



# How to Ally

Including People with  
Disabilities and Chronic illnesses



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@\_franced





Why?



My story

2004

Jaw cracks, problems biting food

Odyssey of doctors



My story

2005

Diagnosis

Arthrosis due to **Factor-V-Resistance**



# Factor-V-Resistance

- Genetic disorder
- Enzyme which controls fifth blood clotting factor is not present or in low numbers
- Whole host of challenges



# Factor-V-Resistance

## Leads to

- Low blood pressure
- Bad circulation
- Blood clots and thrombosis
- Heart attacks, strokes
- Necrosis
- High propensity for miscarriage
- Misformation of the fetus due to bad circulation
- Painful periods
- 5-10 times higher feeling of pain
- Ineffectiveness of Ibuprofen
- Cold limbs
- Lethargy, low energy levels



## My story

Factor-V-Resistance is not researched, no cure!

5% of Caucasian population

Primarily thin women

0% - 99% symptom spectrum





# My story

2006 - 2017

“Getting by”



## My story

2017

Allergies?

Short breath, digestion, 10kg loss



My story

2019

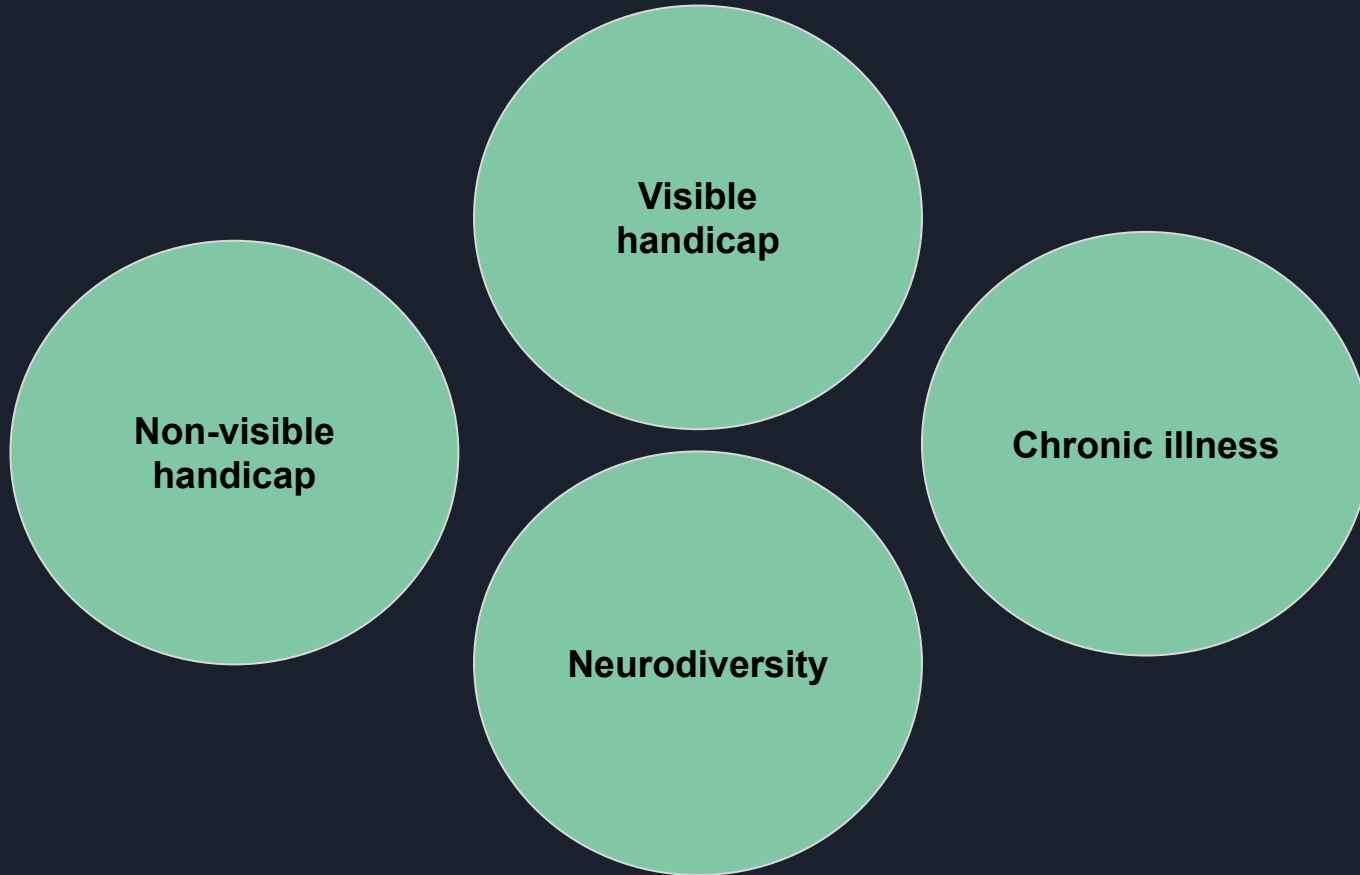
Severe intolerances caused by antibiotics?



What?



# More than the obvious





Mechanics = easy



Barrier-free



How?



# Support by

- Ramps / free of steps / elevators
- Subtitles
- Tools for reading & understanding (Braille, lenses, screen reader, audio commentary)
- Sign language interpreter
- Events at different times
  - Tired after work
  - Chronic illnesses get worse over the day
- Speakers who are living with a disability!
  - Representation
  - Attracts attendees with disabilities





The other

How to support people  
with non-visible  
disabilities?



# Room for individuals

## Spaces

--- for the body

--- for the mind



# The mechanics - fairly easy

- Quiet room for the hyper-sensitive, introvert, ... and easily “breakable”
  - Also: some people need to give themselves a shot or change dressings, etc.
- Caretakers: free caretaker / companion tickets, support animals
- Ask how someone wants to be greeted
  - Hug?
  - Kisses?
- Offer (plushy) chairs and networking opportunities sitting down



# The mechanics - fairly easy

- Mellow lights for those who deal with epilepsy or migraines
- Breaks for those who need to eat intermittently
- Food options - buffet makes picking and choosing easier!
  - Less mixtures, more containers
  - Follow pseudo-allergenic diet -> that already covers quite a lot
  - Add sign with ingredients
- Activities should be inclusive
  - One activity that can be done by all
  - Or: alternative options



# Language



Original quote

“To me, you are normal.  
I don’t see your disability.”



Original quote

“Everybody needs to recover  
and regenerate.

We all need our time.”



Original quote

“Others surely have it worse.”





Original quote

“Are you sure that it’s not  
psychosomatic???”



Original quote

“You just need to eat more!  
Everything will be fine then.”



Original quote

“But you were able to walk  
the stairs yesterday!”



Original quote

“Why are you always  
unable to commit  
when we want to do  
something?”



Language / Reactions

Is the comment...

... ableist?



# Ableism

“Ableism ([/ˈeɪbəlɪzəm/](#); also known as ablism,<sup>[1]</sup> disablism (Brit. English), anapirophobia, anapirism, and disability discrimination) is discrimination and social prejudice against people with disabilities or who are perceived to have disabilities.”



# Reactions

- Don't assume that everyone can eat / do / practice everything.
- Don't reduce people to their disability and their disability only.
- Don't negate their disability.
- Somebody explains what they live with? Don't overrule them or generalize!
  - Don't assume that you know more than them.
  - People have done (extensive) research.
- Try to remember! But don't make a fuss.
- Asking is ok with some people, and not with others.



Reactions

Middle ground  
is the best choice.





Reactions

Nothing to say?

(Just) listening is enough.



# Enabling PwD

- Don't assume people with disabilities don't want to be high performers.
- Work with them to create working conditions for them to thrive, they will surprise you!
- Create ways to support them without putting them on the spot (not putting the pressure on their shoulders to make space for themselves).
- Have everyone write user manuals to distribute and learn among the team.



# Attracting more people with disabilities

- Read and educate yourself.
- Collaborate with groups that have PwD as their target group.
- Research programs that support developers with disabilities (hard of hearing, autism spectrum, etc.) and collaborate with these organizations.
- Show commitment by handing in talks on the matter.
- Encourage and develop speakers with different needs (visibility!).
- Organize events focused on technology that helps PwD / that trains developers in this.



Questions?

Just ask!

I am open.



Questions?

Thank you for your  
understanding.

Thank you for being an ally.