

PMDD with Anna Cooper and Rebecca Tomlinson

Speaker Key:

CB Chantal Boyle

AC Anna Cooper

RT Rebecca Tomlinson

VO Voice Over

VO

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

00:00:20

CB

For people who've just joined, let me introduce our guests tonight. We have Anna, who is the co-founder of the Menstrual Health Project with Gabby, and I will let Anna talk little bit about that in a moment, and then we also have Rebecca, who is a general practitioner, and she has a passion for women's health and those assigned female at birth. I just want to say, from the outset, whenever I'm referring to women's health during this conversation, it's also those assigned female at birth.

So, yes, Rebecca sits on the Medical Advisory Board for the Menstrual Health Project and, as I say, has a passion for women's health, including PMDD, also doing menopause, endometriosis, so she's very, very knowledgeable. So thank you, both, for joining. So, we've got PMDD, we've got PMS, and we have PMT. So, Rebecca?

00:01:24

RT

PMS and PMT, that's just interchangeable, so it's premenstrual syndrome or premenstrual tension. PMDD is premenstrual dysphoric disorder, and that is actually under the category of a mental health condition, so that's more significant and moves to be needing a more warranted, detailed treatment option.

CB

Thank you. Anna, can you please just give us a little overview about the Menstrual Health Project, for those people who are joining?

AC

Yes. Hi, guys. I'm Anna. I'm co-founder of Menstrual Health Project. We are a UK-wide charity who focuses on supporting women and those assigned female at birth with any kind of menstrual health condition, and women's health in general, really.

We focus on education as a core aspect of our charity, because education is really lacking in all areas of menstrual health and menstrual health education, and it varies across the board, so we focus on creating toolkits, educational tool kits, that are easily accessible, easily readable and people can access them at any point.

And they're now seen across loads of different GP practices across the UK. They're with school nurses, teachers and individuals as well. So you can access them on our website, free-downloadable, and it's user-friendly, so phone, iPad, website, whatever you want to download it on, or you can email us and request a physical copy, because we do send them out to you.

But our main aim is to reduce the stigma surrounding talking about your menstrual health and conditions that are linked to that. For both me and Gabs, who are the co-founders, we both suffered with endometriosis, adenomyosis, PCOS between us, so it's been a journey, and we found so many issues facing and accessing healthcare, so that's why we wanted to do more, more of our advocacy work, and that led to the Menstrual Health Project.

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And now we have a team of 20, including trustees, volunteers and Medical Advisory Board members, like our lovely Rebecca. And it's incredible, but it just shows you how needed it is this space within healthcare.

CB

Absolutely, definitely, you've grown so rapidly. The amount of people, it shows you there's a clear and direct need for the service you're providing, there's a huge gap in the healthcare market.

AC

Yes, definitely.

CB

Rebecca, I'm going to start with you with the questions that have been sent over

to us ahead of this recording this evening. So, the first question, and it seems a very sensible and obvious question, is what are the common symptoms of PMDD, please?

RT

I think if we're talking about PMDD, we've also got to put PMS or PMT in there. Your premenstrual syndrome or tension is those symptoms that the majority of us will probably get just a couple of days before our period, where you want to eat everything in the fridge, snappy, And we generally manage that, our periods come and everything settles down.

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PMDD is a lot more significant and a lot more impactful. So it can be those symptoms, but generally they are symptoms that are more severe, more impactful on mental health, on physical health, and also longer lasting. So we've got really that gap in the window from day 14 of our cycle, where we're ovulating, to the point of when our period starts, and so PMDD can actually affect women for two weeks or even longer.

And the classification of PMDD, why it differs from PMT, is it has to be five or more impactful symptoms. So that can be mental health symptoms such as very low mood, even to the point of suicidal ideation. There can be eating disorder symptoms. There can be a lot of physical pain and things like that. But generally five or more impactful symptoms that are affecting you on a cyclical basis. So it has to be [inaudible] kind of diagnosis.

And with those factors, then we can look, as clinicians, to say, well, yes, this sounds more like PMDD, and that will bring about a different set of treatment options for us.

CB

Okay. And just out of interest, I know that there's the mental health impact, but I'm recalling back to when I used to have heavier periods, when I was younger, when I was really young, the pain in my stomach was really intense. Is there increased sense of pain with PMDD or not?

RT

There doesn't have to be but obviously, as Anna knows, there's a lot of crossover with all of these things. We do have women who will be suffering with heavy menstrual periods, people with PCOS, people with endometriosis, and generally your symptoms will feel more impactful than others. So yes, definitely for these ladies will be a big feature as well. Some ladies will experience ovulatory pain, so they can tell you at the point of ovulation, very significant [?].

00:07:36

So it's really for women to document, and I think this is a thing that the Menstrual Health Project really champions, just monitoring your symptoms, recording them all for your clinician, so you can go with that list and say, these are the symptoms I'm having.

Because everybody's going to be different. Some people won't have problematic periods, they will just have the mental health symptoms. Some will have other things. But it's that impact over a longer period of time, a cyclical impact, and also to the point that it's really affecting their relationships, affecting their work. Things like that are really important to note, so that we, as clinicians, can go, ah, we need to sit up and listen to these ladies.

CB

The Menstrual Health Project, do you actually provide tools to help track cycles?

AC

Yes, both our toolkits. Our first toolkit released was the endometriosis diagnostic toolkit, but it does briefly go into other conditions that can be linked to painful, erratic, heavy periods, but also the mental well-being symptoms that you can experience whilst on your period, and just during your menstrual cycle in general.

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But one of the biggest things I think both me and Gabs, when we were talking to clinicians, was one thing we were never taught, and unfortunately it's still not taught, is how to track your menstrual cycle. And often, most of the time people only tend to start tracking their cycle when they're trying for a baby, or when there's something they've noticed has gone wrong, that they then think, actually I need to do this off my own back.

Where actually, we're not advising people from a young age to be... Even if there are no issues at all, it's always really important to know what's going on with your body, and the only way to think how you're feeling is by looking at something that you've written down and tracked.

And that, as I'm sure Rebecca will say, is incredibly important when you're accessing help from your doctor, because that's the first thing your doctor will say, what does a normal month look like for yourself? And if you haven't got that written down, it's really easy to forget. And I used to forget a lot.

One thing for us that's really important is in each of our toolkits, our second one is a menstrual health toolkit for under-18s, and it's got all about tracking your cycle. And the difference between the trackers in the two toolkits is the endometriosis diagnostic toolkit is a bit more adult-focused, whereas the under-18s one is easier language to understand, and also we've put mood trackers in there, and we use that as emojis, which is really easy to explain how you're feeling.

And I think that's so important for conditions like PMDD, because, like Rebecca was saying, there's both mental and physical symptoms for some people, but sometimes there's only the mental well-being symptoms that they're experiencing. So I think tracking periods is absolutely key, and tracking your cycle in general, not just while you're bleeding.

00:11:00

CB

That's an important element, when you're feeling great to make a note of that as well.

RT

Yes, it definitely is, and it's just because, as clinicians, your GP will be seeing a vast range of diagnoses in a day, and you may not have got your appointment with somebody who is women's health-focused. And so you go in with just the mental health symptoms, then if their brain is not thinking, oh, this could be PMDD, then you're going to go down the more antidepressant route.

And there are good reasons why that may be an appropriate treatment option, but if you go, here are my cycle, here's my mood, there seems to be a link, then that switch will be turned on in your GP's head to go, actually, okay, we know which way we need to look. And if they're not confident, they'll say, hopefully, I know which GP you need to speak to about this.

CB

If you're interested in any of the advice discussed in this podcast, please follow up with your GP or healthcare practitioner.

AC

It's often overlooked, isn't it, I think, because it often coincides with that person's got anxiety or that person's got depression, and doesn't really always look at the full picture. And I think that's when, for us as a charity, I think teaching people as young as possible to track their menstrual cycles is incredibly important.

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Because it gives you so much information about what's going on with your body, and I think it's key for trying to access health and support in whichever form that is, whether that is for conditions like PMDD or endometriosis or fibroids. Any of these conditions, it's so important.

RT

Yes, definitely.

CB

So do yourself a favour, get ahead of the game, start tracking today.

AC

When you speak to people who've been suffering with PMDD and continue to suffer, they didn't always put two and two together, initially. And I think that's down to the lack of education, the lack of knowledge that we've had about these conditions. I could say the same about endometriosis. I had no idea I had any of those symptoms before I had it, and I think it's very similar for people with PMDD. They often think and almost blame themselves as to how they're feeling, the way they're feeling.

And I think tracking your symptoms and tracking your cycle in general just validates how you're feeling and validates and gives that validity for when you're going to the GP and saying, look, here it is, in black and white, this is how I've been suffering.

CB

Yes, we will move on to the next question, but I just wanted to say that I think the validation is a really good point that you raise quite simply because traditionally someone is having a moment, shall we say, then the standard response has traditionally been, are you on your period? Are you on your period?

00:14:16

AC

Exactly, yes.

CB

So actually, let's get tracking. Let's get tracking.

AC

Exactly.

CB

So the next question you have already answered but I just want to see if you've got any more to add to it.

Somebody asked what's the tipping point between PMS and PMDD. You said five symptoms?

RT

Yes, it's going to be different for everybody, and if you do struggle with PMT it

does not necessarily mean that you will end up with PMDD. There are a lot of factors at play, but interestingly what we do know is that the PMT symptoms, moving into a PMDD is a lot more prominent for women who are entering the perimenopause.

And so the numbers peak at that point, and they go up because, obviously, with the perimenopause, those ladies, between probably 40 and 50, suddenly having very erratic hormone spikes, and that really just highlights those mood changes. And so again, we need to be incredibly focused on that group of women specifically.

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And I think that's the part of the medicine that we obviously have been missing, because I would say up to five years ago the perimenopause and PMDD were very poorly known about. So it's an area that we haven't really trained in. I definitely didn't train and learn about it until recently, and that's me just doing extra training. So it's really lovely that now it's talked about and discussed, and actually we are learning more and more about it each year.

AC

When we went to an event, they were saying 90% of clinical psychologists didn't recognise PMDD as a condition that impacted people's well-being, mental health. Now, it's being spoken about and there's more research being done. Having said that, a lot more needs to go behind it, as with a lot of things with women's health, but it's being spoken about, which is the main thing. And I think Lives and things like this and continuing to raise awareness is the only way things will improve for women suffering with PMDD.

CB

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RT

As I said, with PMDD it is impactful, and it's impactful on all parts of your world. And so it's really with understanding and getting support, is it going to be less impactful for you? But obviously you have women who are going to be struggling in the workplace and struggling in relationships, because a lot of these cases, if you don't know what's going on with yourself, it's going to be very difficult to tell anybody else.

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And as you said, it's that very derogatory comment of, oh, it's that time of the month, it is? All your work colleagues going, I'd stay away from here because I

think it's that time. And so you can feel very isolated at work, and you can also feel very separated from your partner. You're snapping at your children.

I have women coming to me and they just go I can feel it coming out of my mouth, I can feel the anger and the intolerance, I cannot stop it. And then they've just obviously beaten themselves up about it, and so you get these women who are just in tears, sobbing their hearts out because they're not who they want to be, but they can't figure out a way to stop it.

So it's really understanding, is this something that the GP can help with? There are a lot of things we can offer if you didn't want to try medication, there's a lot of CBT, supplements. There are some supplements out there that can be very supportive. But your doctor also has a lot of things that they can offer as well.

CB

Okay, that's good to know that there are, because the next question actually is will the symptoms ever get better on their own? Will they lessen, will they become less severe, and would it ever just fix itself, without treatment?

RT

A lot of the time, what you will find is, with the hormones, once menopause comes and goes and your hormones are quietened down by that, then that's when your symptoms will settle down, because obviously it's your internal hormones that are being very chaotic and are causing this dysregulation of everything.

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So that is why, if you look at the treatment options, it is really hormonal control, so be that with contraception, be that with an HRT regime. And some women even go to be put into a medical menopause, even a surgical menopause, because their symptoms are so severe. So there is this range of women that we need to be supporting.

CB

Is it a lack of oestrogen, or is it more complicated than that?

RT

No, because it's more of a dysregulation of the peaks and troughs. You'll see these nice, normal curves of a normal cycle, where everything's going up and down in line, and with this peaking, this is making you ovulate. But what happens during perimenopause, which is more worse, is that's all erratic. You peak high, you drop low, and everything goes very erratic and irregular, so there's no rhyme or reason as to why that is.

So it's not so much a drop, because once your oestrogen's dropped at the

menopause, which is where your oestrogen's at the lowest, that's where your symptoms will settle. It's just a more erratic wave of hormones.

CB

Right, okay, so there is some hope. And the other thing is, I asked Amani this last week, about, for her, when did it start, so does it start generally as soon as people start to have periods, or can that vary very much from person to person?

RT

It's very variable. Just some statistics that were in the recent Welsh conference, between the ages of 35 and 45, about 40%, first of all, have PMT, PMS.

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CB

Was that 35 and 45?

RT

40% of 35 to 45-year-olds have PMS. Then, you've got 24% having a more significant PMS, with about 5% to 8% of women in that age category having PMDD. But that rises, the PMDD rises, from up to 8% to 23% in your perimenopausal women. But these things can start at the point you start your periods, and that's why it's really important for young women to be involved in this conversation as well.

Because if we're just saying, oh well, it's for perimenopause, you've got this group, for 20 years, of these women having periods and going, it can't be me because I'm not that age. But actually, these can affect women of all ages, so it's really important to just be aware of what could be happening with your menstrual health and what's happening with your mood, and seek advice if you're really struggling.

CB

Yes, good hormone health or awareness. I'm just going to look through because I think there was another question, I'm not entirely sure. My brother's girlfriend's got... I think it's polycystic ovaries. She's a nurse and she's had a child, and she wants another one. What options are available to her? I guess, first of all, polycystic ovaries, what is that?

RT

Polycystic ovaries is different from PMDD, it's different from endometriosis, but it's where instead of there just being one follicle being created on a monthly basis, the ovary can be covered with multiple follicles, and those eggs are being produced at different, variable rates, so you can have very erratic periods, so you

might not have any bleeds for months, and then you'll have bleeds every couple of weeks.

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So it makes it very hard for women who are trying to conceive with polycystic ovaries to know where the norm is, whether they're ovulating. Because sometimes they will ovulate but it won't be a viable egg.

For those ladies, it is really getting support earlier rather than later, because it's difficult but there are medications that the specialists can use to try and regulate the cycles. There are things like weight loss, which is always a useful tip as well, because unfortunately polycystic ovarian syndrome and weight gain are interlinked, and research has shown that trying to get weight down can be really helpful.

But I think if you're trying to conceive with polycystic ovaries, and you haven't been able to and you've tried all the normal ways of trying to conceive, it's going to a clinician and probably being referred, sooner rather than later, to the fertility team, just to get some added extra support.

CB

Okay, thank you very much, Rebecca. And the charity also supports people with that, do they?

RT

All menstrual health conditions, yes. Any menstrual health condition or concern, so pre-diagnosis, during, post. Post-menopause even. I think it's really important that it's from puberty to beyond menopause, because often people think everything stops when you get to menopause, and it most definitely does not. So yes, we support everybody in the best way we can, and we will always try and signpost to further resources if we don't have them under our charity.

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CB

Yes, I think that's actually quite an important point to note for everybody, really, that it doesn't necessarily stop once you're going through the menopause.

AC

No. I'm living proof of that, because I had surgical menopause nearly three years ago, so it doesn't unfortunately stop. And menopause in itself can be really challenging, and I think it's not the answer. I think a lot of people with menstrual health conditions and concerns, and I've heard it from people who suffer with PMDD as well, where they go, oh, but when you have a baby, things will settle, or have a hysterectomy and you'll be fine. These things don't come without their

consequences. And I think nothing is an easy answer or a straight answer when it comes to these conditions.

RT

There is never one-size-fits-all.

AC

No.

RT

And so that's why it is really important to just know that they may not get the right treatment first, so don't give up really, knowing what options you've got. But there is a vast range of options. Just listening, getting the support and just trying things. And there may be things that work fantastically well, and there may be things that actually don't work at all. But it's all trial and error, unfortunately.

00:26:58

AC

Yes, and I think one thing just to add on that is to never compare. Don't ever compare to somebody else that you may have seen online during their journey, or a friend or family member gone through similar. It is individual to you about what you're going through. So just because one treatment option or one medication didn't work for you but worked for somebody else, don't beat yourself up for the fact that it hasn't worked for you. It's not your fault, it's just you need to find your rhythm of what works for you.

And I think that was something, during my journey, I used to do quite a lot. Why's it not working for me but it's working for somebody else? And comparison is the devil, so I think we need to just be gentle on ourselves and figure out what's best for us and not feel guilty for that.

CB

So have you created a community for people to come together to share their experiences? How does it work?

AC

Yes, we, as a charity, don't do support groups online at the moment, but we do do a lot of events where people come to our events, and also our emails and our direct messages are always open for people to share their journeys. And if they're then happy for us to share on our platform, we then go and share it on our platform, because a lot of people find it really therapeutic to actually share what they're going through, and it gives them access to a community that they didn't know was out there.

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And actually the women's health space is incredible and there are so many people out there sharing their journeys, and equally wanting support themselves, but also wanting to help other people by sharing their journey. And ultimately that's how me and Gabs started doing what we do. We advocated online, just by opening up as a virtual diary online of what we were going through. And we quickly realised there's an incredible community out there.

So yes, through Menstrual Health Project there's nothing we like more than connecting people with other people and sharing people's journeys and what they've gone through. Because it's really important to give people the voice that they need so that they know they've been heard.

CB

Absolutely, definitely. There's a comment there, we are strong, together we are strong.

AC

Yes, we are. I think it's so important that by sharing your story, that isn't giving in to weakness or making you seen as any weaker than you think you are. I think by sharing somebody's story, it gives you so much strength. And I think, for me, it's about empowering people to know their bodies and to advocate for themselves and know what their worth is and to know what they're entitled to.

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I think that's the most important thing, like Rebecca was saying, they don't always get it right the first time on trying to access healthcare. And that isn't their fault, necessarily, it can be a lack of education and a lack of knowledge that they just haven't received.

But that doesn't mean that you should suffer in silence, and I think that's where we come in to give people that voice to keep trying, and to keep trying to access the care that they deserve, so they have answers. Because no one should have to suffer with symptoms that make them struggle, day to day, without knowing what's causing it. Because when you know what's causing it, that's when you can really try and take control of your life and how to manage it.

CB

Listening to the challenges, and you've used the word struggle quite a lot throughout this conversation, and when you consider it's mental health as well, the fact that you and Gabby have been able to create what you've created is just brilliant, to support and give a voice and platform to so many other people. You should be so proud of yourselves, to start off with, of course, but then...

AC

Thank you. No, we do. I think we couldn't do it without our team. Rebecca is one of our team, and we're just a team of people who are incredibly passionate to improve things within the menstrual health space. I think that's the biggest take-away I've had of meeting everybody on our team, and then meeting incredible people as we do the work. We all have that same drive to improve things.

And the only way it will change is through education. Knowledge is power. As much as that can be cliché to say, knowledge genuinely is power. And I think the younger we give this education, the better. It can only be a positive for people to know what's right and what's wrong with their bodies, with knowing how they're feeling.

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Because for me, I think, even though I didn't suffer with PMDD, I can relate to a lot of the symptoms with going through endometriosis and struggling with anxiety. I do often think that I thought I was just going nuts when I was younger, because everybody was telling me I just needed to get on with it and get used to my period the way it was.

And I think I just want people to know if they're having any of the symptoms of any menstrual health condition that they have the right to keep fighting to have answers and to know what's going on with their bodies. Because there is nothing more lonely than not knowing what's going on with you, and you know something's not right but everybody's telling you you're okay.

And it's knowing, like Rebecca said, that there will be medical professionals out there that are there to help you and willing to help you, and it's just finding the right one for you.

RT

Yes. I always say on these platforms, as a GP, I know how difficult it is to get a GP appointment, but I would say if you're not aware of who you are best to talk to in the practice for these things, ask the receptionist. When you're speaking with the receptionist, say this is about my female health, which is the best doctor to see? And there will generally be somebody who's got the expertise in female health, and you have to prebook for them four weeks down the line, ensure that you are seeing the right person, because that can make the first contact a lot easier.

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Ask for a double appointment if it's a bookable face-to-face, say, look, I'm going to have a lot to talk about, and that just gives you and the GP either ten, 15, 20 minutes, however long their appointments are, that little bit of extra time so that you can talk through your problems.

And I think that's the most important thing, because when you're faced with the barrier of trying to get an appointment in the first place, and then you get somebody who you feel has dismissed your symptoms because they're not

confident in being able to answer the questions, I think then you just go away and go, leave it, I can't be bothered. But if you're speaking to somebody that's listening to you, I think it gives you a much better experience of medicine.

AC

I think women are very good at put-up-and-shut-up and ignoring how they're feeling. And I think it's important for people to know that they have every right to know what's going on with their bodies. And like Rebecca's saying about asking your receptionist about who is better to go to, another one I noticed recently is if your practice has a website, they tend to list the doctors and what they specialise in, or have specialist interests in.

So if you don't always want to ask the receptionist, because I know sometimes people have struggles with receptionists, websites are always a good thing because they tend to list them on there. So that's another good option.

00:35:38

CB

That is a very good idea, both of those, because I would never think to look at the website of the doctor. I just phone, and you obviously can then feel, as you said, frustrated. It takes you a lot to make that telephone call in the first place, and so, yes, that's...

AC

Telephone calls are difficult, sometimes. They can take a lot of brain power when you're struggling. The last thing I've wanted to do, I've done it with my whole menopause journey, is where I've had to pick up the phone and try and explain what I need and what I need help with. And you almost have to do that before you get to the GP, just so you know you're going to the right person. So I think sometimes that is an easier, more straightforward option. It's just something you don't always get those details with every practice. So it's worth checking.

CB

They are great top tips. I have to ask you, before we close, what do you think of the Hidden Disabilities Sunflower?

AC

I love it. Chantal, you know that I love it because I've used it for years now, especially travelling, I use it everywhere I go, if I'm flying, if I go by train I use it. And I even now use it when I go food shopping, because since I've had my last surgery I suffered with sepsis, I have real issues with weakness in my joints, and I'm just slower than I used to be, and I use it round shops so people understand that I might look fine, I might look healthy, but actually I just need a little bit of space and I just need that bit more understanding why I'm not moving as quickly

as I should be and things like that.

00:37:35

And I used to really struggle with getting out of my car in a disabled bay, because I've got a disability badge, but I used to get judged quite a lot. Whereas I feel if I have the lanyard on and I put my badge out, they don't really question me.

So for me, I'm a massive... And I know Gabs is because we both use it all the time. And it's actually something that we talk about in our presentations to schools and colleges, unis, workplaces, how to navigate chronic illness in general, not just in menstrual health but chronic illnesses. What are these little things that can help support you along the way? And the Hidden Disabilities Lanyard scheme is one of the biggest ones, alongside Radar Keys. I think it's such a helpful tool.

CB

We do hear very often of people who need to use the toilet but who are judged, but by having the Sunflower on, it seems to just stop people in their tracks and there's just, okay, there's something happening here. We did another interview with somebody, he had been in an explosion, he used to be in the army, and he had to have his leg amputated, so he had a prosthetic leg, but if you look at him, he's a big, burley guy, you can't see what's underneath the trousers.

And he'd say the same thing, when you pull into a disabled spot, the [inaudible] was really hard. And I don't know if you wouldn't mind just explaining, just briefly, what is it like to be on the receiving end of judgmental looks and stares?

00:39:25

AC

I'll be completely honest, I used to avoid parking in a disabled bay because I was petrified because, and it always sticks in my mind, I've had a couple of incidents. But one of the biggest ones was I'd parked, I'd plucked up the courage...

Because I used to park in a disabled bay if I had my husband, because I knew he'd always come to my defence if someone said anything, whereas sometimes, especially when you're poorly, you just do not have the energy to have to explain yourself. And nor should you have to. I think that's the biggest thing.

But I've had it where I got out of my car and this old gentleman turned round to me and said you can't possibly be disabled driving that car. And I said... I was only driving a Discovery Sport, it's not a monster truck [?], it was just a normal car.

And I had a long maxiskirt on and, at the time, I had a catheter and my leg bag, it went under my knee so it was quite long and it was summer, and I moved my skirt out the way because it dangled down so low and showed him my bag, and I said, you have no idea what's under my clothes. You don't know what I've been through.

And he didn't say anything, he didn't apologise, he just shuffled off, walked off. And in that moment, it absolutely destroys your confidence. It destroys it. And it also makes you feel like you almost question are you deserving of people's understanding. And you think, actually, no, everybody should just be compassionate and understanding.

00:41:14

And I, myself, would never judge anybody for using a disabled toilet, a disabled bay. They were banging on the door. They'd seen me go in and they were queuing up, and I'd gone in and my stomach bag had leaked everywhere. And they were banging on the door, saying we need to go. And then she muttered under her breath and went, she's not even disabled anyway.

And I opened the door and I was mid changing my stoma, I had poo all over my jeans, it was awful. And I said, will you just leave me alone? And I was like, floods of tears. And you shouldn't have to ever explain that to anybody. And I think that's one of the biggest life lessons I've taught my daughter, who's eight.

And she came up with the broken biscuit analogy. And she says why do people leave the broken biscuit? I was like, I don't know. And she said, because it's just as tasty, even if it's broken. And she turned round to me and she said, mummy, it's like you, you think you look different, but that doesn't make you any less of a person. And that is exactly it. Just because you have a hidden disability, it doesn't mean that you're any less worthy of anybody else's time or understanding or compassion.

And you do, you do grow a thick skin with being chronically ill, especially the younger that you are, because you get so much judgement of but you look fine. But actually, you don't know what I've gone through. You have no idea. And I think a part of MHP is making people understand that these conditions have such an impact on somebody's life. And actually just because they're linked to your menstrual health, they impact the whole body and can really go into every aspect of your life.

00:43:19

And we were talking earlier about PMDD impacting your work life and your relationships, and that's the side people don't see of what you have to deal with on top of judgement of when you're trying to just access things that you're entitled to access. Yes, it is difficult, it is really difficult. But I've learnt now, even Grace will turn round and say, well, that's a bit mean if somebody says something.

Because I think it's important to teach younger generations now, just because you might look different or have aspects of your life that are different... For me, when Grace was toilet training, I had a stoma bag so I didn't go to the toilet the same as her, but it's taught here that not everyone's the same. And that's absolutely fine. You don't want everyone to be the same.

And I think, yes, it's been a learning curve. And it's something that you don't actually get any support on navigating, I think. And I didn't realise the sort of mental torment that you go through with being chronically ill and being judged.

It can throw you back to if you've ever been gaslit and ignored in your medical world of trying to access diagnosis, when somebody judges you or passes comment on you using a disabled toilet or a disabled bay, it often throws you back to that point because you almost feel like you have to defend yourself and prove how ill you are.

00:45:12

CB

You wouldn't dream of going up to somebody in the non-disabled toilets and question them as to what were they planning on doing in there, show me what you're doing. The whole thing, when you break it down, is absolutely bonkers. And the broken biscuit theory, I'm going to use that, that is absolutely superb. Superb, that just describes it so well.

AC

Yes, definitely.

CB

That's what we want to do, we want the Sunflower to be in school, so you've got the guide for young people in schools, so that they can start being aware of their health, their menstrual health, from an early age, and the Sunflower is inclusion for everyone, so [overtalking] important.

AC

Yes.

CB

Thank you so much. Rebecca, do you have any closing thoughts that you want to share?

RT

No, I just think it's been really lovely to just talk about the subject, because, as I said, it's not so often talked about or understood, and I second Anna, if we could just get people talking, advocate for patients to be the voice but supporting me, as a clinician, supporting patients to be able to access us, and get the most out of consultations.

I think is the best thing because I know all GPs are all time-limited, but actually if we sit and listen to patients, they are telling us what we need to know. We learnt

that in medical school, consultation skills, [inaudible]. But yes, we just need to sit and listen and hopefully, with all the support now in the research and knowing about PMDD, we're going to be better prepared to give you the best options.

00:47:09

CB

Thank you. So, first of all, thank you to both of you, thank you so much for giving up your evening for this. And thank you to everybody who joined and took some time out of their evening, everyone who submitted questions. The Menstrual Health Project, it's the same name across all social media platforms, it's also on TikTok as well, so reach out to the charity, also their website, but we will include it in the show notes as well on the podcast.

AC

Thank you so much for having us.

RT

Definitely, thanks.

CB

If you're interested in any of the advice discussed in this podcast, please follow up with your GP or healthcare practitioner. If you enjoyed this podcast, please share it. Leave a rating and review to help raise awareness of non-visible disabilities and the Hidden Disabilities Sunflower. You can also follow and subscribe to the Sunflower Conversations podcast.

00:48:05

VO

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