

# MENSTRUAL MATTERS

**Menstrual Matters:** Hi Robyn! Thank you for letting us interview you. I really enjoyed your book and, even though I've had periods for over 10 years, I still learnt so much by reading it. Can you tell me what inspired you to write 'an Autism Friendly Guide to Periods'?

**Robyn Steward:** It's funny, I can't say I found periods especially inspiring initially but, as part of my work, I deliver training about autism to teachers and, during the Q&A sessions, periods was a topic that came up time and time again. So I did a survey to find out more about what the gaps were in the way that we educate people about periods and, when I read the survey feedback, I realised how important this issue was.

For example, one of the things I noticed is that a lot of people were talking about period underwear, menstrual cups and cloth pads as alternatives to tampons and non-reusable pads but it appeared that this wasn't something people had been given information on. I certainly hadn't heard about any of those things before and, when I did an informal literature review of the books available on periods, I found that none of those books talked about all three of the main alternatives. Rather, it was something that people had learnt about through talking to other people. While the actual act of menstruation hasn't changed at all, I realised that the tools that we have available to us have changed a lot in the last 20 years but nobody had thought to write about them.

So I suppose what inspired me was the lack of specific information about periods, especially for autistic people. I have autism and I work with people with autism but, when I read some of the books available on periods, I still had lots of questions that I felt were pretty reasonable like 'how big is a fallopian tube?'. People were talking about centimetres but I don't really know what that means. Autistic people are very literal so, when you say 'you have eggs in your ovaries', that can be very scary, especially if the only eggs you have seen are the ones in your fridge.

**MM:** So what are the specific challenges that autistic people face when managing their periods?

**RS:** Firstly, many young people are scared of blood. Like I said, autistic people only really work with the information that they're given and, if up to that point, the only time they've seen blood is when they have fallen over or if they've been ill, they will associate blood with being broken or damaged in some way. But, when you have a period, there is nothing wrong with you; that's just part of what your body does.

Secondly, a lot of autistic people experience sensory issues. Diagnostically, autistic people can be hypersensitive to senses like sight taste touch and so on, or hyposensitive, meaning that they don't take in enough information. Of course, within the autism community, there are lots of different sensory experiences; sensory issues can also vary environment to environment, mental state to mental state and sense to sense - for example, you might have hypersensitive hearing when you're anxious but a normal hearing response the rest of the time. Not everyone experiences period pain either and it's hard to measure people's pain tolerance because it's so subjective. However, at least anecdotally, autistic people seem to be more sensitive to period pain. One theory to explain this is that lots of autistic people experience anxiety and anxiety will tense your muscles up which makes you more sensitive to pain.

# MENSTRUAL MATTERS

Periods are also very unpredictable. Everyone's cycle is different: some people have a three-week cycle, some people have a six-week cycle, and, once you start having periods, you are always somewhere within that cycle. Each part of the cycle has symptoms, both physical and emotional. Not everyone will experience all of those symptoms all of the time - there might be bits of your menstrual cycle where you don't experience any type of symptoms – but it is very normal to have fluctuation in physical and emotional symptoms within your cycle and the symptoms you experience will probably also change every cycle. Autistic people can struggle with that kind of uncertainty and unpredictability. One way to deal with it is through introspection, that is, understanding the signals within your body. You know, a lot of people, before they have a period, sort of sense that they're going to have a period, even if it's very subtle. But, for autistic people, if you have sensory issues, this can be really difficult to do.

Finally, a lot of autistic people have problems with executive functioning, that is, working out what to do and in what order to do it – for example, do you buy your milk before you go to the cinema or do you go to the cinema and buy your milk on your way home and then you have to make sure that you time your cinema trip for when the shops will be open. Periods require quite a bit of executive functioning. You have to learn the sequence of changing a pad or a tampon and then remember to change them. The great thing about menstrual cups is that you can pop them up there and you can almost forget about them. You just need to set an alarm on your phone to remind you to take it out. So there are lots of ways you can overcome the challenges that periods can create but you have to work with the person's neurology and other books out there don't necessarily address these issues.

**MM:** That's why your book is so important! What makes your book autism friendly?

**RS:** The first thing I did was get rid of gendering people. I really didn't want to say girl or woman or young woman because, when you're 8 years old, you're not a young woman, you're a little person, a tween! Some people got very confused about that and even the autism community was like, 'this is no good for autistic people, we need things to be literal!' but it is literal. If you have a womb and fallopian tubes and ovaries and a vagina, you're probably going to have periods, and if you don't have those, then you probably won't have periods. So, in the book, I talk about people with periods, rather than people who menstruate, because 'period' is a word people are already familiar with.

I was also aware of the fact that, having read lots of parents' forums, that kids can get really freaked out by periods. It's something new, it's a change and, for lots of kids, it might be the first time they have really had to take responsibility for something. But periods aren't like a plant. If you forget to water a plant, it dies, but, if you don't take care of your period, you get blood everywhere and it becomes very noticeable and you smell. There is a lot of information that you need to learn to look after yourself and, although it's not necessarily complicated information, I realised that it was really important to help people not be overwhelmed. If I felt that there was information that might be a bit scary or too much to take in at once, then I put it into a grid. I also made a frame that you can cut out to create flaps or windows and place over a page so you can hide or view the contents of each square.

Speaking as literally as possible was really important because autistic people don't often do well with metaphors. I specifically tried to avoid words that might seem misleading because they have several meanings. For example, I live in London. Live is spelt the same as live in 'I like listening to live music'. I also avoided giving any opinions because the difference between facts and opinions is not always clear to autistic people. For example, I suggested that people

# MENSTRUAL MATTERS

could, if they were worried about hygiene, wipe their hands on disposable wipes. I am very deliberately not saying that that is bad for the environment because that adds anxiety. It's not something I would do but, if it's the difference between doing that and not being able to leave your house, you are going to choose to leave your house. I'm not trying to tell people what to do with their lives; it is important to give them the options.

I think that sometimes non-autistic people downplay the anxieties of autistic people because to them it might seem really silly but, for the autistic person, that anxiety is really real. Speaking to children in schools and looking at the responses to our survey, I noticed that the two main worries about periods for autistic people were their periods starting unexpectedly and blood going everywhere; and period pain. In the book, I address those issues in as much depth as possible. Autistic people love detail-oriented information, especially if they are anxious about something. If you can give them the information, explain why it hurts, how it will affect your daily life and what you can do about it, then they can make a plan. That's why the book is structured so that, if you just want the basics, you read the first part, but, if you want more detail, it's in the last part.

I also included photos because some autistic people struggle to follow instructions. The photos I included in the book aren't actually photos of blood – it's food colouring, water and strawberry jam – but it was really important to me that it looked as realistic as possible. I also include photos of what spotting looks like and what blood and poo looked like together. All the photos are taken over my shoulder. Often, when you see a picture in a book, it's the mirror image so the right hand in the photo is not the reader's right hand. There is a very common co-occurring condition with autism called dyspraxia which affects co-ordination and sequencing and lots of autistic people I know struggle to flip the image in their head.

**MM:** What are your top tips for autistic people to help with managing periods?

**RS:** I would say to autistic people that you should try and find out as much information as you can but always use good information. If you're in the UK, we are very lucky to have the NHS website and Menstrual Matters but there is also the Menstrual Health Hub, which is an online worldwide resource that has some good information. In particular, investigate different menstrual products because there might be some stuff out there that you haven't even heard of before and could be really useful. For example, it can take a while to get used to using tampons but they make smaller ones for teenagers. I hadn't heard of those before.

The second thing would be to take your time and don't worry about making a mistake. It might take you a couple of cycles or periods to learn how to use a menstrual cup or cloth pads or period underwear. When I first started using a menstrual cup, I could only tolerate it for about five minutes. All the literature says that you're not supposed to be able to feel a menstrual cup, however, the muscles/ organs outside your vagina may be able to feel something has changed and I could feel that but I still gradually worked up to using a cup now. Periods are stressful for a lot of people and all we can do is learn from our experiences and try to be positive about it.

The third thing is don't be embarrassed to talk about periods and menstruation – or anything else for that matter! It is maybe not a conversation people would be comfortable having walking down the street and shouting but it's really important not to feel shy about asking questions because not asking questions leads to people having the wrong information. Find people in your life that would be happy to talk about it with you, perhaps in their home or at the doctor's

# MENSTRUAL MATTERS

office. You might want to talk about it with someone who has had periods for a while and can help you work out what the best plan for you is to manage the pain or your other worries. If you don't have somebody like that in your life, you can talk to the NHS 111 advice line, GPs, nurses, sexual health clinics. They are there to give you information.

Equally, don't feel embarrassed if you get blood on something because you can very easily wash it off with a cold damp cloth and some salt. If you're staying in a hotel and you leak a little bit, there is no need to feel embarrassed or to apologise. They will have come across that before. Periods are a normal part of everyday life and leaking is something that happens to everyone. If you are particularly worried about that, you can sleep on a towel. A lot of people also worry about starting their period and everyone seeing. Most people's periods don't start in a big gush of blood. However, if this is something that worries you, you can use period underwear with a cloth pad and a menstrual cup all at the same time.

Finally, if any of the symptoms of periods are causing you so much difficulty that you can't carry on with your daily life activities, talk to your GP. If you're not happy with their advice, you are always allowed to ask for a second opinion and you can ask to be referred to a gynaecologist. There is lots of help out there, including for pain, but it's important to seek advice to make sure that there are no underlying health conditions.

**MM:** How can friends and family support autistic people in managing their periods?

I think, make sure that you're actually informed and that you haven't just assumed something. If somebody asks you a question, it's okay to say 'I don't know the answer but I will find out' or 'Let's find out together'. I really encourage parents to read the book with their kids because, looking at the research data from the survey, it did seem like it was really important for people to be able to have someone that they could talk to and ask information from because, otherwise, they got information from their peers who were also ill-informed and then things might get confused. For example, one of the research participants said that she tried to put a tampon up her bum because somebody had used the word bum instead of vagina when they were telling her about tampons.

It's also important to take the anxieties of the person really seriously, even if to you they seem small or inconsequential. To that person, they are just as important as your anxieties.

One way to help combat those anxieties is to help people make a clear plan and make sure they have all of the supplies you need. A lot of autistic people take longer to process information and often really struggle with in-the-moment things, especially if they have any kind of problems with executive functioning. While most people end up learning how to put a pad on when they get a period, autistic people often need to practice before because, for them, it's not just about the learning to do something new, it's also all the sensory experiences, the noises, the sounds, the smells. I have included a section for making a plan in the book that friends and family can help the reader to fill out.

But, at the same time, I would encourage friends and family to help the person to think for themselves. I remember when I was about 14, I woke my mum up and I was very insistent that I was bleeding out of my anus. She asked me why I thought that and I told her that there was blood when I wiped my bum. She explained to me that it was probably coming from my vagina because I was laying down. She explored it with me, rather than just saying 'oh no, don't be stupid'.

**MM:** Your book is a brilliant guide for navigating periods and menstruation but there are still lots of barriers in the real world that can make managing your period challenging for autistic people. Is there anything you would change about the way that periods are managed or talked about in society that would make them more accessible for autistic people?

I would make the packaging of period management products more reassuring. For example, with a menstrual cup, most people don't pop it up there the first time and it all works. Everybody probably has had a bit of leak here and there and that's perfectly normal. It takes quite a while to get used to it. It would be really helpful if the packaging advised that you try using it at home first, maybe at the weekend when you're not stressed or under any time pressure; or reassured you that you can use more than one period product at one time if that makes you feel more secure.

I think also, if people talked about periods more in an everyday context, it would help autistic people to feel less embarrassed about asking questions. For example, when you're in the supermarket, deliberately go down the aisle where period management products are displayed and talk about them with your children. It's easier if you are a person who has a period because you can talk about your own period but, if you don't have periods, you can talk about the people in your life that do, like a friend or a family member. In the book, I included photos of people that you can talk to about periods and I purposefully chose men because I want people to know that everyone is connected to someone that has periods. Everyone, regardless of what gender they identify as, should learn about periods because, even if you're not going to have a period yourself, you will have friends who will, or siblings, or cousins. It should be a very matter of fact thing.

**MM:** Hear! hear! Thank you so much for answering our questions Robyn.

**RS:** No problem!

---

'The Autism-Friendly Guide to Periods' by Robyn Steward is available to buy at all major online book retailers. [https://www.amazon.co.uk/Independent-Womans-Handbook-Autistic-Spectrum/dp/1849053995/ref=tmm\\_pap\\_swatch\\_0?encoding=UTF8&qid=1587562441&sr=1-2](https://www.amazon.co.uk/Independent-Womans-Handbook-Autistic-Spectrum/dp/1849053995/ref=tmm_pap_swatch_0?encoding=UTF8&qid=1587562441&sr=1-2)

First published on the Menstrual Matters blog April 2020- <https://www.menstrual-matters.com/blog/autism/>

Cite as:

Crosfill-Morton, T. (2020, April 22) '*Managing your periods when you have autism*' Menstrual Matters Blog. Retrieved from <https://www.menstrual-matters.com/blog/autism/> on [insert date accessed].