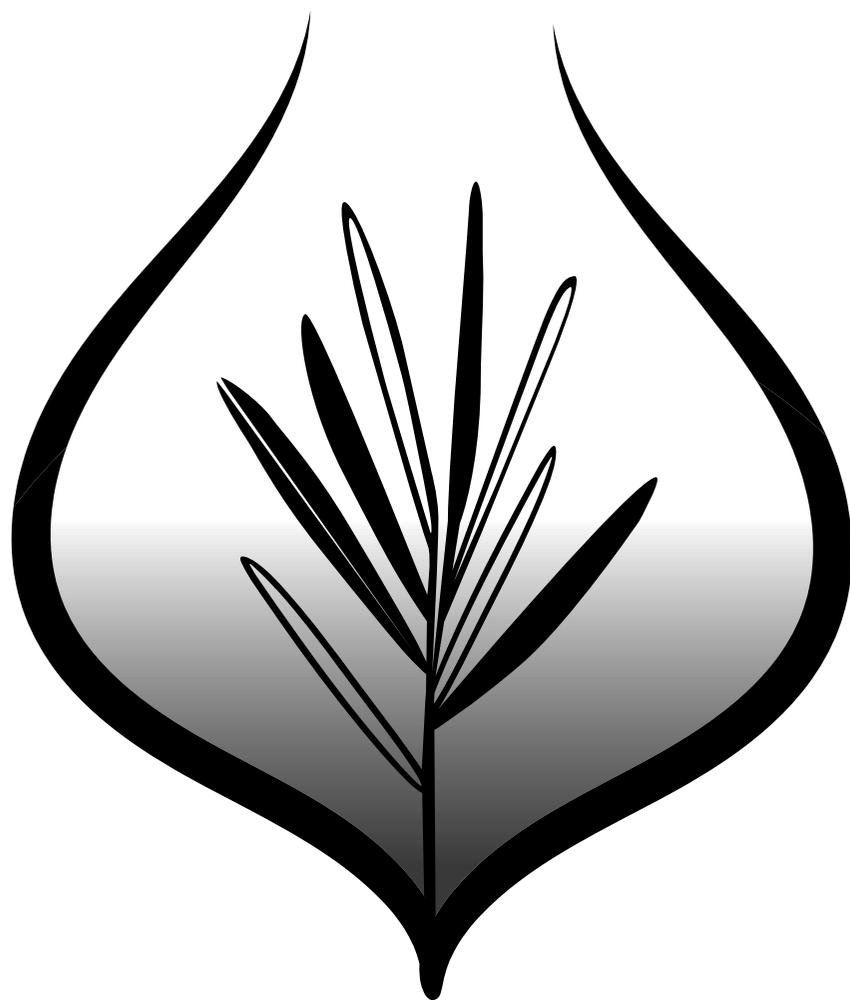




NOTES
for the
Waiting
Room



MEDICAL QUESTIONNAIRE

DO YOU FEEL THERE IS SOMETHING SERIOUSLY WRONG WITH YOUR BODY?

HOW WAS YOUR GESTATION AND BIRTH?

DO YOU DRINK?

WHAT ARE YOUR PRE-EXISTING CONDITIONS?

IS THERE A HISTORY OF DISEASE IN YOUR FAMILY?

DO YOU READ FOOD LABELS?

WHAT KIND OF MOVEMENT UNITES YOUR BODY AND MIND?

DID YOUR ANCESTORS EXPERIENCE PERSECUTION THAT LASTED FOR GENERATIONS?

WHAT FEEDS YOU?

HOW DOES COST INFORM YOUR DIETARY CHOICES?

DO YOUR EXTREMITIES FEEL FAR AWAY?

IS BLOOD THICKER THAN WATER?

IS FOOD ALSO MEDICINE?

ARE YOU HEARTBROKEN?

TELL US ABOUT THE GHOSTS OF YOUR KIN.

ARE THERE TREES WHERE YOU LIVE?

DO YOU GET WEAK IN THE KNEES?

DO YOU EAT WHAT YOUR ANCESTORS ATE?

HOW DO YOU GET AROUND?

ARE YOU WAITING TO EXHALE?

WHAT IS THE FIRST SOLID FOOD YOU REMEMBER BEING FED?

DO YOU LIVE IN A FOOD DESERT?

DOES YOUR PAIN COME IN WAVES?

IS YOUR DIGESTIVE SYSTEM EMOTIONAL?

HOW IS YOUR NEIGHBORHOOD POLICED?

IS YOUR BODY HAUNTED?

ARE YOUR EYES BIGGER THAN YOUR BELLY?

HOW DOES YOUR BODY RESPOND TO CHEMICALS?

IS YOUR BODY A TEMPLE?



WHERE DO YOU GET YOUR DRINKING WATER?

DO YOU KNOW YOUR NEIGHBORS?

DOES IT TAKE A VILLAGE?

WHAT GIVES YOU THE MOST PHYSICAL PLEASURE?

WHAT IS YOUR RELATIONSHIP TO YOUR OWN DEATH?

HOW DO YOU SMELL?

HOW IS YOUR LIBIDO?

DO YOU HAVE ANY INTERSPECIES RELATIONSHIPS?

DO YOU FEEL DEPLETED BY SOCIAL ACTIVITY?

WHO KNOWS THE MOST ABOUT YOUR BODY?

WHO KNOWS YOUR BODY BEST?

The Morning Question, What Good shall I do this Day?	5	Rise, wash, and address <i>Powerful Goodness</i> ; contrive Day's Business and take the Resolution of the Day; prosecute the present Study: and breakfast?—
	6	
	7	
	8	
9	Work.	
10		
11		
12	Read, or overlook my Accounts, and dine.	
1		
2	Work.	
3		
4		
5		
6	Put Things in their Places, Supper, Musick, or Diversion, or Conversation, Examination of the Day.	
7		
8		
9		
10	Sleep.—	
11		
12		
1		
2		
3		
4		

In *The Autobiography of Benjamin Franklin*, Franklin mapped out how to organize life around work in order to achieve "moral perfection." For the series "Crip Time," *Notes for the Waiting Room* editor Taraneh Fazeli invited Canaries members to resist this universalizing vision by "cripping" his timetable to better represent the experience of chronically ill people. "Crip" is a political reclaiming of the derogatory label "cripple."

DOES MORE MONEY MEAN MORE PROBLEMS?

IS THE GLASS HALF EMPTY OR HALF FULL?

HAVE YOU EVER HAD A SUPERNATURAL EXPERIENCE?

HOW DO YOU RELIEVE YOUR SUFFERING?

ARE YOU OVERREACTING?

ARE YOU A PUSHOVER?

DO YOU WALK INTO ROOMS AND FORGET WHY YOU ARE THERE?

DO YOU REMEMBER YOUR DREAMS?

DO YOU HAVE BLURRED VISION?

DO YOU HAVE VISIONS?

WHERE DO YOU SEE YOURSELF IN FIVE YEARS?

DOES TAKING CARE OF YOURSELF FEEL LIKE WORK?

WHAT FORMS OF UNPAID LABOR DO YOU PERFORM?

WHAT DEBTS DO YOU CARRY?

ARE YOU INSURED?

DO YOU LIVE PAYCHECK TO PAYCHECK?

ARE COMMITMENTS OBLIGATIONS?

EMERGENCY CONTACT

[Empty rectangular box for emergency contact information]

PERSON WHO WILL CARE FOR YOU IN WAYS THAT THE BIOMEDICAL INDUSTRIAL COMPLEX WILL NOT



BEING YOUR OWN ADVOCATE

DOCTOR'S APPOINTMENT PREP QUESTIONS

On the day of a doctor's visit, you might be too fatigued or too worried about incoming test results to think clearly. Since appointments tend to be quite short, there might be pressure to cover a lot in an insufficient amount of time. Perhaps your doctor's bedside manner is rushed or dismissive. Stressors like these can make it difficult to remember and voice your questions and needs. It can be helpful to write out notes before visiting your doctor. That way, you can refer to them and remain grounded and clear about what you want to get out of the appointment. Remember, you are paying for a service: you are the client and the purpose of the appointment is to address your needs. Below are some prompts to consider before and after your appointment. —Jesse

BEFORE APPOINTMENT

My main concern/the reason I am coming in today is:

My most prominent symptoms are/ I notice these symptoms at the following times:

My symptoms seem to be triggered by/I am not aware of any triggers:

In addition to my primary concern(s) I would also like to talk about:

Practitioner, last time I was in the office you said something(s) I didn't understand (*write out below*) Can you please clarify?

Question(s) I feel embarrassed to ask or that I think I am supposed to know the answer to:

Note: You may not feel safe or comfortable discussing certain things with your practitioner during the appointment. Regardless, write your question or questions here as you may want to find another practitioner/person/friend to speak to at some point.

QUESTIONS/CONCERNS ABOUT TREATMENTS

Treatment plan I am currently on:

Treatment plans we will discuss during this appointment:

Treatments I've heard about and would like to discuss with you:

Treatments I've taken in the past:

Question(s) I don't think this practitioner can answer, but which I would like to ask someone/another practitioner:

AFTER APPOINTMENT

Question(s) for next time:

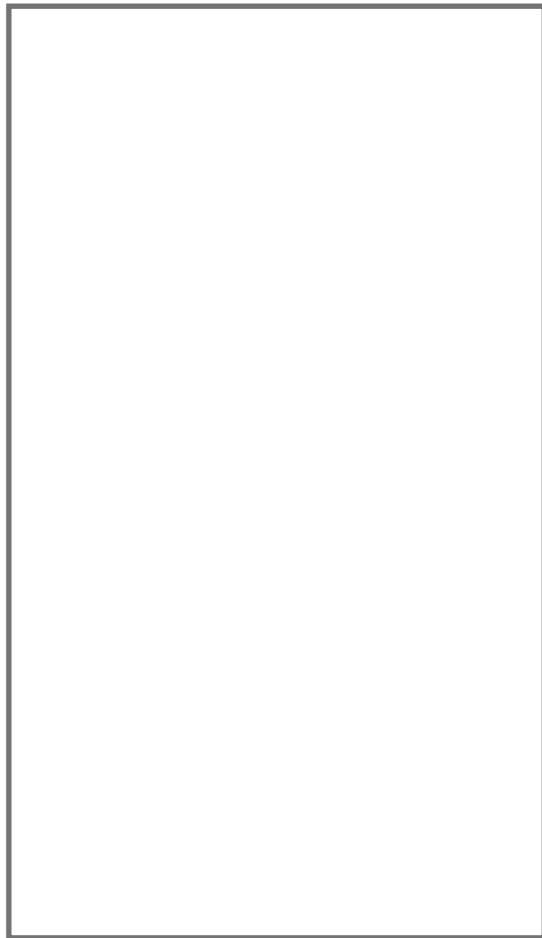
Do I feel satisfied with this practitioner's work? Why or why not?

Would I like to find a different practitioner? If so, what are the qualities I am looking for in a new practitioner?

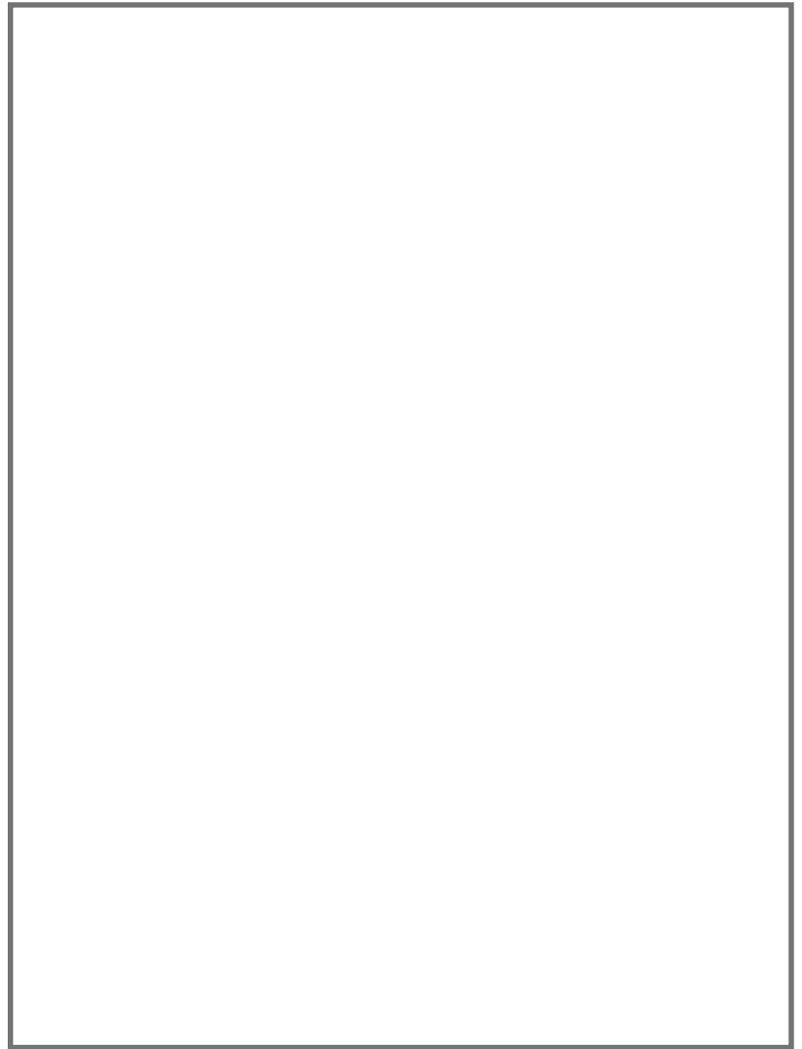


PAIN ADDENDUM

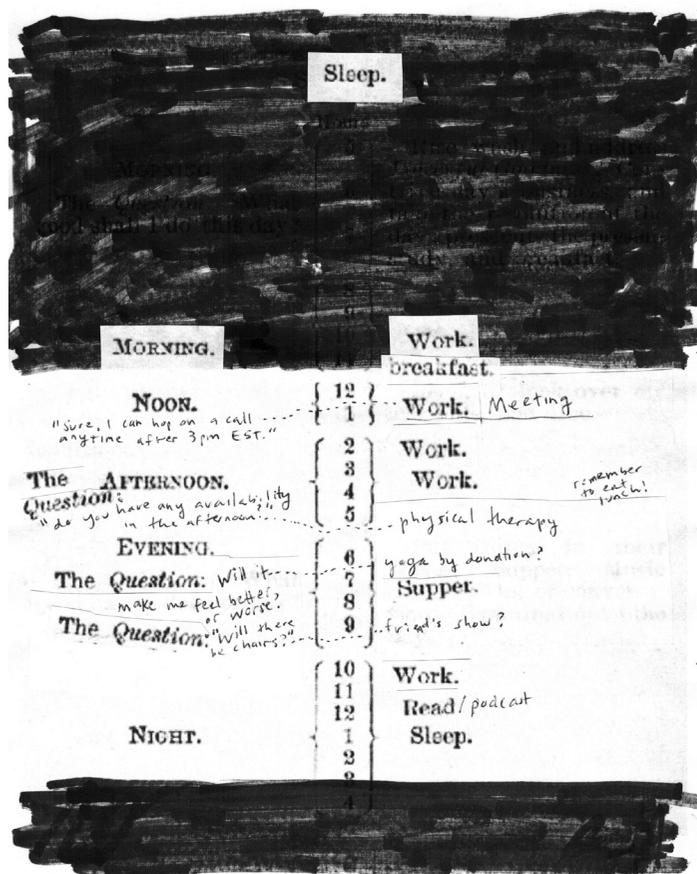
CLOSE YOUR EYES AND SIT QUIETLY FOR A MOMENT. REST YOUR HANDS ON YOUR KNEES. FEEL THE SOLES OF YOUR FEET PLANTED EVENLY ON THE GROUND. HEAR THE SOUNDS IN THE WAITING ROOM. FEEL THE WEIGHT OF YOUR BUTT IN THE CHAIR. BRING YOUR ATTENTION TO THE TOP OF YOUR HEAD AND LET IT MOVE DOWN THROUGH YOUR ENTIRE BODY ALL THE WAY TO THE TIPS OF YOUR TOES. DO YOU FEEL PAIN ANYWHERE? BLOCKAGE OR TENSION? IRRITATION? IMBALANCE? WHERE? DRAW YOUR BODY AND NOTE THE PLACES WHERE YOU FEEL THESE SENSATIONS.



IF THESE SENSATIONS WERE TO HAVE FORM, A COLOR, A PERSONALITY OR AN EMOTION, WHAT WOULD THEY BE? DRAW THEM BELOW.

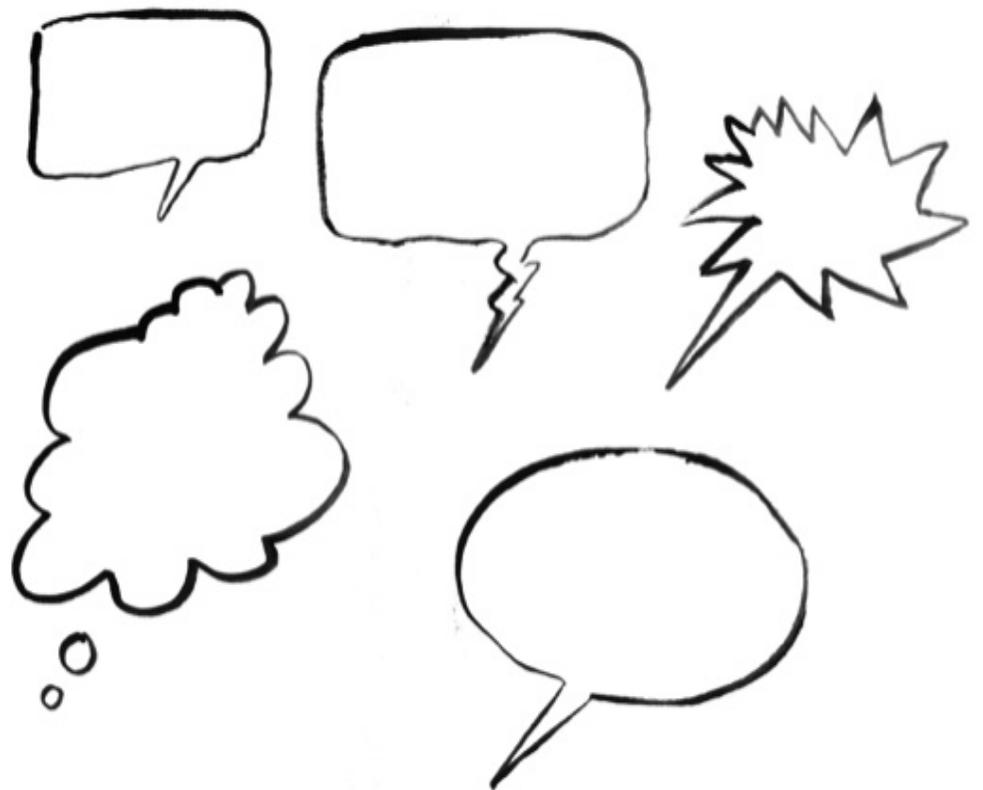


For example, if there was pain in your abdomen, would you describe the feeling as twisting and tight, like a rag being wrung? Or hot, like embers in a fireplace? Is it red and angry, or green and nauseous?



Amy Berkowitz, untitled, 2016. From the series "Crip Time," 2016-

IF THESE SENSATIONS WERE TO HAVE VOICES, WHAT WOULD THEY SAY?



For example, a headache might say, "leave me alone," or "fuck you," or "pay attention to me," or "I don't have enough space in here."

—Jesse



TOOLKIT FOR LIVING

WITH IDIOPATHIC DISEASES

THE GUIDE / NOT GUIDE TO SURVIVING A FLARE

Many members of the Canaries have suffered more in times of overwork and/or when they have been uninsured. This is a fundamental issue with autoimmune conditions: they tend to worsen when stress is placed on the body by work schedules mandated by capitalism, and these conditions are frequently exacerbated by the inability to financially or physically access things that could help heal the body over time or provide long-term treatment for difficult conditions. The following list consists of suggestions to address this problem. This shouldn't become another source of stress, but it hopefully will provide a rough guide of further options for when the dominant forms of medical treatment do not completely resolve autoimmune issues. Many of the suggested products and services may seem cost prohibitive, but they can be obtained through community programs (mentioned in my essay), or at a discount. Any medicines and supplements should be used with caution and introduced very slowly, as even ones that are "natural," can interact with other foods, medicines, and treatments, and will vary in terms of reactions and effectiveness. Taking it slowly, and finding ways to demand slowness, are possibly the most radical things you/we can do to help your/our body through ongoing illness. —Catherine

Sometimes seeking diagnosis can really be besides the point when dealing with chronic illnesses (beyond the validation of bodily intuition that can be found in a diagnosis). In Western medical practice, the point of a diagnosis is often to identify a "pathology." And identifying a pathology is often for the purpose of prescribing medication or surgery or some other protocol in an attempt to (as doctors say) "restore normal functioning," which is often a euphemism for "forestall death by this particular thing."

Before giving what might be construed as prescriptive advice, this is where we are supposed to make a disclaimer limiting our authority by saying that this "is not medical advice" and "we are not doctors," so "if you are considering making any changes, please consult your doctor." But our input is valuable precisely because we came at our knowledge about the efficacy of various treatments not from within the biomedical paradigm as doctors but as individuals who have tested treatments with our own bodies. We must emphasize that our bodies and experiences are different, so while there are many overlaps in our methods of treatment, even people who have the same conditions often wind up with different strategies for managing them. Recognizing this is one of the key points of Canaries—inherent in the architecture of the collective's support is the sharing of information, techniques, and treatments, but we never share information as universal fact. We offer our experiences and methods, we never prescribe. Listen to your body alongside others. —Canaries

In other words, Western medical practice largely exists to prevent or slow death once an individual is in a state of crisis. This is not to discount Western medicine: if I were to get hit by a bus tomorrow, I would hightail it to Mt. Sinai Hospital—not to my acupuncturist.

But there's a flip side to crisis-mentality medicine—it more closely resembles a slash-and-burn approach to clearing a rainforest for a temporary cow pasture than a patient, skilled approach to permaculture gardening. Crisis professionals tend to be unwilling or unable or uninterested in helping you garden with a long view in mind.

For instance, the non-steroidal anti-inflammatory drugs that Western medicine uses to quell acute autoimmune flares also eat away at the gut lining that keeps our insides safe from marauders. And in the long term, a damaged gut lining actually promotes inflammation, feeding into a cycle of dysregulation that is extremely difficult to reverse. Ironic. Useful in the short term—especially if you are in danger of dying!—but maybe not so smart in the long term.

I'm not a doctor and I don't give medical advice, but if you have a pathology that can't be treated with medication or surgery, unless or until you develop (or until they detect) a worse/different/downstream pathology that has been previously identified and successfully treated with Western drugs, surgeries, or other protocols, your condition will be labeled "idiopathic." In other words, you have what they might classify as a chronic lifestyle problem of unknown cause. A non-emergent problem that they can't help you with. Or, as some doctors call it, a "NMP" (not my problem). ["Unless or until you develop or they detect..." you know the drill.]



So what do you do? There are a few options. And none of them are contingent upon a diagnosis. It can be scary to start working step-by-step on little things, but they add up. And as long as you plan on being alive ten years down the road, does it really matter if it takes you ten years to figure it out? You can start making changes now, or in six months, or in six years.

Working on it isn't guaranteed to make it better, but in my opinion and experience it's a lot more likely to make it better than waiting for a diagnosis. —Bonnie

DEFINING A FLARE

In my case, the period of relapse within chronic illness is associated with Crohn's disease, whose symptoms often include intense abdominal cramping occurring several times a day, colon spasms, intense smelly gas, blood in my stool (like your period, but out your butt), consistent diarrhea (Calmoseptine ointment is available behind the counter at pharmacies and can help keep you from getting raw—imagine mint chewing gum for your bum), anemia that leads to exhaustion, dehydration (putting nuun, a brand of re-hydrator that separates electrolyte replacement from carbohydrates, in my water has been the best solution), mouth sores, leg pain, and muscle spasms at night (rubbing magnesium cream into calf muscles can help). Then there are the side effects from drugs like Prednisone, a synthetic corticosteroid I am currently taking, but talking about that would require another long list of survival skills... —Brina

SECONDS 1-10

BREATHE: I always get nervous and forget to breathe, which immediately makes the situation worse by shutting down my circulation and making my body tense up.

SECONDS 20-60

FOCUS: Spinning out of control is the scariest part; you simply can't know how long this will last and how bad it will get. I am usually alone when this happens, so I look for a mirror in which to focus on my own eyes. Having another being there to make eye contact with is great, even if it's a pet. Engaging with something outside myself helps focus and ground me, and then allows me to move to the next steps I need to take.

MINUTES 1-5

HEAT: I warm up my body in by running a hot bath and sitting in it. Ideally I would have a sauna in my apartment—no joke—but I'm pretty sure there's a "no sauna" clause in my lease. So my options are the bath, which I sometimes poop in while the water runs down my back, a heating pad in bed for cramping, and hot tea for gas cramps (especially after surgeries). Even just wetting the toilet paper you use to wipe in hot water can help stop painful colon spasms. —Brina

TOUCH

To deal with pain I try to trick my mind. I can really only register one sensation at a time, so I massage another part of my body. Any part works, but if I'm being honest—as honest as someone else once was with me—try massaging your lady parts. The sensation this produces can win out over the pain and really help sooth. Hey, why not. —Brina

MENTAL EXERCISES

I have gone to hypnotherapists who have given me helpful visualization

tools. These are little things to do in your mind to help calm you down. It's just good to have them because they give you something to do instead of spiraling into panic. —Brina

DRUGS

If you are taking medication, get pills in you. Sometimes it gets bad and the drugs are important for physical and mental relief. My favorite doctor once told me that pain doesn't build character—it's true! [It might help develop your sense of humor, though.]. —Brina

HELP

There have been times that I have waited too long to ask for help. I would think, "oh, maybe this will get better," or, "I don't think this is as bad as that other time," and so on. I am stubborn when it comes to asking for help, but I've gotten way more comfortable asking my friends and family. I've learned that some people really do want to help! Call them. When others aren't so helpful, stop calling them. People are good at random things. As long as you cast a wide net you won't feel like you are taxing any one person. Also, strangers can help. Ask for that seat on the subway. Very few people will say no, and if they do, the person next to them may get up instead. I've had to ask random people for assistance and have been so surprised by how an Uber driver to the ER could be so giving, and a tow truck driver, or an old lady sitting next to me on an airplane. She didn't speak English, but she held my hand for a long time. —Brina

INFLAMMATION

New research suggests that those with compromised immunities might have a harder time in general with healing. Though doctors are sometimes reticent to take a "holistic" approach, if you can convince your doctor to assess your inflammation from a broad bodily standpoint and ask them to be open to trying a variety of options with you (while avoiding products/medicines that could potentially harm your body), this might help limit other symptoms and help with general wellbeing. Many of the suggestions in this tool kit could be helpful in conjunction with each other in treating inflammation, which most autoimmune sufferers see as a root of multiple related ailments—for instance, how someone with Crohn's disease may also have eczema and rheumatoid arthritis. (Some research suggests that there is a relationship between these ailments and the "malabsorption" of food-based nutrients in the stomach and intestines—meaning that once one imbalance arrives, others can follow in a domino effect.) People take supplements like turmeric or cat's claw for inflammation; sometimes it requires testing a particular supplement and seeing if it works for you. You also can make your own: instead of buying turmeric in expensive pill form, you can get root or powder and mix/blend it yourself. Cat's claw boiled as a tea can be consumed by people who can't tolerate turmeric. As with any supplement, it's a great idea to tread cautiously when seeing how the body reacts to it. Keep a journal of your reactions to each new thing. This is a process, there's no for-sure outcome. All these strategies are meant to be a part of a longer-term process of negotiating bodily pain, and the oscillation between feeling well and feeling sick, or acknowledging that feeling sick is sometimes normal. —Catherine

ACUPUNCTURE

This healing modality, a key component of traditional Chinese medicine, can help many on a need-by-need basis, though it takes time. Many people report relief only after months or even years of treatment—two-to-three months of



treatment can help alleviate pain for periods of time. If a condition returns, the treatment may be resumed. One of the downsides to acupuncture is that it can be painful and frightening.

Acupuncture involves inserting very thin needles into the body at acupuncture points, which can sometimes hit sensitive nerves and/or can be especially painful if targeting an area that has a great deal of tension because of inflammation. Protocols to help increase effectiveness include “avoiding alcohol, caffeine, exercise, and anything that is potentially too stimulating or too depressive to the system for six hours after a session. If possible, rest almost all day after a session. Plan sessions on days when you have nothing to do, or at least a minimal amount of things to do.” From my experience, acupuncture works best if done at least one or two times per week. This of course is difficult for people who work forty hours a week, which is part of why this treatment tends to work best for those in a position to “rest.” Although many medical insurance companies will not cover treatments, there are community acupuncture spaces that offer sliding-scale payment cropping up in many cities. —Catherine

MEDICAL MARIJUANA

Medical marijuana may be an alternative for anyone prescribed drugs like the narcotic Oxycodone for chronic pain. This is a challenging recommendation in light of its complicated legal status—in the United States it is only legal for medical use in some states, though many chronic pain and/or inflammation sufferers have seen great results from using it. For those worried about the legal ramifications or psychoactive effects associated with smoking or ingesting the plant, there are now tinctures, salves, and other kinds of marijuana delivery systems. Included are various cannabidiol (CBD)-heavy products that tout minimal to no “psychoactive” effects. (CBD and tetrahydrocannabinol (THC) are two main components of the marijuana plant: THC is the psychoactive ingredient while CBD is a non-psychoactive ingredient.) This all comes with a caveat, which that, according to severe pain sufferers, the products named above work best in combination with at least some amount of THC. It is imperative that activism continue around marijuana use, and that users stand up to pharmaceutical companies seeking to patent and capitalize on healing plants. Additionally, it’s crucial to take a stance against the corporatized approach to incarceration, which imprisons large

numbers of people for minor offences related to personal drug use. —Catherine

5HTP/B VITAMINS

Depression and malaise are common symptoms of autoimmunity issues that can cause doctors to misdiagnose conditions and overprescribe anti-depressants. Some people have had success with supplements like 5HTP that increase the production of serotonin. Like any supplement, 5HTP should be taken cautiously. You should never take things like 5HTP while you are on MAOI inhibitors, and you should always be aware that though supplements are labeled as “natural,” they are powerful. Plants are powerful medicines, too. Though they work at slower paces than their more refined medical/industrial counterparts, they react with bodies in very different ways, and can also react with medicines prescribed by medical professionals. The benefit to some of these supplements is that they can be softer (and slower) on the body than anti-depressants. There is also new, compelling “empirical” evidence that immunity issues can be related to depression, suggesting that many autoimmune sufferers may be diagnosed with depression that is really the result of underlying bodily conditions. —Catherine



Zoey A. Hart, *Nocturnal Diagnostic*, 2015. From the “Invisible Disability” series, 2015–.

DIET

Omitting gluten has had a high success rate in easing inflammation among those suffering from autoimmune conditions. Dairy, soy, and sugar can also be cut as a first attempt at healing. Taking extra-strength turmeric, fish oil, and probiotic (live bacteria and yeasts taken in pill or liquid form) on a daily basis can help with dietary supplement. Ground turmeric, which can be purchased as a spice more cheaply than in pill form, can also be added to smoothies and

juices to aid with chronic inflammation. If taken in powder form, adding a pinch of black pepper helps absorption (the expensive capsules are essentially powdered turmeric and black pepper). Turmeric, like acupuncture or medical marijuana, is not a quick fix nor is it guaranteed to work with everyone (see the information about “cat’s claw” in the inflammation section). Depending on an individual’s condition, people can also add supplements such as selenium, magnesium, and licorice root (these are specifically suggested for thyroid conditions). Since these supplements can be expensive, consider joining a community food cooperative where you can order your supplements, or find discounted grocery programs where you can buy powders such as turmeric in bulk. Fermentation is also helpful in re-introducing healthy bacteria and probiotics to the body, though some bodies will be too sensitive for the alcohol and sugar involved. The book *Wild Fermentation* (2003) has many recipes ranging from short-term easy fermentations to more difficult ones that can cut down greatly on the cost of things like kombucha or probiotic pills. Many immunity issues also manifest on the body as allergic reactions such as rashes or flushing, which make products like coconut oil (which can be taken internally and used for oral health) good options. —Catherine

EXERCISE

Even done just two times a week, pilates can help immensely in treating mysterious or chronic joint pain. This suggestion may be difficult for those with “limited mobility”—limitations to their time and access—and additionally, pilates has become very expensive. Still, because it combines with physical therapy to aid in muscle development and circulation, people with severe injuries report incredible results. It was originally developed to help people recover from injuries while bed-ridden, so many of the exercises can be done with limited mobility. Aside from pilates, any exercise that does not impact the body and the individual joints but moves and strengthens muscles is ideal. For those who are hyper-flexible and have autoimmune or joint issues, yoga can be dangerous. Swimming is also a good low-impact muscle strengthening exercise. Access to pools can be tricky: in some parts of the country public pools are closed most of the year, while other areas have indoor public pools that are open to the public and free or under \$5 per swimming session. Programs like the YMCA (as mentioned above) also offer discount packages to the economically disadvantaged. Proof of income or unemployment



can be used for exercise classes, swimming, and many locations also have saunas or spas that can be very good for healing. It should be noted for those with chemical sensitivity that chlorine is the main method for sanitizing pools, though some pools are now switching to salination processes, which produce much less harmful effects when absorbed into the skin (though these pools are still partially chlorinated). To help limit chlorine absorption, try showering before and after a swim: showering before removes the oils on your skin, which chlorine likes to bind to for easier entry into your system; showering after removes the residual chlorine. If you can swim in the ocean or a cove, do that. Submerging yourself in the salty water of the ocean and inhabiting that cosmic soup can bring on a deeper sense of connectivity between mind and body. —Catherine

SOUND MEDITATION

This form of meditation is one of the easiest to perform, plus it is great for those who are skeptical about spiritual rhetoric but would like to engage in a body/mind reset. The basic method is to find somewhere to lie comfortably (though you could even perform this standing in a crowded subway car). With your eyes closed, try to focus on every sound as it comes and goes. This means sometimes jumping from sound to sound, or honing in on one sound over others. The most important thing is just to attempt. —Catherine

MUSIC

When I'm feeling isolated during a flare, just turning on the radio every day can change my mood and make me more calm and motivated. I think it has a lot to do with the illusion of other people being in the room with me. —Brina

ENVIRONMENT

I've had to spend long periods of time in various bathrooms, especially my own. So I say: make it a fucking palace. When you are crouched down on the cold floor you'll be happy you got that fuzzy Ikea bathroom mat and that the bottom of the toilet is clean. When you light that scented candle and it masks the noxious smell that just came out of your butt you will feel an ounce of relief—when piled on everything else, this may tip the scales in your favor. When you are sick, get help around the house. A cleaning person or friend coming

over just once during a bad spell can take some of the weight off your shoulders. It's hard when you are making all your own meals and cleaning up is the last thing you can handle. Being in a clean, comforting space makes it so much easier to handle a flare. When I can't control my environment (if I'm stuck on an airplane, in a public bathroom, or at work) I'll carry a scent with me to inhale, or I'll take out my phone out and look at Instagram or do something else to take me away from the gross place I'm stuck in.

But now we are moving past the first five minutes.

When the flare becomes a chain of flare-ups that go on for a week, a month, or a year, you will have to adjust everything. It's a tough balance between controlling your situation and not isolating yourself.

If you had the flu would you go to work and expect to get better? Would you do all your usual chores? Exercise the same way? Socialize the same way? Well, maybe, because we are hard on ourselves. That's when I ask myself: if I had a sick child what would I do for that child? Think about that, and do that for yourself. —Brina



Jesse Cohen, *Night Window*, 2014. From the series "Results," 2014.

PSYCHIC DIET

Rest, snuggle, and watch television. I would not watch my favorite zombie show but my favorite period piece instead, as less gore and more opulence is better during these times. I learned this once when I was really feeding my inner

fears by binge-watching a Netflix sci-fi show about an alien infestation of human hosts, and the resulting nightmares confirmed that this was bad for my psychic diet.

Emotional energy is sparse, so during longer flares I have to limit or eliminate interactions with some family members, ex-lovers, selfish friends, and demanding co-workers. Socializing is part of a diet, just like taking bone broth and protein, so only consume the exact things your body needs to rebuild itself. —Brina

NAVIGATING BIOMEDICINE

I wish I had a solution for dealing with health insurance companies, doctors offices, and pharmacies, but I always get mad and lose my cool with dealing with inept systems. At your doctor's office, I suggest you try to find the kindest administrator and remember their name and be nice to them. Also, find out when your favorite blood drawer is in so you can request them. You can always ask for another nurse in the hospital—don't feel bad for them, some of them don't feel bad for you. The number one thing I learned is to never be alone in the hospital. Don't even ask why, it's not worth finding out. Always bring an advocate—it will make all the difference. Other positive people will make the flare bearable, so spending time with friends and family helps.

—Brina

TRY IT ALL

Engaging in acupuncture, massage, therapy, yoga, keeping an eye on your nutrition, and doing anything else that helps you even slightly will really make a huge difference when you are sick. Try it all—you have nothing to lose. I tried all kinds of docs and therapies and some were amazing and some were less amazing, but you never know.

Never give up on trying new drugs and therapies—advances move fast and I'll take any shred of hope that

comes along. After I lost one part of my body and was told I was going to lose another, I tried everything under the sun and I'm still holding onto that body part now. I may still have to lose it down the line, but I also may feel better when I lose it. Everything under the sun is starting to work for me for now. —Brina

SCORE FOR PATIENT INTERACTION

Tonglen is one type of Tibetan Buddhist meditation. In Tibetan, “tonglen” means “giving and receiving.” These meditations can cultivate compassion for oneself and others, and can be adapted and practiced by anyone regardless of religious affiliation. Tonglen is a practice that helps put a person in touch with their own vulnerability and suffering while also connecting them to the vulnerability and suffering of others. This is a variation on a Tonglen meditation that’s been adapted to the particular needs of the waiting room. —Carolyn

ONE

Begin by sitting in a waiting room chair.

TWO

Close your eyes and take three deep breaths. On each inhale, fill your lungs and your belly with as much air as possible. Count to four. Hold the breath. Count to four. On each exhale, release the breath fully while counting to eight.

THREE

Breathe naturally. Feel the air coming in and out of your nose. Just observe.

FOUR

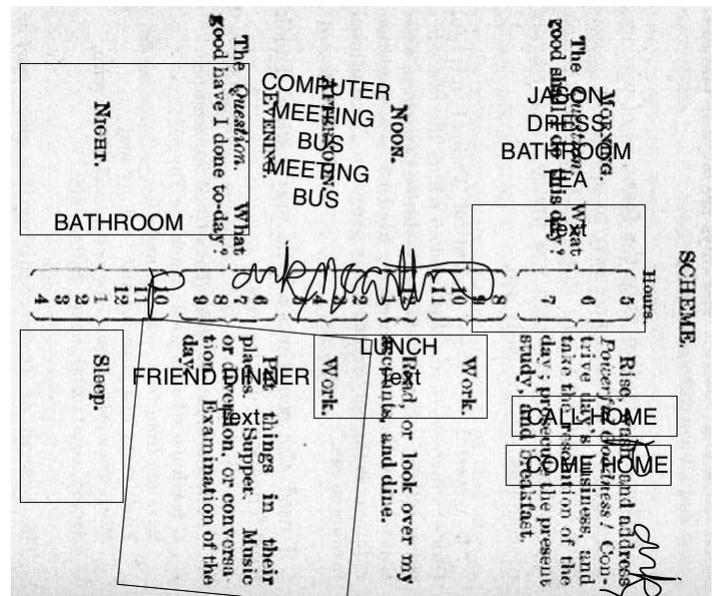
Feel your feet planted firmly on the ground.

FIVE

Feel your body’s weight seated in the waiting room chair.

SCHEME.	
Hours.	
MORNING.	
The Question.	
WHAT IS THE MEANING OF THIS?	
The Question.	
WHAT WILL BE POSSIBLE TODAY?	
The Question.	
WILL I GET FIRED? CAN I AFFORD THE MEDICATION I REALLY NEED?	
NOON.	
The Question.	
WHAT IS THE TOMORROW WE IMAGINE FOR THE WORLD? WHERE IS MY LIGHTER?	
EVENING.	
The Question.	
HOW WILL I GO ON? WILL I DISAPPEAR?	
The Question.	
IF I STAY IN BEDREST FOR A COUPLE OF DAYS WILL I FEEL WELL ENOUGH THEN TO MAYBE SEE A FRIEND OR GO TO WORK? (AND IF I HAVE TO CHOOSE, WHICH?)	
NIGHT.	
The Question.	
AM I STILL ALLOWED TO DREAM?	
5	DREAM VIVID AND PSYCHIC DREAMS. OR STRUGGLE TO SLEEP AT ALL.
6	...
7	AWAKEN. DRINK BLACK TEA. GIVE MY PLANTS SOME LIGHT. READ FOR CLASSES. EAT IF I CAN. TAKE MEDS. GET DRESSED FOR WORK. LIE IN BED EXHAUSTED.
8	
9	
10	
11	REALIZE I'M FLARING. STAY HOME. TRY TO REMEMBER THROUGH THE BRAIN FOG WHAT WILL HELP ALLEVIATE SYMPTOMS. DRINK BROTH. TEA. CRY BECAUSE EVERYTHING HURTS AND IT IS HARD TO LIVE. BEDLIFE. LIE NEAR WINDOW FOR SUN.
12	
1	
2	
3	
4	WRITE LETTERS OR POETRY TO FRIENDS ABOUT HOW TO KEEP FIGHTING TO CHANGE THE WORLD. OR, IF STILL FLARING, LIE IN BED, EAT CRACKERS, DRINK TEA. SELF-MEDICATE FOR PAIN.
5	
6	
7	
8	READ FEMINIST THEORY. OR RESEARCH MY OWN ILLNESS SINCE NO DOCTOR IN EIGHT YEARS HAS HAD ANY ANSWERS. FEEL ANGRY THAT PROFIT IS A PRIORITY OVER HEALTH IN THIS COUNTRY.
9	
10	
11	
12	TRY TO SLEEP. CALL MOM OR XYZ. TOSS AND TURN IN PAIN. SLEEP.
1	
2	
3	
4	

Heidi Andrea Restrepo Rhodes. And still I search for the tiniest splendor in this island of my bed. 2016. From the series “Crip Time.” 2016.



Park McArthur. untitled. 2016. From the series “Crip Time.” 2016.

SIX

Open your eyes and survey the room. As you do this scan, look at every single person in the room and recognize their presence, while maintaining awareness of the breath entering and leaving your lungs.

As you look at each person, try to imagine what they might be feeling even as you recognize that you can never fully know. Perhaps they are really dreading their appointment. Or maybe it took them three months to get the appointment they needed and have long been anticipating it. Did they have to take off of work to make it today, and are they worried about getting back? Did they need to find someone to watch their children or their elderly parents? Are they waiting for a diagnosis or are they coming for routine lab tests? Are they hoping for good news or anticipating bad news? Do they have someone who will hold their hand, someone to share these results with later? Will they hear that their condition is terminal or chronic? Can they afford their visit? Is their medical care being contested by their insurance company—do they even have health insurance?

As you ponder these questions, imagine yourself breathing in each person’s pain and anxiety with every inhale. Then, with every exhale, imagine yourself breathing healing energy out in their direction. Perhaps this energy has its own color or is of certain quality: is it a warm golden light or a cool blue mist? Imagine it enveloping each person’s body as you continue to breathe in and out slowly.

SEVEN

Slowly, begin to imagine all the doctors who work in this practice that are behind the waiting room door. Imagine how many patients they see in a day. Imagine how often they must deliver bad news. Imagine how often they don’t have answers or solutions for desperate patients. Do they have to spend hours after seeing patients updating charts for bureaucratic reasons? Do they work with staff members to battle health insurance companies refusing treatments in lieu of taking lunch breaks? Do they have their own sick children at home, or aging parents to support? Imagine their long hours and the resulting fatigue.

On every inhale, imagine yourself breathing in your doctor’s fatigue and stress. On every exhale, imagine yourself breathing out healing energy in the form of golden light or clear blue mist. Imagine this energy enveloping your doctor’s body.

Continue to do this for as long as it takes to breed equal compassion for your suffering and the suffering of others, or until you are called in for your appointment.

ENERGY RIPPLES

PART I

In her book *Caliban and the Witch: Women, The Body and Primitive Accumulation* (2004), Silvia Federici provides a historical account of women and reproduction in “the transition to capitalism,” describing a type of female who lived in communal situations prior to capitalism. This included peasants, artisans, and day laborers. Federici’s scholarship traces the bonds that existed outside of the emerging nuclear family unit and explores knowledge about healing and the body that was later excluded by the systems that became medical disciplines. These shared, sometimes “feminine” ritual practices of healing came from communal knowledge of plant uses, and would be prohibited in the professionalized and male dominated medical practice. The women who participated in these forms of healing were often classified as witches.



Witches challenge dominant orders by prioritizing cosmic relations and care over the individual and the accumulative. This isn’t to say all those categorized as witches were forces for good, but according to Federici, relegating witches to the status of “evil” conveniently suited the rise of capitalism and patriarchy. The rationale behind burning witches at the stake was tied as much to their possession of knowledge as it was to their perceived social evil. The repression of witches allowed for healing to become part of the medical system that compartmentalizes the body. Humans are complex matrixes that host and inhabit space with other organisms, yet much of Western medicine still relies on Cartesian dualism—a conceptual universe where mind and body are seen as separate, and parts of the body are seen as compartments. This system also promotes “the great chain of being,” which categorizes certain living things and materials as “inferior” to others, and places white able-bodied men closest to “god.”

The Canaries collective (the group producing this publication) constitute a haunting of the bonds that existed before this systemization. Although we must also rely on healing that is state sanctioned and professionalized, our impulse is to question the certainty of “one method” and think about

instances in which older lineages might help supplement or even counter the dominant medical models. Many of us hope to establish care/bond relationships that extend beyond patriarchal family ties and medical authorities, and to approach bodies as non-compartmentalized beings that do not always behave according to standard rules. Many members of Canaries have hit walls with regard to the treatment options on offer from Western medicine, and question how treatment is offered (and denied) to certain bodies. Additionally, we seek to challenge a rhetoric that sells care as a kind of lifestyle branding. These alternate bodily/metaphysical conversations are very personal, and take place in a considered and shared cosmic space.

The Canaries are very porous. We are sensitive to the chemicals and environmental agents that touch our skin or are ingested into our bodies. Some of us have developed hypersensitivity to foods that are tolerated in so-called “normal” bodies—exposure to particular types of processed food particles, or mold or chemicals used in everyday items like cleaning products can cause a variety of visible and invisible symptoms in our bodies, even producing swellings and reactions. A bout of food poisoning or parasites can trigger the onset of mysterious ailments that in some cases can take decades to diagnose. Perhaps we are more permeable than other humans, or just more sensitive to the living, breathing world that we all inhabit. Perhaps we are a warning system for what all bodies eventually encounter. Or perhaps we are teetering on a precipice created by the incredible hubris of our species. Our bodies are like archives of touch and sensation, archives of the materials that humans combine in their desire to know the physical and metaphysical world. Materials such as plastics or other super-refined substances can be incredibly dangerous to life, alone or in combination. Nature itself has toxic elements (like Uranium), though our current material system hides toxicity behind multiple layers of production. In the style of some of our ancestors, we might return to thinking deeply about material power, to considering the substances we manipulate in our environment—“natural” or not— as potentially more precious and more dangerous to our



bodies. Such a re-thinking would necessitate questioning our position at the apex of the world of things and creatures, and examining how we use and how much we use.

There is also a danger to perceiving contemporary forms of “natural healing” as the only or “best” modes of negotiation. Some diseases become hard to combat with plant knowledge alone, especially once they have advanced to certain stages—cancer being one example. The rhetoric of “naturalness” has also been absorbed into the capitalist system to such a degree that many of the substances that could potentially help a body negotiate healing and sickness are cost-prohibitive to those at an economic disadvantage, or are packaged in misleading ways to convince the buyer of purity. “Natural” or “less refined” forms of plants and foods that could aid in negotiating the sick body can take notoriously long to reveal positive effects, and are frequently most effective in combination with other things. A hybrid or pastiche method is potentially the best solution to negotiating illness, as is practicing self/other care with an ethical mindset, one that challenges the structural systems of ordering and studying bodies that carry within them a legacy of othering. There are modes of being, material caution, and communal healing that can run counter to the accumulative forces of capitalism that prioritize individualistic forms of possession. Allowing an elite few to treat plant and medicinal knowledge as a form of power is a problem that plagues history, the present, and potentially the future.



PART II

I now would like to switch narrative styles to address you, the reader, as a person seeking help with a fellow unwieldy mind/body. Some of the ways in which help is framed within the current system can force a reliving of trauma in front of a disbelieving audience of “experts.” Sometimes even the closest family and friends will feel incapable of helping you/us, or will simply have a difficult time believing or understanding what

you/we feel in your/our body/ies. In this part of the text, I hope to push up against the edges of the confessional form. I don’t want to be another person trying to pitch or persuade you, especially as my own relationship to sickness/wellness has oscillated dramatically and frequently, and my approach to healing has been incredibly idiosyncratic. This form is also not my voice, nor is it the voice of personal storytelling and didactic revelation, or of auto-ethnography. Part of my discomfort with the “I” form extends from the sharing we do for the state in the service of categorizing and judging more than healing. “State” powers frequently cite their authority in “knowing what is best” for a given person or community while failing immensely at actually helping that person/community. I am also alert to the increasingly corporatized personalization of the “I/you” narrative, for we are sold all kinds of items as “necessary” to constitute our individual identities within a larger social body. Many of the things we buy to keep us healthy are sold strictly for profit, and are increasingly difficult to obtain and maintain.

The corporatized rhetoric of health and happiness is ultimately an appeal to the confessional you. In this schema, the virtuosity of products suggest an improving you, a perfected you, a you that takes care of your body and others by buying things that are fairly produced. This is also an inaccessible you for those who live in food deserts and places where there is no accessibility to nourishing food. The relatable voice of “personal experience” is sinister and ubiquitous in mass advertising, selling a false-stable lifestyle to those who can afford it. And even those who can afford it will sometimes find themselves failed by the system when their doctors and families will not listen to their plea: “I don’t feel well.” Sometimes, despite their privileges, they are shut out as well. If they can’t fake perfect, they fail to maintain the hierarchy. The auto-ethnographic storyteller can wield tremendous power in bypassing the corporatized lifestyle circuitry, but they/she/he still must be careful, because telling a personal “story” involves revealing a so-called “weakness” of the mind or body before the ears and eyes of judging parties. Retelling one’s “story” as ethnography also risks over-particularizing the self in ways that can then be collected as data to be generalized—this is the psychoanalytic dimension of state healthcare.

In order to access the most meager forms of healthcare and economic assistance, you might feel as if you are constantly forced to relive your/



our trauma and shame, and “reveal” inequity. Institutionalized state altruism reveals its sinister side in assessing “needy” groups through statistics and generalization, rather than by looking at individuals. Monetary gain and cutting corners often take precedence over care. Notions of meritocracy are deeply seeded here, as shame and embarrassment are how the sick and the poor give proof of need, which in turn proves their failure to meet so-called “normal” body standards. Need is also used to identify inferiority in the eyes of progress, for it demonstrates the inability to rise. I appeal to you, fellow seeker of mind/body negotiations, to think both universally and particularly about your body/mind problems, and those of others. Not one versus the other, but all in dialogue, oscillating—just as healing and sickness are states that exist together, intertwined. There may be no permanent cure, but it is possible to enter into a state of continual considered negotiation, ebbing and flowing. Hopefully, through revealing your/our weakness, you/we can flip it categorically to strength. Survival occurs in self-testing, self-seeking. Because a cure might not be immediately accessible or permanently obtainable, because “normalcy” is elusive, all suggestions for how to “get better” must always be taken with a proverbial grain of salt. No two bodies will react the same when faced with different elements.

Keep records, test feelings against experiences. If people are using your energy negatively, tell them, with love, that you have to distance yourself because of your limited resources. You/we can set boundaries and/or exit certain relations with love, even if you know in your body that you are cutting entities (family/friends/co-workers/bosses/lovers/doctors/loose acquaintances) the fuck out because they are energetic vampires. Your/our temporality is just very different from theirs, from other “sick” bodies, from the bodies of experts. Exiting with love can be a powerful healing tool—hold on to your energy. Find new humans/animals/plants/minerals to bring

closer, with frequency, to help you negotiate the reality of healing/being sick. Learn to advocate for yourself. Just as you/we set boundaries in toxic relationships, do the same with healthcare practitioners who attempt to wield their authority over what you feel in your body and the things you want to consume and/or are forced to consume. Be unafraid in self-advocating, seek help from people in your/our community. You are both an individual and part of a collective. If and when you/we gain more stability, try to help your/our friends out, too. Keep distributing knowledge about healing/negotiating as much as possible. Even if the idea of “health” is tenuous, pass on whatever stability exists. When one or more members of the community fall into states of precarity, use “positive debts”—non-monetary, socially based forms of repayment and care, as detailed by Fred Moten and Stefano Harney in *The Undercommons: Fugitive Planning and Black Study* (2013)—to help them stabilize and combat the “lack” that they may feel under the current system.



In the search for good healers and doctors, don't be afraid to try a few people. Expertise alone does not mean a doctor or healer is the right fit. Should you encounter privileges, ride them like waves. Take what you can from state/personal altruism, but try to refuse things that counter longer-term freedom and the freedom of others. If you need to parasite onto the state, do it until it does not feel right anymore—or until another option presents itself. Release yourself from the shame of needing help. It's not a fair system; there is no shame in where you/we are. If you are yet to encounter the privileges and communities that can help, keep looking. Social capital is difficult to gain in a system where meritocracy is a big wet blanket over social inequity. Structural inequality is very real. If you have any stable/sympathetic family/friends, seek them out as part of a healing network, whether you need to borrow a windowsill to grow herbs, to accept money or rides to treatments, or to find a place to rest when between jobs or living



situations. Parasite onto major institutions that can provide forms of stability. Suckle off school or government programs as long as they provide forms of nourishment. Do anything to level the ground that feels shaky. Poverty and lack of access to things like good food, herbal treatments, acupuncture, meditation and exercise are some of the greatest obstacles to healing—use the energy of people you/we love and who love you/us to get as many resources on the cheap or free. Befriend people in healing professions; offer exchanges for healing treatments or strategies of coping (say you are a writer, or a plumber, or a seamstress, or a mechanic, or a gardener—find a person who does healing work and trade with them). Treat healing practices as if they are a “commons” of knowledge, sharing and distributing. Find medical practitioners who are sympathetic to various healing modalities outside of the dominant medical complex.

My address to you, fellow mind/body seeker of healing, provides a broader view of some of the discomforts that exist within the system. In solidarity, I reveal that my own “conditions” took their worst dive during a period of semi-homelessness, when I was uninsured, on welfare and working three jobs, six days a week, while living in environmentally unsuitable housing. A recent semblance of normalcy has been provided through a public university, where, as a PhD candidate, I am able to work a much smaller number of hours with full-coverage health insurance that includes \$10 acupuncture sessions in a student health clinic, free access to

a gym, pool, and discounted classes, as well as an extensive network of specialists to help address the various issues that arise because of my compromised immunity. Additionally, because of my accumulation of so-called “cultural capital,” I have been able to have relationships across wider class divides—I have friends and loved ones who are willing (and have been willing in recent years) to give me concrete aid in the forms of cheap or free temporary housing, small interest-free loans, and buying me groceries or healthcare.

My healing was greatly helped by all of these “privileges.” But even before this, I still managed in my period of perilousness to gain access to healing through local programs. Universities and community colleges sometimes provide discounted healthcare treatments, programs and alternatives to Western healing practices. There are “teaching” situations in which you can volunteer to be a patient for someone still learning their craft. Many places, such as yoga studios and acupuncture clinics, offer community classes one or more days a week that are less than \$10. Among them are Osenta, a women's spa in San Francisco, which offers sliding scale payment for those with limited economic means, and Lyon Martin, a clinic also in San Francisco that specializes in women's and LGBTQA health and provides extremely discounted health services. (Years after I went there for services, they called and offered me free health insurance as part of a pilot program).

Tenant unions and pro-bono law organizations

are powerful allies when dealing with difficult housing situations. I was able to negotiate an untenable living situation through a local program that provided free legal aid from experienced lawyers. With their help I was offered a settlement from a landlord who had refused to provide heat, managed apartments with mold and toxicity issues, and frequently cut power to my apartment as threatening way to assert his authority. In New York, the YMCA provided me with an economic hardship scholarship to use at one of their locations in Brooklyn. This \$24-a-month need-based package included free yoga, tai chi and pilates classes, plus unlimited access to a pool, sauna and work-out equipment. The YMCA offers these packages to individuals as well as families. In San Diego, Occidental College offers highly discounted acupuncture, massage and nutrition classes. One of the most difficult aspects of many of these programs is the sheer amount of paperwork some of them require. If you have trouble filling out forms, have someone in your community/family help you with the paperwork and with finding a system that will make it easier to fill out forms in the future. You/we can also gather friends and community members to fill out aid forms together, and you/we can put together a list of services for everybody's benefit. If you receive help, help others find out how to get it. Keep on keeping on sending the ripples of energy that provide semblances of stability throughout your intimate/social communities. —Catherine



Photographs by Carolyn Lazard
From the series "Color Where Least Expected" (2012-2013):

Page 11, left-hand side: *Still Life: Penn Presbyterian Medical Center, 51 N 39th St., Philadelphia, PA 19104*

Page 11, right-hand side: *Pig: Penn Presbyterian Medical Center, 51 N 39th St., Philadelphia, PA 19104*

Page 12, left-hand side: *Beach: Penn Medicine Radnor, 250 King of Prussia Rd, Radnor, PA, 19087*

Page 12, right-hand side: *Palm Tree: Penn Medicine Radnor, 250 King of Prussia Rd, Radnor, PA 19087*

Page 13, top: *Black Bird: The Perelman Center for Advanced Medicine, 3400 Civic Center Blvd, Philadelphia, PA 19104*

Page 13, left-hand side: *Woman: The Perelman Center for Advanced Medicine, 3400 Civic Center Blvd., Philadelphia, PA 19104*

Page 14, left-hand side: *Couple: Penn Medicine Radnor, 250 King of Prussia Rd., Radnor, PA 19087*

FEELING-MATTER TRANSFORMATION

This is a visualization exercise to locate and release emotions held in specific parts of the body.

I do this exercise to ground myself when I'm feeling afraid, anxious, sad, or when I'm in some other kind of physical or emotional pain. In states of discomfort, I find that I am better able to process my feelings when I'm able to focus my attention more evenly throughout my body.

We are trained to stifle discomfort. We do whatever we can to make it go away or to separate from it. For this exercise we are going to treat discomfort as information. By bringing our attention to it, we are bringing attention to ourselves. The whole body is connected—you can think of it as a gossip circle—every part knows everything that's going on in the body. This means that if you are able to relax one tense muscle, the rest of you will be affected as well. The simple act of being with a feeling instead of pushing against it already shifts things. Here, the question is not, "how do I fix it?" but rather, "what does it have to say?" —Jesse

Sit or lie in a comfortable position.

Close your eyes. Let your breathing become deep and slow.

Think of a feeling or a situation that you find challenging, and concentrate on it.

Gently let your awareness roam over your whole body. Ask yourself: where is the difficult feeling most concentrated in my anatomy? For example, if you are angry, you might feel your jaw clenching, burning in your belly, or tightness in your throat.

Bring your hands to this place, and visualize pulling the feeling out. Maybe the feeling looks like a tangled rope as it comes out, or maybe a ribbon, or maybe dark taffy—imagine whatever makes sense to you.

Once you feel you've gotten the substance all out, ball it up between your hands and imagine it turning into a thick, dark paste.

Now, rub your hands together vigorously until you feel heat build up from the friction.

Imagine the dark paste lighting up with potential.

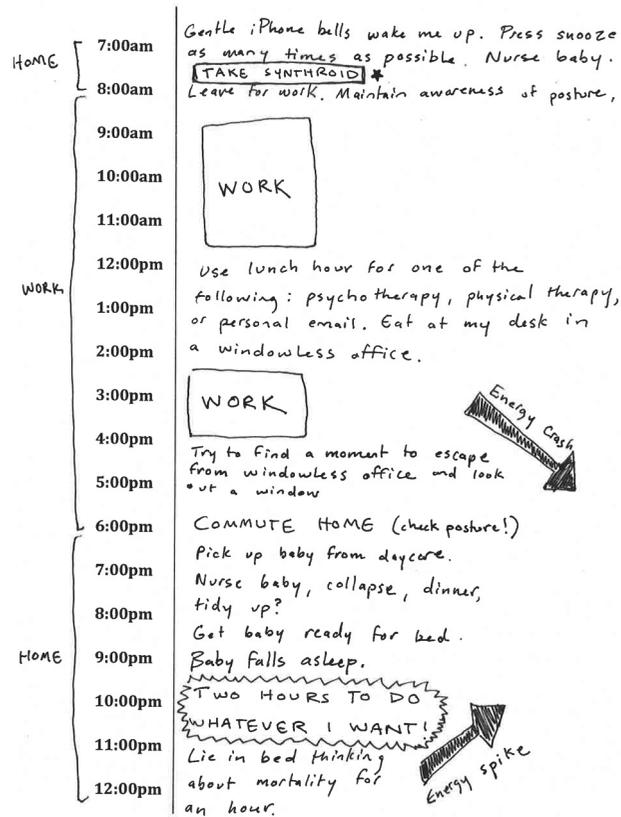
Slowly let your hands come apart and, with your eyes still closed, observe what is between them. The first thought is the best thought. Anything can appear (it doesn't have to make logical sense).

Whatever comes to mind is your feeling transformed into its own remedy.

Now bring your hands up over your head and pour the transformed feeling-matter down over you. Feel the new material, luminous and healing, trickling into the part of your body where the feeling originated at the beginning of this exercise.

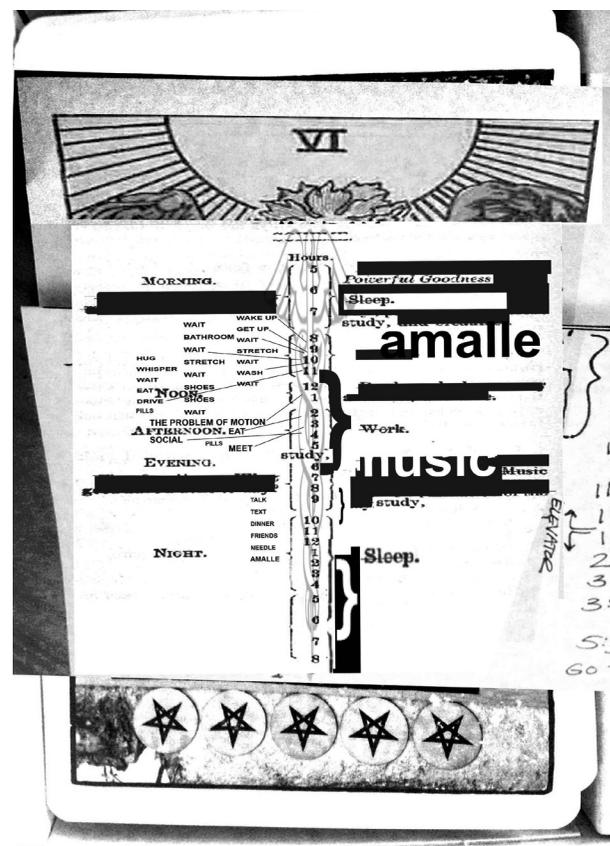
Breathe deeply, and relax.

In the future, whenever you sense this difficult feeling arising, you can do a shortened version of this visualization. You can be walking, on the subway, at work, at dinner with friends—wherever you are, take a moment to breathe, center yourself, and notice where the feeling is most concentrated in your body. Imagine your transformed feeling-matter flowing into this spot.



* Every day for the rest of my life.

Citron Kelly, Check Posture, 2016. From the series "Crip Time," 2016.



Amalle Dublon and Constantina Zavitsanos, Caduceus, 2016. From the series "Crip Time," 2016.

DO UNTO ROSEMARY

The practice of burning herbs for purification is rooted in indigenous spiritual practices. It is a tradition that has existed for many years in cultures all over the world. The aromatic smoke released by dried plants and resins such as cedar, lavender, myrrh, sage, palo santo, and rosemary is ritualistically used to cleanse bodies and spaces. A recent study published in a journal of pharmacology corroborates indigenous knowledge, indicating that smoke from medicinal herbs quantitatively reduces bacteria in the air.¹

Rosemary, like sage, is very difficult to grow. On an internet forum dedicated to plants, a lay horticulturalist says that one needs to possess acute anti-capitalist intention in order to elicit a plant from the reluctant seed: "It is indeed a stubborn plant to grow in itself," she says. "Respect it. It should only be snipped a few stems during morning hours all the while intuitively asking for it and 'hearing' an acceptance in return. If you get greedy with it, your clippings will likely turn to mold, or will not have the healing potential properties to hand over that it is known for. P.S. Not every plant just because it grows is meant to be used. Not every fruit on a tree known as food is meant to be eaten. Ask the plant/fruit off of the tree. Use your gut to hear its response."² The lesson can be applied to any person in need of clean air. —Tess

¹ Chandra Shekhar Nautiyal, Puneet Singh Chauhan, and Yeshwant Laxman Nene. "Medicinal Smoke Reduces Airborne Bacteria." *Journal of Ethnopharmacology* 114.3 (2007): 446-51.

² "How to Grow Your Own White Sage." *House Plants for You* RSS. 22 Nov. 2013. 15 Mar. 2016.

Procure
seed • Scavenge
sand and soil to make an
adequate medium for growing •
Sand from a river is less saline, blood and
kelp can contribute nutrients • Fill small pots
with soil • Thumb holes into the surface • Turn
on a peaceful radio station, or offer an ad hoc prayer
• Hold the seeds with good intention • Tuck them into
the dirt like they are your young cousins • Keep the
soil damp until something green pierces the surface •
If twenty-six seeds are planted, maybe only three will
sprout • Rosemary is a desert plant, so do not to water
the seedlings too much • Encourage them verbally • Show
them to people who come through, saying: "Look at this
astonishing life." • Clip the plant's stem, feel gratitude
• Articulate this gratitude: give thanks for the green,
for the smoke, and for the space that will be made
clear • Dry the stem on a plate, or any surface
• Burn a dried leaf • Carry smoke to the
corners of the room. Give this generous,
slow attention to your own earthly
vessel, in sickness and
in health

ON A HEALING RELATED TO STILLNESS

My body malfunctioned in 2011. I was often in extreme discomfort, red-faced and covered in rashes. The triggers were the subway, humidity, yoga mats, bread (or even proximity to a bakery), as well as other unnamable causes. The doctor told me that what was happening to my body was highly unusual but s/he offered little support other than prescribing an antihistamine. I had stomach problems. I was flummoxed. It took maybe two years and visits to five or six doctors to get my symptoms under control.

After that I was fine for a few years if I was careful about my diet and sleep. Though the symptoms were sometimes present, I could often avoid triggers.

Then at some point I realized I was in pain all along my right side, from my foot to my hand. This pain was not there all the time, but it was present about forty percent of the time. It was inflammatory in nature and had, perhaps, been ailing me for many months. But I didn't know what to do about it, so I did nothing. At that time I worked a very physical job and one Monday morning I threw out my back so badly that at first that I couldn't walk. Everything locked up. I was immobile and had to hobble down three flights of stairs. I was given a week off work. Later that month I went to the doctor for a check-up, and was sent to see an autoimmune specialist since my blood work was off. That doctor told me I had a connective tissue disorder and likely lupus. After that, I went into a deep haze of healing. I would feel deeply tired in the middle of the day, so I would take naps on the floor. Whenever I was tired, I would nap. My body thanked me. I was comforted by my lack of choice, and so I let myself relax into healing. —Marley



I've never worked directly from observation. It makes me pay more attention.



There's no shame in lying around all day when you have four legs. I'm so deeply ashamed of not doing anything with my time. But laying here, drawing my best friends, I'm transported.



I look at their bodies, and see how vulnerable all bodies are, not just my own. It's comforting to acknowledge butt holes. Mine really stings.



The love I need takes its toll. I see my partner's exhaustion. It is tremendous to depend on and be depended upon.



When I'm really looking, I leave my body. Sometimes I put it on something else. The fleshy mess of a wrinkled coat. The bulbous door. That's my inflamed body.

BIBLIOGRAPHY



Jesse Cohen, *Appointment*, 2014. From the series "Results," 2014.

In addition to our TOOL KIT (which suggests various approaches to healing, ranging from heat and music to drugs and communal activity), we offer this BIBLIOGRAPHY. This document compiles a variety of texts that Canaries members have found invaluable for navigating life as chronically ill people, particularly ones who make art or discourse from that position.

Instead of assuming the form of a traditional annotated bibliography in which synopses are presented anonymously with the presumption of impartiality, we want this

bibliography to stress how certain texts were useful to us at specific points in our lives. By utilizing the first-person perspective, we are in one sense mirroring the resource sharing process that happens within the Canaries support network via monthly meetings and an email group. Because some Canaries tend to interpret their experiences from an explicitly socio-political angle, others from a spiritual one, and others still from a medical perspective, we engage each other with an understanding that our collective resource pool reflects a diversity of life programs—and that contestation happens during the negotiation of support. —Canaries

CRITICAL THEORY

Chen, Mel Y. *Animacies: Biopolitics, Racial Mattering, and Queer Affect*. Durham, NC: Duke University Press, 2012.

Animacies, a book by disability and queer studies theorist Mel Chen, primarily examines the divisions that are drawn between the animate and inanimate. By questioning whether the body is as ontologically fundamental as it seems, Chen's discussion of leaky and co-constituted bodies destabilizes the liberal humanist subject and stresses the interdependency of various beings and environments. Those of us living with autoimmunity—with immune systems that, in "attacking" our bodies as they would a harmful foreign agent, redraw what constitutes a body's inside and outside—know firsthand what it is to be in such a body so affected by our environment and other beings. All *Animacies'* chapters weave together theoretical perspectives on affect, disability, and medicalization while taking into account racial, gender, and class politics, yet it is Chen's very personal account of living and moving through the world while dealing with the effects of mercury poisoning and multiple chemical sensitivity disorder that is perhaps most relevant to the chronically ill. "Following Mercurial Affect" brings together personal memoir and theory to make a case for "an ethics of care and sensitivity that extends far from humans." —Taraneh

Didi-Huberman, Georges. *Invention of Hysteria: Charcot and the Photographic Iconography of the Salpêtrière*. Boston: MIT Press, 2003.

Jean-Martin Charcot's clinical work on diseases like multiple sclerosis and Parkinson's made him a pioneer of neurology, but he is most widely known for his studies of hypnosis and hysteria—in his early career he attributed hysteria to neurological causes and later, to psychological ones. In *Invention of Hysteria*, French philosopher and art historian Georges Didi-Huberman analyzes images taken in the Salpêtrière, the infamous French asylum for insane women where Charcot worked. Didi-Huberman focuses primarily on the concomitant birth of a new pathology with the rising popularity of photography in the late-nineteenth century. He offers the hysteric as both an object and the co-producer of her own images, as victim and resistor, insane and yet still a calculating manipulator. This picture of the hysteric emerges as a figure of contradictions, an image familiar to many women who have lived with illness. I am interested in the fear of hysteria and in what the hysteric suggests about the contagion of emotion, the dangers of empathy, the tensions surrounding where we locate agency under limited conditions, and the persistent anxiety about the Cartesian border between body and the mind. Hysterics, above all else, questioned borders. —Danyel

Kafer, Alison. *Feminist, Queer, Crip*. Bloomington, IN: Indiana University Press, 2013.

In *Feminist, Queer, Crip*, feminist studies scholar Alison Kafer uses the concept of “crip time” to examine how concepts of futurity and time have been deployed in the service of compulsory able-bodiedness and able-mindedness. A political reclaiming of the derogatory label “cripple,” crip is a term that gained wide usage in the 1970s and has been popularized in disability theory and activism. Kafer defines crip time as a way of “recognizing how expectations of ‘how long things take’ are based on very particular minds and bodies,” which in turn allows us to reimagine “our notions of what can and should happen in time.” In this, her goal is to consider how temporal logics might shift within a more just political framework. This book is not only very clearly written, it is grounded in examples from environmental and reproductive justice, transgender and race politics, and disability activism, all of which make her case for “disability as a site for political reimagining” highly intersectional. In order to address how some disabled people’s desire for medical treatment does not preclude the need for us to imagine futures where disability can be understood as possible or desirable, Kafer opens with a distinction between “curative time” and a cure. The former describes the assumption that medical intervention is the only way to address disability (thereby reading disabled people as obstacles to the arc of progress), and the latter designates disabled people’s varying personal relationships to particular medical interventions. As someone who feels trapped by normative temporalities rooted in colonial logics, this book makes excellent arguments for how we might inhabit time in a way that is not shaped by dominant economic rationalities that command individuals to enhance human capital at all costs, but rather, to a modality that looks towards a better life for all beings. —Taraneh

Nancy, Jean-Luc. *Corpus (Perspectives in Continental Philosophy)*. New York: Fordham University Press, 2008.

I came to this book in a different way than I’d usually come to a theoretical work. I had read some of Jean-Luc Nancy’s political theory during my undergraduate studies, but had never touched these texts until I watched the film *L’Intrus* (The Intruder) (2004) by Claire Denis, about a Swiss man who goes in search of a heart for transplant on the black market, all while uncovering past heartbreak and trauma. The film is based on what, in my perspective, is the most important essay in French philosopher Jean-Luc Nancy’s compendium of theoretical writing on “the body.” The majority of the essays in *Corpus* contemplate the role of the body in different philosophical disciplines, from ontology to phenomenology to theology. In “L’Intrus,” Nancy discusses the familiarity and foreignness of our bodies in relation to his own heart transplant in the most beautiful theoretical prose. In doing so, he explores a technological intervention that so many people now rely on to stay alive and how, as humans, our ability to exist in excess of our bodies has always been what defines us: “that man begins again by passing infinitely beyond man.” I have never read a philosophical text like this, so close to the heart. —Carolyn

Sontag, Susan. *Illness as Metaphor and AIDS and Its Metaphors*. London: Picador, 2001.

Illness as Metaphor looks to a wide range of historical sources, from seventeenth-century medical texts to literary depictions of tuberculosis from the Romantic era, to explore the semantic conditions of illness. In this collection of essays, Sontag problematizes Western frameworks for understanding illness and argues that metaphorical references to the body are not only imprecise, they also gravely harms patients whose bodily experiences are imbued with cultural mores. While critics claimed Sontag could not be impartial while having cancer herself, *Illness as Metaphor* was one of the first texts that I ever read to critically address otherwise private

experiences. Sontag elucidates the ways in which the words we use are deeply embedded in structures of power. This opened the door for me to not just engage these ideas theoretically, but to reflect on my own position as a patient and how my illnesses have been framed by both biomedical practitioners and loved ones. —Carolyn

HEALING TOOLS

Ballantyne, Sarah. *The Paleo Approach: Reverse Autoimmune Disease and Heal Your Body*. Riverside, NJ: Victory Belt Publishing, 2014.

I only wish this book had come along with my diagnosis of an autoimmune disease at age eleven. I think of it as the textbook for how chronic autoimmune and inflammatory diseases are affected by diet and lifestyle choices. *The Paleo Approach* provides practical and economic advice about adopting a paleo diet to reduce inflammation and calm the immune system, and it offers a wealth of information on common medical tests and treatments that are either scarcely mentioned or are glossed over in most books on autoimmunity. Ballantyne not only has a PhD in medical biophysics—her research focused on innate immunity, inflammation, and anti-inflammatory mechanisms—she lived for years with multiple autoimmune diseases before getting diagnosed. So along with a rare combination of practical guidance, clear, accessible illustrations, and high-level science made simple for a layperson, *The Paleo Approach* offers perspective (and, for me, validation) from someone who negotiated illness. Whenever I begin to wonder whether I’m making up elements of my unusual condition, or whether the symptoms I’m not currently having were ever there at all, this book helps me feel less alone. Understanding the complicated science underpinning nutritional and medical treatments can allay the fear, uncertainty, and “un-realness” that often comes with having invisible or non-mainstream illnesses. I hate the title: I think it probably turns off a lot of people who aren’t paleo, or interested in anything associated with fad dieting. I think every copy should come with a sticky note on the cover saying, “this is so much more than a diet book.” —Bonnie

Bainbridge-Cohen, Bonnie. *Sensing, Feeling and Action: The Experiential Anatomy of Body-Mind Centering*. Contact Editions, 1994.

Bonnie Bainbridge-Cohen is a movement artist, therapist, educator, and researcher. Drawing largely on her experience in the areas of dance and physical therapy, she developed experiential teachings called “Body-Mind Centering,” and opened a school centered around this approach in 1973. What I love about Bainbridge-Cohen’s method of embodiment is that she works with different bodily systems—nervous, skeletal, etc.—as centers from which one can experience feeling and consciousness. This vision of a body’s innate intelligence and communicative capacity provides a stark contrast to the commonly held belief that discomfort or illness are dysfunctions, mechanical failures, or that we must “declare war” on our ailments. From the perspective of Body-Mind Centering, bodily symptoms are not “good” or “bad” per se; rather, they are articulations of what is happening within us. So, silencing “sick” or uncomfortable feelings without considering their causes is like killing the messenger. After years of being told that I was physically malfunctioning, it was radical medicine to learn that when we tune into our bodies with curiosity and interest, they can be tremendous sources of information and guidance. —Jesse

Bernhard, Toni. *How to be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers*. Somerville, MA: Wisdom Publications, 2010.

In *How to be Sick*, Toni Bernhard provides a much-needed guide for the emotional rollercoaster that is living with chronic illness. This is not a book that tells you how to reduce inflammation in your body, what to eat, or what drugs to try. This is a book that simply shows you how to be in a body that is in pain, or in dis-ease. Bernhard fell ill while at the peak of her career

as a law professor and found herself unable to work or engage in spiritual practices due to limited energy and chronic pain. *How to be Sick* grew out of Bernard's experience navigating the disheartening changes that attended her illness, and it was invaluable to my psychological and emotional well-being in the early days of my own diagnoses and illnesses. It helped when the physical pain was very trying, and it helped even more when mourning my former life as an able-bodied, healthy person. These life changes rarely affect only the chronically ill person, and Bernhard also addresses caregivers in this lovely book, making sure that they also receive the emotional and physical care that they need. *How To Be Sick* applies the basic Buddhist principles of impermanence, equanimity, and compassion to chronic illness, illustrating that all circumstances in life, even the really shitty ones, contain opportunities for grace and joy.

—Carolyn

Halifax, Joan. *The Fruitful Darkness: Reconnecting With The Body of The Earth*. San Francisco: Harper Collins, 1993.

In *The Fruitful Darkness*, teacher and anthropologist Joan Halifax uses accounts of shamanic traditions, Buddhist practices, and her own personal experiences to talk about the potential richness of the “shadow” aspects of ourselves—the parts we disown or consider to be negative or unacceptable. I find that when I've gone through a difficult period I don't usually think of it as a part of the continuity of my life; instead, I've viewed it as a time that I was “off track” or “not myself.” This book helped open me up to the notion that when we marginalize aspects of ourselves or our experiences we make ourselves less than whole. Halifax says, “As a Western woman, whatever I have learned about the nature of the self, both the local and the extended self, has been by going inward and down into the fruitful darkness, the darkness of culture, the darkness of psyche, the darkness of nature.” —Jesse

Maté, Gabor. *When the Body Says No: Exploring the Stress-Disease Connection*. Hoboken, NJ: Wiley & Sons, 2011.

In this book, Gabor Maté, a physician specializing in addiction, stress, and childhood development, suggests that emotions express themselves physically and that by investigating our emotional lives, physical ailments can be better understood and treated. While emotional stresses are by no means the only causal factors of illness to consider, I've found that they are some of the most often overlooked. I really appreciate that Maté advocates for each individual's agency in the healing process through connection with

their own personal narratives, narratives, and that he rejects approaches that place authority solely in the hands of the physician. Touching on the inadequacy of existing language around the mind and body, Maté says that, “even to speak about links between mind and body is to imply that two distinct entities are somehow connected to each other. Yet in life, there is no such separation; there is no body that is not mind, no mind that is not body.” —Jesse

Minger, Denise. *Death By Food Pyramid: How Shoddy Science, Sketchy Politics and Shady Special Interests Have Ruined Our Health*. Philadelphia: Primal Nutrition, 2014.

A scientifically savvy layperson, Minger wrote *Death By Food Pyramid* to teach us how to follow her lead. In order to challenge various kinds of conventional food wisdom, her nutritional history is structured around three sections. “Shady Politics” shows us how political interests have skewed actual food science, “Slippery Science” includes case studies of American scientist Ancel Keys (whose work linked saturated fat and heart disease) and British nutritionist John Yudkin (who promoted low carb diets as healthy), and “New Geometry” looks at Mediterranean, paleo/primal, and vegan/vegetarian diets. I identify with Minger's dietary journey: as teenagers we were both taken in by claims that a raw food diet would offer health benefits, and experienced serious and lasting side effects after adopting the diet. Upon seeking out scientific explanations for the results, each of us became righteously indignant about the pseudoscientific lies we were told. Ultimately, we both got on to healthier eating plans, and Minger went ten steps further and wrote a book. Similar to how a liberal arts education is thought to free pupils by giving them the ability to weigh different arguments, Minger's scientific analysis emancipates the reader from blind trust in the hot/cold yes/no world of health advice, experts, and science journalism, which is built on soundbites and headlines. *Death By Food Pyramid* is full of examples of how diet and lifestyle research have been misinterpreted and misappropriated to support the standard American diet. A handy primer on the history of diet in this country, this book encourages us to rethink dogma, and to see nutritional science as limited, flawed, and yet still useful. It also provides us with the tools to move forward in a world that's always trying to sell us on something. —Bonnie

Pollan, Michael. *Cooked: A Natural History of Transformation*. London: Penguin Books, 2014.

When I read *The Omnivore's Dilemma: A Natural History of Four Meals* (2007), I was convinced

it was Pollan's masterwork: journalistic and opinionated in equal measure, with enough personalization to keep me interested while I swallowed some difficult truths about why we eat the way we do. I was wrong. If *The Omnivore's Dilemma* made us think about the impact the world has on our meals, *Cooked* shows us the impact that our meals can have on the world. With spiritual, social, and environmental-political insights, Pollan tells stories about how he learned to use the transformational power of the four classical elements (fire, water, air and earth), to turn the materials of nature into different dishes. Above all, he makes the argument that spending the time and energy it takes to practice intentional cooking is not just more enjoyable, it's essential to ensuring a healthier, more equitable, and more sustainable food supply. And he does it without preaching. I would give this book to any home cook who's fallen out of love with the kitchen, anyone who feels alone because they cook while their friends go out to restaurants, or anyone who thinks about nutrition only in terms of rules and numbers and facts and unpronounceable words. —Bonnie

Velasquez-Manoff, Moises. *An Epidemic of Absence: A New Way of Understanding Allergies and Autoimmune Diseases*. New York: Scribner, 2013.

This book is a real page-turner. Several years ago, Moises Velasquez-Manoff was chronically ill with an autoimmune condition, and despite not being formally trained in science he set off on a quest to investigate “worm therapy,” a risky and far-fetched remedy in which one intentionally infects oneself with parasites in an attempt to regulate the immune system. *An Epidemic of Absence* offers a layperson's exploration of a set of controversial theories that are often seldom strung together—especially since putting these unproven ideas into practice would run afoul of the Hippocratic oath. When considered as a whole, they could offer a plausible key to the recent (and growing) worldwide explosion in autoimmunity and allergies. The reliability of Velasquez-Manoff's narration is suspect for several reasons—first, his personal biases (conscious or unconscious) cannot fail to influence his account, and, second, his lack of training sets him up to make rookie science reporting mistakes. Yet as a piece of storytelling, *An Epidemic of Absence* is impeccable. While Velasquez-Manoff occasionally succumbs to the cardinal (and extremely common) sin of suggesting correlation is causation, he does so rarely, and when he does, he immediately recognizes it and offers a disclaimer. In that way, this book is a great mirror to how I typically go about evaluating whether scientific ideas are relevant to my own condition: manic fantasies of

what it all means followed by sobering caveats, and finally, settling on what I suspect actually happened (which often lies somewhere between the fantasies and the caveats). *An Epidemic of Absence* feels like talking to a very smart friend about a fantastic journey they had: discoveries, missteps, epiphanies, and all. —Bonnie



HISTORY

Kapsalis, Terri. *Public Privates: Performing Gynecology from Both Ends of the Speculum*. Durham, NC: Duke University Press, 1999.

Public Privates looks at the historical roles of race and gender as they pertained to medical and gynecological subjects. Terri Kapsalis was a former professor of mine at the School of the Art Institute of Chicago. She is an artist, professor, and performer, and, for some time, she worked as an alternative gynecological teaching model. That is to say, she was simultaneously the body being examined and the instructor guiding medical students on how to properly insert a speculum or take a pap smear. Kapsalis grounds her insightful and well-researched book in occupying the position of being both object of observation and pedagogical voice of authority, even producing and analyzing her own images. I wanted to include this text because the troubled and productive dual position that Kapsalis holds is familiar to many people with illness who engage in making or writing about art. *Public Privates* has, for me, been a means of thinking through how this position is productive, not in that it suggests some as-yet-unachieved vision of a future unity of assumed oppositional positions but, rather, as a stance from which to rethink and remake our relationships with medicine and institutions of power. —Danyel



ILLNESS MEMOIRS

Berkowitz, Amy. *Tender Points*. Oakland: Timeless, Infinite Light, 2015.

Tender Points tells the story of my chronic pain and the rape that preceded it in the only way trauma can be told: in pieces, fragments, flashes of light, recollections, quotes from Kathleen Hanna, and memories of doctors' offices, torn apart and torn out of time. I wrote *Tender Points* to explore the connections between pain and trauma. I wrote it to feel less alone. I wrote it to call out all the bad doctors. I wrote it to remind us that hysteria was only removed from the DSM in 1980. I wrote it because as a fibromyalgia patient and a rape survivor, I am doubly disqualified as a reliable narrator of my own experience, and that is a challenge I can't resist. —Amy

Firestone, Shulamith. *Airless Spaces*. Los Angeles: Semiotext(e), 1998.

Shulamith Firestone, known as Shulie, was a key figure in America's radical feminist movement. Her first book, *The Dialectic Of Sex*, was published in 1970 when she was twenty-five and quickly become a classic of second-wave feminism. Firestone's first work of fiction was published some twenty-eight years later, and a great deal happened in the interim: the "airless spaces" described throughout her text not only reference the institutional spaces of bureaucratized poverty that she and friends had fallen into, they also allude to her adamant refusal to build a career around being a professional feminist. Grouped within five sections—"Hospital," "Post-Hospital," "Losers," "Obits," and "Suicides I Have Known"—*Airless Spaces* is a series of very short vignettes (most run from one-to-two pages) of female "losers" who find themselves in and out of (mostly) mental hospitals. If you can't tell by those titles, the book is dark. Rather than seek to accurately represent the afflicted individuals and their narratives, the deadpan stories often mirror clinical language, eliciting a drained feeling much like those produced by the eponymous spaces of the book. But there is subtle humor hidden within that mimetic act. If you are like me and enjoy getting meta, read this in doctors' waiting rooms when feeling down.

—Taraneh

Lazard, Carolyn. "How to Be a Person in the Age of Autoimmunity." *Cluster Mag*. January 16, 2013.

"How to Be a Person in the Age of Autoimmunity" is an essay I wrote after I came out of one of the darkest periods of illness that I have ever experienced with my autoimmunity. I felt incredibly isolated and that my experiences were often misunderstood by the people that I loved. Friends and family were having a hard time accepting the shape of my new life. I could barely accept it, so I had to write it down for myself. This auto-ethnographic text describes the onset of my autoimmune symptoms and their subsequent diagnosis and treatment. Weaving together theoretical passages, historical examples, and personal memoir, I address the shame of illness and the life of the body under the tyranny of capitalism. I explore the language of medicine and the ways in which illness resists representation and can be impervious to narrative forms. I wanted to contextualize the incredibly harmful effects of Cartesian dualism in biomedical care, and how illness always suggests a porousness that breaks down the boundaries between me and you, between the body and its environment. I wrote this to let people know that the health we take for granted and hold sacred and depoliticize,

is way more complicated than any of us could ever imagine. —Carolyn

McArthur, Park, and Constantina Zavitsanos. "Other Forms of Conviviality: The best and least of which is our daily care and the host of which is our collaborative work." *Women & Performance: a journal of feminist theory* 23, No. 1 (2013): 126–32.

"Other Forms of Conviviality" is a short experimental essay that is comprised of scores written in ongoing acts of care. This piece grew out of our work together as friends and as artists, and was written during our experience as part of a care collective formed in apposition to the medical insurance industrial complex. The text was made at the seam of necessity and surplus; it seeks an entanglement of being beyond individual bodies, while maintaining the disabled lived experience as one of the primary conditions for the preservation of social life. While the piece was shaped in correspondence, we often wrote from one another's conditions to blur the distinctions between who gives and who receives care. In this, we sought to recognize the fact that receiving care is often a gift and that the care we give away is a mutual indebtedness. —Park and Tina

Sedgwick, Eve Kosofsky. *A Dialogue on Love*. Boston: Beacon Press, 1999.

Poet, artist, literary critic, and educator, Eve Kosofsky Sedgwick is perhaps most well known for her role in creating the academic field of queer studies. Considering that much of her theoretical work questioned dominant discourses of sexuality and gender and suggested a move away from binary homo/heterosexual definitions towards understanding gender and sexuality as moving across a spectrum, many have wondered about Sedgwick's own experience as a woman in a long-term marriage to a man (which outwardly appeared quite traditional). That was why I initially picked up *A Dialogue on Love*, Sedgwick's confessional memoir about receiving treatment for depression following a breast cancer diagnosis. Structured like a Japanese haibun mixing prose and haiku, half the book is from the perspective of Sedgwick and the other half is from the perspective of her male psychotherapist. I had heard that it quite directly addressed desire and mortality, particularly in how Sedgwick's chemotherapy and radiation treatments resulted in a waning libido that shifted her sense of self. Some of the best sexual relations I've ever had recently ended abruptly due to an autoimmune disease relapse and a cancer scare, so Sedgwick's frank reflections on the unmooring, delibidinizing effects of illness helped me redefine my own sense of embodiment and erotics. —Taraneh

**WE ARE THE RELUCTANT VANGUARD
REGISTERING MODERN IMBALANCE AND TOXICITY;
THERMOMETERS AND FIRST RESPONDERS
GAUGING THE EARTH'S WELLBEING
THROUGH OUR OWN. WE ARE CANARIES
IN THE COAL MINE SEEKING NEW FORMS
OF ADDRESS THROUGH THE ASSERTION OF VULNERABILITY.**

**WE ARE ARTISTS.
WE ARE A SUPPORT GROUP.**

**OUR MALFUNCTIONING PARTS ARE SILENCED
OR REPLACED WITH APPROXIMATIONS,
OUR GROWTHS ARE REMOVED AND IRRADIATED
WHILE WE SHRINK IN A DISCOURSE
THAT DENIES OUR EXPERIENCE AND ITS CAUSES.
OFTEN OUR BODIES DEFY POSITIVIST LOGIC
AS WE FIND OUR OWN SOLUTIONS
TO "INVISIBLE" PROBLEMS.**

**WE ARE SICK.
WE ARE GROWING IN NUMBER.**

**WE INJECT OURSELVES WITH MOUSE PROTEINS
AND EAT BUGS ENGINEERED TO REGULATE
ENDOCRINE AND GASTROINTESTINAL FUNCTIONS.
HOW CAN WE BE LEGIBLE WHEN DOMINANT LANGUAGE EXCLUDES US?
CAN THERE NOT BE, IN SOME WAY,
A NEW SCIENCE FOR EVERY PERSON?**



US

Canaries is a network of women (cis and trans) and gender non-conforming people living with autoimmune conditions and other chronic illnesses. The name references the phrase “canaries in the coal mine”—shorthand for those whose sensitivities are early indicators of adverse conditions in the environment. Canaries functions as a support group with monthly meetings and it is comprised of a listserv of 100+ members and an art collective. While not all of its members are artists, many are painters, actors, and writers whose somatic experiences exceed interpretation by biomedical discourse. Canaries members come together to build shared languages and exchange strategies for coping with and learning from their conditions. For more information, go to:
www.canaries-collective.com

CREDITS

Edited by Taraneh Fazeli and line edited by Jessica Loudis, with support from Jesse Cohen and Carolyn Lazard. Designed by Lily Benson.

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Thanks to The EFA Project Space for being the first official distribution site during the “Sick Time, Sleepy Time, Crip Time” exhibition from March 30 - May 13, 2016, and to numerous doctors’ offices that unwittingly offered distribution. Our continued appreciation goes out to the extended Canaries who have distributed this publication during their visits to doctors and have submitted documentation to an ongoing installation entitled *Notes for the Waiting Room*. We’d also like to recognize the patience and care we’ve shown each other in the process of production, which, due to the ebb and flow of illness, made the duration of this project expand more than ever anticipated. It isn’t always easy to renegotiate commitments made to work and to each other while also practicing self-care, but that is where the real work lies.

Most importantly, thanks to all official or unofficial Canaries and Canaries allies.

ABOUT

In Fall 2015, member Taraneh Fazeli commissioned this publication by the Canaries. *Notes for the Waiting Room* is the initial engagement in her ongoing curatorial project “Sick Time, Sleepy Time, Crip Time: Against Capitalism’s Temporal Bullying.” Her call to arms, a history of the Canaries, and the conceptual framework for its operations can be found in an accompanying essay “Notes for ‘Sick Time, Sleepy Time, Crip Time: Against Capitalism’s Temporal Bullying,’ with the Canaries,” published in the Museum of Fine Art Houston’s 2015-16 Core book and on *Temporary Art Review*.

Taraneh invited members of the Canaries listserv to answer the question: “How do you take care of yourself during a flare-up of your symptoms?” Born out of our interactions as a collective, some responses were practical—such as the tool kit for navigating flares and a guide to patient-doctor relations—while others were more contemplative, such as a play on medical questionnaires and pain scales. While many of us rely on the institution of biomedicine to stay alive, our experiences necessitate inquiry beyond what is traditionally understood as relevant within its parameters. We hope this publication offers ways to re-envision engagement with this system: how you relate to it and how it relates to you.

It’s impossible keep tempo with a society that refuses to integrate illness as an acceptable state. Sickness is a taboo, producing social and economic marginalization that can be internalized as feelings of shame. In response, this collective holds space for speaking freely. Many of our treatments are experimental or new, so there is not a lot of available information about their use. Sharing our individual coping techniques saves many of us from having to experience chronic illness alone. Our community as Canaries is based in the power of the first-hand and the personal: a commons is formed through sharing anecdotes, strategies, and simply being with each other.

Our aim is to extend our commons through this publication. We have left it in spaces that we feel some familiarity with and which we feel are relevant to investigations of our embodiment—the gallery and the waiting room. This publication offers methods to reclaim our agency as stewards of our health. While these resources were organized around the condition of chronic illness, most of us are exhausted by living and working in a capitalist system as the already insufficient infrastructures for care continue to deteriorate.

Whether we are occasional, frequent, or perpetual patients, many of us in the U.S. have been taught to leave our care in the hands of doctors. Yet while we often need to collaborate with doctors, no one knows our lives or our bodies better than we do. We hope that *Notes for the Waiting Room* will challenge the unilateral and hierarchical transmission of information from doctor to patient and, much like the overall art and advocacy work of the Canaries, foster solidarity and embodied knowledge sharing instead.

WE ARE NOT ALONE. THERE ARE MANY LIKE US.



Jesse Cohen, *Results*, 2014. From the series “Results,” 2014.

PLEASE
PASS
THIS
PUBLICATION
ON
BY
LEAVING
IT
IN
A
WAITING
ROOM

Stool Chart

