



Brooke M. Faught

Persistent genital arousal disorder: The uninvited guest (Part 2)*

By Brooke M. Faught, MSN, WHNP-BC, IF

Healthcare providers (HCPs) need to understand a patient's experience of a health condition in order to provide effective care in a holistic manner. This recommendation is especially important in cases of elusive health conditions that may be unfamiliar to most patients and even to some HCPs. In Part 1 of this two-part series, readers learned that persistent genital arousal disorder (PGAD) involves unwanted, unwarranted, persistent symptoms of genital arousal that frequently border on pain. In many cases, these symptoms are debilitating. In part 2 of this series, two women share their personal experiences with PGAD. Two additional accounts of PGAD are available [here](#)^A.



*The patients who have related their experiences with PGAD have provided their consent to have their stories published in *Women's Healthcare: A Clinical Journal for NPs*.

Patient story 1

I am 36 now and have had PGAD for about 10 years. My symptoms started after a traumatic experience of having a Pap smear that was very painful both during the test and for some time afterward. To me, it seemed too much of a coincidence that my symptoms started right after this experience.

The first symptom I had was what seemed like an oversensitivity in my vulval area. At first, I didn't think much of it, really, because it didn't happen all the time. When the strange unwanted symptoms kept coming back, I decided to see a doctor. I saw a few GPs who just brushed it off as a *woman's problem*. Eventually, I managed to get a referral to the women's unit in our local hospital. There, the consultant diagnosed me with VIN [vulvar intraepithelial neoplasia]. I was treated with meds to clear it and needed to keep returning to have it checked to make sure that it wasn't getting worse. It took many years for the VIN to clear up. Once it cleared up, the unwanted arousal symptoms were not only still there, but worse.

I was prescribed Lyrica (pregabalin), codeine, and EMLA cream (lidocaine/prilocaine) to help lessen the symptoms. The meds helped quite a bit, but not enough. The doctors eventually diagnosed me with vulvodynia, basically a term that they use for any type of vulval pain—even if something else is really wrong. To me, the doctors were just being lazy; I felt that they just couldn't be bothered to do more work to find out what was really causing my symptoms.

I told them about PGAD, and they eventually listened to me. Over the years, they tried me on lidocaine, which worked well a lot of the time. I also tried gabapentin, but it stopped working after a short while so they took me off it and just upped my dose of Lyrica. I went to the pain clinic, but all they did was send me back to my consultant after telling me to try injections and if they didn't work, to return for a nerve block. They also reduced my dose of Lyrica. Apparently, the dose I'd been put on was higher than the company recommends, which scared me. But it's not uncommon in my country (Wales) for medical people to mess up patients' meds.

I tried the injections, and they worked for only a day and a half, maybe 2 days, and that was it. So I returned to my consultant to get a referral for a nerve block. At that time, I was pregnant with my second cute little babba, so understandably they couldn't do anything whilst I was pregnant and said I was to return after I had given birth, so I did. Now I am waiting on my appointment with the pain clinic and hoping that they will do a nerve block.

Having PGAD does get me down at times and I just wish there was a cure for it. I've said countless times to doctors that I would love to be numb down there.

Over the years I have tried ice packs, which at first worked but now do not. The feeling in my clitoris is still there, even with the ice packs. It is like there is something hard under the skin, so I don't use ice packs now. However, hot water bottles just under the top of my bum when I'm lying down seem to help. Warm baths help too—whether or not it's because they are relaxing I do not know, but I think that may be a factor because when I am stressed, that causes me to flare. The one thing that helps me when I'm having a really bad flare is to have a nap.

The med I take for my PGAD is Lyrica, which I find really helps. If I miss a dose, I know about it. I take codeine to help dull the horrible arousal feeling. It helps too. I also use EMLA cream and lidocaine cream on the vulval area, the clitoral area, and sometimes the vaginal area. I also use it on the knicker line area. For some reason, I get the horrible feeling there at times, which causes me to flare.

I have slight incontinence and when I go out I need to wear pads. Unfortunately, the pads sometimes trigger flares. What I do to lessen the flares is to put on one pair of knickers and then a second pair with the pad on, which lessens the arousal feeling. It makes me wonder if there's some kind of chemical in the pads. When we go out, if I'm having a flaring day, it's hard if my pads are irritating the area and I often have to apply creams. It would be nice to just be able to not have to go through all that. I also find I can't wear jeans. Before going out, I've tried on a pair of jeans, only to find the seams caused a flare to start. A lot of the time, I just wear loose bottoms or skirts.

For me, when I get a bad flare, it starts with an unwanted feeling like there's something on my skin that I don't want there. It makes me tense and my body clench up. Then I get the overtaking pushing feeling, which makes me leak urine, which is humiliating. It truly is the worst pain/feeling ever. I've had a broken bone before, and I have given birth twice, once without any pain relief. These pains were so much easier to deal with than a PGAD flare.

I feel the arousal mainly in my clitoral area and to either side of this area mainly, but a lot of the time in my vulval area too. The way I have described it is it feels like there are bugs crawling slowly under my skin, an irritating feeling. Sometimes I get a swollen type of feeling just under the skin under my clitoris and to the sides in my vulva. It's almost like instead of my pelvic floor muscles being tensed up, they feel like I am pushing out, still tensed, if that makes sense.

Sometimes even the light touch of my knickers make my symptoms worse, so I find tight knickers are better on me than anything loose. Any light touch in the area goes

through me. The strange thing is sometimes tight jeans can cause a flare, but I think that's probably due to the seams. A lot of seams in trousers never seem to be sewn flat down.

Unfortunately, PGAD has affected my sex life, but luckily I have a very understanding husband. I would say this condition definitely affects my day-to-day life: having to apply EMLA cream every day to dull the symptoms, using pads when I go out, and often using cream to dull a flare caused by the pads. Sometimes I have to go and reapply the cream if the first dose doesn't work as much as I need, and it's a major inconvenience. I just wish doctors would do something instead of saying they are running out of ideas.

Having PGAD does get me down at times and I just wish there was a cure for it. I've said countless times to doctors that I would love to be numb down there.

At the moment, the consultants I've seen say they don't know what more they can do. I would love to get a referral to England because I believe there are specialists there who would be able to help me more, but the health service in Wales seems to hate doing that. At the moment, I am hoping the pain clinic will help. I've also been referred to the physio for help with the incontinence so I don't have to wear the pads. I don't know how well this will work. Sometimes when I have tried Kegels, it has set off a flare.

I want healthcare professionals to do more research into this debilitating condition, into different treatments that have been used worldwide, and to get more funding. Right now in the U.K., it feels like anything to do with genital pain/discomfort is treated as a joke, which in this day and age is unacceptable.

Patient story 2

I am a 36-year-old Canadian mother of two young chil-

dren. I was 32 when I got PGAD from an SSRI drug here in Canada. I only went on the drug because I was having sleep issues caused from anxiety over my child's health issues. When I started the drug, within 3 days I started to notice a weird pulsation—almost like a twitch—in my vagina. I was concerned but felt that maybe I was getting a bladder infection so I went to the doctor, who told me I did not have a bladder infection. I decided the only thing I had done differently since getting the weird vaginal symptom was start the SSRI. So I discontinued it after being on it for 10 days total.

This is when it all got worse. I started to get horrible arousal sensations and the twitching continued and was really bad. I also had restless legs sensations and a very overactive bladder. It was awful. It was like a switch was flicked to full on in my spine and affecting my bladder, vagina, and legs. I then went to my family doctor because I couldn't sleep; the sensations were constant. He told me he thought it was *pudendal neuralgia*, even though I told him it only started after the drug. He then put me on gabapentin and clonazepam, and over the span of 2 years, it calmed down.

PGAD has destroyed many aspects of my life. I was diagnosed with PTSD from the whole PGAD ordeal because it was so scary and unknown.

I decided to go off the medications and my PGAD has remained calm. Also during this time, I saw a vascular surgeon who treated me for pelvic congestion syndrome. I don't think it helped too much. (I have an identical twin with pelvic congestion syndrome, and she does not have any PGAD symptoms.) I had an MRI done, which showed I also have two Tarlov cysts as well as sacral joint dysfunction and inflammation. My symptoms in the beginning were very traumatic and bothersome. Four years later, they are mostly mild, but I still have some flares with it, usually if I sit too much or if I get a bladder infection. I

avoid anything that messes with serotonin or dopamine because I feel this is why I have PGAD. I believe I have some type of dopamine and serotonin dysregulation in my brain from the SSRI.

PGAD has affected my daily living to the point where it makes sleep difficult. I had to find a job where I could stand instead of sit; sitting too long can make the PGAD worse. PGAD has also affected my marriage. My husband does not understand that it affects every aspect of my daily living. It has added to our marital breakdown and we rarely have any intimate relations because of it. PGAD has destroyed many aspects of my life. I was diagnosed with PTSD from the whole PGAD ordeal because it was so scary and unknown.

The worst part of PGAD was not PGAD itself; it was the feeling of hopelessness. I went to my family doctor, who refused to believe that the SSRI caused this and was mean and very dismissive. He refused to order the necessary tests and just said it was pudendal neuralgia—even though I had only PGAD and no other pudendal neuralgia symptoms. I know it was the drug and what I want all doctors and the public to know is that these drugs can and do cause PGAD and it is permanent. I will never be cured because the damage to my brain is done. But I have managed to survive it and help make it mild. First, I stay away from all medications if possible. I take only natural things for symptom relief such as chamomile, magnesium, and valerian root. I also use a TENS machine and get pelvic floor physiotherapy.

My hope is that someday PGAD will be better known and there will be effective mainstream treatment for it. I wish that doctors will be more knowledgeable about it and help their patients who come to them with PGAD from any of the known triggers. Until then, I continue to persevere and cope the best I can and help others who also suffer from PGAD. Thanks for reading my story. ●

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Web resource

A. npwomenshealthcare.com/?p=5841