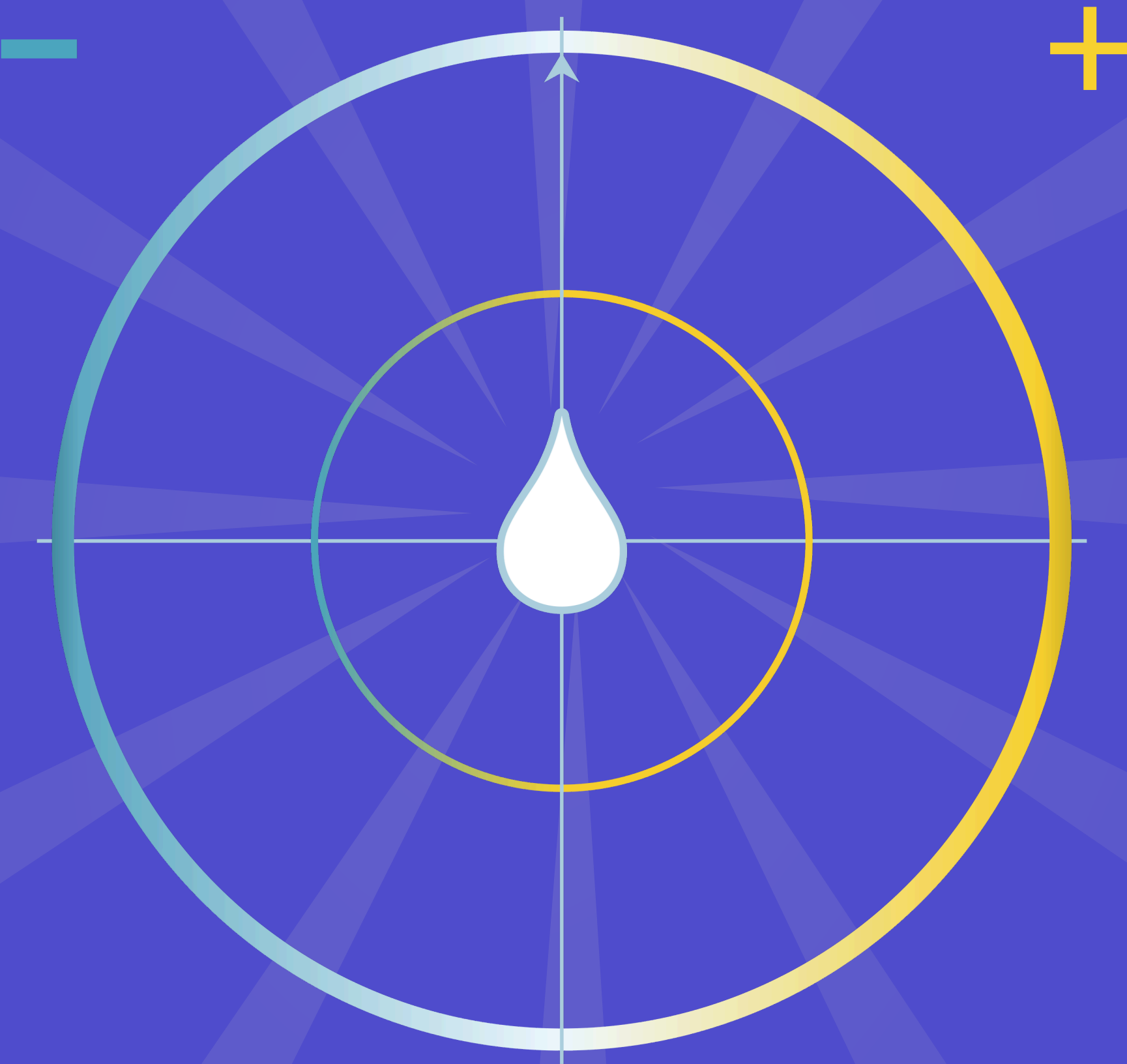


FINDING YOUR WAY THROUGH ENDOMETRIOSIS



Cofinancé par
l'Union européenne

“FINDING YOUR WAY THROUGH ENDOMETRIOSIS” is a guide allowing people suffering from endometriosis to self-write and investigate their experience with their illness starting from their concern, that is to say their pebble in the shoe, what they hold on to, what keeps them standing and what is threatened, inspired by the compass initially designed by the Consortium “Where to land? with the philosopher Bruno Latour.

Its goal is to empower people to take action regarding their chronic illness so that they can equip themselves to live better with it. This guide is one of the training programs of the European ENDOs project, supported by the Erasmus+ program for lifelong adult education.

This educational program was tested for a year at the Clinique Mutualiste de Pessac with the support of the ARS Nouvelle-Aquitaine and the Fondation de France as part of the EndoTalk&Yoga self-care educational program of L’Agence Créative/Endométriose Academy.

It uses the resources created by the Rivage Collective, holder of the Where to Land? protocol.

It was designed by four qualified patient-partners, a surgeon and a yoga teacher.



WHO IS THIS GUIDE FOR?

Are you lost when it comes to endometriosis? That's normal; endometriosis is like a continent whose typology is only just being discovered. Whether you've just been diagnosed, perhaps after years of wandering, or you've been living with the disease for a long time, this guide is for you.

It is aimed at people who live with endometriosis and who want to regain control over it during collective educational workshops on self-description of their existence with endometriosis.

This isn't a magic guide to curing endometriosis, as there is no cure today, in 2025. Nor is it to say that everything depends on your willpower. Absolutely not! This view would be completely wrong and would only fuel your guilt.

This involves listing the entities (people, treatments, objects, etc.) that threaten our good life and those that maintain it, in order to take action and create alliances based on your concern (see next page). It may seem dizzying. But if you are reading this brief introduction, it is because, in a way, your investigation has already begun and you are ready to move forward. There is not just one path; there are many, just as there are as many types of endometriosis as there are women. Regaining power over your endometriosis means finding your own path. So, as the disease fluctuates and your concern evolves, you will need to constantly reorient your compass.

We invite you to conduct your self-description and take action with kindness and without prejudice.

WHO CAN LEAD THE WORKSHOPS?

The workshops are led by qualified Patient-Partners involved in endometriosis to educate patients within the framework of discussion groups or patient therapeutic education programs and by people trained in the Where to land? survey protocol.

It is possible to use the compass individually, however it is initially designed to be activated during collective workshops and discussion groups which allow alliances to be created and one's own compass to resonate with those of other patients affected by the same illness.

The workshops also involve the body through various exercises such as yoga, as well as arts and cooking.

Learn more about the Where to Land? protocol on the Rivage Collective website

WHAT SCIENTIFIC DATA ON ENDOMETRIOSIS WERE THE WORKSHOPS DESIGNED?

WHAT DO WE KNOW ABOUT ENDOMETRIOSIS IN 2025?

Endometriosis is a chronic, inflammatory, homo-dependent, systemic, complex and common disease (1 in 10 women) characterized by the presence of endometrial-like tissue (but not endometrium) outside the uterus (1, 2).

“Long considered a gynecological disease, now recognized as a systemic disease” (Lancet 2021). It involves:

- Systemic inflammation
- Deregulation of the immune system
- Dysbiosis (microbiota imbalance)

Its impact on women's quality of life is therefore global. It can lead to painful and/or heavy periods, intense and chronic pelvic pain that can spread throughout the body, such as lower back pain and lower limb pain, it leads to fertility problems, gastrointestinal disorders. In addition, women report chronic fatigue, depression, and psychological difficulties.

Endometriosis pain has multiple origins:

- Nociceptive pain due to endometriosis lesions that “bleed every month” and trigger inflammation and neuroangiogenesis mechanisms (biological process that consists of the creation of new blood vessels from pre-existing vessels)
- Neuropathic pain: damaged nerves
- Nociplastic pain that results in central sensitization. Central sensitization is a disorder of pain modulation by the central nervous system resulting in an increase in pain perception.

The treatments offered are:

- hormonal (continuous pill, “artificial menopause”)
- painkillers
- PMA / fertility preservation
- surgical

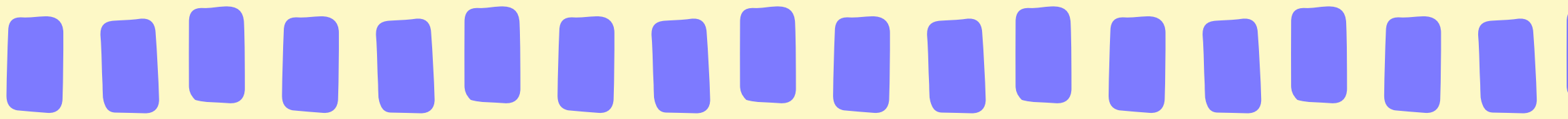
There are no curative treatments for endometriosis.

Up to 83% of patients have persistent pain despite surgical and/or medical treatment (O’Hara 2022), which is why, in accordance with the HAS recommendations for multidisciplinary management of chronic pain, supporting patients in the self-management of their symptoms, in addition to the conventional care pathway, is essential.

BRIEF PRESENTATION OF THE ENDOTALK&YOGA PROGRAM:

"EndoTalk & Yoga" is a program of educational workshops co-constructed by caregivers from the Clinique Mutualiste de Pessac and patient-partners holding the DU of "Patient-trainer in chronic care pathway" from the University of Bordeaux and trained in Therapeutic Patient Education. It is aimed at patients suffering from endometriosis and their loved ones in the form of discussion groups and adapted yoga, in a safe and caring environment with professionals trained in facilitation and engaged in the field of health humanities. The objective is to better support women in the care setting through personalized support adapted to the specificities of this highly disabling disease and its multiple symptoms in order to: increase women's power to act, promote the therapeutic alliance, enable them to acquire knowledge and self-care tools to manage their chronic disease, free their speech, meet as peers, reconnect with their body and increase their autonomy in order to gain quality of life on a daily basis.

"EndoTalk & Yoga" affirms the recognition of the status of qualified patient-partners in healthcare settings and the promotion of their experiential knowledge by integrating them into programs with caregivers.



THE OBJECTIVES OF THE ENDOTALK&YOGA PROGRAM:

1. Create a safe space for humanizing care, free expression and listening, which allows women to speak freely about topics related to their experience with their chronic illness, no longer feel alone, meet other affected women and discuss subjects without taboos.
2. Involve patients and support them “in understanding their illness and treatment, in collaborating together and in taking responsibility for their own care, with the aim of helping them maintain and improve their quality of life.” (definition of therapeutic patient education by WHO-Europe published in 1996)
3. Developing patients' self-care skills through yoga to reduce their pain by working on their pelvic mobility and supporting patients to help them find solutions to the problems they may encounter in their daily lives.
4. Campaign for the recognition of the status of patient-partner users by integrating them into the creation and supervision of programs and educational pathways and increasing the involvement and power of patients to act in their care pathway.

FINDINGS AND NEEDS:

The project was born from a meeting between Nadia Russell Kissoon, a patient-partner, and Dr. Géraldine Chauvin, an endometriosis surgeon. They identified patients' need to participate in discussion groups and receive complementary care for pain management, to improve their daily lives with the disease.

This finding corroborates the responses of 1,000 patients in the INSERM ComPaRe Endometriosis survey. "If you had a magic wand, what would you change in your care?"

- "Improve therapeutic care by offering more alternative and complementary medicines and self-management methods."

- "Promote patient involvement in care".

- "Provide more support to patients: Give patients the opportunity to participate in patient groups; "provide more advice and better support to patients so that they feel less alone or lost in the face of the disease"; involve the partner or family in the care (...) and support from them." Furthermore, in France, the number of women of childbearing age suffering from endometriosis is estimated at between 1.5 and 2.5 million, or 1 in 10 women. Since January 2022, President Emmanuel Macron's national strategy has aimed to: "guarantee rapid diagnosis and access to quality care throughout the country (...) through personalized care pathways (PPS) developed for patients in order to organize real collaboration between the different professionals from the moment of diagnosis and allow each patient to have concrete access to the care they need (...) and improve the management of chronic pain." The "EndoTalk & Yoga" project aims to participate in this national movement and respond to the needs identified by caregivers and patients, by actively involving qualified user-partners in its co-creation to improve access to care pathways.

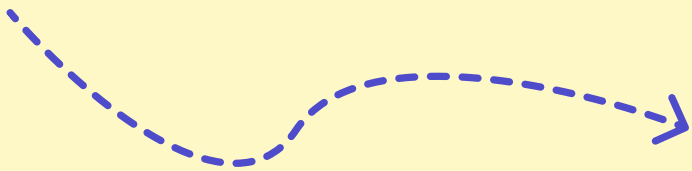


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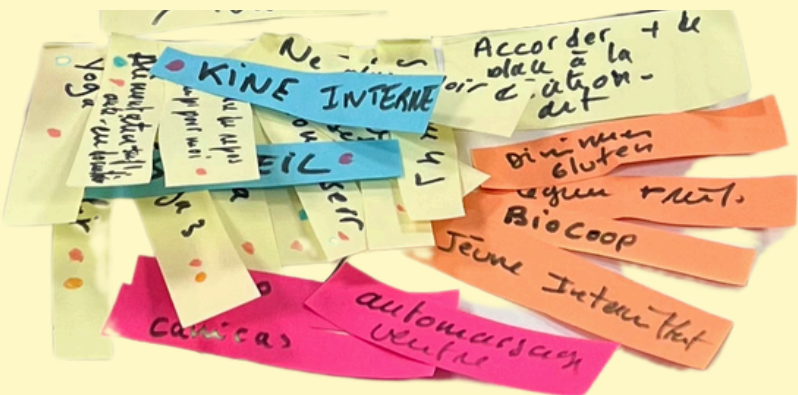
SESSIONS TO
FINDING YOUR
WAY THROUGH
ENDOMETRIOSIS

MATERIALS NEEDED:

PRINT THE COMPASS We invite you to print it (in color or black and white) in 4 A4 format pdfs which will need to be taped together from the back to obtain an A2 format



Get some Post-it notes in different colors and a pen or pencil



Cut the post-it notes into strips to take up less space on your compass when you place them.



From a yoga mat



Paints, pencils, felt-tip pens, sheets of paper and any other material to fuel your creativity



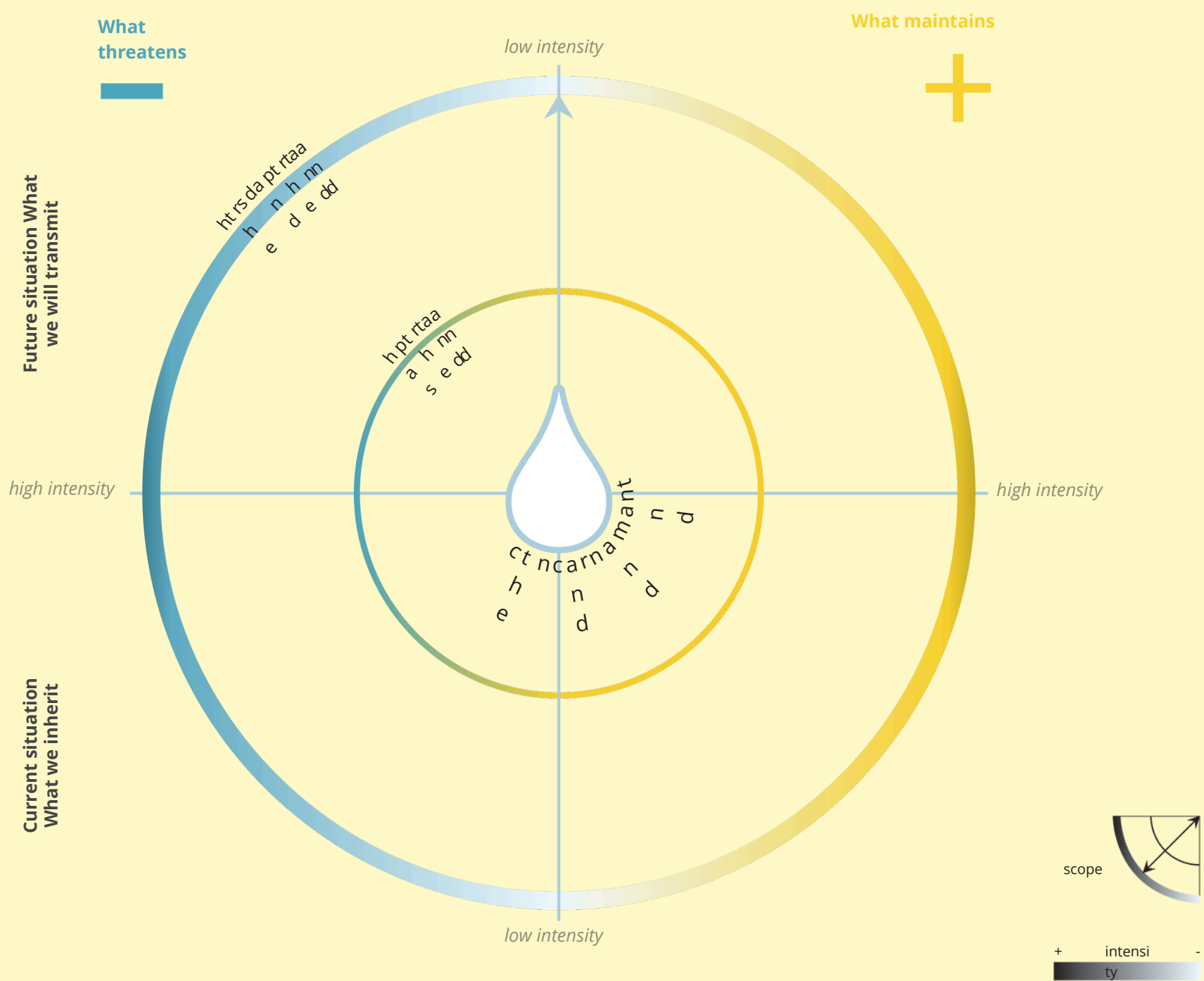
Ingredients needed to make spring rolls!

HOW DOES THE “WHERE TO LAND” COMPASS WORK?

The compass is a spatial self-description device that will allow you to visualize your investigation.

At its center, we place our “Concernment,” what we care about and what seems threatened. It’s not about feeling sorry for ourselves, it’s about mapping our concern to create new arrangements that contribute to improving our living conditions. What actions can I put in place? Example of concern: for “Pain-free sexuality,” for “Living well with my endometriosis,” for “Talking about my endometriosis with those around me.”

- What threatens his concern is on the left (-)
- What maintains its concern is positioned on the right (+)
- The central line represents my current situation, my present. That is, what is closest to me at the moment.
- Everything above the line is my future
- Everything down is my current situation and what I inherit.
- The arrow points toward the future. This is the time axis. The goal is to orient this arrow toward the positive, that is, the desirable future, toward positive action and not toward the negative, which would be sterile or negative production. However, negative entities will always exist.
- What I can control is close to the center of the circle. The further I am from the center, the less control I have, the less scope I have over my concern.





CONDUCT OF EACH WORKSHOP:

1/ DISCUSSION GROUP: 1H30

- **Saying hello and waking up the body: (about 10 minutes)**

Examples:

<https://labase-gironde.fr/wikiCollectifRivage/?ProtocoleS> <https://labase-gironde.fr/wikiCollectifRivage/?ProtocoleS> <https://labase-gironde.fr/wikiCollectifRivage/?ProtocoleS>

- **Discovery of the day's theme (5 minutes)**
- **List your entities and place them on the compass (20 minutes)**
- **Each person presents an entity in turn (40 minutes, distribute speaking time well)**

The golden rule that we adhere to in the workshop and until the end of the experiment:

We never give our opinion, we don't discuss, we don't respond, never. Even if at first we have difficulties and we feel like we really want to respond, we cling to the rule to listen to the citizen-expert's description.

- **Ending ritual (10 minutes)**

Example:

<https://labase-gironde.fr/wikiCollectifRivage/?ProtocoleS>

2/ LUNCH (INFORMAL AND FRIENDLY TIME): 1H

3/ YOGA Each workshop ends with a Yoga session adapted to endometriosis.



SUMMARY OF THE 6 WORKSHOPS

Workshop 1:

My endometriosis

Workshop 2:

Well-being and mental
calm

Workshop 3:

Pain and
complementary care

Workshop 4:

The pleasure of food

Workshop 5:

Emotional and
sexual life

Workshop 6:

What the compass
made me do



WORKSHOP 1: MY ENDOMETRIOSIS

Goals:

- Meet and establish a climate of trust, kindness and listening
- Present the program
- Define your concern (see next page) based on your experience with the illness.
- Knowledge of the disease: understanding how endometriosis works Understanding the syndromes and pathologies associated with endometriosis (urinary, digestive, vestibular, etc.) Knowing and understanding. Self-management programs for the disease help reduce anxiety and improve quality of life (Farshi 2020)

Unfolding:

Meet:

Hello exercise:

<https://labase-gironde.fr/wikiCollectifRivage/?ProtocoleS>

Introduce yourself Introduce the workshops, the compass and “the ruler”



DEFINE YOUR CONCERN:

To define their concern, the person is invited to answer 7 questions.

This guide already focuses on endometriosis. But there is no single form of endometriosis. There are as many different types of endometriosis as there are people affected by the disease.

Each person will therefore define a concern that is specific to them and that is closest to their current concerns with their illness. The aim here is to be as specific as possible in your answers.

The 7 questions:

- Name one element, one being, that is essential to your existence with endometriosis, and that you must maintain at all costs. List 5 elements
- Why is this essential to you? What are your dependencies on this element? Choose one element from your list that is more important than the others and describe in a few lines precisely why it is essential and vital to you.
- By whom or what is this thing threatened?
- When did you become aware of this threat?
- To defend this essential thing/entity, what do you plan to do? What actions do you plan to take? We describe in list form the entities that participate in maintaining the concern and we describe the action of each entity.
- Can you list the beings or entities that should be addressed to help maintain this element? We describe in list form the entities that should be addressed to prevent the concern from disappearing.
- Now describe what you are willing to do to counter this threat.

Once the concern is chosen, the person will place the entities that threaten or maintain it on the compass.

Each entity must be described and explained in detail. It is based on the concerns of each that we will collectively define what endometriosis is and how it impacts our lives and daily life.

The round of concerns

<https://labase-gironde.fr/wikiCollectifRivage/?ProtocoleS>

The Investigator's Kit:

<https://labase-gironde.fr/wikiCollectifRivage/?KitDeLenqueteur>

WORKSHOP 2:

WELL-BEING AND MENTAL CALM

Patients with endometriosis are at greater risk of anxiety, depression, or mental health-related pathologies (Laganà 2017, Estes 2021), among other things due to chronic pain. In animals, stress accelerates the development of endometriosis (Reis 2020). Psychological interventions (including CBT, relaxation, and breathing exercises) can improve quality of life and reduce symptoms of endometriosis (Meissner 2016, Petit 2020, Zhao 2012, Jafari 2017).

Objective:

The objective of this workshop is to free up speech in order to regain well-being and mental calm.

Work on accepting the illness.

Express yourself and discuss your experience of the illness.

We know that 67% of women face psychological difficulties (Endovie, Ipsos, 2020), significant stress and/or anxiety.

Managing chronic fatigue on a daily basis

Tool:

The compass

Description:

Based on their own concerns, each person will identify factors related to their physical and mental well-being. What maintains it, what hinders it? We will share our experiences and list all the solutions we have or can implement.

See the sources of the Lyv application: <https://www.lyv.app/categorie/bien-etre>

WORKSHOP 3:

PAIN AND COMPLEMENTARY CARE

Objective:

Understanding the mechanisms of pain Understanding the mechanisms of pain, particularly chronic pain, and understanding the triggers Knowing the treatments and therapies that can relieve it Managing a pain crisis through non-drug therapies (relaxation and breathing exercises, hypnosis, art therapy, etc.) Practicing body movements and self-massages to relieve pain Expressing your own representations and discovering those of others.
Becoming aware of one's personal point of view

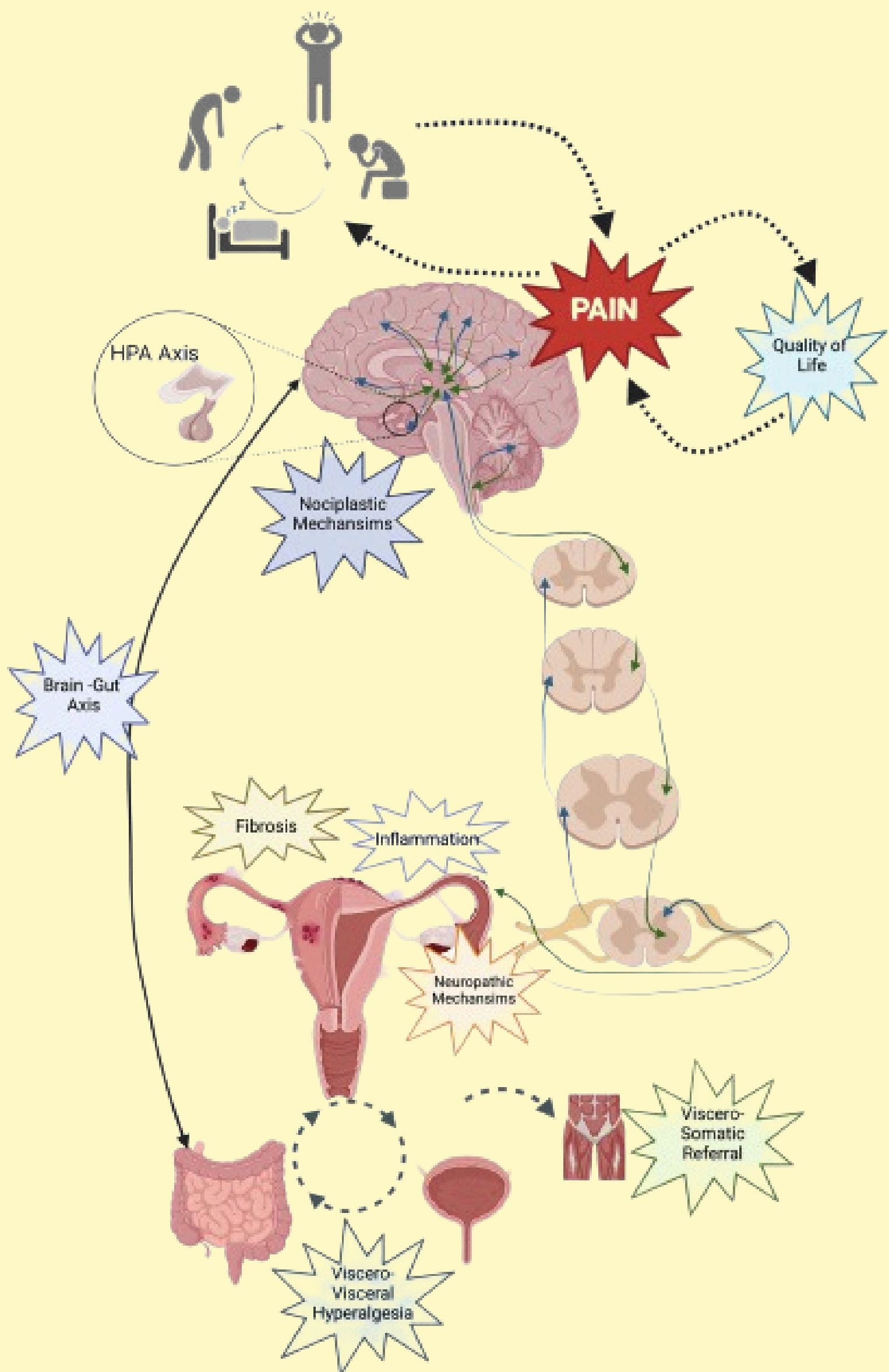
Tools:

Images (page 23 and 24) Body diagram to draw and locate your pain The compass

Unfolding:

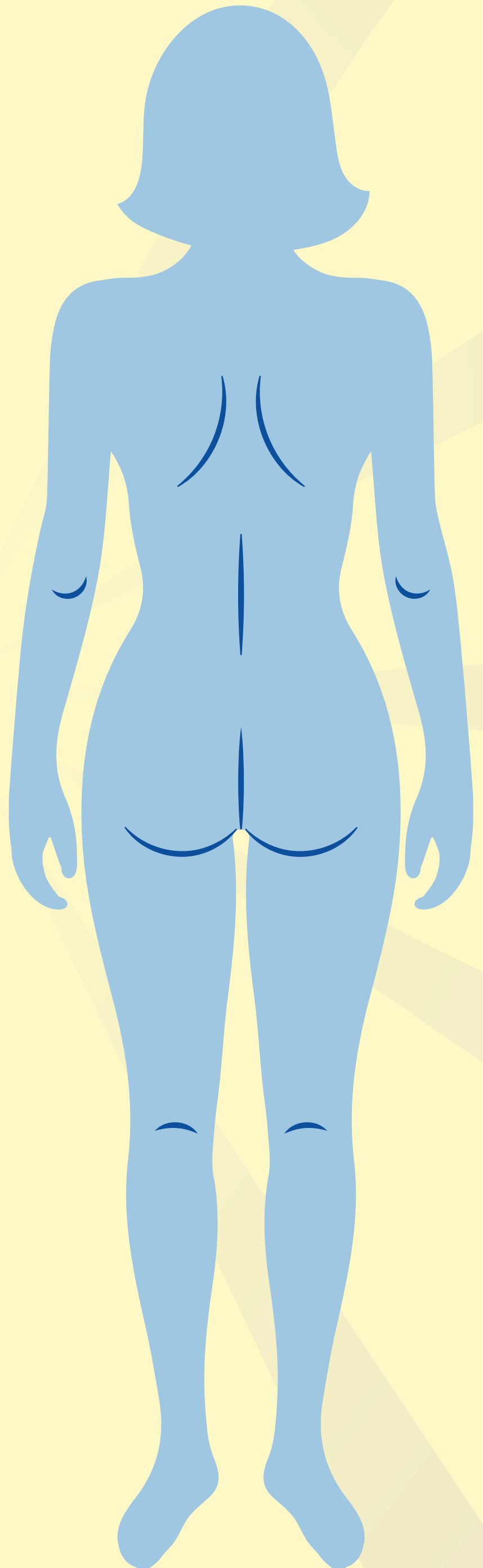
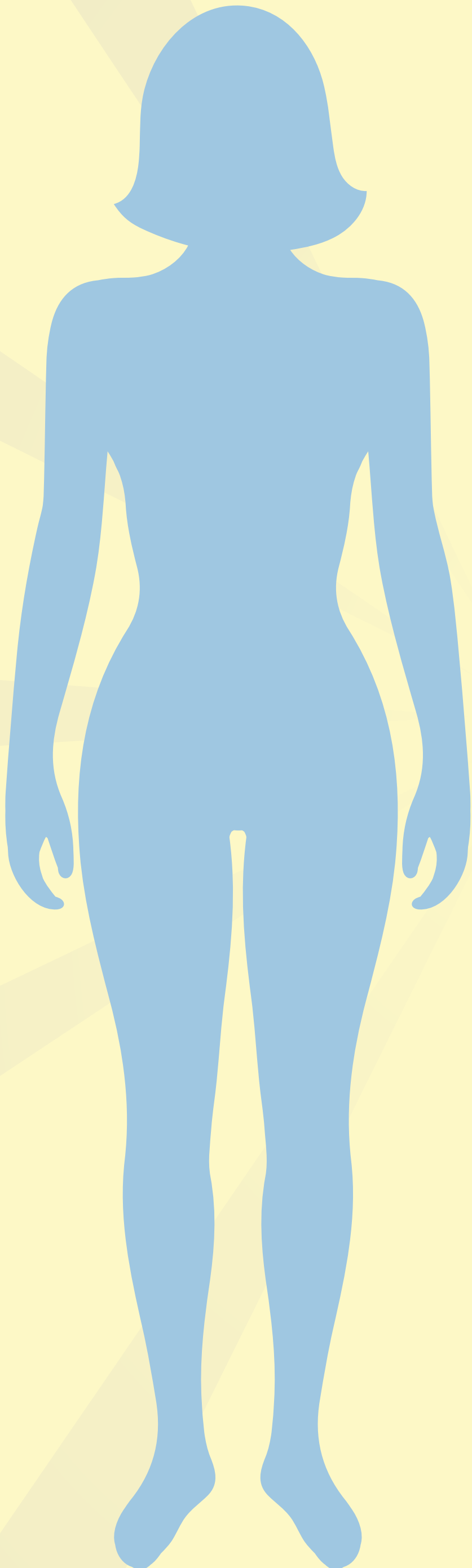
Photo-Expression: Using Images to Give Voice to Pain This tool aims to tell the story of pain. By choosing three evocative photographs, the patient gives form to their intimate experience of the illness. Each image allows them to describe their pain.

Based on their own concerns, each person will position entities related to their pain on the compass. What maintains it, what hinders it? We will share our experiences and list all the solutions we have or can implement.



Pain mechanisms in endometriosis (Coxon 2024)

Locate and draw your pain due to endometriosis



WORKSHOP 4:

THE PLEASURE OF FOOD

OBJECTIVE: FOOD

Discuss ideas and beliefs about the links between diet and endometriosis. Rediscover the joy of cooking.

Tool:

Compass Spring Roll Recipe

Description:

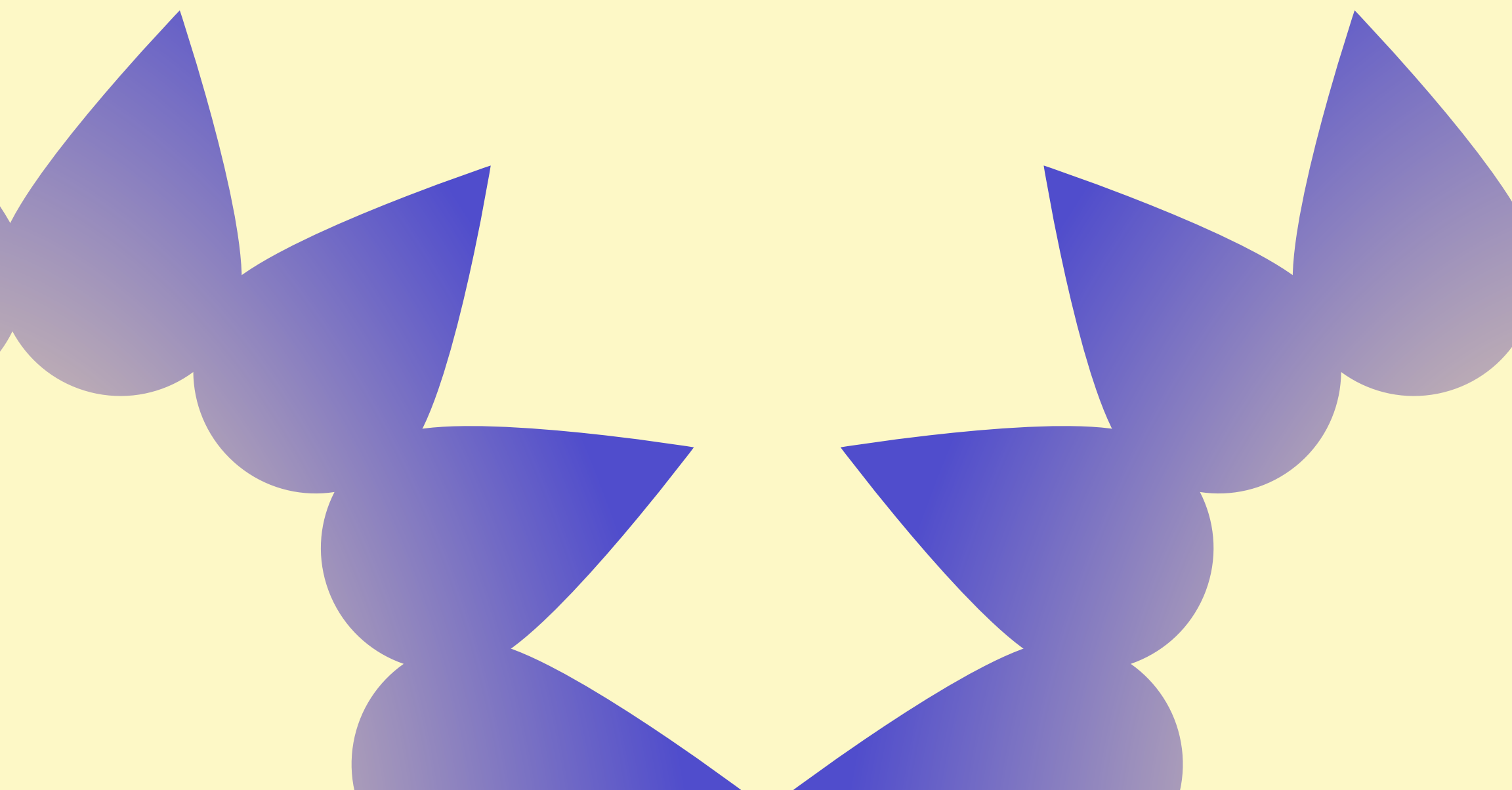
80% of patients with endometriosis experience gastrointestinal symptoms. (Maroun 2009) It is also known that nutrition can help target the dysbiosis of the intestinal microbiota characteristic of endometriosis (Zizolfi 2023). Furthermore, dietary changes are favored by patients as the most effective self-management intervention (Armour 2019). Dietary changes can help reduce pain and alleviate symptoms (Ciebiera 2021, Piecuch 2022, Meneghetti 2024, De Araugo 2025) while also acting on inflammation.

Unfolding:

Self-reflection and making spring rolls.

The compass is materialized by the rice cake.

Based on their own concerns, each person will position entities related to food on the compass. What maintains it, what hinders it? We will share our experiences and list all the solutions we have or can implement.





THE RECIPE FOR SPRING ROLLS

Materials needed:

- 1 bowl of cold water (to soften the pancakes)
- 1 damp cloth (to cover the pancakes)
- 1 cutting board
- 1 sharp knife

Ingredients (for 8 rolls):

- 8 rice cakes (22 cm in diameter)
- 100 g of rice vermicelli
- 8 cooked shrimps (or smoked tofu in a veggie version)
- 1 carrot (julienne)
- 1/2 cucumber (sticks)
- 1 mango (slices)
- 1 avocado (slices)
- 8 lettuce leaves (oak leaf type)
- Coriander, mint (a few sprigs)
- Sauce: 3 tbsp nuoc mam, 1 tbsp sugar, 1 tbsp lime, 1 pressed garlic clove, chili pepper (optional)

Unfolded in 5 stages:

1. Prepare the ingredients:

- Soak the vermicelli for 5 minutes in boiling water, then drain.
- Cut all the vegetables into regular sticks.

2. Soften the pancakes:

- Dip a pancake in lukewarm water for 10 seconds.
- Spread on a clean cloth.

3. Fill (on 1/3 of the cake):

- Lettuce → vermicelli → carrot/cucumber → mango/avocado → shrimp → herbs.

4. Roll:

- Fold the sides inwards.
- Roll up tightly, holding the filling.

Total time: 30 min ● Level: Easy

Enjoy your meal! 🌿

WORKSHOP 5: EMOTIONAL AND SEXUAL LIFE

OBJECTIVE:

Understanding dyspareunia, knowing the methods to relieve it Expressing yourself and discussing the place of sexuality in your life Communicating with your partner on the subject of sexuality Expressing your experiences to those close to you, knowing how to adjust/adapt your communication depending on the people you are around Identifying the people around you to talk to about it.

Understanding fertility, the role of infertility in endometriosis, and the different methods of assisted procreation (PMA, preservation, egg freezing, etc.)

2/3 of women with endometriosis suffer from sexual dysfunction (Barbara 2017) Sexology programs reduce sexual dysfunction related to endometriosis symptoms (Matloobi 2022)Description:

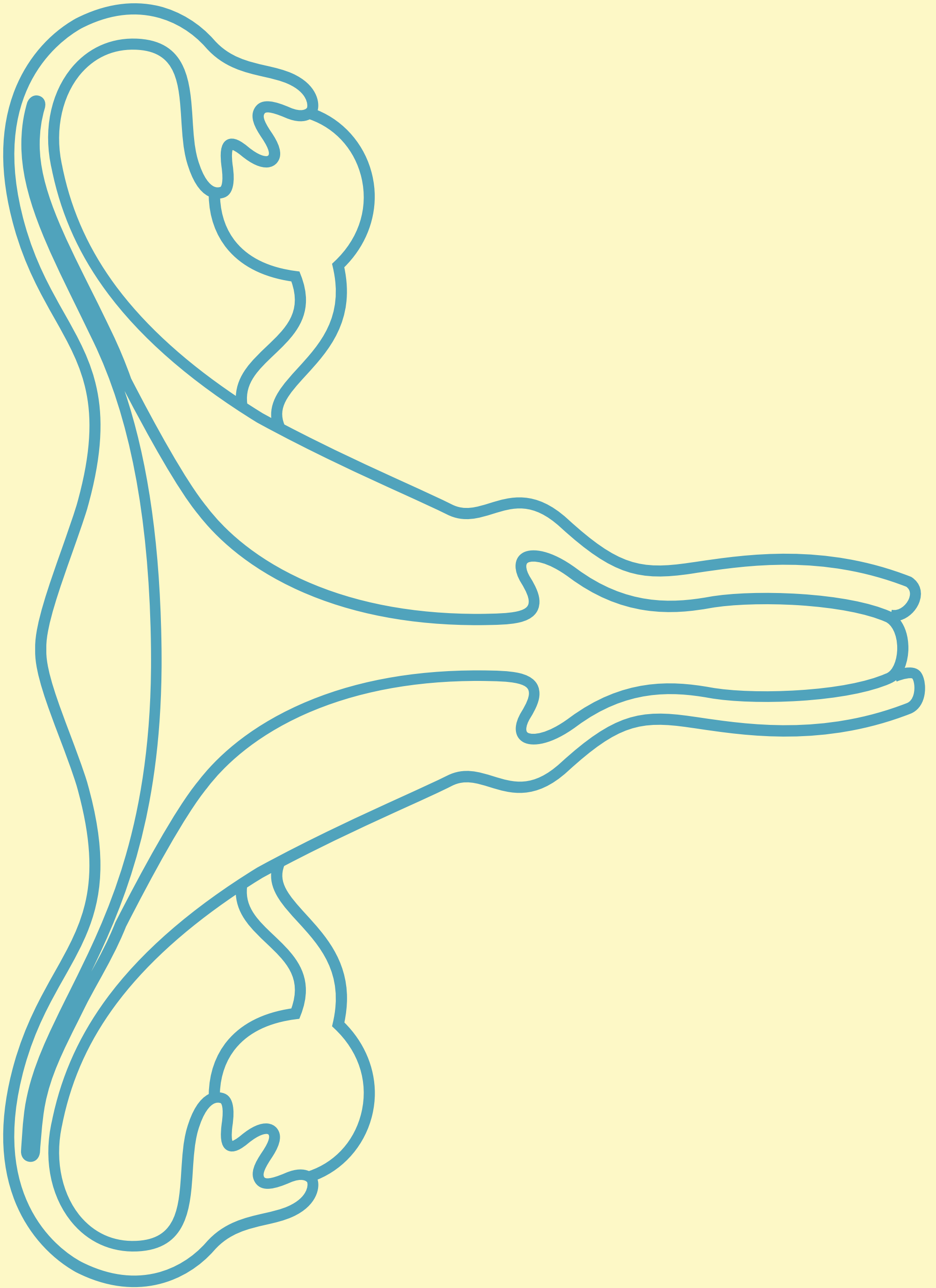
Tools:

Images (page 23 and 24) The compass

Unfolding:

Photo-Expression: Using Images to Give Voice to Pain This tool aims to tell the story of pain. By choosing three evocative photographs, the patient gives form to their intimate experience of the illness. Each image allows them to describe their pain.

Based on their own concerns, each person will position entities related to their emotional and sexual life on the compass. What maintains it, what hinders it? We will share our experiences and list all the solutions we have or can implement.



Reconciling with your uterus:

By using the arts (painting, felt-tip pens, pens, collages, etc.), you are invited to transform your uterus into a colorful, joyful, positive space.

WORKSHOP 6: WHAT THE COMPASS MADE ME DO

Objective:

This workshop is the self-assessment of the program and invites patients to express their emotions and take stock of the evolution of their representations of the disease. This workshop uses a creative medium to allow the person to express themselves.

Tool:

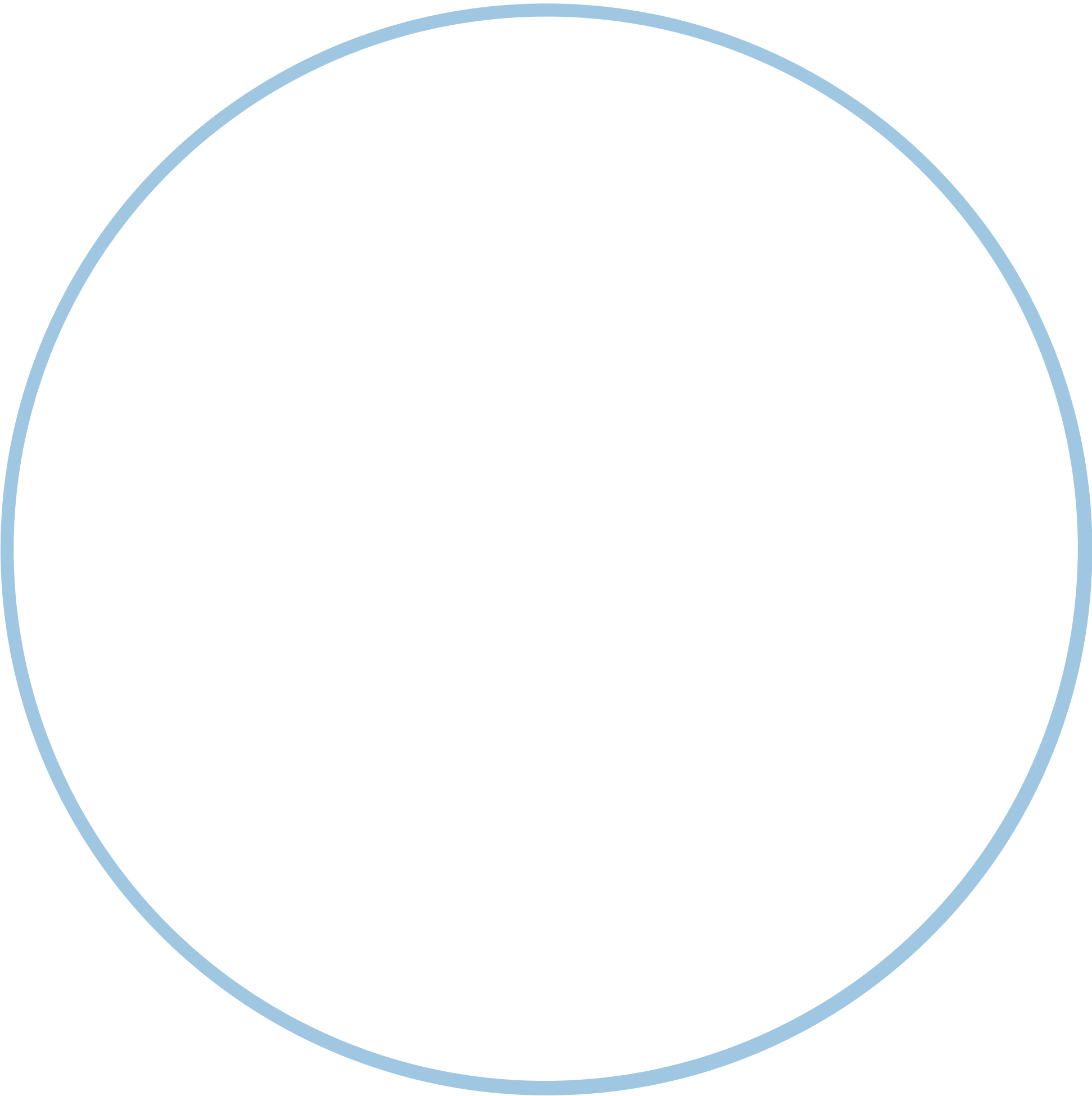
Paper with a circle drawn on it (replaces the compass) Drawing materials, paint, pencils, chinks...

Unfolding:

On a sheet of A3 paper or larger, draw a circle (see page 25). This circle is the place to express the emotions and self-knowledge experienced during the 5 sessions. The circle will materialize the compass. Once the drawing is completed, each person will express the path they have taken by describing it.



THE PRINTABLE COMPASS





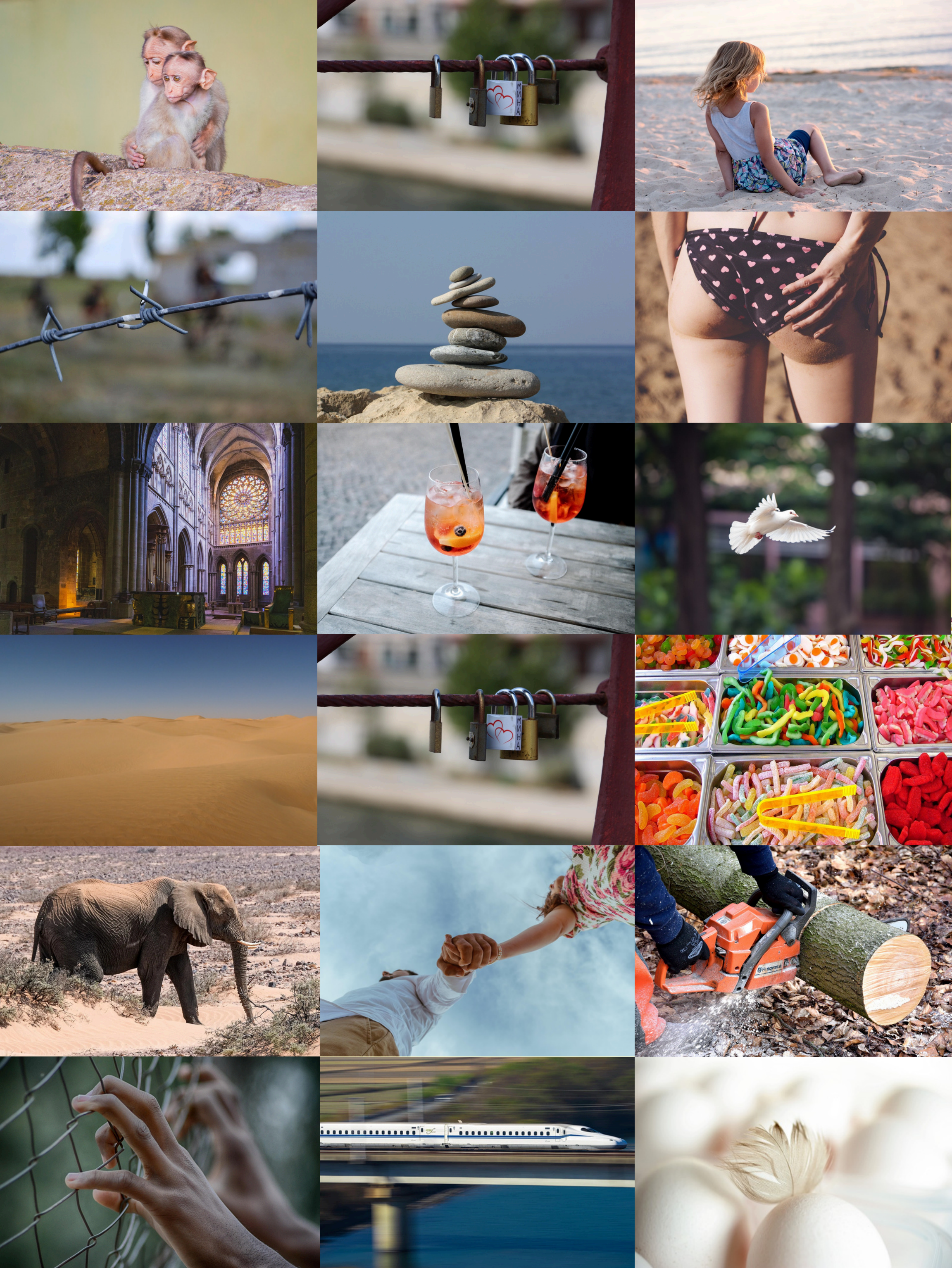


PHOTO-EXPRESSION



SPECIAL ENDO YOGA

Remobilize the tissues Understand the benefits of adapted physical activity (APA) and develop your motivation to practice regularly Know how to adapt your APA practice to times of fatigue and/or low morale

Managing stress and emotions

The practice of yoga helps improve the symptoms of endometriosis (Gonçalves 2017, Awad 2017, HAS 2017)

Physical activity has a positive impact on quality of life, pain, and mental health (review and metanalysis Xie 2025)



SPECIAL ENDO YOGA

RESOURCES:

Meditation and Yoga Nidra

<https://www.youtube.com/@CedricMichel>

The Insight Timer app Stéphane Faure teaches mindfulness meditation in the region and frequently speaks at hospitals. You can train with him or one of his colleagues in MBSR (Mindfulness Based for Stress Reduction).

If you are interested in yoga Nidra, you can train with Philippe Beer-Gabels, no prerequisites required:

<https://beer-gabel.com/formations-certifiantes/>

Yoga:

Gentle and dynamic practices

<https://www.youtube.com/@YogacoachingFr>

<https://youtu.be/HWLhtJ0TTwQ?si=U4J7xwF5odclxRlO>

The Moon Salutation, 2 versions

<https://www.youtube.com/watch?v=d7LlnnDwoyk> <https://www.youtube.com/watch?v=c2VeXVxz-AQ>

Groupe Facebook EndoYogaSophroNaturo

<https://www.facebook.com/groups/326106864821773>





From left to right, the creators of the program:

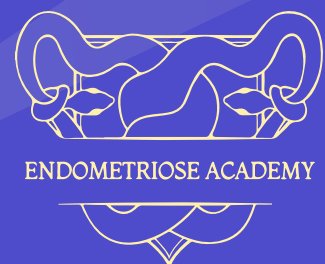
- Sandra Servat, nurse and patient-partner
- Doctor Géraldine Chauvin, gynecological surgeon at the Clinique Mutualiste de Pessac, representative of the program
- Nadia Russell Kissoon, patient-partner, program manager, director of L'Agence Créative
- Cathy Schwartz, patient-partner and president of ACV AIT Carpe Diem
- Maëliiss Le Bricon, patient-partner and health simulator

Photo taken at the Clinique Mutualiste de Pessac: January 2025

FINDING YOUR WAY IN ENDOMETRIOSIS



VULGAROO



dm DIGITAL
NARRATIVE
MEDICINE



Università
degli Studi
di Palermo



UNIVERSITY
OF TURKU



Maynooth
University
National University
of Ireland Maynooth

momentum
[educate + innovate]



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