



Airing Pain Programme 132 – When Children Have Arthritis

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How do you identify illness in young children and coping as a family?

This **Airing Pain** programme was recorded at the Scottish Network for Arthritis in Children SNAC's 2022 Family Weekend at Crieff Hydro, which brings together families recently affected by juvenile idiopathic arthritis and some of the country's leading paediatric rheumatology experts.

This programme exists due to funding from Trefoil House Organisational Grants, the New Park Educational Trust and WCH Trust for Children.

Issues covered in this programme include:

juvenile idiopathic arthritis, autoimmune disease, coping as a family, rheumatology, paediatrics, support networks, identifying illness in young children, movement and exercise, steroids.

Contributors:

- **Parents (and their children) of 23 children between the ages of 5 and 14 who have juvenile idiopathic arthritis.**
- **Sharon Douglas — SNAC (Scottish Network for Arthritis in Children) chairperson & co-founder.**
- **Julie Duncan – General Paediatrician NHS Lothian District General Rheumatology Clinic.**
- **Vanessa Raimondo — Rheumatology Nurse based in Edinburgh.**
- **Alison Ross – Children's Arthritis Nurse working in Aberdeen.**
- **Jo Walsh – Paediatric Rheumatologist based in Glasgow, working as part of SPARN (Scottish Paediatric and Adolescent Rheumatology Network).**

Find certain speakers easily throughout this transcript with our colour coding system!

Paul Evans:

This is **Airing Pain**, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain and for those who care for us. I'm



Paul Evans. And this edition of ***Airing Pain*** is supported with Grants from Trefoil House, the New Park Educational Trust and WCH Trust for Children.

Sharon Douglas:

[Over the background noise of the conference]

Can everyone hear me? Hi guys, if you just bring your children to the different age groups that they are meant to be in. Thank you.

[Male voice and Douglas call out directions to attendees as to where to gather in the conference hall by age]

Evans:

In March this year, that's 2022, at the time of recording, SNAC – that's the Scottish Network for Arthritis and Children – brought together families affected by Juvenile Idiopathic Arthritis – JIA – and some of Scotland's leading paediatric rheumatology experts for a weekend at Crieff Hydro Hotel in rural Perthshire.

So, SNAC Chairperson and Co-Founder, Sharon Douglas, welcomes twenty-three families, including the parents of twenty-three children, between the ages of eight and ten who have JIA and their two- to fourteen-year-old siblings.

Douglas:

It's been so nice to be back and welcome everyone.

Many families have been booked on this weekend for two years and it's so nice that we've finally got back at Crieff and are running our family weekends again. I think this is about our thirteenth weekend so it's been nice to keep that tradition going and I hope everyone has a wonderful time.

The main thing is that we all meet people, we chat, we find out more about JIA, our kids give each other tips. The kids will get some fun but they will also meet other children like them and they'll know that they're not the only child with arthritis which is, for me, the main aim of the weekend. That they make some friends, realise 'It's not only me', but also meet their clinicians and hospital staff in a friendly, relaxed environment and have – make sure that you sit with the clinician at lunchtime, or anyone else, just – they're here to have a weekend with



us too and they normally feel in the clinic [that] it's so rushed and it's so busy so it's nice to have time to just chat with families over lunch, and everything else, and nice for your children to see them in a different setting.

So, if you recognise your rheumatology professional here at the weekend make sure you say hello to them. So, we're even more grateful for them for their time this weekend and putting the program together because although the SNAC Committee, can do lots, we can't actually do the education part because all of SNAC Committee are parents with JIA so we all know what it means to have a child with arthritis but what we can't help with is the education part so it's so vital that they come and help us with that.

So, our main aim for this weekend is for the kids to have a ball and to meet others and for you guys to do the same.

Child speaking to another child:

Do you lie to me? Did you lie ...? [laughter]

Evans:

What's he doing?

Child 1:

Laser tag.

Evans:

So, how's that work?

Child 1:

[Noise of 'shooting' in the background]

So, you've got these guns and you have to reload you have to shoot, like, the other team. It's like really fun because you get to, like, run around and you get to like shoot everybody. But it's just pretty much really fun.

Evans:



So what team are you on?

Child 1:

I'm Team Blue, definitely.

Evans:

Team Blue – and Team Blue are winning?

Child 1:

I'm not so sure about that but, we'll see. I think we're really good though 'cause, you know, we can run much faster.

Evans:

Are you enjoying yourself?

Child 1:

Yes, I'm enjoying myself very, very much.

Evans:

Good, see you later.

Child 1:

See you later.

Evans:

There are many ways to have a ball and laser tag is just one of them. Those activity sessions were integral to the form of the weekend.

For the educational components the group was divided four ways by age. So, the parents, the five- to eight-year-olds, the nine and tens and then the eleven-pluses. Each group had its own age-appropriate workshops delivered by specialist clinicians.

The parents' introduction to JIA was given by Julie Duncan. She's one of the General Paediatricians in NHS Lothian District General Rheumatology Clinic and also in Edinburgh.

Julie Duncan:

[Addressing the conference]

Juvenile Idiopathic Arthritis means that you've got inflammation in your joints occurring before your sixteenth birthday. The 'idiopathic' means we don't know why some children get it. We know that there's some trigger factor. Some infection can trigger arthritis. Some people have got a genetic susceptibility but we don't really know why one particular child will develop arthritis at any given time.

And then the arthritis is pain and swelling within your joints and it has to be there for at least six weeks because children can get swollen joints because they've injured themselves or they've had an acute infection and they get a bit of a swollen joint that might just last a couple of weeks and then settle down.

And it's also excluding other causes of joint swelling. So, some children who might have a condition called haemophilia, [meaning] you can bleed into your joints so that could cause swollen joints. Or you can get infection in your joints and that can cause them to be swollen, so there's other reasons that you can have swollen joints and most of the investigations that we do initially are to make sure that there's *not* other conditions that are present and that it is Juvenile Arthritis.

It's an autoimmune disorder and it's when the immune system is unable to recognise the joint as part of itself. The body is attacking the synovium which is within the joint. That's the bit that produces this sort of oily lubricant and that should just be like lovely and free-flowing so that your knee can bend easily. But, when you develop arthritis, you get inflammation within that synovium and it becomes an angry, hot, swollen joint. And the joint can become stiff because that oily lubricant isn't there to help the joint move. And it's the commonest form of long-term inflammatory joint condition in children and young people and it's *not* the same as rheumatoid arthritis which is a common condition in adults. Children present differently. What's going on within their joints and their body is also a different process and it occurs in about one in 1,000 children.

And there's different descriptions that we give to JIA. Some children just have a few [affected] joints. Usually, we describe children with less than four [affected] joints, sort of maximum four joints, as 'oligoarticular'.

If, within the first six months they have four [affected] joints but, after that, they go on to develop more, we talk about 'extended oligo'.

If they've got lots of [affected] joints, which often involves the hands as well as some of the other joints, then they've got 'polyarticular'.

For some children it can be associated with other medical conditions such as psoriasis, and that can either be within the child themselves or, if brothers or sisters or parents have got psoriasis and then the child develops arthritis, we'd refer to it as psoriatic.

Some children can be much more unwell. They have temperatures, they can have skin rashes and they might end up in hospital with it. And this is known as 'systemic'. Systemic as in the whole body is affected, more than just the joints. And then tendons join the muscles to the bones and, in some children these, the tendons, can be inflamed as well as the joints themselves and this is known as 'Enthesitis' or 'ERA'.

And I just wanted you to have a think for a few minutes about, sort of, how your child or other children might present, either initially with arthritis or, once they've got the diagnosis, what symptoms they might have because it's easy for me to say here they get pain, stiffness and swelling in their joints. Most children don't have a clue what stiffness is. They don't rock up and say 'Oh I've got stiff joints'. Swelling's quite subtle for parents and for us. We often are not sure whether joints are swollen or not, particularly in young children.

One of the things I've heard a lot about is children who used to get out of their bed, probably annoyingly at the weekend, they would jump out of their bed, come through, climb in to mum and dad's bed and then often they just, they don't get out of bed. It's all of sudden- well not all of a sudden, but over time they wait in their bed until mum and dad come and get them. Or, if they do get out of bed all of a sudden, you can hear them. They're kind of thumping through the floor because their joints are not quite as free-flowing. Just daily activities – they might struggle to brush their teeth, they might have [previously] washed their hair independently – now they're struggling to do that.



Lots of children don't like getting their shoes and socks put on if they've got inflammation in their feet. For ages they have been absolutely fine with it and then, all of a sudden, they just don't want to put them on, it's a bit of a fight to get them out the door and, especially that's common with children that are young toddlers and it might just be oh are they having a bit of a toddler tantrum sort of thing, but actually it's because it's sore but they don't understand how to tell you that it's sore.

It's often something that people don't tend to notice to start with but, once we treat it and they start to get better, that their whole personality changes but it's so gradual that you don't often notice and it's only when they get better that you think 'Actually they've come alive again'. They're much happier, they're much bubblier, much more confident again.

Evans:

We heard from Sharon Douglas, Chairperson and Co-Founder of The Scottish Network for Arthritis and Children welcoming everybody earlier. So, why is there a need for an organisation like SNAC?

Douglas:

When my daughter was diagnosed with arthritis when she was at the age of two, it felt a very lonely time because we didn't know anybody else who had arthritis and I felt that we were the only people that it had affected.

So, we went on to a parents' event up in Aberdeen that the hospital staff had put on for parents to find out information about JIA. So, we had gone up to that and we met lots of like-minded parents who also felt quite isolated and quite alone. And we chatted with the hospital staff who were able to support us in setting up in this network for arthritis in children.

So, we, basically, how it started was we got all the families together, we did an email mailing address and then we just asked people 'Would the network be helpful and do you think that it would help other parents and your children to realise that they're not alone?' And that we could work together so – and what we did was all done by asking the parents what they felt would be helpful.

So, we do events, as you know, and Information Days, education is key but really, I think it's just [important for] children and parents to meet other families living with the same condition.



Evans:

What they say is that when a long-term chronic condition enters a family it's not just the person *with* that condition who suffers and has to adapt to it. The unwanted guest has to be dealt with by the whole family.

Douglas:

And actually, that's probably the key to what SNAC does. In fact, every event that we do, we always have parents and siblings. We never just keep [restricted to] children with arthritis. Their whole family is involved.

Laura:

We are Laura and Jamie and we're here with our daughter Sarah who's eight who has had juvenile arthritis since she was three years old.

She was diagnosed with the condition so we're here to learn more about how to help Sarah, support Sarah in managing it. I suppose it's quite an emotional thing actually [to] just really try and be better informed as parents to try and navigate through this journey.

Jamie:

I think it's good for her also to see that there is [sic] other children, you know 'cause she doesn't have any other friends or family with this condition at her age. So, coming to a place like this she gets to play and see other children in real life. She's not alone, I suppose, with the condition. We were here three years ago but she was only five at the time. So hopefully now she's an age to have a better understanding as well.

Evans:

When you came here three years ago, how did coming here change her and your approach to her illness?

Jamie:

For me it probably helped us realise what she's going through every day 'cause we almost got into a bit of a habit. She had a weekly jag and she would get the weekly jag and go off. I think she's maybe one of the luckier ones 'cause we did hear from other children who had to

get jags maybe once a day or had a really tough time with it. Whereas I think it showed us actually Sarah was maybe one of the more lucky ones at that time.

Laura:

I think 'cause she was so small it almost just became part of life. You know when she's been getting injections for so long it just became part of how things were. But coming, I think, last time we, we certainly learned better coping mechanisms like around, you know when she's having her jag having, you know, a teddy or the environment that she was in and you know the people that she wanted in the room – like maybe her brother to hold her hand and things like that – so you know it was nice in that way 'cause you also learn a lot from the other parents that are here because you tell each other stories about what your life's like and you learn other ways to deal with situations.

I actually think that's probably been one of the best things is chatting to other parents. Though the presentations are all wonderful as well, you know they're so informative, but you just learn so much from other parents that can empathise with exactly what you're going through.

Evans:

How did you know when the condition started? When Sarah was three – how did you know that something was going on?

Laura:

Oh, it took a long time to get a diagnosis. She had pain in her ankle. It was swollen, it was red, it was hot.

Jamie:

Sometimes we would go to the GP 'cause she'd complain of sore ankle but when she was in the doctor's surgery they'd be, you know, twisting her ankle around, moving and it wasn't sore so it wasn't maybe flaring up so they would send us away and we weren't really sure 'cause we knew she wasn't making it up as such but it was very strange how one day she was in agony, you know she was screaming in pain, but the next there was nothing at all. No pain so that it did take a wee while – a good kind of couple of months before we got to the bottom of that initially.



Laura:

At one point we went to A&E because it was so bad the GP couldn't do anything apart from say give her Paracetamol, give her Ibuprofen. They didn't know what was going on. We went to A&E, they scanned it, they said there's nothing mechanically wrong with her ankle so this journey started and, like I say, it took a few months. But she was getting to the point where she was lying in bed and the weight of the duvet on her ankle was making her cry 'cause it was so painful and it was just getting worse and worse. She couldn't run at nursery, she had to sit with a chair out in the playground. We had to carry her lots of places or use a pram as it got worse. And then finally we got a diagnosis which was very emotional. We did not see it coming at all. Yeah...

Jamie:

Well for a three-year-old to be diagnosed I suppose with arthritis – it's not something we would ever have really expected. I suppose it opened up a bit of a new world.

Evans:

Was there any relief to get a diagnosis?

Laura:

There really was because to get that 'OK, we know what it is' - although it was quite devastating it was a good thing in that we knew...

Jamie:

It meant you could then move on and look at the treatment options.

Vanessa:

[Addressing the audience]

Hi, is it ok if I just start? I'm conscious that I don't want to keep you guys too long 'cause it's gonna be nice and sunny hopefully outside.



So, I'm Vanessa. I'm a Rheumatology Nurse in Edinburgh and I'm just going to speak to you a wee bit about medications. Why use medication? What medications do we like to use for JIA and how are medications given?

So those are really the big questions and what are the side effects of those treatments?

So currently there are no cures for JIA but what we want to do is control the disease and we want less inflammation obviously and less joint damage so those are our reasons for moving on to giving treatment. It's not 'cause we're mean and we want to make our children suffer with injections and infusions and things. It really isn't. We're definitely not about that.

So, we are looking really for a better outcome for child and patient. So, we have happy children, that [are]able to get about and do the things that children should be doing. So, you can be happy as well 'cause when your kids are in pain you're not happy and basically so they can do the things that kids are meant to do, including school.

So, we also want to think about their long-term outlook. You know if you ignore the fact that they've got arthritis and you let joints get damaged the future is not particularly great. We can replace joints but only to a limited degree and they only last for a few years.

So why do we use medications? To get you well in the first place. To keep you well. And then we have a plan for their ongoing in the future when medications work. If there's problems, what do we do next?

If you were on the waiting list to be seen to come in and have your first appointment and somebody phones up and they say my GP's referred me, my child is really in pain. Some of the things that we would say to you on the phone would be 'Are they asthmatic? No? Can they then take some ibuprofen – that might tide you till we get you seen, because we would wait six weeks usually till a patient is seen for the first time and then when they are seen that very day if there were a little bit of swelling, not a huge amount, we might say we'll move on to a non-steroidal anti-inflammatory and, that picture that Julie had up earlier in the presentation had a child with really quite swollen knees, and, if that was the case, we would say look we need to settle that down quickly, we're going to use some steroids and you would get those steroids either as a tablet or as an IV infusion, put in a cannula. Or we might do it as a joint injection.



Joint injections are great because you can put a small amount of targeted steroid exactly where you want it into the joints that are affected. They're usually pretty fast in working. Most patients will get results within a day or two, at least within a couple of weeks if it's going to work.

And now, for most of our patients, if they're not too small, we can get away with doing it under some gas and air – some giggly gas some Entonox so we can do it quite nicely while they're awake without needing to have a general anaesthetic.

Our next line of treatment after that is usually, if we don't think a joint injection on its own or a short course of steroids is going to settle things down, then we would usually move to what we call DMARDS which are 'disease modifying anti-rheumatic drugs' and the one that probably everybody in the room has heard of is Methotrexate, would that be fair to say? Yeah [laughs] that tends to be our first line treatment and that comes in either a tablet, a liquid or as an injection which we can now use in like an auto-inject pen which is so much better.

Then our next line, moving up in the treatment, we would be coming on to biologics, so that's a particular medication that is targeted towards changing or switching off a part of the immune system so helping to control that overactive inflammation.

Evans:

[Background noise of children playing]

I just have to explain what's going on here. Two girls are dressed in these enormous bubble-like sumo wrestler suits and they're charging at each other trying to push each other over. And the winner is the one who can push the other one out of the ring just like proper sumo wrestling.

Kay Sinclair:

My name's Kay Sinclair.

David Sinclair:

And David Sinclair.

Kay:

And our daughter is Eve.

Evans:

Eve – Did you win?

Eve Sinclair:

Oh no, it's 2:1 – well 3:1.

Evans:

Yeah, but you've got your own back because you pulled him down from behind after the game finished.

[Laughter]

David:

Gamesmanship!

Evans:

Are you enjoying yourself?

Eve:

Yeah, it's fun.

David:

And you've made friends?

Eve:

Yeah.

Evans:

So how does a weekend like this – meeting the doctors and the other parents? What's it mean?



David:

It's a lot more relaxed than meeting the doctors like in a hospital environment. It's a lot more relaxed so you can ask any questions that you maybe wouldn't think of when you're at the hospital. And it's obviously quite fun getting to play the games and see the kids kinda meet other kids that have the same condition as them.

Kay:

It's nice hearing other parents' question as well some things 'cause, like you say, it's quite hard to remember everything that you want to ask at the same time. And then someone might bounce in and say something that you were thinking. So yeah, it's quite good being in the relaxed environment. I like it better than being in a hospital or a clinic.

Evans:

And I guess you have questions for other parents and other parents have questions for you.

Kay:

Yeah, absolutely yeah. Uh huh, 'cause one of the mums I was speaking to there was saying that she's going through the process of changing medication and then I obviously was saying that we're in the process of Eve stopping medication so that was quite uplifting to hear I think from our side to them as well. So, there is hopefully, fingers crossed, some of the children will grow out of it.

Shardie Sutherland:

I'm Shardie Sunderland.

Robert Nightingale:

I'm Robert Nightingale.

Hayley Sutherland:

Hayley Sutherland.

Evans:



Hayley, you've just been sumo wrestling with Eve. How'd it go?

Hayley:

[Laughter]

It was funny.

Shardie:

It's important for the children to be able to meet and see that there's more people like them 'cause it is so, you don't know anybody with it. I mean, I did think that children never got it, it was just older people you know, that was my opinion. So, I was so shocked when they diagnosed Hayley with arthritis.

Evans:

How old was Hayley when she was diagnosed?

Shardie:

She had just turned six. She was just six. And now she's ten. It's gotten a lot worse since she got it. It was just her knees – now like we're waiting. She might be getting joint injections in her jaw, her shoulders, her wrists, her hips, her knees, her ankles we're told.

Evans:

How do your friends feel about you having arthritis, Hayley?

Shardie:

[Addressing Hayley]

What – do they make sure you're OK? [Hayley agrees] They worry about you.

But I don't think the children understand how hard it is. I think that is the problem is that...

Hayley:

I think they think I'm a like they think I'm very different to others.

Shardie:

Different? No, I think, I just don't think that they understand how hard it is 'cause like a lot of things she'll have to sit out from doing sometimes 'cos she's really sore. A lot of your closer friends understand but I don't think they just understand fully.

Vanessa:

[Addressing the conference]

One of the big problems when we talk about medicines is the potential of side effects. So, just to simplify this, when we're talking about side effects it's the unwanted effects so in non-steroidals that might be something like a potential for a stomach upset which we can counteract by using other medicines, but, then that's another one for your child to take, and there is no such thing as a medication that doesn't have the potential for side effects.

So, we try to get away with as little as we can. I think steroids are the medications that we now consider the most toxic that we use and we try and use them sparingly because they're great at switching off inflammation but, long-term, to keep using high doses of them can cause all sorts of problems so the things that teenagers, for instance, don't like is the weight gain, the moods, the acne, that kind of slightly rounded face. Those would be short-term, generally, side effects. But, if you continued to use steroids and you get weight gain, you also can have that increased chance of developing diabetes, you can have risks to your blood pressure going up, bone density can be a problem if we've used a lot of steroids so that's not great for long-term use. Fantastic for short-term so we often get kids they go 'I just want to have more of those joint injections please, because they work' [laughter] 'just get that over and done with and then we can move on'. But long-term we can't keep doing that. So, we couldn't keep treating a knee with arthritis every two months with another joint injection for instance. If it kept coming back, we have to move on to other treatments because we can't stick at steroids.

For biologics each one has a slightly different function and each one works in a slightly different way so some of them will switch off certain parts of your immune system. The anti TNF's we're aware that children shouldn't have things like piercings while they're on them because they might not heal up so quickly. So, whilst you wouldn't think of that as a traditional side effect, you know, you're talking to teenagers that want to go and get their nose pierced or want to do things and you're like 'Oh, here's another drawback for having



this chronic condition, I can't go and do what I want to do'. For most of them they laugh and say that it's not a problem but we'd ask them not to drink non-pasteurised milk or eat smelly cheeses and things and you're like yeah that's not an issue for most of us [laughter] but I always remember one boy who was, I think, twelve and I asked him what his favourite food was and it was lobster. So, I was like 'OK' [laughs] you have more expensive taste than me! In a different league slightly!

[Audience Applause]

Alison Ross:

Hello everyone. My name is Alison Ross and I'm a nurse that works in Aberdeen with children with arthritis and, this afternoon, we are going to look at coping mechanisms with Juvenile Idiopathic Arthritis.

But I know not everybody here has arthritis. You either have a brother or a sister that has that, is that right? Yeah? OK so we'll talk a bit about that as well.

So, how does arthritis affect a young person?

So, it's your own immune system attacking your joints and we don't know why it does something strange like that and the symptoms are you're stiff, especially in the mornings. It's really hard to get going and it's really you at your most sore. We know there's swelling and tenderness at the joints, some people have a rash depending on what type of arthritis you have. Most people have some type of pain and some people have restriction in their movements. Maybe they've got a stiff arm or a stiff elbow, stiff ankle with that. Sometimes some people feel a bit irritable and angry and feeling a bit sad and 'Why me' but most of us feel like that, that's not unique to children with arthritis.

So why do we bother treating arthritis. Well, we want everyone to have healthy joints. The idea is, if you're affected by arthritis when you are little, when you grow up you can do everything that you want to do, you're pain free, you're comfortable, you're growing because we want – we see some children who are really small with arthritis. And as they get older, I've been in the job twelve years, I've seen two-year-olds that are now fourteen so we see them right through their whole growing spells. We want that to do well.



So, we all know that our brothers and sisters, or you yourselves, take medicine so the medicines can sometimes be tablets. The medicines can sometimes be an infusion in a vein. And a lot of people take injections, alright, and we know that a lot of the drugs have side effects, so you maybe feel a bit sick, you feel a bit grumpy with it, you can have increased infections. Coughs and colds with it – come around a bit more frequently and we do this funny thing – we do these blood tests quite a lot. I'm sure that people who have got arthritis are sick of having blood tests but it's really important that we do that because we need to know that inside everything is working ok.

So, what do we mean by inside?

So, we're talking about your liver and your kidneys are all working properly so we can do that by looking at what blood says. Sometimes the treatments can lead to lots of anxiety because we do a lot of needles in rheumatology, don't we? We *do* do a lot of needles. I wish we didn't.

What helps with coping with taking medications?

Be open and honest with the doctors and nurses that are looking after you. And we've looked after lots of boys and girls over the years and we've heard lots of stories of people doing different things. We've had people saying I take my meds but actually don't. I actually spit it out or I say I take it and then I hide it in the cupboard, in the bedroom. We've had a few people have had a stash of medicines in their bedroom. Or people say, well we just pretend that we take it and we don't let on to anyone.

So yeah. Everybody's different and they are hard medicines to take. And it's always good to go back to the doctors and nurses looking after you and say 'This is really hard for me to take this', and give a reason why and we'll try our best to help you.

All of the doctors will give you some sort of choice in your medication as to how it's taken so it might well be that what works well for you is an infusion but you can have a choice – you can have it in a drip or you can have it as an injection.

Not many of them come as a tablet but there is some choice with it – also how frequently you can have it. So, you can talk about what works for you. Some people say 'I can't stand needles, but I can take the actual drip going in, I don't find that sore' and some people are like 'Oh no, I don't want to spend all that time in hospital – half a day having an infusion or



two hours of my life, I don't want to do that no' so we've got lots of wee tricks that we use. I don't know if any of you have used numbing creams and you can get anti-sickness medicine against Methotrexate and we use Buzzy, a little device that can help with injections to stop it being so sore, and there's something, this funny thing, called meditation techniques. And some people that take some medicines they look a little bit different for that time in their treatment – maybe a year or two years. And the ones that do that tend to be the steroids and the way that you look different when you take the steroids doesn't last once you stop taking it, it fades away – all the symptoms. Sometimes some people, have a slightly chubbier face, they can feel more grumpy with it, they put on a bit of weight, but that comes off again and people look different.

So, what helps?

We're always on about being active and that's what's great about this weekend, isn't it? Everyone here is really, really active. You've all been out doing Laser Quest? Yup, before lunch? Fabulous, good. And you need to take time to learn what works for you because I'm not sure that *everyone* was able to do Laser Quest today. Am I right in saying that? Maybe somebody went off to do some different things, yeah? And staying active might be low impact exercises, so it might be something like swimming. I don't know if some of you like to swim? It's really important for your arthritis. Maybe you do yoga? Or meditate with it. Has anybody here, pop up your hands, do you use any Apps on your phone that help with keeping fit?

Have you heard of The FitOn App? It's a free App. You might want to have a look after this session that helps you do exercise at the level that your fitness is at. It's not designed for an athlete that is running lots and lots and lots of miles, or doing athletic things. It might be something you want to do and something all our physios say as well is we don't want you doing boom/bust exercises so things like 'Great, I'm going to go out today and I'm going to cycle my bike for four miles and then I'm going to run in with the dog and do this' and then, for the next two weeks, you're not able to do anything. That's not helpful.

We've to remember the physio therapy is a treatment in arthritis but it targets specific joints so we don't send everyone away to do physiotherapy. It might well be you've got a bad knee and maybe the muscles here are a bit not – as pronounced as they would be – and matching [with] the other side. So, the physio does specific exercises for that.



So, coping with emotions. Keep the lines of communication going. I know you're all looking at me thinking when is she going to end and it will be soon. So, it's good to talk to your friends and family and meet all these people here today.

Take time to relax. Take breaks from the screen and lots of people spend a long time on their phones or their iPads. Remember everyone is different. None of us here today, with the exception of two young ladies who look alike, I've noticed everybody looks different. Everyone has good and bad days. And be kind to yourselves.

Kirsten:

My name is Kirsten and my daughter, Rosanna, who's eleven, had JIA diagnosed at fifteen months. Had steroid injections, started on Methotrexate and it all went fairly well and then at four years old she was then diagnosed with Uveitis. So that was then changes of medication and in general she's really, really well. Just some ups, some downs and when it's the ups you've just got to go with the ups. She just copes so well.

Evans:

How old is she now?

Kirsten:

Eleven. She just gets on with it and she hides the pain a lot. She knows herself, if she's in pain, she'll take medication or just slow down with what she's doing. And she knows if she overdoes it the day before, the next day she just needs to rest.

Evans:

It's often in these occasions where you concentrate on the kids. But what about the parents?

Kirsten:

Yeah. It never stops, never stops and hospital appointments – just you never get a break and sometimes you just want a couple of months off, especially with injections when you have to do injections every week – if they get upset. Sometimes the child is OK and they'll go through a phase of being OK with their injections and then they'll start to get – they hate them again and they'll get sick and then that's when you just want time out and just take time for yourself. But you've got to just keep going for the child.

Ross:

[Addressing the conference]

So, we're going to look at coping with JIA as a family. What makes it better.

So, on your tables today I have put out 'What is a Good Day?' and what I'd like you to do is, I did this yesterday in my office before I came here, is I'd like you to draw around your hand. And you've got the five fingers and I want you to tell me five things that make it a good day.

So, yesterday I did mine in my office and I wrote that I'd slept well. So that's a good day for me. It was sunny weather, even better day for me. I had exercise outdoors, we had our favourite meal for tea and I felt happy with life. So that was five things. So, see if you can do that. There's no rush and we'll go around and have a chat about that.

Hmm but then my life is not perfect. I have bad days. Look at my bad days. So, I thought about what was a bad day, which wasn't that far away – I think it was the Tuesday of this week – so I slept badly, I'd sore feet because I'd done a lot of walking with my dog -feeling a bit grumpy because I was a bit tired. There was no milk in the fridge when I got up in the morning – made me very upset – and we had a fall out over it as well.

So, my life is not perfect. So, we're just looking to see what would be a bad day for you and when we look at what everybody does, we can come together as to how we think we can make things better.

So, on your other page, we have 'Things to Make It Better'. I didn't write the title on it because you might want to write a different title on it.

So, I thought about my bad day and I thought what actually made me better. So, there's no rights and wrongs with this. There's no marks for spelling or anything else that's there. We want to know what *you* think.

So, I put down. Hug a family member or pet. I'm very partial to a collie dog and I love her dearly so I gave her a wee hug. What's your favourite film? I've got quite a few that I particularly like to see. Take a break from the screens because I've done a lot of IT work this week and exercise outdoors and read a book. So, stepping down and chilling out. So, if we all write down this and then we can come together and have an idea and see if we can



identify things, that actually make things better for *all* of us not just 'Oh it's alright for you, you've got a dog so it makes you happy' or do whatever – what works for you.

So, a bad day might be, well, you know 'It's a Tuesday, get an injection and have a trip to the hospital, have to have a blood test, fell out with my sister, didn't get my favourite tea' – so whatever you think. There's no rights and wrongs. Just write them down and we'll have a look and see if we can come to some conclusions.

Karen Barrie:

I'm Karen Barrie.

Gordon Barrie:

Gordon Barrie.

Evans:

So, you have a child here?

Karen:

Yes, Kathleen who's ten. She was diagnosed when she was sixteen months old.

Gordon:

She'd only just started walking and then...

Karen:

Yeah, yeah or she got it sixteen months and then got we, we got, got a full diagnosis at eighteen months. Yeah, so it was over those two months to get her diagnosis. What was wrong so yeah, she was tiny.

Evans:

Well, I'm just thinking of my own grandchildren and my own kids. How on earth would you diagnose an arthritic condition in a sixteen-month-old child?

Karen:

So, she started walking at fourteen months. She was a wee bit later in walking and then just one day she came home and she'd had a fall at nursery and she developed a limp and it just didn't get better. So, it was her doctor that thought maybe she had a toddler fracture so we took her up to the A&E hospital. She got X-Rays and there was, there was nothing, so we had a couple of months of keeping going back with this constant limp that wouldn't get better. Eventually it was the orthopaedic doctor took her in for an MRI because she wasn't right at all. She was grumpy. She was really not herself at all and then had this limp and eventually with the MRI they realised it was arthritis in her knees.

So, it was actually in both knees. Although she was just limping with one. If she didn't have the limp, we wouldn't have known what was wrong. So, she then had her steroid injections in her knees but it then spread so she had the extended Oligo. So, it then moved around until they got it under control and every now and again it will flare up into different joints. Usually when they take her off her medicine and then she kind of flares back up again. But we've had a couple of years, fingers crossed, that's it's kind of been OK, but she's also got Uveitis. So, it also appeared in her eyes a few years ago. So yes, she had to then switch medicine and things so. But, at the moment she's, yeah, you wouldn't know she had it. Which is good.

Gordon:

And she does loads of sports and ballet and gymnastics.

Karen:

Oh yeah, she does loads of dancing.

Gordon:

So, it's not held her back at all.

Karen:

No, which is great.

Evans:

What surprised me most about being here this morning is that, I mean, I've just been watching sumo wrestling, they're all shooting each other with laser guns at the moment

[laughter], goodness knows what they can do to each other next. You would not think that these children have life changing pain conditions.

Karen:

I know.

Gordon:

They just get on with it. As kids do...

Karen:

That is the good thing about them. She's always just kind of got on with it apart from, obviously, when she couldn't communicate with us. Other than that, she has just got on with it. It's a bit of a battle with the medication now and again, although it seems to be a bit settled now she's a wee bit older, but we did have a phase where she didn't want the injections and she'd forgotten why she was taking them because she hadn't had a limp or anything for a wee while and she'd been on it a few years, so she'd forgotten why she was taking it. And you know it was 'Why do I have to take it, like I don't know why, and why is it only me?'.

That's why this is great because she is meeting other kids that have the same thing 'cause she's not really met anybody that has the same condition as her before. So, this is great for her. Yeah, It's the constant medication that's the main thing for them I think but that makes them able to do this.

Gordon:

Yeah. I think they get to a certain age, it was at six or seven, where they start to realise their friends aren't in the same position. You know, they're not getting fortnightly injections, or they're not having to take a tablet every morning. It's only once they get to that age that they kind of realise that's not the norm because every kid thinks their norm is the norm until they discover otherwise, and it's usually that six or seven mark and they realise.

Evans:

Do her circle of friends, school friends, realise that something is up and treat her differently?

Karen:

I don't think so. I think they forget that she's got arthritis. They do know but, because she's been so good recently, they don't remember that she's got it, I don't think, half the time, and she does quite a lot of dancing. And she does ballet and goes to the Royal Conservatoire for ballet and stuff and I don't think *they* realise she's got it at all.

Gordon:

No, it's not changed anything. Not made any allowances for it but they've not needed to so...

Karen:

I think it was a bit different when she started school, when she'd had a break off her medication and her arthritis flared up again and she couldn't get in quick enough to get joint injections. So, she started school with a limp and I think people did treat her a little bit differently then. So, I think, when it's visible, if you're flaring and you're not moving quite so well, then they would start maybe to treat her different – 'Why are you doing that?' or 'Why can't you keep up' or, you know, she had a wee bit where she couldn't keep up with her friends so she would get a wee bit lost. You know a big playground and her friends would run off and she couldn't. But, other than that, when it's under control, no it's fine.

Ross:

[Addressing the conference]

So, how many people on a bad day said that they were sore? Five, that's quite a common thing, isn't it? About having a bad day? How many people are in a bad mood on a bad day? Oh Wow.

So, it's quite common these themes, isn't it? Wow o can't do the things you want to do, or tasks that you want to do. Ten, yeah, right hands up, who feels tired? Will we just say everyone on a bad day [laughs].

Do you know what? You're not going to believe this you've nearly all written the same things. We're all kind of similar, aren't we? So, friends not available mostly – so on a bad day I've got here – no motivation. How many people on a bad day just can't be bothered?

The back table want to tell me what you wrote on your good day? What, what's good for you on the back table?

Child 2:

[Shouts out]

Nice and sunny.

Ross:

OK, so good weather.

Child 3:

[Shouts out]

Going out with my friends.

Ross:

OK so going out with our friends, yeah, absolutely.

Any ideas on the back table?

Child 4:

[Shouts out]

Football.

Ross:

Football, yeah, yeah, we've got sport here. So, we've got favourite food, we've got Pop Tarts for breakfast, better than my milk that wasn't in the house, isn't it? Yeah, definitely Pop Tarts for breakfast.

Playing with friends.

A warm day.



Listening to music.

Favourite dinner, sunny days, playing with friends, spending time with my dog, favourite films, slept well...

So, looking through all the comments about what can make it better, there's definitely – I can't pick out from any of these who has arthritis and who doesn't. We all think and feel the same whether we do have something wrong or not. So, if we look at things – we all like to sleep well, we all like nice weather, we all like friends and to be popular, and to be liked and to be with people. And we also like our space as well. Because people have written 'Time to say "I want to be on my own"'.

People like music. There wouldn't be a music industry if we didn't would there? So obviously people like that as well.

So, we can conclude that we're actually not that different.

Tammy Fraser:

I'm Tammy Fraser and this is Tim Fraser. Our son, Sam, has JIA. We're from the Shetland Islands – as far north as you can possibly go in Scotland – we're the second most northerly island in Britain. An Island called Yell. Sam didn't really know anybody his own age with arthritis so it was, yeah, a way for him to kind of see that he's not alone. It's not just him, there is [sic] other kids his own age that suffer with the same thing.

As parents it gives us a chance to speak to other parents and, you know, find out their experiences of just having a kid with JIA, but whether it be medication or just day-to-day living, our uniqueness or how we're able to get treatment for Sam because of where we live, it's a bit different and it just that gives another perspective I suppose.

We're part of the SNAC family group on Facebook which has been really helpful. And if we've ever had any questions, we can put it on there and parents are really good at responding. And our local health centre, our local practice nurse, has been excellent because she's done extra training with the nurses in Aberdeen so that we can get information from her rather than having to go to Lerwick or go to Aberdeen. She's been brilliant because, without her learning how to work the injections and things that we give Sam, we would have had to go to mainland Shetland to get training at the hospital and



would have had to go three/four times for them to see us giving Sam injections to make sure we were doing it correctly whereas with Rosemary, learning how to do it and how to show us we can just literally nip across the road to our local Health Centre and it's taken five minutes, whereas if we'd had to go to Lerwick it would've taken the most of the day. She's been brilliant.

Jo Walsh:

[Talking to attendees]

In you come, if you want to put anything, just put it on a chair or table. Hand gel anyone? Hi, hi everyone, hi.

Right, where's your badge? Oh, you got it already. Can I do, do you want me to help you put it on? Yes? What's your name again? Rebecca, that's right...

Walsh:

I'm Jo Walsh. I'm one of the paediatric rheumatologists based in Glasgow, but working as part of the SPARN network.

Evans:

What is SPARN?

Walsh:

So SPARN is 'The Scottish Paediatric and Adolescent Rheumatology Network'. It's a managed clinical network that was started at the same time as SNAC, actually in 2009, and it's how we manage to look after young people across Scotland with arthritis and other rheumatic conditions.

Whether you live in Shetland or deepest Stranraer or in the central belt you will have the same access to care and specialist treatment wherever you live in Scotland. And that's one of our major clinical goals for SPARN.

Evans:



Now, on this weekend I've talked to people from all over Scotland. I talked to a couple and their children from Shetland yesterday who were the only people on the Island who have JIA. How do you, in SPARN, sort of give them any core treatment?

Walsh:

There's many ways that SPARN can help there. So, they have access to the team in Grampian so they have clinical staff, a nurse, doctor, physio and OT access there. But I guess if you do live on Yell, which is as far North practically as you can get, you have to accept you have to travel there. But we use video as well to keep in touch with patients. Our nurses are open to emails and phone calls so they are getting good access to care albeit they have a distance to travel for whatever they do in life and we have the same approach for other young patients using the network centres of which there are fourteen in Scotland, each having a paediatrician with an interest with specialist contacts with the rheumatologist.

Evans:

Now another thing about this weekend is parents are meeting their practitioners in a social context and I guess it makes a huge difference.

Walsh:

Yeah, I mean Scotland is a small country when it comes to networks and the whole SPARN network knows each other and, with that, we bring a certain personalised medicine for our young patients and their families. And I think that is a lovely relationship to have. SNAC helps us with that and our close collaboration with SNAC is paramount to the work we do.

Evans:

Another thing I notice is that their pain is invisible. These kids don't look ill.

Walsh:

So Paul, you're quite right in your observation. Our aims of treatment for these young people is to ensure that they're able to do the same as other children and young people without arthritis and, as we saw when we're seeing our patients in groups, it's difficult to know who's got arthritis and who hasn't. Which means our treatments are working, whether it be medicines, psychological support, physiotherapy, occupational therapy and all the modalities



that we use. So our aim is to have young people, albeit on treatment, but in remission of their condition so they're not experiencing the pain, swelling and stiffness seen in active joints.

Evans:

Some of the parents talk about their children developing JIA at fifteen months. How do you spot that?

Walsh:

You're quite right. Young people do get arthritis even from the age of less than one year.

In some ways it's easy to spot because the child may not want to pick something up that they were previously picking up or stopped walking or walk with a limp so it's quite easy in the young ones to pick it up and I think educating medics, orthopaedic people about persistent swelling being a sign of young people's arthritis, getting that message out there, is one of SPARN's goals. You know we educate people to recognise arthritis early because that makes a big difference to treatment.

Evans:

Now, at the other end of the scale, these kids go from being children, young adults to adults – where they're lost from your service I presume?

Walsh:

Well, I wouldn't say they were *lost* from our service. What we do is we have a really effective programme of transition to young adult care and we have good links with our adult colleagues in all the network centres and transition for young people starts at, you know, eleven or twelve. We go through a standard process using a program called 'Ready Steady Go' to prepare the child, young person and their parents for moving on up to adult, so I see it as a transition and not getting 'lost' to an adult service.

Evans:

And do the adult services work well with you?

Walsh:



Colleagues in each of the network centres, who are interested, will take on the young people with JIA because it's a different type of arthritis to adult arthritis and they will always have JIA throughout their life. But that programme of 'Ready Steady Go' is followed by 'Hello, Welcome to Adult Services' and so that works really well.

Walsh:

[Addresses the attendees]

Today we're going to be thinking about how we treat JIA and make it better, alright.

Who takes any medicine for JIA? Whoa – so medicines are one thing but there's more than medicines that help JIA get better. One of the other really important things for JIA is keeping moving. In the morning sometimes we feel a bit stiff with JIA. And we had our bandages on yesterday didn't we – for those that don't have JIA to make them see how it felt and what it felt like didn't we? Rebecca it was a bit tight round the knee, wasn't it? Got a bit sore after a while.

So, to get moving, particularly in the mornings, it's quite good to do some stretching and moving and maybe even some yoga. So, two people to a blanket or a space down here and we're going to go and do yoga.

Come on, oh my goodness, could we look to see what Madeline is doing? She is a balanced tree.

[Addresses Madeline]

Oh my – can we do it on the other leg?

[Addresses the attendees]

Now shall we bend down? Whoa – who feels the backs of their legs? It's tight sometimes – that's our hamstrings that were stretching. OK, up we come nice and slow. Shall we stretch out and welcome the world?

Dominic come and welcome the world with your arms out straight. Leila, come on... *[fades out]*

Kailen Templeton:



I'm Kailen Templeton. I've had arthritis for coming up to nine years now.

Paul Templeton:

I'm Paul Templeton. I'm his parent.

Evans:

Now arthritis – people with arthritis JIA cannot do sport, they must keep away from everything – True or False?

Kailen:

False. I play rugby and I started playing it in Primary 5. I played football from Primary 1 to Primary 7. And I've continued my rugby and I'm going on next Saturday for SRU development because I've been nominated by my Club.

Evans:

SRU – Scottish Rugby Union? So that's the path to professional rugby? Any concessions made about your condition?

Paul:

No, there's been nothing. On the form there's a part if you have any existing conditions and that's been filled out so we're all good. We're good to go.

Evans:

So how did you start that? How did you get into it?

Kailen:

Primary 5 I went to see an All Blacks game versus the Scotland team. And that really got me interested in rugby and I asked my dad if I could start playing. I enjoyed it. Then I went through a phase of not really enjoying it. Then when I got into P6 I really enjoyed it and I've really enjoyed it since.



It's been one of the main highlights of the past few years getting to play rugby with my friends and going through to competitions and then, recently getting nominated for further development.

Evans:

How did you feel about him getting involved in rugby because parents can be fairly protective, I guess?

Paul:

So, there was a lot of trepidation for a start, my wife especially. It's obviously it's something he wanted to do so I thought 'Well we'll give him a chance and there's a chance he might not like it'. And fortunately, he took to it like a duck to water.

He had a bit of a role model when he was growing up, told him before, you know, you have to keep trying to push on and try to drive through this and he said 'Ah but dad, you don't know what it's like, you've not had it, no-one else has got it plays sport.' So, I had trawled the internet for a couple of nights and found a rugby player in New Zealand, called James Lowe, who had JIA growing up and was playing professional rugby for the Chiefs in New Zealand. Followed him on Twitter, started 'liking' some of his stuff. He started 'liking' some stuff back and then it snowballed from there and we've stayed in touch.

Evans:

So, we're not talking Sunday hack players we're talking about...

Paul:

We're talking elite professionals. James Lowe. Just missed out an All Black squad for a 2015 World Cup due to shoulder injury. And now he's playing professional rugby for Leinster, arguably the biggest club in Europe unfortunately [Evans laughs] and playing internationally for Ireland.

Evans:

And you still keep in touch with him?

Paul:



Yeah, I still keep in touch. He just got married on Thursday so I wish them all the best.

Evans:

Thank you very much both. Best of luck with your rugby assessment in a couple of weeks' time.

Kailen:

Thank you.

Evans:

I hope not to see you thrashing Wales over the next few years.

[Laughter]

Evans:

I make no apology – some national stereotypes just run too deep.

Coming to the end of this edition of ***Airing Pain*** I'll just remind you that whilst we in Pain Concern believe the information and opinions on ***Airing Pain*** are accurate and sound, based on the best judgements available, you should always consult *your* health professional on any matter relating to your health and well-being. They are the only people who know you and your circumstances and, therefore, the appropriate action to take on your behalf.

Do check out Pain Concern's website at painconcern.org.uk where you can download all editions of ***Airing Pain*** and find a wealth of support and information material about living with and managing chronic pain.

Now I can't tell you how uplifting it was to spend the weekend with the Juvenile Idiopathic Arthritis families and the clinicians who look after them, so a huge thanks to them all, including SNAC, The Scottish Network for Arthritis in Children who made this family weekend happen. Its website is SNAC.uk.com. SNAC – S N A C .uk.com. It really is an excellent place to find out more about JIA and not just for those living in Scotland.

Thanks also to the professionals in SPARN – that's the Scottish Paediatric and Adolescent Rheumatology Network who gave up their time to be with their patients and families over the



weekend. And their website is sparn.scot.nhs.uk and SPARN is S P A R N. It's another excellent resource for information and support.

Sharon Douglas, Chairperson and Co-Founder of SNAC opened proceedings on the Saturday morning so it's only right that she should close them.

Douglas:

It's been really special this weekend, particularly because we've had a family from Shetland, which we've never had before. I think there are a handful of families up there. We've got somebody from Benbecula and we've got somebody from Arran. So, actually, three of the Islands people have travelled to this weekend to meet other children and parents – to meet others and find out more about the condition.

Even when you live in a city, you can still feel alone with the condition if you haven't met other children and you might be at the hospital but you don't know if that child beside you has got arthritis or diabetes or why they're there, so it's much harder to make the introductions and to have the conversations.

Evans:

I was listening to a discussion between all parents and one common theme seemed to be the issues of getting a diagnosis in the first place. How do you think SNAC could get involved in improving that?

Douglas:

We have to recognise that we're volunteer parents who have day jobs but I think, for me, it's all about raising awareness of JIA. And that's been a key thing for SNAC. It's on our Mission Statement from the moment we were created in 2009, one of the key things is to raise awareness as well as support families, and I, personally, think that's our biggest thing so, for a tiny example, from one of the talks today is that some of the parents are going to take leaflets – the SNAC leaflet – to their doctor's surgery and see if they'll display them in the clinic or a poster from SNAC and I think we just have to work with the other Juvenile Arthritis charities to help them to raise awareness to and work, maybe, on a campaign with the other charities that are already doing good work as well.

Evans:



The other thing that came out in the discussion is that the advice to parents has changed over the years.

Douglas:

That's right.

Evans:

I mean somebody saying they had a leaflet some years ago and they showed children in wheelchairs and splints, this that the other, so treatment has come so far.

Douglas:

It really has. And even my daughter is now twenty, so she was diagnosed when she was two. But even in her journey you've seen the huge advancements in treatments over the years and, where children might have been in wheelchairs a generation ago, they're really not now and I think we need to be careful that we give positive advice. And personally, our main support for families is actually trying to find ways to tolerate the medication. Trying to recognise the importance of these drugs that help children and stop the joints from being damaged. [The medication] is trying to prevent that long term damage to the joints but yet [there's] the horrible side effects. It's trying to just help families to make sure that they go to their hospital team if they're really struggling to just open up those communications and have good relationships with their rheumatologists, with their team, with their nurses so they can then discuss problems they're having and if there is a real problem with the medication [the nurses can help them change] to another one. And the psychology talk yesterday was all about tips of taking, you know, the medicines which is really key because these drugs are making a huge difference to these children's long-term outcomes.

But all I would say, is like getting families together, children realising they're not alone, parents meeting other parents – it's that shared experience of JIA and everybody's story is very different and it's a very invisible condition. So, we're all coming from different places but I think we've so much in common and we all recognise how invisible this illness is, and we all just can share lots of experiences with it – just helps families bond and I would call SNAC almost a family of parents.

END



Transcribed by Fiona Clunn, edited by Georgia Gaffney

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