In the visible disability world, we see ramps, braille, and other supports. What would meaningful disability inclusion look like for someone with ME/CFS in the community?

- Six years of this and I still find effective pacing almost impossible. Able bodied folks should try it for a week and see how impossible it can be.
- Early warning signs are crucial. Can start subtle but if ignored becomes impossible to ignore!!
- PEM feels like punishment and the tole that takes on wanting to do activities you enjoy is torture
- Don't tell me exercise more please - Public Health System - Chronic Pain Service
- One thing I'd want people to know. I may look fine and like I'm coping well but that doesn't mean I'll be okay tomorrow if I don't stick to my limits.
- Its like living in an invisible box - and its hard to know that you've gone outside the lines until you run smack into the PEM. The consequences for doing that is the box shrinks..
- PEM gives a bitter aftertaste to everything, even joy and fun.
- Very lonely. Those around me do not understand, and I have had no success in being able to explain my daily life situation to them. It is despairing!!! I have had to cut family out of my life due to the stress of them not understanding.
- Everyone would be racing around doing all kinds of things if it weren’t for this rotten energy limiting illness (PEM)
- People don’t seem to know that it hurts you more than them that you can’t participate properly in social events.
- PEM means I can't do what I feel like doing.
- Never ask pwME to push through
- One thing: that everyday social interactions can cause PEM. That when we say “no”, it’s not that we don’t want to socialise.
- The pain and despair for moderate - severe cases is... so hard.
- There’s also a lot of judgment of those in bigger bodies. There’s an assumption from doctors etc and people generally that you’re using it as an excuse to be lazy