



NEURO
INSTITUTE

Continuing Education for Rehabilitation Professionals



The New Normal—Understanding Individual and Family Dynamics Following Traumatic Brain Injury

Deborah Gutteridge, MS, CBIST
Clinical Evaluator

Learning Outcomes

- Identify the 6 stages of grief and acceptance families experience following TBI
- Describe the 6 stages of grief and acceptance experienced by the survivor with TBI
- List key factors impacting adjustment, coping, and acceptance for families and survivors
- Describe how “awareness” impacts every level of recovery after TBI

TBI.....The Most Challenging Issue....



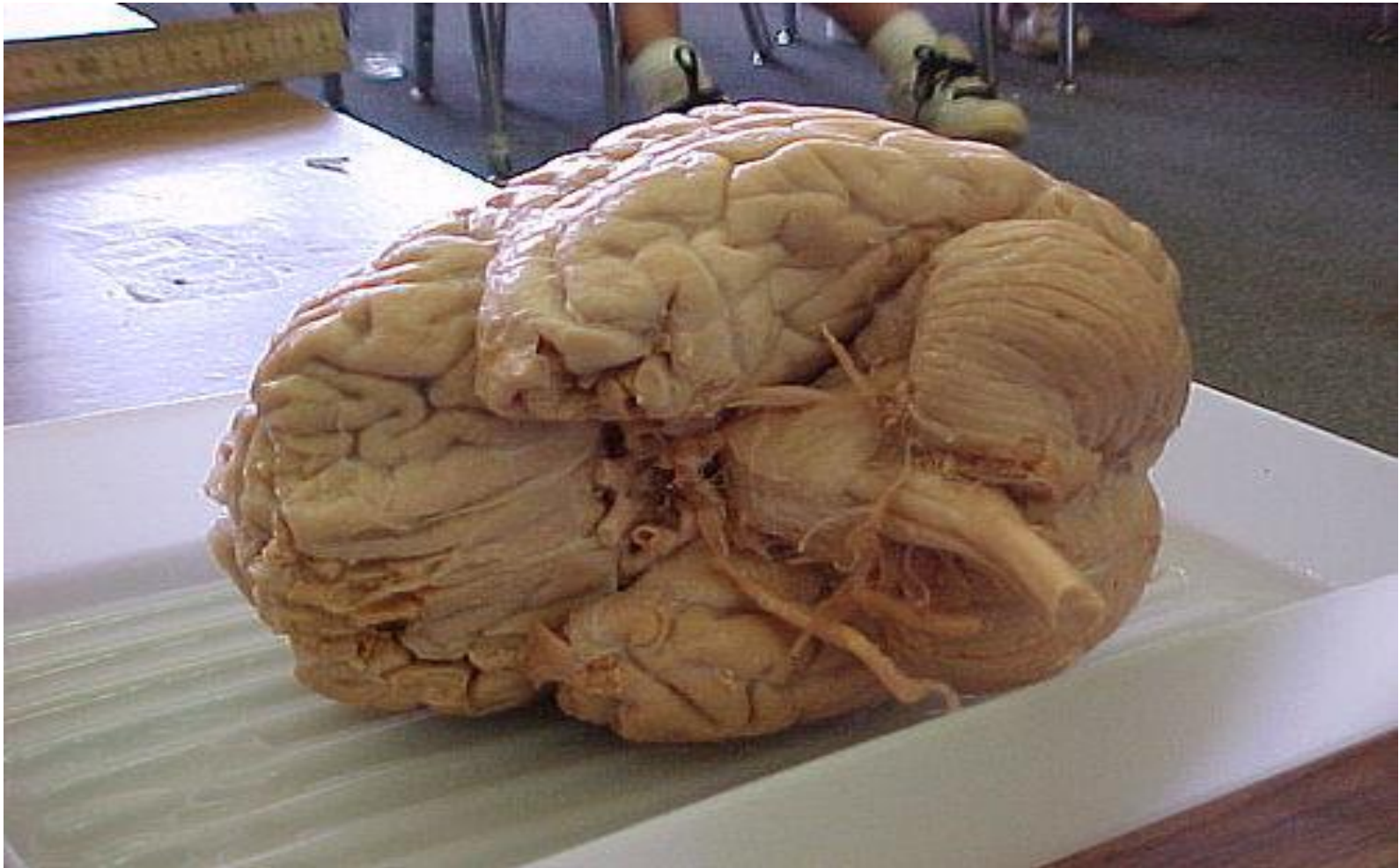
- ...for survivors
- ...for families
- ...for professionals

Essential Basics That Must Be Considered

*“Every brain is different.....
every brain injury is different...”*

Physical Givens

- 3 pounds “jello”
- 18 years old/25 years old
- Bones, walnuts and mushrooms
- “I feel no pain”
- 100,000 miles of vessels
- Fattest organ in body
- 75% water
- Have most all cells you will have at birth

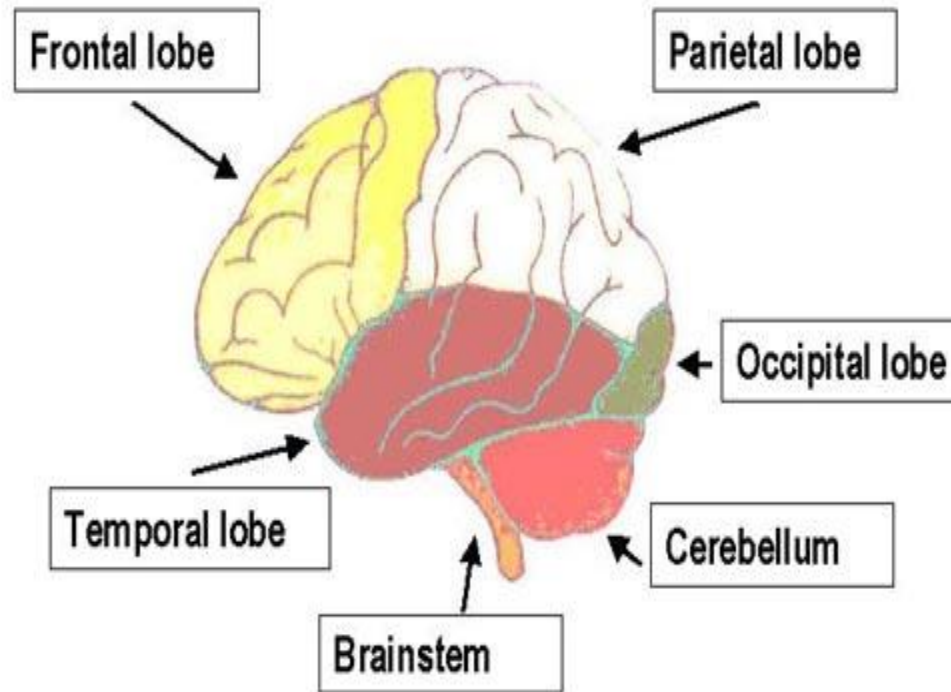


Key Factors Impacting Recovery

- Pre-injury lifestyle of family
- Location of injury to brain
- Pre-injury lifestyle of IwABI (Individual with Acquired Brain Injury)

And Here It Is!

Brain Anatomy 101:



Occipital Lobes

- “Am I seeing what I think I see?”
- Okay, I am “seeing stars”

Temporal Lobes

- “I’m hearing what you’re saying!” (hearing)
- “I remember what you’re saying!” (memory)
- As Popeye says, “I am what I am!” (sense of self)
- “Déjà vu”

Parietal Lobes



- “I feel no pain!”
- “I feel ‘that’ pain!”

Cerebellum



- 1/8 of total brain weight
- Skilled repetitive movements: running, swimming, writing, holding a drink

Frontal Lobes



- $A + B = C$ (I'm thinking)
- "Let's go to the store" (I'm planning)
- *Per-so-na-lity (teens!)*

“Getting Thicker As You Use It!”

- Uppermost “cerebral cortex” is 80%
- “Brain Work”—thinking, perceiving, speaking and understanding
- Other structures underneath—moving, sleeping, eating, smelling, seeing, breathing, etc.

“My Half Is Better Than Your Half!”

- Left Cerebral—analytical, reasoning, logic, language
- Right Cerebral—artistic, creative, art, music, voice recognition, orientation in space, mapping
- Corpus Callosum—bridging the halves!

“1 Cup ‘o Fluid’ Helps The Medicine Go Down”



- Cerebrospinal fluid—brain and spinal column
- “Your Brain’s connected to the Spinal Column” by the “Stem”
- Medulla—1 inch for temp, breathing, swallowing, vomiting, HR, and BP

Injury Site Plays Role

- Damage to the frontal lobe is significant for behavior problems
- Frontal lobes are “regulators” of integrative behavior
- Poor attention to task, initiation or participation in goal-directed behaviors

Other Injury Sites

- Damage to temporal lobes may cause verbal or physical outbursts
- Damage to hypothalamus may cause appetite disturbances, mood swings, and irritability
- Diffuse damage has shown to result in depression, poor frustration tolerance, and sexual dysfunction

Pre-Injury Lifestyle of IwTBI

- Personality
- Body image
- Previous satisfaction with life activities
- Religion and philosophy of life
- Life stage
- Ability to live with uncertainty

Additional Factors to Consider

- Premorbid level of functioning
- Severity of injury
- Depth and length of coma
- Age at time of injury
- Premorbid educational level
- Socioeconomic status

Adjustment, Coping, and Acceptance in Families



Stage 1 (1-3 months)

- Shock of the injury
- Hopes for full recovery
- Denial of severity

Adjustment, Coping, and Acceptance in Families



Stage 2 (3-9 months)

- Recognition of severity
- Helplessness
- Frustration

Adjustment, Coping, and Acceptance in Families



Stage 3 (6-24 months)

- Possible annoyance with survivor
- Family expects full independence
- Start to recognize the reality of impairment
- Start information seeking about ABI

Adjustment, Coping, and Acceptance in Families



Stage 4 (10-24 months)

- Realism of situation sets in
- Family begins to get exhausted
- Reduction of time with loved one
- Bereavement-like emotions may occur

Adjustment, Coping, and Acceptance in Families



Stage 5 (12-24 months)

- Profound sadness
- Families begin to grieve again
- Mourn the loss of loved one's personality

Adjustment, Coping, and Acceptance in Families



Stage 6 (2-3 years)

- Greater understanding of the situation
- Understanding person may never be the same
- Begins to accept loved one's condition
- Can now address needs of entire family unit

Adjustment, Coping, and Acceptance for lwTBI



Stage 1: Denial of Trauma's Impact

- Denial that recovery won't occur
- Denial of past abilities or current limitations
- Avoidance of tx/refusal of rehabilitation
- Denial can be adaptive* (in control, reduce stress)
- Long-term denial can be detrimental

Adjustment, Coping, and Acceptance for lwTBI



Stage 2: Grieving Over Perceived Losses

- Helplessness, sadness, sorrow
- Anger directed toward others
- Little dying/deaths along the way

Adjustment, Coping, and Acceptance for IwTBI



Stage 3: Depression

- Limited control over life
- Loneliness
- Impact of varied losses upon life
- Can come out as anger

Adjustment, Coping, and Acceptance for IwTBI



Stage 4: Guilt

- Accident is their fault (seatbelt; motor cycle helmet; alcohol)
- Families blame person for injury as they can't believe what has happened

Adjustment, Coping, and Acceptance for IwTBI



Stage 5: Coping Styles

- **Displacement:** anger over what one has lost may be displaced to family friends
- **Regression:** reverts to past methods of gaining gratification
- **Intellectualization:** “could have been worse” “now I’ll be a better person”

Adjustment, Coping, and Acceptance for lwTBI



Stage 6: Acceptance

- Gain new perspective on living
- Mental decision to live with realities
- Renegotiate old relationships
- Redefining self based on new interactions with others

Taking Adjustment, Coping and Acceptance to the Next Level!

Through AWARENESS

Impaired Awareness

“Person lacks or has reduced insight into deficits, present changes, and their implications on daily life.”

- Due to damage to certain areas of brain
- Denials of illness secondary to psychological distress

Awareness in Our Lives



- We all struggle daily with awareness
- Impacts all aspects of recovery
- Impacts getting back to life activities
- Requires self-monitoring
- Guides our actions and approach

Pyramid of Model of Awareness

- Intellectual Awareness: What has happened
- Emergent Awareness: “I get it” but don’t do anything about it
- Predictive Awareness: What happens if I don’t do anything different? Breakdowns?

The Struggle...



Understanding..

- they have a problem and need to change
- how awareness impacts their life
- what they need to do about it

#1 Strategy for Increasing Awareness



Videotaping...

- allows person to analyze their behavior
- watch & ask how they think they deal
- break down task steps
- teach compensatory strategy

Recalibration of Self

- Re-evaluate yourself
- Strengths and weaknesses evolve
- What you do in your 40s versus 20s
- What are my strengths, weaknesses and challenges?
- Don't let the "weakness dialogue" overshadow the strengths!

Empower People

Give someone a greater sense of confidence and self-esteem.

- Families
- Friends
- Professionals

Conclusions

- Life changes for everyone after a TBI, but does not have to be for the bad.
- Grief theory provides a framework for adjustment.
- Take time to relearn who you are now and how you have changed.
- Exploring how you have changed can be empowering!

Thank you for listening!



Deborah Gutteridge, MS, CBIST
Deborah.gutteridge@neurorestorative.com