Experiences of Endometriosis in Wales

This booklet is one of the outputs of a research project that collaborated with the Welsh Government and was conducted by an undergraduate student and a group of female academics at Cardiff University.

Research team

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In partnership with

Fair Treatment for the Women of Wales

Booklet design

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CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

What is this booklet about?

The content

The experiences of endometriosis described by women living in Wales using their own words and artwork.

The women involved

A group of fourteen women living in Wales who are part of the organisation Fair Treatment for the Women of Wales (FTWW). All of the women have an official diagnosis of endometriosis.

The workshop activities

We carried out several drawing exercises designed to encourage the women to share their experiences of endometriosis:

- Draw yourself thinking or talking about endometriosis
- If your endometriosis symptoms were an object, what would they be?
- If they were a creature or an animal, what would they be?
- If they were a place or situation, what would they be?
- How would you draw your relationship with medical staff?

Finally, we asked the women to describe to us any positive experiences they have had in relation to endometriosis.

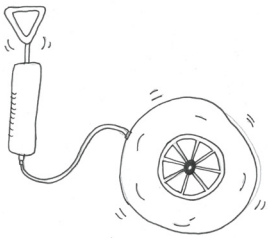
The main conclusions

The women talked about

- the negative effects endometriosis has on their physical health, mental health and social life.
- the lack of understanding that their friends, family and doctors have about endometriosis due to its invisibility
- how the healthcare system does not recognise and treat endometriosis well
- how they have taken responsibility for their own health
- the importance of the support they receive from other women with endometriosis

What is endometriosis like?

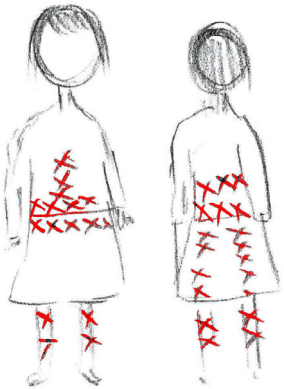
"WHEN YOU GET BLOATING YOU LITERALLY FEEL LIKE YOU'RE GONNA POP"



"I HAVE A CRUSHING PAIN THAT'S ALWAYS THERE, YOUR INSIDES FEEL LIKE THEY'RE IN A VICE"

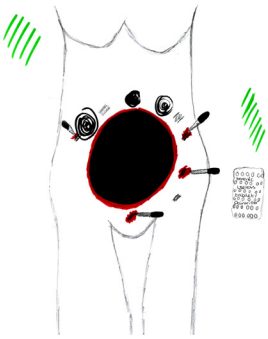
"I CONSTANTLY FEEL LIKE I'M BEING STABBED"

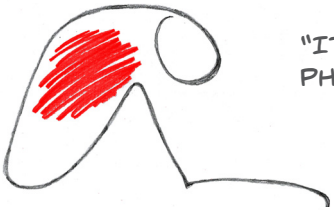
"I WOULD RATHER GO THROUGH LABOUR THAN SUFFER MY ENDOMETRIOSIS FLARES"



What is endometriosis like?

"I FEEL LIKE IT'S TAKING EVERYTHING AWAY FROM ME AND EVENTUALLY IT WILL PROBABLY TAKE EVERYTHING INSIDE AWAY FROM ME"

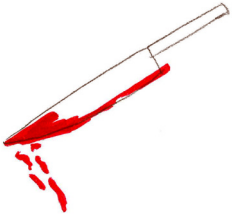




"IT'S MENTALLY AND PHYSICALLY EXHAUSTING"

"YOU FEEL LIKE YOU'RE GETTING PUNCHED DOWN"

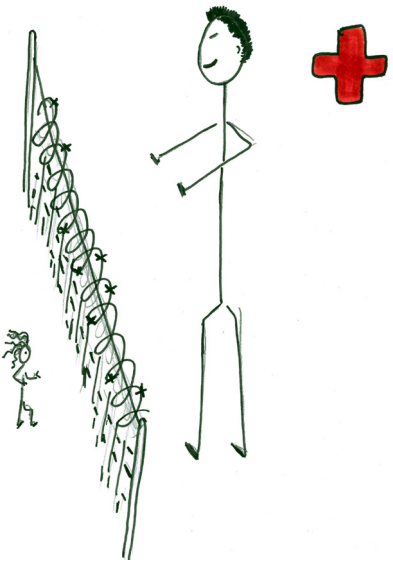
"THAT TOILET IS MY LIFE... I'M CONSTANTLY STRUGGLING WITH POTENTIAL BOWEL OBSTRUCTION"



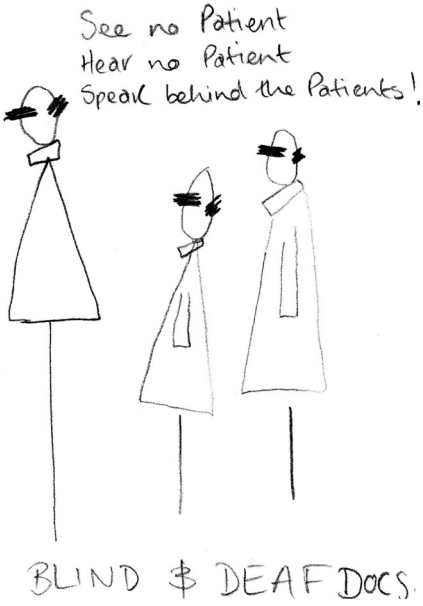
"EVERY TIME YOU HAVE A BOWEL MOVEMENT, IT FEELS LIKE SOMEBODY'S KILLING YOU"

Our illness is invisible: Others often do not see or understand our pain...

"YOU'RE JUST CONSTANTLY HAVING TO GET THROUGH OBSTACLES TO GET TO THE RIGHT DOCTOR"



"I FEEL LIKE I'M REALLY SMALL SOMETIMES BECAUSE NO ONE UNDERSTANDS"



"THESE ARE MY DOCTORS IN THEIR STRAIGHTJACKETS AND NOT BEING ABLE TO SEE US, NOT BEING ABLE TO HEAR US AND ALL THEY DO IS SPEAK BEHIND YOUR BACK"

... and often we do not show our pain

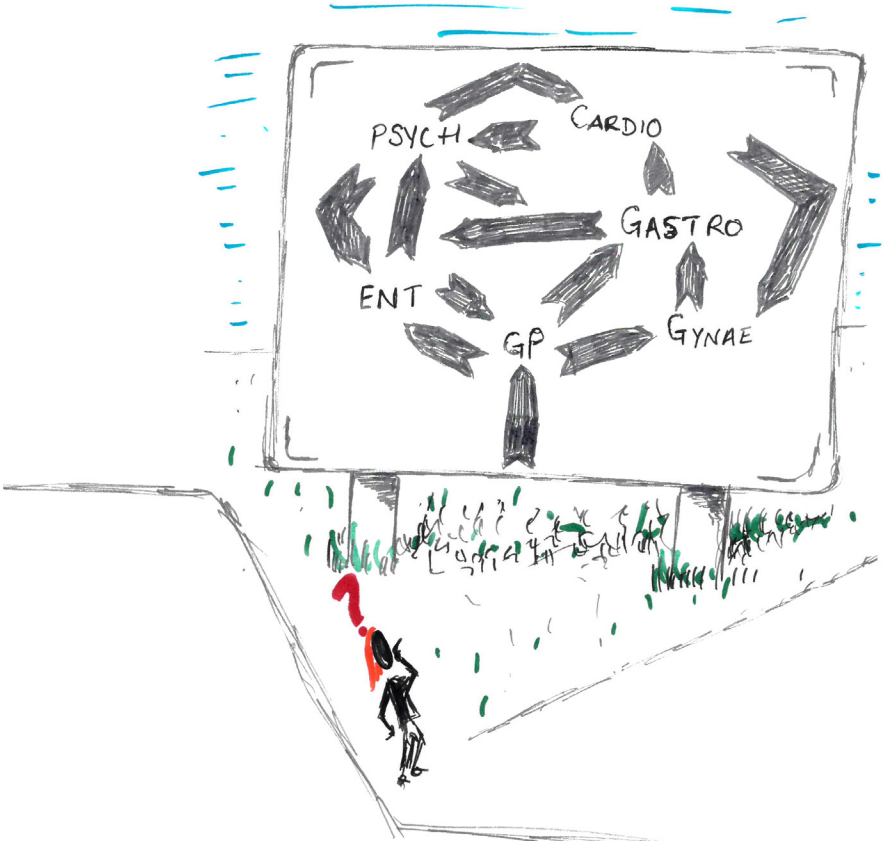
"I AM A BROKEN VASE...WHAT ONCE WAS LIGHT, BRIGHT AND BEAUTIFUL NOW HIDES...DARK, CRACKED, DAMAGED AND BROKEN"

"YOU LOOK PERFECTLY NORMAL, NOBODY CAN SEE YOUR PAIN AND YOU WEAR A MASK ALL OF THE TIME. YOU TELL PEOPLE THAT YOU'RE FINE, BUT REALLY THAT'S HOW I SEE MYSELF"

Our healthcare struggles: Confusion and delay

"IT'S LIKE A MAZE AROUND THE DOCTORS BEGGING THEM TO LISTEN TO YOU AND THEY DON'T LISTEN"

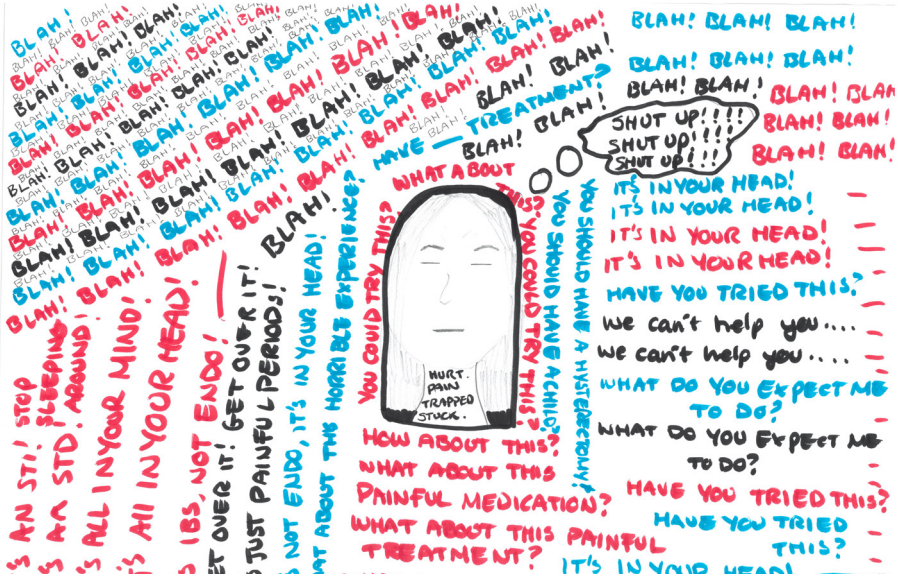
"MY DIAGNOSIS TOOK NEARLY THIRTY YEARS"



"EVERYONE IN THIS ROOM HAS PROBABLY HAD SOME PROCEDURE THAT THEY SHOULDN'T HAVE HAD BECAUSE THE DOCTOR WAS JUST SEEING IF IT WOULD WORK"

Our healthcare struggles: Uncertainty and mis-diagnosis

"I WANTED A WAY TO VISUALISE BLAH BLAH BLAH BLAH BLAH AND I'M JUST TIRED OF HEARING ALL OF THIS"



"I WISH MEDICS WOULD REALISE THAT IT'S NOT A SIGN OF WEAKNESS AND WE'RE NOT GONNA JUDGE THEM HARSHLY IF THEY'RE HONEST AND SAY I DON'T KNOW"

Our healthcare struggles: Not being heard

"THERE'S ME, MY HOUSE IS BURNING DOWN AND I'M SHOUTING FOR HELP AND THE FIREMAN SAYS BUT THIS BRICK LOOKS FINE. THE BIG ISSUE IS THE LACK OF CONNECTION BETWEEN DIFFERENT SPECIALISTS; THEY ARE NOT LOOKING AT THE BIGGER PICTURE"

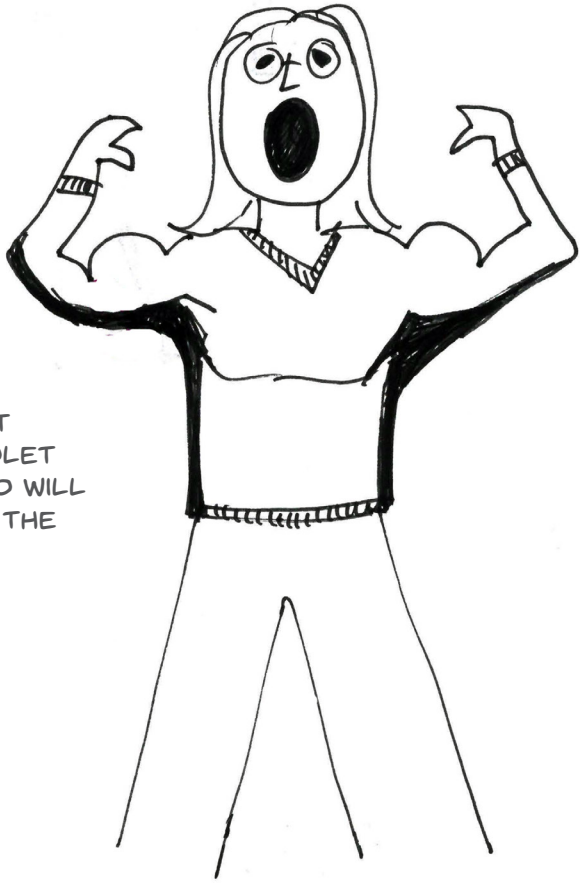
"I'VE BEEN TOLD THAT I CAN ONLY GET ONE OPERATION IN CARDIFF, BUT ENDOMETRIOSIS IS A CONSTANT THING"

"IT WAS JUST ROUND AND ROUND UNTIL I HAD A HUSBAND, A MAN GOING WITH ME TO AN APPOINTMENT. MY HUSBAND SPOKE UP AND SAID THIS ISN'T RIGHT, SO FINALLY THAT WAS WHEN THE ROUTE TO BEING HEARD STARTED"

Taking matters into our own hands

"I NEED TO FIX MYSELF BECAUSE THE DOCTORS AREN'T FIXING ME ANYMORE"

"TAKE ME SERIOUSLY"



"I'M NOT THAT SHRINKING VIOLET ANYMORE WHO WILL JUST ACCEPT THE NONSENSE"

"THE FUTURE GENERATIONS OF WOMEN ARE GONNA BE SNOOKERED IF WE DON'T DO SOMETHING, IF WE DON'T START SHARING MORE OF OUR STORIES AND SPEAK OUT"

Working together to face the future

"I've learned from dealing with chronic pain that it's okay to ask for help"

"I don't have to be invincible, I've learned it's okay to value myself enough to fight for what I need"

"Joining Fair Treatment for the Women of Wales is the best thing I've ever done"

Supporting each other

"I WOULDN'T HAVE STARTED MY OWN GROUP IF I HADN'T HAD THE CONFIDENCE THAT I GOT THROUGH FINDING FTWW"

"IN THE BEGINNING YOU ACTUALLY THINK THAT YOU'RE ON YOUR OWN BUT THERE IS ALWAYS SOMEONE ELSE TO TALK TO"

"IF OUR EXPERIENCES HELP WOMEN GET DIAGNOSED FASTER THEN FOR ME IT'S WORTH EVERY MINUTE OF PAIN I'VE EVER BEEN THROUGH"

Who created these drawings?

All of the women who took part described their difficult and challenging journeys with endometriosis. However, each woman is much more than her endometriosis diagnosis:

She is a mother of two girls with a passion for music. She is a long-ago Welsh Judo Champion who loves listening to the rain but glows in the sun. She is a vintage hairstylist and all-round enthusiast of the yesteryear. She was a Ballroom and Latin American dancer and still loves dance, drama and theatre. She cares for people in crisis. She crossed the ocean for love, travels the Universe through books and is a mother of cats. She is a business-owning feminist who wants answers, autonomy and bunnies. She is happiest at home surrounded by cats. She is an LGBT+ woman who aims to make a difference for others through all she does socially and professionally. She bakes every cake with love and care. She loves to cook up a storm and experiment with new cuisines. She is a lover of the colour purple. She once lived to work but gave it up to be a perpetual student. She does beauty treatments for others to help pick them up. She is tall of stature and big of heart towards people and animals. She is wide of smile for friend or stranger.

Further Information and support

Fair Treatment for the Women of Wales (FTWW) - bit.ly/2HErZEi

A proactive, patient-led organisation set-up for women and girls in Wales who need practical advice, help and support dealing with their local health services and accessing optimum care. Medically approved educational resources are provided in Welsh and English. Two other support groups in Wales are Swansea Endometriosis Support Group: carly@endo-swansea.uk and Cardiff Endometriosis UK Support Group CardiffGroup@endometriosis-uk.org

Endometriosis UK - bit.ly/2oR7RT8

A national charity providing support services, reliable information and a community for those affected by endometriosis.

National Health Service (NHS) - bit.ly/2EUDRQU

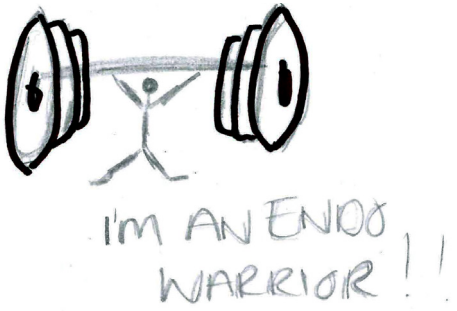
Detailed patient information about the symptoms, causes, management and treatment options of endometriosis through the NHS.

National Institute of Health and Clinical Excellence (NICE) - bit.ly/2j3NthG

Evidence-based recommendations that guide decisions in health, public health and social care in the UK on endometriosis, intended for both healthcare professionals and patients.

My Experience with Endometriosis - bit.ly/2HFrRo3

An online comic by an artist suffering from endometriosis about her experiences with the US health system.



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