

Disability, pleasure and ageing: The pleasure principle

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Sep 3, 2024



My butt has been roughed up lately. Unfortunately, not in a fun way. As a wheelchair user for over 40 years, I typically sit the entire day, except for when I sleep.

Throughout my life, I have used a variety of cushions. When I was a child, my parents didn't know what I needed, and I sat on woven mats and other firm surfaces that are not healthy for a butt that needs to be repositioned to improve circulation and prevent pressure sores.

As wheelchair cushions advanced to ones inflated by air, I thought my butt was going to be okay. Over the years, my butt became a bony, flabby region with little fat and muscle.

My ass isn't a luscious, juicy apple for someone to lick, caress, and penetrate. I never paid attention to it except for health reasons; it wasn't a part of my body that I admired or felt good about. My butt's sole function is to keep me upright allowing me to do everything I want to do.

Recently, the ischial tuberosity, also known as the sit bones, protruded enough that I began to have a few scabs on my butt. Nothing to worry about, or so I thought. The scabs quickly developed into open abrasions – angry, pink open patches on both butt cheeks that threw me into panic mode.

Like many wheelchair users, I know how easily skin can break down, how its abrasions can deepen to the point where bone, tendon, and muscle may become exposed and infected.

Several years ago, I had a pressure sore on my ankle that took eight months to heal. At the time, I remember thinking I was lucky that it wasn't on the butt after a lifetime of sitting.



Image by: [María del Río](#)

Now, shit had hit the fan, and my deepest fears came true. Not only was I concerned about these abrasions becoming pressure sores, but they furthered the sense I was undesirable.

Because of increasing weakness with swallowing and breathing, I had a serious hospitalisation two years ago, resulting in a tracheostomy at my neck that's connected to a ventilator. I am dependent on the ventilator 24/7, and I use a feeding tube for nutrition and hydration. It's a miracle I am alive, but I've lost my relationship to pleasure.

The seeping wounds on my butt only added to the fear of a future without sexual pleasure. I respect my disabled body for it has withered from progressive neuromuscular disease but remained resilient, fighting back multiple serious illnesses, chronic pain and brushes with death.

My bony, bent, weakened bits have been held together through sheer will to adapt and to keep living my best life. I am grateful to my body, but do I love it? I know I should, but there are moments that are exhausting, one crisis after another, or concurrent to other major medical concerns.

In the Before Times, I was able to please myself with great creativity and dexterity. Because of muscle contractures, my elbows are bent, making it difficult for my hands to reach my genitals.

The first time I masturbated, I remember in the heat of the night, wet and horny in bed, I couldn't touch my clitoris with my hands. And then I realised my watch wristband has a firm curved shape. I took it off and dropped it down, my hand holding it like a fishing pole waiting for contact. I slipped it under my pajamas and slowly began stroking my clitoris by moving the watchband up and down to the point where I orgasmed.

Sweaty with sweet relief, I then went further down and was able to slip it into my vagina, slick with secretions, and enjoyed the sensations as I moved it in and out, careful not to let go and drop it, which would puncture my privacy by requiring someone to pick it up for me.

I was not (and still am not) at the place where I felt comfortable having a carer pick up the watchband, or subsequently a vibrator. However, many disabled people have their carers assist with sexual activity, ranging from getting them ready, positioning their bodies and cleaning up afterwards.

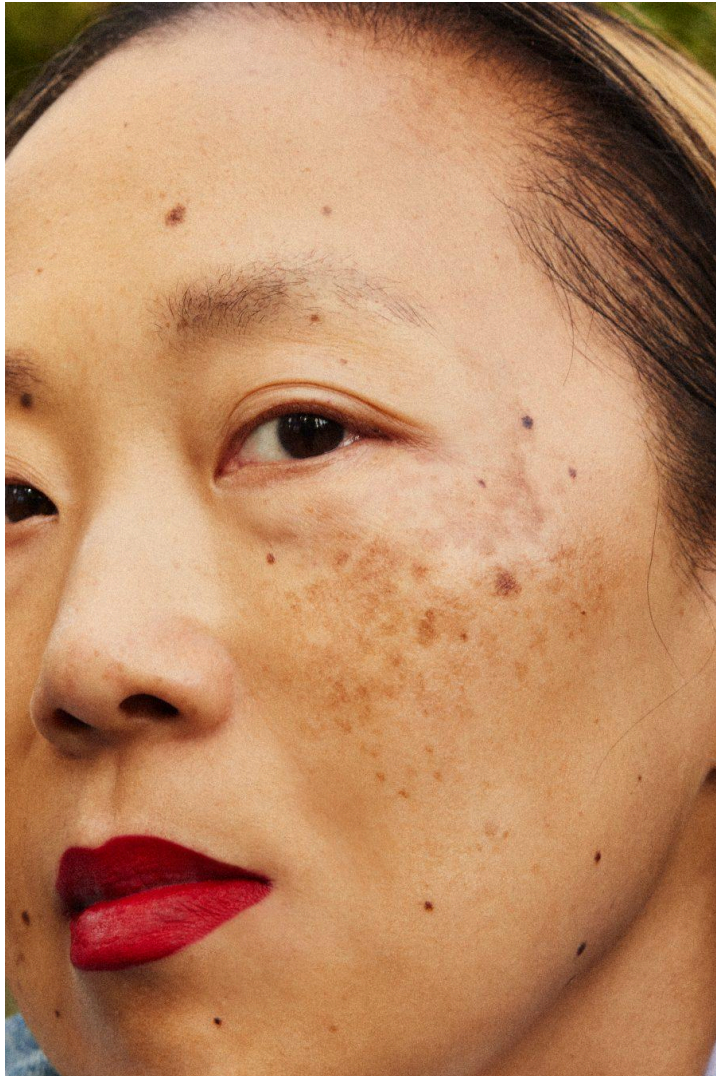


Image by: [María del Río](#)

Later on, to maintain my ability to discreetly masturbate when I lived with family, I looked for various clitoral vibrators and found one that looks like a pen that could be easily reached and hidden in plain sight.

When sitting at my laptop, it allowed me to masturbate independently. I took a pencil and wrapped it to the top end of the vibrator several times with tape. Secured, the

vibrator could reach my clitoris without much effort. I tilted and reclined my power wheelchair and placed a cardboard coaster – one you can find in a bar – over the top of the pencil.

Guiding the coaster like a joystick, I applied pressure and stimulated myself from different angles by rotating or moving it back and forth. It was precarious masturbating this way with the chance that parts of my clit kit would drop to the floor, or my parents would walk by and hear the buzzing.

It was worth it each time – I orgasmed multiple times with the satisfaction that disabled ingenuity gave me such pleasure. If I could, I would high five myself after every session.

Even though I never had partnered sex, I didn't feel like a virgin. I was a sexy beast that enjoyed myself thoroughly on my own terms.

This pleasure belonged to me and me alone.

About a year before the hospitalisation, it became harder to orgasm due to perimenopause. Even with a hormone patch, everything was different, coupled with the advancement of my disability.

I became permanently dislocated from pleasure in the months when I came home – in what has become the After Times. There was little time or desire to masturbate or have thoughts of other kinds of pleasure as I had to heal and adjust to a radically new cyborg body, with complex medical needs, that no longer felt mine.

While other people think of their bodies as playgrounds, mine is a treacherous landmine. I had to physically navigate unpleasant experiences that resulted in many trips to the emergency department. I continue to process trauma, loss and feelings of shame and disgust about my body, despite the innate confidence and healthy ego I possess in spades.

These contradictions and tensions can hold true simultaneously. Looking at photos of my pressure sores, I was horrified to see the dark brown leathery skin of my taint

and genitals. This was not what I imagined down there. These feelings are not born out of vanity; they run deeper than that, and I continue to struggle with them today.



Image by: [María del Río](#)

For some unknown reason, I became incontinent after the hospitalisation. I use a straight urinary cath several times a day, requiring a lift to transfer me from my wheelchair and bed.

What used to take only a few minutes on the toilet now takes almost an hour. My pussy is sprayed, swabbed with iodine, and wiped. A carer spreads my labia open, inserting a plastic catheter tipped with lubricant into my urethra. Afterwards, I am sprayed and wiped again to prevent urinary tract infections.

I also have faecal incontinence, which is not fun. Overnight, when the feeding machine is connected to my stomach, I poop on a large absorbent pad that is on the bed. I used to be able to feel the churning in my bowel and push when needed, but now it just happens even when I am asleep. Unpredictable poops make me nervous at the thought of potential skin breakdown unbeknown to me, until I wake up to suction the secretions out of my lungs, turn to the side, or cath once again.

The constant trauma of a catheter poking into the urethra and surrounding areas, the spreading of the labia wide open, the wiping, cleaning, and disinfecting of the vulva and anus has medicalised my genitals out of necessity. It changed the actual physical sensations of my clitoris, numbing them to extinction.

I am no longer a sexy beast but instead a raggedy full-time patient, which infuriates me.

Finding and regaining pleasure is important to me even more so now, since I turned 50 this year and am officially in menopause.

In the Before Times, a disabled friend of mine and I talked about going to a play party. I wonder what that would look like if I went to one in my current iteration, with all the machinery and tubes tethered to a shrivelled, bony yet flaccid body with open wounds on my ass.

Because of, not in spite of, the current status of my health, I still lust for pleasure. Hands stroking my thighs, fingers running through my hair, an arm wrapped around my waist. I want to touch, taste, feel everything. My twisted body writhing from delight rather than pain.

To quote the inimitable Janet Jackson's song 'The Pleasure Principle':

You might say that I'm no good

I wouldn't trust your looks, baby, if I could

I got so many things I wanna do

Before I'm through

Disabled pleasure knows no bounds, bringing an intimacy that goes beyond romantic love, genitals or penetrative sex. My pleasure principle is expansive, grounded in flexibility, access, openness, and innovation – even though I am focused on clitoral stimulation at the moment.



Image by: [María del Río](#)

If I have a lover, that person would not just accept my body but worship it along with all of me.

My brain, the largest sexual organ, is as depraved as ever. However, it is such work resisting all the forces that I encounter as an Asian-American disabled woman: structural oppression, medical ableism, barriers in the social and built environment, personal insecurities and fears. Resistance to the inevitable cumulative onslaught of ageing and progressive disability.

At night, after my carer caths me once again, turns on the feeding machine, props pillows strategically under my arms and legs, pulls the blanket over me, turns off the light and closes the door, I feel exhausted, alone and vulnerable. I am surrounded by people who love me, but there is a void.

Is it the absence of pleasure or is it something more? Is it the absence of someone to love and care for who reciprocates, wanting me for my body and soul? What if something else is missing from my life entirely?

I wrestle with these questions, and I don't know what the future holds. What I do know is that my life is full, and I still have capacity to give and receive what the universe throws my way.

Dear Pleasure, I miss you, my beloved! It's not a failure if we never meet again, but I do yearn for you night and day. Will we have a happy ending together?

If you return in another form, I will welcome you with open arms for you are my joy.

Love always, Alice.