Self Care for Caregivers
Brain injury impacts not only the person injured, but also their family, friends and the community.
Assuming the role of a Caregiver

• Caregivers are often:
  – Spouse
  – Retired family members
  – Children
How a Brain Injury can Impact Families/Caregivers

• Change in family roles and responsibilities
• Financial strain
• Quality of life decisions
• Living situations
• Impact on other family members
• Employment (Family and Patient)
• Responsibilities
Potential Issues Related to this New Responsibility

• Family members may experience feelings of:
  - Being overwhelmed
  - Neglect
  - Guilt
The Process of Recovery for family/caregivers

- Acute Care
- Acute Rehabilitation
- Skilled Nursing Facility (If necessary)
- Home
Acute Care

• Shock of Trauma or Diagnosis
• Crisis mode
• Survival
• Hope/belief in full recovery
Inpatient Rehabilitation

- Hope/belief in full recovery
- Denial and repressed feelings
- Anger/frustration
- Unreasonable demands
- Questions about temporary vs. permanent
- Beginning to recognize the severity of the situation
- Anxiety/fear/depression start to emerge
- Family members may not agree on care
Home

- Experience full responsibility for the survivor
- May still expect the person to become independent
- Hope starts to wane
- Anger/frustration/exhaustion/isolation
- Guilt and the desire to give up
Signs of caregiver stress

– Feeling tired most of the time
– Feeling overwhelmed and irritable
– Sleeping too much or too little
– Gaining or losing a lot of weight
– Losing interest in activities you used to enjoy
– Too much stress, especially over a long time, can be detrimental to your health
Strategies for dealing with caregiver stress

- Have reasonable expectations
- Accept Help
- Focus on what you are able to provide
- Get connected
- Join a support group
- Take time for yourself
- Seek social support
- Set personal goals
- See your doctor
Strategies for dealing with caregiver stress

• Have reasonable expectations
  – For yourself
    • Understand your role and how you are best able to provide the necessary care/assistance
    • Realize your limitations
  – For your loved one
    • What are they able to do for themselves and what do I need to assist with?
Strategies for dealing with caregiver stress

• Accept Help
  – From family and friends
  – Therapists and doctors
  – Respite Care
Respite Care

• The PA Department of Aging operates the Pennsylvania and National Caregiver Support Programs, designed to reduce caregiver burden to primary caregivers of an older, functionally dependent adult, a person of any age with dementia, a relative caring for children under the age of 18 or a relative caring for an individual with a disability ages 19-59.
Strategies for dealing with caregiver stress

• Focus on what you are able to provide
  – Make a list of what you can do and what you may need help with.
  – Ask for help with things that may be difficult for you
Strategies for dealing with caregiver stress

• Get connected
  – There are many national and local organizations that can be helpful resources for you

• Local Resources
  • UPMC PM&R Outpatient Clinic
  • UPMC Outpatient Rehab (various community-based sites)
National Organizations

Family Caregiver Alliance/National Center on Caregiving
www.caregiver.org
Tel: 415-434-3388 or 1-800-445-8106

Brain Injury Association of America, Inc.
www.biausa.org
Tel: 703-761-0750 or 1-800-444-6443

National Institute on Disability and Rehabilitation Research (NIDRR)
www.ed.gov/about/offices/list/osers/nidrr
Tel: 202-245-7460 or 202-245-7316
Strategies for dealing with caregiver stress

• Join a support group
  – Many communities have support groups for both survivors and caregivers. These groups can help couples establish new friendships, find local information and resources, and provide time apart from their partner for reflection.

• UPMC Mercy TBI Support Group
  – The group meets on the second Monday of every month at 6:00pm in the UPMC Mercy Cafeteria

  – Support groups – Butler, Harmarville, Shadyside
Strategies for dealing with caregiver stress

• Take time for yourself
  – Don’t forget to still do the things that you like to do
  – Try not to feel guilty for taking time for yourself
Strategies for dealing with caregiver stress

• Seek social support
  – Engage family and friends in your loved ones recovery process.
  – Reach out to other’s who have been in a similar situation.
Strategies for dealing with caregiver stress

• Set personal goals
  – Take the time to set goals. You can set both short-term and long-term goals.
  – Your goals can be for the day, week, month, year, etc. Personalize your goals to fit your needs.
Strategies for dealing with caregiver stress

• See your doctor
  – If you find that your stress is becoming very difficult to manage, don’t hesitate to see a doctor or health care professional for both physical and mental health.
Recommended Reading
Written by or for Family Members of TBI Survivors

- Where is the Mango Princess?
  A Journey Back from Brain Injury
  Cathy Crimmins

- Being with Rachel
  A Story of Memory and Survival
  Karen Brennan