

I used to be allergic to eggs. And the teto Now I'm just allergic to myself and kiwis and but I'm not sure and I eat them anyways with or maybe it's all in my head. Oh, and Ialso a very low-to-the-ground tightrope. But t means that my lower lumbar vertibra didn't clos up my low back and then I got in a cur cra mess. On! And then there was this time wi then the chicken to co and red pop incident every time since six of or seven eyears ago help my sister pick out a wedding dress and me and I ended up bent over and spitting there were the anaphylactic events—both show. In highschool we realized something pen and taught everyone how to use it. In had to watch what I ate. This was when I I was allergic to! I was allergic to myself, in act do too many things that could cause a react include but are not limited to: alchohol and o avocados, eggplant, spinach, processed or smoked wheat germ, beans, papaya, chocolate, citrus fru

inus-diptheria pertussis shot. But I'm not anymore I shrimp and mushrooms and probably almonds my fingers ocrossed. Because I'm and or laz hurt my back when I was in 8th grade. I fell of hen we found spina bifida occulta which just sh and now my sacro-illiac joint isagoddamne th the too-big bite of steak at some wedding at the Mexican place in Grand Reypids. And Shring . And the time I came home from college to I ate some mushrooms that rebelled against. in the red driveway at my parents' house. Then in theater renearsals-no, one was after my las ng was wrong. In highschool, I got an Epihighschool I started taking antihisthamines and vay. I had to marrage what I ate, to make sure I didn't friggerns histhamine production. Triggers ther fermented foods, dairy products, dried fruit I meats, shellfish aged cheeses, banaris, tomat its nuts and specifically walnuts) (and casheus, and peanut

THANKYOU,

To my sister, Olivia, for all her advice, concern, love, and for being my best friend always.

To Jennifer Metsker for always being the most insightful and enthusiastic voice in this project and for telling me that my writing was worth including.

To my GSI Martha Daghlian, and professors Stephanie Rowden and Kelly Murdoch-Kitt for encouraging me and being patient with me, and for letting me turn this book in a few days late.*

To Jamie Vander Brock for her abundant generosity and for making the Book Arts Studio accessible with online workshops during the pandemic. I don't think I would have made a book without these workshops.

To Spencer for always remaining calm, and for staying in love while losing our minds, during the end of the world. Elbows locked, baby.

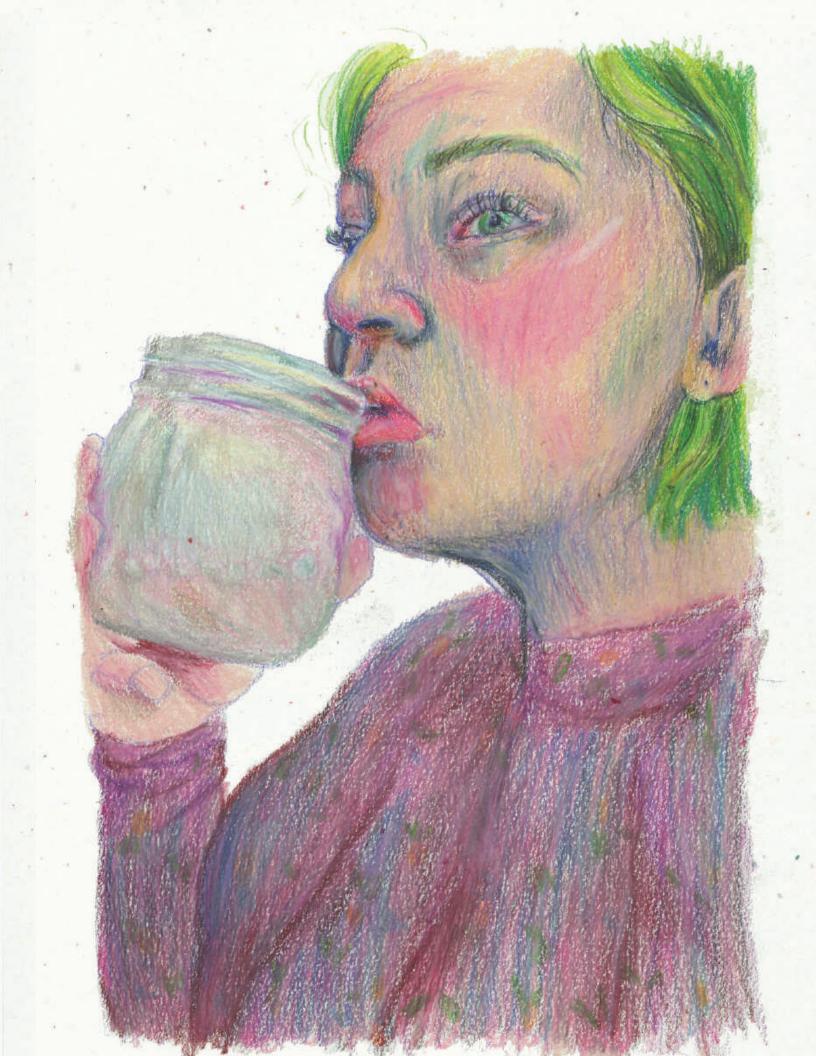
This book felt very impossible several times but it's here and I am so grateful for your part in that.

^{*}sorry if that was supposed to be a secret

BITING MY TONGUE

Ansleigh Joyce Hamilton

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A STATEMENT FROM THE ARTIST,

This book will end without either of us knowing what's wrong. This book is not a story, it is documentation, it is a journal, it is a patient questionnaire, it is proof despite invisibility, it is interactive, it is an uncertain diagnosis. Mostly this book is for me.

The telling is in parts because a life is not a cohesive whole. And because it is too much work to remember every little thing.

I hope you read this and feel seen, heard, present, loved, confronted, whatever it is you need at this moment. I hope you are never fighting alone.

Please, look in, explore, play, and we will both know what we know.

MI Im here

again.

Good

morning.

It's another one.

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losing

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NE

Take us out (into the Living/Kitchen room) to play.

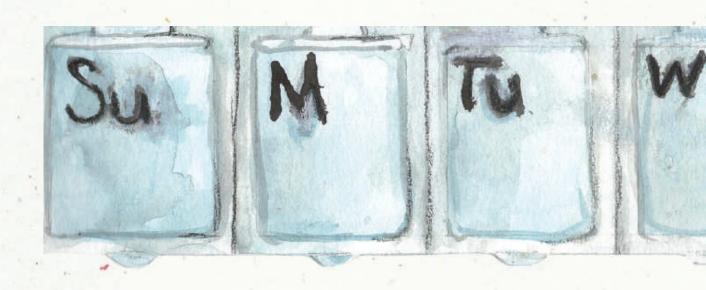


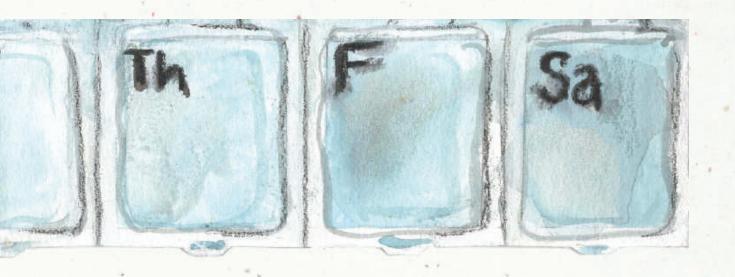


















watching.



waiting.



Isolation is deeper than

physical loss

a hug

and a hug not there.

friends, family, roommates.

distaste with me

and watch

as the

parties and slew of different people each day. were actively keeping my life on pause

It doesn't

matter

I still do not know how

these relationships

will read this. Maybe they won't think it's about them.

in bed all day unable to walk or take stairs to the first floor of my home.

lying

I had already been indoors

I had cashed in all my favors.

That happens a lot when you are sick.

I feel like I'm living in a different world-parallel to the one of those around me but not quite it-different rules, different stakes.

The biggest

risk it by whose life

planned and assessed

difference between us is how we think.

It isn't at all that I do not want

to. I cannot.

So I don't

his cold,

for risk.

quarte

quarters from the bank another time.

Maybe we don't leave the apartment

for over a year.

except to walk the dog.

I'm not fine.

Iam

MAPAM

Eosinophilic Esophagitis

eosinophiqitis. easinophilic esophagitis is caused by the presence of eosinophilis in the esophagus.

C-O-sin-o-fill-ick Ch-sof-un-jec-tis

-a chronic immune system disease in which a type of white blood cell, eosinofil, bulls up in the lining of your esophagus. - discovered in the 908

Symptoms

- · dysphasia (difficulty Embarity) -
- · impaction (foolgething such in esopless)
- · Chest pain (centrally product and despiration antack)
- · backflow of undigested food Oregurantation)
- · Difficulty eading · family .
- · formities to thise

· allagio + athora







I stabbed myself once a week for 18 months with no idea whether or not it would help at all.

Getting a shot is one thing- you can avert your eyes and wince and hold a hand if you're nervous.

A self-injection is so much worse. You have to prick yourself and your hands are clutching your own flesh and the other hand is holding the shot an inch away. You know it's going to hurt, and you have to be aware and in control and you have to force yourself to cause that pain.

After 18 months it didn't get easier and I cried almost every time. I never got to find out if it helped but the steep decline in the months thereafter led me to believe it was helping. Since It was an experimental drug, there is nothing I can do to get a hold of it. It isn't EDA approved for my specific condition and there is no proof that it helped so it was probably 18 months down the drain.



What if what people see in here doesn't fit what they think of me?

That I don't fit in.

That I'm just some tense freak.

That I'm too weird.

That I come across as sad
or pitiful
a downer

too loud

not funny

not interesting

gross

smelly

I'm so afraid that someone will see all the lowest and grossest and scariest goblin parts of me and stop loving me or seeing me or allowing me credibility.

When I was younger my mom thought I had some awful rash and made me see a dermatologist.

I was so ashamed.

I was disgusting and covered in scabs and sores.

But it wasn't because of some absurd and sudden rash.

I couldn't seem to stop picking at myself.

They gave me a weird and stingy prescription acid lotion

to put on the little red bumps I would pick at.

But the lotion made the open sores sting and

I didn't like using it and

No one ever brought it up again.

And I see now why addictions break up lovers because when I started picking at my arms all sound was gone And the world slowed down and it felt somehow relieving A secret affair, mining my pores and follicles For things that are healing, things that are growing, things that are cells doing what those cells were meant to do.

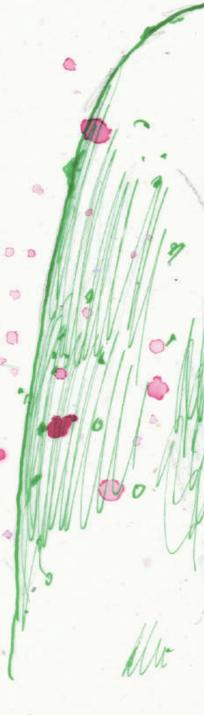
I am disgusting.

I have scars,

I have open sores,

And I knew it was destructive and I'd hide it under long sleeves and turtlenecks and try not to pick at my face.
But then I'd pick my chest.
My legs.

And if it wasn't this it was pulling out my eyebrows,





My nails.

I've always bitten my nails ever since I can remember.

I bite them until they are gone,

Then I bite the cuticle too.



Sometimes I don't notice until I'm bleeding and someone tells me "Hey, you're bleeding!"

Then afterward it hurts and I'm so ashamed.

But I couldn't stop.

And I see now why addictions break up lovers

because when I started biting on a good nail nothing could make me stop.

It was like a kiss in the movies

Nearly passionate

11

a compulsion of nails and teeth!

Biting my nails was allowed in public.

I could do it while people were looking.

It wasn't good manners,

No,

But it was allowed.

And it's crazy- I mean psycho to be doing this.

I have these hands that I love and that make beautiful art with me

And here I am bludgeoning them.

I have this body that is so brilliant it could heal

as if nearly nothing were ever wrong

if I just let it.

Now you know my secret.

HOW ARE YOU?

I tried to eat a sandwich today



and it didn't work.

I WANTED TO EAT A SANDWICH AND I COULDN'T AND I WANT TO TELL YOU WHY AND IT'S GOING TO TAKE A LOT OF DETAILS.

My family isn't good with food.

My dad's side is mostly all too big.

My mom's side is mostly all too skinny.

She would warn me to not eat when I'm just bored And to make sure I was hungry

And eating for the "right reasons"

And "you have got your dad's genes so watch out"

I learned to silently justify my food.

Or make a show of it.

Or make it secret.

watch who watched. Then my mom was allergic. Food can kill you. She would gag. My mouth was tingly. Food is scary. Then at my dad's cousin's fairtale wedding, I ate a piece of meat and it was probably too big to swallow. She told me or that I didn't chew it enough. She told me after it was over. I told her after it was over. I remember chewing. I remember it getting stuck. I could feel my muscles in my throat begging it to go down. I remember checking to see if I could breathe. I could. I could. Spit. I could. Spit. Hot saliva pooling around my tongue, spilling out of my child-sized mouth.

I remember she said she was only mad at me because she was scared of choking. No plastic on the floor.

Is there plastic in my throat?!

- I guess it was because of my brother, who always ate from the floor.
- I guess it was because I didn't chew it enough so when I swallowed it got stuck.
- I remember trying to put my little fingers down my little throat and I remember my grandpa finally found me and I had thrown it up and I was crying but also I

remember I was fine.

There was saliva on my tights.

There was bathroom-floor-tile grime and gray stalls on my tights.

It was a fairtale wedding I remember.

The next time it was red pop

In a faux adobe building on the west side

They serve the best little street tacos, Ansleigh,

And it was local

And it was Michigan

And so they had red pop on tap,

fresh and pink and foamy in a styrofoam white cup that squeaked when the straw moved.

And this was special.

We sat down. I had a shredded chicken taco or at least I tried to.

I remember the stuck feeling and it hurt and I felt shame before I even felt the pain. It was going to be so embarrassing. I was going to die from a shredded chicken taco. No you aren't going to die Ansleigh.

Calmy explain you need help.

DON'T MAKE A SLENE.

I'm panicking. She tells me to take a drink, wash it down. I try.

In my memory, I took a sip of red pop and it angered my throat like a beastly volcano about to erupt.

Red pop shoots out my nose, it bubbles out of my throat like a shaken soda.

It shoots up to the ceiling.

My clothes are pink.

My cheeks are red.

I'm crying.

I made a scene.

I didn't finish my meal.

I used about a hundred napkins.

I've never written this story down before.



ARE YOU UNCOMFORTABLE YET?

I'm sorry I can't make this easier for you
You just have to flip through and watch.
You can't do anything about it.
I know it can be uncomfortable
To sit and watch someone's pain
But please
Be wary to give me advice when I am not asking for it.
Please try not to ask me how I am if you do not wish to know.
Because I'm not going to lie anymore.

So please stop trying to help with
Homeopathy and
Crystal remedies
Or the sage wisdom to call my doctor
I know you want to help,
But you can't physically help me
And that weird diet you heard of through your uncle's cousin's friend is unlikely to be what cures the incurable

But if you want to do something,
Give me your patience, your understanding
Your willingness to find out what's going on with me when I have the energy
to tell you.
Believe me when I say I can't and listen when I say I can

But if you really need to do something right now, You can help me pull this food down my throat.

HOW ARE YOU?

Oh just tryizing to balance feeling like I have to be an expert on my illness because no doctor will ever fully read my story or my chart for god's sake. While also having to trust doctors and hope they have my best interests in mind. But also I am not an expert.

Not enough to treat it or minimize it or know how to tell when it is "bad enough" to get help.

But when the panic sets in I am an expert.

But not enough to know whether this time it is just pain,

and I can move through it until it passes,

or if this time I am actually dying.

My hypervigilance is rewarded
By the EpiPen saves
By the you got here just in time's
By the diagnosis after years of suffering silently because I was told I was fine

Hypervigilance is a curse.

Having an anxiety disorder and,

idiopathic anaphylaxis and,

the feeling of things being stuck in my throat and,

the risk that it might be fine or it might be stuck,

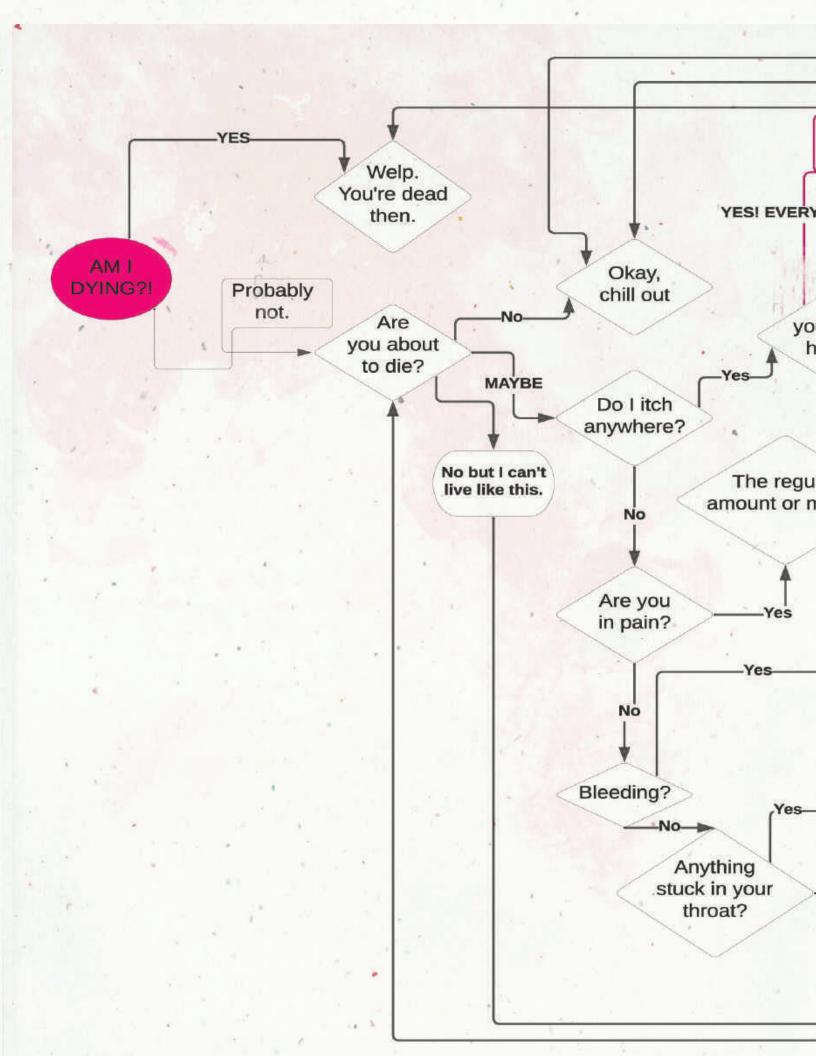
is a fickle pickle to be in.

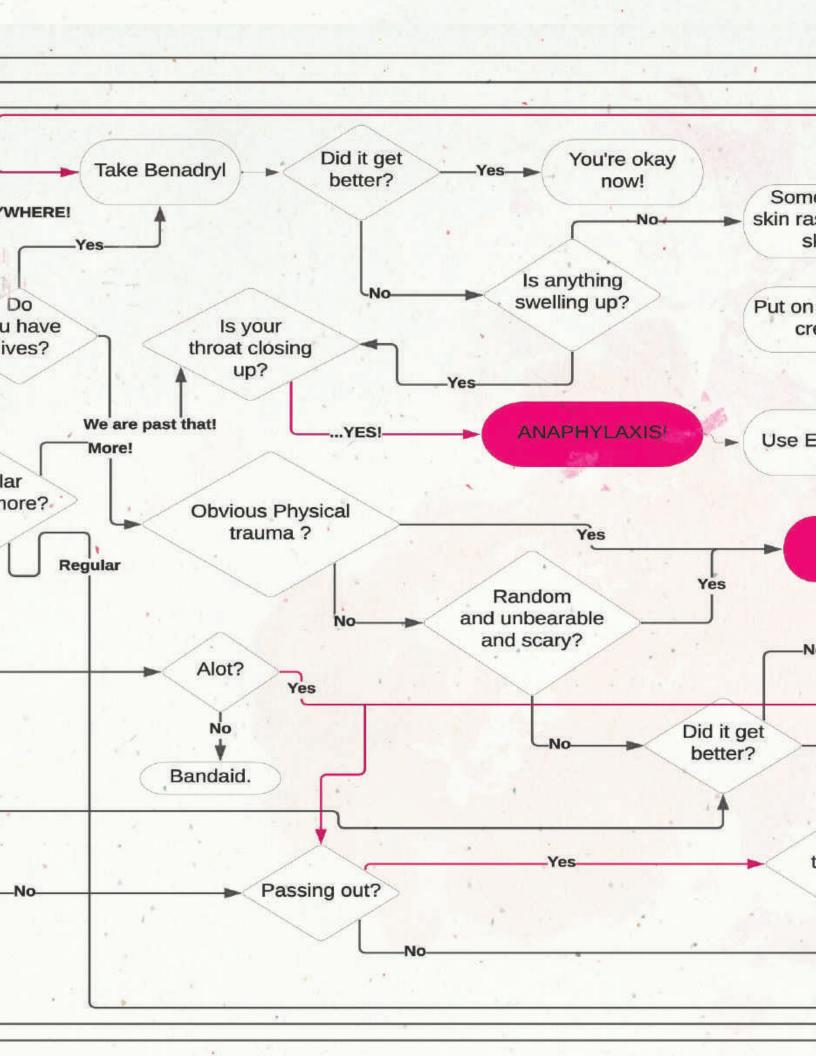
How do I know if I'm actually dying this time?

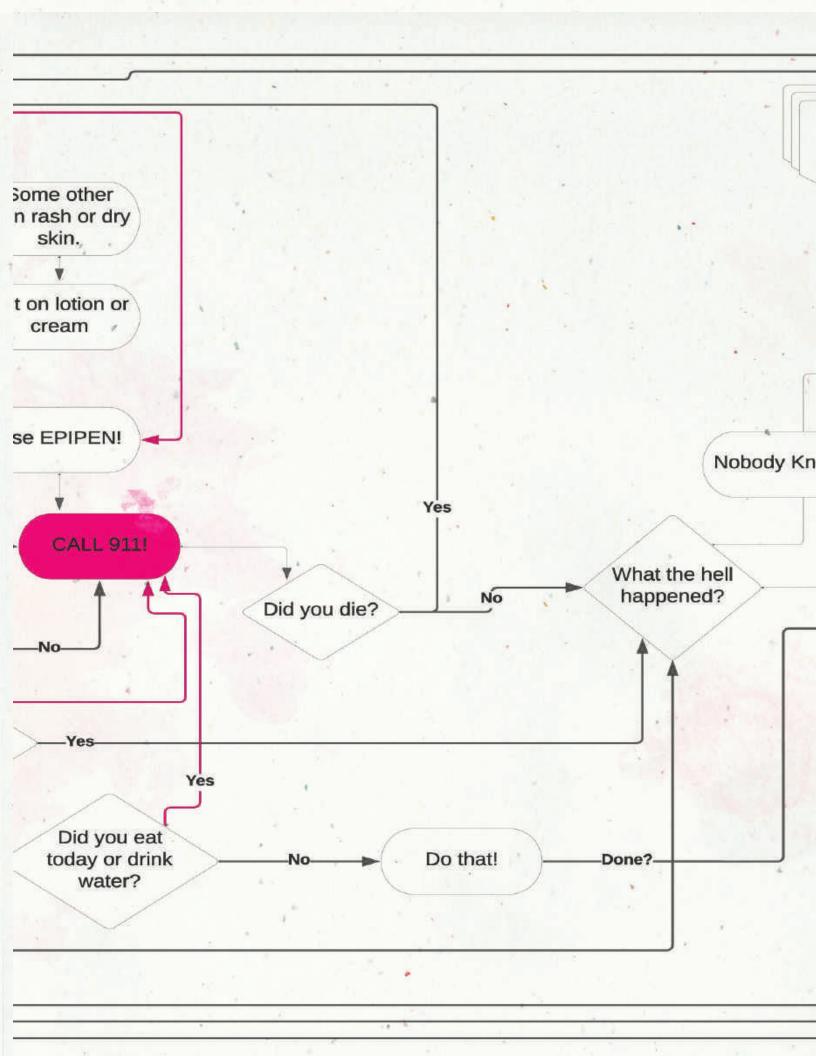
God, it would be so embarrassing if I wasn't.

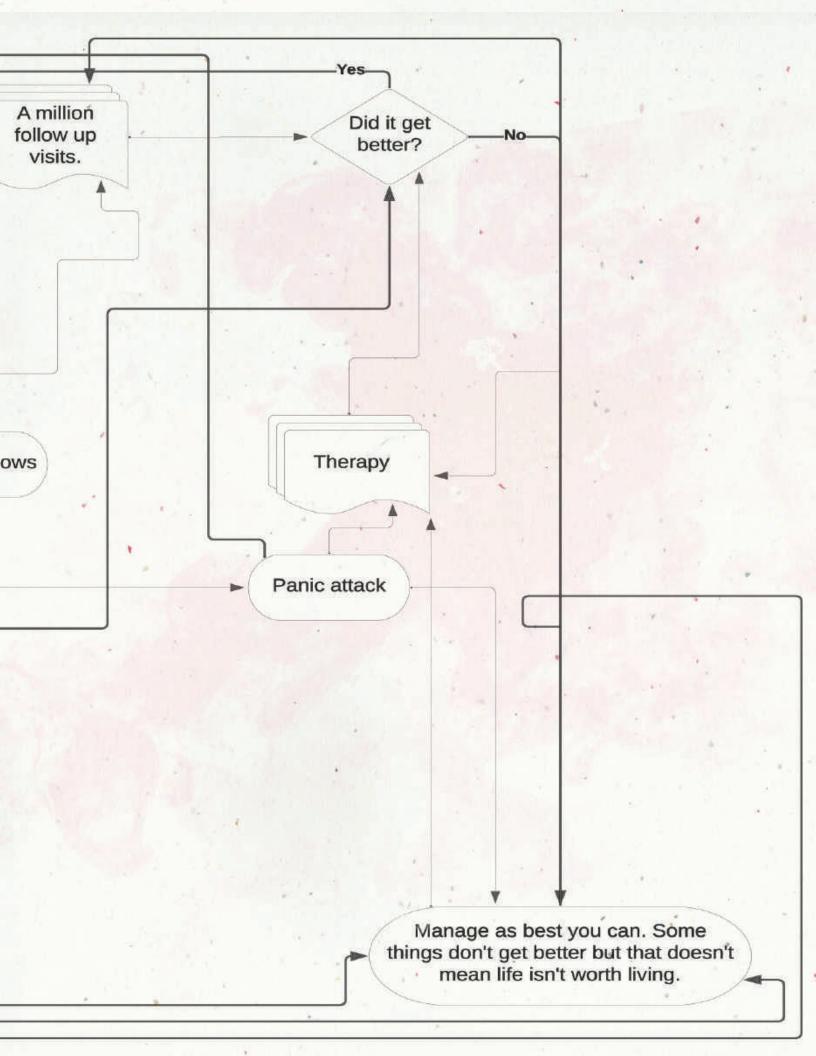
God, it would be so stupid if I was.

If I was dying and simply just too embarrassed to get help.









YOU DON'T LOOK SICK."

"I wish I couldn't eat."

It was my junior year of college and I remember being in a practice for an extracurricular I was involved with. We were doing warm-ups and everyone was goofing off and having a good time wiggling their body. I wasn't. When it came time to share what was going on with each of us, I bit my tongue as I often do. In my mind I told myself "You can't share that you're in pain this week. You shared that last week. Everyone will think you're a downer. Think of something new and trivial and move on".

And that's just what I tell myself. Everyone else says all sorts of things. Sometimes I feel like I'm making it all up but then I remember all the things I wish I'd responded to differently.

"You're not unhealthy, you are young and alive and you've got your health" Did you call your doctor?" "Have you tried taking meds for it?" "Wait, so it will never get better?" "Everyone is tired, stop complaining." "Why don't you just borrow money from your parents" "I would have never known" "You're too young to complain about your back this much." "What are you going to do? Just stay inside forever?" "You're just being extra careful ..." "It's always something with you, isn't it?" "You don't look like you're in pain." "Yeah, but every girl has bad cramps sometimes." "I know it isn't 'safe enough for you to feel comfortable but the rest of us want to do it and are fine with it" "You just need to east more fruits and veggies" "Welcome to being an adult, get used to it."

"Have you heard about these things- it's called an invisible illness- that's like

"I feel like if I was allergic to that I'd get so skinny"

what you have, have you looked into that?"

"Have you tried going to keto? Paleo? Gluten-free?"

"It is probably hard to work creatively when you can barely function"

"Are you sure you can do it"

"It's not going to kill you, get over it"

"You don't look like you are going hungry"

"I figured you wouldn't want to come anyways"

Did you stick to the treatment? It probably didn't work because you weren't following instructions properly"

Three of these things were said to me by a doctor, guess which ones. I don't have the energy to respond to all these or give you the context to explain why they were insensitive. I just need to leave them here and move on. I have the blessing of "passing" as a non-disabled person and the curse of having to explain myself over and over again hoping someone will believe what they cannot see. You can't see pain. You can't see mental health struggles.



It hurts. It hurts. It always hurts.

I want to reach inside and unclench it all.

I want to tug out my insides and make them outsides.

I wish I could pop out my gritty gnawing bones and scrub them clean in the sink.

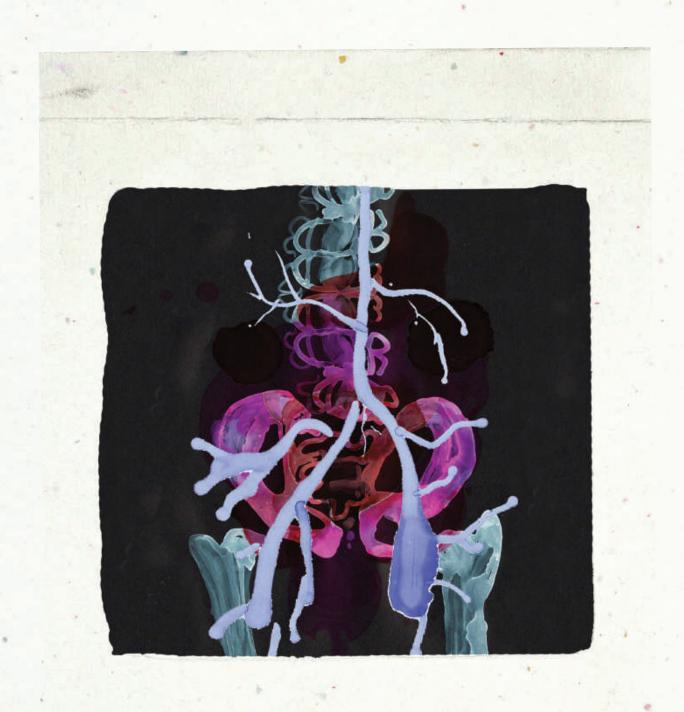
It's all mushed in here and I can't find where
If I could just pull it all out and untangle

Unhook

untether

This unidentifiable pain.





WHAT CAUSED IT? WHERE IS IT COMING FROM?

I didn't want it to be anything but I wanted it to be something because it is something. It isn't nothing. I don't want to be diseased or fibroided or metriosed or inflamed or irritable boweled or any of it! But it is real and I'm in pain and if nobody names it then all the doctors and insurances and the whole wide world will keep telling me it's nothing. So what is it? Because it is something.

It is an understatement, at best, to say that managing a chronic illness without medical assistance (or honestly even with medical assistance) is difficult. Sad. Lonely. Painful. Often harmful. You get the idea. When appointments are scheduled out months in advance but your symptoms require treatment now, one must get... creative.

I have consulted z4-hour nurse helplines, I have texted my sister about a million times (also a nurse), I have scoured the internet (be careful with that one).

I have drank tea with marshmallow root and chamomile.

I have sucked on peppermint oil tummy mints to settle my stomach.

I have lived on a steady diet of chewable pepto bismol and pepto bismol goo; fiber gummies; protein shakes and juices and cookies and bars; and liquid calories anywhere I could find them. But for lack of appetite, poor mood, pain, nausea, and anxiety, I have been reliant on weed.

Every Day I feel a little bit guilty. That deep and dreaded 'drugs are bad' feeling creeps into my self-image. Some days I feel as if maybe I am just some irresponsible and worthless stoner. I know

this is a relatively baseless accusation of myself. I feel better. Less scared. Less pain. I can eat. All good things but I can't shake this outdated and stigmatized identity. I don't even think this way about anyone else who uses marijuana.

We value sobriety but if I'm in this much pain all the time am I even sober? We worship these sober states. There is an ableist martyrdom to it, but I can't see how sitting and suffering helplessly is better than being a little bit high. Is suffering soberly really a better state to be in?

Maybe it is that I do not wish to be reliant on a substance to live comfortably-

though I use other substancesOmeprazole for acid and digestion
Cymbatta for anxiety and depression
Zyrtec to keep my immune system's
histamines from waging a random war in
my body.

Wishing I wasn't reliant on substances is as futile as wishing away my diseases.



I'm in a weird state of mind where I feel I must just move through each day. Just survive it.

There is all this surrounding pressure to do more, be more, work harder. But working harder when I needed rest is part of what got me in this mess.

I can rationalize when it is hard to eat and I have to step back down to mush or liquids. It is much harder to discern when I need to take a step back on my work and stress load. Fewer meetings. Less thinking.

Less talking.

Just rest.

When it is hard to eat it is even harder to move, to create, to care.

But I'm a senior in college.

This is when I am supposed to be busting my ass and proving my work ethic.

It's the final stretch.

It feels like the straw that will break my back.

I will get my degree but at what cost?

I am accruing debt with student loan creditors, with my health and my sanity.

First, you burn out your mind. Then if you continue your body will wear out on you. Then you must rest because it's the only option, and your mind rebuilds in a broken place where all you get to look at is your ceiling and everything is gray on your shuffle to the bathroom

I wish I could show you how hard I have been working-The months of therapy but there is no grade for therapy.

and you learn to listen to the world happening without you.

The rigorous experimental drug trial.

The elimination diets.

The calls and visits and scheduling and insurance and talking to doctors.

The years of trying to find something that works

The hours I spent trying to feel good enough to come to whatever it is you invited me to.

The cookbook in my mind for what I can eat.

I promise I am not lazy.

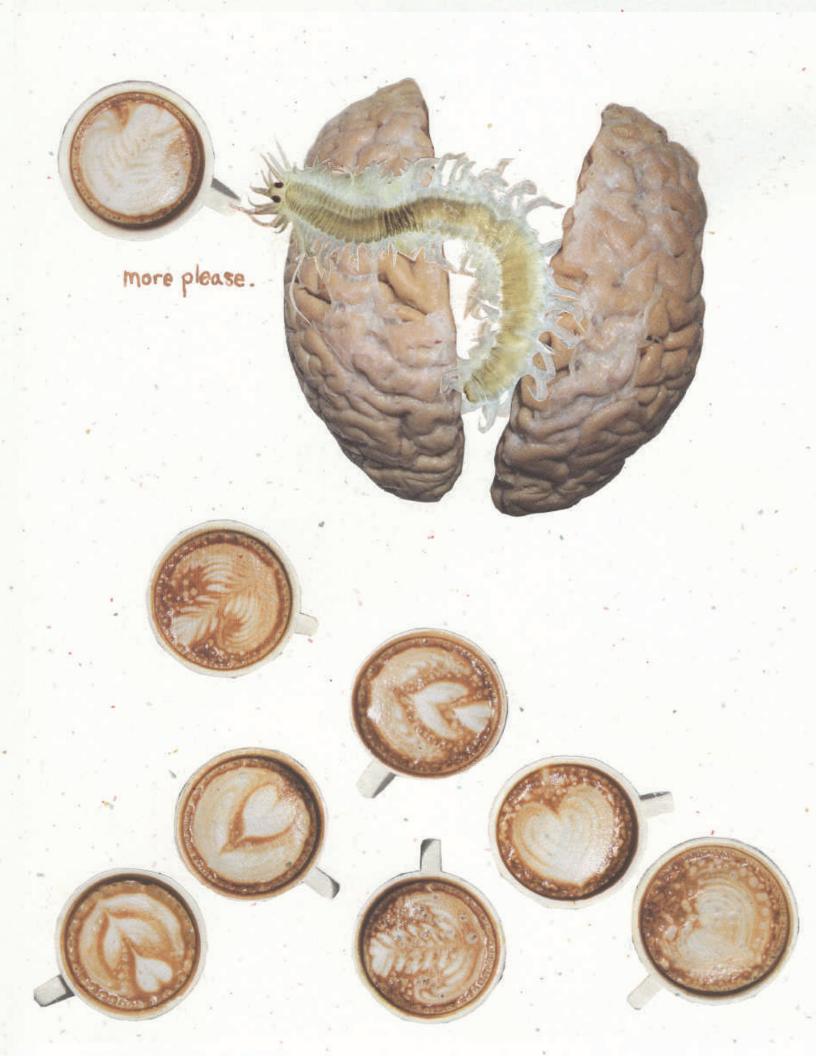
I promise I am not trying to be a flake.

I promise I am not all that picky.

I promise I want to be on top of it all.

Now my decisions and choices seem to come less from rationality and time management And instead, come from a weakened state of being ill.

I am suddenly unable to handle deadlines.



WHAT CAN I EAT TODAY?

My time management is in shambles.

If I plan my time and energy as if I am fine,

I will surely get sicker and miss that deadline and let everyone down.

If I plan my time and energy as if I am ill,

I will surely have more time than I need and miss out on opportunities I could have taken on.

I am never right and I do not know the balance.

And once I have done it there will be more work to do.

Prove to some stranger that I should be the one to do their labor.

Prove to them I really want a job that I probably don't want.

I mean, I do want a job -any job- but working is hard on my body and mind.

I just want to rest but rest is really expensive.

And what happens when I do get the job and then I need to rest? Will they fire me? Will they tolerate my artics of resting?



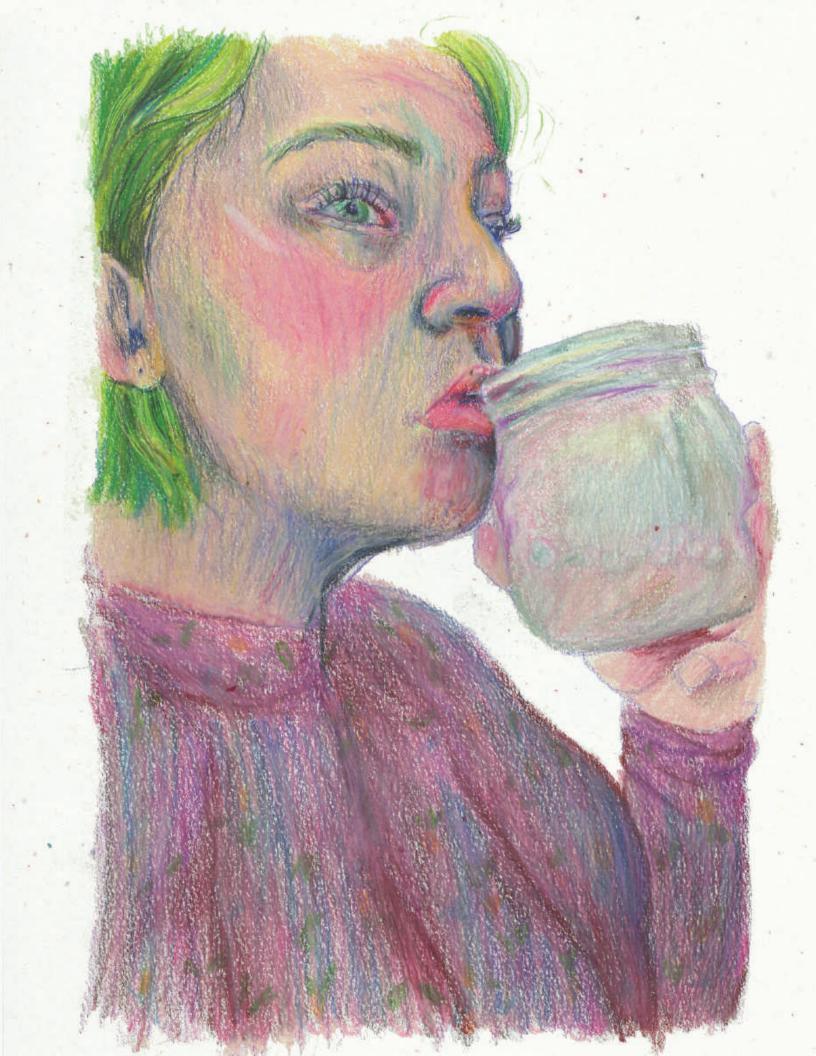


How ugly it is to be sick.

It isn't glamorous at all.

It's bodies.

It's veins and acids and injections and staring into toilet bowls until you fall asleep on the shower mat or up against the tub.



This lifestyle doesn't have an end. If the illness goes on forever, then the book goes on forever. So read it again. It is incurable And so if the end of the book feels like the solution, then there will be no end. It's Cyclical. So read it again. The same thing again. Yes, seriously, this again. "I already saw this! I already death with it!" I Know. But go back and read it again. Having to start over is the most chronic thing. I know you don't want to but go back and swallow it again. I know you don't want to but go back and think about it again.

Go back and read it again like you have to to survive.

actually help with muscle pain and cramping of anaphylaxis, only hives and itchy ears and a attach. Then I went to college and had a through stages of recovery and and duringe and a write, let me fix my penmanship - but I is a bit misle I hough saying I "found out" is a bit misle gears but I was putting it off and I wouldn't want wery good at. Growth is too. But I could then so I stopped taking my meds and my at all and told me I was sich because because I was a silly little girl and I incorrectly and I should get another scope no and he told me to get it again an want to spend thousands on an unrecessary repeat trom my parents and we werent talking too but not really because it wasn't my facity I was untreated still so I got worse. That a lot and rocke my bike to work every day extra a rock bottom that was much needed so that I helped me get insurance and I got right back to repetence was a pandemic and then I went off my meds without them I became a snorling dragon, breathing without them I became a snorling dragon, breathing was very warried, they all told me later. And I was worned was very warried, they all told me later. And I was worned and body aches). Then there was no more constant looming fear of an anaphylactic spotly health insurance coverage and went is covery and of grief. And then I found out found out I had anxiety. And depression eading. It was more that I had suspected it for I let myself see it. Denial is something I int afford to be sick night them gastro doctor didn't read my file or chart everything I had tried wasn't going to help nad probably just done the treatment even bhough I had just had one so I said a I told him I couldn't afford it and I didn procedure and he told me to borrow ma much at the time and so I gave up on the because I was waiting to see a new Gastro b - summer I lived off of Ben & Jennes and sup for when I took the bos. I was in a delections from Gall to could himse histat bottom tooked like. Then a Polend's international myself. And then my toach hurst again and then because I didn't like how I they made me reel but fine at everyone. Biting, Bitter 50 Angrey. And everyone I'd never been so angrey. And I have been in therape care I'd never been so angrey. And I have been in therape are revolting. I am sok again and every verve is my

