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NOTES FROM THE CHEMO ROOM

Today I remembered why I wanted to write about this. I was sitting in the chemo room, as I have done regularly for the past year. It has eight armchairs, each with a small stool in front, on which you can rest your feet while diverse liquids are fed into your veins. Each day, all sorts of women come to sit on those chairs, some on a weekly basis, some less regularly. Most are over fifty, but some like me are younger—in their mid-thirties or so; once I even came across a teenager. All have, or have had, breast cancer. Most are from the former GDR, and speak with a strong proletarian Berlin accent. They don't seem to mind my broken German though. And in this area of East Berlin—Weitlingkiez—which was once famous for its right-wing subculture, they don't seem to mind a foreigner amongst them (at least, a French one—how they would react if I was Turkish or black I honestly don't know). The thing is, being one of the youngest, they often treat me with a slight maternal affection and—with my green woolly hat when I had no hair, and with my punky haircut now it is growing out—I seem to amuse them a fair bit.

Today the room is quite empty, and the woman in front of me, in her sixties, after the usual small talk, looks at me with large, curious eyes. She asks: "you know, last time you said you had this op, you know, where they took out your boobs, but that you could keep your nipples, you said, like this *transdingsbums* [trans-thingummy] op, right?" I can't refrain from smiling. "Well", she announces proudly, "last week there was a programme on TV, a programme about these trans-thingummy people. So I watched it and you know, well, it doesn't look that bad, you know, with the nipples. I thought maybe, maybe I could do it like that too".

She made my day.

She was actually the third woman this week who asked me about my decision to have a mastectomy without reconstruction after I was told my breast cancer was genetic and could therefore come back at any time.[1] All of them knew they were going to have a mastectomy themselves in the next few months and all were somehow fascinated by my story. Not that I

1. I am affected by a mutation in the BRCA2 gene, which—like BRCA1 mutations—results in greatly increased risk of getting breast and ovarian cancers.

think they will all, if any, make the same choice. One of them told me she couldn't imagine living without breasts; that without them her body would not be her body. Still, the idea of having implants bothered her: she had heard many stories of something going wrong with them—they might sit too high, too low, or have different shapes; sometimes they get rejected by your body. "Frankly", she said, "I wish I could be like you and I would not care; that would be so easy!"

But I am curious as well. I want to know what's going on in her head when she thinks of her breasts—or of their absence—so I can understand better what came into my head six months ago, when I had to take my own decision. And I want to understand what fascinates them about my choice. The third woman I met this week, in the chemo room where she had almost fainted a minute before, gave me some hints of an answer.

She too will have a mastectomy in a few months but tells me she doesn't feel ready to think about it, now she's so weak from the chemotherapy. Still, when she thinks about reconstruction, it doesn't feel right. The word itself feels wrong; she doesn't know why. And she's afraid it wouldn't be her body anymore, with those huge implants, those fake breasts which don't feel anything. She's afraid they'll feel alien and she'll hate them. But she saw pictures of women without reconstruction on the internet and she can't imagine that either.

I can understand that. These two wide horizontal scars in the middle of each breast—I couldn't imagine having them either. I'm not yet sure why, so I want her to tell me what's so frightening about this image; what did she think about when she saw it? "It's like an erasure", she says, "like with a pen, when you cross out an error. And this fold in the middle that remains, it looks like... for me it doesn't look human". I know what she means. I know it doesn't have to be this way; that some women make this choice without regrets, but somehow I felt the same. All the doctors I met—who all happened to be women—assumed I wanted a reconstruction. One of them, when I asked how my chest would look if I didn't have implants, told me "it will look like this!", putting both her hands horizontally in front of each breast, with a slightly disgusted look on her face. "No woman would want that!" She immediately realised she had said something stupid, looked at me worriedly and corrected herself: "at least they don't usually".

But the thing is, since I was a child, I have wondered if I am really a woman—or a man for that matter. Both gender roles disgusted me in their own way, and, while I would not have considered a transgender op before, the idea of having two big fake breasts implanted in my body felt completely nuts. But this crossing-out, this horizontal scar—that scared me too. It reminded me of the Buñuel film, *Un Chien Andalou*, with that central scene when we see a close-up of an eye getting sliced across the middle with a razor. I always had to look away at that point. The thing is, when you opt for reconstruction, doctors give you all sorts of options. They often like to joke that you can even get bigger boobs if you want to. But when you refuse implants they give you only one choice: the cut, the crossing-out. If you don't want reconstruction it's because you don't care about how you look, right? But things are not so simple. And I see this in the eyes of those three women.

But I feel the fascination for my case comes from somewhere else. I told them I had to fight to get the op that I had come to realise was the right one for me—without reconstruction, keeping the nipples, with a cut under the breast. And that fascinated them because it meant you didn't need to accept the limited range of options doctors give you: you can first think about what you want and then impose your decision on them. Even when you're sick, weak, depressed, it makes a difference to realise you don't have to accept some kind of standard solution that feels wrong deep inside; that you can fight and make an active choice—even in the shittiest situation.[2]

For me the "fight" was basically: I started crying. One week before my op, I got the chance to meet—for the first time—the surgeon who was to operate on me. I had prepared my arguments, but I still felt weak: after six months of chemotherapy I was afraid I would not find the energy to make my point without breaking down. Fortunately my partner was sitting next to me, and I knew he would help me if I was too weak to talk. But to start with, the surgeon—a woman in her thirties—just did not let me speak. She just assumed

2. There isn't any good or bad choice per se when it comes to things such as whether to have a mastectomy or not, to have reconstruction or not, or how you want your body to look in general. Having the option of a reliable, healthy and satisfying reconstruction is as important as being able to choose how you want your breasts to look without implants. This is a very personal decision: all assumptions, gendered or not, about how bodies should look are potentially dangerous. Two of us in *Endnotes* are currently writing a longer, theoretical and experiential article about the normative pressure imposed on bodies assigned the female gender—in relation to both their appearance and function.

I wanted a reconstruction. So, as a good doctor, she started to explain to me all the risks of such a procedure. It could be that the implants get rejected by the body. They are foreign bodies after all, one should be prepared for that eventuality. If this happens, one might have to operate a second, or even third time. And if the body rejects silicone, we might have to consider implanting some of my own fat, which might be problematic as I am too skinny for this now, but after a few months without chemotherapy, that might become an option. Then there is the problem of capsular fibrosis. It is a possible response of the immune system to implants, and while it isn't dangerous, it can hurt. And in some cases implants may be linked to the development of lymphoma, a cancer of the lymphatic system, even if this is very rare. After ten minutes I managed to interrupt her, in a voice I tried to make sound resolute: "Actually I wanted to tell you, I don't want a reconstruction". Her whole body looked like she'd had a small electric shock. "But I would like to keep my nipples, and I was thinking, if this is possible for transgender mastectomies, why would it not be possible for me?" She remained silent for a second. She looked at me with a strange expression on her face, as if she was wondering how to react and had no clue. Then she erupted: "No, you can't do that, with transgender mastectomies, we don't take all of the breast tissues, because, think about it, men have breasts too"—she looked at my partner, who actually has the most beautiful breasts I've ever seen—"but in your case, because of your gene mutation, we need to remove all tissues, so it will make a HOLE; it will look HORRIBLE, you just DON'T WANT THAT".

Then I started crying. Or rather, I tried to say something, and my voice broke down. I could not believe I had the choice between these weird silicone boobs and looking like an alien with two big holes on my chest. No tear came out of my eyes, but each time I tried to articulate a word, my voice broke, first dropping as I tried to control it, then hitting new heights as I lost control. That changed the situation completely. She took her phone and called her boss. "I have a patient here, a gene mutation, she wants a mastectomy but doesn't want reconstruction, and she wants to keep her nipples, like—she said with a slightly ironic voice—a transgender op". Here I could feel for the first time the irritation in her voice. I was proving a difficult case; some kind of difficult child—but she was going to be patient. After all, I might just be losing my mind—and who wouldn't in my case. She was silent for a moment, listening to her boss's answer, which I couldn't hear, before announcing: "She's coming down". I held my breath. I caught my boyfriend's eyes; he looked as shocked as me.

There was a long silence before the chief surgeon entered the room. She was older than her colleague, maybe fifty or so. She looked pretty amused, and a bit curious, and asked me to repeat my request. She paused a little, then said: "Why not!" She had done transgender ops before, and there was no reason we couldn't use the same technique. But she wanted to know: do I want nipples pointing to the front like most women, or to the side like most men? I looked at her, baffled. She asked if my partner could show us his breasts and sure—he looked delighted to be able to help. "You see, men's nipples normally turn outwards, while women's nipples tend to look forwards". Me and my boyfriend looked at each other, speechless. We had been obsessed with breasts for weeks now, but we had never noticed that detail. I looked back at the doctor, confused. What did I actually want? But then I told her: "I actually don't care, as long as I can keep my nipples". Still I appreciated this new bit of information. "It will be flat but it won't make a hole, and if you go to the gym regularly you might even build some nice muscles there", she said in a smile—before disappearing without warning, like you can afford to do if you are the boss. Her colleague, or rather subordinate, was left pretty embarrassed and clearly annoyed by what had just happened.[3]

I was over the moon. I was imagining myself with some kind of body-builder breasts, and that made me both on an emotional level, and deep inside—somehow on a sexual level—happy. The doctor made me sign some kind of declaration that this op was really what I wanted, and while she finished the papers we left the room, both as if on drugs.

That was six months ago. Now I sit in my armchair alone, getting my second-to-last cancer therapy. I'm slow today and my fellow patients have finished their liquids before me. I think again about the conversation

3. It's still not completely clear to me why these two doctors had such different reactions to my request. One factor might be that the older, as a chief surgeon, was freer to consider 'unorthodox' solutions, while the younger—who had recently taken up that position—felt she had to stay on safe territory. But there may have been an emotional component as well: how these two doctors felt about their own bodies, their own gender, may have affected what they could imagine as desirable for others. In any case, as it turned out, they both operated on me at the same time: one took the left breast, the other one the right. And I have to admit, even if I found it hard to believe at first: the younger surgeon did a better job.

I just had, the "*transdingsbums*" story, and I can't help laughing out loud.[4] I feel happy, happy about my flat breasts and short, punky hair; happy that this nightmare will soon be over, and happy about all the encounters I had in the chemo room.

4. As we discussed in *Endnotes* how to translate this word into English we discovered that *'dings-bums'* is one of the few words in German that can take all three genders.