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Periods and Learning Disabilities

Information for parents
and carers



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Many parents of girls with developmental delay or learning disability worry about the time when their daughter starts their period. Common concerns include how your daughter will cope with the blood, concerns around cleanliness, and difficulties for carers looking after the young person. This leaflet aims to answer commonly asked questions around this.

Can my daughter's puberty be stopped?

Treatment to stop puberty is available for girls who enter puberty abnormally early. In the UK puberty starts any time after 8 years. At first breast buds appear and 18 months, 2 years later the periods start, therefore it would not be considered usual for periods to start before 10 years.

This treatment involves a monthly injection and switches off all of the teenage hormones that come from the brain. This is associated with potential side effects, so this treatment can only be used for a defined period of time. To use it for longer would have adverse effects on bone health.

It is important to note that a normal puberty is crucial for the development of healthy bones as an adult. We build up our adult bone strength between the ages of puberty and 30, Oestrogen plays a vital role in this. Many adults with disability have weak bones which can be down to a number of reasons; for example some antiepileptic drugs, the effects of not weight bearing. Therefore it is even more important that we protect the bone health of this population. **Most young people with disability benefit from a regular vitamin D supplement, please ask your doctor about this.**

So what can be done to help my daughter and family cope with periods?



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 a number of medical options available to make them less frequent, lighter or stop them altogether.

Intrauterine system / Mirena coil

This is a highly effective method of stopping periods or lightening heavy periods, 40% will be without periods after 1 year of use. Once inserted it often takes several months to stop the periods and bleeding during this time can be irregular. The POP or COCP can be used in addition in the short-term to treat this. You do not need to have had children previously to have a coil inserted but it might feel uncomfortable and so this is a short **procedure done under general anaesthetic for our young people with learning disability.**

Mirena coil not suitable for: People who are high risk for an anaesthetic.

Contraceptive Implant /Nexplanon

This is a small, flexible plastic rod that is inserted below the skin in the upper arm. It releases Progesterone over 3 years. It is associated with irregular bleeding and therefore should not be considered as 1st line.

Contraceptive injection /Depo-Provera

This is a high dose Progesterone injection that lasts 3 months. It is associated with irregular bleeding and reduction in bone density, therefore it is not recommended in adolescents.

Depo-Provera injection not suitable for: Patients under 18 years of age.

Progesterone only pill / POP / 'the mini pill'

Progesterone can be taken in many forms, as a tablet, injection, implant or intrauterine coil. In general, we would advise the tablet form as first line, as the injectable forms are difficult to reverse and have more impact on bone health. The POP is to be taken once daily, continuously. The dose can be doubled if bleeding persists.

Combined Oral Contraceptive Pill / COCP / 'the pill'

This contains Oestrogen and Progesterone, historically it was prescribed as 21 tablets and then a 7 day hormone free interval, when bleeding is expected. Nowadays it is safe and recommended to take multiple ways:

- Shorten hormone free interval to 4 days to shorten the length of the period.
- Take 3 packets 'back-to-back' with a 4-day break, this is called 'tricycling', resulting in 4 periods a year.
- Continuous use until breakthrough bleeding, and then have a 4-day hormone free interval.

There are many different options, including low dose Oestrogen COCP. The Oestrogen component is associated with an increased risk of blood clots, heart attacks and stroke, therefore medical history and risk factors must be considered.

COCP not suitable for:

Young people who are wheelchair bound, History of migraine with aura, Personal or strong family history of blood clots and BMI >35kg/m²