

### "Like a Barrier Lifted": The Top Surgery Caregivers Support Zine



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## Quinn Rivenburgh 2016 School of the Art Institute of Chicago, Chicago, IL



author would like to thank Jacoby Ballard, clinton. Jessica Easter, Peek Ehlinger, Elijah Ebbenga, Beth Kathleen Hetland. Katharine Houpt. Korla Masters, Minnesota Transgender Health Coalition, Melissa Raman Molitor Stephanie Peterson, Chase Ross. Isabella Rotman. Sit, Jael O'Hare, Teresa Cael Warren, and Wilder Foundation for their support and guidance this project.

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### WHAT IS TOP SURGERY?

Top surgery is a gender affirming surgery which removes excess breast tissue. In general, it is similar to a double mastectomy, but with different therapeutic goals. It is major surgery and requires general anesthesia, and is usually an outpatient procedure. However, the recipient will need care for about a week during the recovery period. They need someone to help them do that. Thus, this zine.

### WHO GETS TOP SURGERY?

female at birth and who develops breast tissue as part of their secondary sex characteristics during puberty and who 2) experiences a a lack of congruence between their gender identity and particular aspects of their body or how society perceives them, could potentially seek top surgery. A wide range of gender-nonconforming identities including but certainly not limited to transmasculine, androgynous, butch, multigender, FTM, transman, man of transgender experience, agender, nonbinary, genderqueer, and Two-Spirit people can

Anyone who is: 1) assigned

### WHY THIS ZINE?

(and do!) seek top surgery.

I firmly believe that everyone should be able to access the lifesaving gender care they need.

Generations of transgender and gender-nonconforming people have faced violence rather than hide themselves. For



trans folks seeking top surgery, such an undertaking can represent a flowering of personal expression despite, and

in spite of, threats of violence and discrimination.

Transitioning helps people achieve congruence, wellbeing, self— determination, and authentic self—expression, and can alleviate internalized transphobia. Transgender and gender—nonconforming people create pathways themselves for a more fully lived life.

For generations, people receiving top surgery have relied on a friend, family member, or partner to provide care during the recovery period. As this surgery is often not covered by insurance, there are extra barriers to accessing care.

The trans and queer communities have a long history of DIY healthcare and mental health care. Ignored or pathologized by medical and psychological institutions, for decades people have swapped stories, cared for one another, traded resources and tips, and built best practices for transition and living authentically – from the bottom up. The zine is an embodiment of trans and queer people imparting wisdom across generations.

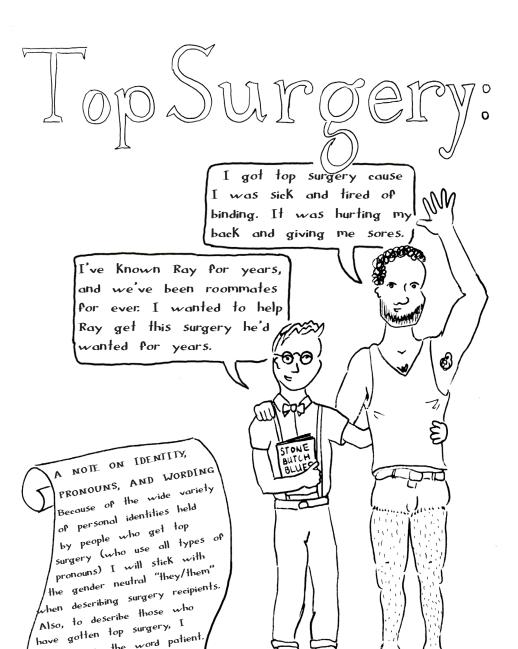
### MEDICAL DISCLAIMER:

Medical research about treatment and medical standards

is always changing. Unfortunately, science and medicine has neglected transition—related care for far too long. For transgender medicine, some of the answers are unknown, or are not the greatest.

I have tried my best to be sure that I am up to date and accurate, as of December 2016. However, transgender medicine is changing rapidly - hopefully for the better. I cannot guarantee

that the medical info in this book is 100% safe or accurate, or that it will remain this way over time. Please discuss questions and concerns with a trusted and Knowledgeable clinician.



sometimes use the word patient.

I dislike this very medical
word, but writing "top surgery
recipient" many times is simply
not Peasible.

MARK

CAREGIVER
Pronouns: he/him
Hero: Alan Juring

### MARK RAY CAREGIVER TOP SURGERY:

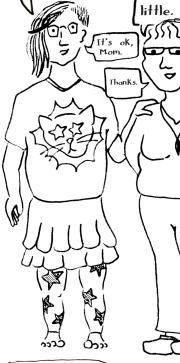
TOP SURGERY: M Pronouns: he/him Hero: Grace Jones



nurturing Bailey between state. like I did when and for me that she was little. meant top surgery, but not taking Oops, honey, I mean when THEY were little.

chest would help me feel more comfortable in my body.

body.







### BAILEY

TOP SURGERY: 📝 Pronouns: they/them Hero: Octavia Butler

### BEATRICE

CAREGIVER Pronouns: she/her Hero: Georgia O'Keefe

### CONNIE

TOP SURGERY: Pronouns: she/her Hero: Sylvia Rivera

### KIT

CAREGIVER Pronouns: she/her Hero:

Audre Lorde

# Top Surgery Procedures

Top surgery includes: Removal of most of the breast tissue, removal of excess skin and the infra mammary fold, and the reduction and repositioning of the nipple.



The type of surgery you'll get depends on size, shape, and skin elasticity of breasts; whether it's important to maintain nipple

sensation, and sometimes aesthetic preference.

I got this, because my chest was pretty big. It's basically the same medical procedure as a double mastectomy.



Check out transbucket.com for a collection of before/ after photographs and surgeon reviews, sortable by procedure.

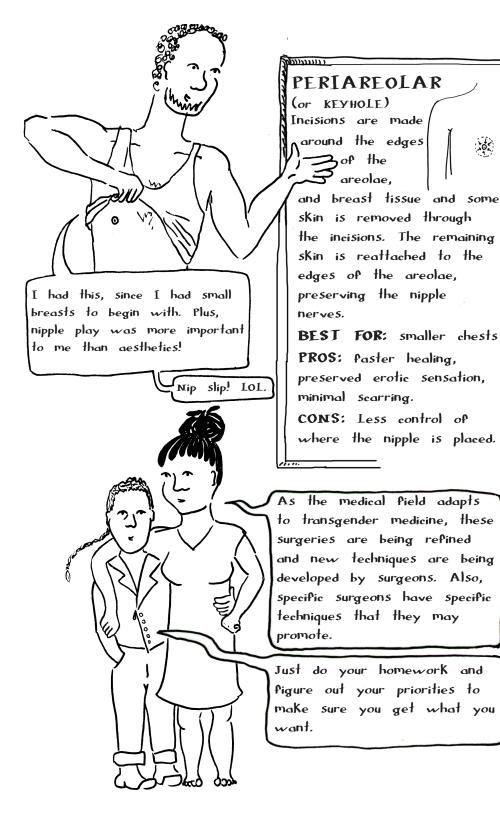
### DOUBLE INCISION\*

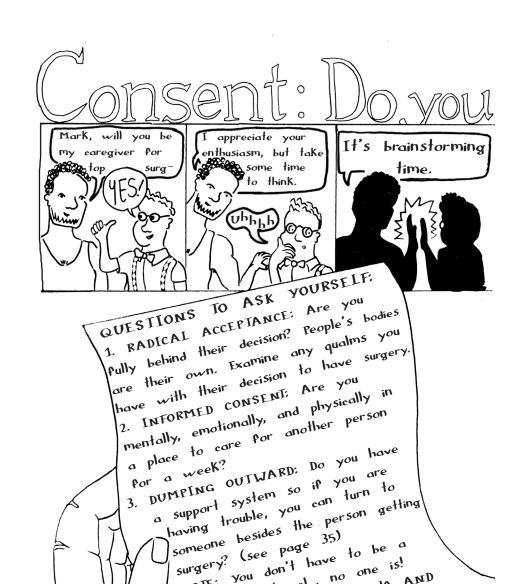
Incisions are made at the base of each breast and breast tissue and excess skin are removed. Nipples and areola are removed, resized, and grafted back into the appropriate position, usually spaced wider apart for masculinization.

**BEST FOR:** large, saggy breasts; inelastic skin from years of binding

**CONS:** leaves sizeable scars; loss of erotic sensation to nipples (may return months or years later); possible need for revision surgery if flaps of skin are left under armpits.

\*A variation of this is T-ANCHOR, which may preserve some nipple sensation.





NOTE: You don't have to be a perfect herolangel... no one is! But you owe it to yourself, AND

do this.

the surgery recipient, to really consider whether you are willing and able to



### Hear cautionary tales!

"I was going to care for an ex of mine, but I realized that we were too codependent and it wouldn't be emotionally healthy. So I said no. He asked his sister to caregive instead."

"I was originally going to get this surgery years ago, but at the last minute my partner bailed, saying that she would miss my breasts too much. I felt betrayed!"

See the possibilities!

"It was like a barrier was lifted. It was a barrier to her happiness. A barrier to connecting with others that I didn't know was there. We were close already so I was very surprised. Like a black cloud lifted.

A bad energy gone."

"Regardless of the nature of your relationship, there is something deeply intimate about caring for a person at this level. It is humbling and enlightening."



### Conversations to have far before the surgery date

MONEY: THE COST OF SURGERY & ASSOCIATED EXPENSES Cost is often the biggest logistical barrier between trans people and surgery. The majority of gender—affirming surgeries are paid for out of pocket in the US. (Health insurance often discriminates by not covering transition—related costs).

Your friend may have saved up for years to cover the full cost of this procedure, often \$5,000-10,000. They may have turned to family or community to help with costs. Other costs may include plane tickets, lodging, renting

a car, and a food budget.

Do you need to help your friend throw a benefit party to fundraise?

An important conversation to have is expectations around who will pay for what. If there is airfare costs involved, will you buy your ticket, or are they covering everything? Who is responsible for food for the week of recovery?



What are your/their coping mechanisms? What does the surgery recipient Know about how they respond to pain? Do they get irritable, snarky? Do they downplay their pain?

You will be involved in the recipient's bodily functions — talk through the normality and embarrasment of that.

You will need to do many things: feed them, wash their hair, adjust their pillows, Keep track of meds - how do you feel about that?

Also, in case of emergency, establish a list or phone tree of loved ones to notify as backup support.





# Ritual & Meaning

For some folks, it feels right to enact a ritual marking this time of transition, saying goodbye to the old body and welcoming the new, and defining what this surgery means for a fully expressed life. If that feels good for you both, go for it! Do whatever feels right; it's all about intention. But make sure you aren't appropriating others' traditions.

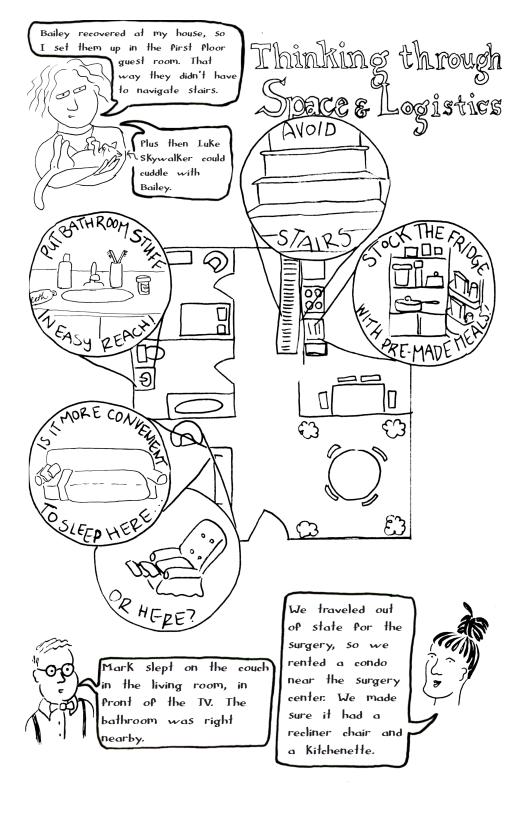


My friends each made me a friendship bracelet. I was able to wear them around my ankle during surgery. It felt like I had their well wishes with me the whole time!



For me, it was just getting big hugs from all my friends — I Knew I wouldn't be able to hug them tightly for a few weeks of recovery!





### Medical Considerations





Some doctors recommend halting I shots during the period of the surgery, and some say it is fine to continue them.

It's best to witness doing a T shot and try it at least once. If a shot date falls in the few days after surgery, you may need to learn how to do it, since the person getting surgery might be in too much pain or feel too loopy on pain meds to do it themselves.

This can be a very intimate, vulnerable thing to ask someone to do, so be as respectful and careful as possible. At the same time, be sure to ask all the questions you need to do it confidently — it's a bit of a tricky process.

CIGARETTES: Cigarette smoke hinders recovery from surgery (even secondhand) so if possible, the caregiver should cut back or eliminate smoking, and definitely plan to smoke away from the person recovering.





### SUPPLIES LIST:

SUPPLIES LIST:
SUPPLIE
oTC MEDS:  benadryl/zyrtec for itching  benadryl/zyrtec for metamucil for laxative
oTC MEDS:  benadryl/zyrtec for itching  benadryl/zyrtec for itching  milk of magnesia or metamucil for laxative  milk of magnesia or metamucil for laxative
milk of magnesia of  PRESCRIPTIONS (pick these up before surgery);
meda
anti-nausea meds
anti-nausea meas antibiotics sleeping medication (may be prescribed this)
offe, peppermini res
FOOD/GROCERIES:  ginger ale, ginger or pepper in meds: prune juice
onsuper ( Votir Ni)
- problemes it live can
tempen, of bananas (also carbon day!,) ner bananas (also carbo
tempeh, or your favorite its tempeh, or your
tea, broins, etc. green ser
*** Make meals ahead of time!***
*** Make meals c." surgeon/PCP):
***Make meals c.  ***Make meals c.  supplements (check with surgeon/PCP):*  supplements (check with surgeon/PCP):*
SUPPLEMENTS (Creek  Good bacteria: probiotics  Good bacteria: probiotics  Anti-inflammatory: bromelain, quercitin, arnica  Anti-inflammatory: bromelain, juniper berry,
Anti-inflammatory: bromelain, quercine, Anti-inflammatory: bromelain, quercine, Antioxidant: coQ10, elderberry, juniper berry, Antioxidant: rasehips
Antioxidant: Coesings  goji berry, rosehips  omega fatty acids: flax seed or fish oil
TATE for more
*See Jacoby Ballard's TRANS CARE SURGERY ZINE for more
*See Jacoby Ballard's TRANS CARE SURGERY ZINE info on herbs and supplements! Site listed in resources section.
вио

### What to wear, what to pack



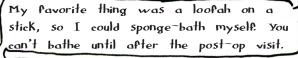
It hurts (and strains the incisions!) to raise your arms, so stick with big button down shirts and zip up sweatshirts. They should be loose and compy, so the JP drains can fit underneath.

Wear loose underwear, and sweatpants, basketball shorts, or pajama pants. Bring lots of socks and slip-on shoes. (When you can't shower, at least a clean pair of socks feels good).



If you normally use contacts, plan on wearing your glasses — it's much less of a hassle.

Get compression socks at the drugstore if you're traveling, to avoid Deep Vein Thrombosis.

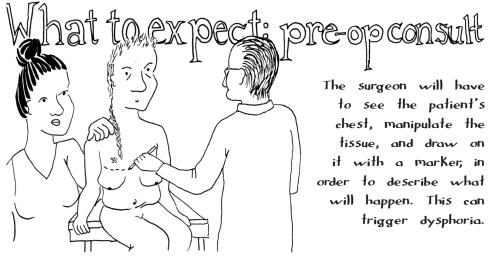


Oh, and bendy straws. It seriously pulls on the stitches to raise a cup to your lips.



Baby wipes for pits and crotch. Lotion.

Leave in/dry shampoo. Cleanliness will feel divine, however you can achieve that.







...no eating after midnight...no perfume...no ibuprophen or aspirin...

The caregiver should take detailed notes, as the recipient might feel overwhelmed, excited, or dissociative. You can also record the conversation on your phone, to refer to later.





Shower and wash your hair the night before. Remove jewelry, makeup, and nailpolish. Shave chest and armpits. Don't apply hairspray/gel, perfumes, or lotions.

Pack a bag the night before to take to the surgery center.

The caregiver should hold on to patient's wallet, phone, and Keys. The patient can't drive after surgery, so arrange transportation.

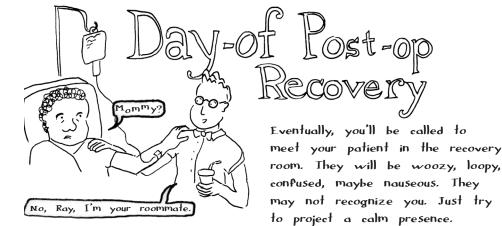


Ouch! Good thing

I don't have to shave my legs.

PRE-SURGERY ANXIETY: Any surgery can cause anxiety. Talk through: should the caregiver stay as the patient is prepped for surgery? Have a conversation about what you might expect while the patient is changing into a hospital gown, having an IV inserted, etc. What if a nurse misgenders someone? What if the patient suddenly feeling that the risks outweigh the benefits? Think of coping strategies that work for both of you.





The patient won't be able to drive. Plan a route to avoid potholes and rough roads. Drive slowly and carefully; the patient will most likely be in pain.



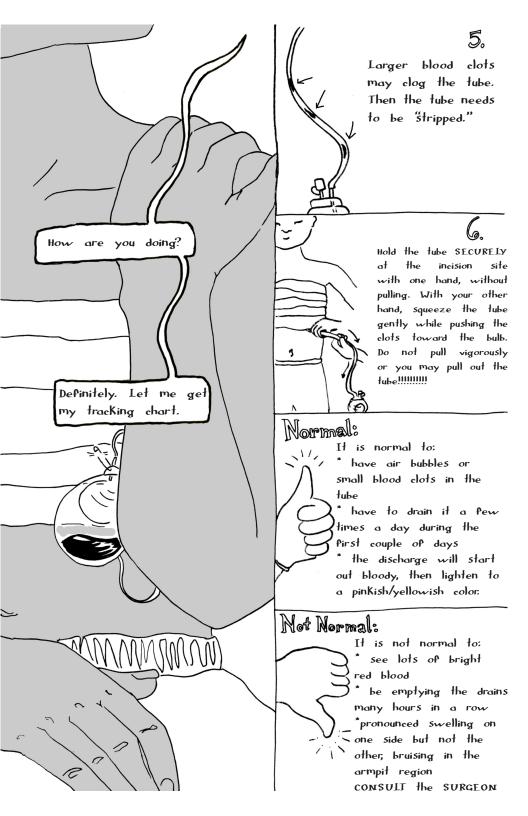


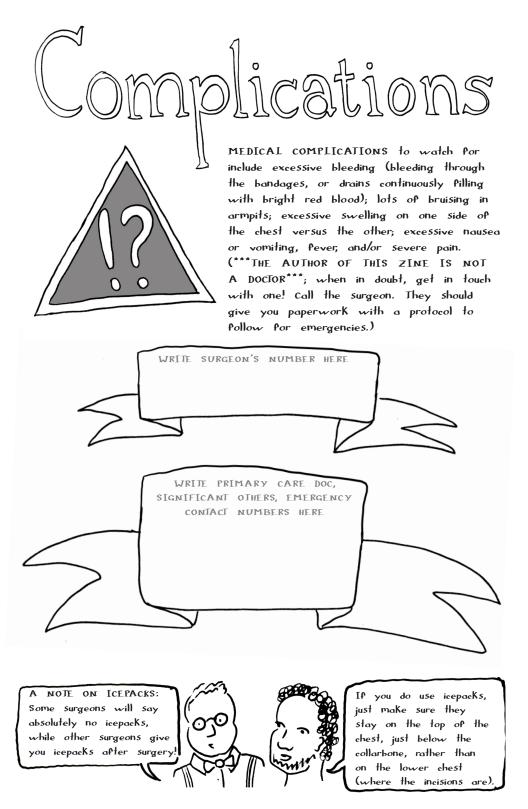
When home, install the patient in the prearranged sleeping area. Push fluids, broth, and a light meal if they feel up for it. Let them sleep as much as needed.

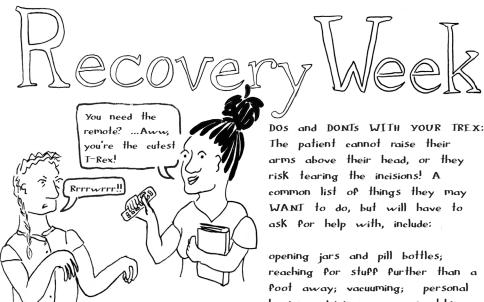
POSTOPERATIVE CARE: MEDICATIONS: One of your biggest jobs is keeping track of meds. Opening child safety bottles requires using the pec muscles, so the patient shouldn't even open the prescriptions. It is important to stay on top of the pain, and not wait until the patient is experiencing a lot of pain before the next dose.

You can either this out ahead based on the instructions, or as you dose.	d of time doctor's - fill it out As they	led	meds accordoctor's go	ure to note
Instructions	ANTIBIOTICS	PAIN MEDS	NAUSEA	OTHER
	DATE/TIME	DATE/TIME	DATE/TIME	DATE/TIME
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Remember; no alcohol while taking pain meds! No tylenol or advil! No smoKing/vaping/nicotine products.	nausea.	eause ( )	ok to	says it is Keep taking our other eds, then an that to the meds hedule.









reaching for stuff further than a foot away; vacuuming; personal hygiene; driving a car; scratching their back; adjusting that pillow behind their head; pulling a shirt over their head, etc. This is known wryly as "t-rex arms."

That means that YOU will help them with these things! Remember, it can be SO HARD to ask for such seemingly simple things, and hard to feel helpless. Do your best to anticipate needs and normalize these requests.

#### OTHER TIPS:

The patient may walk around as they are able, but do not elevate heart rate too much.

When sleeping and lying down, the patient must ONLY sleep on their back! No side or belly sleeping for six weeks. This can be a tough change for habitual belly or side sleepers, but it creates pressure on the incisions.

When lying down on the back, if the arms or legs feel swollen, elevate them slightly with pillows.



# Hygiene & Healing WIPING THE BEHIND



Everyone has different sizes, shapes, and structures. Some people will need help with butt wiping; be sure to talk through this before the patient is sitting nervously on the toilet!

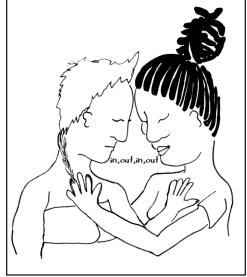
OTHER CONSIDERATIONS:
Might the patient have

a menstrual cycle during recovery week? SPONGE BATHS AND SHOWERING:

It is very important to Keep the chest bandages on and dry!!

A hose fixture is handy for cleaning the lower half. Are you (and the patient!) prepared for you to help with this? Have a conversation. You can sponge-bath the face, armpits, and neck (this can feel very refreshing!) but watch for drips on the surgery site.



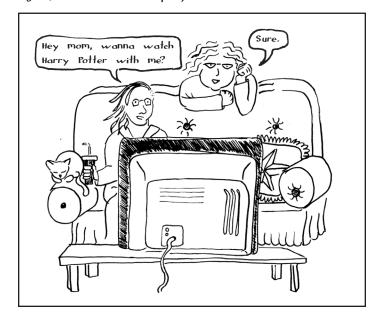


OTHER HEALING TIPS: drink LOTS of water. All the water!! Even if it's uncomfortable, breathe deeply as often as possible. No tylenol or alcohol with pain medications. No smoking. If the ACE wrap or binder feels really tight, you can loosen it a tiny bit; but do not remove it, or any bandages, all the way (follow surgeon's instructions).

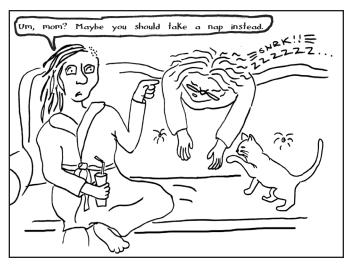
# Occupying the time



DO NOTHING. This can feel liberating, or tedious (or both). It's netflix and chill, but actually chilling; the patient's job is recovering, physically and emotionally, from surgery. Your job is to support them in that — and, potentially, to rewatch all of Six Feet Under: Eat nourishing foods, stay hydrated, go outside, meditate, take breaks from each other, do arts and crafts projects, go on short walks, have low key friend times — do what feels good, and communicate openly about each other's needs.



## DCaregiver DUMNOUT &



Take care of yourself so that you can be more fully present and supportive of the surgery recipient.

You owe it to them, and to yourself.

Set boundaries about what you can and cannot do, which will help you enthusiastically say yes to what you have agreed to do.



Take time away from caregiving to recharge, as you are able. Whether it's a short walk outside, or a different activity to switch gears and focus on yourself for a while, do that.



ay still needs a

Ask for help when you need it. It helps no one for you to be a "hero" by going alone. Some people set up rotating shifts of caregivers.

If you feel like you need to complain or get something off your chest, don't complain at the patient. the principle of "dumping outward"; reach out to a friend who Knows the situation, but is less immediately affected by it, who can absorb what you need. Don't make the patient do that.

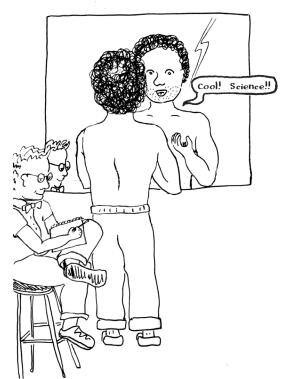
> You may be feeling vulnerable or challenged, and so is the patient. Your feelings valid; its what you do with them that counts.

They will be experiencing pain, nausea, anxiety, discomfort, etc. It is distressing to see someone you care about in this state. But remember, this is not your fault! There is nothing you can do that will remove all their pain and emotions. You are doing the best you can, and it is immensely important that you are there to witness and care for them through the pain, rather than trying to fix it.

try distraction, mindfulness/meditation exercises, deep slow breathing, and reframing the pain as short-term sacrifice for long-term gains (seeing the big picture).



# Post-op Appointment



Four to seven days later comes the post operative appointment, where the surgeon will "eveal" the new chest, discuss ongoing incision and nipple graft care, and talk through any concerns the patient has. They will also remove the JP drains, which is painless but weird feeling. They may snip out a few sutures that aren't dissolvable.

The chest WILL look puffy and swollen, with redness and dried blood. This will decrease as time goes on, and the visibility of the incision sites will lessen over weeks and months. (Follow surgeon's instructions regarding ongoing scar care, not covered in this zine as the patient generally does this themselves).

Beforehand, talk through your role at this appointment. The patient might be dazed, overwhelmed, vascillating between feelings of fear or letdown and excitement or happiness. It is different for each person.

Let the patient decide whether and how the experience should be documented. Photographs? Video? Just be sure to take notes on what the surgeon is saying.

Try to Keep your reaction to yourself at first. Let the patient have their experience to themselves. They have worked hard to get to this point. You can share your congratulations later:



# In Conclusion

### JOY, MILESTONES, AND REVOLUTIONARY CARE.

It is truly a gift to be asked to caregive for someone getting top surgery. You join a long line of folks caring for each other outside of dominant systems which would rather see us disappear. Your action furthers a legacy of health and wellbeing for transgender and gender nonconforming people.

You get to experience the sheer joy of someone who hunched their shoulders for years stand tall and proud. You bear witness to the strength, resilience, and tenacity of transgender and gender nonconforming people. You learn about your own strengths and limitations in the face of difficulty.

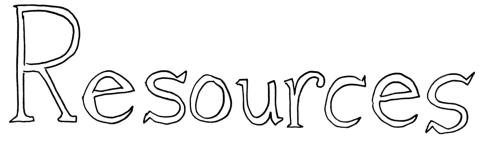
Receiving support from meaningful people can be a life affirming — as well as gender affirming — experience.

### MANAGING THE PATIENT'S FEELINGS OF LETDOWN.

Unfortunately, transphobia still exists. They might still get misgendered. They might suddenly notice other parts of their body may still feel dysphoric. The mental picture of how they thought they'd look might be different than the reality. Empathize and listen; this means, don't respond with, " at least you could get top surgery," or "just count your blessings."

### DEEPENING RELATIONSHIPS (anonymous survey respondents).

- "Their enthusiasm and willingness to go through the surgery details and logistics was very encouraging as I didn't feel so alone in the whole process...Experiencing the depth of love and tenderness my caregiver towards me was so beautiful. Witnessing them being able to express such genuine care."
- "There is something deeply intimate about caring for a person at this level. It is humbling and enlightening."
- "My two friends took intimate care of me and my body and my emotions, and helped each other with the difficult work of caretaking. The strengthening of my relationships with my two friends was nearly as life-enriching as the surgery itself."



(This list is not exhaustive, it's just what I found helpful in writing this zine).

#### ONLINE INFO SOURCES:

Transbucket.com

www.ftmsurgery.net/forums/private.php

http://www.topsurgery.net/

http://www.ftmguide.org/chest.html

www.ftmmagagazine.com

https://neutrois.me/2012/02/14/top-surgeryanalyzing-results

http://jacobyballard.com/product/surgery\_zine/

uppercaseCHASE\_youtube\_channel

#### ORGANIZATIONS:

Rad Remedy — connects trans & gender nonconforming folks to safe, accurate, respectful, and comprehensive care. radremedy.org Jim Collins Foundation — their mission is to fund gender affirming surgeries. jimcollinsfoundation.org

Minnnesota Transgender Health Coalition — improving health care access and the quality of health care received by trans and gender nonconforming people through education, resources, and advocacy. mntranshealth.com

#### BOOKS:

Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health Graphic Medicine Manifesto

The Remedy: Queer and Trans Voices on Health and Healthcare Trans Bodies, Trans Selves: A Resource for the Transgender Community

Trauma Stewardship: An Everyday Guide for Caring for Selfwhile Caring for Others

# About the Author

When I provided care for a transmasculine friend of mine getting top surgery in 2014, I lacked resources—online and off—to aid me in supporting him through the surgery and recovery process. I was fortunate enough to have a community of those who had gone before, to ask what it was like to care for someone in this manner. However, not everyone has a community context from which to draw.

As a gender-nonconforming emerging art therapist, I have a vested interest in revolutionizing the field which I am about to enter. In order to both add to the queer art therapy literature and to provide a service



for my transgender and gender-nonconforming community, I saw a need for a resource guide to aide caregivers of those getting top surgery.

Thanks for reading! I welcome feedback and suggestions at hrivenburgh@gmail.com.



LIKE A BARRIER LIFTED: THE TOP SURGERY CAREGIVERS SUPPORT ZINE is a resource for those getting top surgery, and those caregiving for surgery recipients as they recover. This zine covers emotional, physical, and mental health for everyone involved. From outlining the different types of procedures, to what to expect at appointments with surgeons, to hygiene and meals post-surgery, this zine serves as a valuable guide to making the most of this vital and important experience.