Caring for the Caregivers

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Glut1 Deficiency Foundation 2015 Conference:
Family Program
July 6 - 7, 2015  Orlando, Florida
University of Central Florida (UCF)

- Located in sunny Orlando, FL
- Home of the UCF Knights – American Athletic Conference
- 2014 Fiesta Bowl winners over Baylor
- Ranked #1 of Public institutions NCAA Grad Rate
- Nation’s 2nd largest school: over 60,000 students
- Over 200 degree programs in 12 Colleges
- Partnership University

UCF Stands For Opportunity
UCF College of Nursing

- One of UCF’s 12 Colleges
- Several Degree Programs
  - BSN: traditional, 2nd degree, dual, Post Licensure
  - MS: Nursing Educator., Adult-Gero NP, FNP, Leadership & Management
  - PhD, DNP (APN or Nurse Executive)
- Over 2000 students
- CCNE accredited
Upon completion of this session caregivers of children with Glut-1 deficiency will:

• Identify dynamic role of caregiving parents
• Identify sources of caregiver stress & strain
• Identify actions to reduce stress & strain
• State the why and how to maintain health and wellness of the caregiver
# Roles of Caregivers of Children with Glut 1 Deficiency

## Glut 1 Roles
- Personal care provider
- Chef/dietician/food police
- Care coordinator
- System navigator
- Decision maker
- Nurse/pharmacist
- Financial manager

## Other roles
- Parent
- Partner
- Child
- Sibling
- Employee/student
- Social Group Member
- Household manager
Stressors and Stress (Strain)

- Stressors: Those activating agents which initiate stress; can be actual or perceived
- Stress (strain): response to stressors; tension produced; seen as a physiological, psychological or behavioral deviation from a healthy state of being
Stressors

• Role Conflict
• Lack of physical support
• Lack of educational support
• Lack of emotional support
• Lack of spiritual support
• Financial burden
• Other individual factors
Role Conflict

- Parent: To child with Glut1, other siblings
- Partner: relationship dynamic needs nurture
- Child: sandwich generation?
- Sibling: holidays, reunions
- Employee/student: decrease hours; exit job
- Social Group Member: clubs, PTA, worship
- Household manager: cleaning, pay bills, upkeep
Lack of Physical Support

• Others are unavailable, unwilling or unable
• Arduousness of tasks increase as child ages
• Experience your own physical limitations
• Tired all the time
• Moving equipment especially for appointments
Lack of Educational Support

• Education about resources/services
• Education about physical care such as lifting
• Education about treatments, diet or medications
• Not enough “good” information
• Sort through internet info
• Be honest, prepare families for what to expect
Lack of Emotional Support

- Dealing with feelings, guilt, inadequacy, fear
- Post traumatic stress syndrome
- Expectations of others/showing a “good face”
- Stress from several points/PTSD
- Stifling happier emotions
- Patients verbally and emotionally abusive
Lack of Spiritual Support

- Faith enhanced coping and grief work
- Difficulty developing/maintaining connectedness with others
- Inability to get to formal worship
- Little quiet time for energy renewing spiritual practices such as meditation
Financial Burden

• Uninsured/Private/public & Medicaid order in which families were impacted by out of pocket expenditures
• Perceived Burden higher among lower income
• Employment impact: work reduction/exit
Outcomes: Caregiver

- Physical decline, weight loss, exacerbations of your health issues, lack of preventive care
- “Go it alone”
- Depression/PTSD
- Erosion of relationships
- Job reduction or loss
Outcomes: Child & Family

• Child
  – Lower perceived quality of life
  – Greater internalizing of problems
  – Receipt of parental criticism

• Family
  – Poorer family management
  – Lowered family SES
  – Altered family relationships
What is a Caregiver to Do?

- Seek out and accept help
- Establish a Medical Home/insist on education and resources
- Stay connected
- Use technology to relieve physical burdens
- Seek Respite (camps, relatives)
- Maintain physical health
- Maintain spiritual connections
What is a Caregiver to Do?

• Acknowledge and express your feelings
• Engage in a caregiver support group
  – social media like Caregiver Action Network
    www.caregiveraction.org
• Relax: Meditation/Yoga/Tai Chi (10 mins/day)
• Resume old hobbies: gardening, dancing, reading, quilting, painting, singing, music
• Maintain Social connections
Transitions in Caregiving

- Less often considered
- Gauge amount of self-care by child
- Transitioning to another care facility
- Transitioning to day programs
- Transitioning when you eventually need care
- Prepare today for tomorrow
Remember

accept  others  spirituality  resilience
meditation  self  renewal  parent
respite  support  help  relaxation
partner  resources
Thank You!

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