A lived experience Journey

Me & my City

A shaky relationship



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Advancing Gender Equity in the Built Environment Seminar
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LOVE
MÜNCHEN


DOES YOUR CITY
LOVE YOU ?..
LIEBT
DICH DEINE
STADT?

I thought I knew my City‘s challenges…
…until I became one of them…

Experiencing the cracks

“You have Parkinson‘s“

“We won‘t tell anyone“

Parkinson Facts

- Progressive neurodegenerative brain disease where dopamine producing cells die off
- Second most common neurological disease after Alzheimer‘s
- Est. 10% dignosed under age of 50 -> Young Onset Parkinson‘s Disease (YOPD)
- Female brain health barely researched
- Stigmatisation

12 M

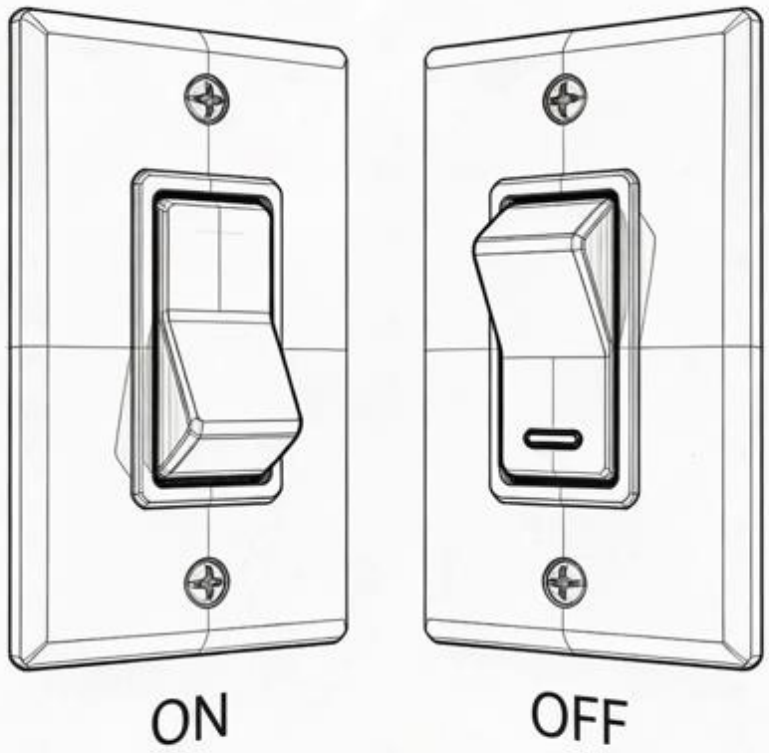
People living with Parkinson‘s

25M

Expected by 2050

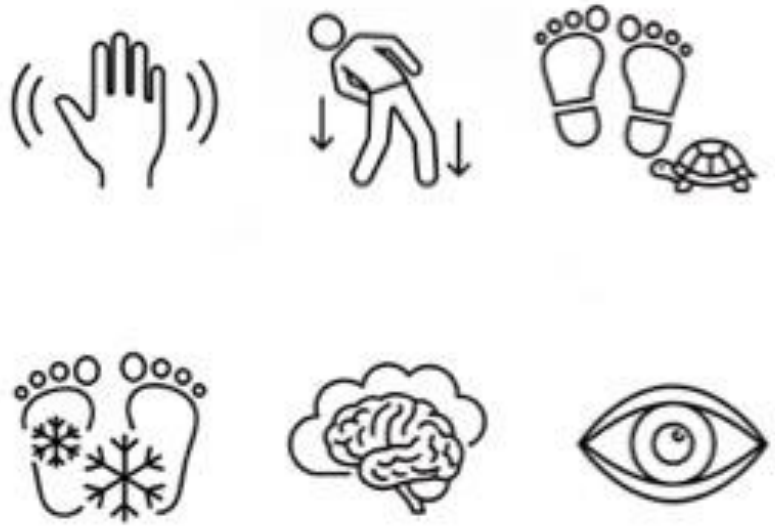
(Global Burden of Disease, 2021)

Like a Switch



Fluctuation

Motor & Non-motor Symptoms









Somewhere between

- visible and invisible
- “normal” and different
- mobile and immobile

Lived Experience: A trip into Town
Scene 1: Small Wins









10:30 am,

- Walking Speed, 6.4 km/h
- Effort excerted Medium
- Perceived Energy Levels: High

- 22 Degrees Celsius
- Comfort medium

"ON" Phase

Scene 2: Trapped

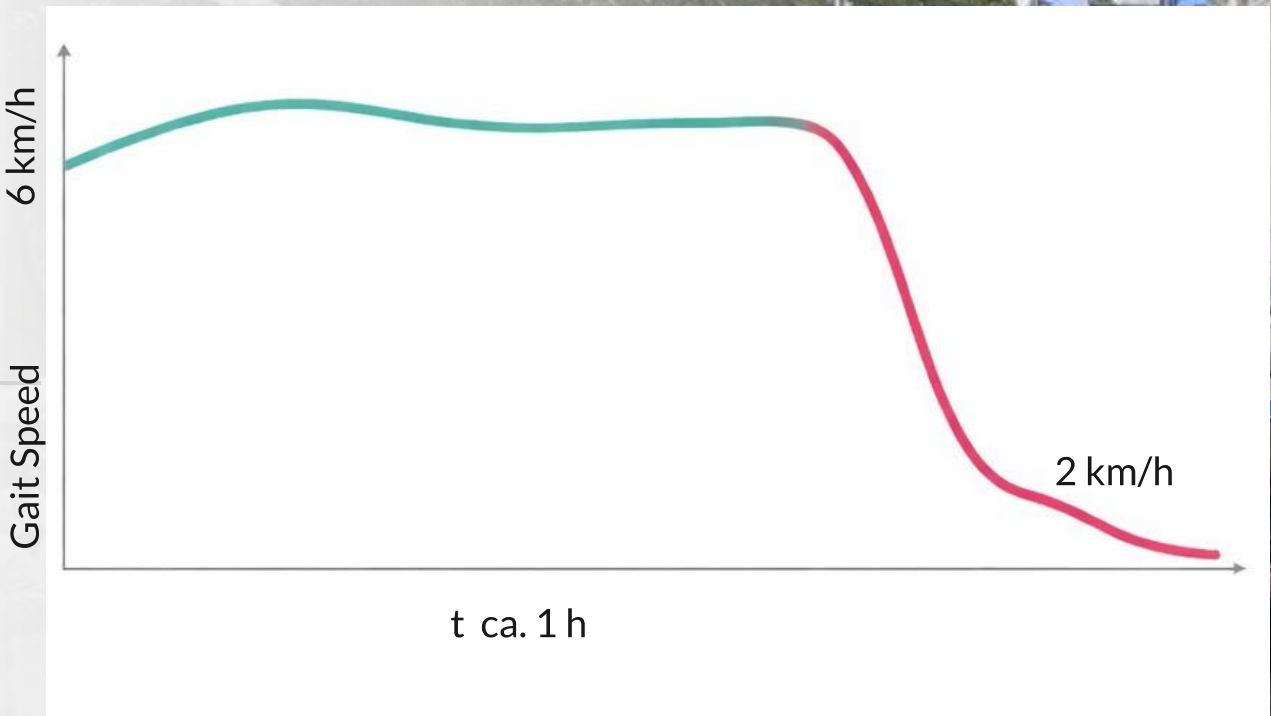
"OFF" Phase

11:40 am

27 Degrees Celsius
Comfort low

- Walking Speed, 2.1km/h
- Effort excerted high
- Perceived Energy low
- Tremour strong

Immediate action required!





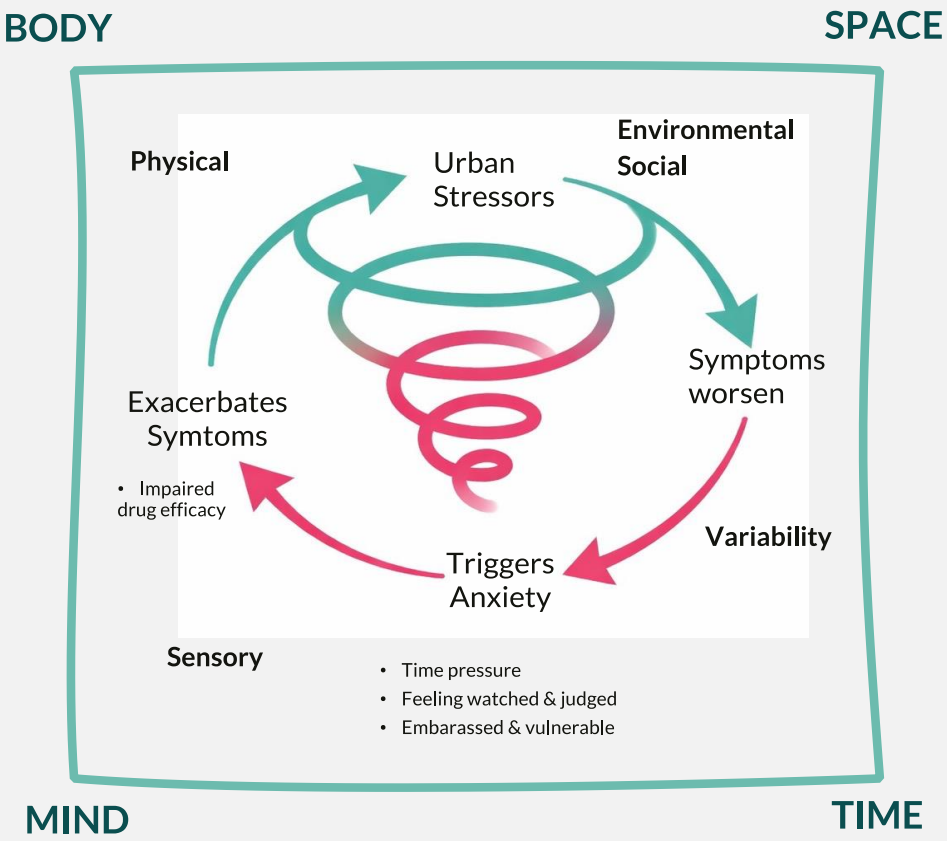
From Refuge to Sensory Attack

- Noise
- Lights
- Flooring
- Air Quality





Real lived stress response





Ability and confidence to sustain societal participation

My lived space risks to shrink with each negative experience

My active participation in society diminishes

Social isolation and increased anxiety

Don‘t add to my load



Patterns & FOG



Ambiguity



Long corridors

Help me manage stress



Longer crossing times

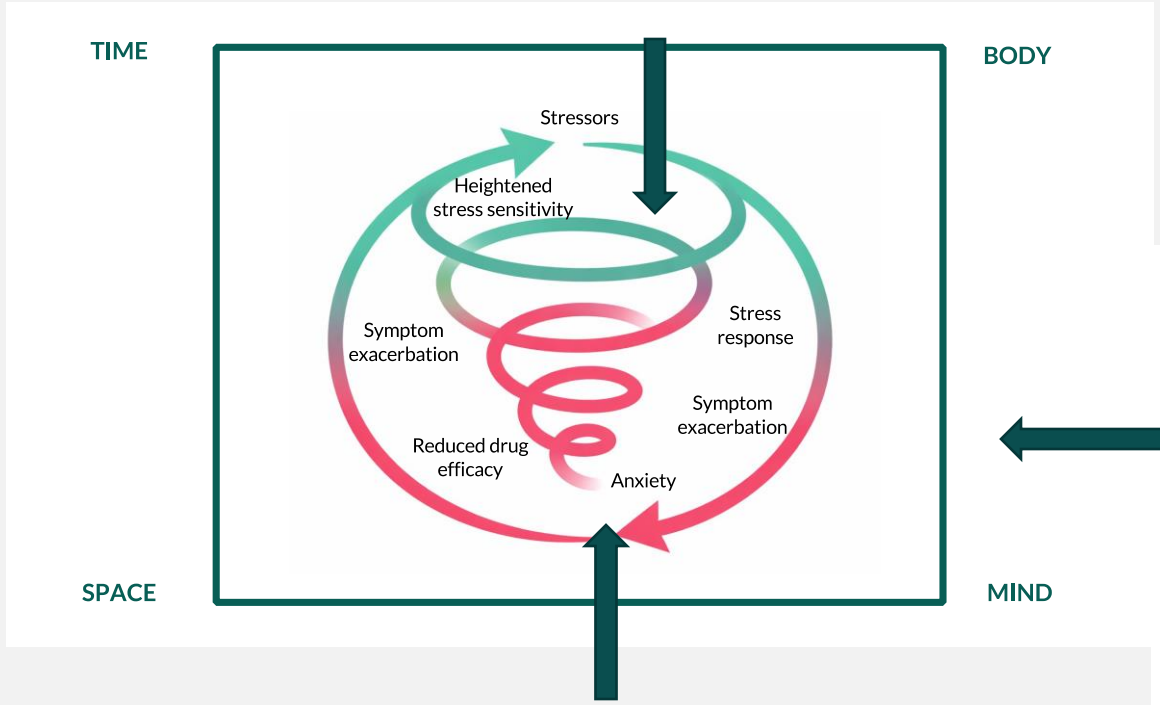


Chance to restore

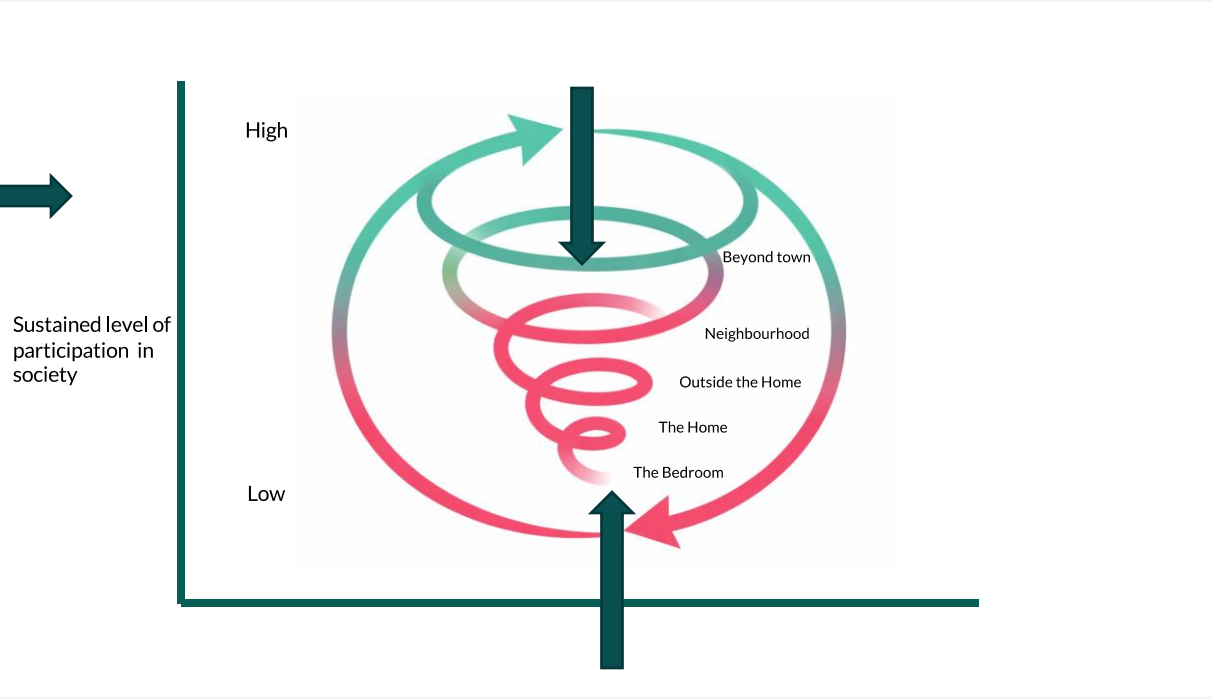


Information so I can prepare

Lived In-/exclusion



"Blending in and taking part- that's inclusion"



My lived experience lens
Thoughts on standards

What works

- Protect my right to participate in society
- Safety baseline
- Reduced need for constant advocacy
- Include lived experience in design

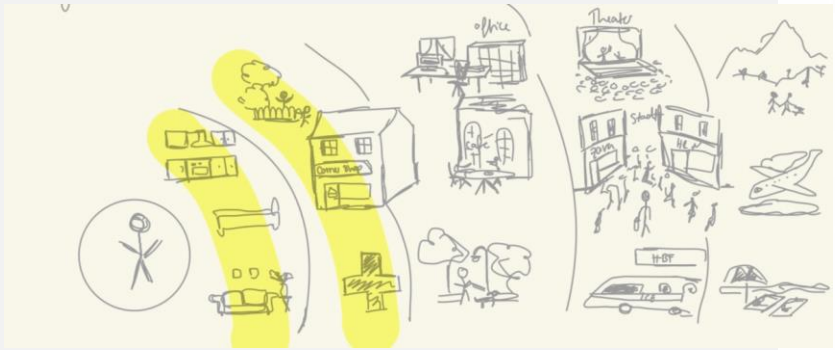
Room for improvement?

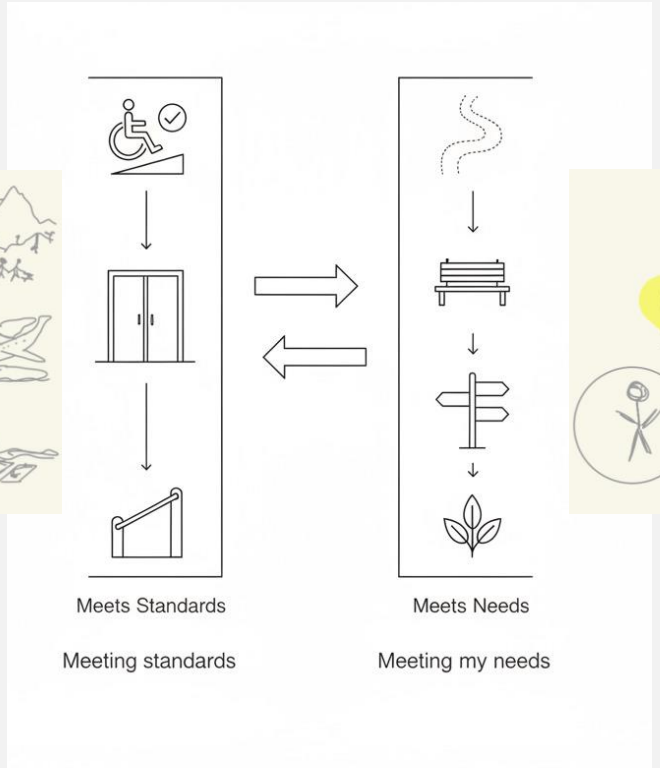
- Static focus, fluctuations & unpredictability not sufficiently covered
- Emerging neurological and sensory coverage - Focus!
- Recognition of “in between“ states and multiple conditions (co-/ multimorbidity)
- Lack of Parkinson-specific data
- Project-based vs. life space coverage



Between Access and Empowerment

Give me access and my world might shrink







Meet my needs and empower me to participate in society for longer

Let‘s stay connected

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This talk is part of the lived experience series

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