

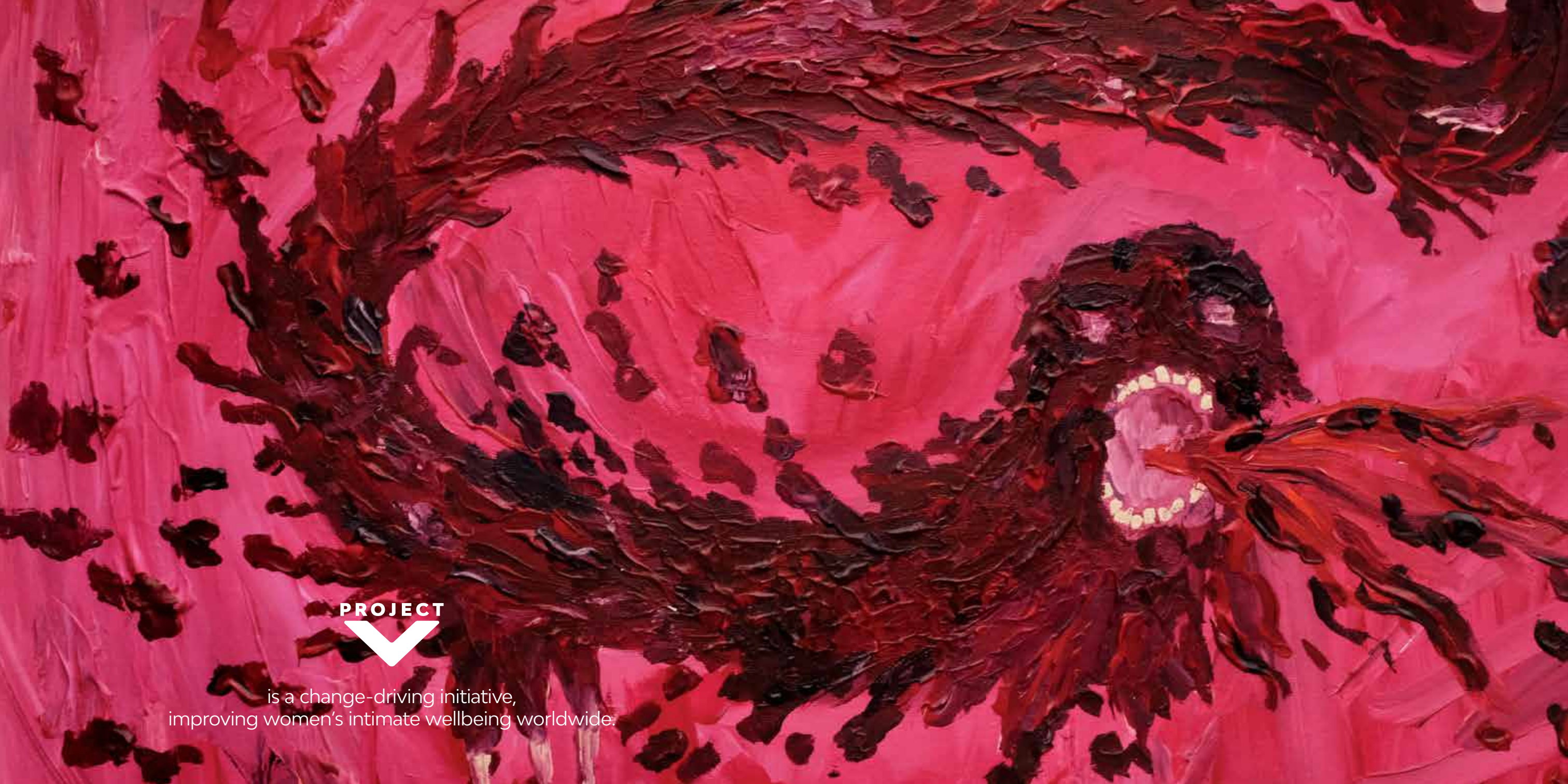
THE PAIN

DICTIONARY

#PAINSTORIES FROM PEOPLE WITH ENDOMETRIOSIS



LIVE FEARLESS



PROJECT



is a change-driving initiative,
improving women's intimate wellbeing worldwide.



A NEW LANGUAGE FOR

ENDOMETRIOSIS

PAIN



An estimated one in ten women have endometriosis.

But it takes, on average, 7.5 years to diagnose.¹

Our pain is systematically dismissed, undervalued, and underreported.

We're told it's 'just' a bad period.

Or we're asked, "How much does it hurt on a scale of 1-10?"

But the 1-10 scale is subjective – one person's 5 is another's 8. The truth is that no number comes close to how endometriosis actually feels. Pain defies quantification – it is felt, not counted.

So, we asked people with endometriosis to tell us how it really feels: from organ-chewing monsters, to wombs full of nails and daggers, and even rabid goats jumping on abdomens.

Their descriptions have given us new language for endometriosis pain.

Endometriosis can be lonely – it's silent, ongoing, and no one else can see or feel it. This Pain Dictionary exists to give endometriosis sufferers a way of expressing and sharing their pain. We hope that by creating a language for pain, we can reduce diagnosis times. The more we share, the more we break the culture of silence that stops us getting the treatment we deserve.

We also hope this book might empower you to seek help if you're experiencing pain but haven't yet been diagnosed.

Bad period pain is not 'normal'. If any of these definitions resonate with you, go and see a doctor, demand to be taken seriously, and give your pain the expression it deserves.

Let our #painstories be heard.

Every pain definition is a real quote from a real person suffering from endometriosis.

Since the condition can be extremely painful, some of the definitions, and accompanying imagery, might be quite graphic.



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ଘ ଙ ଛ ଡ ଢ

“

Like torture. Like somebody is gripping, squeezing, cutting, prodding, stabbing you inside, and won't let go. The waves of pain last for so long you can only take some painkillers, curl into a ball, and cry yourself to sleep.

”



PAIN

DROWN

“

Sharp. Shooting. Sickening. My pain is unpredictable and uncontrollable.
With every endometriosis flare, I'm reminded of my powerlessness.
I'm drowning in pain, I am trapped – yet, I'm still fighting.

”

@hy_stera





B E L L Y
S T O M A C H

“

Like a rabid goat repeatedly jumping on my abdomen.

”

W O M B
D A G G E R S

“

It's a full body experience for me. It starts as a dagger being stabbed in and moved around in my womb. That's the most acute part. Then it feels like the blood is draining from my legs and face. My whole body aches.

”





BOWELS BASHES

“

The pain is shooting and connected with my bowels. It is literally crippling at times and I often fear going to the toilet in the first few days of my period. Sometimes I will be bent over in pain with shooting, searing pains through my bottom and my uterus. Other times I have the constant ache of cramping. It is like my body is being groped and squashed from the inside, with stabbing pains at times.

”



INNER WRINGING

“

It's like someone's wringing my organs. And unbelievable tugging.

”

@theendospectrum

WHAT IS ENDOMETRIOSIS

Over half of people don't know what endometriosis is.²

Endometriosis is a condition in which tissue similar to the lining of the womb grows outside the womb. This tissue bleeds monthly, but there's nowhere for this blood to go. This causes local inflammation resulting in endometriotic lesions, cysts, scarring, and adhesions – and a great deal of pain.

The most common symptoms of endometriosis are pelvic pain, and pain during periods. But we're sadly taught that bad period pain is 'normal'. Just something to put up with. It's not.

Endometriosis pain can occur throughout the cycle and all around the body. It can be a full body disease and, in rare cases, it can grow as far as the diaphragm and lungs.

It can also cause a whirlwind of other symptoms: heavy periods, pain during or after sex, painful

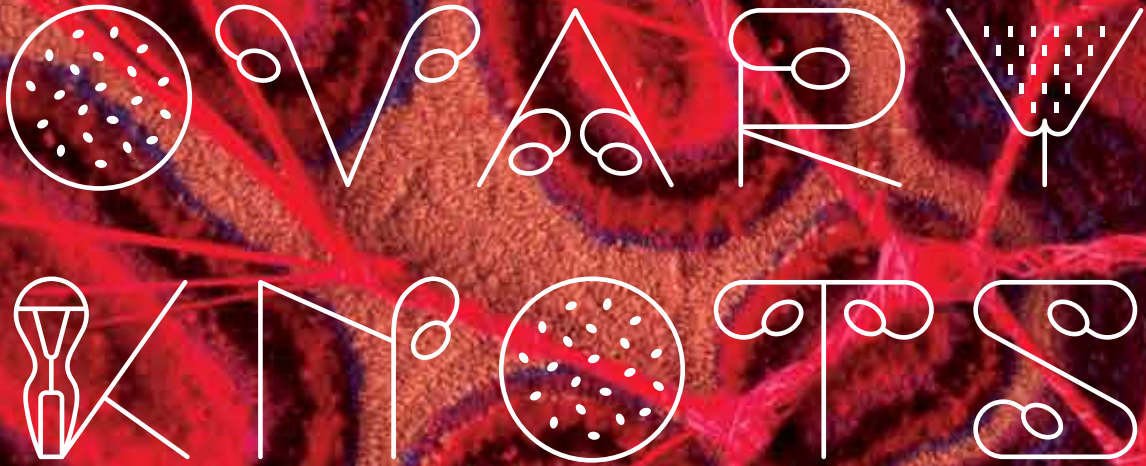
ovulation, fatigue, abdominal bloating (known as 'endobelly'), bowel and bladder problems and, in some cases, infertility.

It affects everyone differently: some suffer chronic daily pain, a lucky few experience very little pain.

Endometriosis is not the only condition that causes pelvic pain. There's also pelvic inflammatory disease, adenomyosis, ovarian cysts, and uterine fibroids. If you're in pain, speak to your doctor.

Awareness of all these conditions is growing thanks to the brilliant work of advocates, charities and medical professionals. But there is still a long way to go – it all starts with talking about it and sharing our #painstories.

This guidance is provided by endometriosis.org



“

It feels like a sharp, sudden tug on my ovaries, as if they were knotted and woven within my womb. As the pain radiates through me, I begin to imagine the adhesions that may be attaching my internal organs together through a tangle of fibrous threads.

”

@elliepearcetextiles



T E N D E R I T Y A T T A C K

“

Like my womb is throwing out tendrils to colonise the rest of my body with its cramping - pulling everything towards it, like it wants to own me with its pain, to contain me. It's a full body attack.

”

Q H P C K V

S T A B S

“

It's like Chucky stabbing my uterus inside and out.

”

@rayraydoesit



PAINCAGE

“

The pain is so deep inside that painkillers can't touch it.
I'm exhausted beyond belief, trapped inside my pain.
All I can do is wait for the pain to die down. I'm in survival mode.

”





NEEDLE
THREADS

“

Like a slow puncture over and over again,
as if thick needles were being threaded through my womb.

”

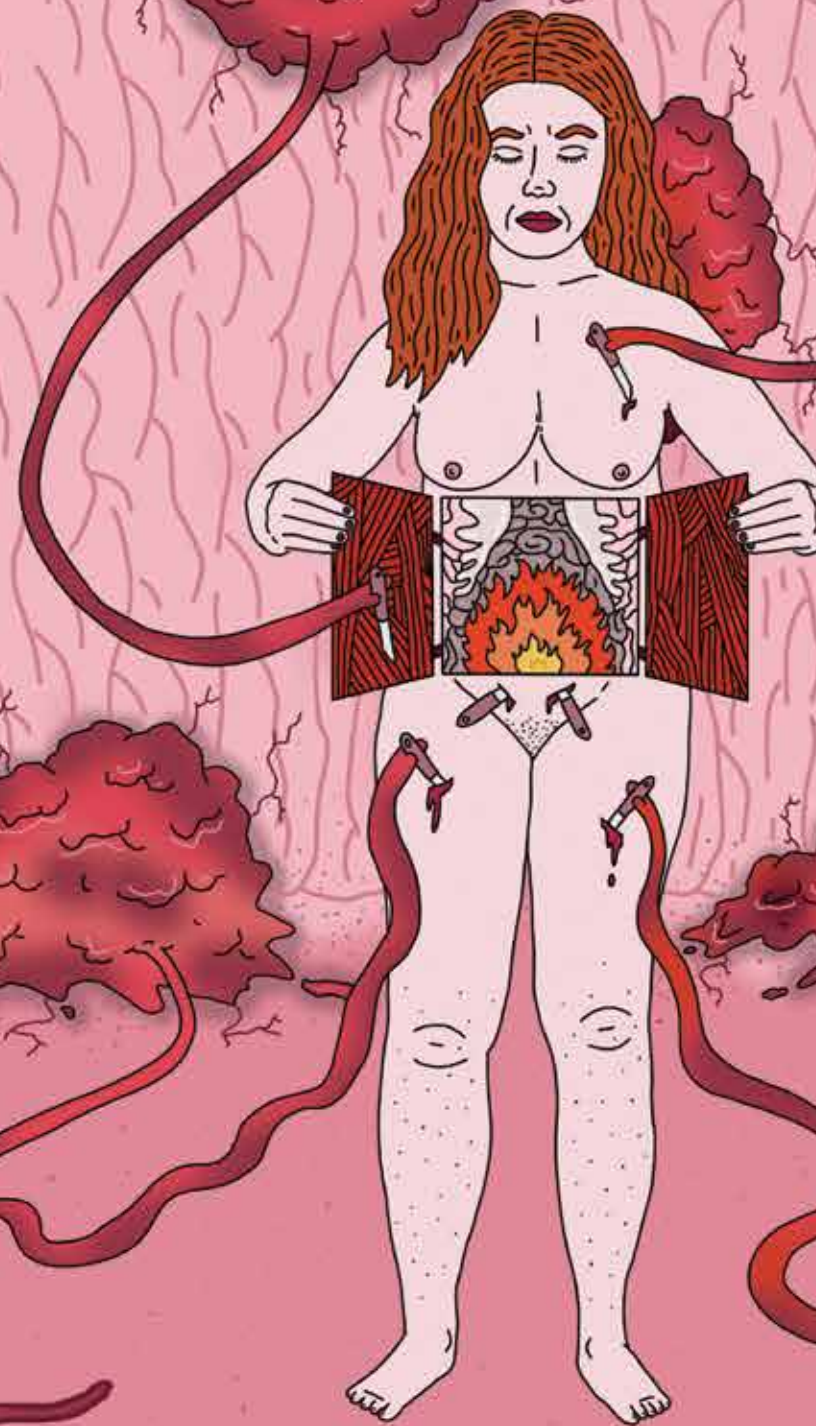
P I R E S I C K N E S S

“

The pain burns, stings and aches sometimes all at once. I feel it build up in my lower body like fire, and hot knives pushing from the inside out. The pain travels from my uterus across my stomach and around my sides, down through my legs and up my back until it starts all over again from the source. I feel sick and exhausted from the pain overriding every part of me.

”

@venuslibido



MIRROR WOUNDS

“

Back and forth shifting stabbing or shooting pain
that mirrors each side of the pelvic area.

”

@_samanthadenae_





EVERAACHIE

“

A constant ache that never goes away no matter what I do.

”

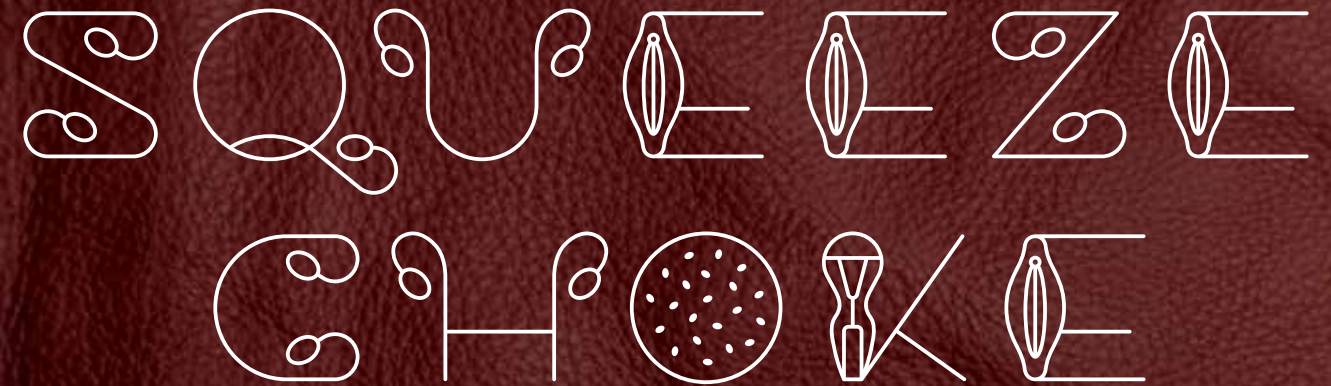
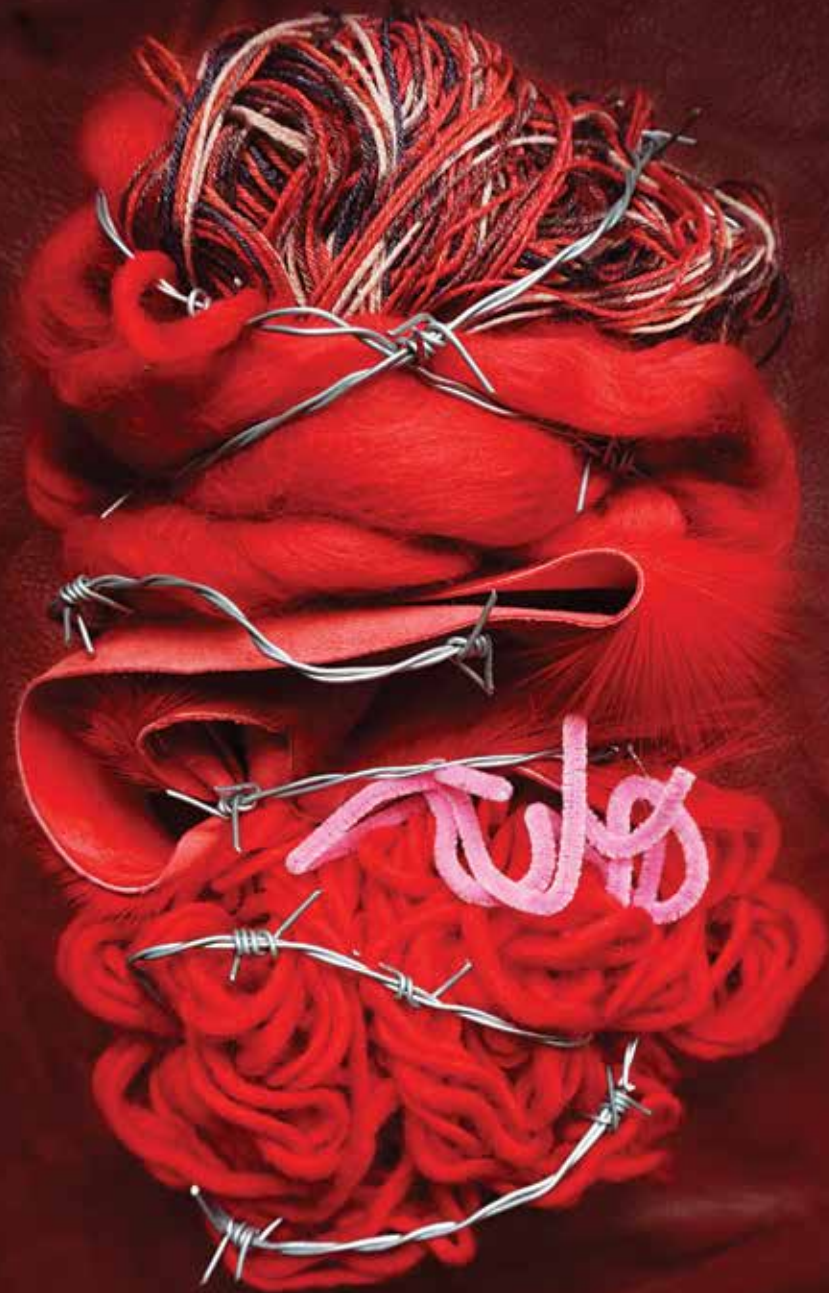


BULLYTWIST

“

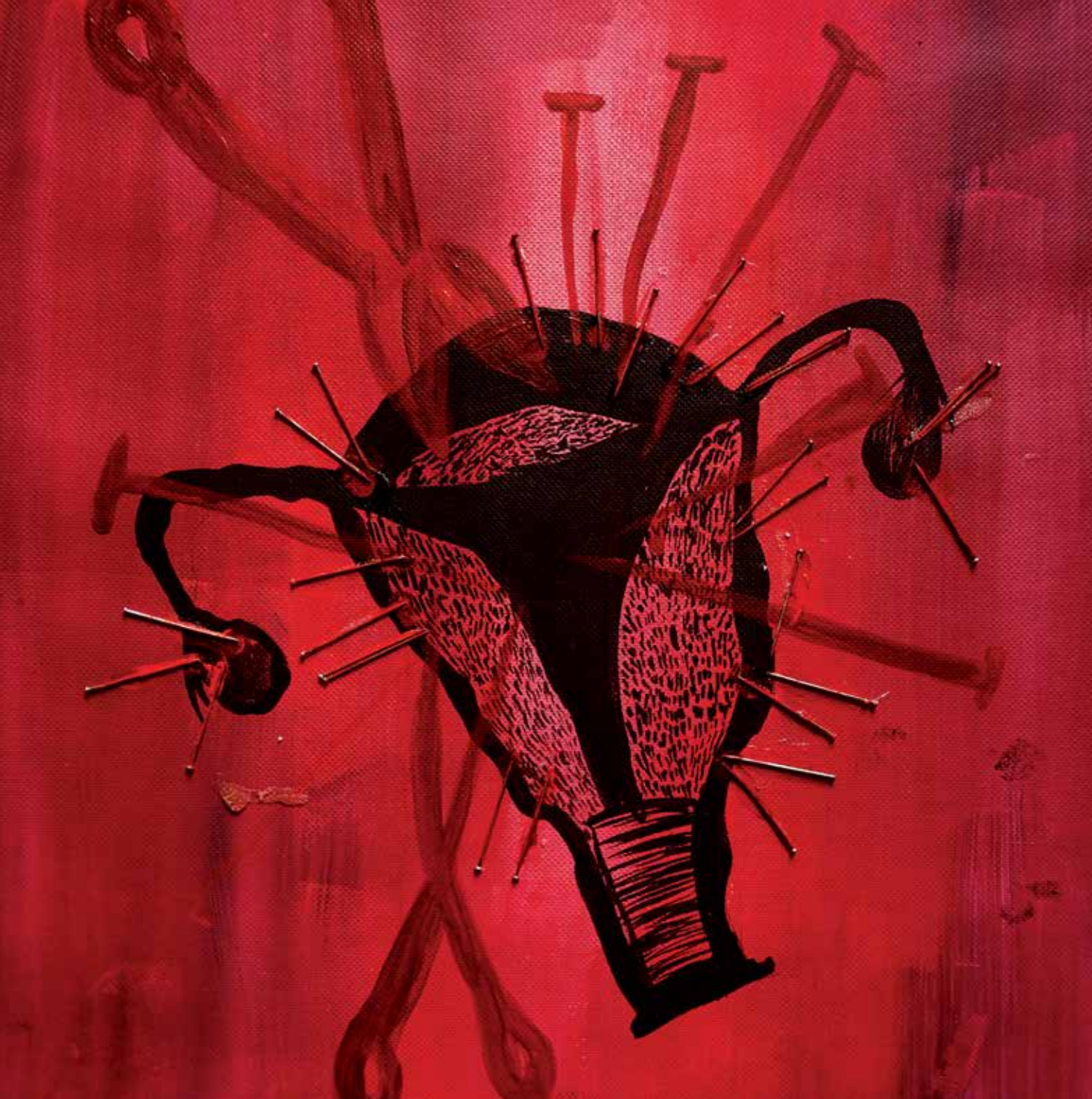
It's like a bully twisting my insides in different directions.

”



It's like someone is pushing down on my chest, on my sides, squeezing my insides. I'm wrapped up, mummified, compressed like some kind of ancient torture ritual. Sometimes it's hard to breathe. My ribs feel like they could break; my upper back is agony, and I'm overcome with nausea.






INFERNAALS

“

Hundreds of nails piercing my uterus, my whole pelvis in agony.
The pain radiates down my legs, and through my whole body.
From one second to the next, I can't stand up.

”



WOMEN BIRTH

“

It feels like I'm birthing my uterus. The pain is chronic,
like labour contractions. I need to breathe deeply to get through them.
It hurts to the point of vomiting, and fainting.

”

MWTH BUSTING

The cause of endometriosis is unknown

Although there are lots of theories knocking about, don't be taken in by them. We need a lot more research to understand what causes endometriosis. There is a distinct lack of funding for endometriosis research, and female pain historically has been dismissed and sidelined by the medical system – this is often called the 'gender pain gap'. This issue is even more pronounced for Black, Asian and mixed heritage women, as well as for trans and non-binary communities.³ Luckily, we are starting to talk more about endometriosis, awareness is growing, and hopefully the tides are changing.

Having a hysterectomy is not a cure

Endometriosis is a full body disease and grows outside of the womb – so removing the womb is not a cure. Whilst it can sometimes put an end to some symptoms such as pain, this relief cannot be guaranteed.

We shouldn't have to say this but, having a baby is also not a cure

Having a child is certainly not a cure for endometriosis, and no one should ever feel pressured to become a parent.

Endometriosis does not "equal" infertility

Too many people are made to feel like their endometriosis means they cannot become pregnant. This is not the case, and most endometriosis sufferers go on to have children.

This guidance is provided by [endometriosis.org](https://www.endometriosis.org)



PELVIC
DEMON

“

It feels like a demon scratching my internal organs
and trying to rip them apart.

”

@pelvicpainjourney

BARBING

“

Organs wrapped in slowly-tightening barbed wire,
followed by sudden intense tightening pain which can be
so intense it's almost difficult to breathe.

”

@emma_sutt





ORGANPULSE

“

Like drowning: a ton of bricks on my chest,
my organs in a box being squashed together and pulling
in all directions at the same time.

”

@endometriosisandme1

BLOAT

BURN

“

Everything feels inflamed. There's a burning sensation in my womb, stabbing pains in my back. Then, the bloating hits. It feels like I'm being pumped with air. I look like I'm pregnant and due any day.

”





BONE CRAMPS

“

Being stabbed repeatedly in my lower stomach, aching like my joints and bones are extremely cold. Life is a struggle always with the pain and the cramps.

”

@livingwith_endo



BRUISE
WEIGHTS

“

I feel like there is a weight pulling me hard, hard, hard, down to Earth's core. I feel bruised, as if I am recovering from someone having repeatedly punched my stomach. On the first day of my period, the pain is accompanied by a clammy sweaty feeling. My hearing goes fuzzy.

”

L I M B
P U N C H

“

My limbs are being pulled apart from my body and a blunt knife cuts from one side of my womb to the other, then back again.

”

I N N E R P U N C H

“

It's like I'm constantly being punched from the inside. Sometimes it's so excruciating that I can't sit up.

”



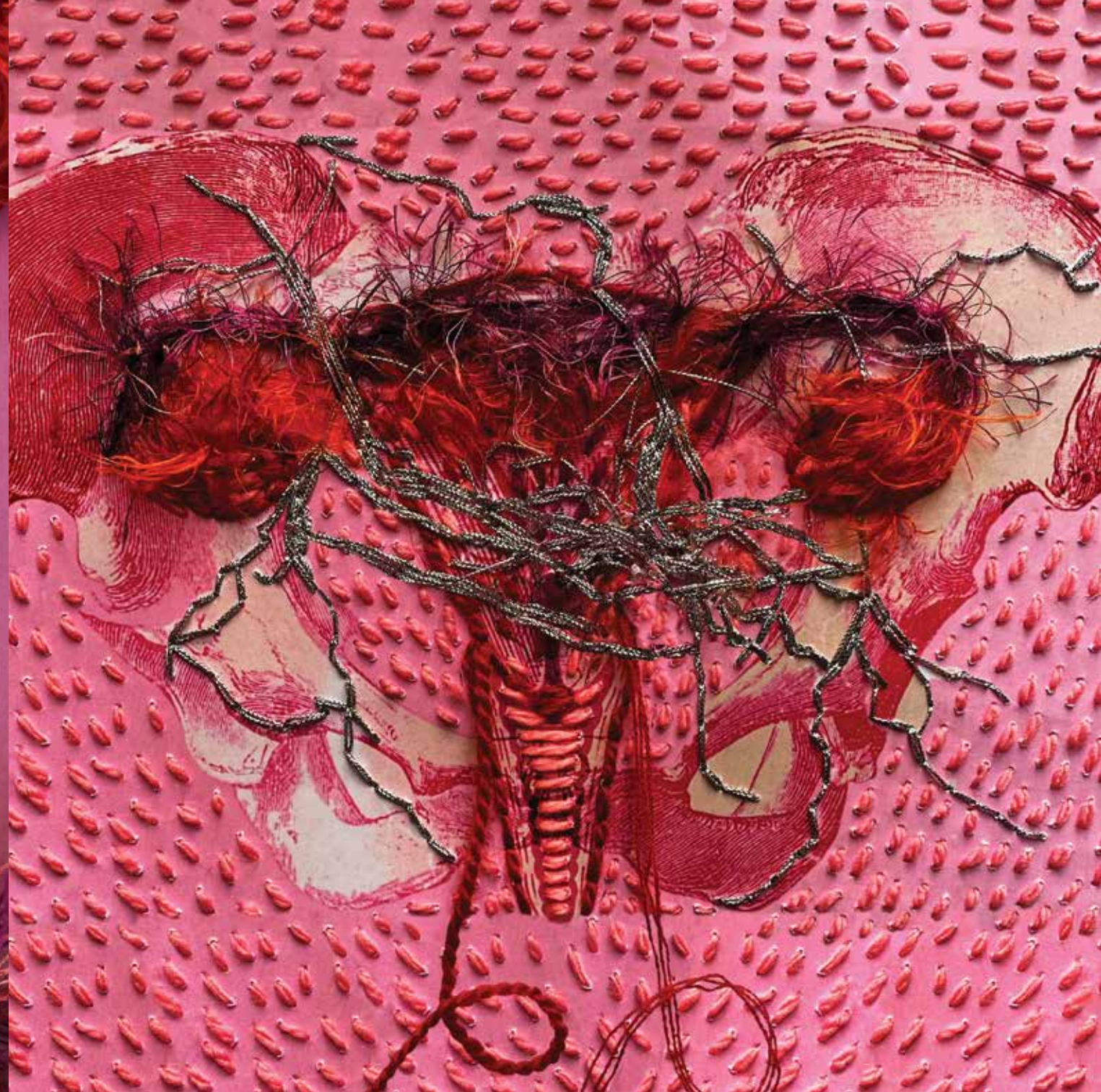
P E L V I S

U O L T S

“

Feels like an electric current running through my pelvis,
with sharp jolts and burning throbs at the same time.

”





F L E S H M A S H E R S

“

Like one of those old iron potato mashers liquidating up my insides with blunt metal – an instrument of torture pulverising, lashing outwards, coming in sickening hits.

”

MYTHS BUSTING

Endometriosis is not endometrium

Endometriosis is when tissue similar to, but not the same as, the one found in the lining of the womb grows outside of the womb. This is an important distinction because misunderstanding the disease means that it's not always treated properly. For example, misinformation that endometriosis is misplaced endometrium can lead to the recommendation of hysterectomies as a cure when it's often not that simple, or to the misleading claim that hormonal treatments eradicate the disease.

The amount of disease doesn't correlate to the amount of pain

Some have a lot of disease and almost no pain, whilst others suffer immensely but have small amounts of endometriosis. No matter how much pain you're in, or the extent of the disease, your pain is real: your health matters. Your #painstories deserve to be listened to and taken seriously.

To find out more about endometriosis, go to endometriosis.org, or bodyform.co.uk/myths-and-facts/period-problems/what-is-endometriosis/

This guidance is provided by endometriosis.org



OVARICULARS

“

It's like a rusty claw on my ovaries and pelvis,
slowly twisting over a long time. I had organs fuse together
and sometimes they would move and it felt like I was being ripped
into bits. I ended up on the office kitchen floor one time.

”

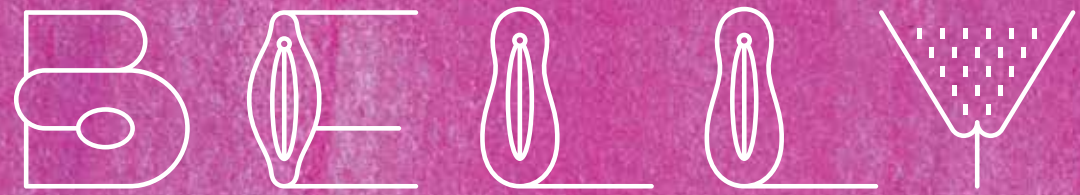


TRAIN CRUSH

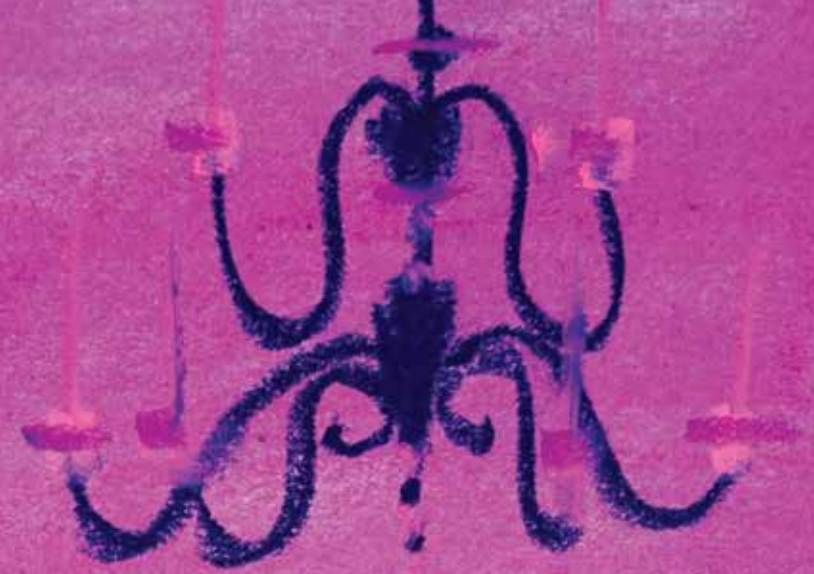
“

It's like a train crushing my pelvis, reversing back and forth over my body. Nauseating cramps legitimately stop me moving and make me fold up in tears.

”



It's a dull ache, like tap dancers gently tapping away on my stomach.
And then, occasionally, it grows into a full ballroom.



MISERY ROULETTE

“

It's a fun-sponge roulette of misery. Cramps that stop me moving, yo-yoing emotions, gut-wrenching nausea, being sick, wanting to eat nothing and then everything, back pain, breast pain, alarmingly painful constipation, diarrhoea so bad you can't leave the house, headaches, migraines, worsening depression, fatigue, anxiety, stress and a whole heap more.

”



BODYPHORNS

“

Hundreds of thorns in my side, in my belly,
in my uterus, growing everywhere and digging into me.
It's amazing how much pain a woman
can take and still look normal to people around her.

”






ଆସଂଗେ ଓଫ ୱଓମିସ

“

A feeling like my ovaries are being pulled left, right and centre. Burning sensations grip my pelvis. There's a weight in my womb, and my ovaries are being stabbed. I'm completely bed bound during my period.

”



K N I P E
T W I S T S

“

It can feel like I'm sitting directly on a knife which reaches up to my belly button and slowly starts to turn. The period pain itself can feel like something inside my lower abdomen has suddenly ruptured and continues to pulsate without relief.

”

@acknowledgingadenomyosis



R A K E S C R A P E

“

Like a rake scraping my insides.

”

BOWLING

BALL

BRUISING

“

My ovary feels like it's being squeezed by barbed wire that is burning hot and it sends shocks down my leg. It feels like a bowling ball is sitting on my bladder, or midline. My bones are aching and feel exposed at times in my butt cheeks due to nerve pain. It feels like my legs are tied with small ropes that are becoming tighter and tighter.

”

@chronicallystill




PERIODS

“

Imagine someone carelessly and aggressively scooping tender flesh from a fruit. It feels like being hollowed out from the inside. During my period my whole pelvis, lower back and thighs vacillate between feeling like they're on fire and strangely numb, as if my sensory system were exhausted.

”

A painting with a dark, somber palette of reds, oranges, and blacks. In the foreground, a woman is seen from behind, crouching or sitting on the ground. She is surrounded by a chaotic scene of fire and destruction. In the background, there are silhouettes of trees and a fence made of barbed wire. The overall mood is one of despair and suffering.

WOMBWAR

“

On a bad day, it's no man's land. Barbed wire, bombs, gunfire. Shooting pains down my legs and through my belly and womb mean standing up is not an option. I feel drained from taking just one step and my eyes struggle to stay open.

”

Diagnosis & treatment

Endometriosis can only be diagnosed via laparoscopy.

Today there is no simple test that can be used to diagnose endometriosis, which may be why there is a diagnostic delay of up to 12 years in some healthcare settings. Only a handful of extremely qualified gynaecological ultrasound experts are able to spot the disease on a scan – and even then only very advanced stages of the disease can be spotted. Endometriosis can never be ruled out based on an ultrasound, or any other type of scan. It can only be definitively diagnosed by laparoscopic surgery.

There is no known cure. But there are treatments to alleviate pain and to make life a little easier.

Surgery

Laparoscopic surgery to remove lesions and scar tissue is one of the

main and most effective methods of treating endometriosis, if done right.

The problem is that there are not a large number of surgeons that specialise in the removal of endometriosis and who are capable of safely cutting out the disease even in the earlier stages. With surgery, there is never a guarantee that the disease will not come back (and it often does) – because the disease mechanisms (i.e. why and how endometriosis develops) are still largely unknown.

Hormones

Hormonal treatments can be used to stop monthly periods, which can be extremely painful. It can be a great relief to do away with periods, but hormonal therapies don't work for everyone, have varying degrees of side effects and, for some, only provide temporary pain relief. It's important to know that hormonal

treatments are not a cure. They do not have long-term effects on the disease itself. But they might just make it easier to live with by suppressing symptoms for a while.

Pain relief

Painkillers can be used to provide some much-needed relief, although many know too well that these often don't quite touch the pain or can't be taken regularly because of side effects or addiction risks.

Everyone is different. Each person experiences endometriosis differently; pain is highly individual and subjective. Different people might find different things helpful, from heat patches, hot water bottles and hot baths, to things like pelvic stretches, breathing exercises, physiotherapy, acupuncture, dietary changes, you name it. It's worth taking the time to figure out what works for you, if anything. Many

find it helpful to also deal with the mental health and wellbeing ramifications of living with so much pain by seeing a counsellor, a psychotherapist, or a mindfulness practitioner. Endometriosis can't be cured, but it may be possible to find ways of living with it. Never give up hope.

This guidance is provided by endometriosis.org

LET OUR

#PAINSTORIES

BE HEARD

Thank you to everyone with endometriosis who shared their #painstories with us.



is a change-driving initiative,
improving women's intimate wellbeing worldwide.

A note on language

Ingrained gender bias stops women getting the treatment they deserve. But endometriosis also affects trans men and non-binary people, too. As does bias.

As a brand, we offer products for anyone who needs them, regardless of how they may identify. And when it comes to language, we are committed to being as inclusive as possible, but appreciate that there are many views that cannot currently be expressed by a common language and we may not get it right for everyone, all the time. We are learning every day.

We have kept the language in this book as inclusive as possible. Some of the research we have quoted did not distinguish on the basis of gender identity and the use of the term 'women' throughout reflects this.

We're committed to highlighting the experience of pain in an intersectional way - our wider #painstories campaign explores and shares the stories of women, trans men and non-binary people.

Sources

1. *What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis* (Fertility and Sterility, 2006)

2. The research was conducted by Censuswide with a nationally representative sample of 2000 adults, on behalf of Endometriosis UK, in 2020.

3. RCOG Position Statement: Racial disparities in women's healthcare, March 2020.

The information provided in this book is intended for educational and general information purposes only. All information has been fact checked to ensure accuracy, however it should not be substituted for medical advice from a doctor or a healthcare provider.

Share your #painstories on social or at bodyform.co.uk/painstories