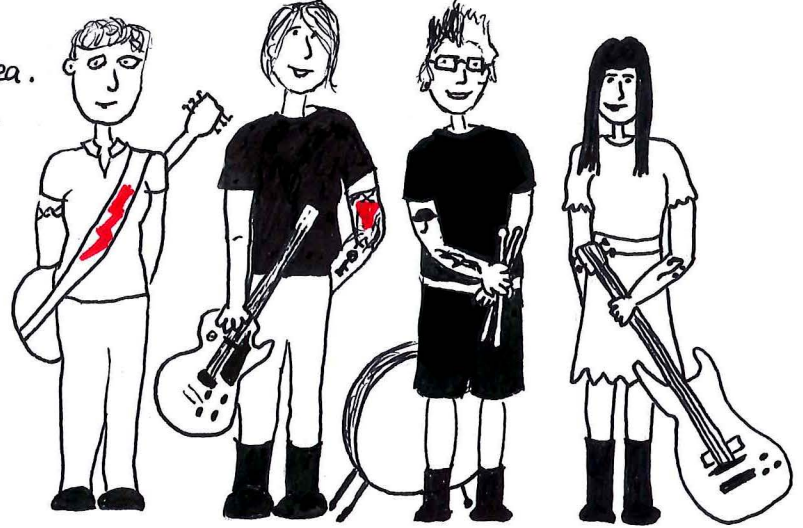


# CHAPTER 6:

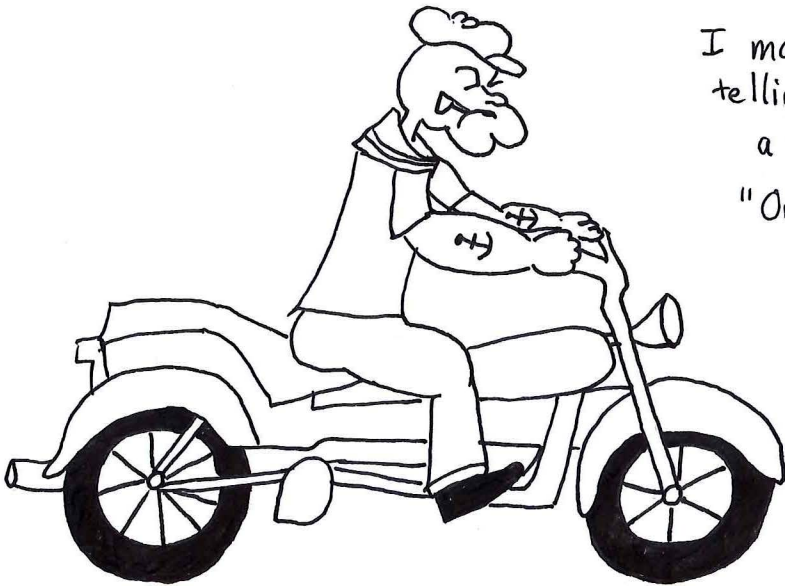
Sweet  
tats.

I've been wanting to get a tattoo for years. I like the look. I like the idea. Many of my friends (and most of my musician friends) have tattoos. Many of the people I want to be more like have tattoos.



To me, tattoos signify creativity, self-confidence, bad-assery. You don't get a tattoo unless you know yourself really well.

I want to know myself really well. And also be badass.



I made the mistake once of telling my parents I wanted a tattoo. My mom gasped, "Only sailors & bikers have tattoos." she desperately didn't want me to "do that" to my body.

Something I think of as everyday but imaginative, regular but bold, to my mom symbolized:  
Sailors. On motorcycles.

In the months that followed, my mom studiously mailed me newspaper clippings about the risks of tattooing.

In the United States, licensed tattoo parlors must follow safety standards to protect against blood-borne infections. Standards such as employing single-use needle kits, and using separate ink pots for each individual client.

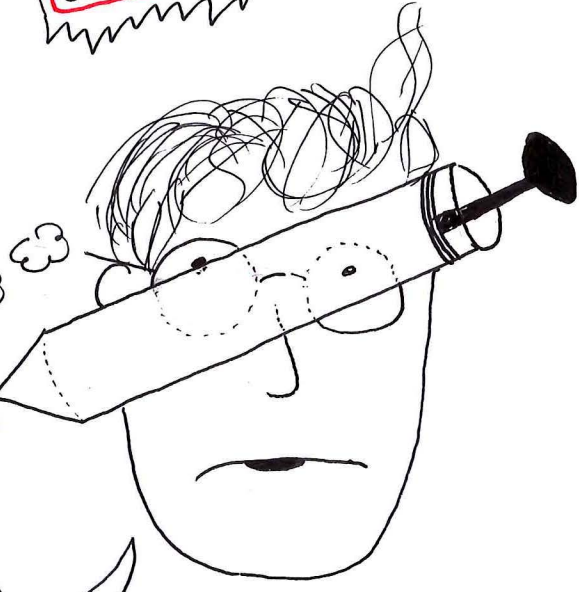
Still, if you get a tattoo, especially from an unlicensed person, there is inherent risk in a process involving needles and blood.

**HEPATITIS C LINKED TO TATTOO INK**  
REUTERS - A study found a link between hepatitis C and body art. People with the virus were more than 4 times as likely to report having a tattoo. The CDC recommends having tattoos or piercings done only by trained and licensed professionals. The most common routes of contracting hepatitis are injection drug use or blood transfusion before 1992... what she highlighted what we should have read

WHAT MY MOM THINKS IS WHY I HAVEN'T GOTTEN A TATTOO:  
these newspaper clippings.

WHY I ACTUALLY HAVEN'T GOTTEN A TATTOO:  
My fear of big damn needles.

WHAT I CLAIM TO MY FRIENDS AS TO WHY I HAVEN'T GOTTEN A TATTOO:  
The cost. That's all.



not to put too fine a point on it

A lifetime ago, on May 17, **only 3 weeks earlier**, I was at a fundraiser for the Girls Rock Camp where I volunteer. I won the best prize in the raffle: a \$150 gift card for **a tattoo**.

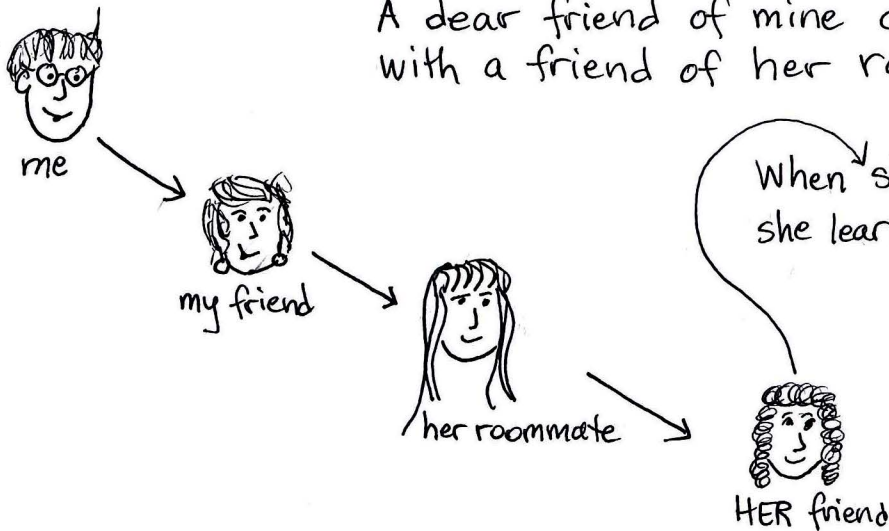
I had no remaining respectable excuse. I started planning my tattoo visit, before **I opened the Blood Bank's letter**.



Now I am waiting -- tattoo-less -- for my medical care team to tell me something, anything, useful.

In the meantime...

A dear friend of mine connects me with a friend of her roommate.



Like me, she found out after donating blood.

Like me, she was born prematurely in the early 80s.

Like me, she received blood transfusions in the NICU.

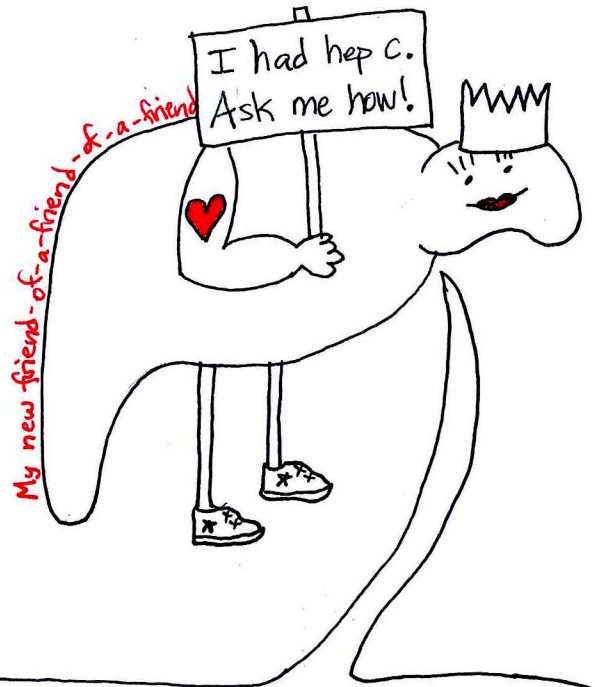
Unlike me:

She was already treated, in 2007.

And.

She was **cured**.

I call her at night on June 9. She is generous with her time and effusive with her story. She is living, breathing proof that this thing is not only treatable, but curable. And she is a bottomless source of information, something I am desperately craving in this **void** of waiting for medical appointments and worrying that I won't qualify for treatment.

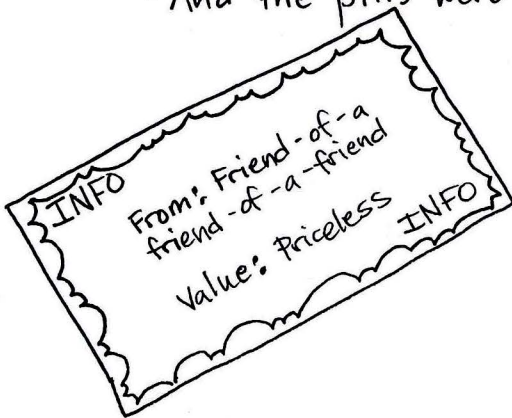


Among the things she shares with me:

- How treatment worked for her in 2007.

I took pills twice a day, and I injected myself weekly with interferon. Interferon is the chemical your body produces to fight the flu - and is in fact what makes you FEEL sick. Its effect causes aches, fever, fatigue.

- And the pills were?



Anti-viral drugs like ribavirin that attack rapidly-dividing cells. This includes attacking viruses-- but it also includes normal body cells like your gut and your hair, because the drugs can't all tell the difference between the bad viruses and good body cells that also happen to divide rapidly. This is why chemo patients feel horrible and nauseous and lose their hair - not because of the cancer, but because of the treatment.

- I'm willing to do anything.



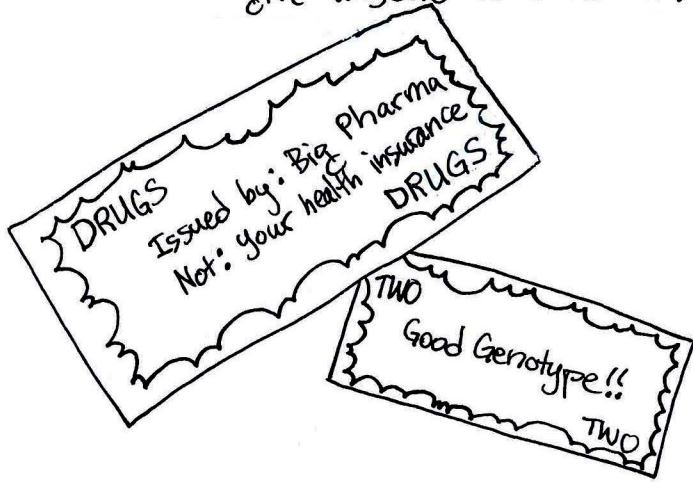
However! This was in 2007. Now there are new, better direct-acting antiviral (DAA) drugs that know how to target just the hep C viruses and don't make patients feel so sick. And, they work better.

- This is even better. But I'm afraid my HMO won't cover the new medicines.

When I was treated, it was more expensive to get the meds through my insurance than to buy them directly from the drug company through a Patient Assistance discount program.

- Why would a drug company give anyone a discount?

I don't know - maybe they feel bad for making them so expensive in the first place? I had genotype 2, it was the easiest to treat.



It sounds weird, but having had hep C has in many ways changed my life for the better. I'm more aware of my body, health, and wellness. I eat a healthier diet, pay attention to self care, and work to keep myself strong & fit. Without this diagnosis making me hyper aware of taking care of myself, I'd probably still be eating junk and letting stress rule me.

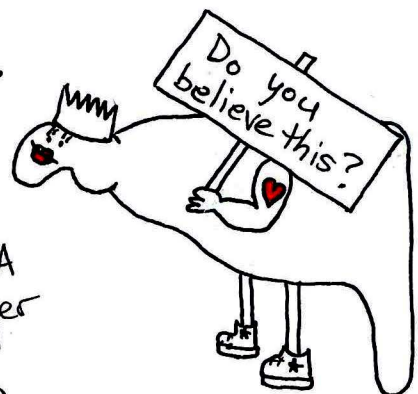
- Well. I can't imagine ever being grateful to hep c. But what can I do to help my liver while I wait?

Essentially everything you would do to be healthier generally is also good for your liver. Cut alcohol, fried foods, sugar, processed foods. Eat more green vegetables and fruits. Exercise. Get enough sleep. Oddly, one food you can eat that is good for your liver is: liver.



This sounds like utter medieval pseudo-science: "Have a rash? Here, eat this skin, to help heal your skin!" But, livers have lots of good iron and vitamins like B12 & A that are good for livers. In order to choke it down, my new friend recommends pureeing & freezing it, then

**SWALLOWING IT WHOLE.**





I'm willing to do a lot of things to get well. I'd be willing to give myself shots (with a big damn needle), to be nauseous and weak, to lose my hair,

I'm willing to avoid alcohol for the rest of my life if necessary.

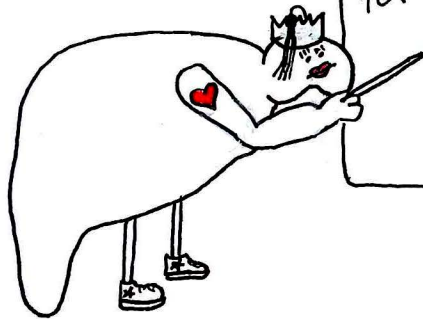
But I'm not yet willing to eat liver,

Not in ice cubes or any other form.

• She tells me the most important thing of all:

Treatment is most effective - most likely to result in a cure and in improved health outcomes - for patients who are:

- young
- healthy
- have as little liver damage as possible



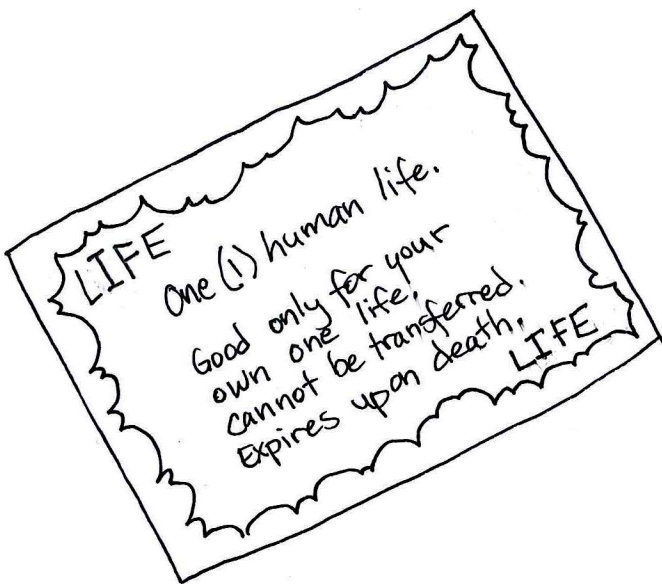
• The thing is.

The thing is. THE THING IS:

I could BEAT this. Now.

If I'm not forced to wait for more liver damage.

If I can just get my hands on the medicines I need, I can be cured.



She talked to me for over an hour, during a work break, and even though she was in the middle of studying for finals.

How do you thank someone for this kind of kindness & time?

I vow to someday share my time & knowledge with someone else newly facing hepatitis C.

I had been waiting to call my parents until I could tell them something - anything - concrete:

- what genotype (strain) of virus do I have?
- how much of it do I have (my viral load)?
- what's the prognosis (how scarred is my liver)?
- what are the treatment options?

But it is taking forever just to get the genotype & viral load test results back.

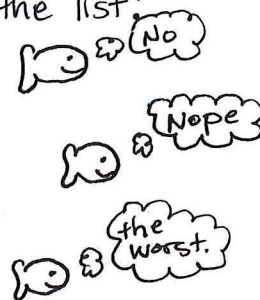
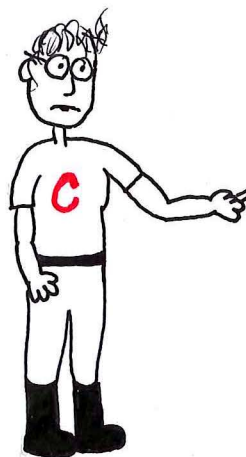
- Who knows when I'll get the ultrasound results back after June 16?
- Who knows if that's the last test I need?
- Who knows if I'll even get a treatment plan from the Hepatologist on July 2?



After talking to this friend-of-a-friend-of-a-friend is when I finally called my mom & dad. At least she gave me something my doctors were lacking so far: **Information.**

I had resisted telling my parents for many reasons, but three topped the list:

- Not wanting to worry them
- Not wanting them to insist I move home with them
- Not wanting them to ask me if I use drugs, or got a tattoo, or had sex.

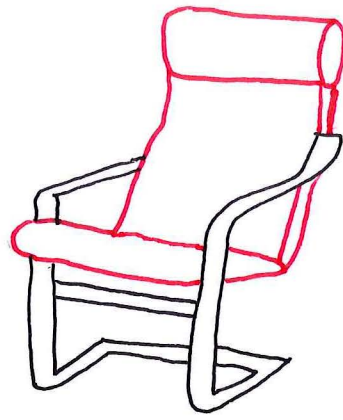


So even after I decided to tell them, on the day I planned to call them, it took me almost 2 hours after work to prepare for the phone call.



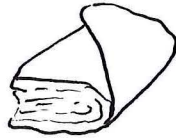
# I TOLD MY PARENTS I HAVE HEP C. ASK ME HOW.

1) I sat myself down in my comfy chair.



Poang.

2) I covered myself in blankets.



Blankets.

4) I did a quick calming meditation.



Max.

5) I smiled. I breathed.



Zeke.

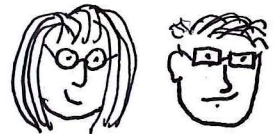
6) I dialed their number.



Me.

7) They answered.

Parents.



8) I freaked the eff out.

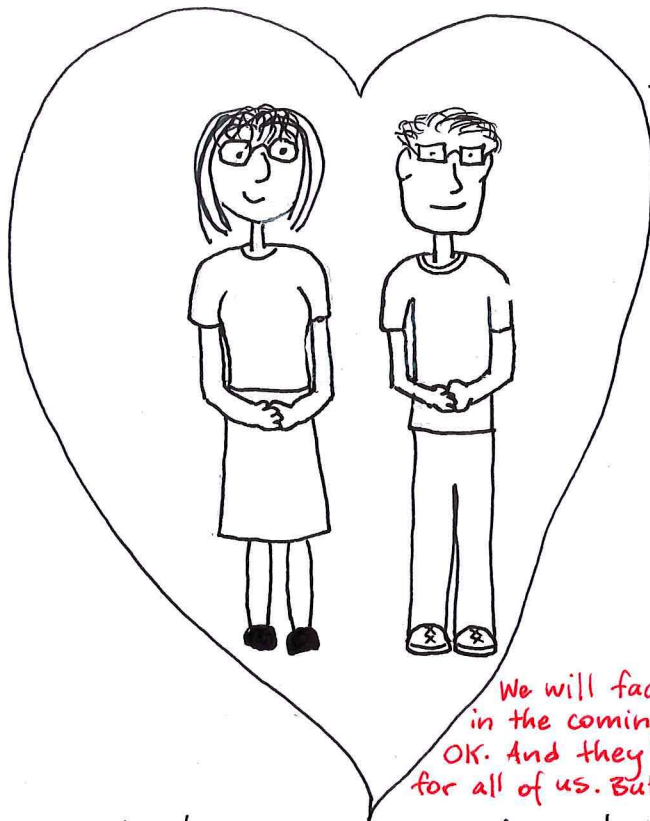


Weight hung over my head.

Total Panic.

I am afraid of scaring them.  
I am afraid of hurting them.  
**I am afraid.**





They were great.  
They were perfect.

They were also afraid.

But, they listened carefully,  
they waited until I was done speaking.  
They asked good, important questions,  
but not too many and none repeatedly.  
They asked what they could do to help,  
and accepted it when I said nothing yet  
except listen and wait with me.

They didn't even ask if I use street drugs.  
Not even one time.

We will face hard relationship times  
in the coming months. Because I'm not  
OK. And they can't help. And that sucks  
for all of us. But today, we were good.

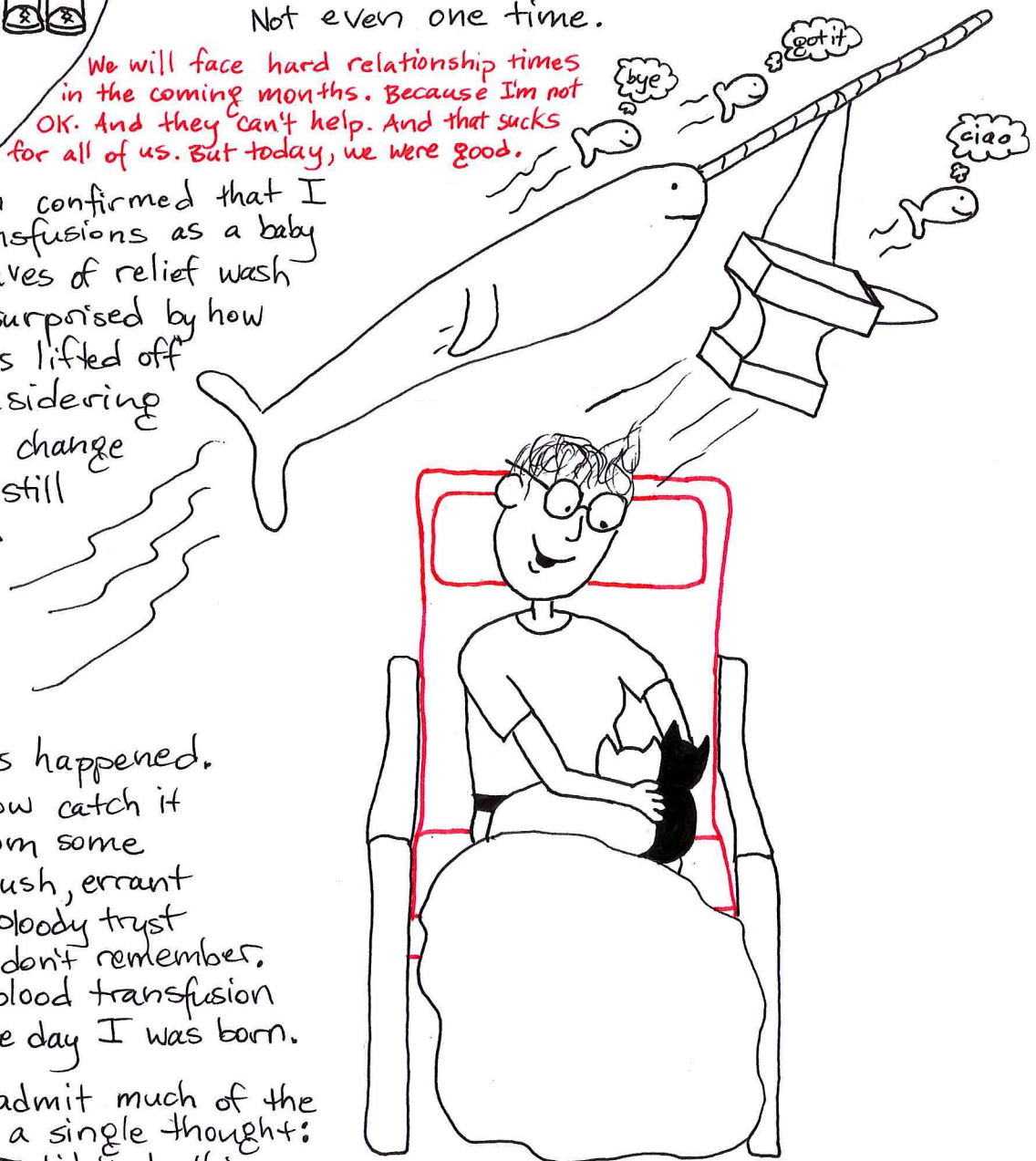
And when my mom confirmed that I  
received blood transfusions as a baby  
in 1981, I felt waves of relief wash  
over me. I was surprised by how  
much weight this lifted off  
my shoulders, considering  
this didn't at all change  
the fact that I still  
had hepatitis C.

But it meant  
that one mystery  
was solved --

I know how this happened.  
I didn't somehow catch it  
mysteriously, from some  
passing toothbrush, errant  
needle stick, or bloody trust  
that I somehow don't remember.  
I got it from a blood transfusion  
in the hospital the day I was born.

I'm ashamed to admit much of the  
relief came from a single thought:  
"I am innocent." I didn't do this.

I didn't deserve it. I didn't make a mistake. I was a brand new baby,  
barely arrived on the scene. I'm not a druggie or sexual deviant. **I'm no sailor.**




Now, many weeks later, I am trying to sort through and stop this deeply buried instinctual prejudice. Do I really think I'm more pure & holy than someone who got hep c from sharing needles, or sex, or a tattoo? I'm working to stop myself from mentally dividing my fellow patients into buckets. My shameful prejudice brain yells:

I am one of THESE people!

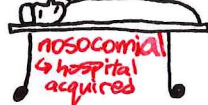
Not one of THOSE people!!

**INNOCENT?**




babies  
↳ perinatal - soon after birth

dialysis patients, hemophiliacs, and people who had surgery before 1992



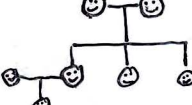
healthcare workers who suffered a needle stick injury  
↳ occupational

nosocomial  
↳ hospital acquired



one needle for all!

veterans who received unsafe medical care



people who got it from their families

**BUT WHAT ABOUT:**


people fighting addiction?

people who tried drugs just one time?


people who got tattoos?

people who had "safer" sex?

**NOT INNOCENT?**




people who inject drugs?  
addiction...




people who deal drugs?  
poverty....



people who have "unsafe" sex?  
public health...



sailors?



motorcyclists?



**PATIENT.**

Anyone who gets a diagnosis that says  
**CARRIER OF THE HEPATITIS C VIRUS.**

That is to say:

**150 MILLION OF OUR CO-HUMAN BEINGS**

No one deserves this. No one needs to be asked how they got it. Everyone deserves patience, compassion, and cure.

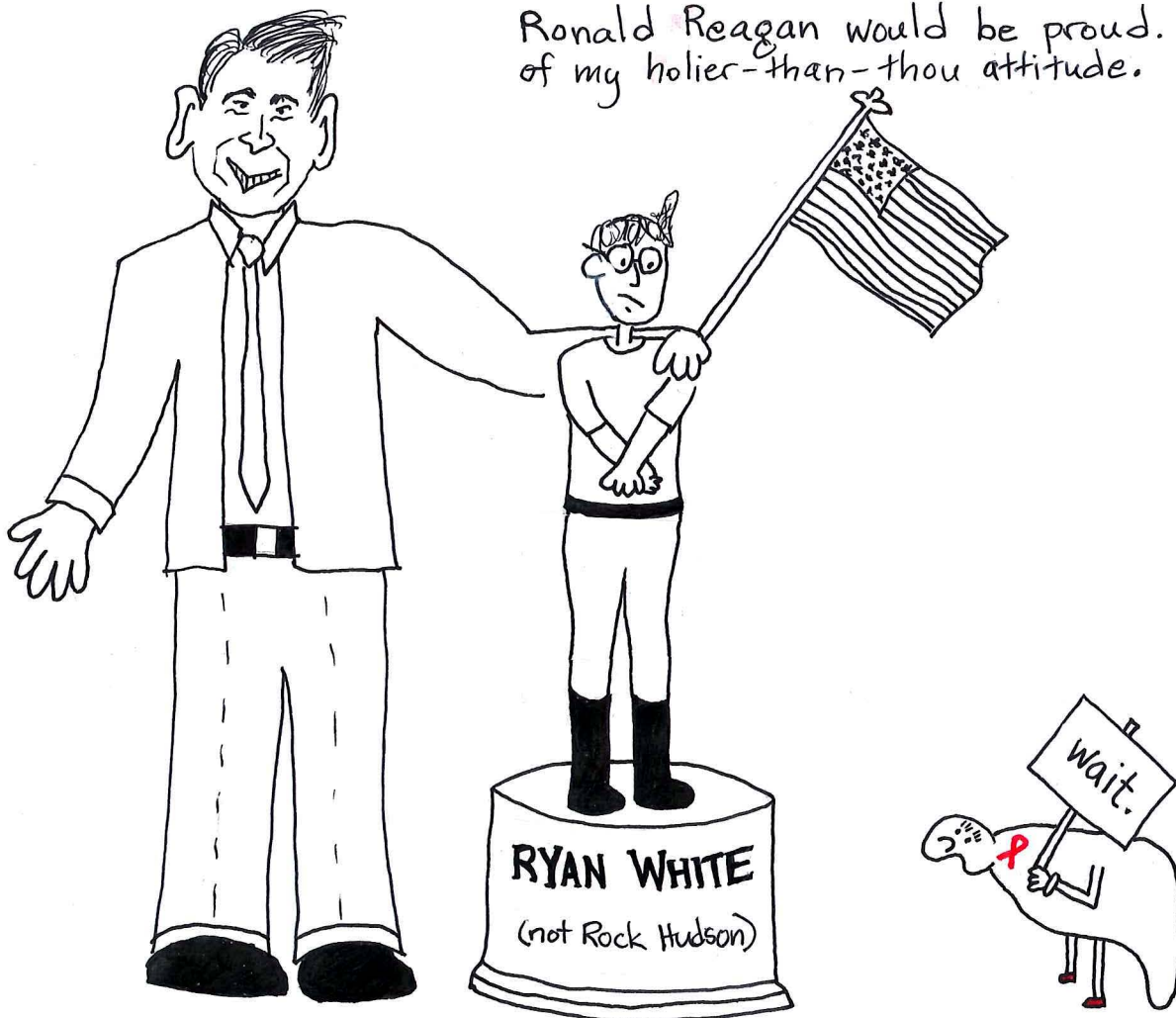
And yet.

Every time I tell someone new about my diagnosis, it is in the form of a single, apologetic, run-on sentence:

"I-just-found-out-I-got-hepatitis-c-from-a-blood-transfusion-as-a-baby."

I am shocked to find this out about myself: I am judgemental & prejudiced. Over the years, I've read & learned a lot about the history of the HIV/AIDS pandemic, and in particular the gut-wrenching, shameful story of how the US government specifically ignored, covered up, and even hastened its spread because they believed it was a disease only gay (i.e., bad) people got. People who deserved it. I have never once thought an AIDS patient deserved AIDS. But now look at me.

Ronald Reagan would be proud of my holier-than-thou attitude.



I loathe myself for subconsciously thinking I'm innocent & other hep c patients aren't. But here in June, a few weeks post diagnosis, and for weeks to come, I'm not yet quite able to stop myself from thinking it. Until I start to meet other hep c patients.

\*KORE SHADOWING!

I told my parents everything I know **except I try to leave out my worst fears**

I know more than I think I know **except I don't know if I'll be OK**

I know I have hep C **except I don't know what strain**

I know there's a cure **except I don't know if I can get it**

I know my liver function still looks good in bloodwork **except I don't know if my liver is scarred & just compensating for damage**

I know I feel healthy & well **except I also know I'm sick**

I know I probably don't have cirrhosis, **except I might, or may later**

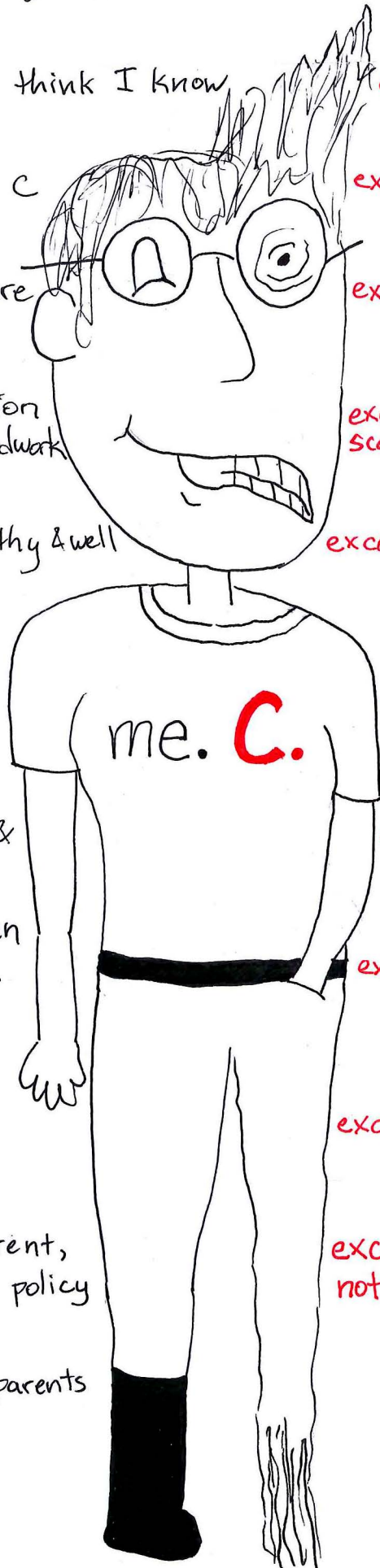
probably won't develop liver cancer, & **except I'm at higher risk**

probably won't die an early, painful death. **except I have a killer in my blood**

I know we will do whatever it takes **except I don't know what it will take.**

I know I have a current, valid health insurance policy **exception: hep C treatment is not covered until you are about to die.**

I know I have two parents firmly on my side.



My mom also reminds me I have a cousin who is a doctor.



from ring bearer to groom!

I have adored my doctor cousin ever since she married my environment-saving cousin when I was in 3<sup>rd</sup> grade. I was the flower girl in their wedding, and caught the bouquet, awkwardly. she has always treated me like a grown-up, & spoke to me like a real person, even back when my brother & I were the family babies & could get left on the sidelines of conversations, of family dinners, of games. Today, she treats her own kids like grown ups, and I also adore them --officially my first cousins once removed, I prefer to think of them as my Great Cousins. We had all just spent a happy family week together for my brother's wedding back in Texas. Collectively, we had danced & analyzed Garfield, played drums & laser tag. It is a fluke of history that we hadn't seen each other in 4 years, but spent a fantastic week together a week Before Hepatitis C (BHC).

We didn't connect by phone that night, but I walked to the cafe on the corner to get a smoothie and write her an email right out of left field. She left me a long voicemail the next morning.



BULGARIA

BLACK SEA

GEORGIA

ARMENIA

AZERBAIJAN

• Istanbul

• Bursa

• Ankara

TURKEY

• Hope.

• Izmir

• Konya

Antalya.

• Gaziantep

• Adana

IRAN

SYRIA

IRAQ

LEBANON

Your HMO is wrong to not cover treatment. If you lived in Canada or Africa or India, they wouldn't wait for your liver enzymes to get bad before treating you. We'll research drug company assistance programs, or class actions that help people infected via transfusion.

You're young & healthy & have no bad habits. You can be cured. We can go to Turkey ← "health tourism!" Hey, I've never been to Turkey. We'll do what it takes.

And she sent me a link with scientific information. I had reached the limit of what I could get from Google, and was dancing along that line where you can't tell whether what you're reading is science or pseudoscience.

My newest advocate sent me actual science papers.

Science is comforting to me. No matter what it says, good or bad, science is solid, definite, an answer.

Something I'm craving these days.

Even when it dances against the limits of my understanding.

Even when the Science has question marks.

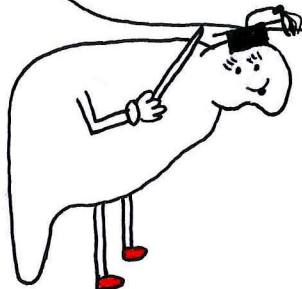
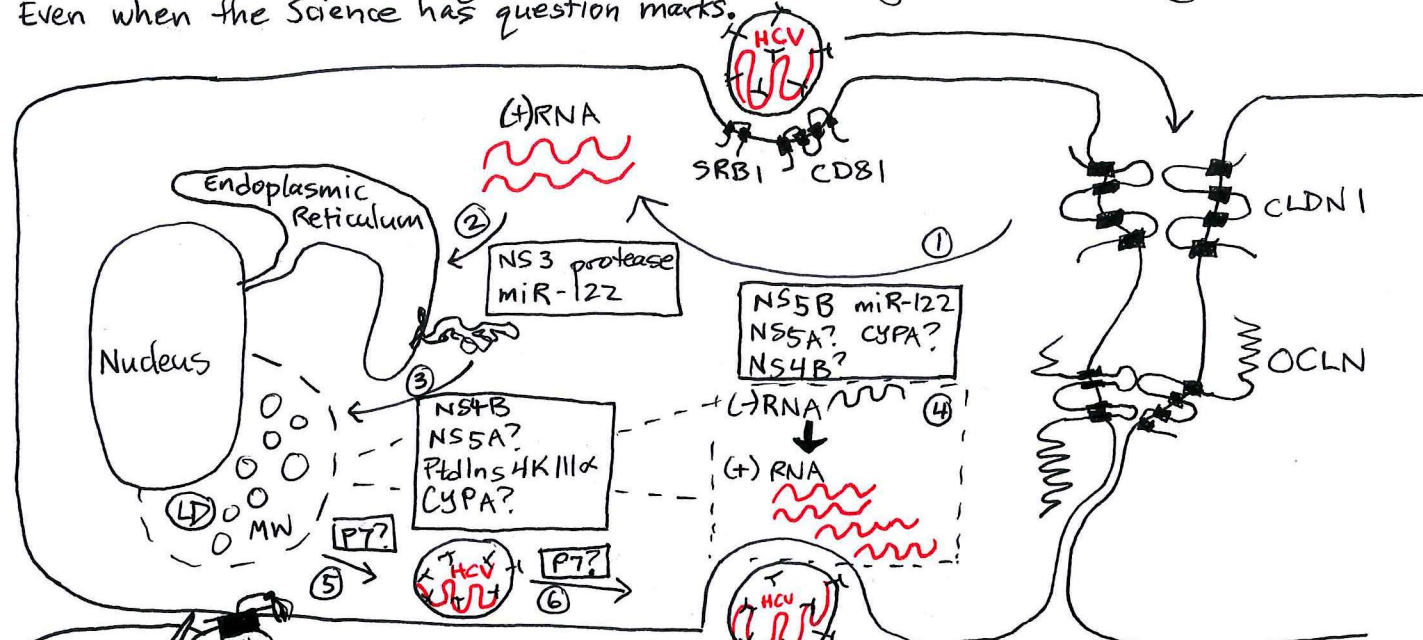


Figure 2. The hepatitis C virus replication cycle.

From: The molecular & structural basis of advanced antiviral therapy for hepatitis C virus infection.

Ralf Bartenschlager, Volker Lohmann & François Penin. *Nature Reviews Microbiology*. 11, 482-496 (2013)

As Françoise Barré-Sinoussi (Nobel laureate, French virologist, humanitarian, professor, and discoverer of HIV) says:



There is always hope in life, because there is always hope in science.

She knows what she is talking about.

I sat back in the poang and thought back on the various bombshells I'd called my parents with over the past year.

## ABOUT ONE YEAR AGO...

Spring 2014.

I'm getting divorced. After 15 years together & 8 years of marriage.

What do you need? How can we help?

A few months later...

I'm seeing someone... A woman.

She sounds neat. When can we meet her?

Then, as now, my parents were caring & affirming. Worried, parentally. But they loved me no matter what. They asked enough questions to be supportive but not too many to be intrusive. I know I'm lucky.

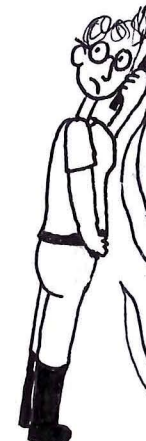
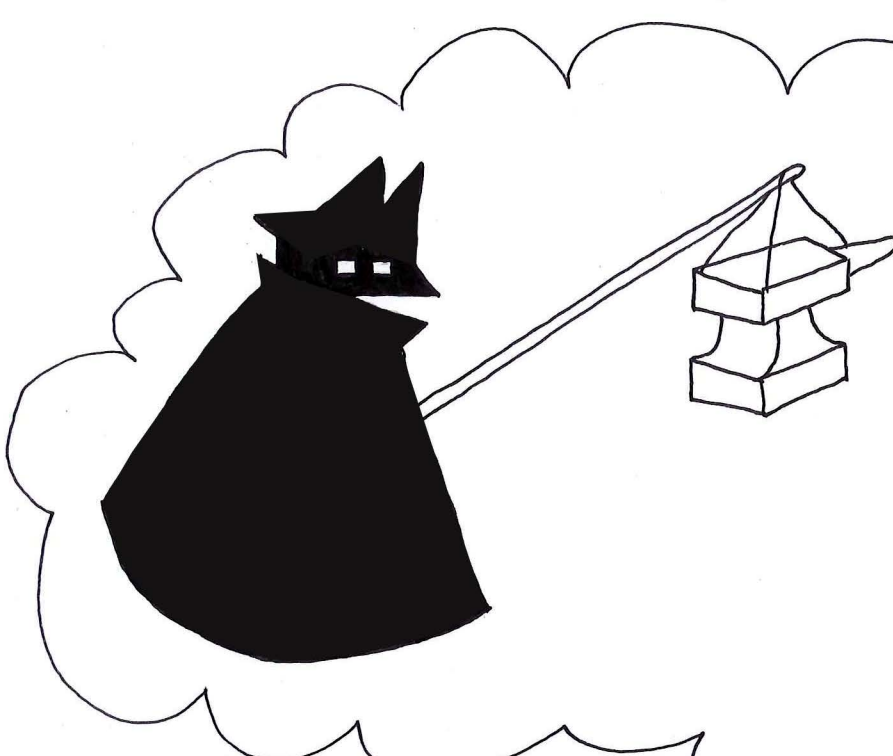
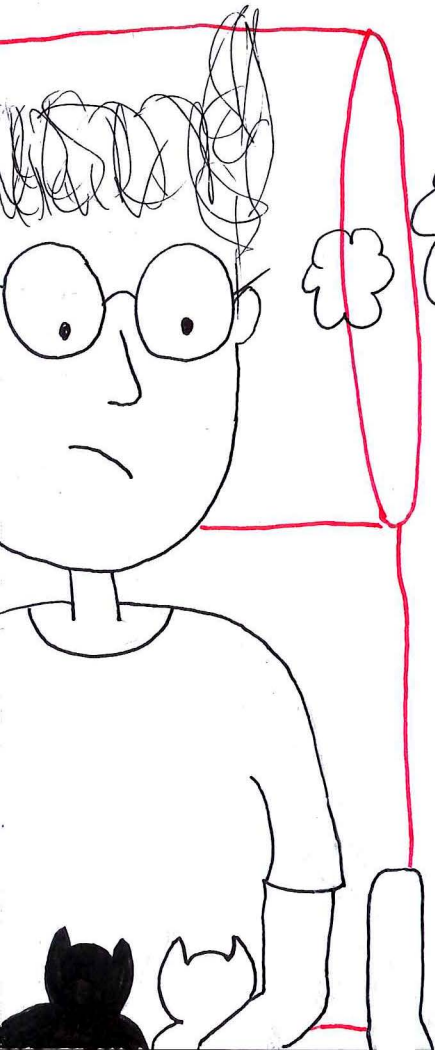
... A few months later... Summer 2014. My mom had come for a visit. As that weekend ended, I asked her:

I know there have been major changes in my life this year. Is there anything you are worried about? Want to ask more about?

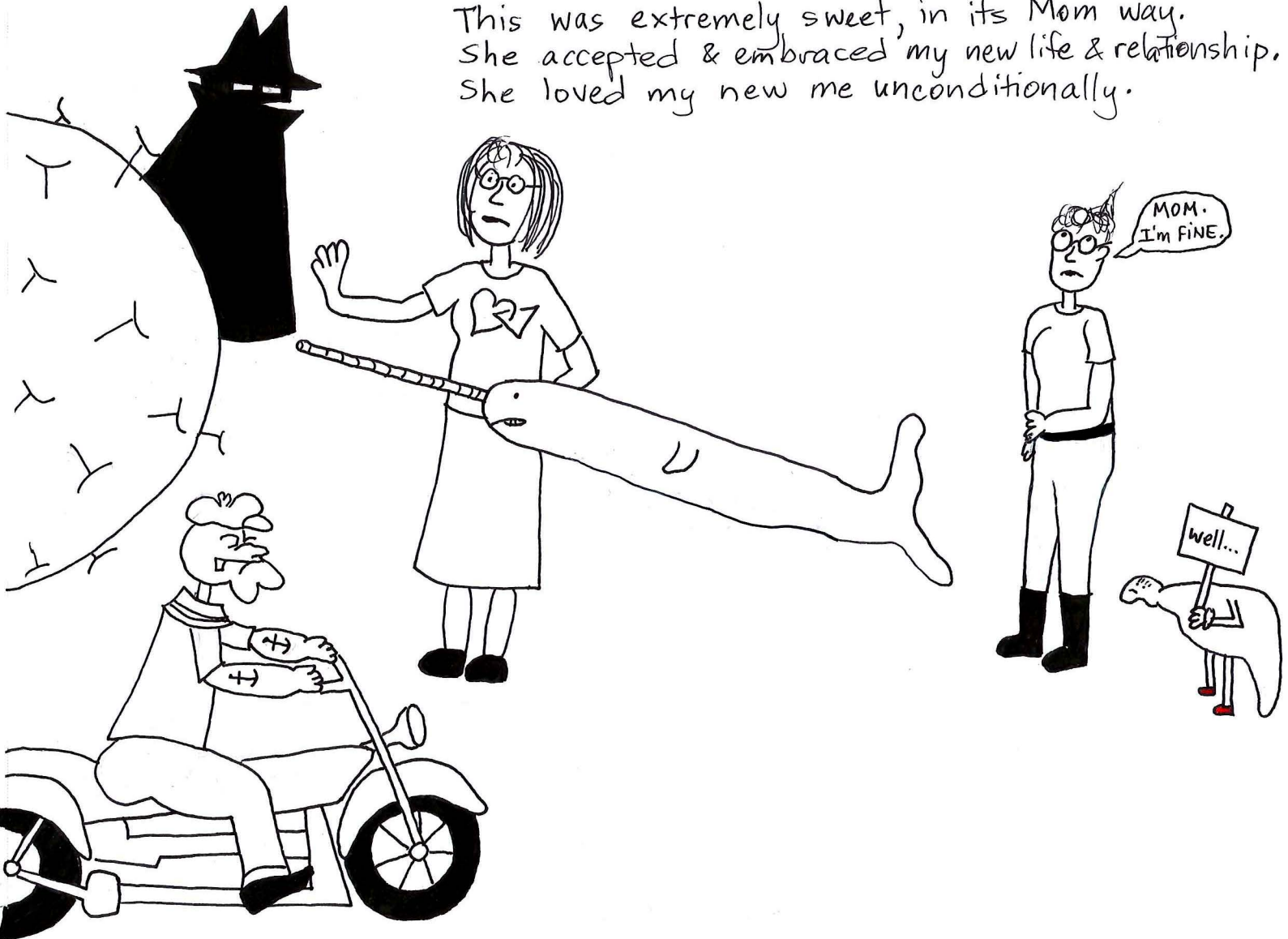
She hesitated.

You're not really going to get a tattoo, are you?

listening on speaker phone



This was extremely sweet, in its Mom way.  
She accepted & embraced my new life & relationship.  
She loved my new me unconditionally.



She just didn't want me to get hep C.