

Premenstrual Dysphoric Disorder (PMDD) by Susie Grady

Premenstrual Dysphoric Disorder (PMDD) is a potentially harmful condition that unfortunately is under recognised in the UK as most Doctors, Psychiatrists and Allied Health Professionals (AHPs) are still unaware of it as it is not taught routinely in medical schools and Universities. PMDD is a hormonal condition affecting woman that means their mood and behaviour is severely affected by the cyclical rise and fall in their hormone levels during the menstrual cycle. It is not the same as Pre-menstrual syndrome (PMS) because PMS does not result in such severe mental health issues and symptoms. "PMDD happens during the time between when you ovulate and when your period starts. This is known as the luteal phase of your menstrual cycle. For most people, the luteal phase lasts around 2 weeks. But it can be longer or shorter." (www.mind.org.uk)

"Prevalence estimates for PMDD range from between 3 and 8% of all menstruating women" Left untreated "many women have attempted, and in some cases succeeded, in taking their own lives" (Osborn, 2020).

For us our journey began at the start of Covid when my child also started puberty. What we first noticed was an inability to sleep and issues with eating. This progressed to periods of intense distress resulting in suicide attempts as the symptoms worsened over the first 4 menstrual cycles. This resulted in an initial hospital admission onto a paediatric ward for 14 weeks, where we were told they had anorexia and they were then force fed by nasogastric tube under restraint. As symptoms continued to worsen my teenager then became psychotic for 5 weeks and started their first mental health inpatient stay.

Unfortunately, Covid complicated all matters, and our child was quickly put on a toxic mix of antipsychotics and antidepressants which meant that we could no longer recognise them or their menstrual cycles. He was also diagnosed as Autistic by the Maudsley Hospital, and we were offered family therapy by a fantastic Psychologist working as part of the CIPP@SLAM team. This was vital as having something like this affect your family causes distress to all family members.

Unfortunately for my son the Psychology he was offered initially was not helpful as they did not recognise his Autism and started with CBT work. This failed because you cannot change someone's Autism; it is much more about looking at ways to adapt the environment to help someone with Autism to flourish. The most helpful people he met in the Tier 4 units were the peer support workers as they had lived experience themselves of a mental health

illness. They did not judge or try to change my son. But rather they sat with him and allowed him to talk if he wanted to.

One of the aspects of Autism that a lot of NHS staff including Psychologists seem to be unaware of is that when stressed my son becomes non-verbal. That means that in a standard one hour therapy session he may well be non-verbal for 50% of it. This causes added distress as he feels he cannot participate, and he has failed. Which is why the peer support workers were much more successful than the trained therapists. Because they had the time to sit with the children on the Tier 4 units and allow them the space to breathe.

As a mother I also found a lot of the therapy sessions unhelpful as I was not given any strategies to help my son for the rest of the week. While I appreciate confidentiality is key; it is also worth recognising that the child is with the therapist for 1 hour a week; but they are with their parents (who are often their main carers and may have given up work to do so) 24/7 all week.

We went through a cycle of repeat hospital admissions, A and E visits and a second 10-month admission to another Tier 4 Child and Adolescent Mental Health service (CAMHS) unit. During this time a whole host of psychiatric diagnoses were made including Bi Polar, Eating Disorder, Severe depressive illness with the hormonal issues being totally missed.

Finally, we ended up seeing an amazing Paediatric consultant in a General Hospital who referred us to their Gynaecological team. Within a few hours the diagnosis of PMDD was made and continuous contraception was started. This allowed my child to come home and lead a normal life. When we were then referred to our local Gynaecologist he said that he could make a diagnosis of PMDD confidently because it all began at puberty and it is possible to show a cyclical nature to the symptoms.

I now work as a Lived experience expert for the University of Bedfordshire as well as being on the committee of the Chartered Physiotherapists in Mental Health. I have written a presentation on our journey and any opportunity I have to inform others I take. This has involved talking to Social Services, CAMHS, Mental Health Physios and Paediatricians.

I am currently collecting signatures for my petition which I intend to present to the Royal College of Psychiatrists and the General Medical Council asking for all professionals to be trained in PMDD.

<https://www.change.org/PMDDeducationNOW>

References and useful sources of information

Womens experiences of receiving a diagnosis of PMDD: a qualitative investigation. 2020. Osborn,E, Wittkowski,A,Brooks,J. Briggs, P. O'Brien,S. BMC Womens Health 20:242

www.ipamd.org

www.mind.org.uk

www.pms.org.uk

Chartered Physiotherapists in Mental Health

