

Coping with Periods

This guide focuses on periods and menstruation. It includes information, advice, and signposting for further support.

What is menstruation?

Getting your period is a regular part of life for most people with a vagina, and one that will be around for a significant part of their lives. Everyone's menstrual cycle will vary; however it lasts approximately 28 days.

Over the 28 days there are various changes to hormone levels that can affect our mood, brain functioning and bring physical symptoms. Menstruation is part of the cycle is when someone bleeds from their vagina for around 2 – 7 days. For some young people this can need some extra preparation and planning.



Most people start their periods in late childhood/early teenage years. They continue until their late forties/early fifties. So, it is important that we develop their independence and help them to develop ways to cope with the changes.

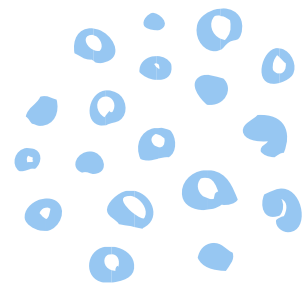
Additional needs and menstruation

A young person with additional needs is likely to begin their menstruation at the same chronological age as their peers. However, additional needs may mean they need more support to understand their periods and learn ways to cope with the changes they bring. This leaflet will talk you through some things you may want to think about and ideas of ways to support them. You will want to link up with their school and ensure you are all working together.

Autism and menstruation

We increasingly understand that autistic people experience the world in a different way, this can also apply to their experiences around periods. Research suggests that some of the symptoms associated with a period can be experienced to a greater degree for autistic individuals. For example:

- Increased challenges around sensory sensitivities (e.g. sensitivity to the smell and sight of menses, the body feeling more sensitive to touch or increased change of sensory overload).
- Increased challenges around emotional regulation and remaining in a calm state.
- Increased difficulties around executive function (e.g. finding it more challenging to focus or organise their thoughts).
- Significant menstruation symptoms (e.g. heavy bleeding).



Regardless of your young person's additional needs, it is important to consult with your doctor if their periods are excessively heavy, long and/or accompanied by PMS (premenstrual syndrome) symptoms, such as mood swings and difficulty sleeping, that are affecting your daily life

MENSTRUAL *Calendar*

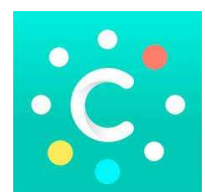
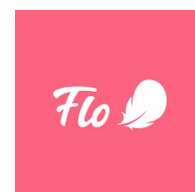
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- SPOTTING
- LIGHT
- MEDIUM
- HEAVY

Tracking

It can be *really* helpful to keep a log of cycles and symptoms. This can be a simple pencil and paper method (example to the left) or there are a variety of Apps that offer a similar option. When choosing an App you may wish to consider their data usage policies. Some examples below.



Tracking can monitor your young persons periods, and also (hopefully) help predict and prepare them before their bleed each month. Some young people can experience discomfort at different times of their cycle (for example when ovulating), tracking can help spot any patterns that do not fit the 'norm'.

Management

Before we prepare our young person, it can be helpful to consider how you and your family plan to manage. There are a range of products available, and it is a very personal choice. There are pros and cons to all the methods and your young person may have their own views. But here are some options to consider...



Disposable Pads

How do they work? A single use pad designed to be secured into your underwear to absorb the blood and go in the bin after use.



Pros Easy to use

- Can practice routine ahead of periods
- Effective when like to move a lot
- No washing required

Cons Can be tricky for those with sensory differences
Can be costly overtime
Not reusable

Reusable Pad

How do they work? A sewn cloth pad designed to be worn into your underwear to absorb the blood. Range of shapes and absorbencies. Washed and dried ready for reuse.



Pros Easy to use

- Can practice routine ahead of periods
- Becomes more cost effective with repeated use
- Reusable

Cons Significant initial cost
Must be washed and dried after use
Can be tricky for those with sensory differences

Period Pants

How do they work? Specially designed underwear with built in absorbency. Comes in a variety of colours and styles. Washed and dried ready for reuse.

Pros Easy to use

Can practice routine ahead of periods

Effective when like to move a lot
Becomes more cost effective with repeated use

Reusable

Particularly helpful for those with sensory differences with a variety of styles available, including shorts and leggings for those who struggle to wear underwear

Cons Significant initial cost

Has to be washed and dried after each use



For many of the young people accessing SCAN the options above are the most suitable, however there may be some where the following are also an option.

Tampon

How do they work?

A single use cotton or rayon plug inserted into the vagina to absorb the blood. There is a



string to aid removal. Different sizes and applicators to suit need.

Pros Effective when like to move a lot
No washing required

Cons Can be tricky to insert and remove

Not appropriate for many

Can be costly overtime

Not reusable

Menstrual Cup

How do they work?

A bell-shaped silicone device inserted into the vagina to collect blood. Comes in different sizes and styles.



Pros Reusable for up to 10 years, becoming more cost effective with repeated use. Effective when like to move a lot

Cons Can be tricky to insert and remove

Not appropriate for many

Significant initial cost

Needs to be washed and

disinfected

Menstruation and contraception

Many families are offered and seek hormonal contraception methods to help manage the symptoms of the menstrual cycle and for some they are helpful.

The best option is to wait and see what happens when they start. Many girls surprise us by coping well with periods. At first periods may be quite light or infrequent and are easier to cope with than full adult periods. Once periods start, if they are causing difficulties then there are medical options available to make them less frequent, lighter or stop them altogether.

Combined pill

The combined pill is known as "the pill". It contains artificial versions of female hormones (oestrogen and progesterone). If you have heavy or painful periods, PMS (premenstrual syndrome) or endometriosis the combined pill may help. There are ways to use the pill shorten or reduce the frequency of periods.



Intrauterine system (aka Mirena coil / IUD)

This can be an effective method of stopping periods or lightening heavy periods, 40% will be without periods after 1 year of use. Once inserted it can take several months to stop the periods and during this time bleeding can be irregular. (The pill can help in the short-term). It might feel uncomfortable having the coil fitted and so this can be a short procedure done under general anaesthetic for our young people with learning disability. (Therefore, Mirena coil may not suitable for those at high risk for an anaesthetic).

Contraceptive injection

The contraceptive injection releases the hormone progestogen into your bloodstream to prevent pregnancy. Depo-Provera is most commonly offered in the UK and lasts for 13 weeks. It may reduce heavy, painful periods and

help with premenstrual symptoms for some women.

Be careful to consider...

What are you hoping to help with?

What are our options?

How can we explain this to our young person?

How and who will monitor the impact?

Living with menstrual cycles

As well as living with the bleeding associated with the menstrual cycle it can also be important to consider the physical sensations periods can bring and how your young person can help managed them.

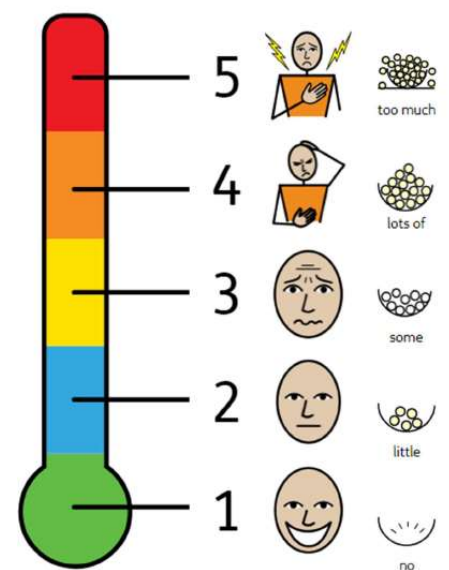
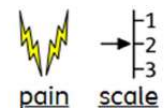
Part of this may be educating them about their body and learning about their experiences. For example, if someone finds focussing on work particularly difficult, they may need to wear headphones to cut out distract noise or break work into smaller tasks at that time.

They might need to rely on lists and visual supports to maintain their routines at this time. If they have people around them to support them, make sure they know what time of the month it is and how best to support them.

Individuals with sensory differences can find it really tricky to recognise pain and locate it in their body. This is linked to differences in their interoception, known as the 8th sense, and relates to understanding the signals our body might give around physical sensations. This makes it especially difficult to share this with others and know what might help.

Having a plan to manage pain is crucial. A visual to help them let you know how they are feeling. If this is too difficult, then focus on them labelling their body parts by pointing. This can be done supported by visuals or using games such as 'Simon says..' or songs such as 'head, shoulders, knees and toes'. There are online games that can get you child building and labelling bodies.

Mary Barbera is a mother to an autistic son, a registered nurse and a behaviour analyst, here she give some more advice around teaching body parts <https://marybarbera.com/teaching-body-parts-children-autism/>



For many young people it can help to embed these strategies into their daily lives, especially when they are starting their cycle. This can help to access the pain relief proactively and manage the number of changes around their cycle. Suggestions of how to manage pain may include the following...



<p>Light exercise for example walking, yoga or stretching.</p>	<p>Applying heat, such as a hot water bottle or heated bean bag.</p>	<p>Take ibuprofen or naproxen, there are some medications specially designed to target menstrual pain.</p>	<p>Acknowledge the need to rest and lie down.</p>
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REMEMBER: Talk to your doctor or nurse if pain is not manageable, they can discuss pain relief options, alternative treatments and consider if there is a physical cause of the distress that needs further investigation.

Preparation

Preparing your young person for their menstrual cycle will be important. Helping them to understand changes to their body and not be frightened when they begin to bleed. We know that many neurodiverse young people can be resistant to change, and it can be tricky to establish new routines.

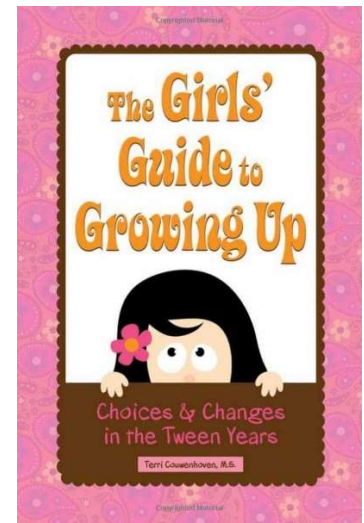
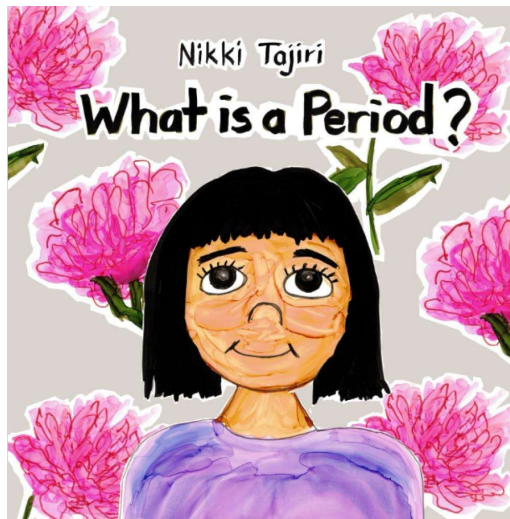
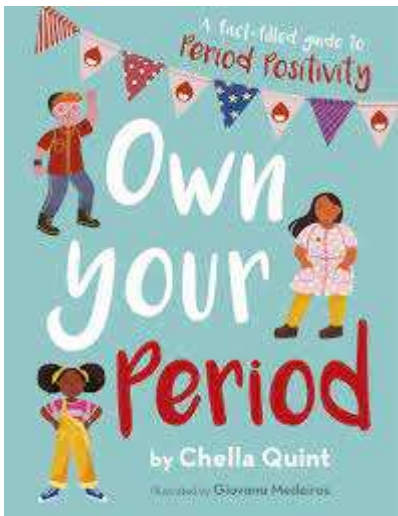
Changes to their body

It will be important for them to understand that there will be changes to their body and that they are normal. Their school will be able to offer lessons to support this understanding, so speak to them and find out when and what they cover. There are books and resources that you can access at home to help them become familiar with change. For females changes you want to consider go beyond their period and include:

- Increased body hair (under arm, legs and pubic)
- Growing breasts and wearing a bra
- Sweating more, so needing to shower regularly and wear deodorant
- Getting spots on their face



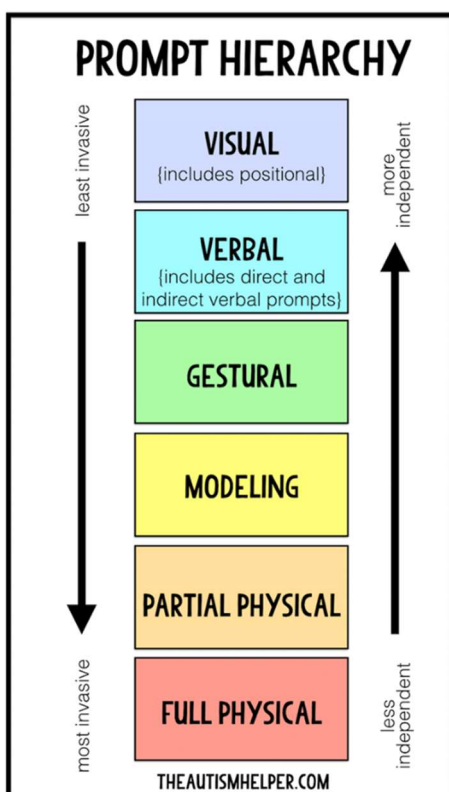
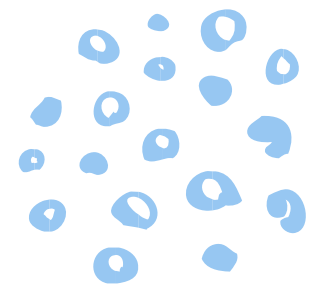
A wealth of books are available now that positively frame periods to break down the stigma and educate young people.



Healthy routines

Establishing healthy and safe routines around their periods is crucial to developing their independence and keeping them safe. Here are some things to think about.

- First step might be think about how you plan to manage their menstruation, suggestions are above in the management section.



- Start preparing them before their period starts to give them time to process the pending changes, reduce stress when their menstruation begins and make the changes smaller for them to cope with. Demonstrate how you manage your periods if you feel comfortable to do so.
- **Practice!** Get your young person to practice the skills they need to manage their periods as independent as possible. Think about all the steps to they need to complete to achieve independence and work on one step at a time. Gradually decrease the prompts they need for each task.

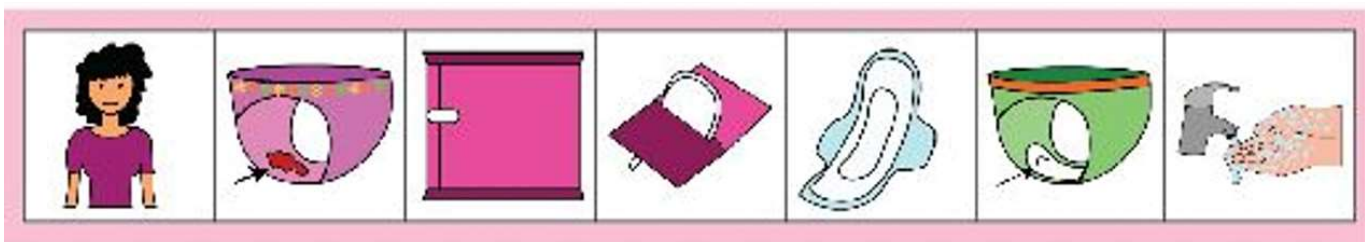
Remember! Your young person will only menstruate for a week a month, think about this in practice rather than creating routines that are every day.

- Think about giving them set people whom they can talk about their periods with. For example, yourselves and a few named adults at school. This will help them understand it could be risky to talk to strangers about it.
- **Visuals!** Using visuals to help teach them safe routines can be really helpful. It helps everyone to give a consistent message about the routine we are teaching them. It can also help individuals who struggle to organise themselves to remember all the steps they need to follow and get them in the correct order.

You can even get creative with some food colouring to use photos for someone who benefits from photos.

Visuals can help give a young person a plan to cope if their period arrives unexpectedly. For example...

Changing my Pad



Think about integrating learning about periods in older life. Preparing them that they will enter perimenopause which will involve bodily changes and the menopause will be when their menstruation stops. Then there is life after menopause.

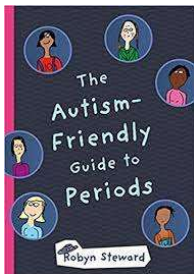


There are lots of sources of information that can help you feel more knowledgeable and get further ideas.

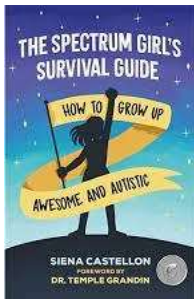
Recommended Reading/ Podcasts for parents



28ish days later Podcast from the BBC, accessible via Apple Podcasts and BBC direct



The Autism-Friendly Guide to Periods By Robyn Steward



The Spectrum Girl's Survival Guide: How to Grow up Awesome and Autistic By Siena Castellon

Organisations with support and advice around menstruation

NHS

Offers an overview of periods and how to manage problems with your periods.

<https://www.nhs.uk/conditions/periods/>

The National Autistic Society

Information, advice and support for autistic people.

Website: www.nas.org.uk

Raising Children Network

Based in Australia, but offers lots of advice and guidance for supporting young people with additional needs.

Raising Children Network

Little Puddins

Following their own lived experiences, this website has been set up by a mother who wants to share the knowledge they have acquired along the way

<https://littlepuddins.ie/about-me-2/about-little-puddins/little-puddins/>

Beyond Words

Provide books with clear pictures to help increase peoples understanding, work through problems and open up conversations. Titles include *Susan's growing up* and *Keeping Healthy 'Down Below'*

<https://booksbeyondwords.co.uk/>

BBC Bitesize animated clips

Topics covered include first periods, personal hygiene during periods, dealing with feelings, appropriate/inappropriate behaviour, peer pressure and sex, and lots more

<http://www.bbc.co.uk/education/topics/zr9dxnb/resources/3>



Secret Girls' Business

A children's book publisher specialising in books that make learning about periods accessible to children. They also make some that specifically address young people with additional needs.

<http://www.secretgb.com/>

Scope

A charity aiming to provide practical advice and emotional support when needed. Access to parent forums to help access support from others experiencing similar challenges.

<https://www.scope.org.uk/>

