

## When Things Go Wrong

Sometimes, things go wrong with the surgery.

It has many names and many acronyms, SRS, GRS, GCS-Sex Reassignment Surgery. Whatever you call it, it is an irrevocable commitment and irreversible step should you choose to take it. Male to female (MtF) transpeople talk about it a lot. You know; Are you, or aren't you? Is she pre-op, or post-op? Who did yours? Whom are you going to have do yours? We talk about it a lot, except...when things go wrong. Then—we don't say much at all. In fact, we won't talk about it publicly, but it happens. We cover it up as if we should be ashamed. We feel damaged. Something odd ensues, much like forty or fifty years ago. Back then, people spoke in hushed tones, if at all about the family member, colleague, or friend who had certain illnesses—the “C word”—only whispered. Many times this lack of openness about such matters led directly to preventable consequences—even deaths.

We need to talk about healthcare for the transgender individual and I want to talk—openly about my experience--about what can happen when things go wrong with SRS.

While death is an unlikely result of complications from sex reassignment surgery, things can and do go wrong with the procedure. Even the most skilled of surgeons are, after all, human and as with any surgery, there are risks.

### I Knew There Were Risks

The information packet sent to me from my surgeon's office listed the possible things that could go wrong. I had read extensively about what my body would have done to it after propofol sent me to a dreamless sleep. Everything I found on the internet listed possible complications. One was a worst-case scenario, but the websites always mentioned it last and even then, it happened so seldom, most said, that it was a risk hardly worth mentioning. My pre-operative appointment, a scant two hours before I signed the waiver, was brief. The surgeon asked a few questions, looked me over, pronounced me suitable for surgery and added that I had enough tissue for good depth. Almost as an afterthought, she said we needed to go over “this stuff”. We got to that last, not worth mentioning, possible, worst-case scenario--thing. Of course, it needed to be brought up but in almost four hundred surgeries “it had only happened *just* once, so we don't worry about it”. I didn't.

Just before I walked into the surgical suite, I signed the waiver.

I slumped to the floor of the shower that morning in Trinidad Colorado, water and reality raining down on me. Bewilderment and terror replaced hope, which swirled toward the drain along with the feces and the blood. Emergency surgeries there, four more at home in Kalamazoo and another in Denver have all failed. Chronic pain, heavy narcotics addiction, and bouts of deep depression are the hushed legacies I have battled. Left with a possibly permanent colostomy and a painful, fibrous lump between my legs where a vagina should be, it is nearly impossible not to revisit the devastation daily. It is now two and a half years later.

The infrastructure of a natal male body is not the same as a natal female. The male pubic bone is lower and in my body, tipped somewhat, making it hard for my surgeon to get the geometry just right. In my case, there probably wasn't really *quite* enough space to allow

for the proper thickness of septum between the new vaginal wall and the rectal wall. A slight tear in my colon from a retractor, was all that was necessary to compromise an otherwise flawless procedure. I had developed a rectal-vaginal fistula. This problem happens to natal women too, often as a complication from difficult childbirth or certain cancers. Frankly, the success rate for repairing the defect in natal women is not good either. It often takes multiple surgeries for them too. What makes it even harder for the transwoman?

My story--and my surgeon's illuminate important problems endemic to healthcare for the transgender and specifically, the transsexual person.

- **Lack of access**  
Discrimination by doctors and hospitals and inability to get insurance or pay outright makes it difficult, if not impossible, for many transgenders to access care, primary or specialized.
- **Lack of knowledge**  
Documentation of protocols for care of patients undergoing transition is severely limited. Additionally, techniques for remedial care of complications are not well developed; instead, procedures designed for amelioration of fistulae in natal females are used.
- **Lack of training**  
There exist no specialized courses of study or teaching hospitals for SRS surgeons.
- **Lack of experience**  
While some surgeons learn techniques from other doctors already performing SRS, there are no residencies for those wishing to become SRS surgeons.
- **Lack of inter-disciplinary collaboration**  
Ignorance, discrimination and arrogance on the part of specialists often block those needing specialized post-SRS care.

In 2008 both the American Medical Association and the American Psychological Association issued white papers-policy statements calling for equal and fair access to healthcare for the transgender community. Both organizations recognized lack of access to health care as a growing crisis among transgender people. Significantly, however, while both bodies asked the insurance industry to remove discriminatory blocks for transpeople, neither the APA nor the AMA asked for better training and documentation of skills. Neither organization called for unilateral coverage of transition related care and procedures. The APA resolution reads thus:

**THEREFORE, BE IT FURTHER RESOLVED THAT APA recognizes the efficacy, benefit and medical necessity of gender transition treatments for *appropriately evaluated individuals* (my italics -A.H.) and calls upon public and private insurers to cover these medically necessary treatments;**

And the AMA:

RESOLVED, That our American Medical Association support public and private health insurance coverage for treatment of gender identity disorder *as recommended by the patient's physician.* (Again, the italics are mine- A.H.)

Ok, pretty strong statements, right? Look again and in particular, consider the italics. The APA resolution makes one BIG assumption-*that you will be able to be "appropriately evaluated"* this requires you to have found and be able to pay for a psychologist, assuming of course, that you want to be evaluated. The AMA resolution assumes much the same thing; that you have a physician and that he or she is willing to make such recommendations, if, in fact, they are so qualified. I am associated with a LGBT resource center so, I get calls for things like, "who is a trans-friendly electrologist" but the most frequent call I get is "My family doctor won't prescribe me hormones. Whom should I see?" To my knowledge, there are only two therapists in this area who take transgender clients, neither is a clinical psychologist who can render a surgical readiness opinion for SRS. There are one or two primary care physicians in the area who will prescribe hormones but, after hearing stories of one of them prescribing the exact same regimen for every patient, I am more than reluctant to send people to him. The nearest endocrinologist who takes transgender patients is ninety minutes from here. My own primary care doctor, admittedly, has no knowledge of how to dose a transwoman either pre-operatively or, post-operatively. He has left it up to me to tell him.

There is no curriculum, no specialization, no residency, and no board certification for SRS surgeons. No medical texts detail the procedures. Most SRS surgeons have followed in the footsteps of pioneers. In my doctor's case, the legendary Colorado surgeon, Stanley Biber M.D. whose compassion for a social worker led him to develop the most celebrated sex reassignment practice in the States. The surgeon who did my SRS learned from him and took over his practice when he retired. Soon, she began refining his technique and developing and teaching her own. Today, she routinely performs SRS as many as two hundred times a year. There are surgeons who want to do SRS-who have trained under doctors as mine did, but find it difficult, if not impossible, to find a facility that will grant privileges for SRS. Often, these surgeons may have the technical skills for SRS-urology, gynecological and plastic surgery, but hospitals will not grant access because there is no accredited course of specialization or board certification. This may not be all bad. While there are a few new surgeons doing SRS every year, are they really getting the training necessary to accomplish not just the surgery itself but, adequate follow-up care too? Again, no curriculum, no specialized course of study, no board certification, but perhaps more significantly, certainly for the patient, *there is no roadmap for what to do when things go wrong.*

### **She Doesn't Know How to Fix it**

Then, seemingly, neither does anyone else. My SRS surgeon attempted to fix the two-inch tear in my colon while I was still there, the repair failed in less than twelve hours. Next, a colon-rectal surgeon was found in the nearest large city and brought in to look at me. He aborted his attempt to repair the defect and instead, performed a full colostomy. I flew home to Michigan with a bag attached to my abdomen and thick pads between my legs to soak up the blood. A local colon-rectal surgeon, persuaded to see me by my primary care physician, was upbeat. Each time I went into surgery with him he would encourage me, saying "this time we'll get it". Coming out of surgery, my spouse Cindy would hear from him how well it went and that he was "optimistic this time" the closure

would take and a new defect would not open up. Another surgeon who has had some success with other fistula patients seemed promising, but eight months later, under the pressure of a barium test, that repair too, failed.

I have had stitch-overs, mucosal flap advancements, pelvic floor muscle mobilization, each one; each new approach diminishes what viable tissue I have for another attempt. I have tried to go into every surgery with a realistic outlook; multiple failures however, become difficult to bear. Still, I am one of the fortunate ones with this complication; I stand a chance, albeit small, for an eventually favorable outcome. Many transwoman are not able to find a colon-rectal surgeon who is willing to work on a transperson, much less “someone else’s problem”, nor do all of us have the means. Even if you are fortunate enough to locate a doctor--and in my case, privileged to have insurance and financial means to cover remedial procedures, then there is still only a slim chance for alleviation of this humiliating and debilitating condition. One surgeon, out of frustration no doubt, finally washed his hands of me saying, “well, you did this to yourself”.

I am not writing this to slam the physician who did my SRS. Far from it, she is a dear friend. We have shared much together, laughing, and holding each other; the two of us have grappled for footing. We have cried together, and yes, yelled at each other. She is an icon in the transgender community and heroine to many transsexuals. She is also perhaps the most accomplished of the few surgeons doing primary SRS in the United States. However, even a surgeon as accomplished as mine cannot overcome obstacles that she has no training for and little experience resolving. There are unseen and unsaid barriers that come into play when someone with complications from SRS must seek treatment aside from their original surgeon. As I mentioned before, most surgeons just do not want to deal with what they may perceive to be another doctor’s mistakes, if they are willing to look at you at all. A person would be hard pressed to get a doctor to admit that they are closed-minded, yet there are many doctors who simply will not work on—or treat a transsexual.

### **Losing the Patient**

My surgeon had told me, and has repeated often, that she would see me through this. I believe she has tried, but somewhere in the mix of discrimination, ego, and fear, the patient has been lost.