Children in Scotland

LEARNING WEEK 2021

Talking about Endometriosis

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My name is Dionne, and my presentation is going to be on Endometriosis Awareness. I'm delighted that this is being presented in March, as it's Endometriosis Awareness month.

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So I'm hoping to just chat a bit about the condition and how you can support young people, that have either got symptoms, or have been diagnosed. So, yeah, I hope this is helpful.

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So what is endometriosis? Endometriosis is when cells that are similar to the ones in the lining of the womb, grow in other places within the body. So, each month, these cells would react in the same way to those in the womb, so they would basically break down and start to bleed.

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So normally this blood would exit the body as a menstrual period.

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However, with endometriosis, the blood has nowhere to go, which results in pain and inflammation. And the condition can be very debilitating and have a huge impact on someone's life, which can be devastating.

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So the symptoms of endometriosis are variable, so the main ones are pain. So you could be experiencing painful periods, it could be where you're not able to go to school.

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Or go to work, you can't function well.

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And pain when you're ovulating, pain during an internal examination, pain during or after sex, pelvic pain.

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Quite a lot of people experienced bleeding, heavy periods with or without clots.

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Some people bleed for a prolonged period of time, spotting or bleeding between periods, or having irregular periods.

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Also with the blood, before you're starting your period, the loss of it being kind of an old, dark colour, is a symptom as well. Looking at the bladder, that can be can affected.

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So painful bowel movements going to the toilet can be excruciating for some people. You could be getting rectal bleeding, symptoms might be similar to those you get with irritable bowel syndrome, which is why you get so much misdiagnosis with endometriosis patients.

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So, the symptoms of that is diarrhea, constipation, bloating, particularly during the period, Bladders - people have pain when passing urine, you can get urine infections, you can have pain before or after passing urine as well. The other symptoms of endometriosis are tiredness and lack of energy, depression. Back pain, and leg pain is a big one that's been mentioned as well. So there's different stages of endometriosis, and not all gynecologists will give endometriosis a stage. But this is based on location.

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So Stage one, you're looking at minimal disease.

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Stage two is mild.

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Stage three is moderate, And stage four is severe.

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But it's really important to remember that the staging doesn't reflect the level of pain experienced.

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So it could be that somebody that has stage one, they have severe pain, whereas someone with stage four has minimal.

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So the management of the condition – there isn't a cure for endometriosis, but that are treatments available to try and make it manageable. So you're looking at painkillers. So it could be an inflammatory, quite a lot of people require products like co codomol, so prescription painkillers.

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But for people in more severe pain, You're looking at opiates like morphine or oxycodon.

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Sort of these drugs, but obviously there's access, or pain teams for that.

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Looking at hormones. Hormones is a big sort of, it's used quite a lot in terms of managing the condition. So, there's all different types. And you can look at kind of the combined pill, the patch, the progestin only pill, the contraceptive implant's another one as well and also the merina coil.

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These are your kind of frontline treatments for endometriosis. You've got GnrH analogues, .

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`Sounds quite complicated, but basically it's an injection that can be given monthly or every few months, and it basically puts the body into a false menopause.

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So it basically suppresses the ovulation which stops the production of the oestrogen and progesterone.

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And, finally, surgery. to remove, the endometriosis.

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And hope that this, will give someone a better quality of life and relief from any pain.

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So, my experience, the symptoms I first had were pelvic pain, periods were bad, they were causing pain. That was so intense, that I couldn't function and bleeding was heavy. There were occasions when I bled right through clothing and then, because of that, I was given tranexamic acid for try and lighten the bleeding and mefenamic acid to help with the pain.

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But I was just a matter of trial and error for me

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Because not everything kind of worked first time. So, the issue was to getting diagnosed. and that was the sort of main problem for me. Getting someone to take me seriously. And I was told that is normal. It was all in my head. I was told, I needed psychiatric help. And I had a doctor say to me that having a baby

would solve the problem, despite only been 16 at the time. I think the turning point was when I

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Was at our training, I'd just left school, and I was training for a new job and I remember I was struggling with the pain that day. I ended up not toilet cubicle, doubled over.

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I was bleeding heavily vomiting and just the pain was the pain was so severe. So it was more about managing that and at one that point, they would give you hormones, which work for some people but unfortunately didn't work for me.

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In 2016, it was, sort of came to that option, where they decided that I had to have surgery. So I had a diagnostic laparoscopy, so that's when

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They go and have a look inside the abdomen and just kinda try and diagnose the problem.

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So I was diagnosed with Stage four and severe endometriosis.... So I've had three surgeries, and I'm currently on the waiting list for further surgery.

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So the impact of endometriosis is that, basically, it can grow anywhere in gthe body. I actually have endometriosis on my bowel and bladder so this has an impact on how these organs function.

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So, in terms of the bladder, it's happened to kind of self- catheterise because I'm not able to pass urine myself.

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So that's been kind of a big change for me, and having to deal with that, the impact the condition has, for a lot of people, is that for some, it can be difficult to work, and function day-to-day cancelling plans due to symptoms being bad. Relationships are being affected and sex life. Mental health is a huge one.

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And dealing with the sort of physical side, so the lack of energy and fatigue. Quite a lot of individuals described that as 'just existing and not living', and it sort of robs you of a normal life.

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I was on a call a way back a couple of years ago, and you know, I do see endometriosis as an enemy, generally I really do, as it's devastating.

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So I felt that awareness was needed for this condition, and individuals need to know what a normal period is and what isn't. Do you know I was told for years that that what I was experiencing was normal and it would get better as I got older, but that wasn't the case.

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And so I just started a blog, which cover topics such as body image, and surgery, and I just kinda used this as a way of raising awareness.

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Then I started my instagram page, which I used to capture the good and the bad days with the condition, but for me, it's also about raising awareness. A lot individuals feel that social media is great for support for chronic illness.

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Then I had a campaign with Fixers UK which is an organization, and you can sort of do awareness campaigns for things that mean something to you. So I did a video on endometriosis awareness and shared my experience and opened the platform up

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For other people to share their experiences with me and get the word out there.

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The media has been a big one as well and I have been in the Evening News recently just highlighting menstrual well-being and the education curriculum needs to be a priority.

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So, through my Instagram account, I have actually met so many young people that have been diagnosed or have symptoms and are going through the diagnosis process.

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So, I've had messages from so many young people who talk about having to go back and forward to the doctors. having to beg for help, been dismissed. I spoke to two young people who shared their experiences with me.

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And, and, for one of them, it was heart-breaking. Obviously, for confidentiality reasons, they will be known as Personal Experience 1 and 2.

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So, Personal Experience 1 - she said the process of being diagnosed was overwhelming, I was experiencing pain, the type paraceptomol just doesn’t touch.

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I was scared to ask for help because of the fear of not being believed, as I was told, it was normal.

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I ended up having emergency surgery.

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I was diagnosed with Stage three endometriosis and polycystic ovary syndrome which is a condition that affects how the ovaries work.

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In terms of my mental health it has been a struggle. I have days when it really gets me down.

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Some days I have felt unable to cope and had thought of not wanting to be here anymore.

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I have got support for this and people to speak to when I feel like this and that helps.

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This begins number two.

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I'm 16 years old and I haven't been officially diagnosed yet due to Covid and not being able to see a gynecologist. I find my Mum to be very supportive and she was able to advise me as she has endometriosis too.

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The difficulty in getting help from the GP was basically because support wasn't great.

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I didn't reach out for help for a while until the symptoms became too much.

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I'm good at coping with the cramps and heavy flow, but there have been times I've been sent home from school due to the pain and bleeding.

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The pain absolutely floored me.

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There have been days when I've had to spend days locked in the bathroom because of how bad it is.

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So, if you were to come across young people that have endometriosis, these are some things that can help the conversation.

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So the most important thing is being there to listen, you don't need to act as a counsellor.

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But simply being supportive is enough, you know. And just knowing a bit about the condition as well. You don't need to have an extensive knowledge on it, but have an awareness of it, and knowing what it is can be a huge help.

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It can be really hard to talk about the symptoms as young people find aspects of this really embarrassing, so you're looking at like the bleeding issues and being compassionate about that and that is the most important thing.

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It's also letting that young person know that you're there to help them access the support if they need it. So in terms of accessing support….

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Speaking to the GP is always the first step.

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And sort of outlining symptoms as well, and pain diaries can be a huge help, just charting what days you're having more pain - is it days around your period?, it is all the time?, These things can be really helpful.

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The Period tracker app can be helpful as well. The one that I use is Clue. And I actually do find that to be quite helpful, because I can track my periods.

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I can track my pain levels, and any sort of, other issues, like I have to take, medication. And also like talking to others, and let people know that, if you are struggling with symptoms, I think that's really important, it's being able to talk about it openly and honestly.

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There is the Endometriosis l Specialist Centre at the Royal infirmity in Edinburgh for individuals who have confirmed diagnosis via laparoscopic surgery.

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And I will come onto this a bit later on, to give more information and also support groups as well.

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We actually a support group called Endo Warriors West Lothian, this does cover, Edinburgh as well. Due to Covid, we've not been able to have meetings so we've been doing Zoom meetings.

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And when we get back to non Covid times, we meet at St John's Hospital in Livingston and Spire in Murrayfield in Edinburgh and it's just an informal meeting, where we talk about issues and, give people time to talk.

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as well, it's about making sure that people don't feel alone.

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They sort of struggle living with the condition.

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So the Edinburgh Endometriosis Centre - this is a specialist centre for the management of endometriosis. It's known as EXPPECT which stands for Excellence in Pelvic Pain and Endometriosis Care and Treatment.

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So referrals to this centre are completed by hospital consultants.

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And it basically gives patients access to gynecologists, pain specialists, dedicated nurse specialists, radiologists who can read the MRIs or any ultrasounds you have, There's also colorectal and urology surgeons for input if your bowel or bladder is involved or likely to be involved.

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The team kind of take a multi-disciplinary approach and provide per person centred care.

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This can be really helpful, because with endometriosis affecting different areas of the body, having the different specialties kinda speaking to each other is a huge benefit.

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The EXPPECT team also undertake research into endometriosis, they have quite a lot of sort of research trials.

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there's one at the moment looking at, I think it's DCA, which there has been results from that, also there's a criteria.

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Stage. You know, you have to be at a certain point to kinda qualify.

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But so far, someone has said that this treatment has made a difference, which is great.

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Because good research is being done. Because it is condition which has no cure. It is common but not that many people are actually aware of it

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The centre also have access to patient information leaflets. So any sort of treatments that are discussed by your consultant, so looking at different hormones or surgery. Now there's information available to answer questions about that. And you've got the nurse specialist. If, you need to ask them about anything.

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They have helpful links as well, signposts to support groups that are available in the Lothians.

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There are also links to to Bowel and Bladder UK, Endometriosis UK, toolkits for chronic pain.

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And that some people do find really useful.

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So everything kind of, is there, and all the care is provided through the centre. So endometriosis in education.

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A lot of individuals I have spoken to have found that education has been affected quite a lot, but some of the young people had told me that they developed their own ways of coping with the symptoms.

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It can impact on someone’s ability to concentrate in class.

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Attendance can be quite an issue just having to take days off due to pain.

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I spoke to one individual, who had missed two years of herr education. And she was told, if you were here more often, maybe you would learn.

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And d’you know, to hear that.

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It was hard

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It was heartbreaking because this is impacting on a young person's life, and they've got no control over any of it and, you know, they can't help, being unwell, and having to take the time off.

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So a few young people had also spoken about how they had to cope with situations at school, when they bled through pads and on to clothes, and the sort of general feel from that was the embarrassment of it.

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And do you know people kind of being judgemental and, you know, being at that age, where it's really embarrassing and things like that

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And it's a lot of people I had spoken to were just,

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they didn't feel, you know, they couldn't, it was all just too much for them.

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And with all that pain and having to be sent home as well

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Some people didn't want a miss lessons, but obviously, just didn't have the ability to concentrate because the pain was just too much.

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So supporting a young person within the school environment, situations like bleeding through pads

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Some people had suggested

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There is a designated place they could go, where they would have the privacy.

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to get cleaned up as well, without the fear of being judged by their peers.

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And I think as well, it's the fear of being sent home from school

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A lot of people are quite worried about it because generally what if the person's not understanding, and it's about the person being understand that the pain from endometriosis is debilitating and reassurance is important because they

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might be anxious about falling behind in lessons

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Concentration can be an issue as well.

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If this is the case, it would be helpful speaking to the young person's class teachers and highlighting that they have endometriosis and this is how it's impacted on their learning, and they may be able to arrange extra support.

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Also, if attendances is an issue, as well, it's about approaching it really sensitively, when pain is so bad.

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It does stop your ability to function. For some it could mean that they're having to take strong painkillers, and stay in bed.

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So there's the importance of early intervention. So early intervention is key with this condition.

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Over the years, I have learned myself that need to be your own advocate in this.

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The reason I share my own expedience openly is because I want to raise awareness, but I don't want any other individual to have to face that delay in diagnosis that sadly I've had, and obviously, due to that, the consequences of not being diagnosed early enough, now living with stage fou disease, So there is kind of a gap in best practice and the experience of girls who present to the GP.

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The specialists or the hospital, you know, it just depends on how bad is, because some girls do get admitted to the hospital because the pain is so bad. But they frequently realising that the pain is minimised or it was put down to part of being a woman. And I think this is another barrier as well because as it's just seen as normal, it's a woman's issue, you know.

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It's a period, it’s just a bad period and that’s how its perceived, and obviously the delayed diagnosis can have devastating consequences on things like infertility, which is a big one.

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So going forward - we must continue conversations or endometriosis and raise as much awareness as possible.

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I will continue to campaign for menstrual wellbeing to be Implemented in education, so such as PSE in schools. And also looking at getting posters up,

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Possibly targeted in West Lothian and Edinburgh is next on the list , with Covid and everything else, it's just not been possible to do that poster campaign right now.

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But, also, just having information available for schools.

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That is something that I'm in the process of with Edinburgh Council but Covid got in the way so it's kinda put a halt to all that

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So, I'm Senior Admin at Endo Warriors West Lothian Support Group.

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It's really important that we give information and support to individuals.

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So, it's about making sure that they've got access to information such as treatment options available and about signs and symptoms.

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We continue to raise awareness and spread the word so that all individuals in Edinburgh and the Lothians have access to our support group and are able to express themselves and are in a confidential and safe place.

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Because I think that that is really important for a lot of the women that we meet

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it's about having that kind of place, and even just having that hour to two hour meeting and getting everything off their chests, talking about their fears and things, and just talking to someone else who understands.

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So this is a recent article that I was in

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So it's about looking at menstrual wellbeing.

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I'll add a link to it at the end

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But I believe that, I know a lot of people might disagree, But…

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It should be taught all school girls by the age of 13, because it might sound young but girls need to understand what might be happening to their bodies because girls are starting their periods younger. We had someone that started their periods at 11.

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And you know, it can be a scary time. Because if don't know enough about it and you, you know, realise that you're bleeding one day ... , you can get quite frightened by it.

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So just making sure that information is there is important.

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I was asked to describe pain and the pain for me is like somebody is repeatedly stabbing you over and over. And it is so sharp and intense that it can make you vomit.

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So it is mostly just about highlighting my experiences as well as more focus on menstrual wellbeing.

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In the picture I'm with Claire and Candice who are founders of the support group. They started it and

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We have a small team now, which manages the support group, and we play quite a huge part in supporting people affected by the condition.

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So, I've popped a link here to social media and some articles.

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I have my Instagram.

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There's the username, and you can follow, or, if you've got any questions, you can message me, and I've left a link to my blog, So, if anybody wants to read it, that's absolutely fine.

29:04
The article, the recent article in the Evening News, which has had quite a good response, I've had quite a lot of messages.

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And we've had new members of our group aim more people kinda talking about it, which is great. And, I've also put the link to my Fixers UK project.

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That was done a couple of years ago, and, but this highlights the reasons behind the project, and also, the access giving access to the video.

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And the last link is an article that I did with Common Space a couple of years ago, talking about the need for better medical treatment for endometriosis. For further information I have added some links as well.

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You've got he Edinburgh Uni, EXPPECT the Endometriosis Centre link

30:04
There's a link to the Private Support Group page, Endometriosis UK for further information, or just anything relating to the condition. And Young Women's Health, which just gives a general overview of the condition. And thank you for listening to my presentation. I hope that you've learned something from it, and it can help if there is ever a young person who has shown symptoms of the condition or has been diagnosed.

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If you are looking for further information or have any questions and want to discuss anything in more detail, you can contact me on either Instagram or my personal Twitter account, which is @dionnemcfx

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Thank you.