



INTIMINATM

How people on the autism spectrum experience and manage their periods
A report by INTIMINA



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01 INTRODUCTION

Whilst there are no biological differences between autistic and non-autistic people, neurologically we **are** wired differently, and it does appear that autistic people experience a host of additional issues when it comes to periods – which are often not discussed in school or in media.

Most people recognise that autistic people think, feel and process information differently, but how does that interact with the monthly cycle?

The research highlighted in this report, which has been carried out by intimate wellbeing brand INTIMINA, aims to explore some of those key differences and highlight specific challenges faced by autistic people. Throughout this report readers will find a range of helpful tips, coping strategies and suggested reading materials to help those on the autism spectrum feel more comfortable with understanding and managing their period. As well as help those around them to understand the differences and help to support them.

“...why should anyone feel ashamed about their bodies’ natural processes?”



INTIMINA’s research revealed that **83% of autistic people find period products difficult to use, compared to only 51% of those without a diagnosis of autism.** To try and put some of these statistics into context, the report includes first-hand comments from its author Steph Jones (MBACP) who is autistic herself, and members of the autistic community.

Steph Jones (MBACP) and resident Gynaecologist for intimate wellbeing brand INTIMINA Dr. Shree Datta provide clinical advice and address some of the most common questions: **when to go and see the doctor? What medications and treatments are available to help manage periods? How to best communicate with others about intimate needs?**

This report aims to tackle the taboo, stigma and shame which often surround periods; because let’s face it, why should anyone feel ashamed about their bodies’ natural processes?

a. Contributors

About Steph Jones (MBACP)

Steph Jones (MBACP) is a Psychotherapist, Researcher and Writer who specialises in neurodiversity, trauma and relationships. She is also a late diagnosed autistic. Alongside her private therapy practice, Steph is a passionate autism advocate, manages the popular psychoeducational social media account (Autistic_Therapist) and she is the founder of the Autistic Professional Network, which raises awareness and celebrates neurodivergence in the workplace.

Steph's philosophy aligns closely with INTIMINA. They share a desire to de-stigmatise intimate health matters and ensure that the autistic community is given improved opportunities for representation, meaningful participation and access to high-quality information.



About Dr. Shree Datta, MA MD MRCOG LLM BSc MBBS (Hons)

Dr. Shree Datta is a Consultant Obstetrician and Gynaecologist in London. She has almost 20 years' experience and specialises in all things period related, along with abnormal smears and pregnancy related issues. She has regularly been approached for her opinion on women's health matters and has worked with INTIMINA for over two years, having previously led on studies for fibroids and heavy periods.



About INTIMINA

As an intimate wellbeing brand, INTIMINA truly cares about people's most intimate needs and is on a mission to offer advice and support to everyone. As part of this, INTIMINA has commissioned the research discussed in this report to help the voices of those with autism be heard, shed light on the challenges that they face and overcome the stigma associated with the menstrual cycle experienced by those who have been diagnosed.

02 EDUCATION

a. The first period

The report's author Steph Jones (MBACP) recalls her own experience of the confusion and shock that her first period caused:

I got my period when I was twelve years old. My mum first noticed that I was becoming tearful around the same time each month and decided to sit me down to talk about menstruation.

Although we briefly talked about it in school, we hadn't really discussed how periods might affect us emotionally or physically. The literal specifics weren't made clear, and in my mind, a period was like "shedding a womb lining" – which sounded awful.

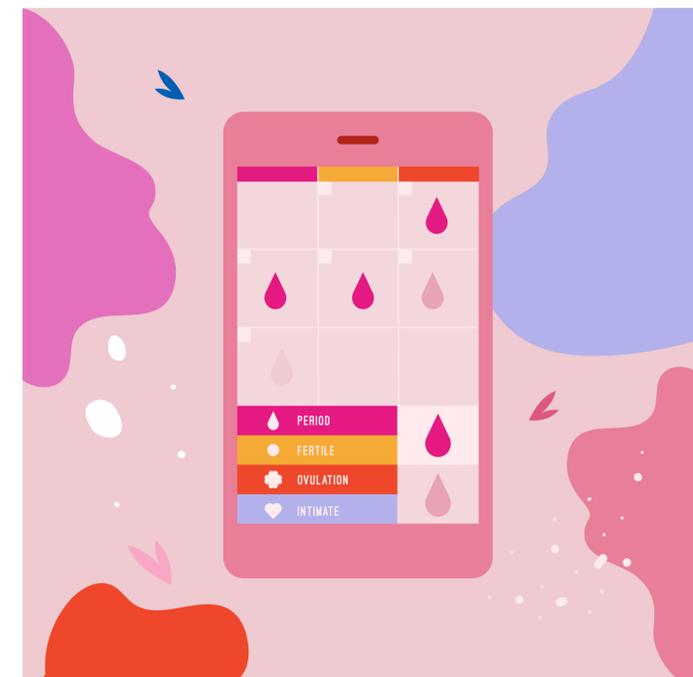
My mum explained that it was a "perfectly natural process" which happened once a month to help our bodies prepare for babies. Babies?! I took this quite literally and completely freaked out. I didn't want anything to change and was absolutely terrified.

One afternoon she took me shopping to pick out some sanitary pads and I remember feeling extremely embarrassed while I was stood in the aisle. My mum did her best to try and involve me, asking which ones I'd prefer but I didn't have a clue and felt completely overwhelmed. Little did I know I was having an autistic meltdown brought on by tricky decisions, stress and the fear of uncertainty.

I hated the pads. They were all packaged in discrete plastic envelopes and had a funny scented smell which reminded me of old ladies' knicker drawers. I kept them hidden at the back of the wardrobe behind my shoes and tried to forget they were there. Somehow it all felt so shameful and secretive; something a bit rude to do with your private bits.

A few weeks later I woke up one morning to find that my entire lower body was covered in blood. I let out a horrified scream and went into physical shock – shaking, hyperventilating – naturally, I assumed I was dying. My mum rushed in to find me a hysterical mess with bloodied clothes and big fat tears streaming down my face. She said: "Don't worry! It's all normal! This will happen every month now until you're my age!"

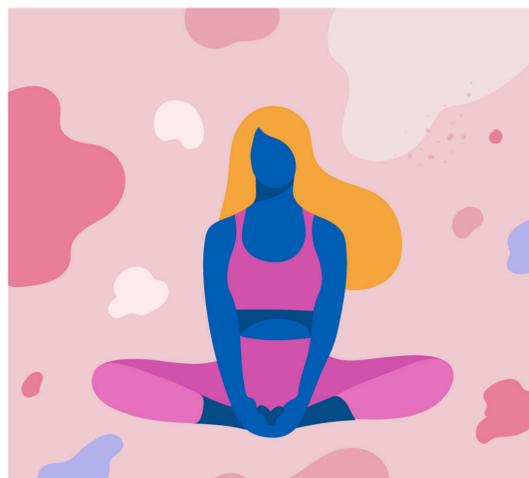
I did not like my period.



First periods can be tricky to manage and INTIMINA's research highlights a difference between how autistic people learn about periods compared to neurotypical people. **Almost seven out of ten (69%) people get advice about their periods from their mothers; however, the statistic is much lower (55%) for those with autism.** There's an even bigger gap when looking at younger millennials (those aged **25-34 years old**) as a massive **78%** of non-autistic millennials were taught about periods by their mum, compared to just **57%** of those who are autistic.

So why might fewer mothers of autistic children be teaching them about their first period? In the later section on **Communication**, this report explores the data which suggests that some autistic people struggle to discuss intimate issues with others at a young age. However, interestingly, **16% of autistic people are reported to have taught themselves about periods.**

The lack of conversation for those on the autism spectrum may be linked to a feeling of shame when talking about periods, or it might be connected to the social challenges experienced by many autistic people. For example, not asking for help because it leaves individuals open to the possibility of being dismissed, humiliated or invalidated. Or maybe due to the autistic traits of determination and self-reliance which shape a belief that the problem can be figured out without external assistance.



Jennifer Bishop, 39:
Though I logically knew this as a fact of life, I felt so removed from others that it was shocking and traumatising when I got my period for the first time. I remember my mother, asking me what I'd expected, and I remember telling her that I thought I might be "like an alien" – a genetic anomaly that was exempt from such things.

b. Parenting tips

For parents of autistic children or teenagers, it's really important to **clearly communicate** what will happen ahead of their period starting in order to avoid any panic, confusion, or unnecessary distress. Try to break everything down into manageable sections of what to expect in as much detail as possible – the cycle, the specifics of what will happen during a period, mood changes, pain, the different types of products available and how to use them (including disposal), and to always communicate if they're feeling worried or anxious.

Parents shouldn't assume that children already know or will intuitively figure out what to do; more specifically because autistic people prefer to have clear instructions and a detailed plan. This includes helping them understand how the menstrual cycle works so they can fully understand the process and what changes to expect. **94%** of autistic people said they have a general understanding of how it works, but only **51%** understand completely.



“For parents of autistic children or teenagers, it's really important to **clearly communicate** what will happen ahead of their period starting in order to avoid any panic, confusion, or unnecessary distress.”

When asked to identify the cervix on an image of the female reproductive system, **39%** of autistic people and **22%** of neurotypical people failed to identify the cervix correctly.

There are lots of useful resources that can help parents to guide their children through the process including autistic author, Robyn Steward's book titled 'The Autism-Friendly Guide to Periods' which is about menstruation and is aimed at young people, aged between 9-16 years old.

03

THE CHALLENGES AND MANAGING THEM

When asked what the primary challenges are during periods, the autistic respondents said that the top concerns were: moods changes (50%), period pain (49%) and using sanitary products (34%). Compared to those without a diagnosis who said: pain (72%), moods (53%) and using sanitary products (41%).

On average it takes autistic people around 4 – 5 years to get used to managing their period (30% vs 4% for non-autistic sample) compared to the average time of one year by the neurotypical respondents (38%):

Autistic people:



Non-autistic people:



The respondents said that the following would help them learn to manage their period:

Top choices for autistic people:



Top choices for non-autistic people:



a. Mood changes and mental health

The results were similar across the board when participants were asked if they experience emotional changes during a period (96% of those on the autism spectrum vs 92% of those not on the autism spectrum). With 38% of autistic people confirming that mood changes were in their top three worries when approaching a period.

It is extremely common to experience some feelings of depression and anxiety just before a period starts and it's helpful to keep track of moods to determine whether they seem related to hormonal changes or reveal an underlying issue. An easy way to track someone's mood is to note it down in a journal or use a mood app to track the flow of emotions across the cycle.

If someone is experiencing personal stress throughout the cycle, it is very likely that this will be exacerbated during the luteal phase of the cycle – which is the timeframe from ovulation to the start of the period. Working with a professional mental health practitioner, like a therapist or a psychologist, on any emotional causes may help that person feel calmer and more resilient, which in turn can lead to less distress in physical manifestations. Treatments such as antidepressants can also be used to treat some of the symptoms of mental health issues – but it's always advised that a doctor should be consulted on the various options available.

Mood changes can often be one of symptoms seen in Premenstrual Syndrome (PMS). This is the name given to a cluster of symptoms that can be experienced before a period and during the luteal phase (second half) of the cycle, which can include physical changes as well as mood fluctuations.

¹Diagnostic and Statistical Manual of Mental Disorders in 2013



If the symptoms are severe and are causing intense problems in being able to function day to day, then this could be a sign of Premenstrual Dysphoric Disorder (PMDD). Symptoms can include: major mood swings, panic attacks, marked irritability/anger, elevated depression/anxiety, loss of interest in activities, lack of concentration, lack of energy, suicidal thoughts, feeling overwhelmed, physical symptoms such as breast tenderness, joint/muscle pains, or weight gain.

Whilst primarily an endocrine disorder, it is also recognised as a depressive disorder¹ and it's recommended that anyone who experiences these symptoms visits a doctor and has at least three cycles worth of data to share

It is extremely common to experience some feelings of depression and anxiety just before a period starts..."

Emma, 36:

I've been struggling with my periods for years. Around halfway through my cycle, it's like my body hits the self-destruct button – but not the instant kind – the slow tormenting kind. Waves of depression, climbing anxiety, panic attacks and random crying outbursts. And to add the cherry on the cake – a couple of days before my period, paranoia creeps in. It's like my whole personality changes. When my period finally breaks, the fog begins to clear, the veil of darkness slowly lifts and I feel waves of relaxation throughout my body.

After years of telling myself that this was 'just me' and that I needed to crack on regardless – I'm now physically and emotionally burnt out from it. So, I've finally started to listen to myself. I've recognised that I am highly sensitive to the hormonal changes and am tracking my cycle so that I can present a doctor with some hard data.

with the medical professional to discuss. One theory² suggests that autistic people have an altered expression of histamine signalling genes, which may account for an increase in autistic symptoms around the time of the month, since histamine rises with oestrogen. Throughout Steph Jones' (MBACP) career, she's encountered dozens of clients who managed to get their PMDD symptoms under control purely through the use of histamine-control options, but recommends to always consult a doctor first.

b. Pain and physical issues

Alongside mood changes, **42%** of autistic participants said that they were concerned about heavy bleeding during their period and **42%** said that period cramps were the symptom that they were most worried about.

Most people with periods tend to struggle with a whole range of physical issues around this time including bloating, headaches, back pain, cramps, cravings, acne breakouts, tender and swollen breasts, fatigue, insomnia, constipation and diarrhoea³.

Ways to combat physical issues during a period:

- Taking over-the-counter pain relief such as ibuprofen or paracetamol.
- Regular low intensity exercise like light stretches, a short walk, yoga and gentle movements such as Tai Chi. All of these increase blood flow in the body and can ease cramps.
- Take time to de-stress through activities like meditation and reading.
- Eat well by reducing fat, salt, caffeine, alcohol and sugar and eating plenty of fresh fruit and vegetables. Studies have shown that some people with autism benefit from gluten and casein-

²2017 study (Wright, Shin et al., 2017) <https://doi.org/10.1038/tp.2017.87>

³www.nhs.uk/conditions/pre-menstrual-syndrome

free diets⁴.

- Stay well hydrated.
- Have a regular sleep pattern.
- Speak to a doctor as in some cases they may be able to prescribe other medications such as birth-control pills or antidepressants. Dr. Shree Datta adds: "While contraception is used primarily to prevent pregnancy, some forms may also be used to help with heavy or painful periods. This study suggests that a significant number of autistic people manage periods with contraception (**45%**), with the most common type being the pill

Sam Vernon, 42:

I struggled with being able to predict my periods for years and had really bad PMS symptoms. My GP was really helpful and discussed other methods, and I eventually settled on the contraceptive pill after trialling several to find the right one. It made such a difference to me and supported my moods feeling more consistent.



(47%)."

c. Sensory differences

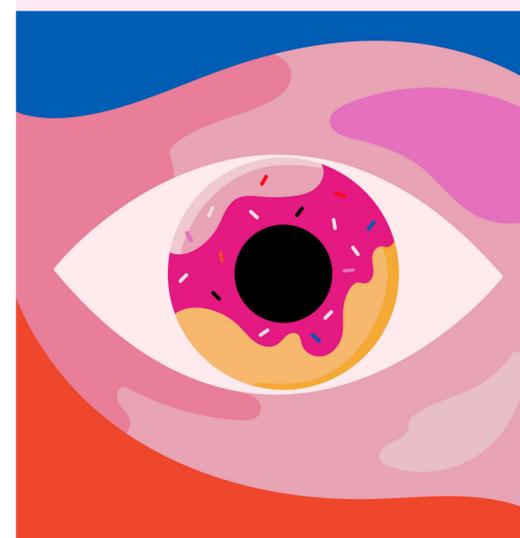
"If you've met one individual with autism, you've met one individual with autism."

– Dr. Stephen Shore, an autistic professor of special education at Adelphi University

This quote reminds everyone that we are all unique human beings. The way one person's specific neurology intermingles with their personality, history and environment will be completely different to another autistic person. That said, there are some defining characteristics of Autism Spectrum Disorder (ASD) which all of those who are diagnosed share to some degree. Including hyper or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment, such as apparent indifference to temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or

⁴<https://www.autism.org.uk/advice-and-guidance/professional-practice/gluten-casein-free>

⁵Taken from The American Psychiatric Association's 'Diagnostic and Statistical Manual, Fifth Edition' (DSM-5) as part of the criteria used to make a formal autism diagnosis. <https://www.cdc.gov/ncbddd/autism/hcp-dsm.html>

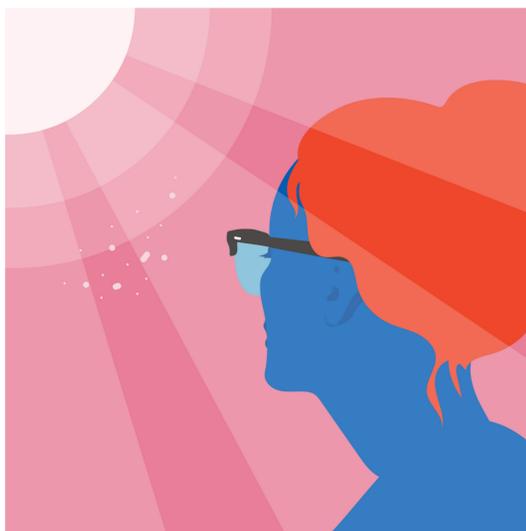


movement⁵.

With such often heightened responses to sensory stimuli, periods can be difficult to contend with. Uncomfortable sensations such as the feel of a menstrual product, not feeling clean, or the sight of blood itself may cause an elevated fear or disgust and affect the ability to self-regulate. Challenges interpreting internal signals as they are magnified or dampened down adds another level of complexity when it comes to managing periods.

When those on the autism spectrum were asked if they notice the scents in menstrual products like tampons, menstrual cups and pads, **70% said yes, 66% said that it bothers them, and 26% of autistic people noted odours as one of their main difficulties when they are on their period.**

Additionally, INTIMINA's study shows that **30% of autistic people feel worried about using a public toilet (vs just 20% of non-autistic people)**. This is further explored in another study⁶ that describes how using a public toilet may be overwhelming on a sensory level due to echoing spaces, bangs, flush sounds, smells, unhygienic surfaces and cramped cubicles. Not just that but they also caused disruption to routines,



Wren Little, 28:
I'm very hypersensitive generally, so when I'm on my period I can smell it and it stresses me out even though I've been assured there's no smell. It just makes me very self-conscious.

TIP:
Reusable pads and period underwear might be more sensory-friendly.

⁶2018 study (Steward, Crane et al) <https://doi.org/10.1007/s10803-018-3664-0>

04 COMMUNICATION

The findings suggest that **41% of autistic people don't feel confident in talking to close friends or family about their period** with another **18% feeling very unconfident**. In contrast to the neurotypical sample where **74% said they felt either confident or very confident**.

What about asking for help?

When asked how comfortable the participants felt asking close friends or family members for help with anything related to their period, **only 36% of autistic people said they felt comfortable, with the many feeling uncomfortable (44%).**

Dr. Shree Datta's advice:

- Periods are the most natural thing in the world, with most women experiencing them, so there are a lot of people with advice about what to do. Always ask – periods are part of our health cycle, not something anyone should feel embarrassed about.
- Don't be shy to approach a doctor in the first instance if simple measures such as hot water bottles, gentle exercise and pain relief do not help manage period pains, or if it's hard to manage the length or heaviness of a periods. The next step may be being referred to a Gynaecologist, who may assess the medical history and consider relevant blood tests. Remember: doctors help people who have heavy or painful periods every day of the week, so go and see them early if there's a problem.

- For those who are feeling nervous about speaking to friends or family, there is a lot of information about periods online – for example, INTIMINA has some useful advice on their website about how to approach periods.

TIP:
Knowledge is power, and if someone doesn't know something, it's always okay to ask. The online autistic community can be such a helpful space – use the hashtag **#ActuallyAutistic** and ask away.



05

PERIOD PRODUCTS

Results when people with autism were asked which period products they preferred to use:



Below are the period products that they found the easiest to use:



a. Tips on how to use menstrual products

Although almost a quarter (**24%**) of those on the autism spectrum prefer to use menstrual cups, it can be tricky to know how to use them, as well as pads and tampons. Below are some top tips from Dr. Shree Datta to help:

How to insert a menstrual cup:

- Remember to take plenty of time and make yourself relaxed in a comfortable environment.
- Make sure that hands are washed and the bladder is empty before inserting the cup.
- Fold the cup and place it into the vagina, making sure it's high enough so that it can't be felt.
- Sometimes squatting or bending the knees by placing the feet on the edge of the toilet seat or bath can help insertion.
- Follow the direction of the vagina when inserting the menstrual cup and make sure it's not painful to insert.
- It can take a few attempts to get

comfortable with a menstrual cup and it's important to consider each of the steps above before changing the size of the cup.

- Signs that there's a need to change the size of a menstrual cup include difficulty inserting it, feeling uncomfortable with it in or leakage straight after insertion.
- Don't forget to remove and wash it regularly. INTIMINA's menstrual cups offer up to eight hours of protection.

How to use pads and tampons:

- There are different styles and sizes of sanitary pads and tampons to adjust to the heaviness of the bleeding. Some find it useful to mix and match sizes and styles throughout the period to avoid blood leaking through onto the underwear.
- Even though over half (**52%**) of autistic people are concerned that a tampon may get lost inside of the womb or vagina, it is important to understand that tampons cannot get lost inside the womb or vagina.



The opening to the womb (the cervix) is too small to allow a tampon to pass through. If the string of the tampon isn't visible, don't panic, just use fingers to reach into the vagina and grab the tip of the tampon to pull it out.

- It can be harder to know when to change a tampon because it's not on show. Make sure that it's changed regularly, for example every **4-6 hours**, even if it's a light period. Leaving a tampon in a vagina for prolonged periods of time can increase the risk of infection.

Izzy Fakkal, 18:

My period is very irregular which I find distressing... I never know when it's going to come so I can't properly prepare myself for it.

Sarah Jane Bellwood, 54:

The worst was that they (the periods) took me by surprise every single time. I never once remembered when it was going to arrive, so the first I ever knew about it was the flooding of my clothes with blood. I never could remember to carry pads and tampons. Not once. I felt feckless, disorganised and stupid that I couldn't remember or organise myself.

b. How to dispose of period products correctly

INTIMINA's research shows that **25%** of autistic people worry about how to correctly dispose of tampons and sanitary pads. It's super easy; don't flush them down the toilet after use as they can block the plumbing system. Instead, dispose of them in the bathroom bin and wash hands after changing the sanitary protection.

c. Period planning, scheduling and preparing

Dr. Shree Datta recommends keeping track of a period by using an app, visual planner, or a diary. This can help to anticipate when the next period will be so that everyone can make sure to have period products on them and they aren't caught off guard when the period starts.

Stock up on the preferred product and keep a supply in a bag to make sure you're prepared for the start of the period.

Check out the different types of products available in pharmacies and supermarkets and trial them before deciding. Sanitary products can vary in size, so everyone needs to choose the correct product to match how heavy the bleeding is.

Change the sanitary pad, cup, or tampon regularly to avoid overflow bleeding. This can vary depending on how heavy the period is and regular trips to the bathroom might be needed to check whether it's time to change.



d. Period poverty, availability and affordability

It should be acknowledged that not everyone has the option to use period products. In many parts of the world, including the developed nations, products may simply not be affordable (or even available) resulting in poor self-hygiene, mental health challenges and increased physical health risks. According to The World Bank, an estimated **500 million** individuals suffer from period-related health inequalities⁷ which is being tackled globally by governments, charities, NGOs and other organisations in an attempt to provide free products and improved access to education.

The Global Menstrual Collective aims to provide international cohesion on this issue, calling for greater awareness, advocacy and campaign work around this basic human need for health and hygiene⁸.

⁷<https://bmcwomenshealth.biomedcentral.com/articles/10.1186/s12905-020-01149-5>

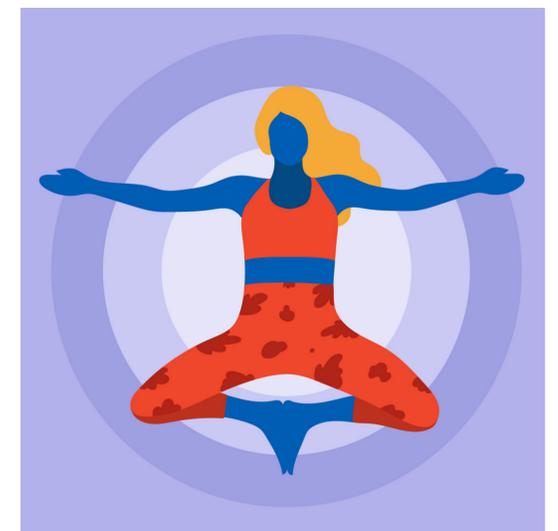
⁸<https://www.globalmenstrualcollective.org/>



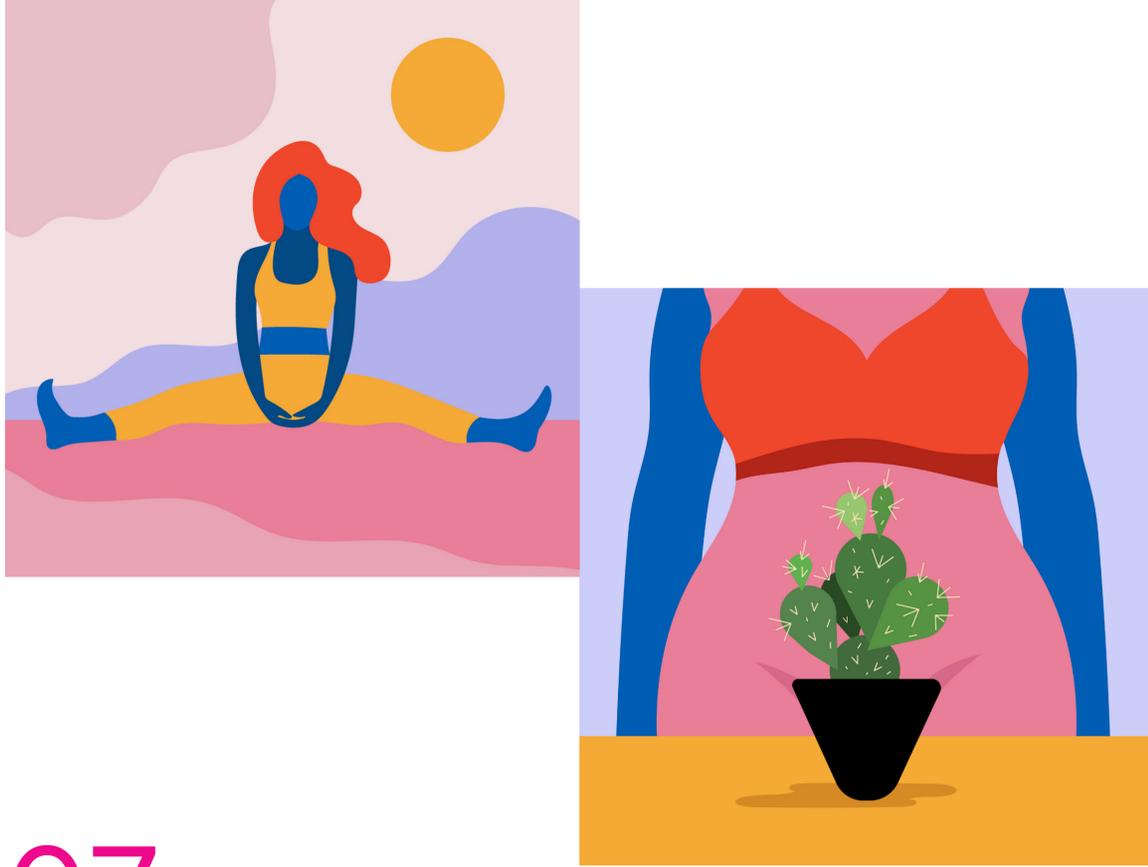
06 CONCLUSION

Whilst it's clear that autistic people and neurotypical people aren't different from a biological perspective, it does seem that autistic people struggle more with sensory and mood issues, as well as communication during their cycle.

Although there isn't any clear explanation as to why autistic symptoms seem to increase with the fluctuations in hormones, there's something that we can all agree on – it can be an enormously challenging time.



“– it can be an enormously challenging time.”



07 SUPPORT

For more information about managing periods please visit The International Association for Premenstrual Disorders (iapmd.org) or pick up a copy of *Period Power* by Maisie Hill (an autistic author diagnosed with PMDD).

In the list below, there are a range of resources including clinical information, lived experience, academic study and other useful websites which will be useful to read and explore this topic more:

- **Autism.org**
<https://www.autism.org.uk/advice-and-guidance/topics/sensory-differences/sensory-differences/all-audiences/> / <https://www.autism.org.uk/advice-and-guidance/professional-practice/menstruation>
- **Autism Awareness Centre**
<https://autismawarenesscentre.com/interoception-and-autism-body-awareness-challenges-for-those-with-asd/>
- **Menstrual Matters**
<https://www.menstrual-matters.com/autism/>
- **Medium**
<https://medium.com/artfullyautistic/this-is-why-pms-sucks-for-autistic-women-8452dc195ad>
- **Autism Spectrum News**
<https://autismspectrumnews.org/hormonal-fluctuations-and-women-with-autism-a-call-for-increased-awareness-and-assessment/>

INTIMINA has also launched a *Wonder Girls Guide Book* to help young girls learn as much as possible about the changes puberty brings. The new audio book can be downloaded at www.intimina.com/wondergirls.



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- ³www.nhs.uk/conditions/pre-menstrual-syndrome
- ⁴<https://www.autism.org.uk/advice-and-guidance/professional-practice/gluten-casein-free>
- ⁵Taken from The American Psychiatric Association's 'Diagnostic and Statistical Manual, Fifth Edition' (DSM-5) as part of the criteria used to make a formal autism diagnosis. <https://www.cdc.gov/ncbddd/autism/hcp-dsm.html>
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- ⁷<https://bmcwomenshealth.biomedcentral.com/articles/10.1186/s12905-020-01149-5>
- ⁸<https://www.globalmenstrualcollective.org/>



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