

# Access Rider

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When you have chronic illness, life is reduced to a relentless rationing of energy. It costs you to do anything: to get out of bed, to cook for yourself, to get dressed, to answer an email. For those without chronic illness, you can spend and spend without consequence: the cost is not a problem. For those of us with limited funds, we have to ration, we have a limited supply, we often run out before lunch.

– Johanna Hedva: *Sick Woman Theory*

I have a chronic inflammatory autoimmune disease and fibromyalgia syndrome. As a result, I experience chronic pain, concentration problems („Fibro-fog“), chronic fatigue and am less resilient than other people. Stress, sitting or standing for long periods of time and cold weather exacerbate my symptoms. Relaxation, gentle exercise (swimming, Pilates, etc.), massages and warmth alleviate my symptoms.

This document is an attempt to communicate my access needs in a work context. It is incomplete and will change frequently over time. I am constantly learning and will update this document regularly.

## **My access needs to be able to work with you:**

**Predictability:** A clear, predictable schedule allows me to incorporate rest periods, physiotherapy and exercise into my daily routine. Important appointments and deadlines should therefore always be communicated in good time or be transparent for me to see. I try to be as flexible as possible with unplanned and spontaneous changes, but I have to prioritise my health.

**Communication:** Where possible, I request that work-related communication be conducted via email. I check my emails very regularly during the day on weekdays. Messages via private chats (WhatsApp, Signal, etc.) outside of my working hours are a source of stress for me. If something needs to be clarified immediately, I would prefer to receive a phone call.

**Physical conditions of workspaces:** Cold temperatures exacerbate my pain. In rooms where I spend longer periods of time (< 1 hour), the room temperature should never be below 22 degrees and there should be no direct draughts. To sit for longer periods, I need a beanbag or a comfortable chair with a flexible backrest. For longer working hours (>4 hours), I need a place to rest (mattress, beanbag or similar).

**Working hours:** I work between 11 a.m. and 6 p.m. during the week. Exceptions to this are possible by arrangement, but should not be assumed. I cannot work more than the agreed number of hours per week, as I would otherwise not have enough time for regular physiotherapy, exercise and relaxation. I cannot usually stand for more than 20 minutes at a time. I count rest periods of 10 minutes per hour as part of my working time. I generally prefer to work from home when my presence on site is not necessary.

**Traveling:** On work-related trips lasting longer than three days, I need to be able to go swimming (50m lane) near my accommodation or the venue (<15 min. Google Maps walking distance); if trips last longer than seven days, I also need at least one manual physiotherapy, osteopathy or massage session paid for. My accommodation should be a private room in a hotel or similar with enough space to put a yoga mat on the ground for stretching. I follow a gluten-free and vegetarian diet. I can usually get around other cities using public transport. For trips lasting longer than three days, I may need a taxi to transport my luggage.

**Other:** I am unable to carry heavy (>20 kg) and/or bulky (p.e. a mattress) objects by myself. I am trans non-binary, use the pronouns they/them and „diverse“ is my official gender record. I kindly request this to be communicated within your institution/project and considered in any bookings, documents or contracts.

I see this as an opportunity for a mutual learning process with my colleagues and do not wish to make any unilateral demands. I am constantly learning and am patient with those around me. In return, I ask that you proactively ask questions if anything is unclear or uncertain.

**I can only enter into working relationships if I know that my access needs as outlined here will be taken into account, planned for and implemented to the best of your ability. By acknowledging this document, you guarantee this should a collaboration come about. Any exceptions from it have to be agreed to by me in written form. I request that this document be included in every work/fee/contract agreement, e.g. with the sentence ‘The submitted access rider is an integral part of this contract.’**