10 Things I Wish I Knew After My GM Diagnosis

A Letter From Me to You

If you're reading this, there's a good chance you've recently been diagnosed with Granulomatous Mastitis—or you're in the middle of trying to figure out if that's what's going on.

First, I want you to know something I wish someone had told me on day one:

Take a deep breath.

I know you're scared.

I know you're probably spending hours on Google.

I know you've likely read stories that left you feeling more anxious than reassured.

I've been where you are.

I'm now in remission, and while every journey is different, I want to share the things I wish someone had sat me down and told me when this all began.

1. You're Not Alone

Granulomatous Mastitis is rare, which can make it feel incredibly isolating.

Many women have never heard of it until they're diagnosed.

The good news? There is a growing community of women around the world who understand exactly what you're experiencing.

2. It's Okay If Your Doctor Doesn't Have All the Answers

Because GM is uncommon, many healthcare providers have limited experience treating it.

That doesn't necessarily mean they're not a good doctor.

It does mean you may need to ask questions, seek second opinions, or work with a team that's willing to learn alongside you.

Be your own advocate.

3. Healing Is Rarely a Straight Line

One day you may feel hopeful. The next day you may notice new redness or pain.

Healing often comes with ups and downs.

Don't let one difficult day convince you that you're not making progress.

4. Stop Googling at 2 A.M.

Trust me... I've been there.

The internet is full of stories, opinions, and advice that can leave you feeling overwhelmed.

Find a few trusted sources, stay connected with your healthcare team, and remember that every person's journey is different.

5. Keep Copies of Everything

Start a medical binder from the beginning. Save your:

- Imaging reports
- Biopsy results
- Pathology reports
- Medication lists
- Lab work
- Questions for your doctors

You'll thank yourself later.

6. Don't Compare Your Journey to Anyone Else's

Some women improve quickly. Others take longer.

Some need medication. Some require procedures. Some experience flare-ups.

Your path is uniquely yours.

7. Take Care of Your Emotional Health Too

GM affects more than your body. It can impact your confidence, relationships, sleep, work, and mental health.

Give yourself permission to rest. Talk to someone you trust. Accept help when it's offered.

Healing isn't just physical.

8. Ask Questions Until You Understand

Never feel embarrassed for asking:

- "What does this mean?"
- "Why are you recommending this?"

- "What are my options?"

You deserve to understand your care.

9. Celebrate Small Victories

Maybe today your pain is a little better. Maybe your wound is healing. Maybe you made it through an appointment without crying.

Those victories matter.

Healing is built one small step at a time.

10. There Is Hope

When I was first diagnosed, I couldn't imagine life beyond Granulomatous Mastitis.

Today, I can tell you that while this journey may test you in ways you never expected, it won't last forever.

Many women, including myself, have gone on to reach remission.

Hold onto hope. Take one day at a time. Your story is still being written.

A Personal Note From Me

If no one has told you this lately...

I'm proud of you.

You're navigating a rare disease that most people have never even heard of.

You're showing up to appointments.

You're asking questions.

You're searching for answers.

That takes courage.

I created Hope After GM because I didn't want another woman to feel as alone as I did.

Whether you're here for education, support, or simply reassurance that someone understands, I'm honored you're here.

Welcome.

We'll walk this journey together.

– Destiny Barry

GM Survivor • In Remission • Patient Advocate

Ready for the Next Step?

Inside the Healing Hub, you'll find:

- The complete Essential Guide for the Newly Diagnosed GM
- Printable Medical Binder Kit
- Symptom & Medication Trackers
- Physician Checklists

- Evidence-based resources
- Survivor stories and practical tools to help you navigate your journey

You don't have to figure this out alone.