



Emilia

Patient Story:
From Red Flags to Peach Ribbon



CHAPTER 1: symptoms, red flags, diagnosis

EMILIA ASKS:

"Lately, I've noticed some **unusual bleeding**. At first, I thought it was just hormones or perimenopause. But now... **I'm worried**.



On top of that, I've been feeling **bloated and tired**, with a **strange discomfort** in my lower abdomen.

Are these things connected?
Or am I just overthinking it?"



Seda Şahin

Gynaecological Oncologist
Memorial Kayseri Hospital
TÜRKİYE

“These are really important observations, Emilia – and you’re absolutely right to **listen to your body**. Abnormal **bleeding** - especially between periods, after sexual intercourse, or after menopause - can be an **early warning sign** of endometrial cancer.

And while **bloating, fatigue**, and pelvic **discomfort** can have many causes, when symptoms like these persist for more than two weeks, **it’s time to get them checked out**.

Also stress or hormonal changes might be behind some of what you’re feeling, but **it’s always better to be cautious**. A simple evaluation can give you peace of mind - or help **catch something early**, when treatment is most effective. Your body knows when something’s off - trust it.”

Emilia

EMILIA ASKS:



“What happens if they
suspect it’s cancer?”

What kind of **tests** should I expect?

I’ve already Googled everything, and now I’m
even more **confused – and scared.**

I don’t want to find out something bad... but
not knowing feels even worse...

What do I do?”



Christian Braun

Gynaecological Oncologist
Lucerne Cantonal Hospital
SWITZERLAND

“These feelings are so valid, Emilia - and totally understandable. The idea of cancer can feel **overwhelming**, but understanding the next steps can really help **ease some of that fear**.

If your doctor suspects something, the first steps usually include a **pelvic exam and a transvaginal ultrasound** to look at the uterus. If anything looks unusual, an **endometrial biopsy** may follow. It’s a quick procedure where a small tissue sample is taken and sent to a lab.

If more clarity is needed, your doctor might recommend a **hysteroscopy** - a small camera that looks inside the uterus. It may sound like a lot, but **each step brings you closer to answers** - and to the right care.

It's also completely normal to search for information online, especially when you're scared. But not everything you find online is reliable. Stick to trusted, **medically reviewed sources** like **ESGO, ENGAGe, patient advocacy groups**, or your **healthcare provider's materials**. And never hesitate to **ask your doctor** to walk you through it. That's what we're there for.

Facing the unknown is scary - but getting the right information and support **turns fear into action**. Early diagnosis can make a **huge difference**. And remember, you don't have to go through any of this alone - **your care team will be with you** every step of the way."

So what have I learned?

"This week, I finally faced something I'd been avoiding: the **unknown**.

There were signs - **bleeding** that didn't feel normal, a **tiredness** I couldn't shake, a **discomfort** I kept brushing off. I told myself it was stress. Hormones. Age. Just one of those things.

But deep down, I felt something wasn't right. **I was scared**. Scared of what it could be. Scared of the word "cancer."



But the **fear of not knowing** eventually became louder than the fear of finding out.

So, **I asked**.

And then... I heard the words no one is ever ready to hear: "It is **endometrial cancer**."

Emilia

In that moment, everything around me seemed to go quiet. I felt **frozen** – like I was watching it happen to someone else. **Numb. Overwhelmed. Disconnected.**

I didn't feel strong. I didn't feel brave. **I just felt lost.** All the quiet worries I had been carrying – the "**what ifs**" I kept pushing aside – suddenly became real. They had names. And weight. And urgency.

And yet... as heavy as the diagnosis was, finally **knowing brought a strange kind of relief.** The fear of the unknown had been its own burden – and now, at least, I could begin to **face what was real.**

Now, I find myself at the beginning of something **I don't fully understand.** And if I'm honest, I don't know if I can do this. But...maybe I don't have to do it all at once. Maybe just **one step at a time** is enough.

So that's what I'll try to do. I'll ask questions. I'll let others support me. I'll let myself feel everything - without pretending to be okay when I'm not.

And in doing that, I've already started to find small things that help. I've found people who truly listen. I've met doctors who speak with compassion, not just facts. I've begun to replace fear with understanding. And little by little, I start to feel less alone in this.

The fear is still there - but something else is beginning to grow beside it: strength. Not the loud, heroic kind. A quiet kind. The kind that comes from simply taking the next breath, the next question, the next step.

I don't know exactly where this path will take me - but even on the days I feel alone, I remind myself I don't have to have all the answers right now. Just enough strength to keep going."

CHAPTER 2: treatment options, emotions, decision making

EMILIA ASKS:

"There are **so many doctors**.

One mentioned surgery, another
talked about hormone therapy.

I'm scared of making the wrong
decision.



Who do I even **talk** to about what?

How am I supposed to **choose**?

And what if I regret it?"



Sara Nasser

Gynaecological Oncologist
Charité Comprehensive Cancer
Center, Germany
IRCCS Policlinico Gemelli, Italy
PARSGO

“These feelings are incredibly normal, Emilia. When you’re suddenly surrounded by medical terms, options, and specialists, it can **feel like a whirlwind**. But you’re not expected to navigate it alone.

Here’s a simple breakdown: your **gynaecologic oncologist** is your lead cancer specialist - they coordinate your overall care. A **surgeon** may perform your operation. **Medical oncologists** handle chemotherapy if it’s needed, and **radiation oncologists** focus on radiotherapy. Then you have **nurses**, **psychologists**, **dietitians**, and others who support your wellbeing throughout the process.

When it comes to treatment, there's no one-size-fits-all answer - because endometrial cancer care is **deeply personal**. For many women, **surgery** is the main approach - often a **hysterectomy**, sometimes with lymph node removal. But depending on your stage, your age, your overall health, and whether preserving fertility is important to you, **hormone therapy** may also be an option.

It's okay to feel **unsure** or even **overwhelmed** by the choices in front of you. What matters most is that your treatment plan **respects you** - your body, your values, your hopes for the future. It's okay to **ask** every question - twice if you need to. Keep a **notebook**. **Bring someone** you trust to appointments. **Ask** who's who. Request a **second opinion** if it helps you feel more confident.

The fear of making the 'wrong' choice is real. But decisions made with **information**, **support**, and **care** are the best anyone can make. **You're doing your best**. That is more than enough."



EMILIA ASKS:

"I don't even know how
to *tell my family*.
What if they fall apart?
What if *I fall apart*?"

Honestly, I thought I'd cry or scream...

But I just feel *completely numb*.

Is that *normal*?"



Zsuzsanna Koós

Psychologist

Mallow Flower Foundation

HUNGARY

“Yes, Emilia - it's completely normal. When you're facing something this big, **emotional numbness** is a very human response. Some people **cry**, others **get angry**, and many - like you - **feel nothing** at all at first.

It's not wrong, and it doesn't mean you're not processing. In fact, it's your brain's way of **protecting you from becoming overwhelmed**. These feelings - or the lack of them - can come in waves. And they **may shift** over time.

As for **telling your family**, it's okay to feel unsure. **Start small.** Begin with someone you trust, and choose a quiet moment. You might say something like, 'I've had some difficult news, and I want to share it with you.' **You don't have to explain** everything at once. You don't have to have all the answers. And **you're not responsible** for holding everyone else together.

This is your experience, and your job is simply to **be honest** about how you feel, even if that's 'I don't know what I feel right now.' If it feels too big, a **counselor** or support person can help guide or even join the conversation.

There is no 'right way' to feel, and **no perfect script** for what comes next. Just your way.”

So what have I learned?

"I found myself **making decisions** I never imagined. Sitting in rooms filled with **unfamiliar words**. Trying to follow conversations about **treatments** and **side effects**. Hearing the word "cancer" still feels unreal – and yet, here I am.

I've been scared to make the wrong **choice**. Scared of saying the wrong thing. Scared I might break down – or worse, feel nothing at all.



And when the time to tell my **family and friends** came, I didn't know where to begin. I was just thinking: What if they fall apart? What if I do?

I thought I had to be strong. That I needed to know what to do, how to feel, what to say. But this week, I started to **learn something else**:

Strength doesn't mean having all the answers. Sometimes, it means just **asking one question** at a time. Or **letting someone come with you** to your appointments. Or **writing your thoughts** down in a notebook when everything feels too loud. Or **accepting help**.

And when it came to telling my loved ones, I started with one quiet moment. One **trusted person**. One **simple sentence**: "I've had some hard news, and I want to share it with you." **That was enough** to begin.

I've learned **it's okay** to feel numb. To be **overwhelmed**. To not feel like a warrior. There's **no right way** to do this - only your way.

Emilia

What's helping me right now is keeping a small **list of questions** to bring to appointments. **Asking** who's who on my **care team**. Saying "**I need a moment**" when things feel too fast. Letting someone in, even if I don't have the words yet.

This isn't easy. None of it is. But **I'm learning** to give myself grace. And **little by little**, I'm finding that **hope** doesn't have to be big or bold.

Sometimes, it's quiet. Sometimes, it's just the choice to **keep going**.

I'm still me.

Even now.

Especially now."

CHAPTER 3: treatment & recovery

EMILIA ASKS:

"Tomorrow is my surgery.

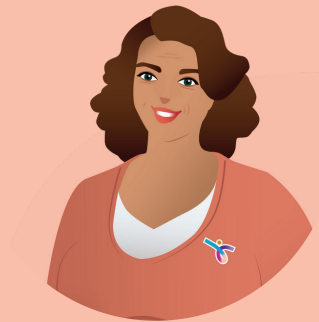
I keep picturing everything that could go wrong...

And after that, they said I
might even need
chemotherapy...

I'm terrified.

What will it be like?

How do I prepare myself for any of this?"



Emilia



Dimitris Zouzoulas

Gynaecological Onocologist
Papageorgiou General Hospital
GREECE

“Everything you’re feeling is **completely normal**, Emilia. Facing surgery - and the possibility of chemo - can bring up so much **fear and uncertainty**. You’re stepping into the unknown, and that’s never easy.

Let’s start with surgery. Anxiety is a natural part of the process, especially the night before. Try focusing on small, **comforting things**: pack a few **familiar items**, ask your care team exactly what to expect, and **lean on the people** around you.

Gentle **breathing exercises** or grounding yourself in a peaceful memory can also help calm your body. Most importantly, remind yourself: this is a **step toward healing**. Toward reclaiming your health, your body, your future.

As for chemotherapy - it can sound overwhelming, especially when you're hearing words like **nausea, fatigue, or hair loss** before anything has even started. But not everyone has the same experience. Some find it more manageable than they expected. Others need more time and support.

Wherever your path takes you, your **care team** will be by your side - **helping** you manage side effects, **answering** your questions, and **supporting** your body and mind.

You're allowed to **ask about every little thing**. You're allowed to feel scared and still move forward. This is a difficult part of the path - but it's also one where you'll be supported every step of the way. **You are not alone.**"

Emilia

EMILIA ASKS:

"I woke up exhausted, in pain, and honestly... still scared.

My body **feels different** now.

I don't feel like myself — it is like I've lost something.

Will I ever feel whole again?

Will I ever feel like me again?

I'm also **learning to rest**. To **accept help** without guilt.
But that's not something I'm used to.

Maybe... that's **part of the recovery** too?"





Virág Karai

Psychologist

Mallow Flower Foundation

HUNGARY

“Everything you’re feeling is completely valid, Emilia. Recovery after surgery - especially for something as life-changing as cancer - **takes time**, and it often unfolds more slowly than we expect. The soreness, the fatigue, the emotional **ups and downs**... all of it is part of the **healing process**.

It’s also very common to feel **disconnected** from your body right now. With the **changes** brought on by surgery, possible **menopause**, or simply the shock of it all, many women feel like they don’t quite recognize themselves. But please hear this: your body is still yours. **You are still whole**. And you haven’t lost who you are - you’re in the process of **rebuilding** something **strong**, and deeply, beautifully **resilient**.

Healing is not just physical. **It's emotional, psychological, even spiritual.** Reconnecting with yourself **takes time.** It's okay to **grieve** the changes. It's okay to not bounce back right away. **Talk to someone** - a counselor, a support group, a friend who listens without trying to fix.

And yes - **rest** is part of recovery. So is **asking for help.** **Accepting care** is not a weakness; it's a strength. Let people show up for you. Hydrate. Move when it feels good. Celebrate the smallest steps forward. And speak to yourself **with the same compassion** you'd offer a friend in your place.

You don't have to rush. You just have to heal - one moment, one breath, **one day at a time.** You deserve that grace."

So what have I learned?

"This was a hard time...

Surgery day came and even though I'd prepared as best I could, I still **felt terrified**. I kept picturing everything that could go wrong. And then, there were whispers of chemotherapy – **another unknown** waiting in the distance.

I woke up the next day groggy, sore, and honestly... still scared. **My body didn't feel like mine**. I felt like something had been taken from me.



Like I'd lost a piece of myself.
There was **pain**. Then **rest**.
Then the quiet **effort** to sit
up, to stand, to walk again.
Each movement felt small –
but **it mattered**.

No one tells you how strange it can feel to **look in the mirror** and not quite recognize who's looking back. How **tired** you'll feel – deep-down tired – and how hard it is to **ask for help**, let alone accept it.

But slowly, I'm **learning**. Learning that healing isn't just about stitches and scans – it's about **emotions, identity, memory, and trust**.

I'm learning to rest. To not feel guilty for **needing others**.

To let go of the version of strength that means doing everything alone. Because **real strength**, I think, might be something quieter – like opening your eyes when it feels safer to keep them closed, asking a question when you're afraid of the answer – or like saying „**I need help**“ when you'd rather say „I'm fine“.

I don't feel like myself yet. But maybe **I'm not meant to rush back** to who I was.

Maybe healing isn't about returning. Maybe it's about **becoming** - gently, slowly - **someone new**. Someone shaped by what I've faced.

This wasn't easy.

But **I made it** through. As always - one breath, one step, **one moment at a time**.

And for now...
that is enough.

CHAPTER 4: long-term side effects, survivorship & advocacy

EMILIA ASKS:

"Everyone keeps telling me I should feel relieved now that treatment is over.



And I am grateful...

But I also feel anxious all the time.

What if it comes back?

What if I can't find myself again?

I've made it through so much, but I don't feel like I've arrived anywhere. I've changed. I want to live fully again – but I'm not sure how.

Where do I even start?"



Houssein El Hajj

Gynaecological Oncologist

Gustave Roussy

FRANCE

“Everything you're feeling is completely understandable, Emilia.

Fear of recurrence is one of the most common experiences after treatment ends. That constant '**what if**' can linger quietly - or loudly - even long after the last appointment. It doesn't mean you're ungrateful or weak. It means that **you're aware, that you're human, and that you're still healing.**

And if it ever comes back, with the close **follow-up programme**, recurrence will be detected early and as before you can fight it and win again, together with your doctors.

Recovery isn't just physical – it's **emotional, psychological,** and deeply **personal**. Life may not look the same as it did before, and that's okay. It doesn't have to. In fact, it can even **become something better** – not by going back, but by learning to appreciate the simple, small things that often go unnoticed.

You will probably need to **reconnect with yourself** in a new way. Ask yourself gently: „What brings me peace? What brings me joy?“ **Start small**. Movement that makes your body feel alive. Food that nourishes you. Moments that calm your mind. People who help you feel seen.

You don't need a perfect plan - you just need **permission**. Permission to **explore**. To **question**. To **evolve**. To be more than your disease.

Talk to your doctor about a **survivorship plan** - one that includes follow-up care, emotional **support**, and tools for **rebuilding** both your body and your **confidence**. You don't have to carry this alone.”

EMILIA ASKS:

"Since treatment, **intimacy has changed** in ways I didn't expect.

I don't feel as connected to my body, and being close with someone feels more **complicated** now – **physically** and **emotionally**.



Sometimes I wonder if I'll ever **feel desirable** again.
Or if I'll ever **want to be touched**.

I feel guilt, frustration, even grief...
But mostly, I just feel **confused**.

Is this something **other women** go through too?
And if they do – **how** do they find their way back to themselves?



Stephanie Christodoulidou

Psychologist

Europa Donna Cyprus

CYPRUS

“Yes, Emilia – what you’re feeling is **very common**, and incredibly real. Many women experience **changes in intimacy** after endometrial cancer treatment, especially when surgical menopause or pelvic changes are involved. These shifts can impact not only how your body functions, but how you feel in your body - and in **your relationships**.

You’re not alone in this, even if it often feels like something no one talks about. But **you can talk about it**. And more importantly, there is **help available**. It’s important to **speak openly** with your doctors about these challenges - because there are many possible solutions, and you deserve to explore them with support and care.

There are options: vaginal **moisturizers** and **lubricants** to ease discomfort, **hormone therapy** when appropriate, pelvic floor **physical therapy** to support healing, and **counseling** to explore the emotional side of intimacy. **You deserve care** that honors both your physical and emotional needs.

It's okay if you're not ready to be close with someone. It's okay if you miss feeling connected to yourself. **This is not about rushing** back to 'normal' - it's about **discovering** what safety, trust, and pleasure look like for you, now.

Let's start the conversation, **without shame**. You are still whole. You are still **worthy of love, comfort, and closeness** - in all the ways that feel right for you now. And **when you're ready**, there is support to guide you back to that space, gently and with care."

Emilia

EMILIA ASKS:

"People keep calling me a **survivor**...

But I don't know what that means. Am I one now?

Because honestly,
I don't feel like it.



I'm still **processing**. I still have **fears**.
And part of me wonders - **how** do I carry this forward?

Could I help someone else?

I do want to **give back**..
I just don't know how."



Kim Hulscher

ENGAGe Co-Chair

Olijf

THE NETHERLANDS

“Hi Emilia, I understand you have all these questions - because I’ve had them myself. I also know other patients who have these questions.

You know, **survivorship** can be a difficult word because **it’s not a perfect point** where you suddenly feel strong and fearless. It is actually very personal, and **it’s a process**. It also doesn’t mean that the hard part is over. In fact, it’s really just the beginning.

Survivorship is hard work, but it does mean **you’re still here**. You’re still **showing up for yourself**, for your healing, for your life, for your health — **even on the bad days**. And there will still be bad days.

But you get to **define for yourself** what survivorship means to you. It means something different to everyone. But it does mean you went through something **life-changing**.

You carry it forward in your own way — **your own special way**, and at **your own pace**. And yes, there are different ways you can give back **whenever you're ready** and whenever you want to. You could start by simply **sharing** your story, joining a local **support group**, **writing** a blog, or perhaps becoming a **peer mentor** for someone who has been newly diagnosed.

It doesn't mean you have to have all the answers, because just being there for someone and listening can already mean the world. I just want you to know that **your voice matters**. When you speak, someone else will feel less alone.

Advocacy is not about being 'done', because, in truth, you will never really be done. It's about choosing to **turn your experience** into something meaningful. And that choice is a powerful act of hope."

So what have I learned?

“We talk a lot about diagnosis. About treatment. About fear, and scans, and surgery. But we don’t talk enough about **what comes after**.

No one really prepares you for the **quiet after the storm**—when treatment ends and everyone expects relief, even celebration.

But often, what you feel is something else entirely: **uncertainty, anxiety, loneliness**, even **guilt** for not feeling more grateful.



You feel different. **Changed**. Not broken, but not quite whole either.

The **fear** of it coming back follows you into moments that should feel free. And the body you now live in doesn’t feel quite like yours.

Emilia

Intimacy is different. Trust is different.
Even joy feels complicated.

I found myself in that in-between space. Not
sure who I was. Not yet sure who I'm becoming.
They call me a survivor. I'm still learning what
that means.

I've survived, yes – but now I want to live. To
rediscover pleasure. To feel safe in my own skin. To
wake up with curiosity instead of dread.

Some days I feel brave. Other days, I feel lost.

But I'm learning to sit with the questions, to take
up space in this new version of myself, and to honor
how far I've come – even when I don't have all the
answers.

I'm starting to ask: **How can I help others?** What can I offer that I didn't have?

Because there's a **power in telling the truth**, even when your voice shakes. There's **healing in being real**. There's **hope** in turning your story into **someone else's light**.

This isn't the end of my story. **It's the beginning** of a new chapter – written in the language of scars and strength, of softness and survival.

And **I'm saying it with love**. With **courage**. And with the quiet **power** of someone who knows what it means to **begin again**."

You are not alone!

If you're facing endometrial cancer,
support is available.

Reach out to your local patient
advocacy group for **guidance,**
connection, and care.

For trusted information
and resources, visit:
engage.esgo.org