

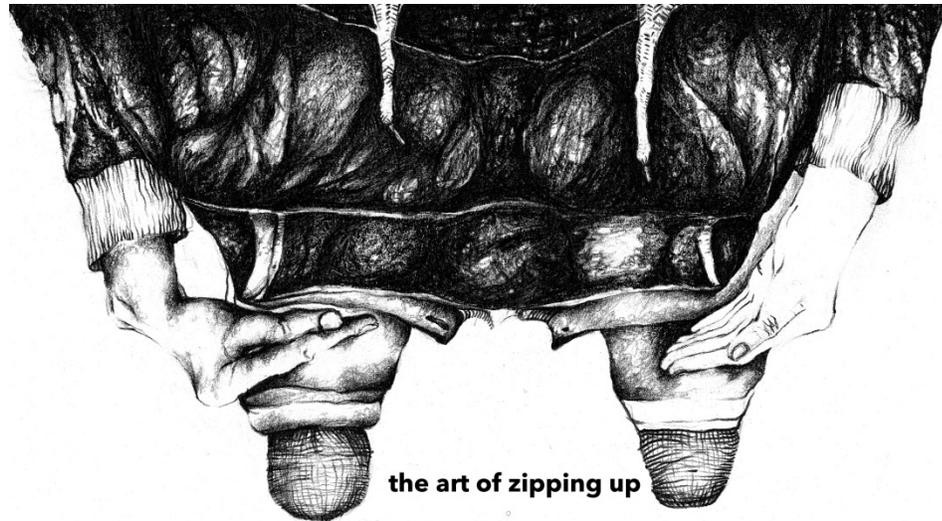
IMAGES OF HEALING AND LEARNING

Performing Pain and Inflammation: Rendering the Invisible Visible

Artwork and captions by Arseli Dokumaci, PhD

Abstract

These drawings represent everyday experiences of an artist who has been living with rheumatoid arthritis since her teenage years. Over the course of 20 years, the disease has damaged a series of joints in her body. Pain and inflammation accompany the most mundane of her movements and gestures. Fatigue and side effects of medications are routine parts of life. None of her impairments are publicly recognized and duly accommodated, as she is not (yet) visibly disabled. Asking for a seat on the bus, for instance, turns into a thorough social negotiation, as does having to constantly remind people that she actually is disabled. Lacking visual signs of disability, she is often accosted for “evidence”—an authentication, a reminder of “her” disability. With these drawings, each of which describes the artist’s daily negotiations with pain, inflammation, and fatigue, she seeks to render visible what remains locked up within the boundaries of her skin.



One morning, I was in the bathroom. Stood up from the toilet, pulled my jeans up in the slowest of motions. Then came the biggest challenge: How was I going to zip up? My hands, elbows, and shoulders were inflamed, tender, and painful (as they often are). My fingers were swollen to the size of mini-bananas. I could not bend them even to slightest degree needed to grasp the zipper. Sliding that tiny thing up meant pushing my fingers in the direction of pain, which would make my fingers bend outward. Within this constellation, that tiny zipper pull felt like a ton of weight put on one side of a lever, and I had nothing to put on the other side. *Dokumaci, 2015*

Figure 1. *The Art of Zipping Up*, by Arseli Dokumaci

Caption

A pencil drawing on a white surface of someone's upper body seen from the person's own viewpoint as the person is standing up. The person's arms and elbows are bent toward the person's belly, as if the person is about to engage in an action.

**Some arms carry things.
Some arms are carried in pockets.**

My left shoulder was damaged by inflammation a long time ago. It is relatively smaller in size than the right one. I can hardly ever move or do things with it. In fact, I often times carry it around. This is why I tend to wear clothes with pockets. I put my hand in my pocket, let the pocket carry my arm, and take its weight off my shoulder.

Dokumaci, 2015

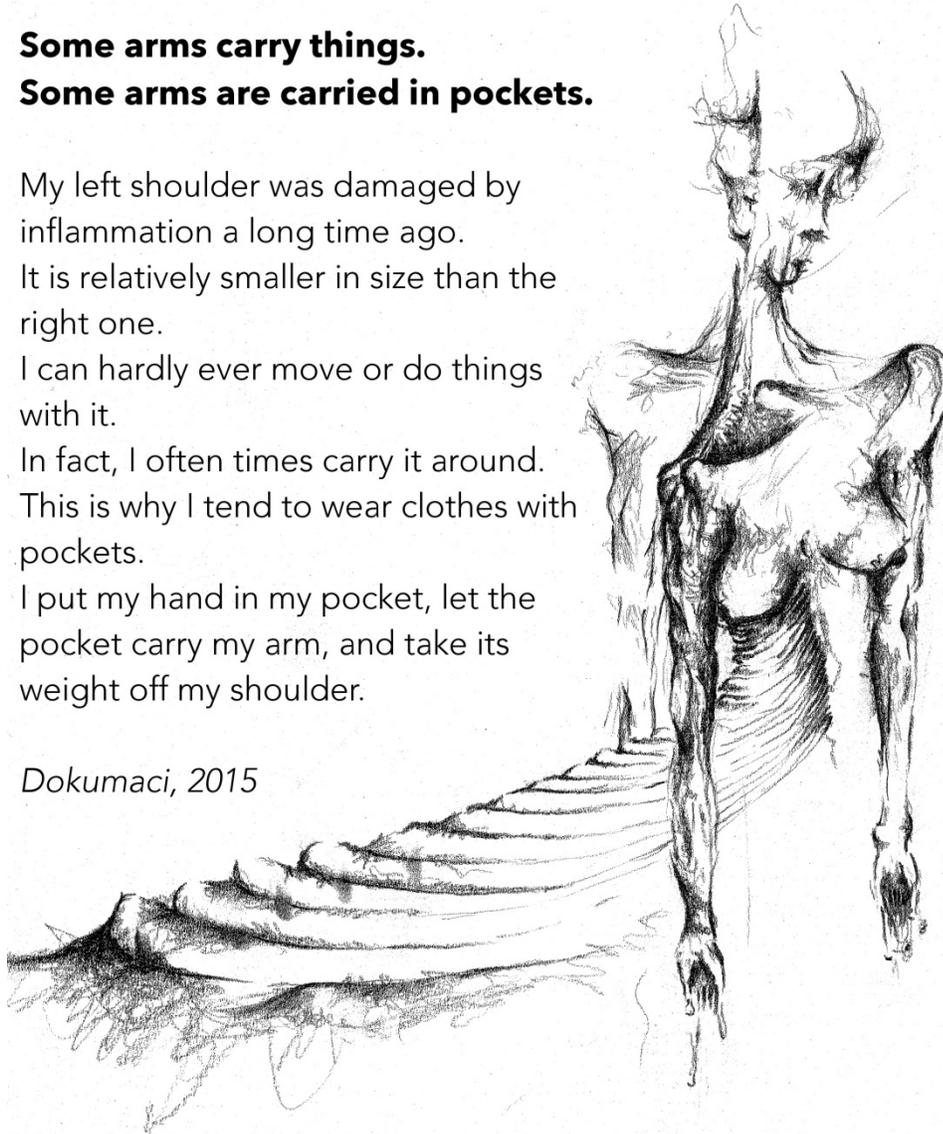
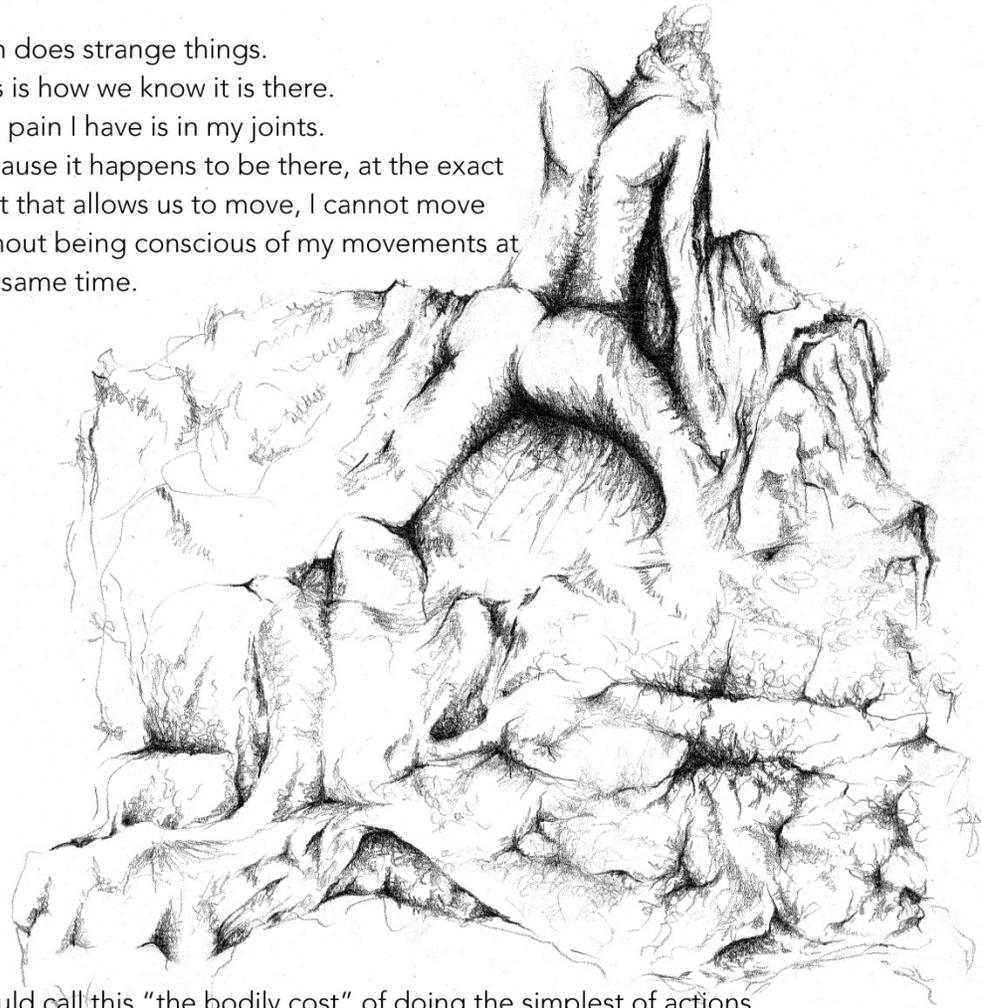


Figure 2. *Some Arms Carry Things. Some Arms Are Carried in Pockets*, by Arseli Dokumaci

Caption

A black-and-white drawing in which the body is split in half from the shoulders and the chest is transforming into steps.

Pain does strange things.
This is how we know it is there.
The pain I have is in my joints.
Because it happens to be there, at the exact
spot that allows us to move, I cannot move
without being conscious of my movements at
the same time.



I would call this “the bodily cost” of doing the simplest of actions.
The bodily cost of lifting a coffee mug to your mouth; the bodily cost of putting
on your socks; the bodily cost of turning the key in the lock; the bodily cost of
hugging a friend. And even, yes, even the bodily cost of pulling the feathery
sheets and fluffy duvet over your body while sleeping at night... Dokumaci, 2015

Figure 3. *Fighting with Feathery Sheets and Fluffy Duvet*, by Arseli Dokumaci

Caption

A pencil drawing in which a woman’s back is mostly exposed and her legs disappear under a cluttered surface.

Arseli Dokumaci, PhD, is a postdoctoral fellow in the Department of Anthropology at the University of Copenhagen in Denmark. She received her PhD in performance studies from Aberystwyth University in 2012 and completed a *Fonds Québécois de Recherche sur la Société et la Culture* postdoctoral fellowship at McGill University’s Department of Social Studies of Medicine in 2016. Her research interests include disability, daily living with

chronic diseases, quality-of-life measures, everyday performances, affordances theory, and visual methods.

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