me more independence and a chance to start learning to self-manage my illness. My parents would then come in at the end of the appointment and say anything that I might have forgotten to say.

When I hit 16 I was asked by my paediatric consultant to start thinking about what hospital I would like to transition to. I had to think about some factors such as where I live, what facilities might be available to me at this hospital – Occupational Therapy, Physio etc, where I might be going to third level education – would the hospital be far from here? All of these things had to come into consideration when I was picking an adult hospital.

I transitioned from paediatric care to adult services when I was 17. I was quite scared to go to an adult hospital as I had spent my whole life under the care of paediatric doctors.

One of the challenges that I found when I transitioned was that I had to speak up for myself a lot more and tell the doctors what I wanted for my care. This was new to me as

I was used to going into teen clinic appointments and having my consultant telling me what drug I was going onto next or saying that I needed a steroid injection straight away. I remember my adult doctor saying to me 'do you think you need a steroid injection?' I remember thinking well you're the doctor! You tell me if you think I need one! It taught me that I am the only person who knows my body and illness the best. I have to start making the decisions now such as realising when I need a steroid injection or when I need to start a course of steroids/change in biologic etc.

I was also used to going into paediatric consultants and them lying me on the bed and checking my joints and then discovering that actually I had quite a few joints flaring. Sometimes I did not even know myself that I was flaring. In adult care they rarely do a full body check of your joints so you have to tell them which joints you feel are flaring.

I also have to now organise all my own blood tests and keep track of my own markers in my bloods. Something that my mam and my paediatric consultant did for me when I was younger.

For me personally, at 17 I found the time of transition hard as I was in an exam year in school which was another added stress. I think transition should not be carried out until you are either finished exams or the year before you go into final year. It just gives you a chance to get settled.

I am now 20 and on a drug that is doing wonders for me. I am in university and I am studying to become a primary school teacher, which was always my dream. I have become much more aware of my illness and know when I need something to be done with regards to my care and wellbeing.

Do not let your illness define you, you can still lead the life you want to live just maybe with a few adaptations. I always say that I have JIA, but it does not have me.

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