



## **If you could tell someone who has never experienced PEM one thing about what the world is like for you, what would it be?**

---

- Meaningful inclusion would mean - removing fragrance dispensers and asking health care workers to use unperfumed products
- Meaningful inclusion for pwPEM (people with PEM) starts for me with total inclusion in the medical system.
- A system here that knows about, understands about PEM
- To me the inclusion system changes are unable to make a huge difference because the level of most of us is too severe to access the world. We need supportive systems to live
- Access to mobility aids early on
- music free days for restaurants / shops etc
- Mobility Car Parks for sure.
- Option to work from home.
- Zero gravity reclining chairs and places to lay down.
- Public Health information TV broadcasts
- Huge level of patience and adaptability required.
- hospital systems need to understand and account for PEM.
- The noise and lights make an emergency visit a PEM buy in