Strategies that Work:

Home, School, & Beyond

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STRATEGY:
a plan of action intended to accomplish a specific goal
Child & Family

Physical/Medical

Social

Academic/Intellectual

Emotional
Physical/Medical

- Diagnosis
  - Average age of diagnosis is about 5-6 years of age
    - Parental Uncertainty
      - “Not knowing what he had was frustrating”
      - “Had we received an earlier diagnosis we could have started treatment sooner”
      - “We wanted to help but didn’t know how”
Physical/Medical

- Uncertainty
  - Arises from absent, vague or complex health information, and indeterminate future outcomes (Han et al., 2011)
Physical/Medical

- Parents who perceive less control over child’s health perceive greater uncertainty
  - Less optimistic parents and parents who feel their child’s disease is more severe (Madeo, O'Brien, Bernhardt, & Biesecker, 2012)
  - May use less effective coping strategies
Coping Strategies

- Clarifying what is known about your child’s condition
- Emphasize those areas over which you do have control:
  - Gathering information to enhance healthcare decision
    - Maintaining accurate records
    - Increasing knowledge about medicine
    - Making testing or treatment decisions
  - Advocating for their child
  - Ensuring your child’s comfort
  - Caring for yourself
Coping Strategies

- Advocating for your child
  - Voicing your child’s needs to a healthcare provider
  - Presenting research to providers
- Ensuring your child’s comfort
  - Maintaining child’s routine and environment
  - Providing emotional support
- Caring for yourself
  - Maintaining a positive attitude
  - Religion/Spirituality
Physical/Medical

- Treatment
  - Ketogenic Diet
    - Cons
      - “Diet is daunting”
      - “Kids don’t like the food”
      - “Cooking for it is hell”
    - Pros
      - Feel better
      - Less seizures
      - Improved Attention
      - More energy
      - Improved speech

Raina, Age 12, Diagnosed at age 9-
making keto cookies
Treatment Compliance

- Factors affecting treatment adherence
  - Age
  - Social & Emotional Development
  - Biological Development
  - Knowledge & Problem Solving
  - Family Support
Compliance Strategies

- Improving adherence may require:
  - Teaching adolescents how to cope with peer pressure and social demands while adhering to the regimen.
    - Communication
      - Frequent check-ins
    - Social support
      - Peer relationship with other Glut1 children
  - Consulting and Counseling
    - Dietician
    - Feeding psychologist
Parent to Parent

- “Don’t be afraid of the diet!”
- “Create your own opinion”
- “tell them to call Raina’s mom for the best mac-n-cheese with bacon recipe”
Academic

- Cognitive and Behavioral
  - Ranging from mild learning disability to severe intellectual impairment
  - Language Skills
  - Adaptive Behavior
  - Attention

- Physical and Medical
  - Seizures
  - Movement Disorders
Preschool & School Age:

- Early childhood intervention services for developmental delays/disabilities.
  - Cognitive
  - Physical
  - Communication
  - Social
  - Emotional
  - Adaptive Development

- Access/Referral:
  - Child Find
  - Parents may contact local program (www.ectacenter.org)
  - Pediatrician /Neurologist referral
Strategies for Navigating the School System

1. Know the Law: The Individuals with Disabilities Education Act (IDEA)
2. Nurture relationships with the decision-makers
3. Work closely with your child’s IEP team
4. Advocate for your child and special education
5. Continue your education about special education
Emotional and Behavioral Functioning

- Children with chronic health conditions make up 10-30% of the general population.

- What we know about Glut1:
  - Attention
  - Sadness
  - Anxiety
Emotional and Behavioral Functioning

- Factor moderating and mediating psychological adjustment:
  - Condition Factors
    - Type of Condition
    - Condition Severity
    - Duration
  - Child Factors
    - Age
    - Temperament
    - Child Coping Methods
  - Social-Ecological Factors
    - Family Functioning
    - Parental Stress
    - Peer relationships
Coping Strategies

- **Active Coping:**
  - Awareness of stressor
  - Attempts to reduce the negative outcome

- **Avoidant Coping**
  - Ignoring stressor
  - Engaging in activities that aid in the denial of the problem
Active Coping Strategies

- Humor
- Seeking Support
- Problem-Solving
- Relaxation
- Adjusting expectation
Social Functioning

- Social skills and behavior
  - Relative strength for Glut1 children
  - Still below what is expected

- Family Support and Peer Support
  - Better adjustment than social support from only one
Strategies to help with Peer Relationships

- Social skills group
- Participate in group activities
  - Boy/Girl Scouts
    - Inclusion Units
    - Disability Units
  - Special Olympics
  - Camps for children with disability/medical condition
Pat’s Wisdom

Peer Relationships:
- Learning to let go and letting him have his social space
- Important to let children be themselves. Let them have an effect on others who will later go on to be amazing adults because they will be more sensitive and empathic.
- It may mean having one good friend
Thank you!