

# chronically

a constant state of sickness  
lived (and written) by Lindsey Esplin



There is no cure.



When I think of my relationship with my lupus  
I think of Mariah Carey's  
*Always Be My Baby*:  
You'll always be a part of me  
I'm part of you indefinitely  
Boy don't you know you can't escape me  
Oh darlin' 'cause you'll always be my baby.

And we're both Mariah and both the boy.

But neither of us can carry a tune so we are also  
definitely not Mariah.

The transition from not sick to sick was sudden—  
Only I was never actually not sick, I was only maybe not sick  
(the doctors would say: "you're not sick" or "it's just \_insert anti-  
science gaslighting explanation here\_" or suggest a lifestyle  
change to address whatever current symptom had made me  
seek out medical care that day, always ignoring the recurrence:  
the clear evidence of something chronic).  
Then in one phone call a doctor finally named it,  
the kind of sick I am,  
and that diagnosis changed everything.





I have been sick for a long time.

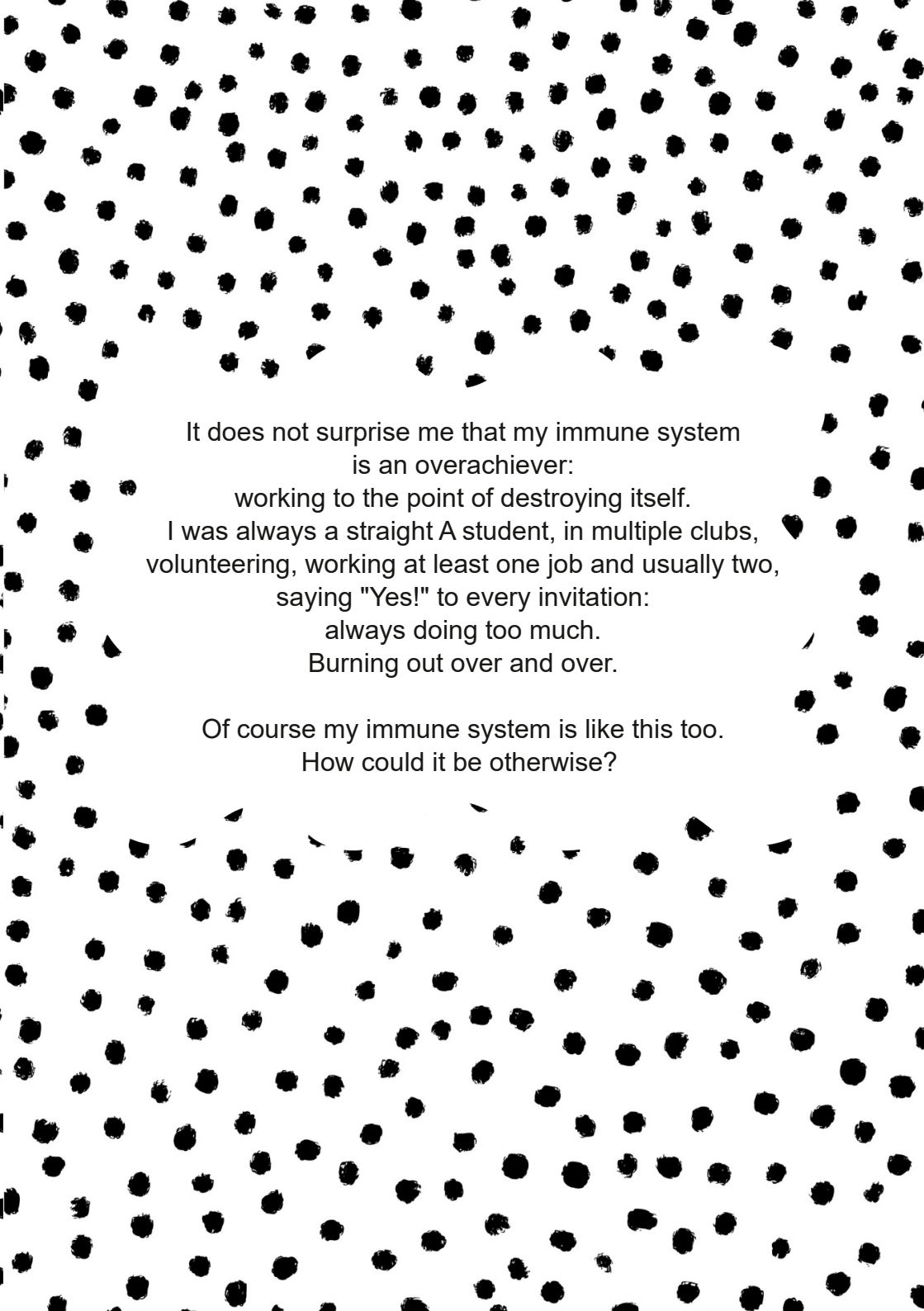
And the naming of the sick, the lupus, explained a lot.

My sensitivity to the sun, my tiredness, my tendency to always get the most sick out of anyone when everyone is getting sick.

When I caught the chickenpox at seven, the spots were in my mouth and down my throat: a knock-off Yayoi Kusama exhibit inside my body.

I wonder if that is what started this whole thing; that varicella-zoster virus caught at school, if it ignited my immune system's overactivity.

More likely it was just the first sign that I am sick, that I will always be sick.



It does not surprise me that my immune system  
is an overachiever:

working to the point of destroying itself.

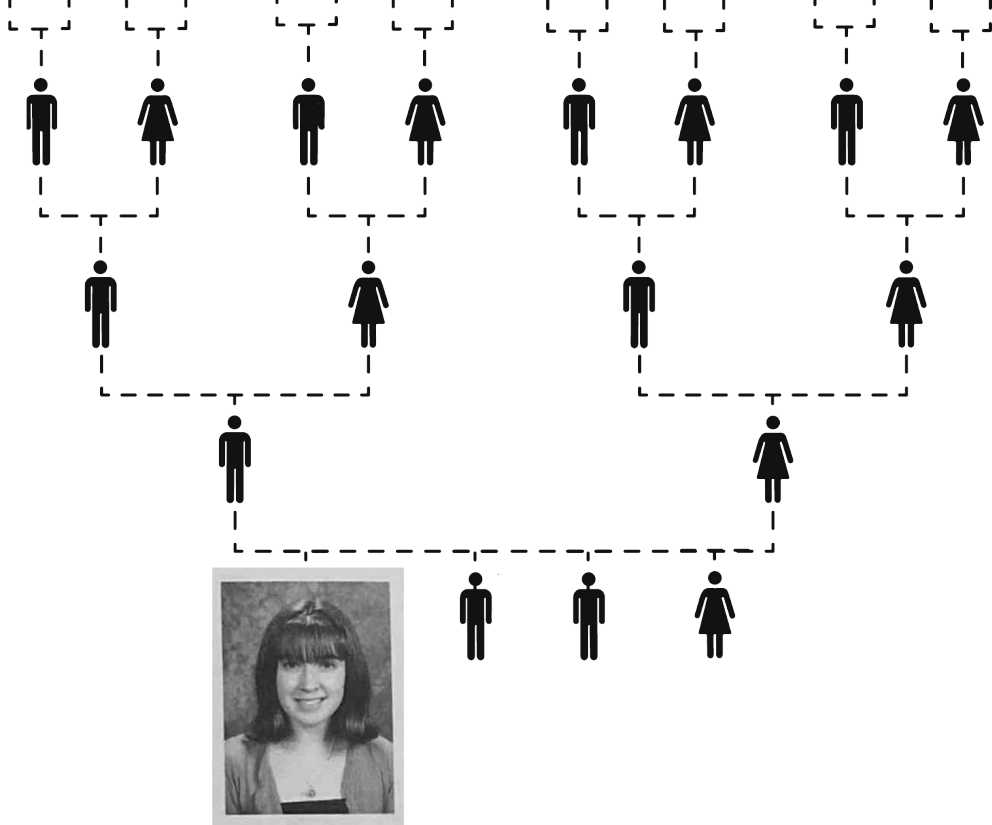
I was always a straight A student, in multiple clubs,  
volunteering, working at least one job and usually two,  
saying "Yes!" to every invitation:

always doing too much.

Burning out over and over.

Of course my immune system is like this too.

How could it be otherwise?



There is no family history.



They ask you about this when you start seeing a  
rheumatologist since autoimmune diseases  
tend to run in families.

But someone always has to be the first, and it's usually me.

"It's probably all my ACEs," I don't say to the doctor,  
but that thought has rooted itself in my brain.  
It cycles through like an As-Seen-On-TV product disclaimer:  
"Studies show that adverse childhood experiences  
impact health outcomes."

There is no family history of lupus,  
but there is a history of dysfunction and abuse.  
It stretches back generations.  
I worry it will stretch forward too.

My day-to-day revolves around medication:  
Eat breakfast on time so I can pop a pill.  
Then lunch so I can take another.  
Can't skimp on dinner, gotta have something in the gut so  
I don't feel nauseous when I have more pills.

Little bitter garnishes with every meal:  
not so different from parsley.

I need to drink a good amount of water too (but not too much)  
to keep the old kidneys properly hydrated. They're the organs  
lupus tends to attack first, if/when organ involvement develops.

And the pills need water too, of course.

The pills are more needy than any pet, plant, or bad boyfriend  
I've ever had.

And there is little possibility of them running away  
or being rehomed or us breaking up.

It's a til death do us part  
kind of relationship.





I can still work.  
From home, and sometimes from bed.  
Sleeping in and logging in when I can.  
Answering emails, taking calls. Nothing is urgent.

Was it ever?

I used to work 5–7 hours waiting tables, and 12–14 hours on  
TV sets, and commute 2 hours for 8 hour shifts at events.

One day like that now would knock me out for a week.

They knocked me out back then too, but  
I would push through, ignoring my unwellness. Then I'd crash.

Sleeping long and late, the days not working spent in bed.

I won't do that again. I know better now. I care more.





My eyebrows are thinning.  
My malar rash doesn't bother me, neither do the other  
more aesthetic symptoms of my illness.

But losing my eyebrows feels like a minor tragedy.

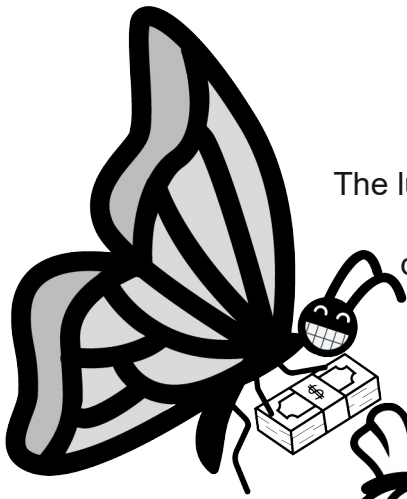
They survived the overplucking trend of the early aughts,  
only to start blowing away now when big brows are the fashion.  
The lupus undoing all my non-work that kept these things full.  
Goodbye Jennifer Connelly comparisons from random  
old women in bars, hello brow mascara.

There is enough hair for now for that to be workable.  
When that stops being the case I guess I'll Whoopi it and shave  
them off. This is also, fortunately, popular amongst celebrities  
currently so I will remain unintentionally fashionable.

I don't think I'll feel as much like myself without them though.  
To betray my emotions, crinkle when I'm thinking, and give my  
eyes a strong assist when someone has earned a glare.

I guess I could draw them in.  
It won't be the same, but that's an option.





The lupus orgs and foundations love to use the language of devastation to elicit donations from people. Calling lupus a "cruel mystery" is great for scaring people into giving you millions to do...

I don't even know what because not a single one of them has ever done shit for me.

"Please give us money to study a disease that is largely manageable with an anti-malarial medication"

doesn't make people click your little donate button or walk in your walks collecting a few bucks from friends and family for each mile trod in the sun.

I'd rather be given money directly.

"Don't give to lupus foundations this lupus awareness month, give money directly to me. Or someone else who has lupus" is going to be my ask this coming Lupus Awareness Month.

Mark your calendars for a May Venmo request.

I'll also accept PayPal or cash.

Friends have ghosted me when I've told them I have lupus.  
People I have known for years.

If there is a hell every single one of them will burn in it for  
eternity: murderers, landlords, and shitty fair-weather friends  
who abandon people as soon as they become ill.  
If I had a time machine I would go back to no-call, no-show on  
every single one of your asses stranding you at LAX  
and forcing you to take the shuttle into Hollywood  
or call an Uber and pay surge prices.  
I would show up to help you move, take two steps inside your  
half-packed apartment and turn right the fuck around leaving  
you with mere hours to get all your shit out  
and no one to drive your U-Haul.  
Fuck you all.

And then there are the others who ooze pity.  
Word of this illness and they spew "poor thing"  
while simultaneously being unwilling to hang out  
in ways that are accessible for me.  
They'll acknowledge my pitiful state but still expect me to friend  
in the ways that I used to: the ways that made me unwell.  
Still go to the shows at all hours, the beach, on long hikes.  
They won't adjust, but they will say what they think is  
sympathetic: "Oh that sucks. Sorry." The ableism loosely veiled.  
And then they pull away too.  
Slowly vanishing into the ether; a glacially paced ghosting.  
Fuck you too.

I don't worry the indefiniteness of my illness,  
not having a cure, having to take pills forever.  
People used to die from lupus.  
It's what killed Flannery O'Connor.  
A diagnosis used to start a countdown: five to ten years  
then you were dead.  
We have time now.  
I'll live just as long as most people,  
or close enough to it for my liking.  
Maybe one day my kidneys will give out. Maybe yours will too.  
Bodies are always changing.  
And healthy is a temporary state of being.





There is no cure.

But there is treatment.  
Symptom management.  
Life with lupus.

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This is a personal account of my experience with lupus.  
Nothing is intended as medical advice.



"My illness is chronic,  
my ass is iconic."

- me (only in my head  
and on this zine)

I am often in my apartment  
and infrequently on Instagram:  
[@lindseysnapspics](#) and [@oh.idontknow](#)

You can see more of my art at: [lindseycreates.com](http://lindseycreates.com)