

Caregivers as Clients: Who's Caring for the Caregivers

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Housekeeping

- Please feel free to interrupt if you have comments or questions
- What happens here stays here – confidentiality please
- Please be willing to share your experiences – we will all learn more

Please silence your cell phones

Learning Objectives:

- To identify caregiver demographics
- To recognize caregivers as clients
- To examine the roles & responsibilities of caregivers
- To understand the risks to caregivers' health & satisfaction
- To explore the impact of caregivers' wellbeing on the patients' wellbeing
- To offer suggestions for improving caregiver support & assistance



Caregiver Demographics

- Unpaid family member, friend, neighbor
- 44 million people over age 18
- 40% are male
- Average age is 47
- Working at least part time
- In need of support



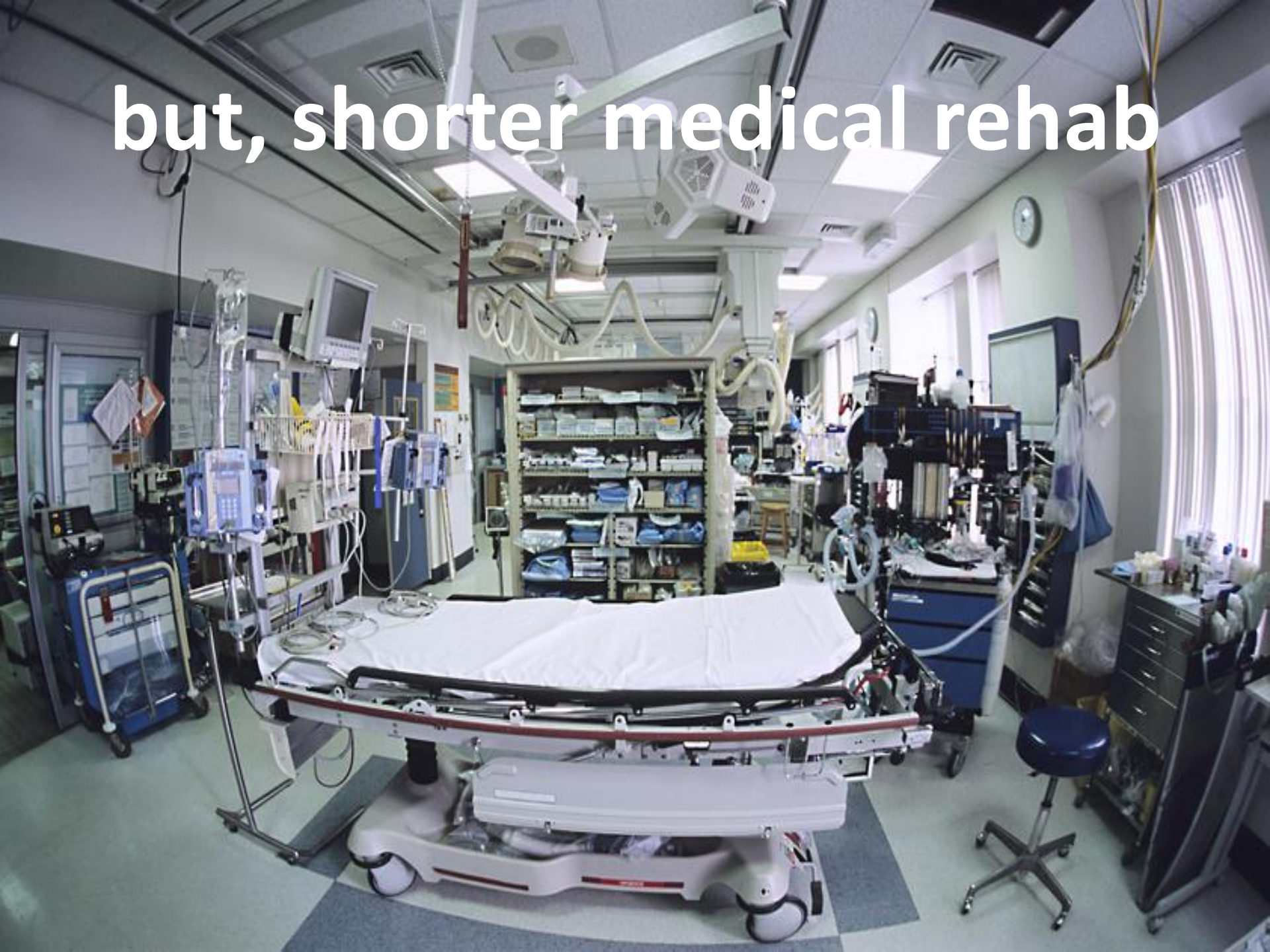
**With Brain Injury there is an
Increased Survivability**



Earlier medical intervention



but, shorter medical rehab



The background of the slide features a blue-grey gradient. Overlaid on this are the black silhouettes of a woman on the left, walking and supporting a person in a wheelchair from behind. The person in the wheelchair is facing right. The text is centered over the image.

**Individuals with greater disabling
conditions being sent home**

“sicker and quicker”

**17 days of acute medical care
in 2012 vs. 57 days in 1990 for
high moderate to severe
injuries**

Ashley, M. Santa Clara Valley Brain Injury Conference, 2012

Occurance of Severe TBI:

- 50,000 to 75,000 people per year
- $\frac{1}{3}$ to $\frac{1}{2}$ of those will die



Cost of Severe TBI:



**\$15-17 million over the
course of a person's life**



It's a Marathon – Not a Sprint!

Community Neuro Rehab Study

2010-2012

**Community-based neurobehavioral
rehabilitation**

Age at injury: 36.33

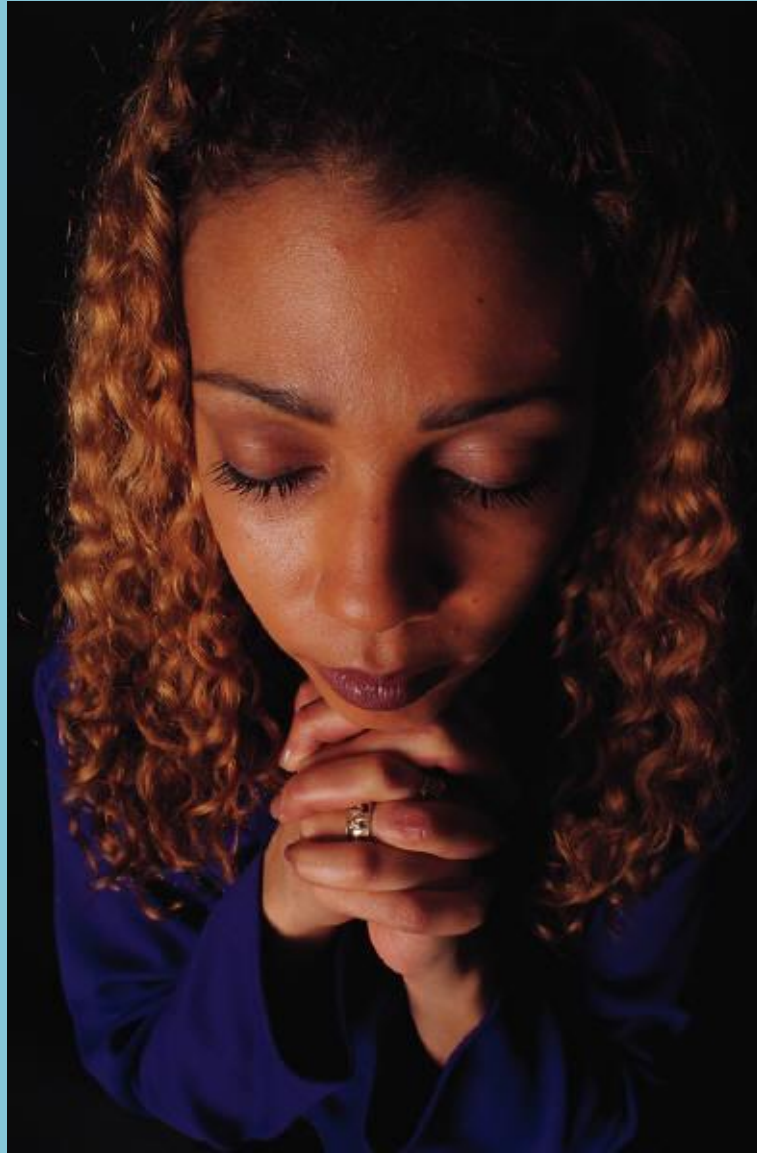
Home support needs

**75% requiring more
than 2 hours/day of
paid support**



When the
Unthinkable
Happens...

Every Survivor is a Miracle!



But as Time Goes By...



The Feelings Come...

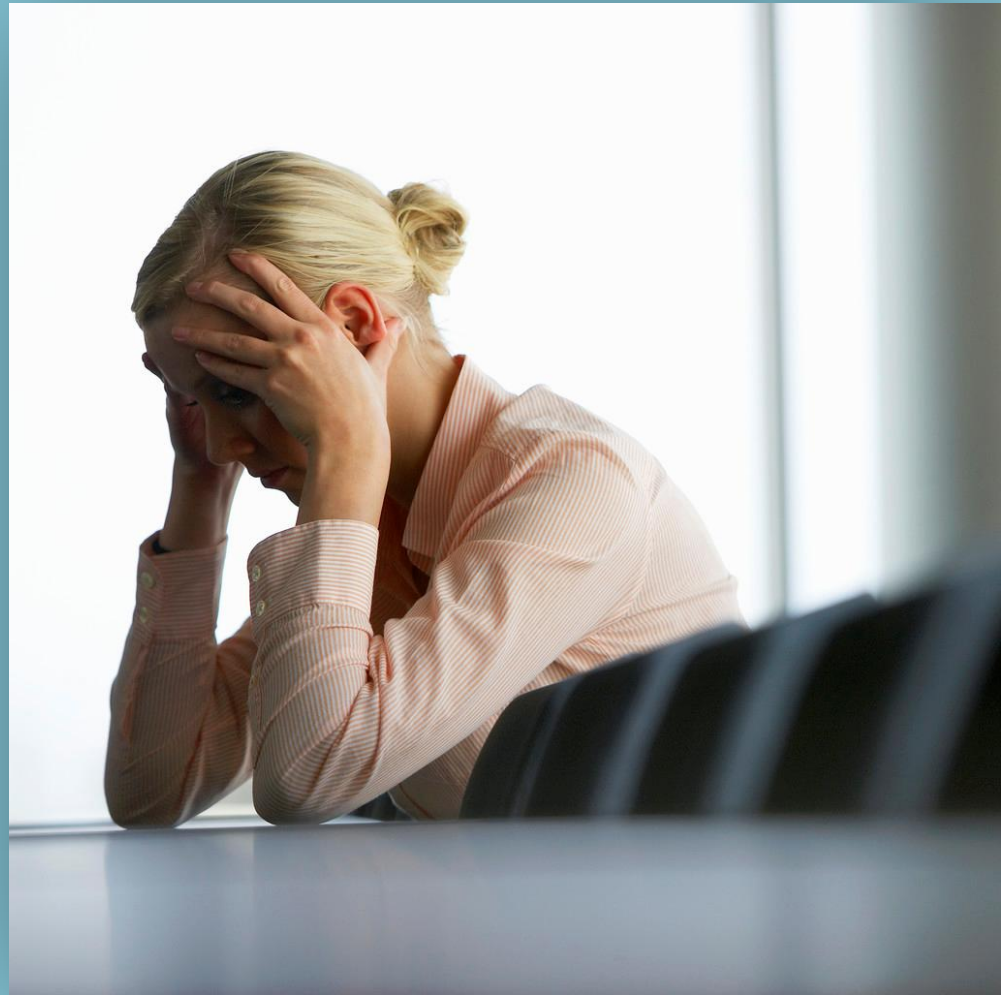
Exhaustion

Anxiety

Anger

Sadness

Guilt



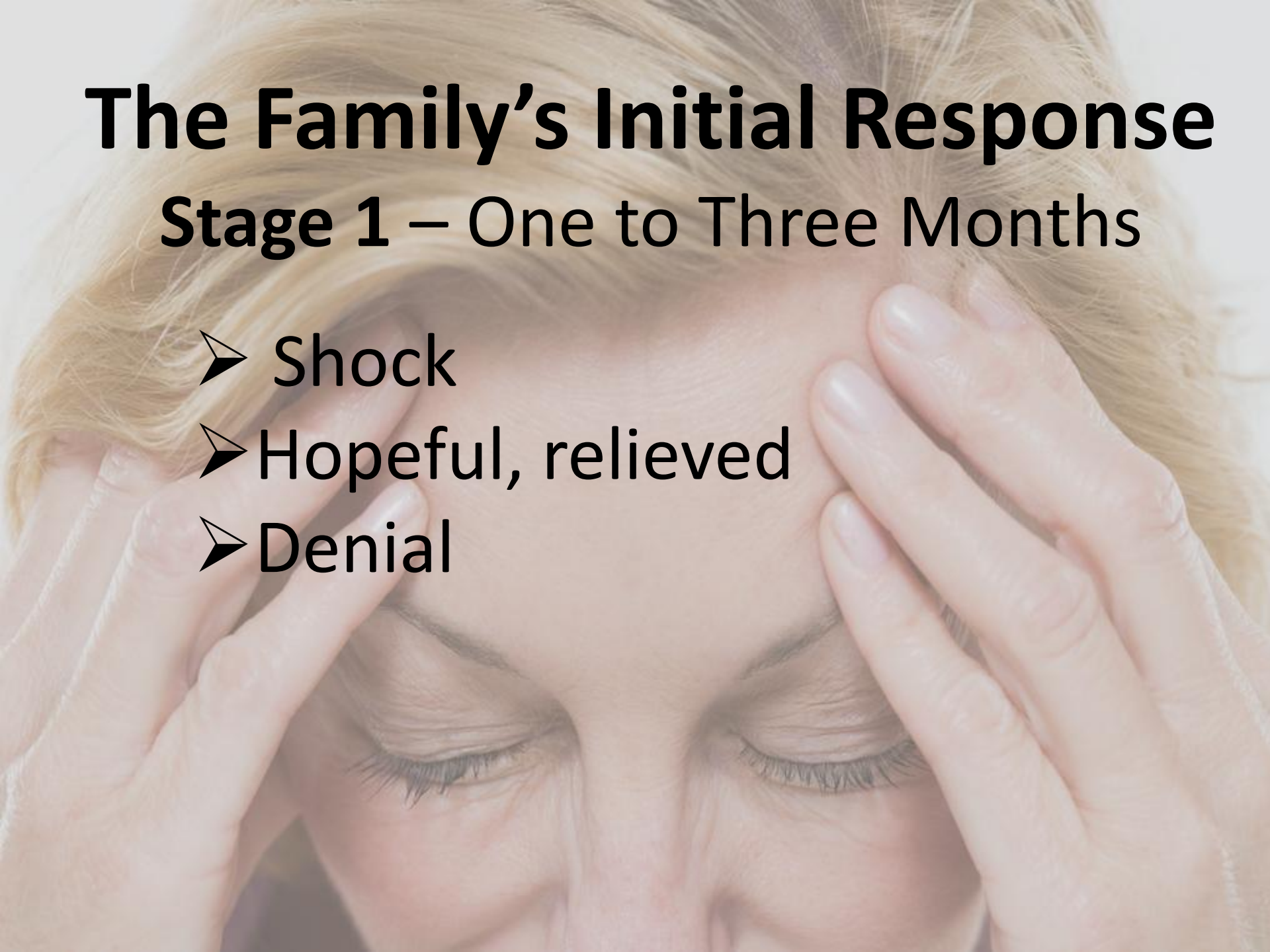
Stages of Recovery



The Family's Initial Response

Stage 1 – One to Three Months

- Shock
- Hopeful, relieved
- Denial



What are the needs at this stage?

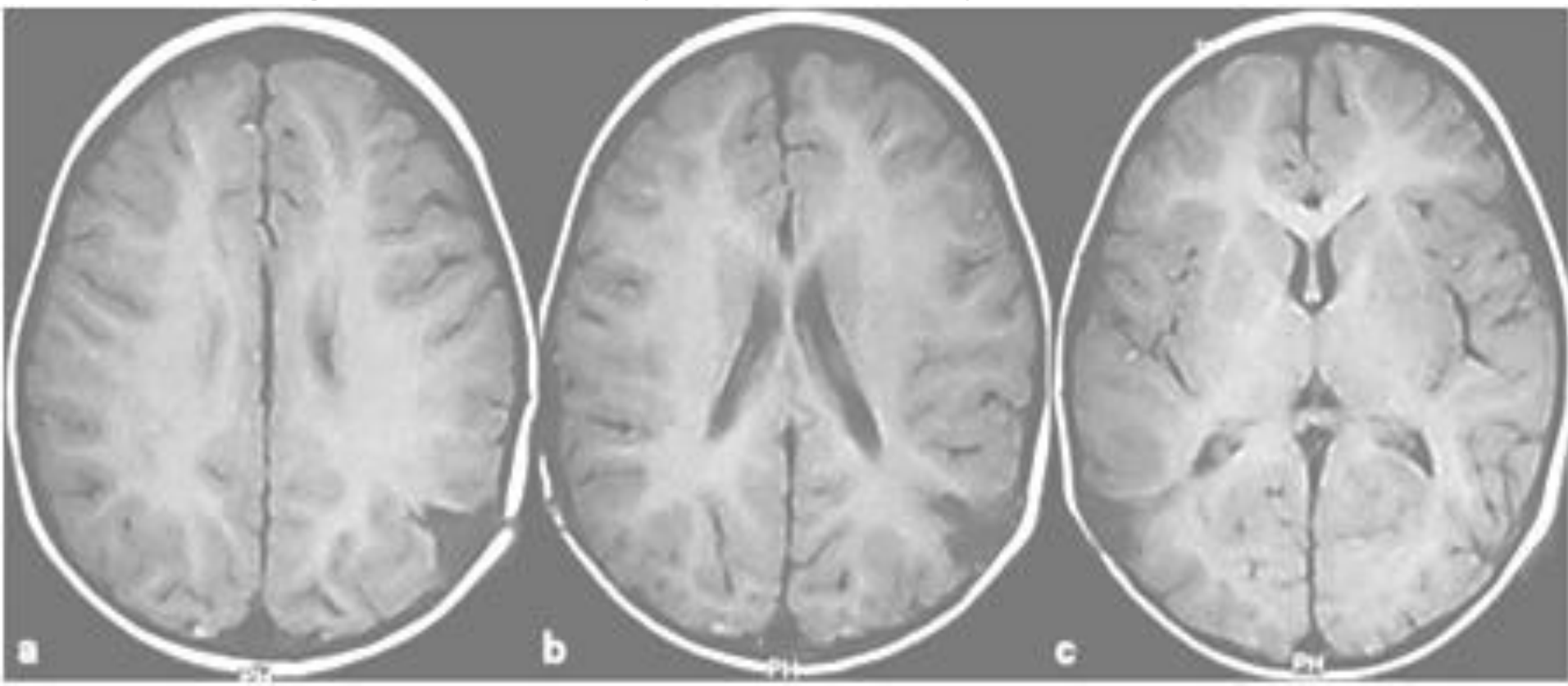
- Support from friends and family
- General information from nurses and doctors – factual without too many details
- Listen



Adjusting

Stage 2 – Three to Nine Months

- Realization of the Situation
- Anger, Anxiety, Fear, Depression, Loss



What are the needs at this stage?

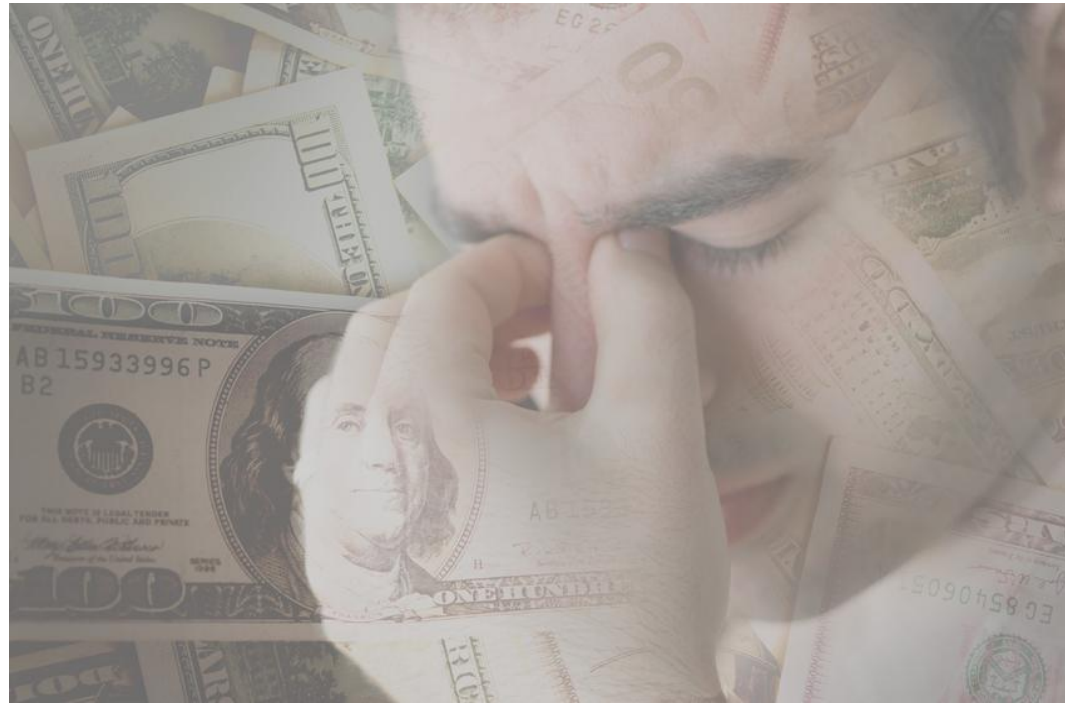
- Ongoing support
- More specific
- information
- Allow for venting
- anger, frustration
- fear, loss



Annoyance

Stage 3 – Six to Twenty-Four Months

- Discouragement
- Depressed
- Reviewing the Information



What are the needs at this stage?



- Information about resources for brain injury
- Support groups for caregivers
- Validation of feelings

Exhaustion

Stage 4 – Ten to Twenty Four Months

- Realism sets in
- Less Time Spent with Loved One
- Grief



What are the needs at this stage?

- 
- Counseling
 - Social Support
 - Time off

Sadness

Stage 5 – Twelve to Twenty Four Months

- Ambiguous Loss
- Accepting the “New Normal”



What are the needs at this stage?

- Expression of grief
- Family- Community-Based Interventions



Acceptance

Stage 6 – Two to Three Years

- Greater Understanding
- Accepting the Person as They Are Now
- From Patient Focus to Family Focus



What are the needs at this stage?

- New Social Networks
- Help with Daily Activities to Avoid
- “Burnout”
- Recognition



I need a vacation so badly,
I've resorted to
plotting my own
kidnapping.



Challenges Facing the Caregiver:

➤ Financial



➤ Social



➤ Psychological



➤ Physical



Financial Resources:

- ✓ Private Funding
- ✓ Insurance
- ✓ Medicaid
- ✓ Medicare
- ✓ Waiver Programs

Social Isolation:

- The Family
- The Caregiver
- The Patient



Increased social support leads to decreased distress in caregivers.

Psychological/Emotional Health of the Caregiver:

- Predictors of Caregiver Burden
 - Global Handicap
 - Level of Executive Function
- Signs of Caregiver Burden
 - Depression
 - Somatic symptoms
 - Anxiety
 - Substance abuse

Physical Impact of Caregiving:

- Increased Health-Risk Behavior, i.e. smoking
- Sleep Disturbances
- Lower Immune Functioning
- Slower Wound Healing
- Increased Insulin Levels & Blood Pressure
- Increased Risk for Cardiovascular Disease
- Changes in Sexual Roles for Spouses

Reinhard, Susan C., et al.,

Predictors of Success:

- Behavioral & Cognitive Function of Patient
- Premorbid Function
- Social Support
- Economic Status



Caring for the Caregiver:

- Caregiver as the client
- Individual as opposed to group
- Counseling
- One-to-one telephone calls
- Home visits



Caring for the Caregiver:



- Improve Confidence & Competence
 - Home Care Team
 - Problem Solving Strategies
 - Safe Plan for Caregiver & Patient

Caregivers as Providers:

- Potentially Harmful Behaviors
 - Abuse & Neglect
 - Medication Errors
 - Abandonment



Positive Consequences of Caregiving:

- Increased Mutuality
- Sense of Meaning
- Developing New Relationships



Assisting Caregivers



Areas of Vulnerability for Caregivers:

- Lack of Funding
- Lack of Facilities
- Lack of Social Support
- Lack of Therapeutic Services
- Lack of Understanding...community,
family, friends, professionals

Resources

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Russell, Debra, Ph.D. Chapter 7. *Brain Injury: A Family Perspective*, The Essential Brain Injury Guide, 4.0 edition, Academy of Certified Brain Injury Specialists, Brain Injury Association of America, 2009.

Questions?
Comments?

Synopsis

Brain injury occurs when we least expect it and few people are prepared to take on the role of primary caregiver.

Research has now shown the long-term effects of caregiving and the impact of the caregiver's health and well-being. What are the risks? Are there warning signs? What can be done to better support and educate caregivers?