

DR.
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1. Seek Support From Other's Caregiver

- Accept the offer but be specific with you would like help with
- Example:
 - *Can you pick of the medication from the pharmacy?*
 - *Can you do this week's grocery shopping, the list is on the counter?*
- Effective communication between you and your support system, will help minimize stress and any anxiety of asking for help and delegating responsibilities



2. Take Care of Yourself

- If your health, physical or mental, is not 100% then you may not be as strong as you need or want to be
- Self care is care for all that depend on you
- Examples include:
 - *Going to your annual physical*
 - *Getting your hair cut*
 - *Spending some time at the beach*
 - *Attending therapy*

3. Reset Expectations

- Focus on aspects what you have right now in your life and what is working
- Example:
 - *That everyone is happy and healthy*
 - *School/work is going well*
 - *You had a fun time together at the pool*
- Do not compare with other families but learn what is working and not working for them
- Embrace your positives while learning from yours and other's negatives

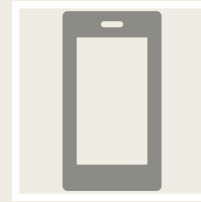
4. Educate Yourself On The Diagnosis/ Condition



Use community
technology available



Telemedicine
appointments & money
towards devices that
can monitor blood
sugar/ketones

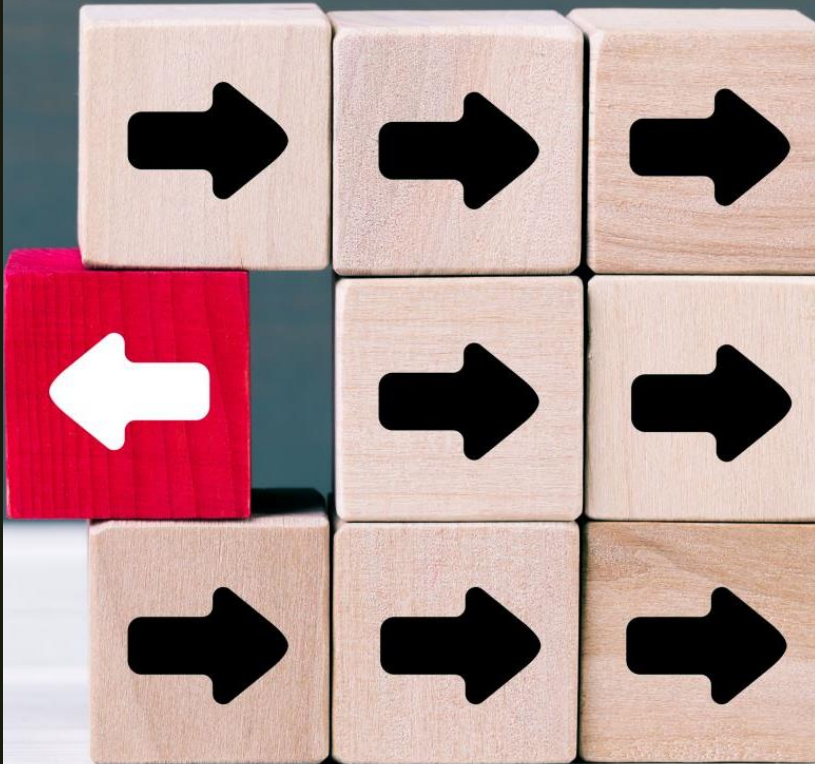


Telephone apps can
make your life easier
& help integrate
device data



Free websites which
help with gathering
both medical and social
knowledge of the
disease

5. Set Goals You Can Reach



- Focus on what you can do
- Learn to recognize your limits
- Create short term and long-term goals
 - *Examples of short-term goals: learning to walk, do ADLs alone, attending a birthday party*
 - *Examples of long-term goals: gaining independence, living alone, getting seizures under control*

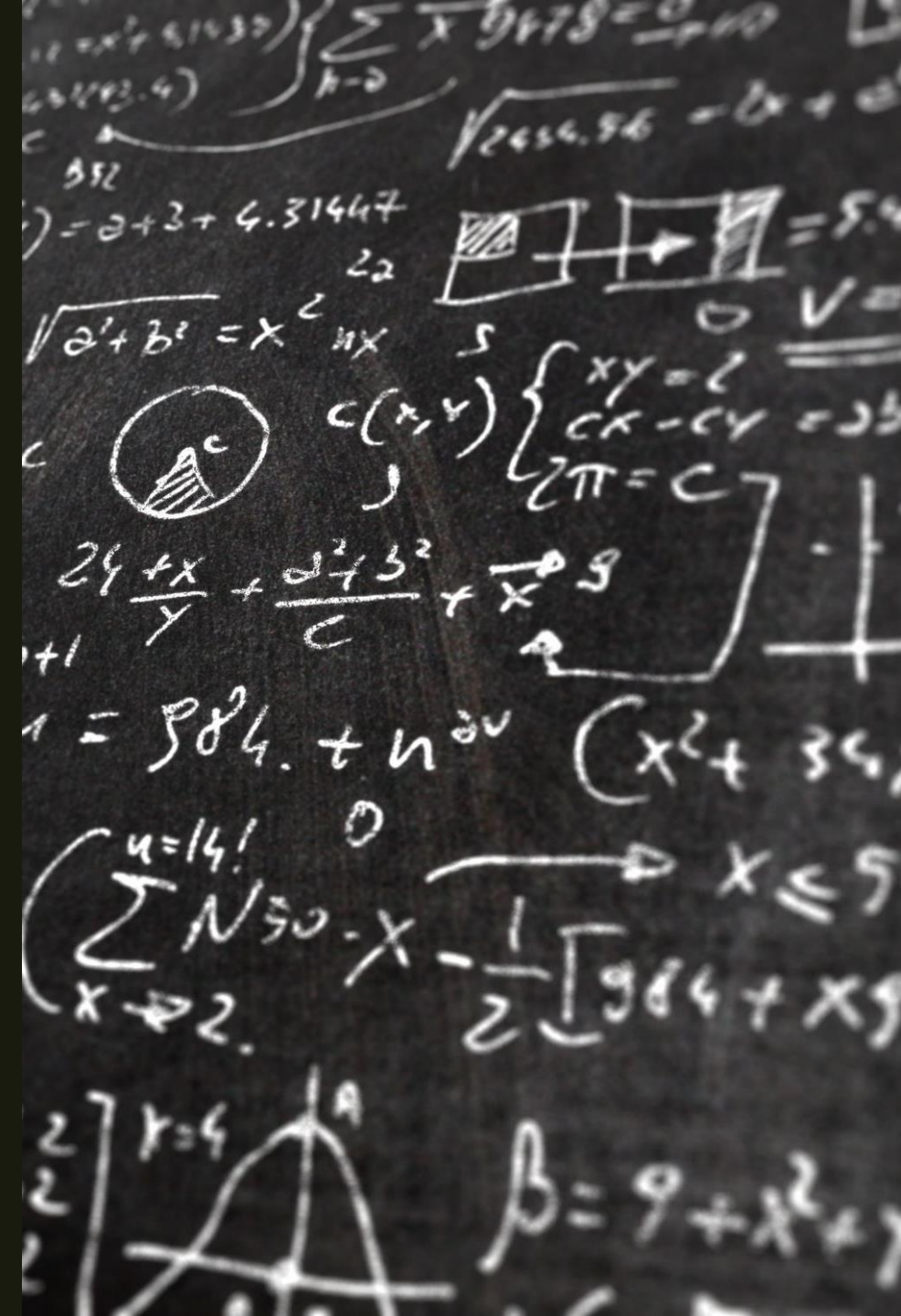
6. Plan For Crisis & Plan For Fun

- Not everything moving forward must be scary or the worst-case situation
- Enjoy your children being a kid, they are only young once
- Make lasting memories with them that will be your light in the darkest of time
- Know what you and your care team will do in crisis so that things can go as smoothly as possible, and some sense of normalcy can be maintained
- Enjoy life and all its ups & downs because your kid sure is



7. Discovering the Uniqueness and What Sets You Apart

- Reframe this rare disease as a highlight, a key point in their life; not many have it
- This can be accomplished through a 3-step method of
 - Accepting: things are going to change, good or bad, how you react to them is what matters
 - Transforming: transform this disease, this life and your outlook on what this truly means
 - “Problem-solution”: identify the problem and create a feasible solution for every obstacle in your path



8. Be



Practical



Empathetic



Flexible



Simple

9. BE EFFECTIVE WITH DOCTOR VISITS AND EMERGENCY SITUATIONS

- Update medication list (OTCs and Rx)
- Update allergies (drug, food and environmental)
- Review symptomatology (acute & chronic)
- Have legal paperwork (POA, guardianship)



10. Be Good and Honest

- Positive emotions
 - *help you to do more things around*
- Negative emotions
 - *help you identify issues that need your attention*
- Autoregulation of emotion:
 - *Identify* the emotion
 - *Interpret* the situation
 - *Modify* the intensity of reaction



11. EXPLORE THE POSSIBILITY OF ADAPTATION OF CHANGES

“Think outside of
your comfort zone”

It is ok to be
uncomfortable



LET'S TALK ABOUT
PSYCHIATRY NOW