

# **Top Surgery Recovery in Community**

No partner, no problem! An experiment in distributed, voluntary post-surgical care as an alternative to normative family and partner models of care.

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# Table of Contents

Introduction .....	1
Notes on Gender.....	4
Stats (FAQ).....	6
Overall Timeline.....	7
Day by Day.....	8
Strategies	
The Network.....	11
Voluntary Participation.....	12
Distributed Work.....	13
Extra Notes & Tips.....	16
Looking Further.....	18
Workbook.....	22

# Introduction

Getting top surgery is a challenging endeavor, from realizing it is an option one wants to navigating healthcare/insurance to undergoing the procedure itself and physical recovery. Unfortunately, the Systems we live under (Capitalism, Monogamism, Heteronormativity, Ableism) keep people from accessing care for acute and chronic medical challenges. Some people are able to leverage privilege based on their socially-approved relationships (in which the general rule is the closer to normativity the better) and other advantages to cobble together what they need for short-term care, but this is inaccessible to many Queer folks and fails to address root causes of the unavailability of adequate care.

As someone committed to challenging dominant relationship models and coercive relating, I had an atypical path to thinking about, arranging, and receiving post-surgical (recovery) care. I, like many Queer folks, am not close with my family of origin. I am also critical of the nuclear Family unit, as the construct is in conflict with my anti-authoritarian, anti-State, and anti-capitalist views. Maybe you personally have a great, intimate relationship with family members who will care for you... good for you! This isn't to say that receiving care from someone legally or biologically related to you is inherently bad, rather problematizing this expectation as a general model for people receiving top surgery.

Some people rely on “partners,” as dating someone(s) often creates a mutual expectation of care; however, I purposely do not live with or have any Partners. I understand the couple form to be a restrictive, harmful model of relationships that limits autonomy and disrupts possibilities for robust Queer community.

Communities of care based on Polyamory fail to adequately challenge the couple form and instead reproduce the same systemic oppression: care is more available to people who fit narrow (dominant) categories of desirability, class, and romantic/sexual/emotional availability.

The underlying relationship structure based on monogamist norms and expectations—though supporting polynormativity instead of strict monogamy—and compromising one’s own desires based on rules, control, and entitlement of others remains in place. (And no, being “descriptive” instead of explicitly “prescriptive” is not an exemption from this critique.) Beyond the interpersonal challenges like entitlement to care, resentment about unwanted tasks, and greater potential for coercion or control, relying on a Partner (or Partners) models narrow possibilities that reinforce the bundling of emotional care work, financial support, and medical/physical caretaking—among other things—instead of consciously seeking an alternative model.

I recognize and acknowledge that each person choosing to undergo top surgery is in a unique social location with many possible relationships and resources. As noted earlier, inability to access care is a result of many systemic issues and not the failing of any one individual. This zine aims to describe my thoughts and experience, and to share some possibilities for an alternative model of care. This is NOT to say, for example, that someone relying on a parent for post-surgical care is “doing it wrong” and should put off top surgery until they can create the perfect environment most aligned with their values; there are always limitations and competing priorities in everything we do. I also see great value in modeling and presenting an alternative to the widely-practiced approaches that are harmful or inadequate for most Queer folks. It’s often hard to know what you want until you see it, and I hope that sharing my experience is useful to others who don’t see themselves or their needs represented by comparatively mainstream narratives around top surgery.

# Note on Gender

Gender is not a focus of this zine; I want to separate the idea of gender from my experience of top surgery. While I recognize the significant overlap of people who experience (body) dysphoria, identification or social experience as transgender, and those pursuing top surgery, this zine is not about social issues related to gender or the resulting construct of transgender identity.

One reason I waited so long to pursue top surgery—though feeling constant dysphoria and binding near-daily for 6-7 years—is that all the information I found about top surgery heavily referenced being or living as transgender. I don't believe in or support the concept of gender and never understood identification or disidentification with any gender over another, so this was confusing and led to a lot of self-doubt and needless suffering.

Separating body dysphoria from gender/trans identity is important to me in working towards gender abolition, so that is the lens through which I will discuss my experience here.

# What did I want? (What was my alternative?)

**My vision:** An interconnected network of community carers who share intimacy with me and with each other. Others do not feel entitled to my body, decision-making process, or emotional labor. Direct participation in my recovery process is voluntary and distributed among many. I feel supported and all my physical/medical and comfort needs are met.

# Stats (FAQ)

**Surgeon:**

Dr. Kenneth Wolf

**Requirements from surgeon:**

None (informed consent)

**Location:**

West Bloomfield, MI (~30 min drive from home)

**Procedure:**

Double incision (DI) without nipple grafts

**Insurance:**

Aetna (employer plan)- not applicable to Dr. Wolf, private practice

**Cost:**

\$5900 out-of-pocket for surgery (\$500 up front to reserve date)  
+ \$300 for mental health letter (Aetna required for coverage or partial reimbursement)  
+ \$600 saved for monthly expenses during recovery  
+ \$150 2nd consultation (in network for Aetna)  
+ \$300 for days off work and 40+ hours on phone for Aetna coordination  
= \$6850 + much unnecessary stress\*

**Drain Type:** Penrose

**Scar care:** Used silicone scar strips for about a week starting at two weeks post-op, but didn't stick with it

**Social media groups/references:**

- Transbucket.com
- Top Surgery Support (removal/reduction) [Fb]
- Non-Binary Top Surgery Support [Fb]
- Top Surgery: Dr. Wolf's Wolfpack [Fb]
- Non-Binary Top Surgery [Fb]
- #drwolfswolfpack [Insta]
- r/FtM [Reddit]
- r/AskTransgender [Reddit]

\*I ended up not using insurance, and as of writing Aetna has still not issued the promised reimbursement over my deductible amount. In hindsight, I wish I never contacted or tried to use insurance at all as I sunk many hours and dollars into an unsuccessful, stressful project with no benefit. I would have saved ~\$500 and many hours by ignoring my insurance provider completely.

# Overall Timeline

**October 2019:** Start thinking seriously about top surgery, contact insurance, schedule consultations.

**November 2019:** Continue talking and filing paperwork with insurance, go to multiple consultations and info sessions (explore options), compare pros and cons (in vs. out of network, results, financial cost, comfort, etc.). Think about my potential support network for post-surgical care and what else I could do to strengthen this possibility.

**December 2019:** In pursuit of reimbursement from Aetna (stated to be near-guaranteed), go to two therapy appointments to get a mental health letter that meets criteria for coverage. Confirm with desired care team members that they are interested in providing post-surgical support. Schedule surgery for April 23 and pay \$500 non-refundable deposit to Dr. Wolf's office.

**March 2020:** Pay remaining balance for surgery, submit claim paperwork to Aetna.

**April 2020:** Surgery postponed due to COVID-19, then rescheduled for May 22.

**May 2020:** Surgery and 1st week of recovery! Resubmit Aetna claim paperwork.

**June 2020:** Continue recovering, and begin the rest of my life!

## Day by Day

**Day of surgery:** No food or drink since midnight. Surgery scheduled for 7 am. I felt very ill on the way home, then immediately took a nap when I arrived. I was able to comfortably go on a walk in the evening when I woke up and had no significant pain (though was taking percocet as prescribed). My care team put together a written schedule to track my medications (see example below). I slept lying on my back only for the first two weeks.

Example Medication Schedule

Day	Amoxicillin	Percocet	Senna	Anti-Nausea
5/22	9 pm	2 pm		2 pm
		8 pm		9 pm
5/23	9 am	midnight	9 am x 1	9 am
	9 pm	4 am		noon
etc.	...	...	...	...

**Day 1 post-op:** Generally feeling good, no pain. Able to use laptop and go on walks. I got tired in the afternoon and took a nap.

**Day 3:** Stopped taking percocet in favor of acetaminophen since I didn't want to take opioids longer than necessary. I had no bowel movement since the day before surgery (constipated, probably due to the percocet), so I began taking an over-the-counter stool softener. The surgical vest was digging into my back, so a friend put folded washcloths under the tight parts to make it more comfortable.

**Day 5:** Poop! I sent a fun selfie of myself on the toilet to my care team. We were all pretty excited for me to no longer be constipated. The surgeon removed my original dressings and I got to see my post-op chest for the first time.

**Days 6-8:** I grew to hate the surgical vest and was very ready to have it off for good. It felt great to have it off for a little bit each day when bathing and changing dressings.

**Day 9:** I went to the beach with some friends! Still wearing the surgical vest and long sleeved button down shirt for sun protection, but able to move around on my own without pain or difficulty (still no heavy lifting or exercise).

**Day 11:** Went for a five-mile walk because it was nice out and I felt like it. No physical issues, though the surgeon later told me not to walk "for exercise" (anything that gets my heart rate up) to avoid fluid buildup in my chest. I didn't do this again for a while, and noticed no negative effects from this instance.

**Day 12:** Drains out! Unfortunately still advised to wear the surgical vest until the drain holes close up... I was so excited to get rid of it this day

**Day 14:** Drain holes closed! No more vest ever! Excited to take baths and move around without a compression garment! Still limited arm motion and no heavy lifting.

**Day 21:** Swimming! I didn't use my arms a lot (not "for exercise," but moving through the water doggy paddle). I moved around fine otherwise and really enjoyed feeling the water on my arms and chest. I wore scar strips and covered them with opaque tape, plus used lots of sunscreen.

**Day 22:** Beginning to reach over my head, but not for long amounts of time and only with a little weight (paintbrush).

**Day 23:** Able to drive for long hours and went kayaking by myself.

**Day 34:** I noticed a small abscess filled with pus on one incision; the surgeon said it was a stitch trying to come out, nothing to worry about. The bubble popped on its own, so I covered it with a bandaid and moved on. Within a few days the spot was unnoticeable.

**Day 41:** I felt good about lifting heavier objects, and my range of movement was unrestricted (arms over head, to the side, reaching). Full motion regained!

**Day 28:** Did some low intensity hiking on an easy trail; it was still hard for me since I didn't have a lot of experience and hadn't done much exercise recently due to surgery recovery.

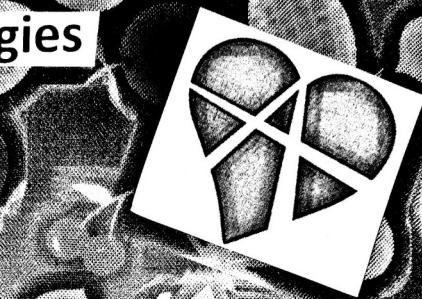
**Day 29:** Strenuous hiking on a difficult trail that required leg and arm use. I went slow and traversed carefully, letting other hikers pass me at every opportunity. I kept my pack light and carried a gallon of water since I still felt nervous about carrying large weights.

## Strategies

### The Network

First, know people who have spent the past 15 years building queer community with core principles of mutual aid, solidarity, and anti-oppression.

Obviously this is a joke... but only kind of! Just as it's good to have skills for dealing with a crisis before the difficult moment hits, building a support network at the very moment you need one is unlikely to be successful. About a year before starting the process to get top surgery, I became involved with an ongoing radical community experiment in which people were already developing these skills and connections.



Building robust networks of care that challenge Monogamism and other harmful patterns of relating is a big project, and this zine will not cover this in depth. Also note that this can be extra difficult due to a combination of conditioning, skills, resources, and other factors. Recognizing that we live under oppressive systems is different than total acquiescence to them; these are things to fight, not capitulate to! Start now, and the benefits for yourself and others will extend far beyond the specific situation of recovery support after top surgery.



### Relationship Anarchy Discussions

A monogamy critical space

# Distributed Work

Providing someone around-the-clock care for multiple weeks is a big task! This can be too much for a single carer, leading to worse care in the immediate situation, increased stress, and possibly resentment later on. For people who don't have experience in a medical caretaker role (eg, home health aide, nurse, doctor), this can be especially overwhelming. Each person has many commitments and priorities, and it was important to me that no one person (or closed small group) was responsible for every task at all hours for multiple weeks. We live under Capitalism and there are other coercive forces at play, so also consider that some people will want to continue earning income and may not have the flexibility to take time off (or even if they do, might not want to do it for this!). I ended up with around eight people involved in daily/routine aspects of my care.

In order to distribute the work of the carer role(s), one of my friends made a schedule with four-hour shifts that people could sign up for, from the day of surgery through two weeks after. Participation in any particular shift was voluntary, and the sign-up process was transparent (in a shared Google Sheet). People who signed up to be "on call" listed their contact information, agreed to be nearby during their volunteered times, and checked in with me when they started and ended their care shift. This shared sheet was also useful for when people wanted to switch shifts or had specific questions for another carer; they could speak to each other directly instead of using me as the go-between. See the example table below.

## Voluntary Participation

When I decided that I definitely wanted top surgery and had my potential payment and timeline worked out, I created a groupchat with the people I thought would be interested in providing recovery support. I explained my goals, some things “care” could look like, and asked people to confirm whether they were interested. See page 20 for a model script based on the message I sent to my potential carers. Some advantages of this strategy were transparency of the process, direct communication between myself and carers, an opportunity (and encouragement) to decline participation as desired, and a way for me to gauge what support I could expect. I felt secure and supported, so I scheduled my surgery and paid the deposit.

Something else important to me was the ability of potential carers to opt out freely! I wanted people to make informed decisions about their participation. That way, they wouldn't feel stuck doing work they didn't want to do and I could avoid most of the costs of frustrated carers. As mentioned in the introduction, I didn't want the responsibility of caring for me to be “automatically” assigned to someone(s) based on a socially-venerated relationship status or the fact that we lived together. Many people generally want to help those they care about, but may not be interested in or well-suited for every task. For example, some people don't like preparing food, others feel squeamish about blood, and some may have experiences with dysphoria or trauma that would make specific aspects of my care distressing for them.

“Voluntary association for mutual benefit” is a phrase that comes to mind as a good heuristic for how I want to interact and build relationships.

### Example Carer Schedule

Time	Fri 5/22	Sat 5/23	Sun 5/24	etc.
midnight-4 am	Friend A	Friend B	Friend A	...
4 am-8 am	Friend B	Friend A	Friend E	...
8 am-noon	Friend B	Friend A	Friend E	...
Noon-4 pm	Friend C	Friend D	Friend A	...
4 pm-8 pm	Friend B	Friend D	Friend A	...
8 pm-midnight	Friend B	Friend D	Friend C	...

I also created a Facebook event and used it as a central place to distribute information and allow carers to coordinate. When I wanted a ride to and from my surgery, I posted the date, time, location, and my expectations in the Facebook event and let people volunteer for the task. That way, I refused the role of assigning people specific duties and kept the process open and transparent. This worked out really well when someone scheduled to drive me to a follow-up appointment cancelled. They knew who was the backup volunteer based on the post in the page, so were able to reach out and secure a replacement. Without this, I would have been stuck not only recovering, but managing all the help I thought I needed. This was also a great place to share updates and fun photos!

Fortunately, my recovery was very easy: I had minimal pain, no complications, and could walk and communicate well by the evening after surgery. By the end of two weeks, I was back to normal activities besides exercise and lifting heavy items. Because of this, my carers were mostly “on-call” and I often didn’t ask them for anything. For people who feel a lot of discomfort or pain during recovery, or have a complication that needs medical attention, each shift may have more activity. If this had been the case for me, I believe the distribution of work among many people would have been especially valuable. Not only did my carers avoid long, miserable shifts that ended in frustration, but I felt good about frequently asking for what I wanted since I didn’t ask much from anyone at a particular time.

## Extra Notes & Tips

- Take photos or videos of your chest before surgery if you're comfortable! You can archive them or put them in a hidden folder to avoid seeing them accidentally. These are helpful for comparison later, for yourself and if sharing your results with others considering top surgery. I also feel differently about photos of myself pre-surgery now, so they're kind of like a weird novelty instead of a constant reminder to be upset.

- Figure out a place to donate binders, both any old ones you were using and the surgical vest (*post op binder*). Prioritize QTPOC/BIPOC folks and individuals or autonomous networks over non-profit agencies. Don't let these needed resources get lost in the cracks of the non-profit industrial complex; take mutual aid and the spirit of reparations into your own hands.

I'm looking to donate some gently used binders. Are affiliated with any binder exchange or do you have any recommendations?

I don't know but I can connect you with a few trans men that might know

(to a local trans woman of color who does outreach and advocacy)

I have 3 binders in good condition and want to prioritize giving to QTPOC. Is that aligned with the safe house you're affiliated with? If so, I'd love to send them to you

(to someone affiliated with an LGBTQ+ safe house a few states away)

- Weigh yourself right before surgery if you want to know how much tissue is removed. I didn't think of this until later, so have no way to compare now. There are also not a lot of comments I could make about the info that don't reify fatphobia, so the niche possibility of sharing the info in a good way is not enough to cause regret about this. I'm mostly just curious.

- Have some button up or zip up shirts to wear for the first two weeks after surgery. Arm movement is very limited for a while, so putting shirts on over your head will likely be difficult and not medically advisable. These are also useful for sun protection, since putting on sunscreen (and washing it off later) are more hassle than wearing a shirt. Consider the temperature when choosing fabrics since changing will be inconvenient and you'll already be uncomfortable enough!
- Join transbucket and top surgery groups on social media, and/or look for hashtags or accounts that focus on sharing top surgery information and photos. This is great for getting practical information and getting used to seeing post-op chests. This also helps to get an idea of what you want for yourself and what to ask your surgeon for (with or without nipples, scar placement, scars connected in center of chest or not, curved vs horizontal incisions, questions about dog ears/revisions, and whatever you think of or notice). Lots of people share their before and after photos, so this is a good way to see that from others and contribute to it yourself later if you want to.
- Have a comfortable chair to sit in, and a place to lie down if comfortable. I was able to sleep on my back starting from the first day, but many other people recommend having a recliner or other padded chair for sleeping. I used this advice and did sleep in the chair a few times, so this ended up being useful for me.
- Practice unlearning desirability and respectability standards; rather, notice and accept the range of bodies and appearances (including yours). Your scars might not turn out close to skin tone or flat or small... and that's okay! Get used to challenging the idea of beauty.

# Looking Further

- Think about how these strategies apply to caring for or assisting someone with a chronic health condition. How might we avoid burnout from carers? What tools and strategies would help someone receiving care to feel comfortable continually asking for what they want or need? A distributed network of care based on voluntary association for mutual benefit could help keep this manageable and enjoyable for all!

- The group of caretakers described in this zine can also be conceptualized as an affinity team. The skills they practice together could be useful in the future, as they would practice working together in specific ways. For example, a later acute injury may also require care and would have less lead time for planning or coordination; an established affinity team could fill the need quickly and with minimal training.

- Not all caretaking is directly medical! There is plenty of emotional support, intimacy, and daily task assistance required for post-surgical recovery. Consider how this applies to the ways we care for each other, broadly. What assistance or support will you need as you age? How can we make life better for our friends with chronic illnesses or disabilities? Especially for people separated from family (by choice or force) and/or social norms around courtship and entanglement, who will be around to provide support for them? In what ways can you invest in giving this support to others? Making intergenerational and otherwise accessible spaces, networks, and care teams can help model this reality and create a sustainable system of care.

- Apply a mutual aid framework to caretaking. Instead of being an act of charity or one-off event, what could non-transactional reciprocal care look like? Everyone needs care at some point; how can you contribute to a culture and practice of care before the moment you need it? What lessons can apply to the next person who needs similar support? This is relevant to acute, severe care and the ongoing care work we do for others' physical and emotional wellbeing.

- Imagine a world where every person has access to a community of care that isn't tied to their biological origins, State-sanctioned family unit, sexual desirability or availability, performance of monogamy, access to financial resources, or ability. People willing and able to offer support can do so voluntarily in ways that feel good, instead of out of a sense of obligation. People who need support—whether after surgery, acute injury, or ongoing—receive the care they want and need. Instead of relying on paid strangers as caretakers, assisted living facilities for seniors, and sole reliance on professionals with supposed specialized knowledge, we keep each other safe and healthy. We can all build skills and capacity to care for one another, and create joy in the process!

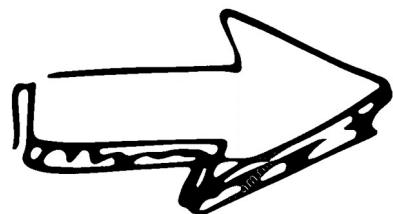
**Preceding text available in essay format:**

[https://medium.com/@camxfree/top-surgery  
-recovery-in-community-89fc49fd9ba9?  
sk=0ffb1b443bf9760aee4c72d404c293c6](https://medium.com/@camxfree/top-surgery-recovery-in-community-89fc49fd9ba9?sk=0ffb1b443bf9760aee4c72d404c293c6)

**Zine available for print and/or download:**

[https://sites.google.com/view/  
radcommunitylibrary](https://sites.google.com/view/radcommunitylibrary)

**Keep reading for a workbook section with  
reflection questions, recommended  
resources, and more!**



# **Workbook**

## **Guiding Questions for You**

What timeline do you have in mind, if any?

Whom do you want on a potential care team? Do these people already have relevant skills or training?

What values or aspects of this process are most important to you?

Is there anything you know you don't want? What would make you uncomfortable, or cause tension between you and the care team?

How do you want to share information, among care team members and with others? Do you have any privacy desires or needs (general info, specifics, photos/video, certain people, etc.)?

What are your concerns or fears? (Bring these up to your care team to ask for specific support, or work on them if personal/internal!)

24

## Medication Schedule Table

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25

**26**

**Carer Schedule**

Time	Day 1:	Day 2:	Day 3:	Day 4:
midnight-4 am				
4 am-8 am				
8 am-noon				
Noon-4 pm				
4 pm-8 pm				
8 pm-midnight				

(intentionally left blank)

27

# Script to request carers

(feel free to modify! - I sent this in a group chat):

Hey, friends! I'm strongly considering getting surgery—bilateral mastectomy, aka top surgery—around [date]. I will need some help at the time of surgery and afterwards; I want to make sure I have a reasonably reliable plan for this before I schedule anything. On the day of, I will need a ride to and from the clinic in [location]. For the week following, frequent bedrest is recommended and I will need help with many activities (moving, cooking, getting things, etc.). For several weeks after that, I may still need occasional help with transportation (for example, the follow-up appointment ~1 week post-op) and tasks that would require more excessive and/or strenuous motion. This is a major surgery that involves a taxing recovery process; I cannot do it alone and will need support from others.

Each person in this chat was intentionally included because I thought they would be able and willing to help with some part of this care. If you're not, feel free to leave the chat. Thanks, all!

# Recommended resources

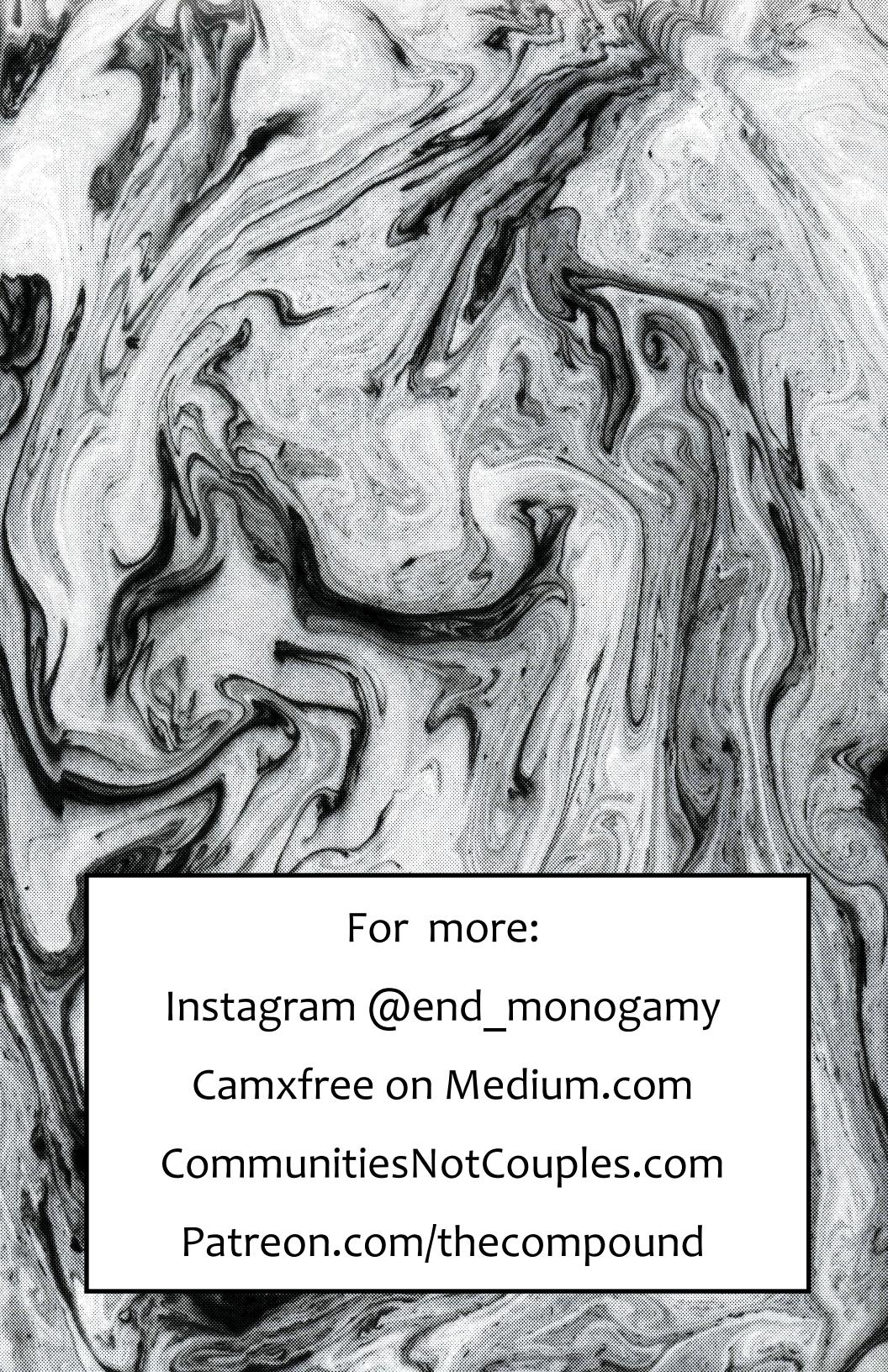
(I shared these + the info page from my surgeon) with potential carers:

Written journal with video links from someone else who went to Dr. Wolf, recovery info starts on page 2: <https://docs.google.com/document/d/11kCbsVn7lOGww-2HQyzUuSaCHStcrHtbp4mjA-8oagY/edit?usp=sharing>

Vlog (note that I will not have the style of drains shown in this video, so that part isn't relevant, but the rest seems applicable): <https://www.youtube.com/watch?v=g-r94PFoy5Q>

Another vlog (again, same thing re: drains):  
<https://www.youtube.com/watch?v=ikCBpVvNFvI>

Expectations vs. reality from a semi-famous trans youtuber: <https://www.youtube.com/watch?v=LbraIM0bSc0>



For more:  
[Instagram @end\\_monogamy](https://www.instagram.com/end_monogamy)  
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