

Caregivers as Clients: Who's Caring for the Caregivers

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Objectives:

- Who are the caregivers?
- What are the stages of recovery?
- What are the risks to caregivers' health & satisfaction?
- What is the impact of caregivers' wellbeing on the patients' wellbeing?
- How can caregiver support & assistance be improved?

Caregiver Demographics

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



**If you've seen one brain
injury, you've seen one brain
injury.**

**Each case is unique and every
caregiver needs case-specific
guidance.**

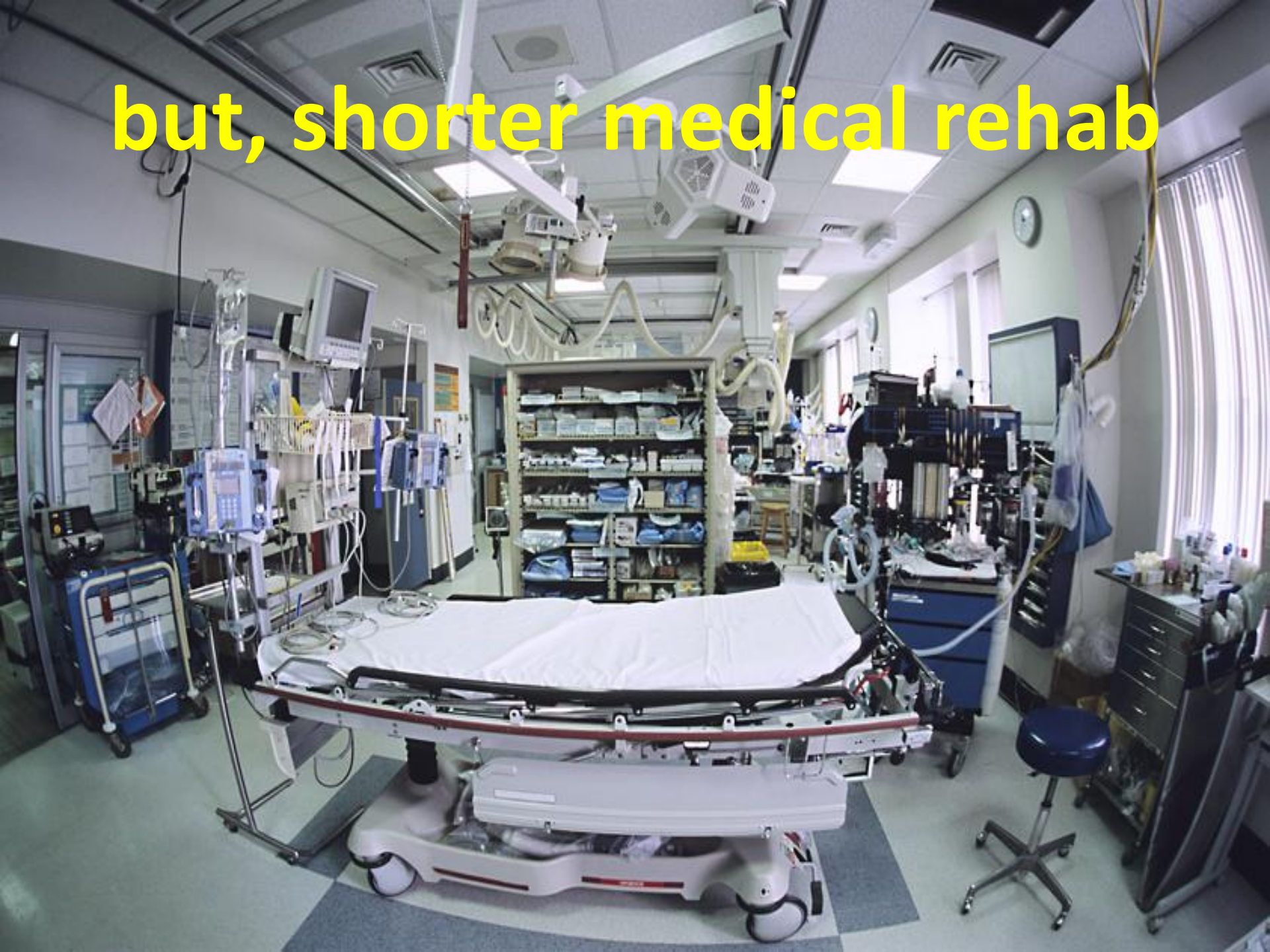
**With Brain Injury there is an
Increased Survivability**



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**

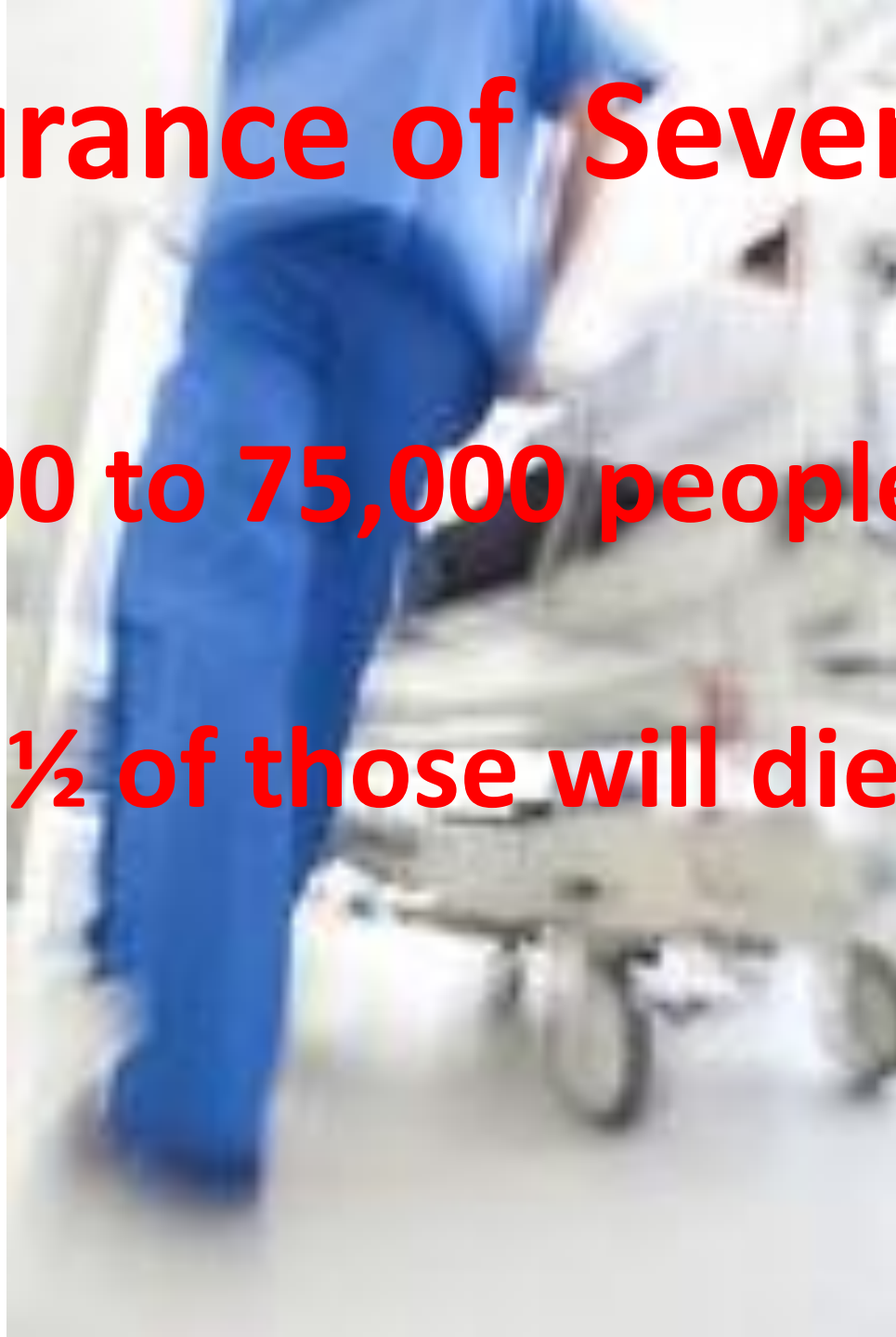
“sicker and quicker”

**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**



**Cost of free caregiver
services:**

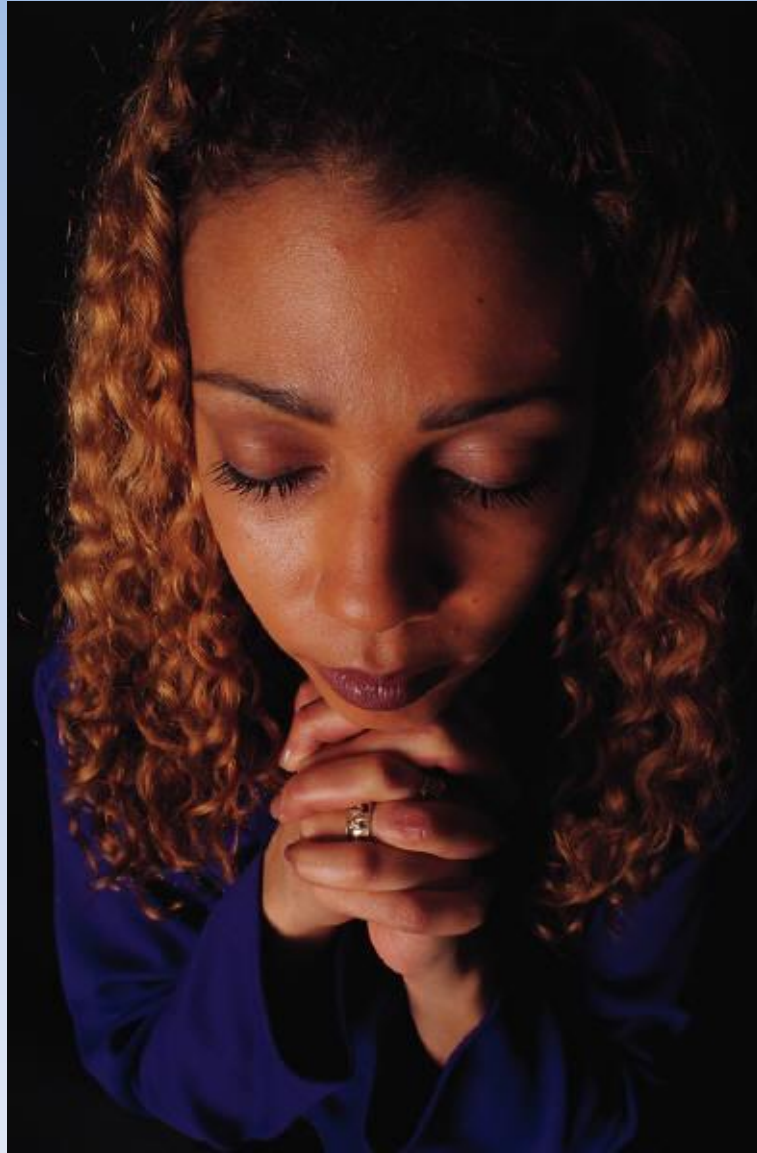
\$375 Billion per year

National Alliance for Caregiving and Evercare. March 2009



**When the
Unthinkable
Happens...**

Every Survivor is a Miracle!



But as Time Goes By...



The Feelings Come...

Exhaustion

Anxiety

Anger

Sadness

Guilt



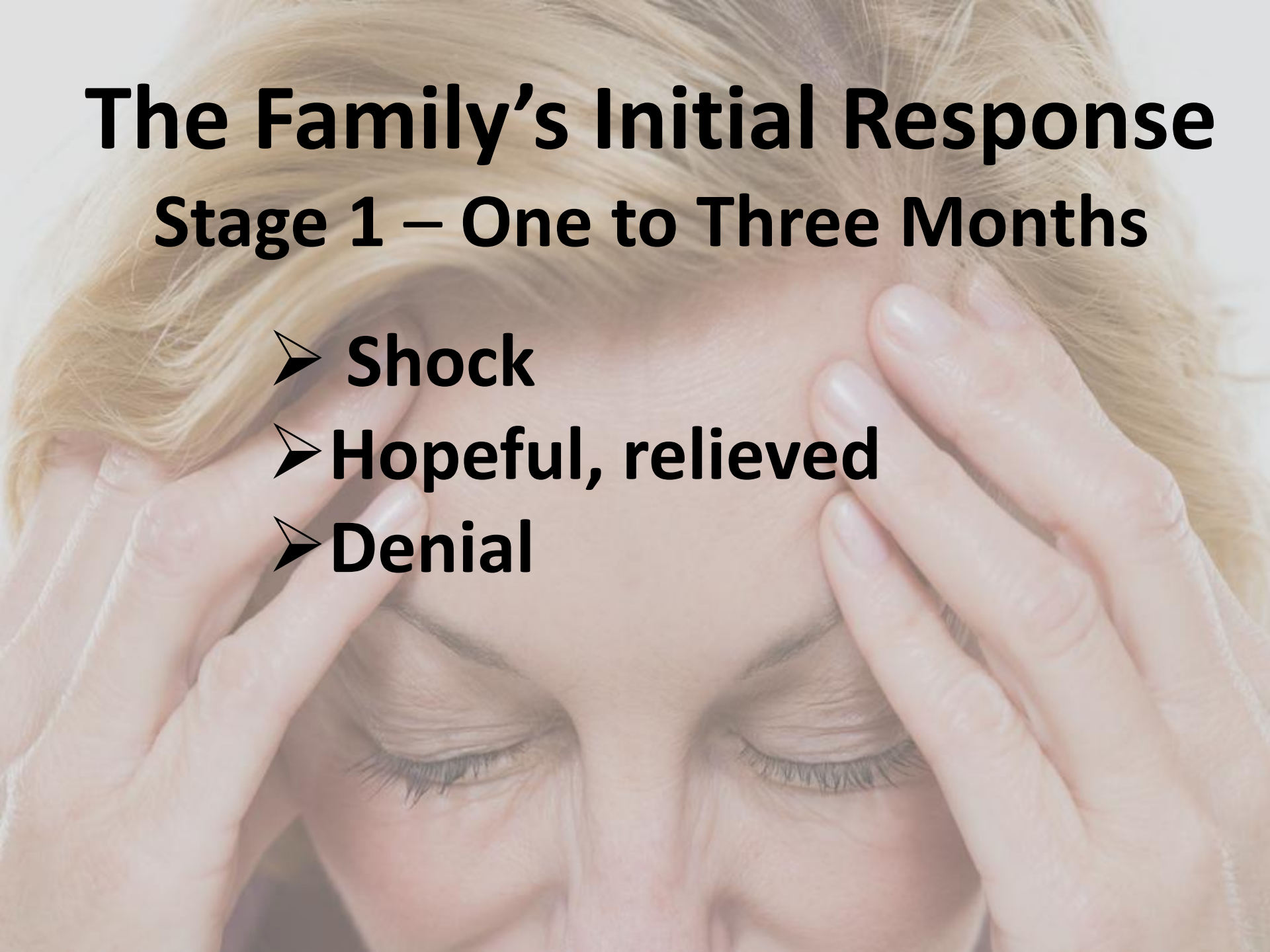
Stages of Recovery



The Family's Initial Response

Stage 1 – One to Three Months

- **Shock**
- **Hopeful, relieved**
- **Denial**



What are the needs at this stage?

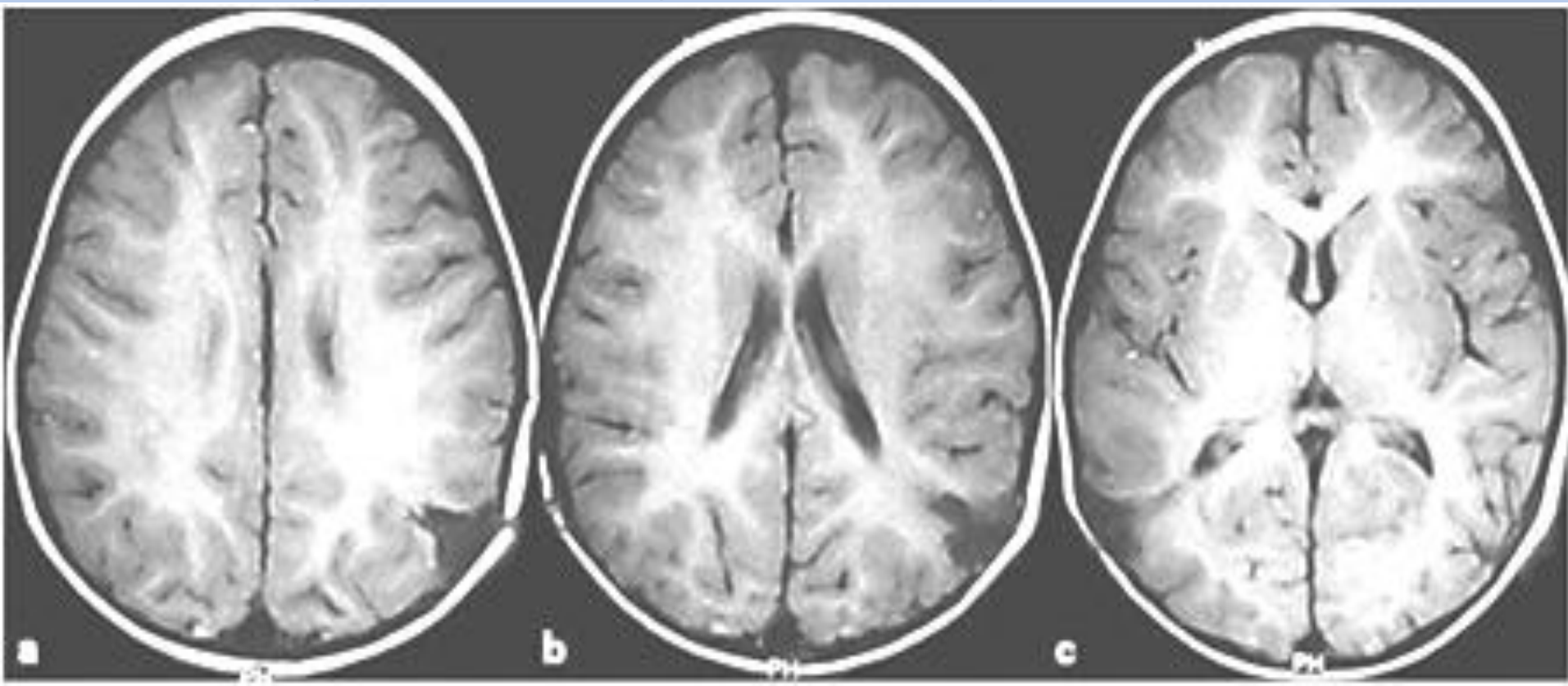
- Support from friends and family
- General information from nurses and doctors – factual without too many details
- Listen



Adjusting

Stage 2 – Three to Nine Months

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



What are the needs at this stage?

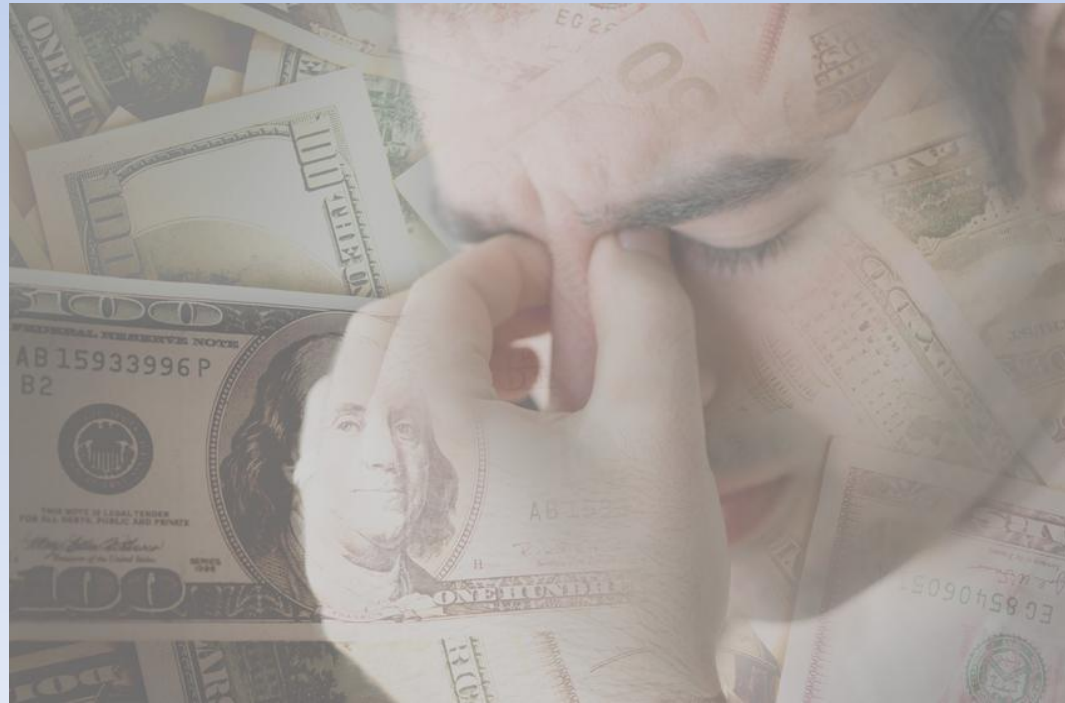
- Ongoing support
- More specific information
- Allow for venting anger, frustration, fear, loss



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.



**It's not a sprint –
It's a Marathon!**



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



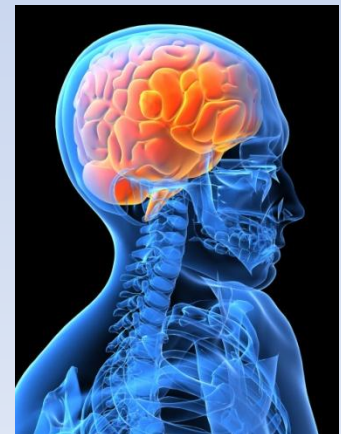
Increased social support leads to decreased distress in caregivers.

Ergh, Tanya C., et al. 2002

Predictors of Caregiver Burden:

Care receiver characteristics

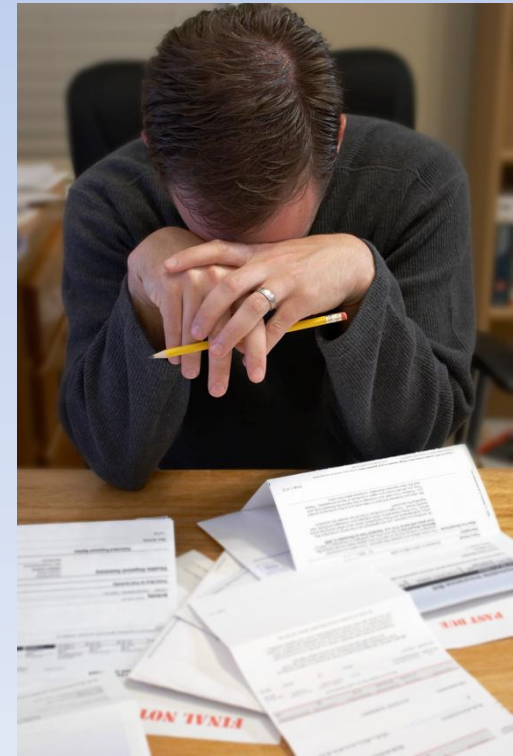
- **Global Handicap**
- **Level of Executive Function**



Bayen, Eleonore, MD, et al., 2013; Kreutzer, J., et al., 2009.

Signs of Caregiver Burden

- **Depression**
- **Somatic symptoms**
- **Anxiety**
- **Substance abuse**



Bayen, Eleonore, MD, et al., 2013; Kreutzer, J., et al., 2009.

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



Goals for 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**



Areas of Vulnerability for Caregivers:

Lack of:

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



Issues Identified by Caregivers

- **Changes in family roles**
- **Social isolation**
- **Expectations of behaviors & recovery**
- **Identity blurring**





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Assisting Caregivers





Ideas:



Resources:

- Caregiver.org
- www.mentalhelp.net
- Caregiveraction.org
- www.caregiver.va.gov
- www.helpguide.org

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Questions?
Comments?