

Learning about dilation...and about myself by Anna

Finding out about MRKH

I was diagnosed with MRKH at 20, although I knew I didn't have a uterus at 17 and had researched MRKH before I was diagnosed.

Relationships before Dilation

One thing to remember is you CAN have sex without penetration, and it can be just as pleasurable. Before I started to dilate, I was able to be intimate with partners in other ways. Being intimate starts with communication. I was clear with them about how far I would go and what I did and didn't feel comfortable with. They were comfortable with this – it was important that I spoke to them first.

Starting treatment

I decided to start dilation when I was 20. I was not in a relationship with anyone at the time, but I felt like it would give me confidence in future relationships. I'd found it difficult to discuss it with partners in the past, and I thought it was a good time to start. Also, being away at University for some of the time, it could be done more privately. The main reason for starting treatment was for myself and how I felt – Dilation was not for anyone else. It was so I know that when I meet someone, I can be as confident myself as they are.

Looking for a Medical Team that could Support Me

Beforehand, I had been referred to doctors who suggested surgery. I knew there were other options that could work. Luckily, I was referred to a specialist DSD team in London that suggested dilation as a first line of treatment.

Dilation may take a little longer, but if you're not sure, do research and get a second opinion – it took me a few years to research and decide, but it was definitely worth it.

Talking to Doctors and Parents

Talking about this to doctors and parents can be very difficult. When I'd got to the right hospital with doctors who presented dilation—a non-surgical method of stretching the vagina—I knew they understood what I needed. It is very important to remember that a lot of other girls/young women have been diagnosed before you, and many will be diagnosed after you. You are not the only person with your condition. I still found it quite hard to talk to them and would mostly refer to the process of dilation as 'treatment'. It got easier as time went on. After a few times at the hospital, my visits regarding dilation now feel like any other regular visit. Speaking to my psychologist about it was easy because they had treated other girls with the same condition.

I found it hard to talk to my parents about it, and I hardly ever talk about it with them. However this is just personal choice. If anything, I say the appointment was 'good' or that I'm 'not quite there yet' and it's left at that. Of course some girls or young women might want to talk to their parents more – that is entirely their choice.

If you are going to talk to your parents about it, choose a time and tell them you want to talk about something specific and that it is important to you; they'll make time then which is really helpful.

I actually talk to my friends a lot more, which can be easier for some girls/young women. I'm lucky in that my friends particularly understand; funnily enough we're at the point now where we joke about it! But I have a few close friends who I know are there for me if I really need to talk or even get upset about it.

Don't hold feelings in – I did for a while. Talk to someone – even if they don't know about these conditions, if you explain, then people are willing to learn. Talk to someone about how you're feeling. Online support groups for your condition can also be helpful.

What nurses and doctors told me

I was given a set of dilators at my first appointment. I was taught how to use them in a three-hour appointment; some girls are admitted depending on which hospital you go to. I was very nervous when I first went in. Luckily the nurse was very understanding and took it slowly. She showed me the dilators first and then we started with the smallest dilator. I found it difficult to relax my entire body but it is very important to try to, as it's not as uncomfortable then. Often the nurse will talk about films, TV or music to try to distract you – mine does and it really helps. Vibrators are sometimes suggested as this can make dilation less painful for women. In my case they were only suggested for maintenance. It is something to think about – it's just not something I wanted to do. For maintenance it's a great idea though. Usually the nurse understands that it is difficult –mine does and is brilliant. At the hospital they have an email and telephone system in place where you can contact them between appointments with any questions, which is great.

Tips for Dilating

- The key is distraction – the more you distract yourself the more you can take your mind off it while it's going on, the better. Often I watch TV or listen to music, which seems to help. Remember to BREATHE! (I made that mistake a couple of times in the beginning - whoops!). It may sound silly but it works – the calmer you stay, the less scary it is. If it is uncomfortable or painful at any point, don't stop but go more slowly.
- I dilate every day, and during the weekdays where possible I try to dilate in the morning so that I don't have to think about it for the rest of the day. Sometimes if I can plan ahead on a weekend, (where I can be more flexible) I'll go and meet a friend afterwards too, which helps in forgetting that I've had to do it. It's about what works for each person though.
- It can take longer than you think – if the doctors say 3 months; don't rely on that, as it can take longer. In my case, it's taking a while longer.
- Go at your own pace– Remember, if you skip a day, you can always start again the next day. Keep motivated – it does make a difference ☺
- If it gets frustrating, talking to somebody can help. I have a psychologist who helps me deal with the emotional aspects of the condition as well as any

feelings or concerns about dilation, and this really helps. I now understand that some of the things I was feeling are very common – shame, anxiety etc. and that I wasn't alone in feeling this way – but also that there is nothing to be ashamed of.

- Friends have helped too. In being open with them, I have realised that there is nothing to be embarrassed about. We have the same conversations as any other young people – if at any point it gets difficult for me, I simply tell them to change the subject – as anybody would with or without a condition. Not many of them know about the actual treatment, but a few do, and if I need to talk or cry they understand that it is frustrating – don't underestimate how understanding your friends can be.
- Talking to other women with your condition can be helpful too. I email women with MRKH of different ages and we keep each other motivated – and have fun too.

Partners

Communication is very important – I personally would tell someone I was in a relationship with so that they would be aware anyway. In the past I've always told them to go slowly and be gentle – seems to work! Using lubricant helps too.

Again a lot of this depends on the person. The main thing is to make sure that whoever you are with respects your privacy and your boundaries and is a good person for you to be with. **Remember, sex is not just about penetration, and intimacy is not just about sex.** Talk to your partner about what feels good and what doesn't – sex is always about individual preferences—helping meet your needs and those of your partner.

Is it worth it?

DEFINITELY! The process of dilation and learning about my body has made me more confident and has helped me build a lot of respect for myself.