

A resource by the LUNA Project on Adenomyosis (Ad – e – no – my – o – sis)

Part of the “From Me and My Friends to You and Yours”Series

What is Adeno?

Adenomyosis is a condition where the cells that usually make up the uterus (also known as womb) begin to grow into the muscles surrounding the womb. Adeno usually affects the older generation however it can anyone who has periods. It’s very similar to a condition called Endometriosis and is often called “Endo’s evil sister.” There’s no known cause as to why this condition happens however we do know that it’s not contagious or an STD.

Adenomyosis can cause lots of pain in the pelvic area (tummy and top of legs.) The most common symptoms on Adeno are heavy/painful periods as well as pain before a period. In extreme cases the condition can also increase the risk of pregnancy miscarriage.

Adenomyosis is a life-long condition that may require pain medication or surgery to remove the organs affected. This can mean that people with Adeno sometimes have to make difficult choices about what treatment is best for them.

How Adeno affects ME...

Physically...

Leading up to and during my period I have to take lots of medication throughout the day to keep my pain levels under control. I also have been known to take a hot water bottle into school with me when the pain gets too much and I need something extra to help ease my muscles. The medication that you take can lead to other problems such as headaches, weight gain and mood swings. The heavy bleeding and painful periods mean that it can be hard to keep up with your daily activities as well as being worried that you’ll bleed through your clothes.

Mentally...

Being diagnosed with a life-long condition can be really lonely and upsetting. It can feel like you've got to make tough choices and potentially have to change your whole life. It can be isolating knowing that most people your age weren't having to make the choices that you are, especially when it can involve surgery. This is where I was lucky enough to have family and friends who I could be honest with about how I was feeling.

My Life...

The condition can be made worse by certain foods and movements so this has meant several lifestyle changes and tough choices about my treatments. It can also affect my relationships with my family and friends as they've had to deal with the long-term changes as well. It can also cause pain during everyday activities such as going to the toilet and having sex which can have a big impact on your sexual relationships. The issues it can cause with pregnancy can with fertility can be a big topic to get your head around, which is why having family and friends who are able to understand and talk through your options is really important.

1 way a friend can help...

- 1) If you're out and about and see one of your friends struggling, slowing down can be really thoughtful. Asking if they feel okay, need some assistance or even if they need to sit down for a few moments. As long as it's done in a way that doesn't make them feel embarrassed, it could make your friend feel like you care about how they're doing.

Resources for finding out more...

If you would like to find out more about Adeno, here's a few places to start:

<https://www.guysandstthomas.nhs.uk/resources/patient-information/gynaecology/adenomyosis.pdf> - An NHS leaflet about the condition

<https://www.cosmopolitan.com/uk/body/health/a13148914/adenomyosis-symptoms/> - An article about the basics.

https://www.instagram.com/acknowledgingadenomyosis/?utm_source=ig_profile_share&igshid=2w34kyti33ma – An Instagram by someone who has both Adeno and Endometriosis.

It's also worth having a look at some of our blogs, podcasts or socials.

About the Author:

Philippa (she/her) is 21 and lives in England. Originally from Devon, she now splits her time between Northampton and Wiltshire. Recently graduated from the University of Northampton as a Journalism student.

Get Involved:

We would love to get as many people involved in creating these resources as possible! If you are a young person living with a chronic illness, disability, or long term health condition, and would be interested in making a similar resource based on YOUR experiences, we would love to hear from you! You can email us at thelunaprojectuk@gmail.com ! You can also find us on social media [@thelunaprojectuk](https://www.instagram.com/thelunaprojectuk) !

