



LETS TALK PUBERTY

PUBERTY & PRECOCIOUS PUBERTY IN CHILDREN WITH CEREBRAL PALSY

This topic explores the links to the early onset of puberty that can be associated with Cerebral Palsy, and opens the conversation we need to be having with our kids about puberty in general. What, why and how to cope.

READ MORE TO FIND OUT ABOUT SOME REAL LIFE STORIES, MEDICAL RESEARCH AND USEFUL LINKS

Lets Start the conversation

Being a mother to two daughters, It's fair to say at some stage around pre to early teens I was expecting to have a conversation about puberty and menstruation with my girls. You prepare for it, and if your children are young, you think you have few years yet before your daughter turns into a young woman. However, is anything this simple when you have a child with a disability? of course not!

I may have uttered these next words a few hundred times in the last 3 years, "You've got to be kidding me, as if she isn't going through enough already". What am I talking about you ask? "Well, at the age of 5, my little girl started to develop body odour and pimples, pubic hair growth at the age of 7 and by 8.5, her breasts have started to develop. And yes, I am having "That conversation"!!

I would like to discuss this as my first topic because, unbeknowst to many, early onset of puberty can be a secondary characteristic in girls (and boys) with cerebral palsy (CP).

I feel as parents, we should be given more information and advice on what to expect and how to cope. As a parent, experiencing this first hand, I have had to go in search of information and ask the paediatricians for help. I have to say, I was very dissatisfied with the little help I was offered. If it is such a common characteristic in children with CP, why isn't more being done and more information being offered earlier?

There can be a lot of anxiety around puberty and periods - how will we manage periods at home, in school or in hte wider community? Not to mention taking into account that many of our children may also have mobility issues and need support around toileting, or have learning difficulties already making their daily life harder. It may also be that our daughters and sons are still just children and trying to explain what is happening and why, can be frightening and alarming for both children and parents.

My own anxiety and worry over how my daughter would cope with dealing with her periods has been enough for it to become my mission to help her, myself and others. I want to empower families by giving them sufficient tools and resources they need to support their daughters and sons on the journey to becoming young women and men regardless of their age.



The why?

Why do some children with CP go through puberty early?

The medical term for early signs of puberty is called Precocious Puberty. Studies have shown that neurodevelopmental disabilities are linked to an early onset of precocious puberty/early onset of sexual development.

We know that a diagnosis of CP means a brain injury that has happened in early neurological growth which affects neurological development and functions. The endocrine system that regulates puberty and determines when puberty starts is controlled by neurological function and this could be a reason why individuals with CP experience early or late puberty

Early or Precocious puberty range:

< 9 years in boys

<8 years in girls

Delayed

>14 years in boys

>13 years in girls

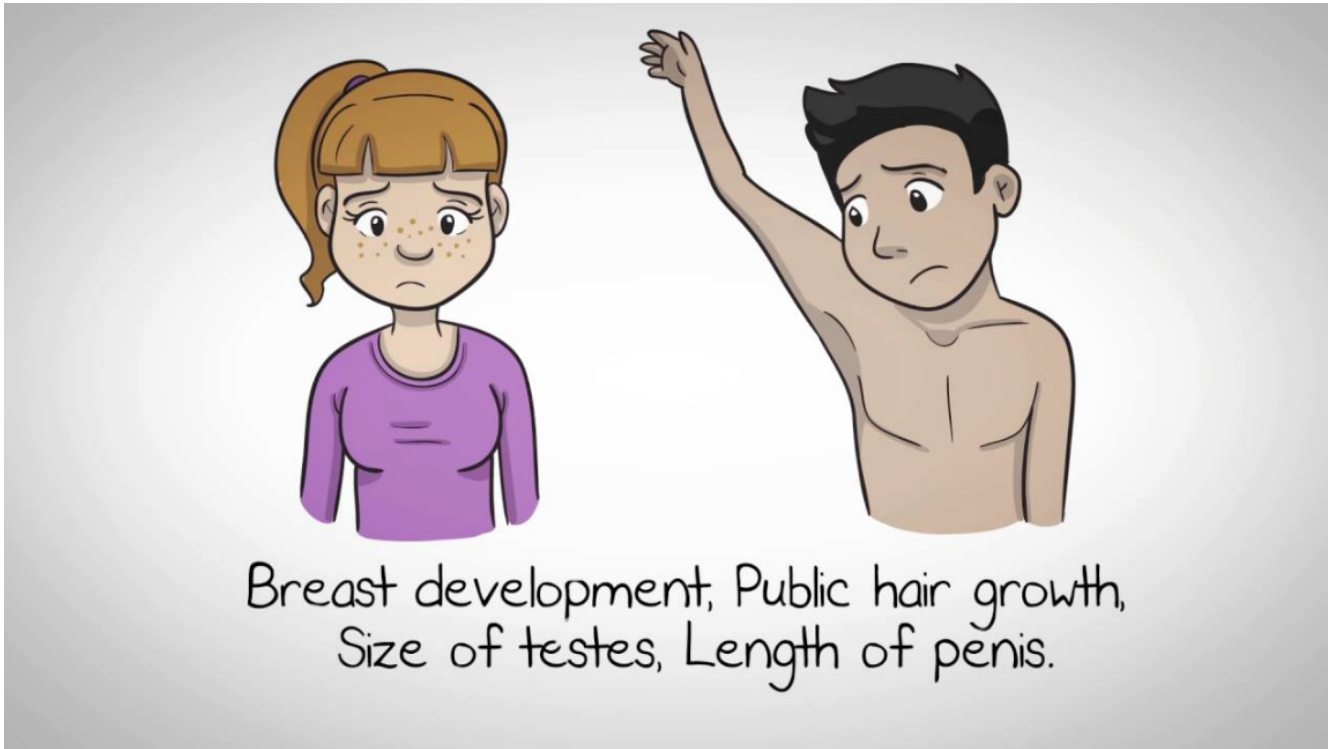


“Studies on precocious puberty have primarily focused on children with typical patterns of growth and cognitive development. This study reviewed diagnostic data from the records of 15 719 patients with neurodevelopmental disabilities for diagnoses associated with premature sexual development/precocious puberty. Thirty-two individuals with premature sexual development were identified, with the earliest changes seen in one girl at 1 year 7 months of age. In this group, the mean age at onset was 7 years 2 months in boys and 5 years 11 months in girls. Central precocious puberty, which was the most common cause of onset of early pubertal changes, was present in 15 of the 32 children. The results of this study suggest that children with a neurodevelopmental disability are at increased risk of premature pubertal changes when compared to children without a neurodevelopmental disability. This study indicates the need for health-care providers to be vigilant in screening for early pubertal changes in children with neurodevelopmental disabilities.” (Siddiqi et al 2007)

Changing Bodies

Early Puberty - What can it look like and what issues may arise?

Signs of early puberty that parents may want to be aware of include: - breast development, period onset, Boys - enlargement of genitals, facial hair and deepening of the voice. In both sexes rapid growth, acne, adult body odour and body hair.

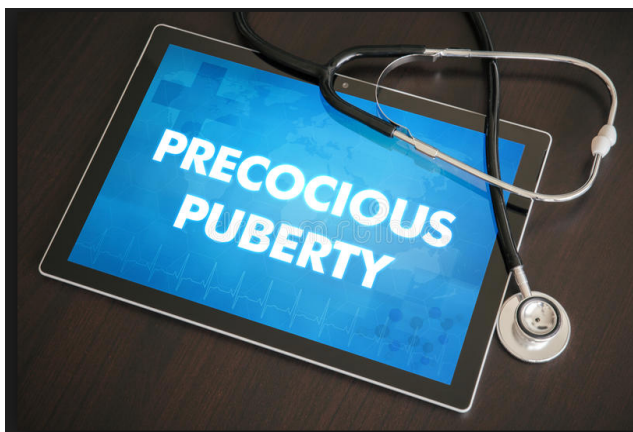
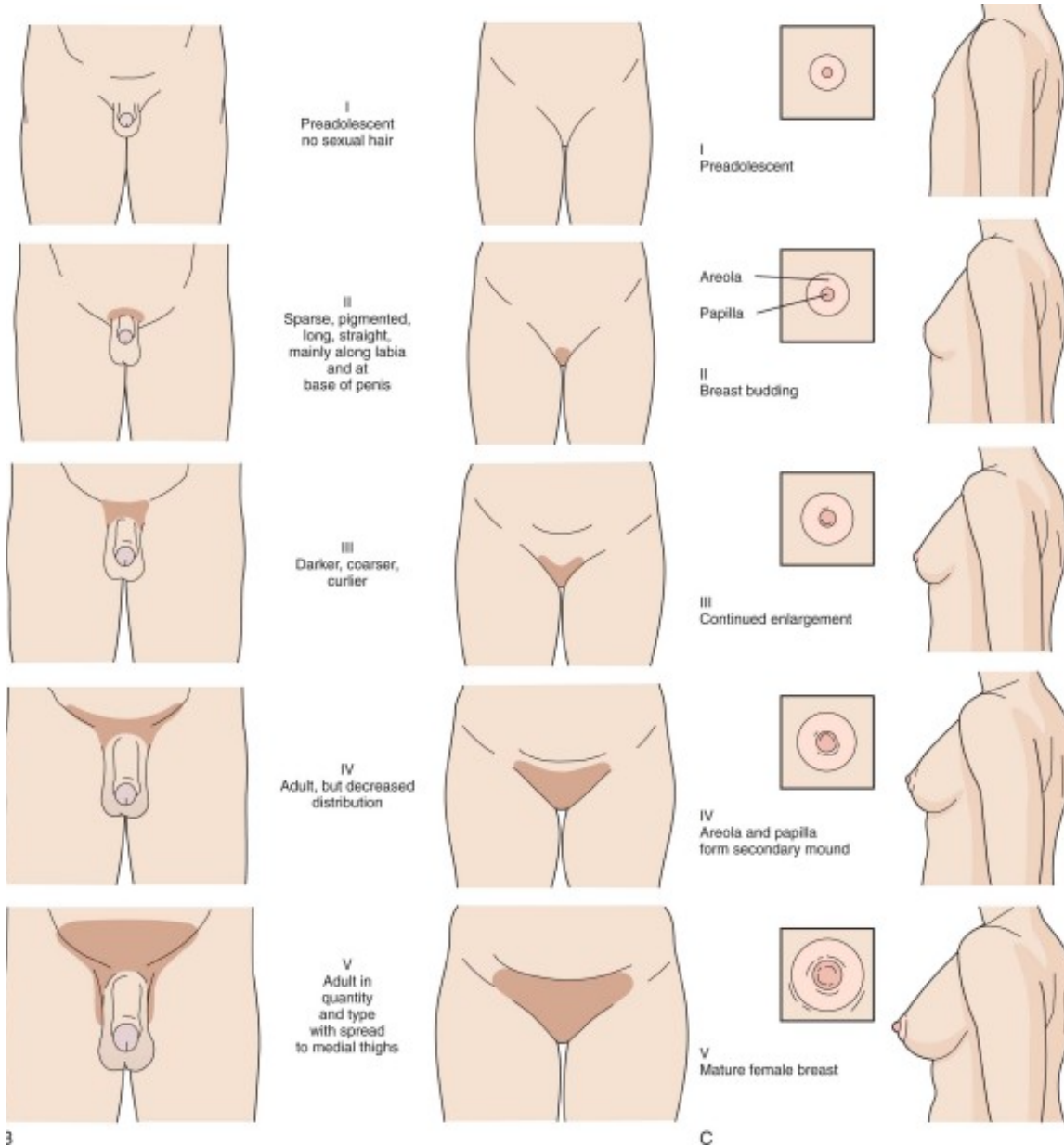


Concerns that may result in early onset of puberty:

- Add a little bit of bChild being too immature to understand changes to their body – anxiety, fear, anger
- Childhood cut short – vulnerability as an adult
- Mood swings and Behavioural changes, can be more acute in individuals who are non-verbal.
- Onset of menstruation
- Growing pains in limbs
- Rapid breast development
- PMS earlier

Tanner Stages

You may have or will at some point hear your GP or Paediatrician talk about 'Tanner Stages' This is the scale that is used to measure the physical development of children/adolescents/young adults



Another study conducted in the USA – Secondary Characteristic's in children with Cerebral Palsy and moderate to severe motor impairment: A Cross-Sectional Survey (USA) shows:

The pattern of sexual maturation in children with CP of moderate to severe motor impairment differs from that of children in the general population. Puberty begins earlier but ends later in children with CP, compared with children in the general population. In addition, menarche occurs later in white girls with CP. There are small differences between male and female development (Worley et al 2002).



SHARE YOUR STORY

Lets here from our members....

For a more personal insight into how families are coping with puberty i asked some of our members to share their personal experiences:

“When Our daughter’s periods started, she needed quite a bit of assistance. We felt this was quite invasive of her privacy, so we spoke to our GP. (We were referred to a gynecologist, but they didn’t really do too much to help. She tried a couple of variations of the pill. All of these had bad side effects, she became extremely emotional on them, so she stopped taking them quite quickly. (The side effects disappeared within a few days too). We were advised about other medical interventions by our GP, with great trepidation we tried the depo injections. Fortunately for our daughter these had minimal side effects and were very effective. If I was to make any recommendation it would be to find a good, practical GP who knows your family history and situation. Our GP has been great and tends to consider the impact of the disability on the rest of the family.”

“My period development was a frightening and disconcerting experience. I began my puberty symptoms long before my friends and needed to rely on family and school assistance to manage periods and pads. There was also too much spasticity involved and hormone irregularity to consider tampons and stopping periods. It took me approx 5 years to develop a system that I’m comfortable with. I recommend that doing lots of research about what is available on the market and experimenting with different products along the way will help you find something that is comfortable and works for you. “

“At age 7 our daughter started developing pimples, and hair growth in other parts of her body along with very oily hair. I found this extremely alarming but with no pre-warning of what could be happening I was clueless. Unfortunately, a trip to our GP did not give us any answers and we were passed back to our pediatrician. He discussed the Tanner Stages and that we were in Stage 2 and not to worry until we noticed Breast development which was sure to be a long way off - end of conversation basically. No discussion about Precocious Puberty or any other medical issues that we should be aware of. At this point I took the word of the Pediatrician. By age 8 our daughter started complaining when we lifted her into and out of positions that it hurt in her chest area, I lifted up her top and for the first time noticed her budding breasts!!! My conversation with the pediatrician came rushing back to me and I thought ‘oh goodness we are at the stage when her periods could arrive and it’s way too early, what do we do!!!’ Another call to our Pediatrician was made and I was told we had to wait until our 1 year appointment (many months away) – after a heated conversation a promise of a referral to a gynecologist was offered. We waited for an appointment letter to come through the post (it never did). Instead of being contacted by a gynecologist we were put in touch with a family Social Worker. Our Social Worker was very helpful and was able to get us immediate assistance from a Public Health Nurse. I did not even know this service existed but 2 days later we made contact with a Health nurse from the local district health board and she arranged to come out to see us.

Our experience of the Public Health Nurse Service was fantastic. A young and very friendly nurse came to our house. She talked about what was happening to our daughter and asked if she had any questions she would like to ask. She then gave our daughter a folder with some information and product samples and a book about puberty. She advised us that she could come into school and talk to the Senco about establishing an action plan around what would happen when periods started. She spoke to us at length about doing some practice periods and making up a little bag with pads inside for school. Other information she gave was that in her experience girls with mobility issues managed better with pads without wings. A new product she told us about were Thinx underwear which could be used whilst at school or away from home. Her visit helped us to feel supported. My recommendation would be to do practice runs and trial various products and research as much as possible all your options both medical and natural.”



SHARE YOUR STORY

“I have always known that girls with CP often get their periods earlier than the average girl as 2 friends who have daughters with CP had talked to me about it a few years ago. So late last year not long after my daughter turned 9 we started talking to her about periods and what they were and why we got them etc. Some things she questioned some she didn't want to know about but we just answered her with honest answers suitable for her age. When she was 9years and 5months old she got her first period.....I was gutted for her, why....because our kids already have enough to deal with on an average day and to have to deal with this at such a young age as well just doesn't seem right. She called me one morning to let me know she had it, I was grateful she got it while at home and not at school (although we had talked to her and made a plan of what to do if it happened at school).

Prior to her getting her period we had had no consolation around this with any of her medical team ie GP, Paed etc. After consulting with Paed a couple of months down track she said they usually refer for a gynaecology consult around 10years of age but now agree they need to look at doing that a bit earlier.

Our first go to was the GP and we talked about optionsat first she suggested waiting a couple of months as it may be a one off.....we soon found out 2 weeks later it wasn't and sadly had continual bleeding for over a month so started on a contraceptive pill....we were offered a few options but one thing we wanted to avoid was weight gain so ruled a couple of those options out early on. From there was referred to gynaecology team which took 3 months to get appointment where we again were given a few different options.....I think it is important for you to do what will work for YOUR child as you know them best and not all options are the right options for you. After trying 2 different contraceptive pills (which haven't proven to help very much) we are now on the wait list for a MIRENA to be done under general anaesthetic.

School has been amazing and we met with the Senco and she organised a couple of people that my daughter could go to if it happened at school and her teach aide wasn't available”.



The different experiences shared by our members shows that there is not one path which works for all. My recommendation for families with children that are showing signs of early puberty are to speak to your GP first. Before your appointment, take the time to research or use information from this article and other sources. Being armed with as much information as possible will help you to receive the right treatment, advise and outcome. There are some great resources available to help both with early onset of puberty and age appropriate puberty. Speaking with families in similar situations can also be an invaluable source of information and ask us here at the CP Society as we can help with making connections. Below is a list of useful links to resources:



Useful links and resources to help navigate all things Puberty and Periods..

Nest Consulting

<https://www.nestconsulting.nz>

Nest Consulting has a focus on health and wellbeing. We're passionate about community; walking alongside individuals, parents, professionals and young people, recognising that every future grows stronger utilising Education, Inspiration, Motivation, Information. Our world is secure when we are connected and belong, are listened to and heard, feel safe and are accepted, are respected as individuals, are challenged, are provided resources, have access to education, are able to make informed decisions and feel empowered.

The Nestbox

<https://www.nestconsulting.nz/product/nest-box/>

A special kit for girls as they start their journey towards womanhood. A fantastic way to open and continue conversations about growing up.

Nest also have some fantastic links to books on puberty and similar topics for children/teens and adults both non-fiction and fiction. Please follow this link to be directed to their book depository collection

<https://www.nestconsulting.nz/books-products/book-to-purchase/>

The Cotton Pony

<https://www.thecottonpony.co.nz/page/about/>

Taking the hassle out of buying your period products. Buy one off or subscribe for monthly deliveries. A discreet and easy to use service.



Useful links and resources continued.....

Luna Periods

<https://www.lunaperiods.co.nz/>

Luna is an online community that supports girls through their first and subsequent periods, and empowers them by normalising periods, busting myths, challenging the status quo and fighting taboos and stigmas.

Along with this community support, Luna provides customers with a highly customisable subscription service, that delivers packs monthly, in phase with their period. Because knowledge is power, educating our audience about periods and what to expect are core founding principles. We promote the values of empowerment, education and authenticity through Instagram and Facebook, which are our most popular social channels

Modibodi

<https://www.modibodi.com/product-category/teen/>

Period proof underwear that looks like normal underwear but contains your period all day no leaks.

"Helping females of the future own their period and take care of the planet while their at it"

Thinx Pants

<https://www.shethinx.com/>

Another period proof underwear product from the USA. Wear Thinx as a replacement or back up to traditional period products.



Useful links and resources continued.....

Libra Girl

<https://www.libragirl.com/>

A good website for girls to find out everything they need to know about periods and links for parents and educators.

Charlie Banana

<https://charliebanana.com/collections/women-1>

Join an Healthier, Eco feminine care product revolution that comes in beautiful fun colors. Available in these utter soft, chemical free, highly absorbent, odor free and very economical reusable feminine pads, breast and nursing pads, make up removal organic cotton reusable wipes at Charlie Banana today!

Watch this space...

The Cerebral Palsy Society will be collaborating with Nest Consulting to provide Parent/Caregiver workshops offering education on sexual health and will be working towards developing group talks for our younger members in the near future.