AIMS For a better birth...

# Maternal Pituitary Support

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*By founders Claire Barlow and Jenn Kenworthy*

Maternal Pituitary Support was established in February 2022. It is a not-for-profit organisation, founded by us, Claire and Jenn, two mothers with pituitary conditions that arose in pregnancy and childbirth.

Becoming a parent is a unique experience and we recognise that coming to terms with a life changing diagnosis during this time requires specific understanding and support. We have both experienced first-hand the lack of information and support, and the isolation that comes with a diagnosis of a rare and often overlooked condition. In addition, we understand the incredible challenges of caring for a baby and recovering from a birth, especially if it has been a traumatic experience, whilst seeking a diagnosis or learning to manage a complex condition.

We have a wonderful, supportive online community where we provide a safe and supportive space for those living with maternal pituitary conditions around the world. We also support mothers with other pituitary conditions, such as pituitary tumours and cysts. We hold online socials and events, with endocrinologists and experts to help us become expert patients ourselves. We are passionate about making a difference and speaking up for these lesser-known conditions. Unfortunately, these rare pituitary conditions are under researched; we hope to change this by campaigning for greater awareness amongst healthcare professionals so as to reduce time to diagnosis and improve treatment and care.

**Maternal pituitary conditions:**

The pituitary is a pea-sized gland found inside the sella turcica, which is a bony hollow within the base of the skull, level with the bridge of the nose. The pituitary is known as the 'master gland' due to its vital role controlling hormones essential for life and bodily function. You can find more information about pituitary hormones here:

https://maternalpituitarysupport.org/your-hormones-1

The pituitary gland becomes enlarged during pregnancy to respond to increased hormonal demands, making it vulnerable to damage. In addition, the anterior pituitary (front) relies on oxygenated blood from both the hypothalamus and the posterior (back) pituitary, making it further vulnerable to damage if it does not receive enough blood.

***Sheehan's Syndrome:*** is a condition where blood loss and low blood pressure during and after childbirth cause pituitary tissue to be damaged. Typically, for a clinical presentation, 75% of tissue needs to be damaged. There is no link between the amount of blood lost and the degree of damage. Hormone deficiencies vary and may include both the anterior and posterior pituitary. There are thought to be other factors involved, including autoimmune responses and small size of the*cella* (the bony hollow the pituitary sits within).

***Lymphocytic Hypophysitis:*** is an autoimmune inflammation of the pituitary, causing it to significantly enlarge. This may be accompanied by severe headaches, visual disturbance, or hormone excesses. If there is tissue damage, there may also be hormone deficiencies. Lymphocytic Hypophysitis can affect anyone but is most common in pregnancy.

***Post-Partum Hypopituitarism*:** is the term given for hypopituitarism that arises following pregnancy and childbirth, where the pituitary does not release enough hormones, due to damage. Treatment is usually life-long hormone replacement medication for each of those hormones that are deficient.

**Jenn's Story – Acute Post-Partum Hypopituitarism**

Jenn had her son in 2014 and had an acute onset of symptoms, resulting in adrenal crisis 13 days later. This is Jenn's story.

> My pituitary was damaged following a 3rd degree tear when delivering my son, resulting in a haemorrhage and sustained very low blood pressure. I had emergency surgery and was

given two blood transfusions.

I was advised by an obstetrician that my milk would be delayed coming in because I lost a lot of blood. They couldn't tell me when to expect my milk, but advised me to keep trying to breastfeed.

I was encouraged by many staff on the maternity ward to keep trying to breastfeed, even though I had no milk. I was advised that if I gave my son too much formula he wouldn't want to try to breastfeed and was repeatedly told that breast was best. This lack of milk should have been identified as an early warning sign of pituitary damage, due to a lack of the hormone prolactin. But it was missed. I wasn't referred to an endocrinologist and wasn't advised to start bottle feeding as soon as possible.

My son was very hungry, and we started to cup feed him with formula. We were told to use a cup so that he could still learn to breastfeed. We kept being advised to try to breastfeed and not to stop in case he would lose the ability to do so.

Each day I would desperately hope I'd see milk, but nothing ever came. I was even advised to start trying to express with a pump, just to see if it would stimulate any milk. It didn't work of course. All that happened was that I became incredibly sore and frustrated.

When it became clear that nothing was happening, my husband went to buy bottles and a big pack of formula. Despite recognising this was the right thing to do, I cried. I had been told over and over that breast feeding was the best thing for my son. I felt my body had failed and I didn't understand why. None of the health professionals around me could explain either. It seemed a complete surprise to everyone.

I gradually became more and more unwell. I was unsteady, unable to think clearly and had a terrible headache. I couldn't eat a thing, or sleep. I went to my GP after experiencing peripheral blurred vision, vomiting and diarrhoea in addition to not producing any milk. My pituitary damage was still missed and nobody realised the danger I was in. When my son was 13 days old, I woke up in a life-threatening adrenal crisis and was rushed to hospital. I had a seizure and was sedated in critical care. It was only then that my pituitary damage was detected.

Looking back years later, I still feel sad about this. There were multiple opportunities for my symptoms to be identified as those of pituitary damage, and I could have had simple blood tests taken to identify my hormone deficiencies. I could then have been urgently referred to endocrinology, to be prescribed the hormone replacements I most urgently needed. These would have prevented my life threatening and traumatic experience of the adrenal crisis, along with weeks in hospital without my son.

What I actually needed on the maternity ward was to be supported to bottle feed formula

milk as early as possible, because quite simply, there was nothing else that could give my son fluid and nutrients.

It felt at the time that there was this obsession with breastfeeding in society. This pressure came from all angles as a pregnant and then new mother. The maternity staff seemed equally insistent on breastfeeding as well.

My son is now a big, bouncy, healthy boy. He did really well on formula milk and has a huge appetite even now! I've been able to forgive my body; after all it was injured and crying for help.

I think there needs to be a shift in attitudes around breast and bottle feeding. There needs to be more empathy, kindness and understanding. There needs to be less judgement of what makes a good mother, and more support for the right choice for each individual.

**Claire's Story – Chronic Sheehan's Syndrome**

Claire had her daughter in 2019 and had a chronic onset of symptoms. This is Claire's story.

I had a long and difficult 40-hour labour after being induced. It ended in an emergency c-section. Because I had pushed for so long my daughter was quite far down the birth canal. A consultant came in and decided I needed an emergency c-section and during this they made a cut so they could remove her. Thankfully she was absolutely fine. I was stitched back up (although it turned out, not completely) and once on the ward I showed signs of a bleed. I held my baby once, before I was taken into theatre again. 3.5 hours later I was back on the ward, but not before losing 3.2 litres of blood.

My milk didn't come in, so I was unable to breastfeed. The medical staff all said it was due to the blood loss and that my milk would be delayed.

My milk never arrived. As well as the hospital consultants, midwives and community health visitors, I saw two lactation consultants and went to the GP to get someprolactin tablets to encourage milk production. Not one professional spotted this major early warning sign. Not one of them mentioned that Sheehan's Syndrome could be a possibility.

It's utterly heartbreaking when you don't have milk to breastfeed.

At the time I wept daily. I grieved the loss of the chance to experience feeding my daughter. I cried so much I was flagged for postnatal depression. I explained I was just sad I couldn't feed my baby and people seemed to understand and accept this. In fact my pituitary gland had been damaged by the blood loss. The hormone prolactin wasn't being produced and my body was no longer functioning properly.

Nine months after giving birth, in 2020, I noticed I started to feel quite unwell. My hair was coming out in clumps. I had lost my sex drive, my skin was dry, nails breaking, I was gaining weight and generally felt dreadful. And when I stopped and took a breath, I noticed that my NCT gang were full of the energy that I didn't have - they were running up hills together with running prams, whilst I was having trouble walking up the hill - I was shattered. I also realised my period still had not returned and began to feel concerned.

At the beginning of 2021, after repeatedly going to my GP, I googled my symptoms and found a match: Sheehan's Syndrome. I couldn't believe it. I literally had every symptom listed, even the wrinkles on my face that I noticed had been coming on more and more over the past year. Dr Google said that Sheehan's Syndrome is a damaged pituitary gland caused by severe blood loss during labour. It says it is rare in the UK. Some further research led me to a private endocrinologist, and I was in a lucky position to book an appointment for the following day. One MRI scan, some blood tests and lots of sleepless nights later, I had a confirmed diagnosis of Sheehan's Syndrome. It was a relief in some ways to have a diagnosis, and in other ways incredibly frustrating and upsetting as I felt it could have been prevented. I wished I had fought for a planned c-section.

As my daughter grew into a toddler, she loved milk. When she was poorly or teething she asked for it over and over. One of her favourite things was milk, from a bottle with me. We cuddled quietly together. We built something together, instead of breastfeeding, and she doesn't know any other way. To her, this was perfect.

I can really empathise with the pain of not being able to feed your baby if that is what you desperately want. I can also say that from experience it's okay not to breastfeed. Perhaps a different experience from the one you had imagined, but it still has the potential to be equally as special for you both.

I was put in touch with Jenn by a kind lady at the Pituitary Foundation. I went there looking for answers and was given a fact sheet. I asked if they had a specialist in Sheehan's Syndrome and the answer was no.

When Jenn and I first spoke, I was so relieved to have found someone like me. Someone who understood. I remember sobbing all the way through our phone call, it was spring 2021 and I was in the garden.

We vowed then that no women should face this alone. After huge amounts of work and energy, Maternal Pituitary Support was born in 2022. The aim is to support women around the globe, to campaign and raise awareness to reduce the time to diagnosis, and to secure funding to research this little known condition.

**Acute and early symptoms**

- Visual disturbance / peripheral blurring / changes in vision
- Lack of breast milk / reduced supply
- Low blood pressure
- Dizziness
- Muscle weakness
- Difficulty sleeping
- High urine output
- Headache
- Fatigue / exhaustion
- Thirst
- Brain fog / unable to think clearly
- Unsteadiness / clumsiness / feeling drunk or drugged
- Diarrhoea / vomiting
- Racing heart
- Irritability
- Anxiety
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Feeling shaky

- Joint and muscle aches
- Mid / low back pain
- Hot flushes / night sweats

**Chronic and longer term symptoms**

- Fatigue
- Brain fog
- Short term memory loss
- Anxiety / depression
- No menstruation / irregular periods
- Hot flushes / night sweats
- Infertility
- Difficulty sleeping
- Weight gain around middle
- Loss of muscle bulk
- Loss of bone density
- Low libido
- Hair loss / thinning / losing hair at ends of eyebrows

- Unexpected weight loss
- Vaginal dryness
- Muscle and joint aches
- Constipation
- Diarrhoea
- Brittle nails
- Thinning of skin
- Wrinkles around eyes and mouth
- Irritability
- Generally feeling unwell
- Heart racing / fluttering
- Shaking hands
- Poor tolerance to cold / heat
- Difficulty sustaining exercise

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**Author Bio**: Thank you very much to AIMS for inviting us to share a little about our organisation in this journal. We are delighted to be working alongside AIMS to advocate and raise awareness. Maternal Pituitary Support was launched in 2022 for those around the world with pituitary conditions arising in pregnancy and childbirth, such as Sheehan's Syndrome and Lymphocytic Hypophysitis. It was founded by Claire Barlow and Jenn Kenworthy, both mothers in the UK with Sheehan's Syndrome.

*To find out more please visit our website https://www.maternalpituitarysupport.org or email info@maternalpituitarysupport.org*

If this article has been of interest, you may like to read more in our Royal College of Midwives – MIDIRS

paper; “No Milk? Think Sheehan’s”: https://maternalpituitarysupport.org/campaign

Our website is https://www.maternalpituitarysupport.org

Our Facebook page is https://www.facebook.com/MaternalPituitarySupport

Website: https://www.maternalpituitarysupport.org

Instagram: maternalpituitarysupport

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1 Editor’s note: The hypothalamus is an almond-sized part of the brain. It secretes hormones that stimulate or suppress the release of hormones in the pituitary gland, in addition to controlling water balance, sleep, temperature, appetite, blood pressure and even some parental behaviours.