

# The Things That Go Unseen, Unsaid and Unheard

Millie Blue Capon • Sep 01, 2021

*Unseen pain,  
Unsaid shame,  
Unheard battle that still remains.*

*She's a thief in the night and in broad daylight  
But each honest word leaves me exposed in the light  
Leaves me free in my fight,  
- I sigh deeply,  
and I try again.*

Chronic illness doesn't discriminate. It can impact anyone at any given moment, regardless of how healthy you believe yourself to be. After a seven-year battle with intermittent appointments, hospital admissions, scans and tests, and countless days of worrying about what was wrong with my body, I received a diagnosis. Endometriosis. Getting this answer was a battle in itself; it was somewhat a relief that at twenty-one, this mysterious chronic pain was finally named.

Endometriosis is described as a 'chronic and often debilitating condition' affecting one in ten people who menstruate. Endometriosis may cause pain, fatigue, irregular bleeding, impact on someone's bowel and bladder, and possibly lead to infertility - though the symptoms vary from person to person. These symptoms are often normalised by medical professionals, invalidating the experience of what endometriosis is like to live with. I often find it is hard to advocate for yourself when medical professionals are so quick to brush you aside (it is worth saying that the right medical professionals are out there - even if as it stands, I am yet to come across them).

It can be hard to describe the pain that endometriosis brings to my body but knowing that it is so often brushed aside has, at times, been more agonising than the pain itself. I, alongside many other people with chronic illness, am known for having a higher pain threshold because the pain and discomfort I face daily has become ordinary. What was once a bad day, becomes a normal day; you just come to accept the illness as part of you and the pain often goes unnoticed as a result. The pain goes unseen; the shame goes unsaid and the battle goes unheard.

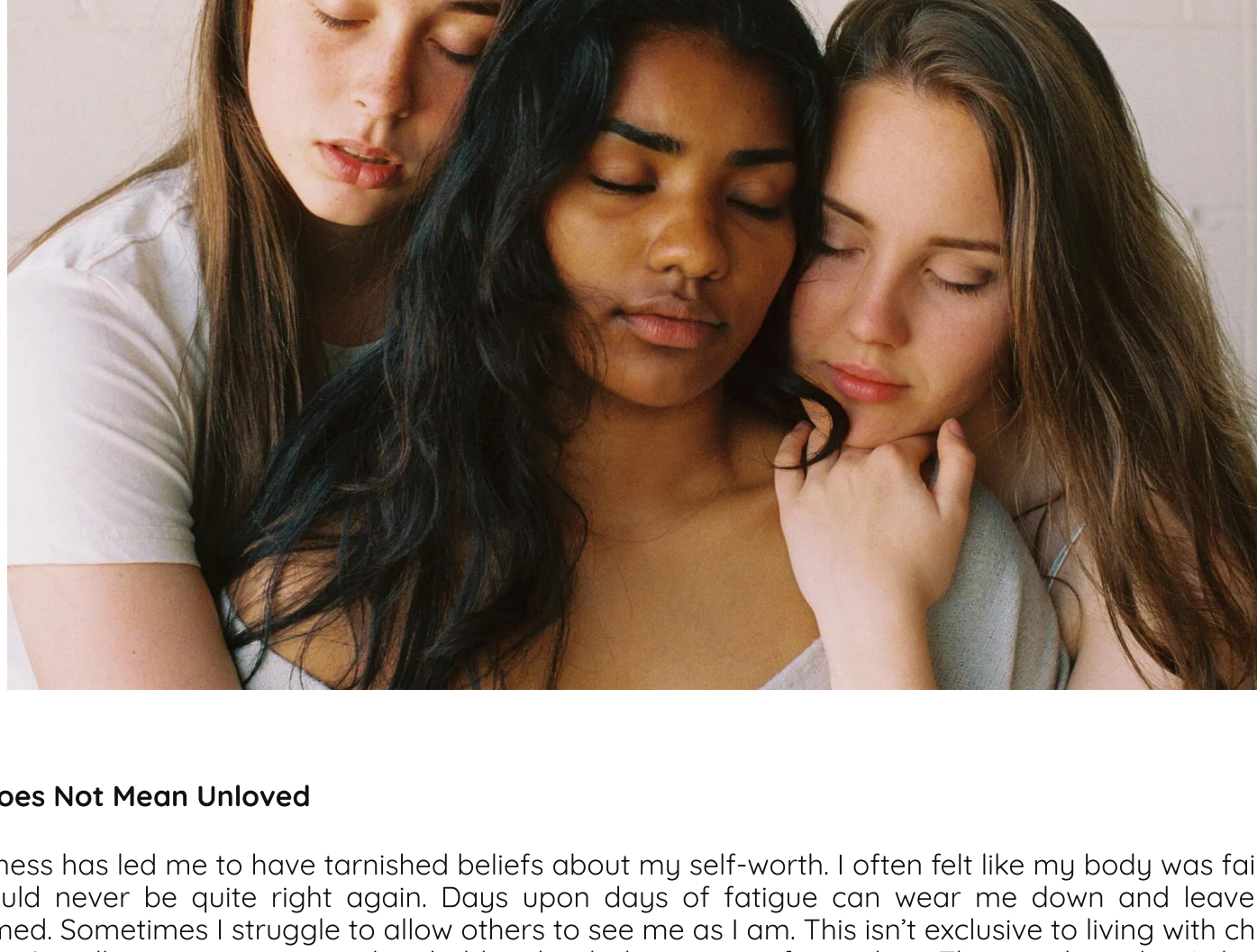
Empathy is vital in supporting someone with endometriosis or any invisible illness, though this isn't always the case, even with medical professionals. It goes deeper than what is seen at surface level - empathy has the power to dissolve the boundaries between individuals. Know that if you're sitting alongside someone with chronic illness, they are likely to be experiencing some level of discomfort which can change from moment to moment. Being aware of someone's struggle doesn't mean you're expected to fix what they're experiencing, but you do have the power to make someone feel comfortable about expressing their silent battle. In your awareness of what goes unsaid, the pain that so often lingers in the shadows, can find a place in the light - leaving the condition seen and heard - becoming a shared fight.

## Recovery?

My experience of the gap between seeing the signs of endometriosis and the long wait for a diagnosis is not an isolated case. Despite the devastating impact that endometriosis can have, it takes an average of seven and a half years from the onset of symptoms to receive a diagnosis, and even then, it is not equivalent to receiving treatment. My experience has been that unless you're talking about the infertility caused by the condition, your symptoms are unlikely to be taken seriously, and even less likely to be treated.

The experience of living with endometriosis changes you. I am stronger because of it, and in spite of it. However, alongside the pain, the way I am forced to live on high alert to protect myself against shame and embarrassment, is exhausting and I'm changed by it. I fear going out and wearing the wrong things in case a flare up occurs - causing sudden breakthrough bleeding. I have felt unclean and unworthy at times; it can be hard to keep going.

I believe my life will always be shaped by endometriosis - even if I was to magically no longer live with the condition. I am learning to manage my symptoms alone as a result of the lack of support out there for women not yet concerned with fertility or pregnancy and I live a significantly reduced lifestyle that allows for the fatigue and fainting spells that I experience. There is no cure for endometriosis, but this does not mean that I cannot live a happy and meaningful life. I'm privileged to live the life that I do, surrounded by people who I love and am loved by.



## Unseen Does Not Mean Unloved

Chronic illness has led me to have tarnished beliefs about my self-worth. I often felt like my body was failing me and that it would never be quite right again. Days upon days of fatigue can wear me down and leave me feeling overwhelmed. Sometimes I struggle to allow others to see me as I am. This isn't exclusive to living with chronic illness. I imagine we've all, in one way or another, hidden the darkest parts of ourselves. The one thing that I cling to in these times is grace. Without giving myself the grace on the days that feel impossible, I would find each day that little bit harder.

*Give yourself grace.  
Give yourself grace so freely,  
that it feels like you are giving it to someone else.*

*Grace will meet you in the depths that you thought no one could see.*

*Grace will inch its way through the darkness-  
Until what you once saw as lightless cracks will glow golden.*

When so much goes unsaid, it is important to find a way to balance out the self-loathing with the grace to have the best day available to me. A good friend once said to me, 'sometimes you have to just have a day, not necessarily a good or a bad day, just a day', and this has carried me through some of the darkest, unseen days with chronic illness. Endometriosis stole the confidence that I once exuded. I used to dance around in red wellington boots without a care in the world, without an inch of self-doubt, and certainly without the chronic debilitating pain.

It wasn't just self-love that I struggled to accept but also the love from others. It can be hard to live like you are loved when the overwhelming voice in our head tells you otherwise. However, let me tell you the truth about living loved.

I used to like going to the gym as it helped my body to feel productive. I would go to the gym in town at unsociable hours to avoid seeing anyone and I would rarely look up from the ground. A lady arrived just as I finished my workout one evening. She clearly took the gym very seriously - I did not. I attended for an hour at a time for the simple pleasure of rowing in time with the beat of the music through my headphones.

On this particular night, I had just finished an hour on the rowing machine. With sweat dripping down the side of my face, I picked up my water bottle and looked up. This lady in pink lycra innocently looked up at the same time as me and happened to catch my eye. Without a second thought, I lowered my gaze again, eyes firmly fixed on the ground, shoulders hunched over, making a quick exit out of the double doors.

A million thoughts raced towards me as I walked home that night. I know now that I made assumptions about what others thought of me before I even entered the gym each evening. I'd decided that the lady in lycra didn't like me, that she was judging me, that she thought I wasn't the 'type' of person you see in the gym. These thoughts were not based in truth and I had no evidence to back them up. Neither of us had done anything wrong, but I had chosen to allow past rejection to stop me from living like I could be loved or accepted in the gym.

I bring this story to light because I think this can often be the case with chronic illness. I don't always give people the chance to love me. I allow the voices of past rejection to echo their lies above the music in the gym, above loving offers to give me a lift somewhere or to meet with me in a moment of need. I allowed untruths to declare me lazy and unworthy.

Living loved frees you from the lies and past rejection. If you live from the place where you are loved, the pain of rejection or not feeling good enough doesn't hurt in the same way. This requires grace and it requires knowing the truth that you are loved. It is a daily choice to live from a place of self-love but also to assume that those closest to you will only speak love and truth into your life.

*If today you wake with the ache of loss,  
When you struggle to see how things might come together  
Or if you find yourself wondering how they fell apart  
Know that love knows no limits.*

*When it is hard to see the beauty in the things that did not last  
I hope you find that beauty in where you are now.  
When you throw open the curtains and rain falls down the window  
I hope the raindrops glisten in the light that breaks through the clouds.*

*Love trades loneliness with friendship, sorrow with joy and heartbreak with wholeness  
Accept it, hold it, feel it, know it to be true.*

*Love, and be loved.  
It will find you where you are, as you are - without judgement.*



## Community

*Hey! I am so sorry -  
I woke early and tried to get ready,  
I spent hours looking at myself in the mirror in outfit after outfit and hated everything,  
I got too anxious and I think the adrenaline got the best of me.  
Now endo has me curled up on the floor in pain and bleeding out.  
I'm exhausted - I doubt I will be up to leaving the house today (at least for the foreseeable future).  
I will have to reschedule lunch today.  
I just have an endless amount of university work to do,  
I left it too late again didn't!!*

I can't describe how many times I have sent this kind of message, censoring out the truth, instead making some lame excuse. I find myself ducking out of more social events than I care to admit. No matter how much I want or need to attend, so often I have missed out on things I care about deeply; either that or I attend and suffer the repercussions of this choice later. Shame thrives within secrecy and I think that is why so many people suffer in silence with the issues they face. I speak from experience. I have missed out on countless outings with friends because I was too worried about saying that my body wouldn't manage it. Chronic illnesses can lead to feelings of isolation. I often say to those closest to me that I value the friendships where you feel comfortable in someone's company without needing to fill the silence. These friendships are precious to me as I can save energy while also freeing myself from the isolation. These are the kinds of friendships that have seen me through the hardest days because often I don't want to talk about how I'm feeling.

I have also lived the tight grip of high functioning anxiety as a result of my endometriosis, afraid of a change in plan or not having access to the right pit stops to be able to rest or deal with an endo flare up. These situations would be less frequent if I only had the courage to allow my friends and loved ones into my daily struggle. Instead, I have allowed the voice of shame in.

The ability to speak about the frustrations of chronic illness came with a real sense of freedom for me. Community isn't just about friendship, it's about being seen and heard by people who can stand with you in a different way to those who don't experience the same things that you do. Community isn't sympathy, it goes even beyond empathy. Community by definition is a group of people who care for each other and who feel that they belong together. This is important within communities of people who live with chronic illness. There are some frustrations and experiences that simply can't be understood by an outsider looking in and therefore being able to share this sense of belonging, connected by something that can't always be said out loud, is powerful.

Community in all its forms, has been the lifeline that I didn't know I needed. Online communities provided by Endometriosis UK allow me to express what I am experiencing while reserving my energy, because I don't have to over explain myself to those in the space with me. Shared experience and understanding transcend the words I say out loud. When I sigh deeply and say that I am tired, this community can see the pain and anxiety behind the mask, while simultaneously shining light in a way that acknowledges the struggle without losing the sense of hope. Being realistic is important but hope will keep you living until you feel alive again.

Community means belonging.  
It finds you as you are with no hidden agenda.  
It seeks you in the shadows and allows you to live boldly in the light - celebrating each mini victory as you go

Community says, "I hear you and I am with you".  
It rallies: "You're not alone in this anymore - it is not just yours to carry".

Community whispers: "Have courage - I see that this is hard."  
Take one day at a time. I am here alongside you"  
It breathes gently "You are loved, valued and accepted just as you are"  
Even on the days this feels a far-off reality.

## Keep On, Keeping On

My chronic illness journey started with an unseen pain. The battle against the unsaid shame of certain symptoms and a disappointment in my body's inability to function as I desired it to. This pain and shame were only heightened by dismissal from the doctors on many occasions as these struggles continued to go unheard - even at the point of diagnosis.

If today you're reading this and you are someone who struggles with unseen illness, know that today:

I see you. I see you. I believe you. I hope you come across the same grace you so freely give to others. Surround yourself with people who only want to cover you in love. Open your heart to the possibility that people can support you, and want you to feel seen and heard.

*Millie Blue Capon is an emerging writer based in North Devon. She is an avid story-teller and she enjoys experimenting with writing form. Following the completion of her degree - Millie is now working on her first book, a collection of letters inspired by anonymous prompts from members of the public.*

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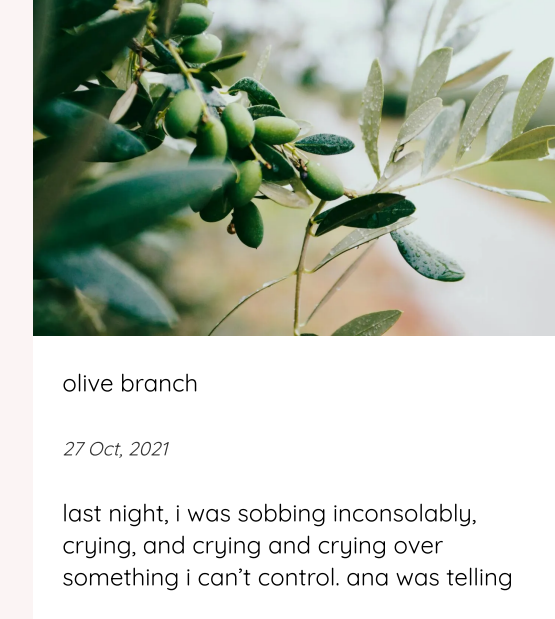
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