

DISABILITY

and the

BODY

A NOTE ON “DISABILITY AND THE BODY”

Writing about the body, as with writing about disability, is often in danger of quickly becoming abstracted from the living thing it’s talking about.

In her book *Bodies That Matter* Judith Butler writes:

I could not fix bodies as simple objects of thought. Not only did bodies tend to indicate a world beyond themselves, but this movement beyond their own boundaries ... appeared to be quite central to what bodies ‘are.’

Bodies are changing things, and things that take a lifetime to understand, yet they are also subject to incredibly simple acts of violence. As people who are often subject to decisions made about us (without us) the complexities of our bodies can be easily ignored by language and assumptions placed upon us: “visible”, “invisible”, “crippled”, “functioning”, “broken”, “abnormal”.

As impossible as it may be to fully or perfectly render our bodies and experiences in words and images, it is important that we as disabled people are the ones doing so. This is our narrative, and we are the only ones who can tell it, as no one is an expert in disability more than disabled people themselves.

This zine is a celebration of the disabled body in all its forms, but also an interrogation of it, a love letter to it, a rant about it, and a prayer to it.

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I WEAR
LIPSTICK
WHEN I SMOKE
CIGARETTES
AND
I WEAR
DRESSES
WHEN I USE
MY
WALKING STICK

*I Wear Lipstick When I Smoke Cigarettes And I Wear
Dresses When I Use My Walking Stick
(Georgina Taylor)*

Bed

Maybe my life would be easier,
If I got out of bed,
And I just did my work,
But each morning I still,
Face the unclimbable mountain,
When I wake up; No energy,
Left; Drained,

Once again I am unable,
So drowning in bed sheets,
I swim back down,
Into the solace of sleep,
To feel nothingness.

(Jess O'Brien)

WORDS ARE MADE IN HIS MOUTH

but you have to make yours
with your hands
and all of your fingers are
broken

HOW DO YOU MAKE YOUR MEALS

it's the same thing everyday
having to make a body
without thinking about a body
when everything around makes you think about a body

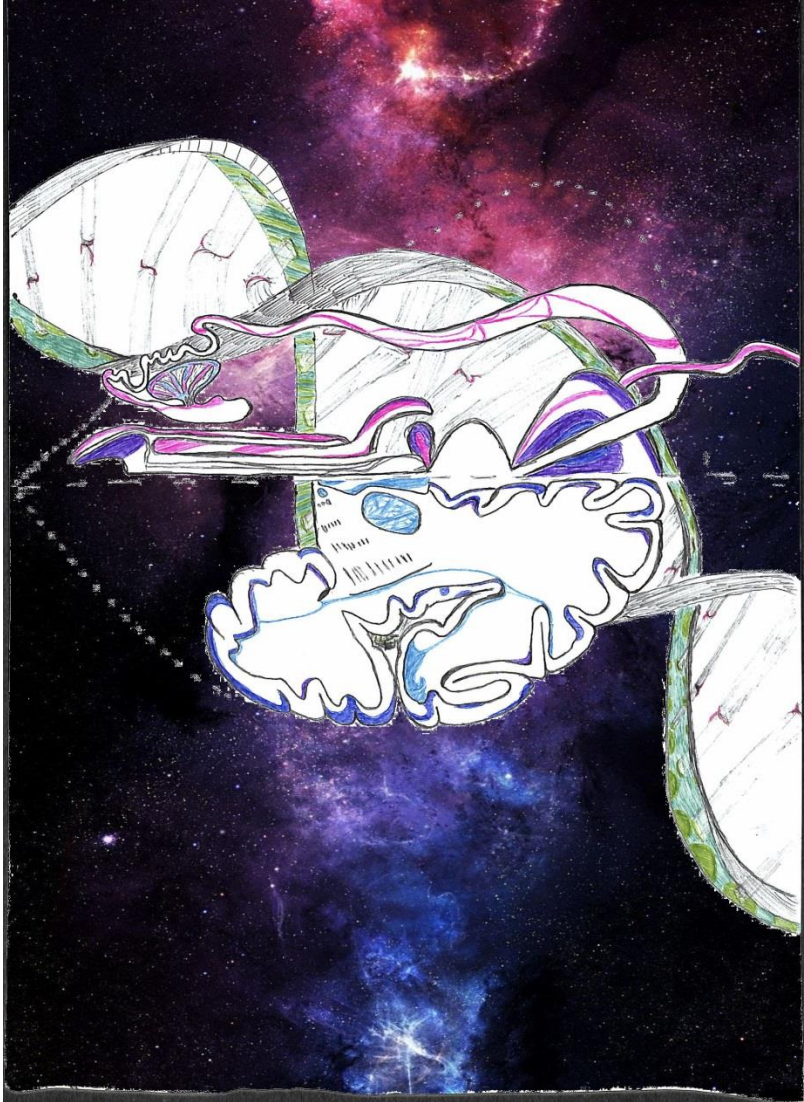
IF A BODY CATCH A BODY

catch my body
on keen mornings
under a rainbow umbrella,
rotting and foul

EXECUTIVE DYSFUNCTION

history has been made by
someone else but please just
make me
get out of bed.

(Florence Oulds)



Dissect
(Work In Progress)

QWOP

Everything is edged in vagueness. I press against it and the fog presses back: a headache that starts between my eyes as I find the boundaries of my body. When I walk my feet drag. My tongue blocks the gap of my mouth. I move through a cycle: scrape, bruise, stub. What is under my fingertips?

A ball flies towards me. Ball and the sun and my body. I see the ball and move my hands. These two things are separate and they don't connect. How could I connect them? The ball is past me and I cannot understand how to move my hands. Moving my limbs feel like a h game of QWOP.

Sometimes I feel my eyes twitch and I know my body is planning a revolt. It's taking me within myself as the pressure is thicker again. The seizure pushes through me and twists every muscle. Think, think and the feeling of *deja vu*. The dream world is only as tangible to me as my numb fingers.

One of my toes faces away from the others. I don't know when I broke it but it's been that way as long as I can remember. The vagueness stays inside me.

Alexathymia sounds beautiful but I don't know how to feel about it

(Isadore N. D. Auerbach George)



(Ximena Barker Huesca)

Aphasia

I could speak perfectly fine up until
the ripe age of five, well
as much as any scruffy infant can

Then I had my stroke (BANG), and as all that misdirected blood left the
hole in my heart and rushed to my brain
I felt my vocal chords still for what would be the longest
chamber of time

It is funny what people whisper about you, when you are unable to talk
Their eyes regard me with suspicion, determined on spotting some
(little) way I am intellectually deficient,

// intent on spotting // why I am intellectually challenged

like I am volatile and liable to throw a hot tantrum at any moment
I nod and smile at them with my oft-gritted teeth
I can hear, think, feel and act the same as anyone
Inside my mind runs a stream of words like yours
It is just the speaking and reading of those verbs which perturbs me
My therapist tries very hard with me
I comply, opening my mouth and slipping it to the desired shape,
I can make a perfect 'O' should they bequest me

// a perfect circle

Likewise, I can write fluently, pressing
pen to page
Yet when I read it back I find that letters
do not add to words
like absurdist stripes
on chalk-white cat fur

Ink will be ink

Do you think that I
am able-bodied?

Aphasia is the name of my medical diagnosis
but before you put your finger on it perhaps you should challenge
yourself

Draw up a new chalkboard and ask where the emphasis lies
with defining a body of *perfect* health

Just recently I was lucky to meet Steven Hawking, perhaps one of the
most luminous minds in his generation

Near-completely paralysed, he sat in his motorised wheelchair with a
motorised voice as he entertained a reception

Maidens in ball-gowns sipped their white wine and gazed at him
Bachelors with shirts undone at the top-button kept one hand in their
pocket

Meanwhile at that same party I met the most indignant woman who
managed to offensively
chat about nothing
and spent all her time swatting away flies...

I sigh,

silently, of course

I yawn in silence too

Cough in silence -

Sneeze in silence!

Except for a swoosh of rushing air

Or soft panting when I laugh in grand company

*/(Do you really make the most of a so-called able body? A visibly able-
body? A body that can say what you want it to say.)*

A gentleman and friend from my charity group intrigues me

He had a stroke at a young age too

Yet unlike me

He has flawless speech

and his face is highly asymmetrical:

Skin waterfalls down a side

Whilst the other is curled like a whirlpool

He was once left and called undateable by a woman he met online

Who was so surprised

after rapport and phone calls
to find she'd fallen for such a guy who she now thought would need too
much support
as she left the restaurant appalled
he scoffed, paid his own bill and later told me 'he's already over her'
and he's dreaming of someone new
I have fingers crossed hoping that it is time for me to make a move

I don't need to be a fictitious, idealised, athletic, rubbery, plastic, mid-
twenties
To be happy and in love or have a conversation that doesn't involve a
quest for perfection

If stress and depression leave someone bed-bound, are you going to
be the one who looks upon them as optimisable?
Or are you the scientist with the technology to free horses by inventing
an automobile?

Lastly, what can you voice about those humans who are left in a
coma?

Those humans who have journeyed into a body that you can provoke
no response from?

But lie them in a spinning, white, circular MRI scanner and watch
the live-streamed images of their brains evoke every colour

Do you give up on them? Switch them off?
Are they unreachable?
Will *you* no longer talk to them?

You have all the power to speak and to listen
infinite languages link us
like the blending seasons.



Still Smiling
(Work in Progress)

Dr. Self-Love, or, How I Learned to Stop Worrying and Love the Cane

CN: medical procedures, ableism, boundaries being violated

I have a disabled body. That alone can be a controversial statement in some circles, for reasons that could take up a whole other article, but the simple truth is that my body cannot do all the things an abled body can, at least not in the same way and with the same degree of ease. I live with a connective tissue disorder (among other things), and various surgeries and misadventures later I have arms of different lengths, a tendency to become fatigued and in pain after minimal exertion, and a shiny black cane to help me get around. And then there are my less visible disabilities – while my autism and dyspraxia originate somewhere in my neurology, they nevertheless express themselves through my body in various ways, be it through my numerous accidental injuries or my reduced tolerance for supposedly ordinary sounds and textures.

Though I was born lacking only functioning collagen, becoming an adult disabled woman has taught me that many well-meaning individuals, especially in the medical field, assume I also lack the basic personal boundaries and autonomy afforded to most abled people without a second thought. In a sense, this is partly true – it's hard to care about having your clothes cut off when you've broken your back and need an IV more than your dignity – but it should not be taken as obvious. There's a myriad of reasons why disabled people are either outright barred or openly discouraged from making choices about what is done to their bodies in a medical setting, but the actual act of existing as a disabled person is not one of them. It is the attitudes taught to everyone in society, not the differences in my DNA, that make establishing boundaries with doctors and caregivers such a challenge for me.

One thing abled doctors tend to assume about my disabled body is that it is a burden to me, and that I want to get it functioning as close to an abled body as possible, regardless of the cost. While there is a part of me that would welcome a cure for my constant fatigue and joint

troubles, agreeing to medical procedures or treatments in order to gain or maintain abilities is far from the obvious choice it might seem. Sure, I could spend a great deal of time and energy on intensive physiotherapy that would enable me to walk longer distances unaided – but why should I be pressured into doing that when I could also spend that time and energy on working, socialising and enjoying my life with the help of my cane? By choosing to use a mobility aid, I'm not choosing to be disabled, as though my disability is something that could have been avoided if only I'd wanted to work harder. Instead, I'm choosing not to sacrifice the parts of my life that are, to me, far more important than being able to walk as an abled person does.

Much as it is assumed I want my body to function in exactly the same way, abled people seem to operate under the assumption that I want to look as abled as possible, too. It's amazing how deeply ingrained this assumption is – I have always tried my best to be body-confident, but still underwent surgery with little expected medical benefit to try and make my arm look more 'normal'. Of course, I see little problem in making these surgeries available to those who want them, but what only struck me as I was recovering was how nobody had ever asked me outright if I did. It was simply assumed that, as there was a way to make my body look more like that of an abled person, there would be no contest between having surgery under general anaesthetic and leaving it as it was. If truth be told, there *wasn't* much of a contest when I accepted the surgery, but not because the appearance of my arm was causing me any great distress. My main motivation came from this very idea that abled bodies are more valued and more desirable than disabled ones, and the knowledge that looking more abled would, unfortunately, be of more benefit to me in society.

I realise at this point it probably seems as though I'm whining about 'the system' with no clear ideas on what should be done about it, and I'll concede that's partly true – I don't yet know how best to suggest a balance is found between making options available to those who want them whilst avoiding pressuring those who don't or perpetuating ableist assumptions and viewpoints. However, just understanding that these assumptions and viewpoints exist has been incredibly helpful to me as I grow up and begin navigating the medical system by myself. Learning that I was allowed to say no or ask questions of my doctors was a life-

changing realisation for me; questioning the reasoning behind proposed procedures and treatments has helped me become a better advocate for myself. It was not at all easy for me to begin viewing my disabled body as something to be valued and celebrated rather than as a problem to be dealt with, and I don't expect it to be easy for anyone else either, especially in the face of so many voices in society telling us the opposite. But it is both liberating and an act of self-love to permit yourself to be visibly disabled, to get that mobility aid you've been wondering if you are 'disabled enough'* to use, to live out your best life instead of putting on an exhausting performance of ability. I am still looking for the courage to do this to my fullest – it is a tiring and difficult journey, but it's one of the most worthwhile things I've ever done, both for my physical and mental health.

*(By the way, there's no such thing as 'disabled enough'. If you're wondering if that mobility aid will help you, and you have the resources to do so, you should absolutely give it a try right now.)

(Emma-Louise Adams)