

MY RARE CONDITION

The pianist takes the first bars on the record. The soft voice of the teacher in the background. I turn to the railing. I let my hands breathe in the opening, then land them delicately on the railing.

*The first position, demi plié...
... and relevé, demi-pointe...*

I loosen up, the body knows what it's doing.
Thoughts are wandering someplace else.

*Bend your right arm over the head...
... same with the left..*

Suddenly skin refuses to give in and movement stops for a fraction of a second, as if this local tension came as a surprise. I feel how the bulges of ribs become visible when the skin tightens around them. My left side can barely do half of what the right one just did.

The third position, demi plié...

The skin on my ankle does not give in either. It has tightened even more since last week. In the mirror, I can see everyone else doing the movement with the greatest of ease while I sink into desperation for a moment. It's not the potential I lack. As I lose more and more of my ability to move, I wonder what I am even doing here. I'll never become a ballerina.

I'm supposed to have an appointment with the specialist, big decisions ahead. To try out new medication or not? To let the tensioning of the skin limit my everyday life or to face the heavy side-effects of another course of drugs? Can the psyche of a small person handle the psychological consequences of the disease progressing without even trying to stop it?

I can't help but feel a little jealous. How many teenagers need to concentrate on something like this during a ballet class? At times it feels like the sickness doesn't leave room for any other thoughts, as if there weren't a single moment for me to breathe freely, as if I always had to strategize my life like a war. The doors are open for the healthy, scleroderma closes mine.

And the leg slides to the floor...

Left shinbone nastily knocks onto the hard floor, the already bruised knee will be bruised again tomorrow. Moments like these you understand the importance of fatty tissue. Such self-evidence, many of us have too much of it. I, for one, have none.

They say that a sick person usually feels loss when the illness takes away something important, like health, from them. It also makes them lose many other things from their everyday life. Some are little, some are big and important. Not only do I lose my fatty tissue, but with it go my looks, my energy, those innumerable opportunities I used to have...

*... port de bras away from the supporting leg...
A large movement with the arms,
back leaning slightly to the back...*

The vertebrae of the spine crack as the back bends and the shoulder blades shiver in pain. The thought of loss still bothers my mind. Haven't I also received something good out of this? I

wonder how much specific knowledge and maturity this condition has brought to my life. Understanding, prioritizing and proportioning. The darkest clouds make us find the brightest silver linings, and those linings are what make a person smile. How many smiles would I have missed without all of this?

Neither the amount of patience nor the support and caring my close ones have shown me can be measured by any known indicator.

*Rise up again,
hands back on the railing.*

The open window brings a fresh autumn-breeze into the room. Breathing it feels wonderful, but at the same time I feel my fingers slowly turning pale while the coldness sneaks into them. Veins contract, blood doesn't flow. Bit by bit a pinching ache has reached every finger.

Maybe that's what positive thinking is all about, trying not to think only about the loss? In the end, what we have here is only for rent. None of us leaves this world in our body, no matter how health or sick you've been. If nothing is truly ours, do we deserve anything more than we get?

*Tendu to the right...
...passé par terre...*

I sigh silently when I feel the sharp pain in my soles. Only yesterday I thought I could ask the teacher to help me to buy ballet shoes. Maybe I could feel like a ballerina for a moment, before scleroderma ruins my chances to do it. But what would I say to the teacher, how would I back this thought up? How to explain to an outsider in a short time everything that scleroderma involves so comprehensively that she would understand, when I haven't been able to explain it all even to myself?

*Back to the first position,
lower your hands,
and the music ends.*

I look in the mirror. My natural will to live beats the desperation, concentration returns to the room. I see a good posture, a smiling face. I see a person who despite the hardships enjoys her life to the fullest.

That moment I make the decision never to let scleroderma keep me from dancing. I decide to focus on the doors that are still open to me, not to the ones that have been shut already. There's potential in me to do almost anything and I won't give up any chance to use that potential.