IT'S A JOURNEY.

A graphic medicine exploration of endometriosis and gender diversity

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First Edition: October, 2024

Creative common of Treat it Queer

www.treatitqueer.org

Creative common of Spaghetti Publishing

www.spaghettipublishing.com

Treat it Queer

Treat it Queer is an **international non-profit** foundation dedicated to **health justice**, with a particular focus on the **queer community**. We seek to cultivate a growing awareness and understanding of the existing health inequities affecting gender and sexually diverse people worldwide, as well as bring greater visibility to the **real, lived experiences** of queer people in clinical practice, policy, and research.

We aim to do so using an **intersectional approach**, examining the ways in which different axes of privilege and oppression simultaneously contribute to health inequities. The **dismantlement of power dynamics** related – and not limited – to gender, race and class is central in our work.

This project has been funded by a Share-Net International Activation Fund. Share-Net International is the leading knowledge platform and member network for Sexual and Reproductive Health and Rights (SRHR).

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Preface

The first time I got my period, in a tent on a French summer night, I stared at my red-stained pyjama pants and knew my life would never be the same. The next morning, before family breakfast, my mom shuffled me into a toilet stall and awkwardly showed me how to put in a pad. Over baguettes with jam, the thick pad uncomfortably pressing between my legs, my dad half-jokingly said that this new physical state of mine meant that I could get pregnant, which made him feel old. I was twelve, not ready to take on the responsibility for my parents' budding midlife crisis, and definitely not ready to imagine my own pregnancy - let alone the road towards it. A private child, I had been keeping my discomfort with girlhood to myself and spent a lot of energy trying to cover up my curving body with oversized t-shirts. Now this disastrous event had finally, brutally exposed me to my family. I wanted to crawl back inside myself. But even there, it turned out, I wasn't safe: inside a storm was brewing. The next day, while my siblings were at the pool, I speed-walked desperate laps around the campsite, the pain so unbearable I was unable to stand still. In the many years following that rapturous summer, my period pain has become sort of a terrible companion, like a very familiar, but very annoying cousin. I cannot recount how many times I asked a doctor if this pain of mine was normal, and received the answer that it was "hormonal", or that I should take more paracetamol. At some point I started using the medical term "dysmenorrhea" in hopes that, as a future colleague, I would get some special treatment. Every month of every year, I crossed my fingers that my period would not fall on a workday, or that if it did, that the pain wouldn't start while I was giving a lecture, or attending a meeting, or doing anything else that didn't place me within one minute of a surface I could lay down on and rock back and forth. Given that two to three days a week my availability was completely unreliable, I doubted I could ever work as a doctor.

Writing as a queer person who always has a strip of heavy ibuprofen in my bag, I am sharing my story as part of this foreword, because stories are witnesses. In this case, my story bears witness to the gendered normalisation of period pain as something that is just part of it. The cramps, the isolation, the fearful anticipation: the world I had been socialised into assured me they were part and parcel of having a certain kind of biology. With me, many others have internalised our repeated agony as, well, normal. So we stay silent, fill another hot water bottle, gulp down another pain killer, and go about our day. And our stories? Like our diagnoses, they remain hidden.

The graphic novel you are about to read is a powerful, and certainly also a colourful aim to not only tell, but show how endometriosis accompanies Colt as an uninvited guest on their journey through life. Colt's story is important, because it is

an intimate revelation of a person grappling with the challenges of living (and loving) with a disabling, but invisible, disease. Whether through visual art or tell-all social media channels, such narratives provide indispensable insight into the everyday-affective realities of people that are our parents, children, friends or patients. But there is more to this particular tale. Although Colt's journey is one among many worth witnessing, its recounting endeavours more than foregrounding the injustices of missed or delayed endometriosis diagnosis. As Colt takes us by the hand, we are gently invited to rethink what we think we know about endometriosis.

They encourage us to challenge two logical paradigms: that of painful periods as normal and natural, and that of endometriosis as a woman's disease. As we come to realise that our understanding of the biological is profoundly shaped by the social, Colt's story, as any queer account, is about transformation... theirs, and ours.

In my late thirties I was finally diagnosed with a type of endometriosis called adenomyosis. While I was relieved, I was also confused. For years, I had had a complicated relationship with my reproductive system – not being able to imagine myself as a "mother", I had never seriously considered carrying and birthing, and therefore I had long accused my uterus of being a useless nuisance. Now that I might have more trouble than others getting pregnant, I panicked. Instead of becoming simpler, things had become even more complex.

Perhaps what I needed was a really cool graphic novel to take me by the hand. Enjoy!

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AMSTERDAM UNIVERSITY MEDICAL CENTER

Introduction

This project has been a **community-based journey**, from inception to final print. We hope that through these pages you will be able to appreciate the transformative potential of **participatory action health research**. Our wish was to **re-centre** the voices and experiences of marginalised communities, not only to offer a more comprehensive understanding of their needs, but also to actively **re-empower** them in the pursuit of **social and health justice**. Working from a community perspective is more than a methodological necessity; it is a form of resistance against systemic oppression, a means of enduring in the face of discrimination, and a path toward collective thriving. Through this work, we wish to reaffirm that true progress in health and social equity can only be achieved when communities are not just subjects of research, but **active partners** in shaping their futures.

As we have done with many projects at Treat it Queer, we have tried once again to **bridge the gap** between the world of academia and the communities that we study - and of which we are an active part of. Too often, research remains confined within the walls of academic institutions, inaccessible to those who could benefit most from its findings. This book is an attempt to counteract those extractive research practices by translating our findings into a more accessible format that brings the research back to the community. We believe that academic research should not just reside in journals or conference presentations but can and should be translated into creative media whose reach can extend far **beyond the borders of academics**.

This work is a piece of **graphic medicine** – a genre that blends the narrative power of graphic novels with the rigour of medical and health-related content. Graphic medicine is a revolutionary medium (not to mention extremely fun and engaging to work with!) because it translates complex and often inaccessible medical knowledge into emotionally resonant, relatable, and thus more understandable, content. By telling **stories in images**, we hope to engage people on a deeper level – one where clinical language often falls short in describing the **complexity** of such journeys of chronic illness and gender diversity.

But a picture is worth a thousand words, as the saying goes, and so without further ado, please enjoy the story of Colt, as they navigate the intricacies, challenges, and triumphs of growing up, and of life as a gender-diverse person with endometriosis. Keep what we have said here in mind as you read, and we will find you again at the end of this book.

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Chapter I

It's a girl!



"I fluctuate, and I fall somewhere in the middle."

S., NON-BINARY PERSON IN THEIR 40s, USA



I WAS BORN IN A VERY GOOD HOSPITAL. MY BIRTH WAS NATURAL, NO COMPLICATIONS. I WAS IN PERFECT HEALTH.

MY FATHER AND MOTHER HAD WANTED ME, VERY STRONGLY, FOR A VERY LONG TIME.

THEY DIDN'T WANT TO KNOW MY SEX AHEAD OF TIME —
THEY WANTED IT TO BE A SURPRISE WHEN I ARRIVED. MY
MOTHER WANTED A GIRL, AND MY FATHER HAD NO PREFERENCE (THOUGH HE SAYS HE FELT I WOULD BE ONE).

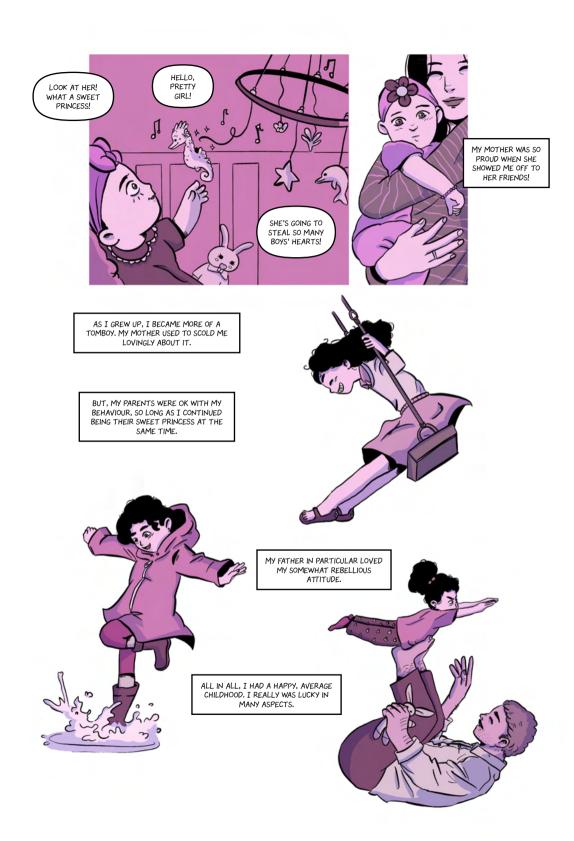
SO, IN THE END, THEY WERE BOTH VERY HAPPY!

MY MOTHER RECOVERED QUICKLY, AND THEY WERE ABLE TO BRING ME HOME EARLY.

SINCE THEY BOTH LOVE THE SEA, THEY CALLED ME MARINA.

"MARINA" MEANS "FROM THE SEA".





"I was used to being strong and fast so I could keep up with the boys.

I loved running, climbing trees and being really active outdoors.

Then everything changed for me because I didn't feel like

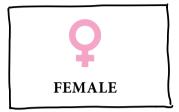
I could trust my body anymore."

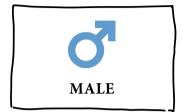
B., NON-BINARY TRANS MAN IN HIS 40s, USA



What does it mean to embody gender and sex?

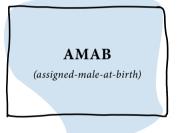
When a baby is born, sometimes even before that, we put them in a box.





This is what we call "assigning people at birth". People are typically either:





We assign someone a **gender** based on their **biological sex** characteristics, which are a complex interaction of genetics, gonads, and genitalia (also known as the "**3Gs**", yes, like the slow internet network)¹. We think that sex is either female or male, and thus gender must also be female or male – what we call the sex/gender binary.

However, both sex and gender are in practice far more varied and diverse than most basic biology books explain. Sex variations are present in myriad animal and plant species². There are fish that change their biological sex each reproductive season according to which sex is most needed in their school, and other species – like seahorses – in which males are the ones who carry the pregnancy. Humans are no exception: about 1-2% of all people present intersex conditions or experience differences in their sexual development³. Likewise, understanding of gender has been expanding well beyond the female/male binary throughout all human history. Gender nonconforming, third gender, and gender non-binary experiences are well documented among indigenous populations at any period of history^{4,5}.

But does gender diversity matter for health?

Well, the short answer is that, yes, it does. Gender is a predictive factor for many health-related behaviours (e.g., how often someone goes to the GP) and of how healthcare providers (HCPs) will respond to a health need (e.g., will they seriously acknowledge pain, or dismiss it?)⁶.

The longer answer is that—

Some people are assigned a certain gender at birth, and, as they grow up within the sociocultural contexts and expectations of that gender, feel comfortable and at ease going so. They can be said to embody their assigned gender. We call them "cisgender people".

But, for some, the expectations and trappings of the gender they were assigned at birth are not comfortable. Being perceived as that gender can make them uneasy, and they can identify differently - in one or multiple ways - throughout their lives. These individuals do not feel at home in their assigned gender. We call them "transgender or gender diverse (TGD) people".

TGD people often experience gender distress/dysphoria because of this "mismatch". Unfortunately, in most areas of the world they are marginalised, stigmatised and discriminated against. They can often be said to embody chronic stress as "minority stress," and this has been demonstrated to have a negative impact on their health8.

This book is about them.

But wait! we hear you say, is gender identity the same as sexual orientation?

No! Someone can identify as any gender, and express this gender in different ways, regardless of who they find attractive. Transgender and gender diverse people can be straight, gay, bisexual... any orientation under the sun.

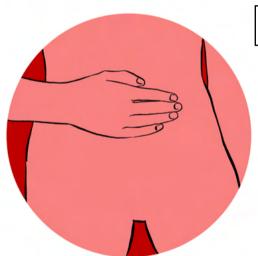
Chapter II

It's a girl. Period.









AFTER A FEW MINUTES THE PAIN WENT AWAY, SO I DIDN'T WORRY TOO MUCH...





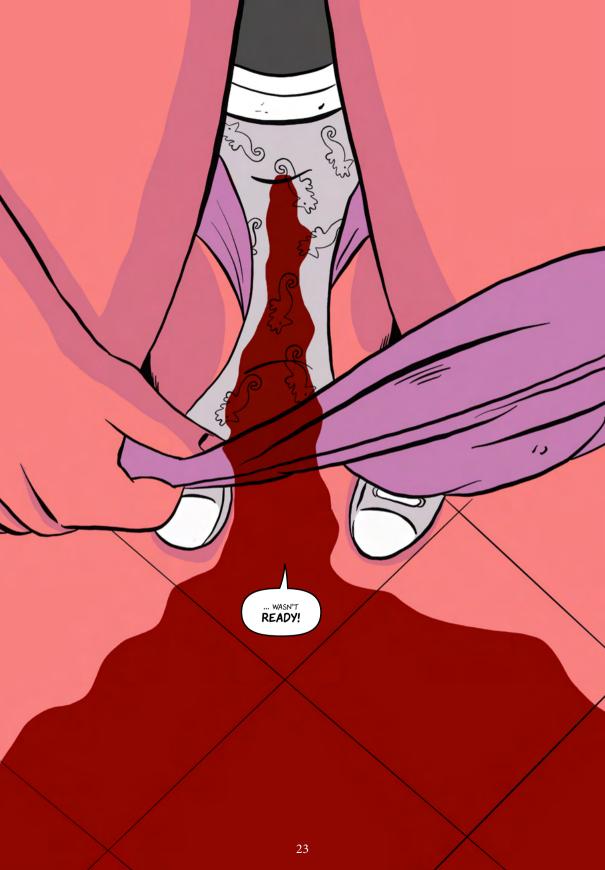
NORMAN IS MY BEST FRIEND. I'VE KNOWN HIM SINCE WE WERE SIX.

WE TALK ABOUT EVERYTHING...



... AT THE TIME I DIDN'T FEEL COM-FORTABLE TALKING ABOUT... WELL... GIRL THINGS.







I KNEW SHE WAS JUST TRYING TO SUPPORT ME. BUT FOR REASONS I COULDN'T UNDERSTAND AT THE TIME, ALL I COULD FEEL THEN WAS SHAME, AND FEAR...



... AND **FRUSTRATION**. HOW COULD SHE CONGRATULATE ME ABOUT SOMETHING THAT WOULD MESS UP MY LIFE EVERY SINGLE MONTH? I WAS ALREADY ANXIOUS ABOUT THE IDEA I'D HAVE TO LIVE WITH IT FOREVER. HOW COULD SHE BE HAPPY ABOUT SOMETHING I COULDN'T BE HAPPY FOR?

"I felt very frustrated (when my mom congratulated me).

How can you congratulate me with something that's going to interfere with my life so many days a month? I am already preoccupied with the idea that this is going to happen for the rest of my life.

How can you feel joy for something I can't find any joy for?

But now that I [haven't had] to deal with this for two years already, now I can feel the joy of not having to deal with this."

T. GENDER-NONCONFORMING PERSON IN THEIR 30s, NETHERLANDS

"I didn't understand what was going on. I remember being so scared and I remember going to bed in pain, then waking up in pain.

So from the first time I remember I associated my period with being in pain, not being able to run around like a kid. I remember [being afraid]... because when I told my mom she was like 'oh, you're like becoming a woman' – the classic things that people say. I remember I was like: but I don't wanna become a woman. I don't want to do this."

"In hindsight, I think I was experiencing dysphoria, gender dysphoria, along with the intense pain and struggle of menstruating."

H., NON-BINARY PERSON IN HIS 20s, GREECE

B., NON-BINARY TRANS MAN IN HIS 40s, USA

II

How to recognise endometriosis

Endometriosis is an **estrogen-dependent chronic condition** of the reproductive tract. It is characterized by **endometrium-like tissue** present **outside** the uterine cavity. Inflammation, immunological and fibrotic processes can interplay in endometriosis pathophysiology. The location and extent of endometriosis lesions impact the presentation of the symptoms. These are usually **cyclic**, but in case of a long-standing condition they can become chronic. The leading symptoms are:

Dysuria

(painful urination)
This is especially indicative
of deep endometriosis in
the anterior compartment.

Dysmenorrhea

(painful menstruation)
This is the most common symptom.

Dyschezia

(painful defecation)
This is especially indicative
of deep endometriosis in
the rectovaginal area.

TGD people report to be further particularly bothered by **chest**/breast **tenderness** and bloating (also known as "**endo belly**"). Chronic pelvic pain and pelvic floor dysfunctions are common comorbidities, and they disproportionately affect TGD people overall compared to cisgender women. Endometriosis is usually present during the **reproductive phase**, i.e. from menarche until menopause, and it tends to progress during the years when it is not adequately treated. It has a high impact on **quality of life** affecting many life domains. TGD persons report being particularly affected at:

Work and employability

The frequency and intensity of endometriosis symptoms often interrupt daily functioning. **Work absenteeism** is common for people with endometriosis, eventually affecting career choices and employment opportunities.

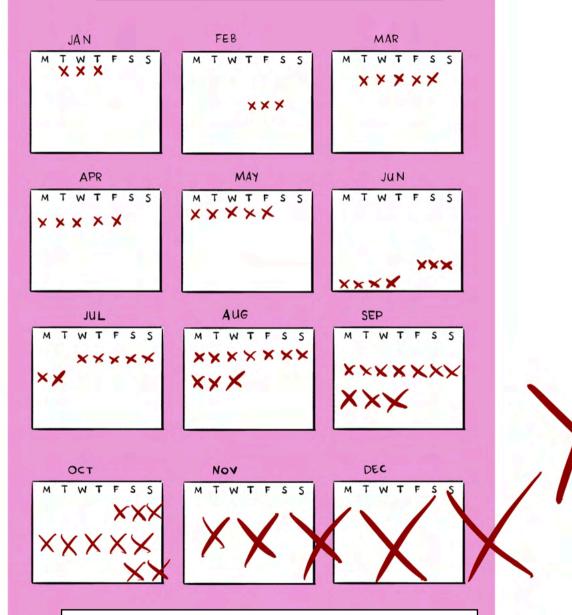
Sexuality and relationships

Pelvic and genital pain frequently impact sexual functioning, and sexual problems are common among TGD people with endometriosis. Sexual problems as well as difficulties in daily functioning and family planning lead to recurrent intimate relationships problems, and possibly termination of such relationships.

Family planning

A well-known consequence of endometriosis is **subfertility**. Some TGD people have a wish for biological children and sometimes to carry the pregnancy themselves. Endometriosis can interfere with their family planning due to e.g. lower germ cell quality and adhesions around the tubes.

I FELT DISCONNECTED FROM MY BODY WHEN I HAD MY PERIOD. MY SELF-IMAGE WAS TERRIBLE. I FELT **MISERABLE**, BUT I DIDN'T KNOW WHY. I DIDN'T HAVE THE WORDS TO EXPLAIN IT.



I WANTED TO HIDE MY CYCLE, HIDE MY BODY AS MUCH AS I COULD. I DIDN'T WANT THIS TO BE PART OF MY LIFE. I DIDN'T SHARE MY RELATIVES' HAPPINESS. I THOUGHT NO ONE COULD UNDERSTAND MY FEELINGS, THE PAIN I WAS GOING THROUGH. IT MADE ME FEEL SO ALONE.



Chapter III It's a period.













DON'T WORRY 'BOUT IT. SEE YOU IN CLASS.

SOMETIMES, I TOTALLY OVERREACTED.

IT WASN'T NORMAN, OR ANYONE ELSE. I JUST... **REALLY** DIDN'T NEED MORE PEOPLE TALKING TO ME ABOUT THINGS THEY DIDN'T KNOW.



I FELT... DISCONNECTED. WRONG. LIKE MY BODY WAS BETRAYING ME.













"To the best of my memory I started menstruating when I was 9 years old and I had no idea what was happening. I did not have any preparation for it from my parents and certainly there was no one in my age group in school that was menstruating at that age. My mother was really excited and she, you know, told me that this meant I was becoming a woman and she kind of wanted me to be excited about it as well, but it just felt embarrassing and painful and scary to me. And I didn't wanna tell my friends or anybody else about it. Certainly it wasn't exciting.

It never really has been. Of course it was painful, too."

B., NON-BINARY TRANS MAN IN HIS 40s, USA

"I wanted to hide my cycle, to hide my body as much as possible.

I didn't want this to be part of my life. I did not share the happiness that my relatives had and thought none could understand my feelings and pain. It felt isolating also because of this."

N., NON-BINARY PERSON IN THEIR 20s, ITALY

"I remember hiding myself in the corner of the changing room to get changed for the school and being so embarrassed that I would hide and turn to the wall so none could see me."

L., NON-BINARY TRANSMASCULINE PERSON, UK/AUSTRIA

"I didn't want to have much to do with my genitals,
I didn't want to put anything up there (like tampons).
It feels like I'm putting my hands into a wound."

M., AMBIGUOUS GENDER PERSON IN THEIR 20s, GERMANY

"I had always thought that a period or menstruation is like a woman's thing. So I think I felt more feminine (when menstruating) but in a bad sense, like a femininity that was imposed on me. So I think that kind of info influenced how I perceived myself in those days as well."

H., NON-BINARY PERSON IN HIS 20s, GREECE

"If periods were not just a gendered thing, I would probably not feel the same level of dysphoria, but that is unfortunately not the society we live in."

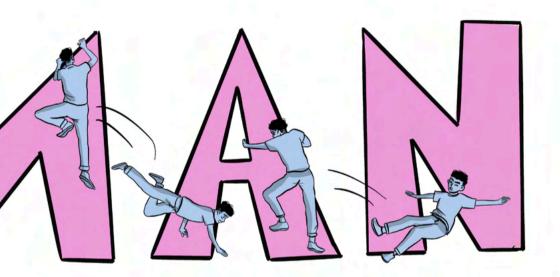
D., NON-BINARY PERSON IN THEIR 20s, CANADA

I OFTEN THOUGHT ABOUT WHAT MY MUM HAD TOLD ME:



"I FELT I'D NEVER BEEN GOOD AT BEING A "GIRL"... AND THEN, THAT I KEPT FAILING AT BEING A "WOMAN"...

... OVER, AND OVER, AND OVER AGAIN.

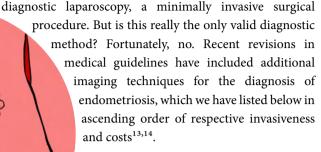




NO, IT CERTAINLY WASN'T **JUST** A PERIOD.

How to diagnose endometriosis

Endometriosis diagnosis has traditionally relied on the "gold standard" intervention of



Magnetic Resonance Imagin (MRI)

Previously considered the "gold standard" for diagnosing endometriosis, diagnostic laparoscopy is a minimally invasive **surgery** that allows the inspection of the abdominal cavity for endometriosis lesions. If lesions are present but are superficial, they can be removed during the same surgery. However, as it is a surgery, potential common complications associated with diagnostic laparoscopy are infections, internal bleedings, and damage to internal organs like the bladder or bowels. Diagnostic laparoscopy is usually performed in a day hospital, or occasionally with a one night admission.

Diagnostic

laparoscopy

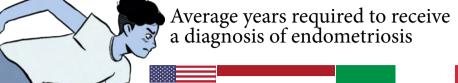
This diagnostic imaging technique provides highresolution images of the pelvic organs, helping to identify and assess the extent of endometrial tissue growth outside the uterus. It is particularly helpful in assessing deep endometriosis and extra-abdominal types of endometriosis. A skilled radiologist should analyse the images.

Internal pelvic ultrasound

Also known as transvaginal ultrasound, this is an effective, cheap, and quick method for diagnosing endometriosis. This method is especially suited to the diagnosis of ovarian endometriosis (i.e., endometriomas/ chocolate cysts). More experienced gynaecologists are also able to recognize adenomyosis and deep endometriosis using this method, provided that a high-quality ultrasound machine is available.

Nota bene: Imaging techniques for diagnosing endometriosis can sometimes be inconclusive. Current guidelines suggest initiating first-line treatment if symptoms are evident, even when imaging results do not show clear lesions. Additionally, internal pelvic ultrasound may not be accessible or suitable for everyone, particularly for those experiencing gender distress or with a history of sexual trauma. In such cases, alternative diagnostic options must be discussed and explored.

Why does it take so long?



4.4 years 7.6 years 11.4 years

Misgendering people

Misgendering is the act of undermining whether intentionally or not - someone's gender identity. This could be done, for example, by using incorrect pronouns, gender markers, or other gendered terms. Misgendering presents a significant barrier for TGD people to access healthcare, as it can intensify feelings of gender dysphoria and of disrespect, invalidation, and alienation, discouraging TGD individuals from seeking medical help. Moreover, misgendering perpetuates stigma and discrimination, contributing to poorer health outcomes for TGD populations in general¹².

Normalisation of pain

The normalisation of pain refers to the social and cultural processes through which pain, suffering, or discomfort are accepted as standard, inevitable, and are thus sometimes trivialised. Menstrual pain in particular is often dismissed outright by someone's close social circle, for example when female relatives brush off complaints with such sayings as "pain is normal" or "we all have to go through this". The failure to recognize pain as a **symptom** leads to delays in seeking aid and care by the people experiencing it. The gendered aspects of pain experience, expression and management play a significant role in the normalisation of pain, as stereotypes about people who menstruate being overly emotional - or even hysterical – contribute to dismissal and trivialization¹⁰.

Medical gaslighting

Medical gaslighting occurs when healthcare professionals disregard or undermine a patient's symptoms, causing the patient to doubt their own **experience** and perception of said symptoms. This phenomenon – which often hinges on the perceived unequal power dynamics between healthcare provider and patient – is severe enough that patients can come to doubt their capacity to interpret their symptoms and their severity, thus foregoing future seeking of aid and care. This, then, further contributes to underdiagnosis, misdiagnosis, and delayed treatment. Marginalised groups, such as TGD people, women, and people of colour, are particularly susceptible as their pain and symptoms are more likely to be attributed to psychological factors rather than physical ailments¹¹.

Chapter IV

It's they/them.



"It is really difficult to go into a women's health center and wait there.

I live in a very liberal area and some places around here
are being more inclusive. They're changing the identity of their clinics
to be more gender neutral so that other people feel comfortable obtaining
health care there. But a lot of them are still, you know, if it's a kind of
college-centered place, then it'll be a women's healthcare center,
it'll say so in the title. [...] There will be a lot of woman-centric imagery
and people will be calling me 'Ma'am' or 'Miss', which is so much worse
to me. Being misgendered in a medical setting happens very frequently
for me. And it's so frustrating. It is to the point that I actually legally
changed my (legal) sex so I'm now legally male because one provider
told me that they can only call me by my legal sex. So they can't use
that as an excuse anymore. When I am misgendered, really aggressively,
I do not tend to go back to that place, and that can really limit my care.

Because if they take such little care with my gender identity, I don't trust them to take good care of my body."

B., NON-BINARY TRANS MAN IN HIS 40s, USA

"I was completely alone for years in this pain. But anyway, people around me, especially cis women, were trying to foresee me in this gender role like pain for women is normal.

So if you are experiencing this pain, it's totally normal because you're a woman. If for you it is too much you're just exaggerating that. So even with my gynecologists it was always like this. It was just my exaggeration. And, my pain was never fully believed.

As something not normal. Even when it was very, very worse just before, a year before my surgery."

N., NON-BINARY PERSON IN THEIR 20s, ITALY

"For many many years I would go to doctors, to gynecologists and I would say 'Hey, I'm in a lot of pain' and they would say 'You're just anxious. You're just worried about exams at school.' [...] I wouldn't mention to my gynecologists that I was in (psycho)therapy because there is still a taboo in Greece. I knew she would just dismiss me then, and that she would be like 'Oh she is just anxious about things. She is just not well in the head. She's not actually in pain'."

H., NON BINARY PERSON IN HIS 20s, GREECE

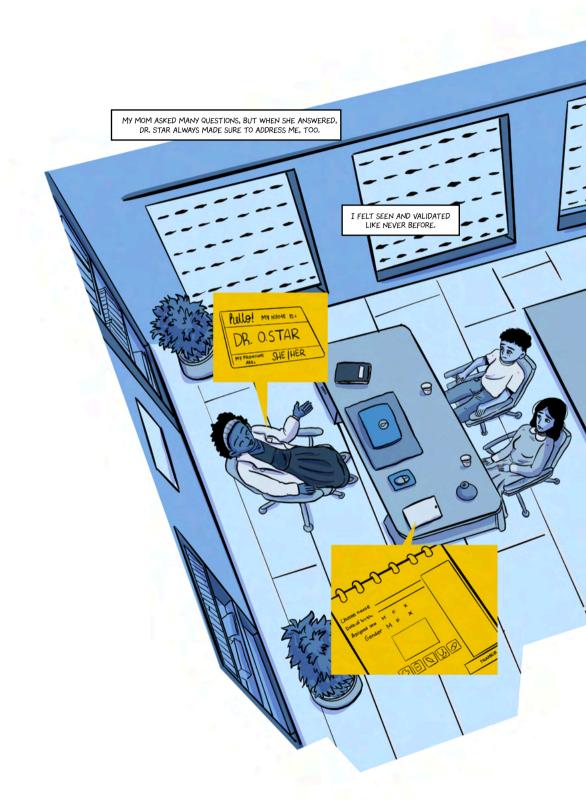
"It was kind of like: do I want to talk about my gender, or do I let it slip and get misgendered? (...] I decided not to speak up about it."

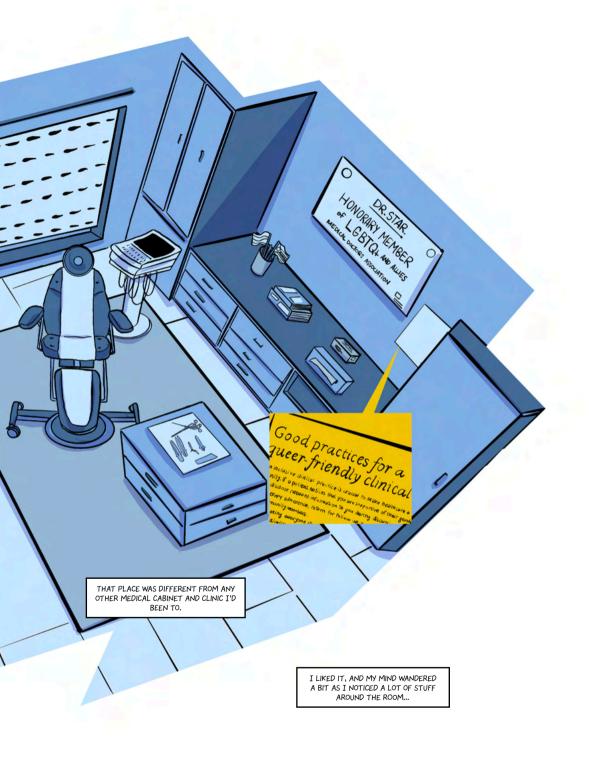
K., NON-BINARY PERSON IN THEIR 20s, AUSTRALIA













Good practices for a queer-friendly clinical practice

An **inclusive clinical practice** is crucial to make healthcare accessible to the queer community. If a patient notices that you are supportive of their gender, they will be more likely to disclose relevant information to you during discussions of medical history, have higher therapy adherence, return for follow-up appointments, and recommend you to other community members.

Just "treating everyone the same" unfortunately doesn't work when someone has been systematically marginalised and discriminated against due to their identities. TGD people experience several barriers to access healthcare. These can be due to individual, healthcare provider-related, or environmental factors. Whereas as a single healthcare provider, you often can't influence individual factors, such as a history of previous trauma, or environmental factors, such as choosing a different electronic data processing (EPD) system to manage patients' electronic files, you can have a very **tangible impact** in other meaningful ways. For example, you can¹⁵:

Display a rainbow-patterned ornament in your workplace or on yourself (no, really!, and it can be as small as a sticker at the front desk)

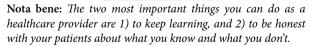
Register yourself in your local database of queer-friendly care providers

Display your own **pronouns** on your name badge and in your email signature.

Make your **work environment** as **inclusive** as possible (e.g., by having a queer-friendly magazine like this one in the waiting room!)

Adopt **gender-inclusive language** and practices (see the bibliography for additional resources)

Update the patient's preferred gender and pronouns in their medical **file**.



The points listed above are merely a few simple suggestions among many more potential actions – the ways in which you can adopt queer-friendly clinical practices are as diverse as the community they are intended for. While in an ideal scenario all possible queer-inclusive improvements would be implemented quickly, efficiently, and simultaneously, in practice, what initiatives are possible will vary from care setting to care setting and may be contingent on available resources and the socio-politico-cultural environment. When exploring these options, check their feasibility and prospective implementation timing according to the specific context. For example, in certain countries it is forbidden to display rainbow flags – in such cases, we recommend using more subtle ways of indicating support for the queer community. But remember: even small steps are steps, and each one matters.

THEN, A QUESTION SUDDENLY MADE ME SNAP BACK. WHAT DO YOU WANT ME TO CALL YOU? WHAT ARE YOUR PRO-NOUNS? MY NAME IS...IT'S... AND THEN I JUST SAID IT.



DR. STAR DID MORE THAN MEDICAL CARE. SHE ALSO INTRODUCED ME TO THE IMPORTANCE OF COMMUNITY.

TO SPACES WHERE I COULD FEEL SAFE, AND WHERE I COULD LEARN SO MUCH FROM PEOPLE WITH EXPERIENCES SIMILAR TO MINE.



DO YOU RE-MEMBER THE **RAIN-BOW HOUSE**?

LOVE THAT PLACE!

YEAH, WELL, I KINDA
PRACTICED THE NAME THING
THERE. THEY EVEN HELPED ME
BRAINSTORM UNTIL I FOUND ONE
THAT FELT LIKE MINE!

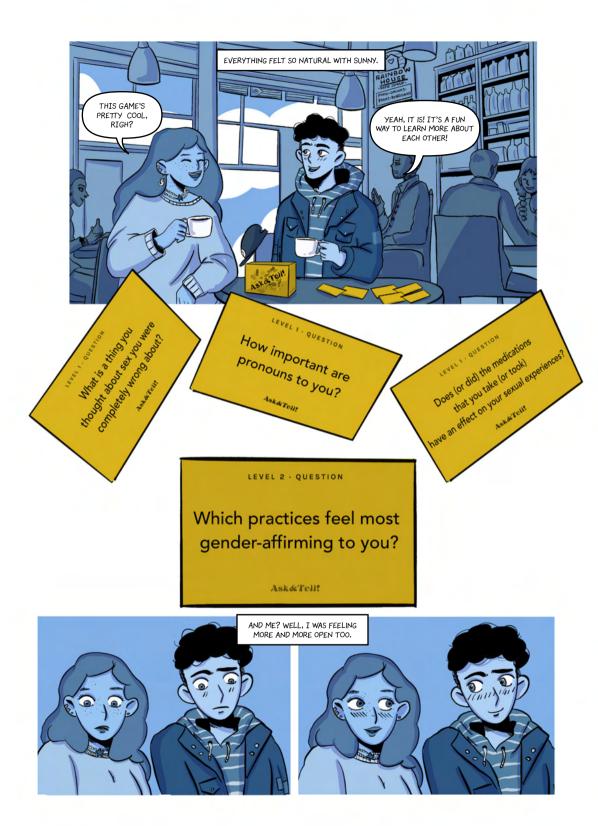
AND GUESS WHO I RAN INTO THERE? SUNNY!

> NO JOKE?! DID YOU FINALLY MANAGE TO ASK HER OUT?

OK, FIRST - HOW DID YOU KNOW? AND SECOND - **YES**, AND SHE SAID YES.

WELL FIRST - I'VE KNOWN
YOU FOR OVER 10 YEARS, AND I
HAVE EYES. I'VE SEEN HOW YOU
LOOK AT HER. AND SECOND...
SHE'S RIGHT BEHIND YOU.







How to treat endometriosis

Endometriosis is a chronic condition that often requires decades-long treatment. A **multidisciplinary approach** is necessary to manage endometriosis effectively and improve a patient's overall quality of life. Most TGD people living with endometriosis have between three and five different specialised healthcare providers that they see on a regular basis. While making a treatment plan, it is crucial to **integrate endometriosis treatment and gender-affirming care** (GAC) as two elements of the same care intervention that inform and influence each other. Such integration can be achieved via shared decision-making with the patient, using a process appropriate for their life stage¹³.

Nota bene: TGD peoples' use of GAC is deeply personal and can involve any combination of non-medical, hormonal, and surgical interventions. Consequently, a TGD person should not be assumed to use any one specific form of GAC, and a conversation to this effect is required with a healthcare provider when envisioning endometriosis treatment. The most common hormonal treatment is exogenous testosterone, and surgical treatments can include mastectomies, hysterectomies, and oophorectomies. About 1/3 of all people using testosterone use it as self-medication – a fact that is thus not reported in their medical file – and discussions on the use of GAC should therefore consider this particular element^{13,16}.

1. Pain management

Pain is a leading symptom of endometriosis, and it has to be relieved properly (remember: pain is *not* normal). **First line treatment** is an adequate regime of paracetamol and NSAIDs. If secondary **neuropathic pain** develops, neuromodulators should be considered. Opiates are not recommended for chronic benign conditions as they can quickly lead to addiction and have a high side-effects profile.

2. Surgery

If non-invasive medical treatment is insufficient for adequate management of endometriosis, a surgical approach may help relieve symptoms. It is crucial to counsel patients about the fact that surgery is **not an alternative** for hormonal treatment, and that hormonal suppression is advised to avoid recurrence even after surgery. Most endometriosis surgeries are conducted **laparoscopically**, sometimes with robot assistance. **Case-to-case considerations** are necessary to identify which surgery is most appropriate. The extent and location of endometriosis lesions, as well as personal preferences and a potential wish for (future) biological children are all factors that should be considered. Some TGD people opt for hysterectomies, tubal ligation and/or oophorectomies for gender affirmation. In such cases, consider removing endometriosis surgically while performing GAC operations¹⁸.

3. Hormones

As endometriosis is an oestrogen-dependent condition, hormonal treatments to regulate oestrogen levels and **suppress the menstrual cycle** play a central role in its management. Many TGD people, regardless of whether or not they live with endometriosis, already ask to suppress their cycle as part of GAC – combining the two therefore appears relatively straightforward. However, a frequent **misconception** is that effective suppression of the menstrual cycle and, by extension, endometriosis treatment, is achieved via a sufficiently high dose of testosterone. While, yes, testosterone does allow for the management of the menstrual cycle, it is not guaranteed: amenorrhea is only observed in 80% of people using testosterone within their first year of treatment, and break-through bleeding becomes more and more common as the treatment goes on. Moreover, many people using testosterone still experience **cyclic or chronic pelvic pain**. The underlying mechanisms of these clinical presentations are not fully understood, but one hypothesis is that excessive doses of testosterone convert to oestrogen through aromatization, thus contributing to the progression of endometriosis rather than its suppression¹⁷.

- If a person living with endometriosis does not wish to experience masculinization, regular endometriosis treatment guidelines can be followed. First line treatment consists of **progestins-only** or continuous oral contraceptives (**COC**), while second line treatments include **GnRH-analogues** or **GnRH-antagonists**¹³.
- If a person is using testosterone and their menstrual cycle is not sufficiently suppressed, progestins can be added¹⁶.
- If a person needs to suppress endometriosis symptoms and wishes to experience masculinization, consider using danazol. This gonadorelin-antagonist agent was long considered the "gold standard" for endometriosis treatment, but its use has been discontinued among cisgender women due to its irreversible androgenic properties. Nonetheless, its use for endometriosis treatment is supported by ample evidence. It is highly effective in the management of endometriosis symptoms, has a high safety profile, and is cost-effective.

Nota bene: TGD people may not tolerate typical endometriosis treatments – such as COC – either because they contain oestrogens, or because of their known side effects, for example on chest tenderness (that are particularly impactful for people experiencing chest dysphoria). Patient needs must always be discussed and considered in the development of individualised patient-centred treatment plans.

4. Long-term non-clinical support

Endometriosis has a high somatic and psychological comorbidity rate. Moreover, its consequences are often multifactorial and lifelong. Therefore, a comprehensive treatment plan should consider and tackle all aspects interfering with a patient's quality of life.

Self-management strategies such as dietary changes and aerobic sports should be encouraged. Digital health interventions – such as tracking symptom patterns – are proven to have positive effects for most people.

Finally, a comprehensive endometriosis care team that will accompany the patient throughout their treatment plan and the subsequent follow-ups over the course of their lives includes specialists in gynaecology, endocrinology, radiology, and surgery, as well as pelvic floor therapists, psychotherapists, clinical sexologists, and nutritionists¹³.

Chapter V

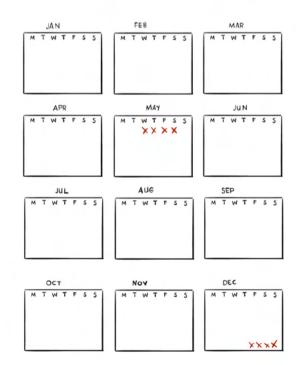
It's home.







... AND "GIRL THINGS" BECAME JUST "THINGS".





"As far as my gender goes, I didn't realize how trapped I felt in my gender until I no longer menstruated, and that sense of freedom was incredible and that is when my sense of gender began to seriously fluctuate."

B., NON-BINARY TRANS MAN IN HIS 40s, USA

"I had no business being in that body, if that makes any sense at all?"

I. NON-BINARY TRANSMASCULINE PERSON IN THEIR 20s, NETHERLANDS

"I felt a sense of relief (when they told me my tubes didn't work and I couldn't count on them) that was a starting point to see the connection of gender and the surgeries. So many people asked me, 'Omg you are so young, and you are going to lose your uterus, how is that for you? As a woman?' [...] I'm fine with my body without a uterus, and I don't feel like I'm losing my feminine side.

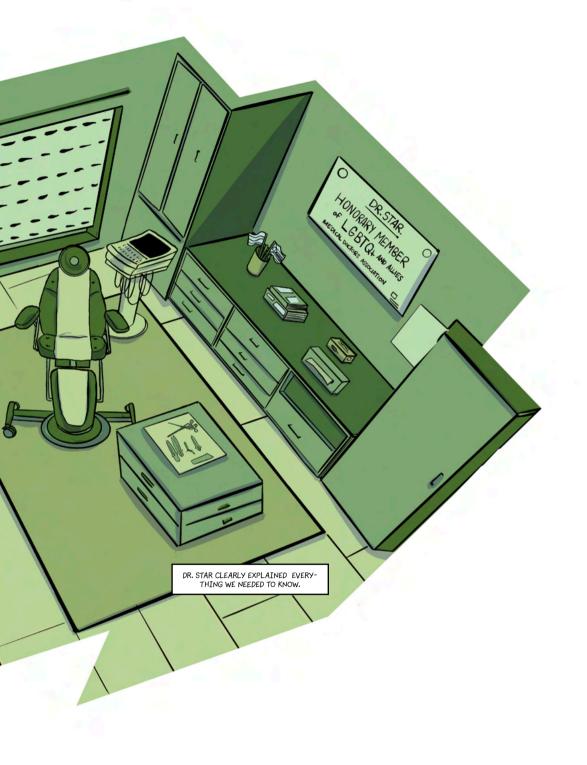
I feel like the loss was kind of put on me."

T., GENDER-NONCONFORMING PERSON IN THEIR 30s, NETHERLANDS

"There is a question in me that may always be present about what my gender is. (My gender) might never be stationary, it might always be in flux. I started transitioning as a middle-aged person in my mid-forties, and so that's going to be really different from perhaps someone that hasn't lived an entire life as a particular gender. I'm not sure how fluid it is for me because I don't know that I will be flowing into feeling like a woman again. It may never happen for me again? So I have learned to live with that question and to treat it as sacred."

B., NON-BINARY TRANS MAN IN HIS 40s, USA





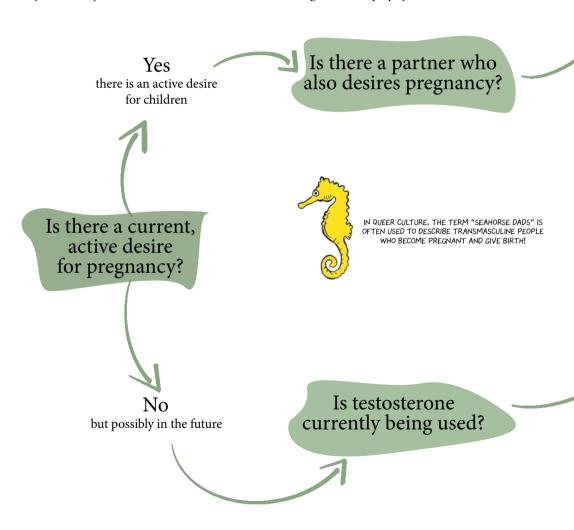


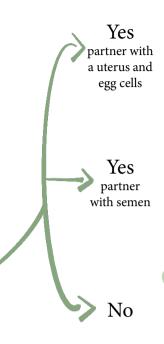
Reproductive health options

Family planning is important to TGD people and their partners, and – contrary to popular belief – many TGD people desire biologically related children.

Endometriosis can lead to **sub-** or **infertility**, and the further the condition progresses, the higher are the chances that a person experiences fertility-related difficulties. Testosterone itself also affects fertility and is not recommended in case a person has an active desire for pregnancy, due to its **teratogenic effects**. Therefore, adequate counsel for people with (suspected) endometriosis and/or who are considering medical genderaffirming care is *essential*^{19,20}. So, let's explore existing options!

Nota bene: The accessibility of these options depends on many factors such as legal and political frameworks, financial barriers, and the socio-cultural challenges that TGD people face in certain contexts.





Egg cells can be retrieved from either partner. Donor semen is then necessary to create an embryo. Pregnancy can be achieved through intravaginal or intrauterine insemination or IVF/ICSI. Previously frozen egg cells or embryos can be used for IVF/ICSI procedures. Reciprocal IVF means that the egg cell belongs to one partner while the other partner carries the pregnancy.

Spontaneous pregnancy is an option if the TGD person has a natural cycle and is not taking testosterone. Frozen egg cells can be used to create embryos with the partner. Alternatively, embryos with both partners' genetic material can be preserved and used at a later date when there is an active desire for children. Pregnancy can be carried by the TGD person or by a surrogate parent.

Donor semen is necessary. Intravaginal or intrauterine insemination as well as IVF/ICSI are viable options. Previously frozen egg cells or embryos can be used for IVF/ICSI procedures. Pregnancy can be carried by the TGD person or by a surrogate parent.



- Egg cell cryopreservation (via IVF)
- Embryo cryopreservation (via IVF)
- Ovarian tissue cryopreservation (experimental)
- Discontinue use for 3-6 months, or until menstrual cycle resumes

Nota bene: Hormonal treatment for endometriosis management must be discontinued in order to proceed with the cryopreservation of genetic material or to achieve pregnancy. This usually implies that, at best, symptoms will return and, at worse, the endometriosis could progress. IVF/ICSI procedures can further contribute to endometriosis worsening, such as by increasing the chance of ovarian cyst recurrence. Every person with endometriosis should be adequately counselled about these drawbacks and side effects for assisted reproductive technologies^{13,16}.



I KNOW I JUST GAVE YOU A LOT OF INFORMATION ALL AT ONCE. GO HOME, AND LET IT SINK IN.

> AND PLEASE -CALL ME IF YOU HAVE ANY FURTHER QUESTIONS.





Chapter VI

It's framily!



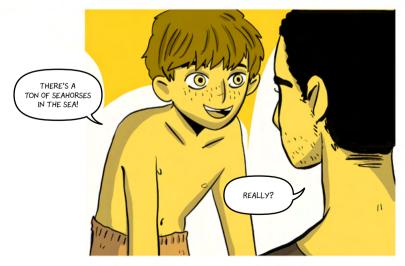




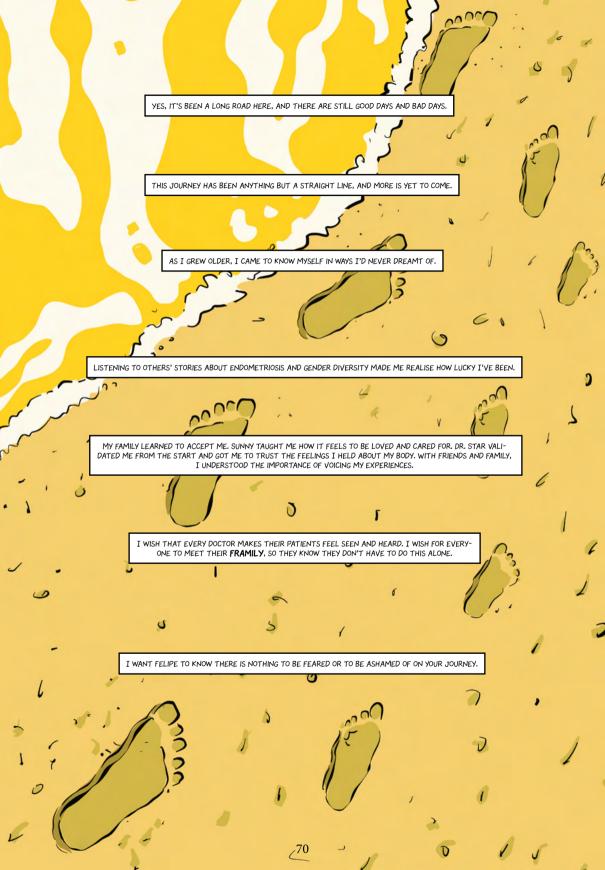
















Gender and endometriosis: A galaxy to keep exploring

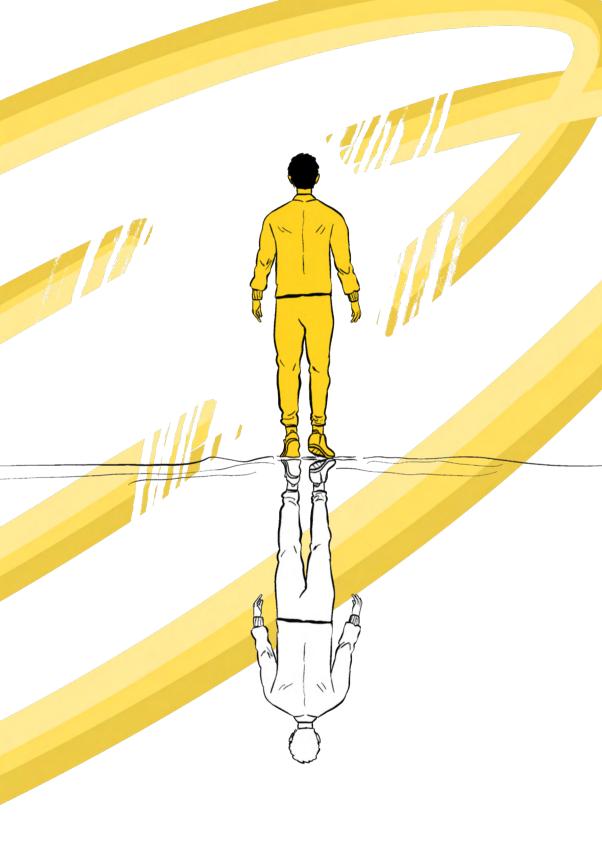
Endometriosis symptoms usually start at **menarche** in the early teens, and remain present and require treatment until menopause, around 50 years old. That is roughly **40 years** living with this condition.

Gender identity tends to develop around puberty and in early adulthood, when many people recognize feelings of gender dysphoria. Everyone has a **different path** in how and when they cope with them. Most TGD people say they never stop learning about themselves and their gender.

The **intersection** of other identities and their realities, such as race and class, can make the path steeper or smoother.

The **social support** that someone has (or doesn't have) makes a great difference in how they walk through life, and how much of themselves they are able to explore and develop.

Awareness of marginalised experiences within medical practice is needed to guarantee an inclusive healthcare system and move ever forward towards social and health justice.



Postface

In telling this story, we faced choices – choices about whose experiences to highlight, what identities to centre, and how to weave a narrative that could speak to the complexities of gender diversity and of lives with endometriosis. We chose not to focus on a single individual but to create a composite character whose story closely reflects the lived experiences of the many people who have shared the details of their lives with us throughout our research. The fictional dialogues and medical information capsules contained in this book are informed both by original research conducted by our team and pre-existing scientific literature. Though this particular story is fictional, stories like this one are not imaginary; they are grounded in the realities faced by many. The quotes you have read throughout this work were provided by individuals like Colt, living at the intersection of gender diversity and endometriosis. Though slightly edited for clarity and readability, they otherwise remain exactly as they were given to us. They are testaments, in trans and gender-diverse peoples' own carefully chosen words, of their lived experiences, and of how they navigate the stormy waters of their reality each and every day. We hope they have resonated as much with you as they have with us.

Every character and every event you have encountered in these pages is based on **real**, **lived experiences**. The only exception is Norman, a cis man, who is Colt's best friend and a supportive character throughout the narrative. He is a pure creation, a deliberate narrative choice, born of our imagination and hope that more cis men can become **allies** in the struggle against marginalisation.

Deciding who would constitute this book's target audience was also a complex puzzle. Ultimately, we chose to place primary focus on **healthcare professionals**. We did so because we recognize the critical need for advocacy within healthcare systems themselves and because healthcare professionals are uniquely positioned to advocate for and enact systemic changes capable of improving care for countless individuals. This book is a tool by which we hope to provide awareness and understanding within the medical community. Of course, this is not to say transgender and gender-diverse people with endometriosis themselves should not read this book. On the contrary, we hope they can find comfort in the representation within these pages.

In closing, allow us a personal reflection. Marginalisation is a heavy, insidious thing that crawls under our skin just as we learn to live with it. But we believe it can be a wellspring of creativity. It is, after all, **in the margins that creative and unique self-expression arises**, born of a need not just to survive, but to *thrive*.

This graphic novel intends to be an example of that creativity. This is a work born from the need to be seen and heard, to tell **stories that matter**, about **bodies that matter**, and to push against the boundaries that often keep these stories hidden and quiet. Our hope is that this book will not only inform and educate, but also inspire others to continue this work – to use creative media to bring marginalised voices not just to a seat at the table, but squarely at the heart of the conversation.

We hope you can appreciate how this graphic novel is not just a translation of research; it is a reflection of a community's resilience, strength, and creativity. We hope it serves as a reminder of the importance of inclusive, community-driven research and the power of storytelling to bring about change towards **social and health justice**.

On behalf of the working group,

DR. MADDALENA GIACOMOZZI (THEY/THEM), MD, MGH, PHD CANDIDATE DEPARTMENT OBSTETRICS AND GYNAECOLOGY RADBOUD UNIVERSITY MEDICAL CENTER CO-FOUNDER AND PRESIDENT OF THE TREAT IT QUEER FOUNDATION

Acknowledgements

We would like to take a moment to acknowledge and thank all the people who took part in the research and whose names have been anonymised throughout this work. Without you, there would be no book.

We would also like to offer special recognition and gratitude to:

Max Jahufer (he/him), Endometriosis Australia Advocate and Ambassador, for sharing their journey as a trans person with endometriosis and into parenthood;

Jaz Brazilton (they/them), research assistant and Treat it Queer intern for telling us about their real lived experience and their professional insights in pain mechanisms;

Jip Bouwens (they/them), research assistant and Treat it Queer volunteer, for their sparkling input during brainstorming, and for coming up with the idea of the seahorse;

Anna Mai (they/them), PhD, postdoctoral researcher at the Max Planck Institute for Psycholinguistics, for coming up with original and well-suited names for the characters;

Stéphane Aubin (he/they), Treat it Queer co-founder and communication officer, for your relentless but deeply caring editing;

Maaike Muntinga (she/they), MD, PhD, Assistant Professor at Amsterdam University Medical Center, for her moving and insightful preface;

and, of course, to

Dr. **Petra Verdonk** (she/her), PhD, and Prof. **Annemiek Nap** (she/her), head of department of Obstetrics and Gynaecology at Radboud University Medical Center, for their warmhearted and meticulous supervision.

This project is sponsored by Share-Net International, and all people who partook in it have been remunerated for their work.

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About the authors

ASIEL [Elisa castellano] (SHE/HER)

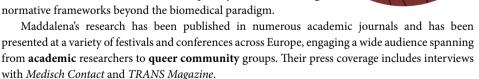
ASIEL graduated from the International School of Comics in Italy with specialisations in both Comics (2019) and Scriptwriting (2020). She is also the founder of Spaghetti Publishing (2020), for which she creates or collaborates on many books as a scriptwriter, illustrator, and main editor. In 2020 she won her first prize for the "Tomorrow People" contest with her comic. ASIEL published with many indie publishers until, in 2022, she joined the agency Tomato Farm, became Art Director for ReWriters magazine in Rome, and started working as an editor for the Shockdom publishing house and as a freelance illustrator

and graphic designer. Since 2023, she has been working with schools, companies, and national and international organisations to publish books and illustrate projects for **education and awareness** in many social subjects, including but not limited to: environment, lgbtqia+ rights, accessibility, and different cultures. In her spare time, ASIEL returned to her alma mater and became a **teacher** at the International School of Comics.

Now, she's opening her own company, teaching, and working on projects she feels passionate about, both personal and professional.

MADDALENA GIACOMOZZI (THEY/THEM)

Maddalena Giacomozzi is a queer medical doctor, PhD candidate, and LGBT+ health advocate. With a background in international medicine and global health, they have dedicated their career to advancing sexual and reproductive health justice for marginalised communities. Their clinical work focuses on endometriosis and sexology, while their PhD research explores endometriosis among transgender and gender-diverse individuals. By integrating intersectionality and embodiment theories, their cross-disciplinary research challenges normative frameworks beyond the biomedical paradigm.



Since 2021, they are the co-founder and **president of the Treat it Queer Foundation**, where they have led numerous projects aimed at promoting inclusivity and diversity within the healthcare profession. Through the Foundation they regularly deliver lectures and workshops on gender diversity in healthcare to both medical students and specialists.

Maddalena's favourite colour is red.



"Colt takes us by the hand, they encourage us to challenge two logics: that of painful periods as natural, and that of endometriosis as a woman's disease. As we come to realize that our understanding of the biological is profoundly shaped by the social, Colt's story, as any queer account, is about transformation ... theirs, and ours."

MAAIKE MUNTINGA