



Caring for the Caregivers

Norma E. Conner, PhD, RN;

University of Central Florida, College of Nursing

Glut1 Deficiency Foundation 2015 Conference:

Family Program

July 6 - 7, 2015 Orlando, Florida

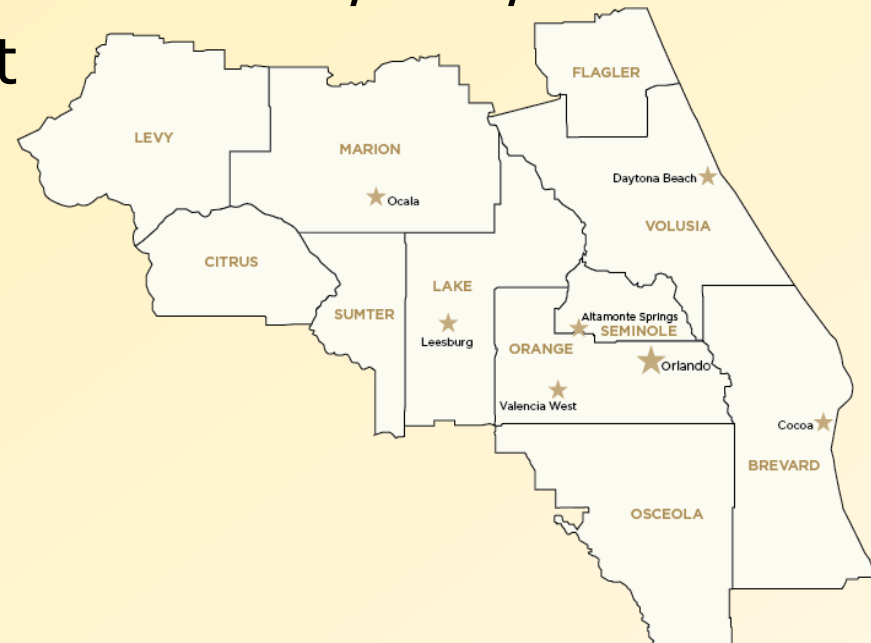
University of Central Florida (UCF)

- 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 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



Objectives

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

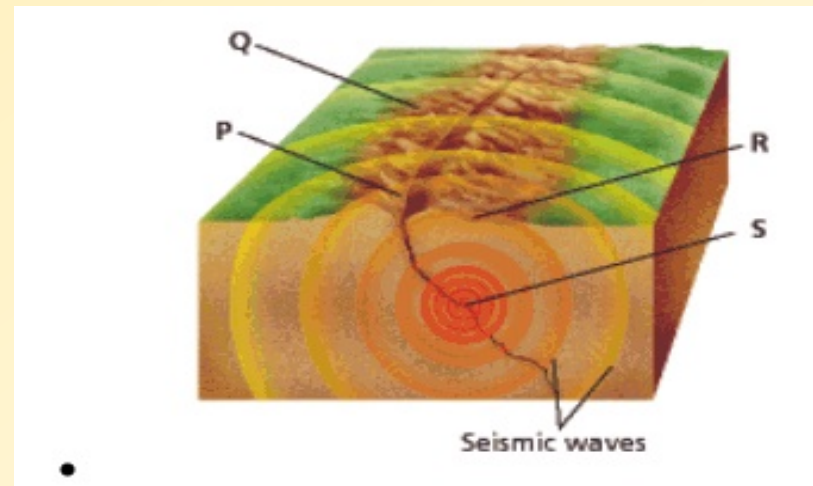
- Personal care provider
- Chef/dietician/food police
- Care coordinator
- System navigator
- Decision maker
- Nurse/pharmacist
- Financial manager

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
meditates self
renewal
respite
support
partner
resources
resilience
parent
relaxation
help

Thank You!



Stands For Opportunity