

EPILEPSY, CHILDREN AND SAFETY

Considerations about safety for parents and caregivers of children living with epilepsy

CONSTANT FEARS AND UNCERTAINTY

- Bad things can happen at any time!
- Concerns are constant in the back of your mind!
- You feel like anxiety lingers around.



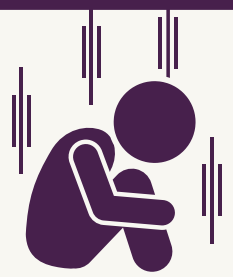
MANAGING STIGMA

- Facing challenges talking about epilepsy.
- Finding balance between awareness, education and possible labelling of your child being placed in groups they do not belong to (disability classifications do not always fit the bill).



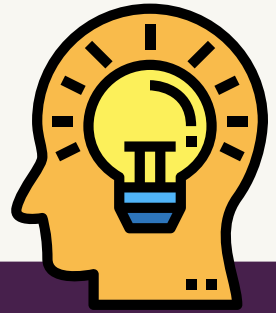
FEELING ALONE

- Need to belong to a community and learning from one another.
- Sharing stories and asking open questions.



NEED TO KNOW MORE

- Know what to ask for and what could be ask of you.
- Engage in difficult conversations.
- Understand extreme risks (such as SUDEP)



BETTER ENGAGEMENT WITH HEALTH CARE PROVIDERS

- Be able to count on a more connected system
- Be integral part of your child's overall health pathway



EPILEPSY AS ONE SLICE OF THE PIE

- Reflect and build what a balanced approach to living with epilepsy means to you and your child.

- Think ahead and be prepared. This may include having pills in many places for emergencies, and knowing procedures for epilepsy first aid.

- Build on what is possible and safe. Learn what your child loves and find ways to make it possible.

- Talk about your child's epilepsy with support groups around them, so they will know what to do when a seizure occurs.

- Make treatment compliance a team effort. Everyone contributes to keeping seizures at bay.

- Learn to contextualize and monitor seizure triggers. When stakes are high be ready. When stakes are lower, consider what you can let go.

- Build safety protocols that work for you and your child, and share them with the people in your child's life.