PMDD with Amani Omejer

Speaker Key:

VO	Voice-over
CB	Chantal Boyle
AO	Amani Omejer

00:00:00

VO

Welcome to The Sunflower Conversations, where we explore the Hidden Disabilities Sunflower and its role in supporting people with hidden disabilities.

This is a content warning. The following subjects will be touched upon during our discussion. Suicide, eating disorders, and self-harm.

CB

So I'm Chantal and I'm one of the hosts of The Sunflower Conversations podcast where we interview people with a lived experience about their disabilities. Very often they're comorbidities, co-occurring [?] disabilities, and we just think it's a great way to help expand knowledge and understanding amongst the community and society as a wider whole. So that's me.

I am joined tonight by Amani and I'm going to allow Amani to introduce herself. We were going to record this in November, but, as is the nature of chronic health, Amani hasn't been very well. So I'm really happy that you've joined us tonight. I do want to say thank you because I know that you're not feeling your best now. So if at any point you've had enough, that's fine. We can just quit. The ball is in your court.

00:01:46

AO

Thank you. Well, I appreciate... Obviously you're the best organisation to do this with because you understand how it is to live with chronic illness. So thank you for understanding.

CB

Absolutely. We're here to support you guys. You're part of the community. So we are... Amani got in contact with me to say, it's PMDD awareness month, so we should probably talk about, what is PMDD? It stands for premenstrual dysphoric disorder. Is that correct?

AO

Yes.

CB Well, I'm going to ask you. Can you explain in your own words what that is?

AO Yes. So I'm not a scientist. I'm not a doctor. So I will just describe it in my lay terms. So, for me, the way I describe it... Everyone has a different description of it. For me, my way of describing it is essentially like... Again, this isn't scientific but a description with the words I use, but for me it's like it felt and was a... Almost like an intolerance to your own natural rise and fall of progesterone throughout your cycle.

00:02:59

So it's like a severe negative reaction to your own natural progesterone and that severe negative reaction comes out in many different symptoms. Again, everybody's different, but commonly things like... And I should say, it starts from ovulation. So it's not the whole cycle. So you can feel okay or feel your normal self and then you ovulate and then it's like... Some people, it can maybe take a few days to brew and come on a little bit later. For me it was always, bam, I've ovulated and... Yes. It gets messy.

So the symptoms... My symptoms were severe suicidality right up until I started my period and then it would often take a couple of days or a few days for it to settle a bit. That's the common cycle basically, is that you have the symptoms from ovulation in your luteal phase and you have your natural spike of progesterone, which is totally normal.

But people with PMDD have... I call it like an intolerance. It's a severe negative reaction to that rise of progesterone and that can cause, like I just mentioned, severe suicidality, rage, heightened anxiety. There's so many symptoms it can cause.

It's mainly... It can cause some physical symptoms. I had other conditions, gynaecological conditions. So I couldn't tell you for me what my physical ones were because they were also connected with my adenomyosis and endometriosis. So it's kind of complicated in terms of the physical side of things, but most of the symptoms are mental symptoms, which obviously can become physical.

00:04:59

But basically the difference... People get confused. So people can think I'm just talking about PMS. People will think, oh, PMDD, it just sounds like PMS. The difference is... There's quite a lot of differences, but the main difference is that PMS, firstly, doesn't last as long. Normally... Well, basically 80% of women have PMS. So it's much more common. It's a shorter period of time before your period.

And the main thing that differentiates between them is that it's just not as debilitating. So you can still have, obviously, bad PMS and that's not to dismiss that because it can be horrible, but PMDD is life-altering. It ruins relationships. It stops you working. If it's impacting your everyday, then something is not okay.

CB

And I would imagine... Because it is a relatively new term, PMDD. As far as I'm aware, it's a relatively new term. I would imagine that having... I think there really wasn't very much support for women who have periods. So if you're having a bad time, you go to the doctor. Well, that's just normal. You'll feel bad and then you'll feel better once your period comes. Is that the kind of response that you were met with when you spoke about how you were feeling?

AO

Oh, my gosh. Well, most of the doctors I tried to get help from didn't even know what PMDD was, as in, they didn't even know what it stood for, that it was a condition. I don't remember when it got added... I should know this. Sorry. Just my disclaimer is, I have a very bad migraine. So I wanted to talk a lot about the science and the facts and figures, but I just can't go there in my brain. But I can't remember when it was added to the DSM, but it is officially in there, which is great in the sense that it's being recognised.

00:07:03

But I was diagnosed when I was 24 by... I just got really lucky and I had a therapist that had PMDD and we worked together for two and a half years and she clocked my cycle before I did, if that makes sense. Because I have other things going on like a lot of people do. I also have severe complex PTSD, so I put most of my mental health struggle down to the PTSD.

And it wasn't until... Obviously we'll get to this in my story, but it wasn't until I entered chemical menopause that I realised, actually a lot more of my mental health struggle is PMDD as well as the PTSD. And I can't remember what you asked me now. Sorry.

CB

No. That was my question. It was, how difficult or easy was it for you to get a diagnosis of PMDD, basically?

AO

Basically, I tried to get help with things, got shoved on... Well, I obviously chose to try them, but I got constantly shoved on lots of different SSRIs, the other group of antidepressants, antipsychotics. I tried so many different things. Some people it can help if you... There's things like... You can take... Again, I'm not a doctor, but some people, for example, will take medication in their luteal phase and that can help or even throughout the month it can help.

For me, unfortunately, everything I tried made it worse. So what I ended up doing is... I ended up going to the doctor and just saying I had PMDD, I'd been diagnosed, and I sort of kind of winged it a little bit, if that makes sense. I was trying to get help and in the end I just gave up, waited a while, and then was being put into chemical menopause for my adenomyosis whilst I waited for my hysterectomy.

00:08:57

And that was when I saw... Literally, it was like magic. When I got put in the chemical menopause, I suddenly didn't want to die every single day leading up to my period. I realised how much the PMDD was overtaking my whole life and my whole self.

And I think the trouble with hormones is that... How do I explain this? I guess they're very convincing. They make you feel as though it's you that's the problem and you're not... If that makes sense and it wasn't until I had a break from my PMDD that I realised just how much it wasn't just, something is wrong with me, or, I'm broken, or, I just need more therapy, or whatever.

It was life-changing. It made me realise how much of a hard time... It made me actually feel quite sad because I was like, oh my God, I've given myself such a hard time through all these years for just needing to get a grip or all these harsh things we say to ourselves and actually it was PMDD.

VO

You are listening to The Sunflower Conversations with Chantal. To learn more about the Sunflower, visit our website. Details are in the show notes.

CB

The suicidal thoughts and the negative feelings, emotions that you experienced every time before you period... Did you say... You got your diagnosis at 24, but when did that actually first start? Because me personally... I started my period when I was really young. So I'm interested to know what kind of age you were when you started that.

00:10:35

AO

Yes. So obviously hindsight is a gift, right? So, looking back, I'm like, it definitely started when my period started, so around 11, 12. And then with my teenage years I had a lot of... It's hard to differentiate what's causing what, but I had a lot of trauma at home. But also there was, now looking back, it's kind of hard to explain it, but there was a way of thinking that I now see was PMDD. The self-harm... I had struggles with eating disorders, the kind of suicidal thoughts, all of that kind of stuff that I never told anybody about.

But now I look back and I'm like... I just feel sad because I'm like, of course, that was because... And then that kind of continued. I thought it was just normal to spend... I guess for me, my cycle was a bit all over the place, but I'd spend up to two weeks of the month just, every day, not wanting to be here. I guess it was just so long-term that I was like, maybe this is normal. It's not about what's normal or what's not normal, but I just was like...

CB

Thinking everybody else was like this.

AO

Yes. I was like, maybe I'm just wired differently, if it's not normal. Maybe it's just me. And then obviously getting the diagnosis at 24 was just... The whole world opened up. But then also what can cause PMDD to get worse or even to start is stress.

00:12:09

So at that time there was a lot of stress going on in my life and I'd estranged from my parents and developed severe complex PTSD. It was interesting because that exacerbated the PMDD and that can happen. There's something called PME, which is premenstrual exacerbation of preexisting mental health conditions. So it's very complicated. I don't know if that made sense, but...

CB

Yes. I would imagine that when you got the diagnosis of that... You said you felt very sad, but it must have been catastrophic to... You must have really felt so sad for your younger you, the child you, that lonely path that you had to walk alone with these feelings. It must not only... I don't know. It must be so tiring as well to feel like that on such a regular basis. Two weeks out of every four, you're feeling that way.

AO

Yes. Just to be totally frank, there were a lot of attempts on my life by myself. It takes its toll. I am in surgical menopause now. I have had my ovaries removed and I know without a shadow of a doubt that if I hadn't have had that surgery and entered the chemical menopause and then the surgical menopause, after my surgery, I wouldn't be here.

There's only so much one... As a human, there's only so much suffering we can take and I think there really... It makes me angry. I could rant about this for hours, but it makes me angry that we can't talk about feeling suicidal as easily as we can talk about something else. And I understand of course it's an emotive subject, but so much stuff we keep to ourselves.

00:13:58

That's why I'm just always determined to raise awareness about things like PMDD or suicidality or whatever it is. Because I just really feel strongly that we don't need to be on our own in it because that's dangerous obviously and also it's just so... It just makes the suffering so much worse.

CB

Yes, and it's 2024 now and we need to stop being afraid of certain subjects. Obviously, we have to be very sensitive to other people's triggers, if you like, [unclear]. However, somebody suffering in silence like that... It could have such a different outcome if talking of these subjects wasn't a taboo and wasn't seen as a sign of shame.

AO

Yes, and this idea that feeling that way is as though you failed or you're not trying hard enough or there's something wrong with you. Of course, there might be something physiologically or psychologically going on, but it's a human experience and I don't think we should shame any human experience.

VO

If you are concerned about any of the subjects discussed in the podcast, please follow up and seek support from your healthcare practitioner.

AO

I really have a passionate hate towards the shame that exists around mental health conditions. Obviously, this isn't... PMDD can be misunderstood as just a mental health condition and it's not.

CB

I was going to ask you, is it classified under the mental health banner?

00:15:29

AO

So I don't know exactly the text in the DSM, but it's in the DSM, which is obviously... I can't remember what that stands for now. It's the diagnostic manual for mental health conditions. So I guess it's seen as a psychiatric condition, but correct me if I'm wrong, anybody, but the actual... The cause of it, yes, is within your brain in the sense of... It's your reaction to the natural rise and fall of your progesterone.

But I don't know... I think a lot of people have differing views about PMDD, as in high-up medical people. And also there's not enough research into it. Yes. So I think... I guess... And also the treatment, some of the treatment that can help people, will fall in the psychiatric medications, but that doesn't mean that it's all in your head or anything like that that people can get judged by.

CB

Well, how we kind of met one another virtually was through some of the work that Hidden Disabilities Sunflower is doing to raise awareness of perimenopause and the menopause. You reached out and said, what about chemical menopause? So we thought it would be an opportunity to share, what is chemical menopause, because many people may not have heard of that term before. So I don't know if [inaudible] talk a little bit about the journey that you've been on and how that's been for you.

AO

Well, yes. So mine's a bit of a complicated story because... So, essentially, yes, there's lots of different types of menopause. So there's the premature ovarian insufficiency, which some people can have since their teens. Other people enter POI due to surgery, which is me. So I... Or chemical menopause, which I... So basically I did chemical menopause and then... Whilst I waited for my surgery and then I went into surgical menopause... I think it was ten months later, nine months later.

00:17:32

So I basically... To try and summarise what happened for me, I had a condition in my uterus called adenomyosis and I had tried everything. I also had endometriosis. They can sometimes come together. They're not the same thing. So I had this uterus condition. The only... The final treatment was a hysterectomy. I was desperate, so I was on the list for a hysterectomy.

Thankfully, which is a weird thing to say, but thankfully there was a long wait. There was a two-year-long wait, which obviously sounds terrible, because it was COVID, but due to the wait, I was put into chemical menopause. Chemical menopause essentially shuts down the ovary-brain connection. It puts you into a temporary menopause. So it basically flattens out that cycle.

CB

[Overtalking] the cycle. Yes.

AO

So it can be quite diagnostic as to whether… So for me it was very diagnostic about how much of my struggle was PMDD because I entered chemical menopause… This is another thing to talk about maybe at some point, but basically there are lots of different types of chemical menopause.

So I entered one type, which is in the UK called Zoladex, which is the main one they normally try first. It actually was horrendous for a month. I was like, what am I doing? And then someone I knew through Instagram thankfully was like, you know you can ask for different brands of… The same drug but different brands and they can be different in your system? So, thankfully, I knew that.

00:19:21

So I went to the doctor and I was like, please give me one more shot, I want to try Decapeptyl, which was this other brand. They were like, it won't make any difference. They dismissed it, but they said, okay, fine. So I went… I had the Decapeptyl. It all comes as injections, so you go in for your injection once a month or every three months. It varies.

Literally, when I had the Decapeptyl, the next day I was… I don't have words for it still. It felt like magic. It wasn't, it was the loads of drugs, but… It was chemicals, but it felt like magic. I was… All my friends noticed the difference. I felt the difference instantly. My therapist spotted the difference instantly.

The change in me was so significant that whilst I was waiting for my hysterectomy… So a hysterectomy is only the removal… It doesn't remove the ovaries. So the ovaries obviously was causing me all the problems with my PMDD. So I got letters from friends and my two psychotherapists and they wrote to the gynaecologist.

00:20:33

Because I was only 34. That's very young to remove someone's ovaries. I do know people that have been 21 and have managed to have their ovaries removed due to PMDD, but they still… It's a big fight a lot of the time because of how misunderstood the condition is and… Yes.

Anyway, I got these letters, sent them to the gynaecologist, and they just straightaway signed me off to have a bilateral salpingo-oophorectomy, which is essentially the removal of both my ovaries as well as my uterus, fallopian tubes, and… I think I've forgotten one part of my anatomy that I lost, but basically… Oh, and the cervix. So essentially I had all of that removed in September 21 and my life has been completely different ever since. Yes.

CB

[Overtalking]

AO

Yes, for sure. Surgical menopause is no easy ride. Neither is chemical menopause. Everybody is different. Everyone responds differently. There's no... The hard thing with PMDD is that there's no one treatment that fits all, at all. Surgical menopause is not easy. If my dose of oestrogen or my HRT isn't quite right, I can feel a lot like I have PMDD again and...

CB

I was going to ask you. Do you experience... It's difficult to know because that's the problem. You can't see what's going on inside your body, can you, particularly with hormones. But like fluctuations... You can sort of feel it instantly. The other thing I was going to ask you... Because of the wave that we get, everybody gets with their hormones... Even if you're a man, sometimes you can be a bit more up and down or whatever. Do you still get that? So do you have to adjust your medication at different times of the month, the week to accommodate?

00:22:31

AO

Yes. It's a really interesting question and I've actually... Yes. So basically I don't really have... I have my being-a-human fluctuations and living-with-chronic-illness-and-PTSD fluctuations, but in terms of the hormonal thing, the only reason I have a fluctuation is if I forget a dose. So I don't have my ovaries. If my medication that I'm taking, the HRT, is giving me a stable... Every day is the same dose and... But again, everybody is different.

For me, surgical menopause... It's been very hard to absorb the HRT and so I'm actually waiting to go to London to have an implant fitted in my belly with the oestrogen in it because we don't do it where I live, so I need to go to London. That will hopefully give me more oestrogen because I do... It's not like I've gone from severe PMDD to, everything is great. Obviously I still really struggle.

Surgical menopause is really no easy ride, but... It's like falling off a cliff hormonally, but when you... It's when you're stuck between a rock and a hard place. Obviously I want to be in the world, so I needed the surgery. People talk about me deciding to have a hysterectomy and I always correct them because it wasn't a decision. If my PMDD was that bad, if I wanted to live, that was what had to happen.

CB

Yes, and thank goodness that this option became available. Because PMDD, if we think about it... And I know we're not going to go into facts and figures because I know you've got a migraine. I'm just having a general chat here, but if you think about it, PMDD must have been around for years and years and years, as the menopause has been around, as perimenopause has been around.

00:24:23

So, years ago, women wouldn't have had this. Without the diagnosis, they wouldn't have had those options and therefore they didn't have that option of life, of choosing life. It makes your heart break for all of those people who didn't have that option and just thank God that you have now and that other women hopefully do. This is an awareness month, isn't it?

AO

Yes.

CB

I know that you're very active with your Instagram page. You're committed to raising awareness. What have you seen in terms of awareness over the last… Since you set up your Instagram page, for example?

AO

Well, yes. I think what's really opened my eyes through joining and sharing and connecting with a lot of people through Instagram about things like PMDD… Firstly, everyone is so brave for sharing their story and so courageous for wanting other people to feel less alone.

Because I think that's what… Myself included, when you live with PMDD and then you get a diagnosis and you realise it's not you, you're not just going crazy every single month… A lot of people get misdiagnosed as well with bipolar or severe mood disorders or… There's a lot of misdiagnosis that goes on, like with any chronic illness.

00:25:45

I feel like people then become… A lot of people become very passionate about raising awareness. I think without everybody sharing their story, without everybody trying to get it in the media, it would still be this quiet subject. I just think everyone that… I'm just always so in awe of everybody that's wanting to share their story and try and raise awareness because it's so important.

And there's amazing… I will just signpost people to one amazing charity. It's IAPMD. I'll put them in the comments below after this, but there's incredible people out there doing incredible work and I think… Around raising awareness. Because the statistics is… I think I read it earlier that it was like, 5.5% of women or AFAB people are living with PMDD.

But in my opinion… Again, I'm not a medic, but in my opinion, I think it will be more because so many people, again, suffer in silence because of all the shame and also there's a lot of history within medicine of labelling women as hysterical or pathologising women's health in a really messed-up way. I think people are scared to go and get help because they might reach out to a doctor and then just get dismissed and then that's the last time they try.

So I think it's so important, people sharing their story, and that's what I love seeing every time the awareness month comes around. It's like, oh, I didn't realise they had PMDD, or whatever. I just love it when people talk about it because that's what's needed.

00:27:31

CB

I'm so pleased that we've... Hidden Disabilities Sunflower has... We've done the bit on endometriosis on the podcast as well in the past and that was so interesting, so enlightening. One of my colleagues said that she had lived with it for years and I didn't know that and what pain she had been in. It's really interesting and I'm really pleased that we're highlighting women's health in this way. You mentioned charities. We're going to be talking to the Menstrual Health Project as well.

AO

They're great.

CB

Yes. They're doing such great stuff. It does seem to be... It's people who have these really traumatic experiences. Because of the link with endometriosis and the other condition that you said, which... I have to be honest, I haven't heard of that, so that's one for another chat, another time. That has propelled you and others to be like, let's create a community and let's really raise awareness of this and get it more out into the public's awareness and knowledge so that actually you don't just say, it's just part of having a period, dear, just have some paracetamol.

AO

Yes, and also I think people say, PMDD awareness is saving lives and it's suicide prevention, and I could not agree more. As soon as you... I think you can suffer so greatly and then, when you have an understanding, a scientific understanding of what is going on in your body, it just naturally helps you have a bit more self-compassion.

00:29:15

It doesn't take away the symptoms. They're still just as strong. But I think that it helps you just have a bit of kindness towards yourself when you're in that state. The state is no less strong, but it just helps you be aware that it's not just you.

CB

Really interesting. We've done half an hour already.

AO

Have we?

CB

Yes. We wasn't going to keep you too long and too late because health is wealth. So we won't stay on for too much longer, but I just wanted to ask you a little bit about the implant that they're going to do, the oestrogen. That sounds really interesting and innovative.

AO

Yes. Funnily enough, I don't actually know heaps about it because it's a new thing that I… Yes. It's kind of happened recently, but there's a whole saga. Basically, it was taken off the shelves. Now it's back on the shelves. It caused a right havoc amongst the menopause community, particularly surgical menopause, because it's a very common issue that you cannot absorb as much oestrogen as you need, particularly oestrogen, in surgical menopause because we need such higher doses than people in regular menopause or perimenopause.

So the implant essentially will give you… It lasts for months. Everybody's different. It can wear off sooner for some people. But it essentially gives you a higher dose kind of in a safer and a much easier way. But it's a postcode lottery. So with HRT… This is a whole conversation, but it's a bit of a postcode lottery. So we don't do it in Bristol where I live, but I thankfully have been referred to London.

00:31:04

VO

You are listening to The Sunflower Conversations. Remember to hit subscribe.

CB

What would you like to leave this Instagram Live with your final message?

AO

It's to trust your instinct and trust your body and your knowledge of your own body because when… There might be people listening to this like, I kind of resonate with that. Don't dismiss that kind of instinctive thought and curiosity and don't be put off by doctors who don't even know what it is or doctors who tell you it's not that or… It can be a hard road to try and get a diagnosis, to try and find treatment that helps, but there is hope out there.

I know I've had my ovaries removed, but that's not necessarily what everybody needs to do at all. We haven't talked about it, but there's a lot of things that you can do to help. For a while, they did help me. Some things didn't. Some people find so much benefit from the lots of different things that are available. The surgical route is the last-line treatment and unfortunately that's what I had to do, but I don't want to put people off. There's a lot of help out there and you don't have to just go and get your ovaries removed.

CB

So this is good to know. There's kind of a ladder. There are lots of options to try. Keep researching. Go in prepared to your healthcare practitioner. Tap into the different communities, the community that you've created through your Instagram account, the Menstrual Health Project, the other charity that you spoke about. There are different ones around doing lots of really good work and sharing best practice as well.

00:32:54

So have some faith that hopefully there will be a solution that will be the right one for you as an individual. We are all different and our bodies work differently. We're not machines as such.

AO

And I think also… 100% and I think also just reminding yourself that you deserve support… I wish I could have said that to myself years ago. So I feel like this is a note to everybody that you deserve support. You don't have to suffer in silence. It just makes things worse. And not to put pressure on people, but it does. The isolation makes things worse. It exacerbates what's already going on.

I think there is a lot more support… The charity I'll put at the bottom of this afterwards, but the IAPMD… They have so many resources for trying to get a diagnosis from your doctor. Just quickly to say about that, the way that… There's no blood test to test for PMDD unfortunately, but the way to do it is through cycling… Tracking your cycle and your mood.

CB [Overtalking]

AO

So there's a lot of resources out there to help you get the diagnosis that you need to get the medication or the supplements or the alternative therapies or whatever it is. Some people self-diagnose and that's enough for them, but for me, I needed more medical support. So everybody is so different and don't let anybody tell you it's just PMS.

00:34:30

CB

What do you think of the Hidden Disabilities Sunflower?

AO

I love it so much. I have it always in my bag wherever I go. I don't leave the house without it. What I find is, I'm not always necessarily wearing it, but I love having it there to wear when I need, if that makes sense. It just gives me that comfort blanket when I have to go anywhere, whether it's an appointment or... I don't travel because of my health, but if I was to, oh my gosh, I would not be able to do that without that.

Also I love the solidarity that when I see somebody else wearing one, it's like a little nod. You know how motorcyclists drive past each other and nod at each other? I feel like it's... Or bus drivers wave at each other or whatever. It's the same thing for me. When I see somebody else wearing one, I always want to go and high-five them and say hello.

CB

That's really satisfying, to hear that, for us to know that that's the emotion that it leaves you with. We do hear that from other Sunflower-wearers, that it's like a little secret community with one another. It just is that... The comfort blanket is a lovely analogy. I love that.

AO

Yes. If anybody does want to message me with any questions or with any anything, reach out. You're welcome. Thank you for chatting.

00:35:52

CB

No. It's been brilliant. It's been lovely. We will keep in touch and we're here to support the PMDD community and, yes, help raise awareness in any way that we can.

AO

We need to get you to have a card. Do you have one yet?

CB

No, but we can work together on that.

AO

We could work together on that. That would be great.

CB

Yes. Watch this space, everybody.

AO

Take care. Thank you so much.

CB

You're very welcome. Thank you and thanks to everybody for joining.

AO

Thanks, everyone.

VO

If you are concerned about any of the topics covered in this podcast, please follow up with your healthcare practitioner.

If you enjoyed this podcast please share it. Leave a rate and review to help raise awareness of hidden disabilities and the Hidden Disabilities Sunflower. You can also follow and subscribe to the Sunflower Conversations podcast.

If you'd like to share your Sunflower story or conversation, please email conversations@hiddendisabilitiesstore.com. Find out more about us or listen to this recording again by checking out our Insights page at hiddendisabilitiesstore.com. You can also find us on Facebook, Instagram, Twitter, YouTube, and LinkedIn. Please help, have patience, and show kindness to others. And join us again soon, making the invisible visible with the Hidden Disabilities Sunflower.

00:37:03