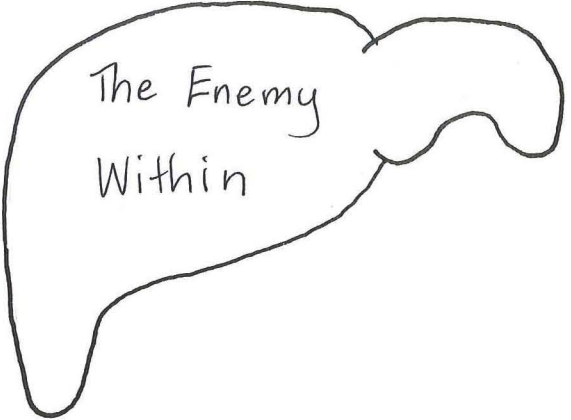


CHAPTER

5:



The Enemy
Within



A simple cartoon villain
is easy to spot.

They wear black,
ominously. They laugh,
sinisterly. They twirl
mustaches, evilly.

With a cartoon
villain, you know
what you're dealing
with. You can
avoid them,
easily. So they're
only just-so scary.

But the most
insidious villains
surprise you. They
sneak up from
within. You think
they're your friend,
your ally, your champion.
Until you find out they're
not.

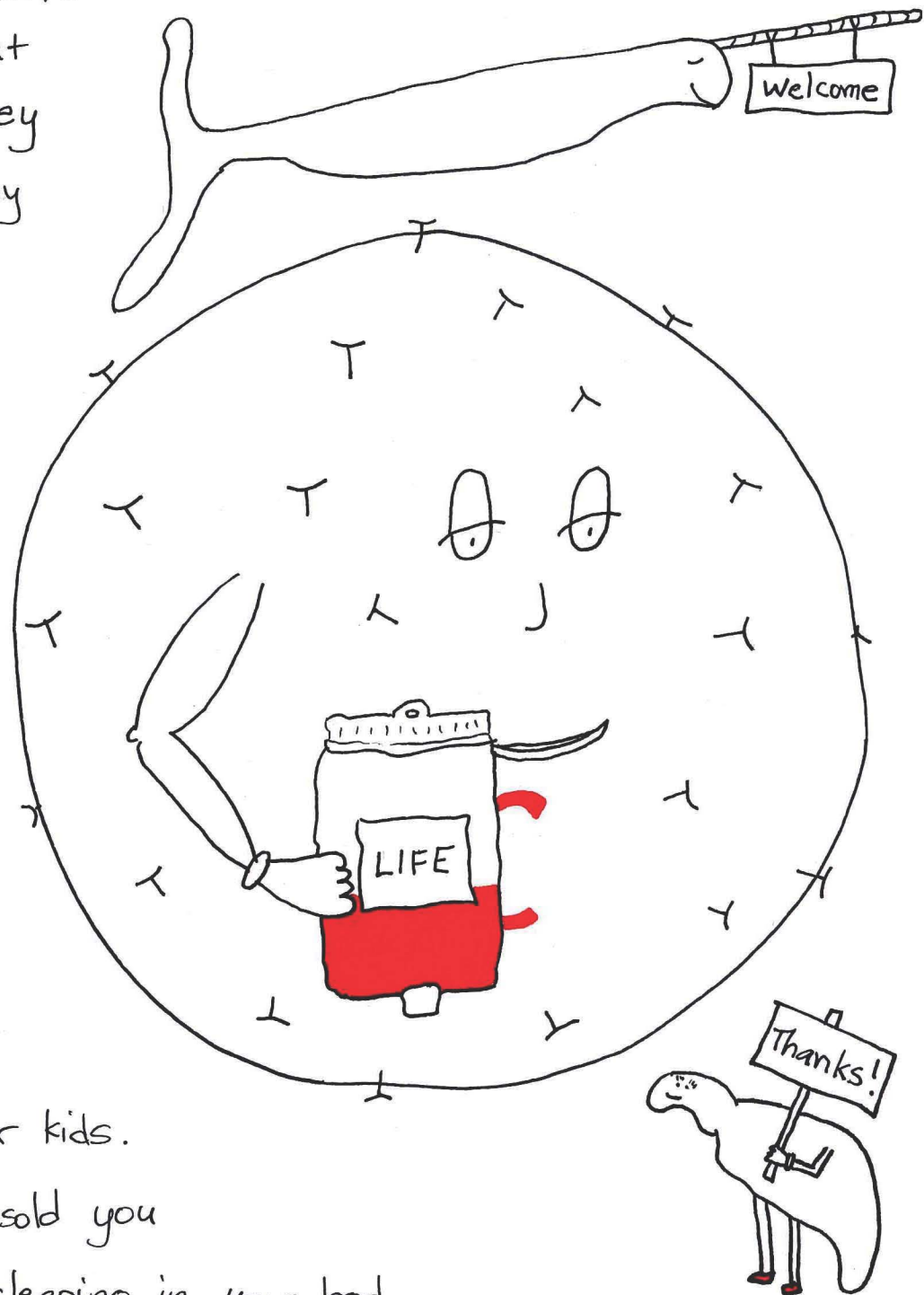
A true horror villain looks not only innocuous, but benevolent. Until they turn on you so slowly that you don't even notice for a while.

These are the secret spies who get the big reveal at the end of the Hollywood blockbusters.

The sister who has been axe murdering your fiancés. The mom who slowly poisoned your kids.

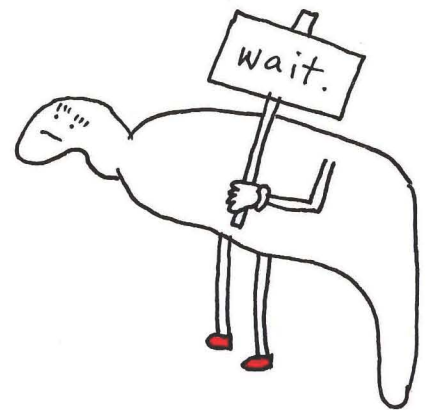
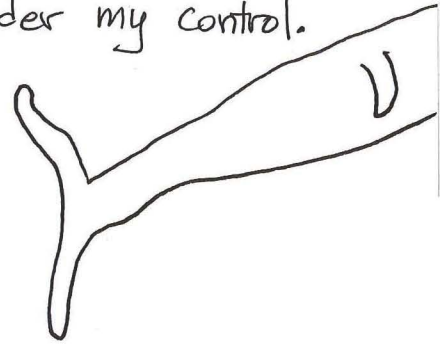
The double agent who sold you out while they were sleeping in your bed.

Hep C has been living silently in my liver, maybe since the day I was born. Quietly using my cells to copy itself. Slowly wreaking havoc. And it arrived in my body by traveling in the blood that **saved my life.**



I have two known enemies so far:
hepatitis C, and alcohol.

The first has its hold on me.
The second is under my control.



My third and biggest enemy
will turn out to be the thing
that is supposed to save me.

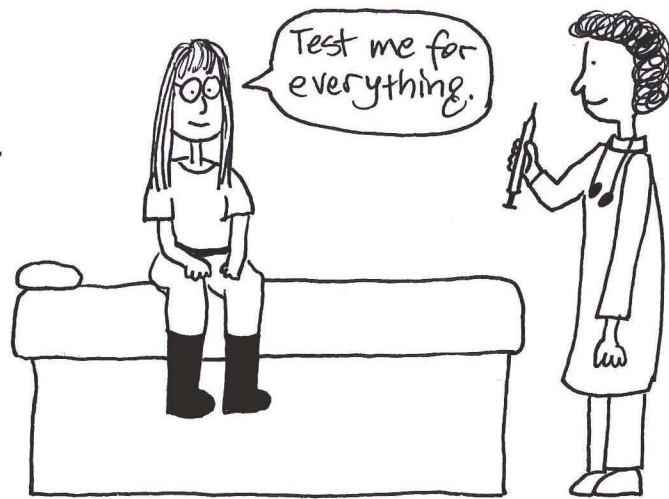
Modern ~~medicine~~ healthcare.

Now that I know how I got hep C,
something new has been nagging at me.
After my divorce, I did my due diligence:
I went to my HMO doctor (now retired)
and requested a full STD screening.

When the results came in,
they pronounced me healthy.

Zero STDs.

So... how come they
didn't find my hep C?



I email my (newly assigned)
Primary Care Provider (PCP).
I ask only:

To: PCP	<input checked="" type="checkbox"/>
RE: Health Records	
Have I ever been screened for hepatitis?	

she replies:

To: Me	<input checked="" type="checkbox"/>
Re: RE: Health Records	
You have never been screened for hepatitis at HMO. Do you have any particular concerns?	

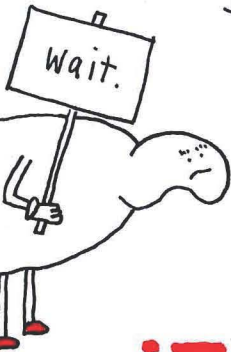
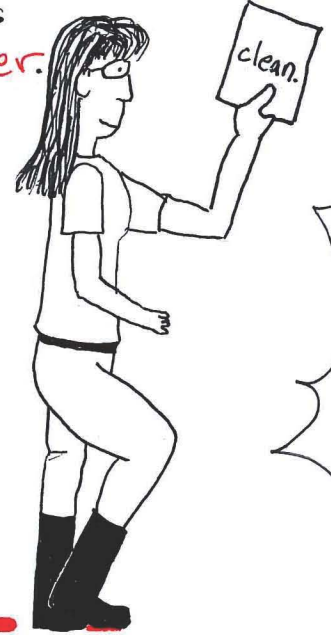
Wouldn't they, shouldn't they, have tested me for all the STDs, when I asked to be tested for all the **STDs**?

Hep C is not considered a typical STD. The CDC doesn't classify it as an STD, and STD screening doesn't include hep C by default, unless you have known risk factors such as IV drug use or a confirmed infected partner.

I guess I get that. I understand risk, statistics. But this omission shifts the stability of my world a bit.

I did what you are supposed to do, to protect yourself and others. I went to my doctor. I got tested. I was a responsible adult, and I walked away with a clean bill of health. And yet. I wasn't clean.

What else could I have that I don't know about?



I reply:

To: PCP
Re: RE: Health Records

I donated blood on 4/29 and got a letter that says I have hep C. I'm trying to figure out if I've never been screened for it before. I'm ready to begin treatment immediately. I'm waiting for HMO to approve my referral to see a hepatologist. I still need genotype and viral load tests. Is there anything we can do NOW, in the meantime?

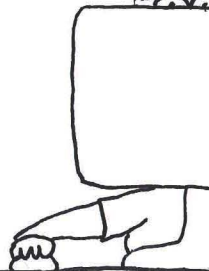
she replies:

To: Me
Re: RE: Health Records

Only a hepatologist - a liver specialist - can determine the treatment plan, if needed. How about a phone call to talk next steps?

... if needed.

...if needed?



The next day.

She calls. We talk.

She is hilarious. so I like her.

She reacts to things the way I react to things. All is going well.

But. She asks me twice in 10 minutes:

Once is enough to get hep c.
But once is apparently not enough to answer this question.

Have you ever injected street drugs?

I want you to go ahead & test me for everything that the hepatologist will need, so I'm ready once I'm allowed to finally see one.

You'll need tests for hep A & hep B, and hep C antibodies, and hep C RNA, and HIV.

I've had those. Twice.

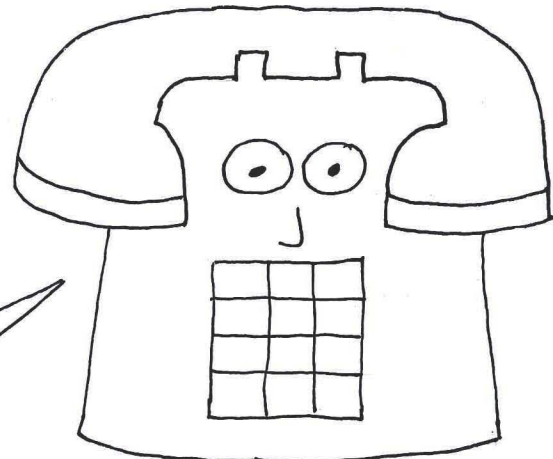
Let's run them again, just to be sure.

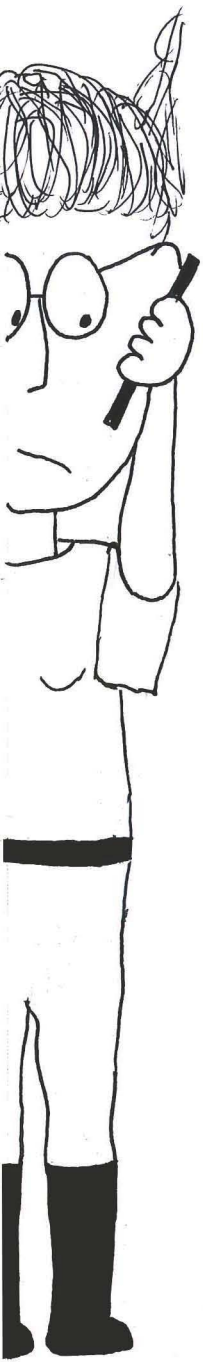
I guess triple checking can't hurt. So I ask three times to confirm that THIS time they'll do genotype and viral load.

Yes. And I'll do a hepatic function panel, to measure the levels of major liver enzymes in your blood.

And then we can start treatment?

This will tell us how well your liver is doing its job. If your enzymes are good, treatment may not be necessary yet.





Not necessary? What? I have a liver-destroying virus. I can't donate blood. No alcohol.

Risk of cancer, stroke, diabetes... infecting others...
How is treatment not necessary?

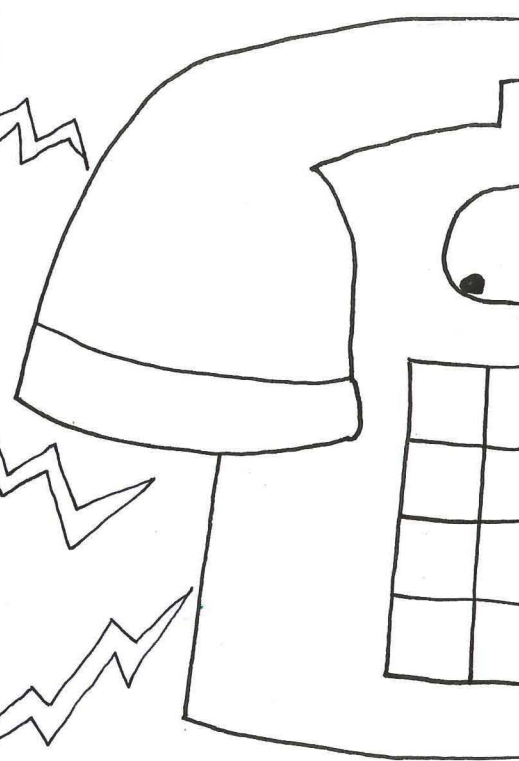
Well, the medications are expensive. If your liver is working OK, you may not need them.

But I have health insurance with HMO. I want treatment.

OK... well, we'll run all the tests.

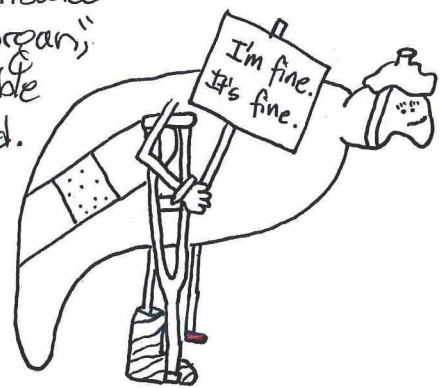
Including genotype and viral load?

Yes, we'll test you for everything necessary.



I remember what I've read about compensated cirrhosis - your liver is a "non-complaining organ," and can continue working well on measurable levels for quite a while even if it is injured.

If the enzymes are bad, we'll know for sure my liver is damaged.
If the enzymes are good, we'll know for sure my liver is sick, but maybe not failing yet.



For the first but not last time, the strange wish occurs to me - I hope my enzymes are bad, but not TOO bad, so someone will help.

At home, I continue an archaeological dig through all of the health records I have in hard copies.

Back ten years to Texas...
 Before leaving my secure job & health insurance for Michigan & grad school, I went to a doctor and requested a full blood panel.

Just to check for anything I might need to know about, before embarking on school with no health insurance.



Test me for everything.

At the time, I got a report back that showed elevated bilirubin (a liver byproduct). The doctor diagnosed me with the innocuous "Gilbert's syndrome," and handed me a pamphlet on this benign condition that leads to extra bilirubin in the blood & nothing else. I stuck the report & pamphlet inside a folder and filed the diagnosis (benign!) deep in the recesses of my brain.

I pull the report out of its folder now and see:

MEDICAL LABORATORIES INC.
 Austin, Texas
 Patient Requisition Date: 07/2004
 Tests Requested: COMP METAB PNL, LIPID PROFILE, CBC, PT FASTING

TEST	RESULTS	EXPECTED RANGE
ALBUMIN	4.5	2.9-5.0
GLOBULIN	2.5	2.0-3.8
A/G RATIO	1.8	0.9-2.5
BILIRUBIN	2.0	0.1-1.3
ALK PHOS	41	30-130
SGOT (AST)	41	5-35
SGPT (ALT)	41	7-56

mail to patient
 Recommend to repeat liver function in 3 months

Elevated bilirubin - liver not fully processing this byproduct of blood recycling
 Elevated aspartate aminotransferase - liver enzyme leaking into the blood
 Recommend to repeat liver function in 3 months
 recommend to repeat to repeat liver function
 to repeat liver function
 to repeat liver function.

How did I miss this? It had been overshadowed by the Gilbert's Syndrome pamphlet and the doctor's "It's fine. You're fine" reassurances. Not to worry. No need for more tests. You have Gilbert's. No bigs.

What is Gilbert's Syndrome?

Gilbert's Syndrome is a common disorder that affects processing by the liver of bilirubin... but the liver itself remains normal.

What are the signs and symptoms?

Usually there are no symptoms but sufferers may experience mild jaundice (yellowing of the skin), bouts of abdominal pain, appetite loss, fatigue and weakness...

What investigations and treatment are needed?

Blood tests are usually carried out to make a diagnosis and to exclude liver disease. No treatment is required...
... normal life expectancy... no hard evidence that the disorder is associated with more serious diseases.

So why bother about it? Suddenly turning yellow can be alarming... more importantly, jaundice can be a sign of more serious illnesses (such as hepatitis). Knowing about the diagnosis of the harmless Gilbert's syndrome therefore provides reassurance... and the family doctor would otherwise subject the yellow patient to a series of investigations to exclude more serious illnesses. Alarm about the possible spread of infection can also be dispelled.

What should we do?

The British Digestive Foundation suggests that all those with Gilbert's Syndrome carry with them at all times the message I am a Gilbert's Syndrome sufferer.

All also symptoms of hepatitis!

No treatment is required!

Good thing you don't have hepatitis!



I even joked to my friends at the time about forming a Gilbert's Support Group. With yellow t-shirts for the members. So we could find peers who know what it's like to have a total non-issue.

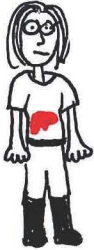
More digging in my "Health Records" file folders...

1999. Referred to dermatology for an itchy rash on my legs. Patchy, scaly skin that never fully heals.



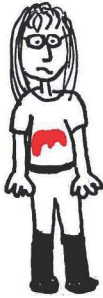
Diagnosis: Maybe eczema. Or **dermatitis**. Benign, except for the itchy scaly incessant rash.

2006. Go to doctor for routine visit and mention monthly bouts of **nausea** and vomiting. Usually feel better afterward.



Diagnosis: Not to worry. Benign. Perhaps due to stress, anxiety. Innocuous, except for **vomiting**.

2013. Go to doctor because fingertips periodically & suddenly lose all warmth, blood, & feeling. My fingers turn paper white & ice cold, lasting 30-60 minutes.



Diagnosis: **Reynaud's Phenomenon**. Benign, except for the discomfort of having frozen fingers.

2013. Referred to dermatology post-Reynaud's diagnosis, to review leg rash and rule out autoimmune disease such as Multiple Sclerosis.



Diagnosis: Still just eczema. Or **dermatitis**. Benign, except still itchy and scaly etc.

2015. Researching:



6 Symptoms of & 1 Risk Factor for Hepatitis C

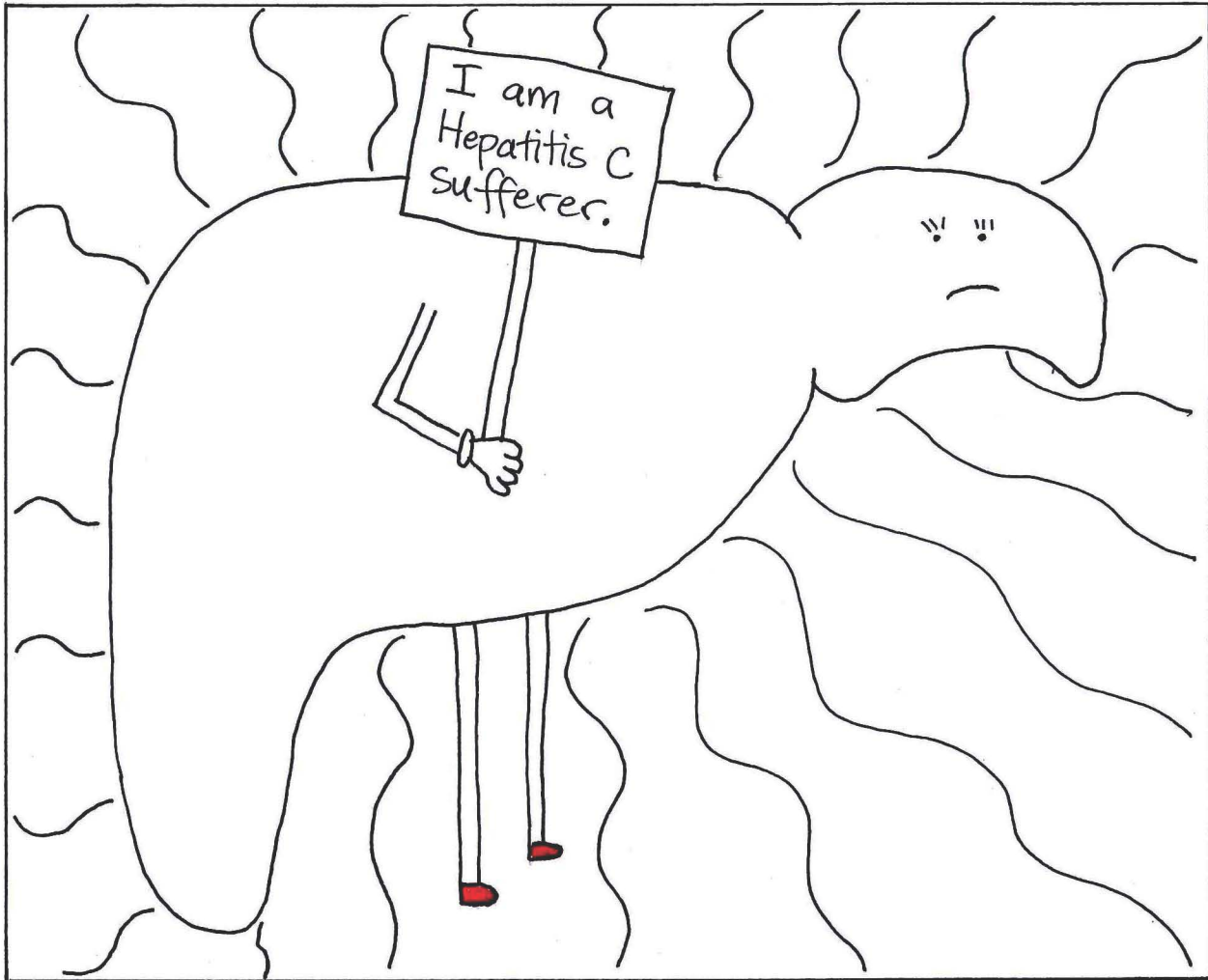
	Yes	No
Dermatitis	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Nausea	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Vomiting	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Reynaud's	<input checked="" type="checkbox"/>	<input type="checkbox"/>
High bilirubin	<input checked="" type="checkbox"/>	<input type="checkbox"/>
High AST	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Blood transfusion, '81	<input checked="" type="checkbox"/>	<input type="checkbox"/>

How did I miss this?

A well-known problem with symptoms:
Everything can be a symptom of lots of things, or nothing.

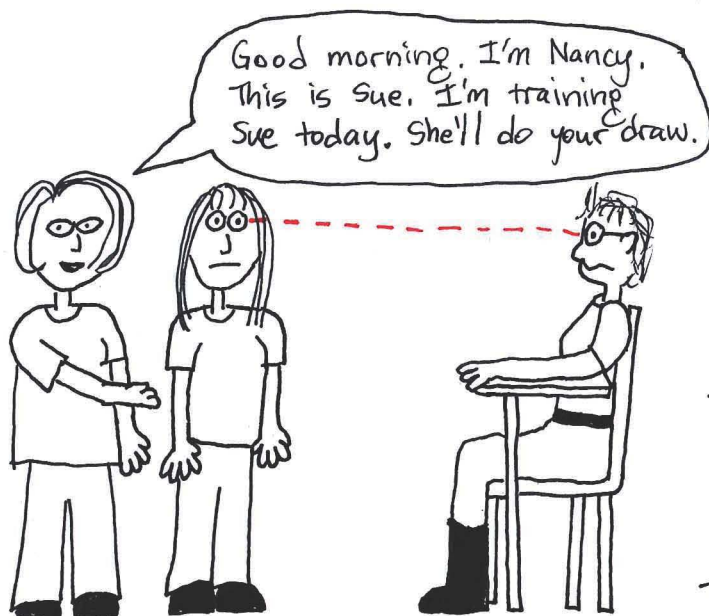
But still.

It seems so obvious in retrospect.



I'm sorry, Hepsie.
You tried to tell us.
You just weren't
complaining enough.

Wednesday, June 3. 7am. Fasting blood draw.
For someone who can never donate blood again,
I sure am giving away a lot of blood.



This is exactly what
needle-phobes want to hear.
Your phlebotomist is a newbie.

Trust me. We LOVE this!

Sue does a good job of getting
the horrible needle into my arm.

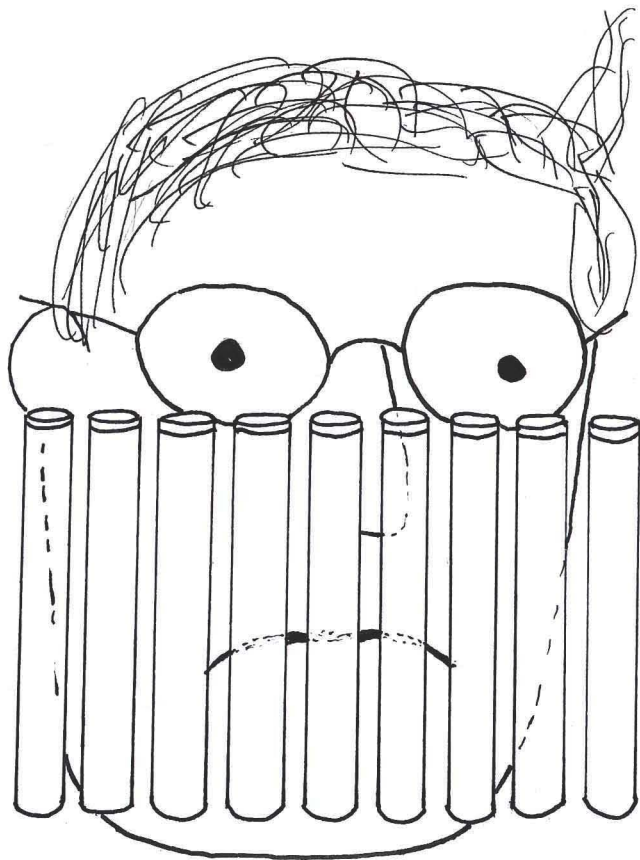
But then.

There are all these vials to fill.
Nine total, one for each test.

As each vial fills, it has to be
switched with an empty one.

And every time Sue pulls off
and puts on a new vial,
she yanks on the needle.

For the first time in a blood-
giving process, I feel pain.



Plus, I am hungry,
because fasting.

Plus, I am sleepy,
because insomnia.

Plus, I am scared,
because hepatitis.

So - I start crying.

This is what I do now.

I cry in public.

It's my jam.

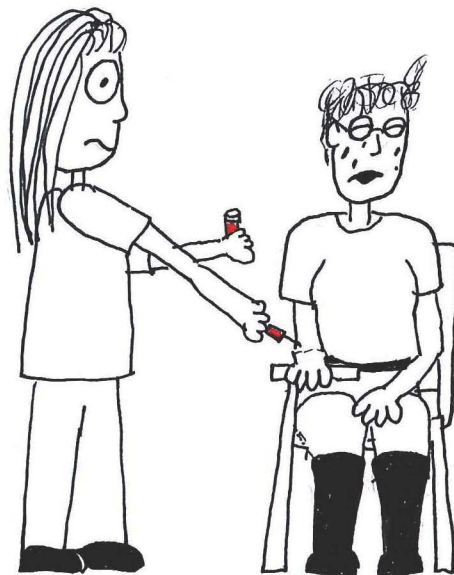
On the bus. At work.

At home. At the store.

Walking down the street.

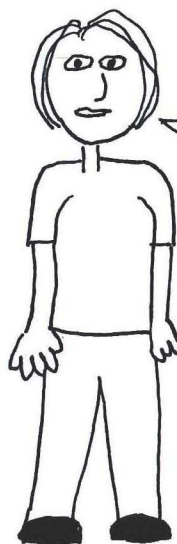
At night, in the morning,

at lunch. All damn day long.



Nancy does her blessed best
to distract me with conversation
but regrettably does not take
over for Sue.

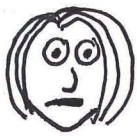
We are all traumatized.



So... you work
in... Transportation?
That must be...
Very... transportationy.

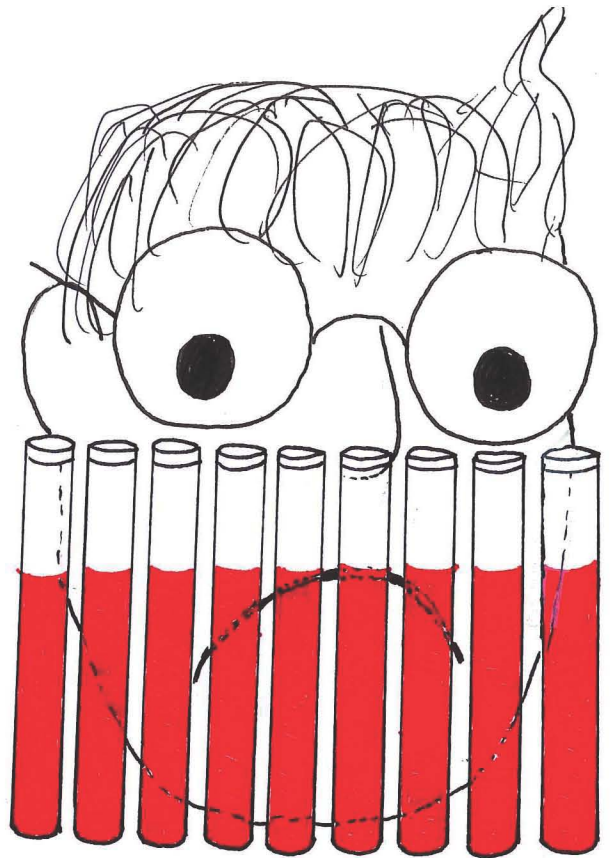
Finally we get nine vials.
Finally Sue tries to pull
the horrible needle out of my arm.
But she pulls it around in
circles instead.

Finally Nancy pushes Sue
out of the way.

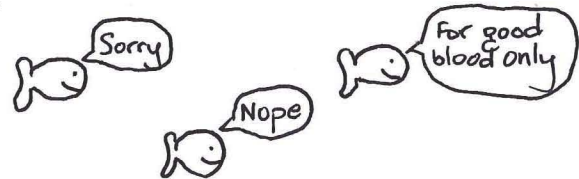


OK, we're done here.
We have *everything*.
We need.

Finally.



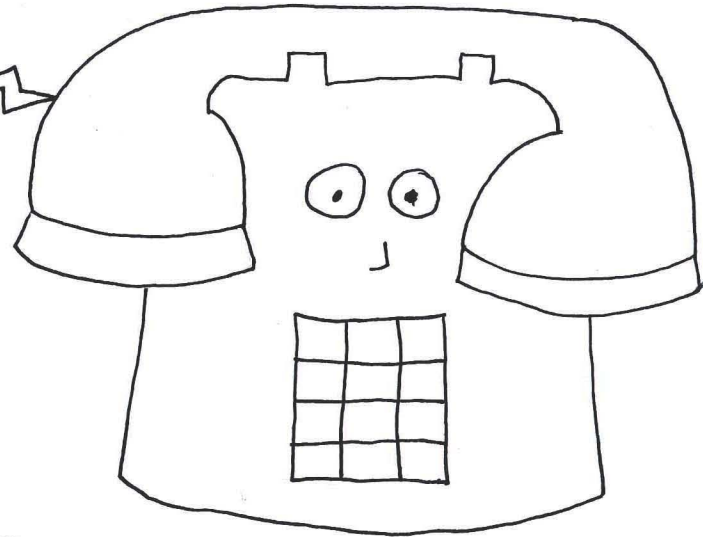
No one gives you goldfish crackers
in exchange for testing your heppy
blood.



... I leave.
I go to work.
To wait.
To make maps.
To wait.

Waiting, and crying in public.
My new favorite pastimes.

Thursday, June 4, 4pm. Phone Encounter with my NP to discuss preliminary results. Crossing fingers for genotype & viral load...



Great news! You don't have hep A!

You don't have hep B!

And... you do NOT have HIV!!!

...I know.

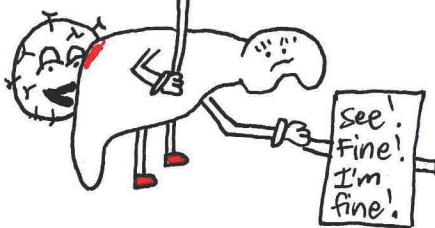
I. KNOW.

I KNOW!! And I will take another moment here to be grateful for all of these results. But, we already knew them. What's my genotype? What's my viral load?

Oh... that's right, those were repeat tests for A & B & HIV. We probably didn't need to do them.

I think of those unneeded vials of my blood...

I don't mean to complain...



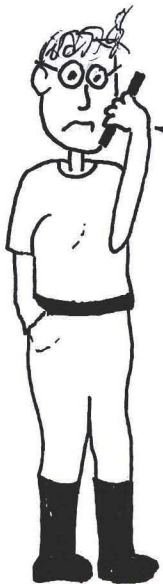
But your liver function looks good! Are you looking at the report we sent?

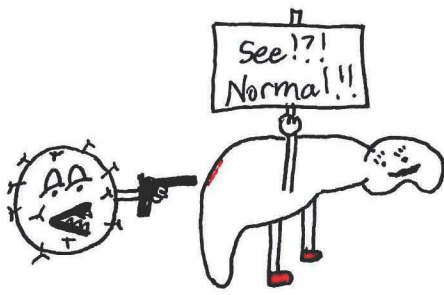
Report??

I rush to check my online patient record.

Well... it shows my AST & ALT are at the very maximum number of normal range. And last week when Clinic tested me, both my bilirubin and AST were higher than the normal limit.

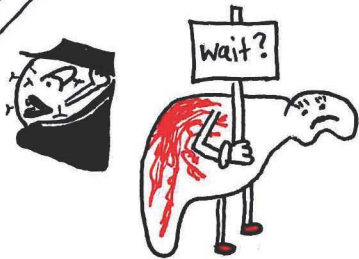
But now all levels are normal.





The normal thing would be to be glad my liver is doing its job. But...

Will you treat me?



There's really no need to jump to treatment. Under HMO's guidelines, we can wait. Test you every 6 months. "Watchful waiting."

But... you could treat me now. You could CURE me. NOW. Everything I've read says this disease is serious, vital, critical, deadly. Why WAIT?

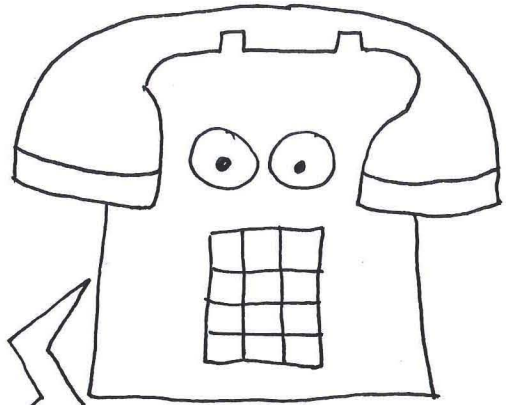
HMO used to offer treatment to all hep C carriers right away up until a few years ago. But so many people are getting diagnosed now. We can't just treat EVERYONE.

What?? What if I had diabetes? Or liver cancer already? Would you refuse treatment because there's just so MANY people to cure? I have INSURANCE! I want to receive CARE!!

Well. We'll know your genotype & viral load tomorrow. I will call you back again by 4pm tomorrow.

I make it through another night.
I wait for tomorrow. Wide awake.
Tomorrow arrives, somehow.

4pm comes. No phone call. 4pm goes.
I call them at 4:01. I get the receptionist.

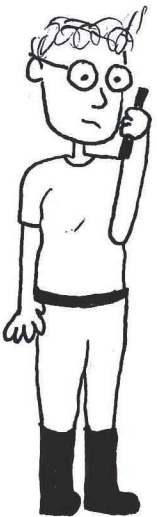


Hello - My NP was supposed to call me by 4pm today.

They sometimes get behind in calls. Do you have a specific question for her today?

I'm checking on my hep C genotype & viral load tests from Wednesday.

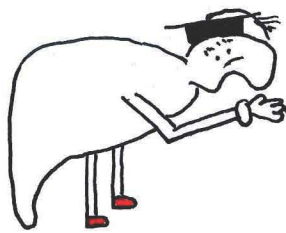
Well, viral load tests take 9 business days. Genotype tests can take up to 3 weeks.



I will start to think the following so often, it might as well be on continuous replay:

Am I being punked?

I've never once seen punked, but I know exactly what it means.



By 4pm = not by 4pm
By tomorrow = somewhere between 9 days & 3 months

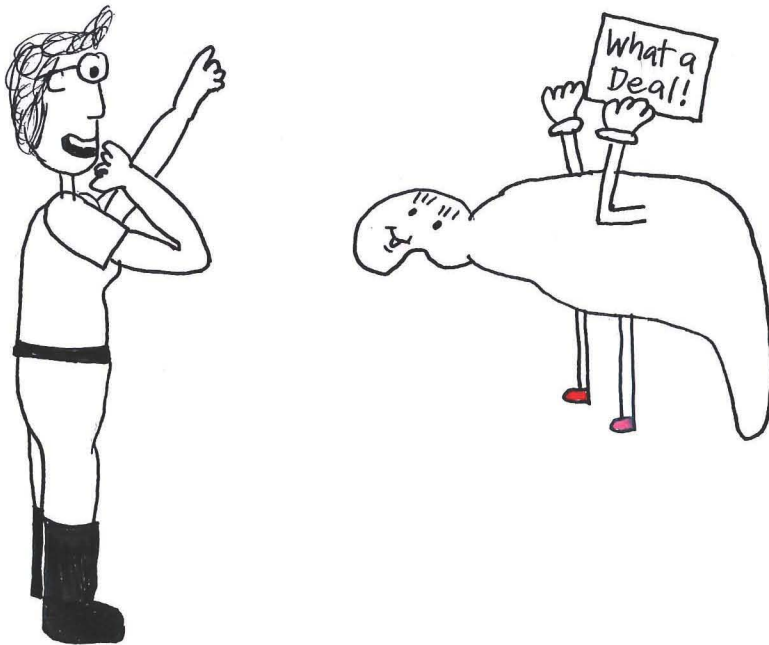
Guess what? I start CRYING!
Suddenly they are able to get my NP on the phone. She says:

What do you want to do? We can reschedule your phone encounter for Tuesday. Or you can schedule a time to come in in person and **cry it out**. That would have a \$20 copay.

HEALTHCARE CLASSIFIEDS

Available in 3-6 weeks: One appointment!
In person! For a mere \$20, you can take
time off from work, travel to a bleak
medical office, and CRY IT OUT!!!

Some restrictions apply. No medicine or
medical care is included. Blackout times
include all times you are available.
Tissues provided at additional fee.



I loathe the phone calling with a
special loathe. I accept the Tuesday
phone encounter (free!) and settle
back to do what I do: cry & wait.

The weekend comes, somehow.
The weekend goes, somehow.

Monday. I check my mailbox and find a letter from HMO. I assume it will be a print copy of the test results so far, letting me I don't have hep A or B or HIV, but do -in fact- have **hep C**.

Instead --- it is the news I've been waiting for (well, some of the news I've been waiting for:

Dear Patient:	06/03/2015
The request for coverage of the service below is approved.	
Specialty: Hepatology	
Service: Doctor's office visit, long office visits, minor lab and x-ray tests	

Start date:	06/01/15
End date:	12/01/15
Quantity:	6
Referring diagnosis: Carrier of hepatitis C virus	
Second referring diagnosis: Liver inflammation	



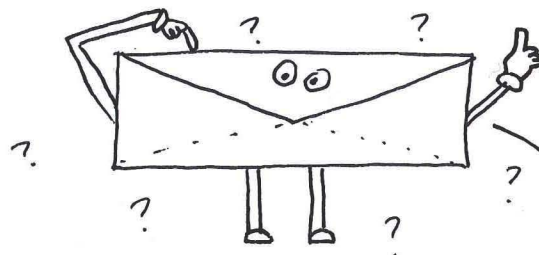
I can see the liver specialist
I need to see up to SIX TIMES!

For the second time in a month, I receive a letter in the mail with life-altering, life-critical information.

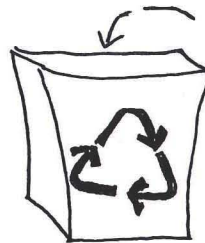
The letter is dated June 3. I was approved five days ago, but I'm not aware of it until now.

A letter.

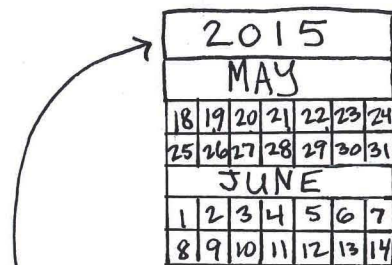
A letter, that could get lost on the way.



A letter, that could be thrown out with junk mail, before it is opened.



A letter, that takes days to travel through the mail.



It is 2015.

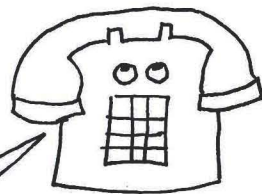
Communication tools available to the world:		
	Yes	No
Text messages	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Email	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Phone encounters	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Voicemail	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Secure websites	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Letter	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Communication tools used for critical health info:		
	Yes	No
Text messages	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Email	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Phone encounters	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Voicemail	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Secure websites	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Letter	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Tuesday, June 9. 4pm. Phone encounter.
Still no news. Except...



I got my approval letter! I can make a specialist appointment!

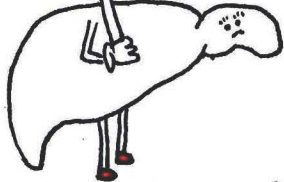


You really don't need to see the specialist. We can wait and monitor your levels...



I AM GOING TO SEE THE SPECIALIST. So, now you've tested me for **everything** the hepatologist will need, right? So when I pay for the appointment and take time off from work, the exam will be as productive as possible?

test me for EVERYTHING.



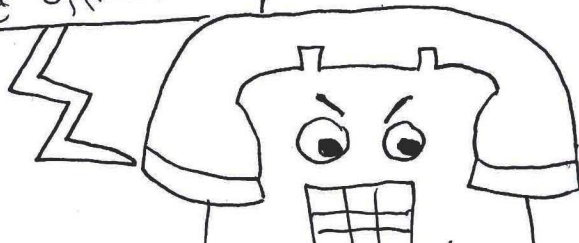
This is the first I've heard of the ultrasound option.

Well. You could get an ultrasound if you want. To check your liver for signs of scarring.



Yes. I want that.

I'll transfer you to the scheduling office.



I call the Radiology schedulers to make the ultrasound appointment.

The first available opening is June 16.

A week away. I take it.

I call the Gastroenterology schedulers to make the specialist appointment.

The first available hepatology opening is July 2.

A month away. I take it.

A month. A month to sit around and wait.

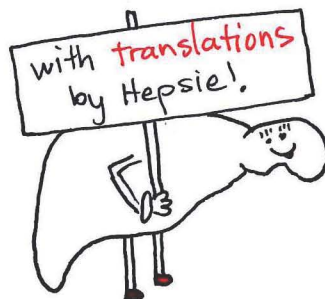
I hope above all that the ultrasound truly is the last test I need. If I have to wait a month to see the hepatologist, and then just find out I need more tests and have to wait another month for the NEXT opening...

← Guess what?
It's not!

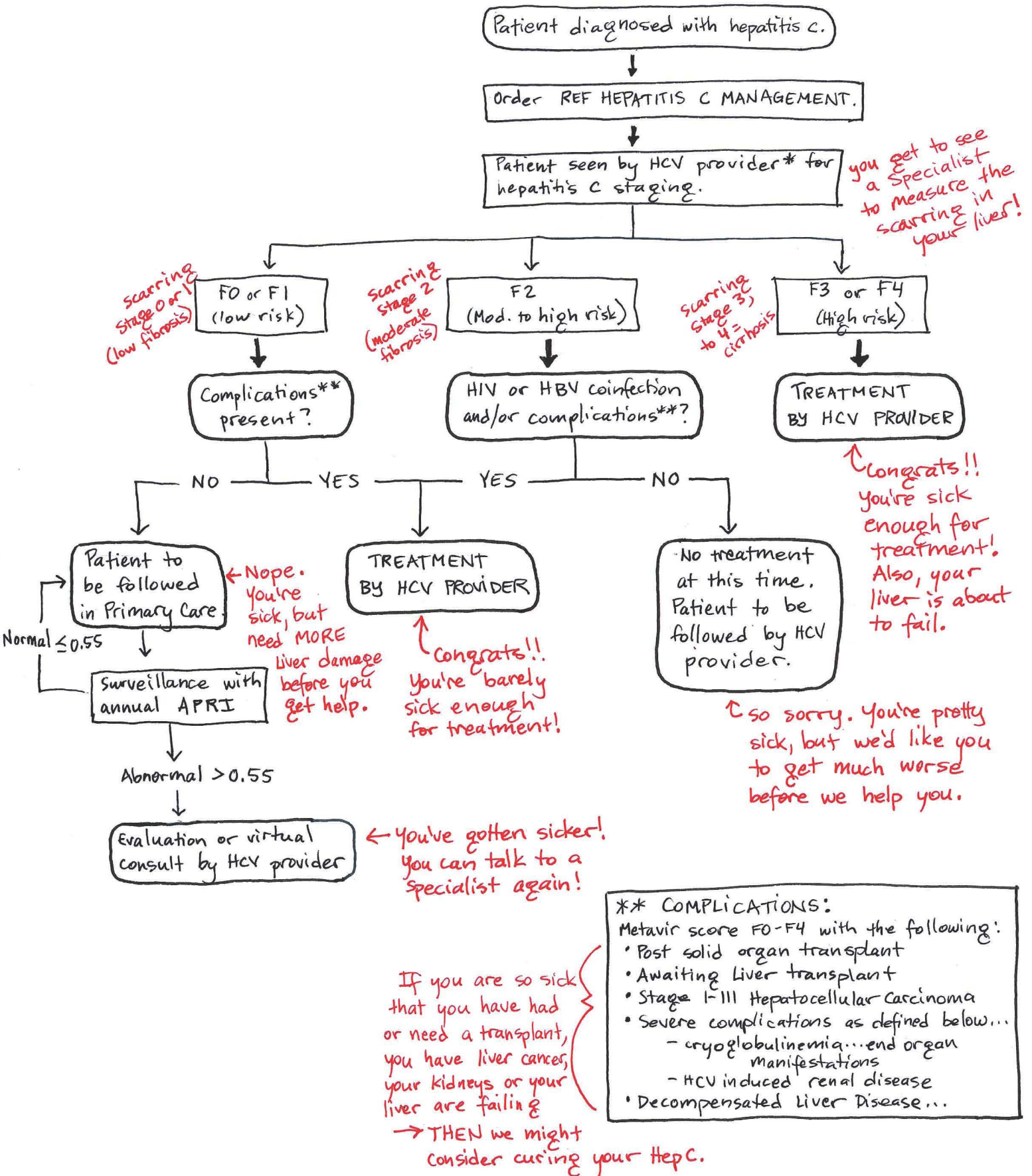
← Guess what?
I will!

I look up my newly-assigned hepatologist on the HMO website. Instead, I come across this confounding, ominous chart:

JUNE						
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30				
JULY						
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18



Flowchart. Hepatitis C treatment & surveillance recommendations.



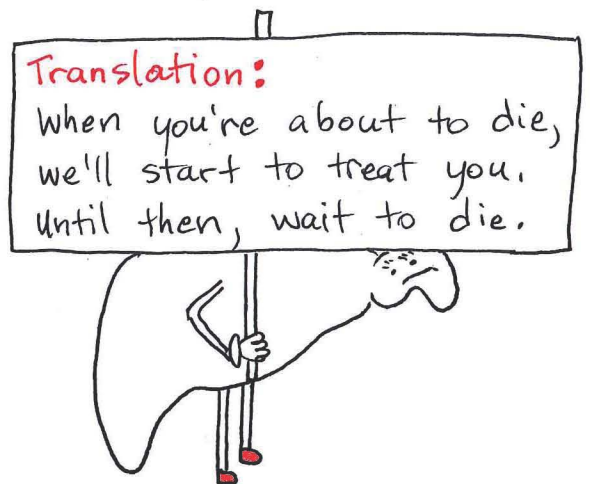
**** COMPLICATIONS:**
 Metavir score F0-F4 with the following:

- Post solid organ transplant
- Awaiting Liver transplant
- Stage I-III Hepatocellular Carcinoma
- Severe complications as defined below...
 - cryoglobulinemia...end organ manifestations
 - HCV induced renal disease
- Decompensated Liver Disease...

If you are so sick that you have had or need a transplant, you have liver cancer, your kidneys or your liver are failing
 → THEN we might consider curing your HepC.

To SUM IT ALL UP:

"In most cases, coverage is available for patients at fibrosis stage F3 or F4. Patients at stage F0 to F2 may or may not be covered for treatment, depending on **medical necessity**; those without complications will likely not be covered unless their condition progresses."



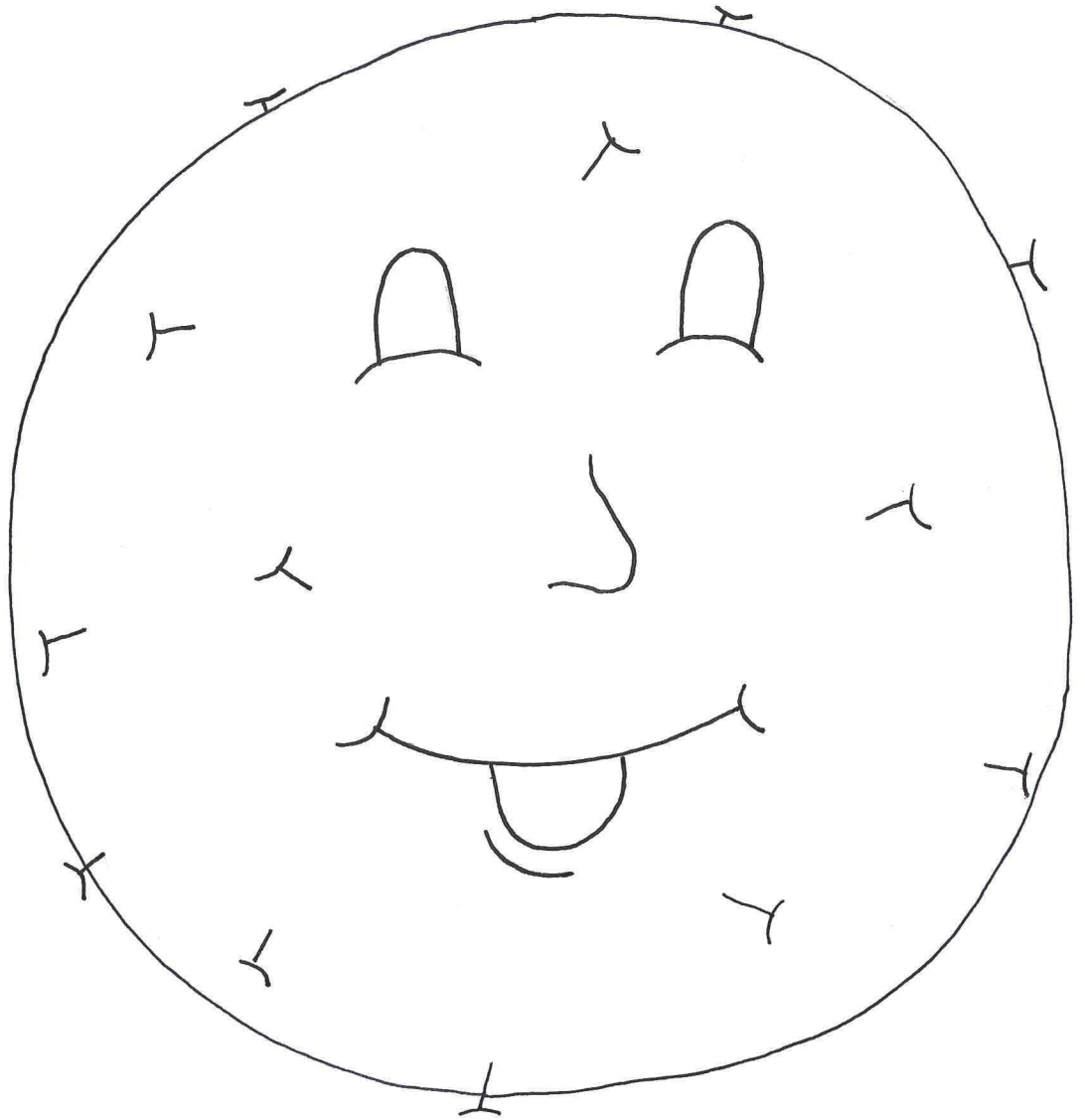
I printed out this document just so I could tear it to shreds. And burn it.

It didn't really help.

My ridiculous, self-destructive, dangerous wish gets stronger:

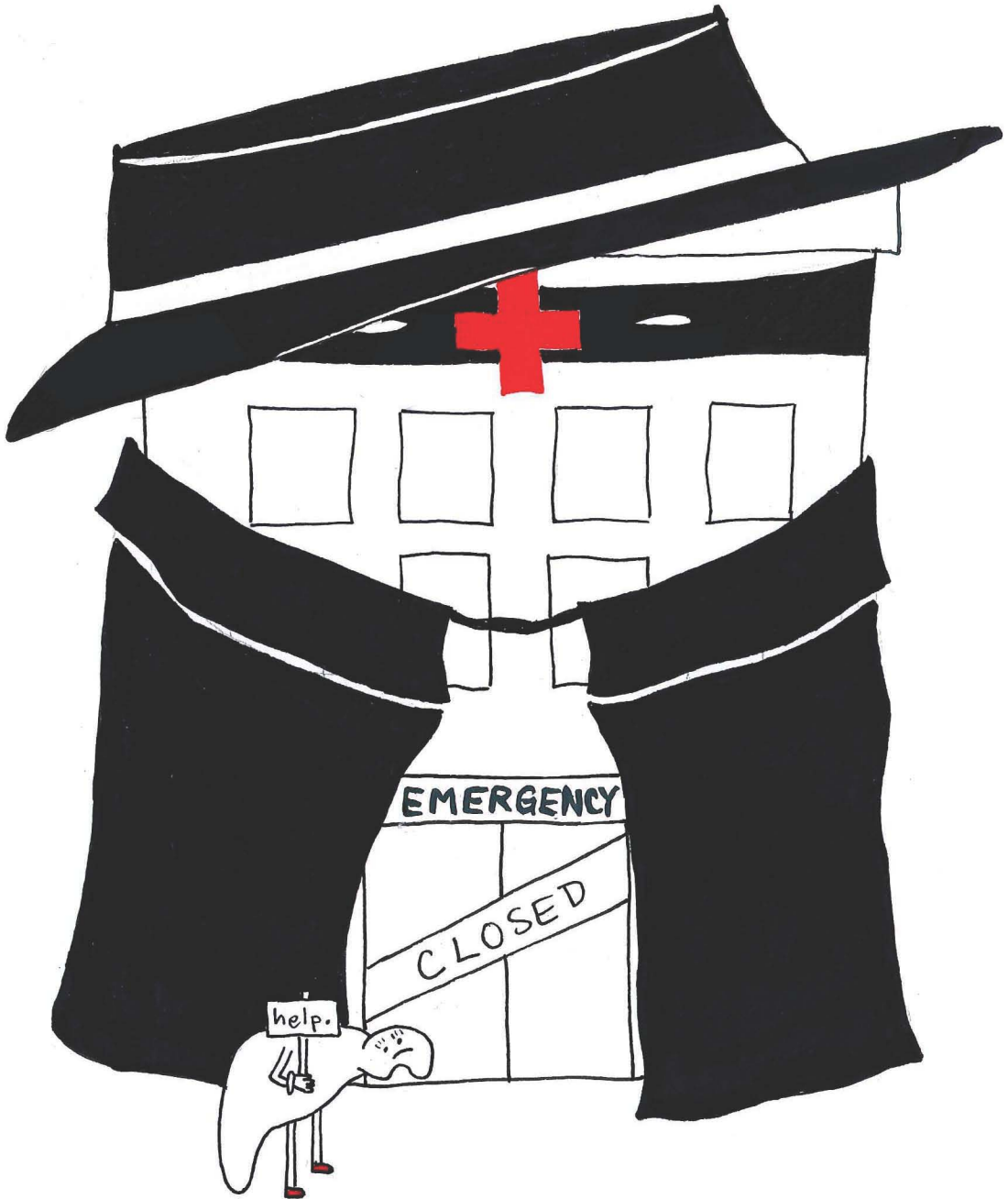
I wish I were much sicker, so I could get well.

A virus is a non-living, non-agentive,
intention-less strand of ribonucleic acid.



Hepatitis C doesn't mean to be hurting me.
It doesn't intend to be using my liver cells.
It doesn't even try to replicate itself.

Hepatitis C does not have a conscience.
But health insurance decision-makers should.



And that makes them
much more scary.