

Supporting Family Involvement in Treatment following TBI

Third Annual Addiction & TBI Conference

NYS Office of Alcoholism and Substance Abuse Services,
Brain Injury Association of New York State
and Schenectady Community College

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Recovery ◇ *Rehabilitation* ◇ *Re-Entry*

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Source

- Northeast Center for Special Care
- 280 bed post acute facility
- 209,000 sq ft therapeutic community
- Designed for brain injury rehabilitation
- Moderate-Severely Impaired
- “Poor rehab candidates”
- Mostly male, average age 40’s
- 13th year of operation



Families and Brain Injury

- Everyone in the Family shares the injury
- Everyone needs to recover
- Everyone deserves time and resources necessary for recovery
- Each person can potentially help the others
- Each can potentially harm the others

Goals of Family Support

- Help each recover
- Help each support the others recovery
- Keep the Family together

Why Families Come Apart

- Too much change: “That’s not my husband”
- Inability to fully re-stabilize: chronic stress, mobile mourning, chronic sorrow
- Incompatible coping styles: one family member sacrifices self/relationships with other family members

Why Families don't Seek Help

- Their focus is on the patient
- Their own perceived responsibility to advocate, motivate, or do therapy
- Not seeking help may also:
 - Be (or become) a method of coping
 - Be conditioned by adversarial healthcare system
 - Be inability to downshift after the acute phase
 - Feel selfish, unacceptable

Other Good Reasons

- No time
- No energy
- No finances

Little Help Available

- Reimbursement limited to patients
- No time (for professionals either)
- Workers may take personally the adversarial stance of some Families
- Hardening of the categories: “The crazy family” (similar to the “bad patient”)
- Loss of empathy
- Attitudes on both sides become reinforced

Trust

- **Essential:** If you want to help
- **Challenging:** You may have lots to do *to un-do* what occurred in previous settings
- **Impossible:** If
 - You take feelings of family members personally
 - Trivialize the challenges they face
 - You're not persistent

Family Challenges

Loss of

- Friends
- Family (most of the extended, even immediate family may be absent)
- Finances
- All that was normal--new routines, places, faces
- Certainty--replaced by unpredictability, *fear*

Challenges, Continued

Hope & Fear Dilemma:

- Hope that there will be a cure—
That all will return to normal
- Fear that it never will—
That I/we cannot survive
- Families may see-saw between these poles

Common Response

- Anything that stops the see-saw
- May lead to choosing, e.g., “He’s going to get better (and everything it going to return to normal)” or, “He’s never going to get better (things will never return to normal)”
- Going to war, or, going away
- Major conflict when individuals in same family make opposite choices

What do *you* Believe?

- It matters
- What's in your gut during your interactions with families/survivors?
- What drew to work with this population?
- What the traumatology data says (many of us have something in common)
- Are you a victim or a survivor?
- What is the individual? The Family?

Change: The Third Choice

- “Things will never be the same *and* you can all get better”
- *You* may need to be the confidence, the hope the family/survivor lacks
- They need to see their strength and ability reflected in us (or they may see the reverse)
- Change is a choice that takes courage
- Courage takes time to develop

We must convey

- Humility
- They are taken seriously
- That we accept what they are going through
- We like them and want the best for them
- These things sow the seed of trust and
- Willingness to consider options

The Message in a Nutshell

- Change is *needed*
- change is *hard*
- change is *possible*--especially if they are willing both give and receive help from each other

Support =

- Information +
- Humility +
- Confidence in their ability to change -
- Demands—it's not your life

Family Education

- Educate about what you do
- How your program functions
- How you see things
- What you can and can't do
- What you expect
- What they can expect

- Educate about how decisions are made
- Team process, everyone gets heard, reconciliation of views, a direction is taken then re-evaluated
- How requests for updates will be handled and how often available
- Single-point-of-contact system

Prognosis

- There are no absolutes
- Age
- Pre-morbid level of functioning, work, education
- Presence/absence of complicating factors
- Personality/habits/attitudes/beliefs

- Level of severity of injury
- Cognitive impairment—level of confusion, awareness, active participation

Prognosis, Continued

- There will be no cure, miracles, or magic
- Limit to what can be accomplished in any setting may be less than what individual can accomplish over months, years, multiple settings
- Best prognosis: How person is doing during most recent treatment period
- No matter what, life will be different

- It will come down to making decisions
- Treatment team decisions, Family decisions, decisions by the individual
- To focus on what can be developed and set aside what is not responding to treatment—at least for the time being

Recovery

- What it is not:
 - A Cure
 - Returning to life the way it was before
- What it is:
 - Ultimately, their decision
 - We recommend: A relentless pursuit of physical, mental, and spiritual well-being
 - Aiming high

Recovery, Continued

- Not “being normal” – there are natural limits to healing that no one can change
- Feeling well – Making decisions about new patterns of living that will tend to produce the best physical, emotional, and spiritual outcome
- For most this means *new habits*, both mental and physical

Some Support Group Topics

- Relaxation
- Mindfulness
- Meditation
- Self Compassion
- Communication & Conflict
- Diet, Exercise, Sleep Hygiene
- Fun

Brain Injury

- Four major types:
 - Traumatic—impact by or against something hard, damage to large areas of the brain
 - Cardiovascular (stroke)—loss of blood supply to specific brain region due to blockage or bursting of blood supply
 - Anoxia—heart/breathing stops, damage to brain as a whole
 - Toxic—overdoses, chronic substance abuse—damage to brain as a whole

Brain Injury, Continued

	Damage to Specific Area/Functions	Damage to Multiple Areas/Functions	Damage to Brain as a Whole
TBI	X	X	
Cardiovascular (Stroke)	X	X	
Anoxia		X	X
Toxic		X	X

Brain Injury, Continued

	Greater likelihood of Specific Motor, Perceptual, Cognitive Problems	Greater Likelihood of Global Awareness Problems
TBI	X	X
Cardiovascular (Stroke)	X	
Anoxia		X
Toxic		X

Motivation

- Families are often pushing their loved one (and us) hard
- They perceive motivation as the key (Sometimes the only thing they think is necessary—more on that later)
- Indeed it very important
- But it's not what they think

John's Story

What does John lack?

- He could not see how his *present* actions related to his *future*

- What was explained *he could not retain*

As a result...

...He lacked “motivation”

But did John lack *desire*?

No way.

Desire

- We may know we need to do something, and do it, without *desiring* it.
- We may desire something we do not pursue.

Basic Concepts of Treatment

1. Motivation Disability is a common, predictable *neurological* concomitant of brain injury based on reduced awareness or orientation

2. Awareness and Orientation are not states but repetitive acts that requires tremendous cognitive power.

3. Any injury may impair motivation at the neurological level *by impairing the cognitive ability to constantly update myself as to where I am, where I've been, where I'm headed*

Cognitive Impairment & Awareness

Past Present Future

|-----noTBI-----|

|-----mTBI-----|

|-----modTBI-----|

|-----sTBI-----|

Because we can “see” the link

(in real time)

- *We resist* (impulses)
- *We persist* (at what we must do)

Associated Clinical Conditions

Some terms and clinical conditions associated with Disorders of Awareness and Motivation:

Abulia, adynamia, anosagnosia, apathy, aspontaneity, confusion, depression, disinhibition, disorientation, executive dyscontrol, flat affect, frontal lobe syndrome, impulsiveness, memory impairment,

4. Pushing may only
push them away.

5. The person has to work harder than ever to get through the day.

- Due to extreme loss of the familiar
- Cognitive load rises as person moves down levels of care
 - May rise as person improves
 - Loss of reserves
- *Increasing* risk of failure, chronic fatigue

6. Over-load is never far off.

- Anxiety, worry, fear.
- Fight/flight response *without ability to do either*.
 - Downshifting.
- Poor “brakes” (inhibitory functions, i.e., thinking!)
 - Flooding/catastrophic reaction.
 - Pushing may only push them over the edge.

7. Your loved one has real fears that you can make worse, or better.

- Their losses are real.
- Their fears the same as yours.
- They cannot force it any more than you can.
- They will respond to pushing no better than you do.

8. Courage comes from belief in self

- Belief in self is supported by belief by others
- Belief by others is meaningless if they don't accept me as I am now
- If I am unacceptable the way I am, and trying guarantees nothing but more conflict, why bother?

9. No one can do anything they put their mind to—not you, your loved one, or your therapists

- Limits will remain
- Pretending otherwise will add to the damage
- If you (or any of us) become adversaries *potential will be reduced.*



**Let's take a 30 *second*
stretch break!**

10. You can't be a therapist *and* a Wife (Husband, Brother, Father, etc.).

- Don't abandon your primary relationship.
- Only you can give approval and acceptance with the weight you carry.

12. If Necessary: “Therapeutic Push-Back”

- “We were both (all) devastated by this injury
- “We need to both (all) recover from it”
- “What I/we feel and think has to matter too”
- “I/we need you to do what it takes to get better”

13. Interaction Skills

- Slow down *everything*
- Say less, listen more
- Preview-review
- Overcommunicate, Don't assume understanding or retention
- Be *delighted* to repeat, encourage asking

- Instructions in bullets—e.g., giving directions,
 - » “2nd floor
 - » Left
 - » Left”
- Ask for return explanation—organization occurs at output

14. Organization Strategies

- Following a Schedule → Creating own Schedule
- Checklists
- Task Completion Strategies:
 - Prepare all the steps in advance
 - Lie out pieces/implements/ingredients in order to be used
 - Leave a reminder of what you were working on if you leave a workspace
 - Use of interval timer to keep track of schedule

15. Medications

- Avoid extremist point of view
- Medications are not a single answer nor to be totally avoided

Self-Care Recommendations

Observe yourself

- Are you feeling very stressed, anxious, depressed, easily angered, or irritable?
- Do people say you are depressed or exhausted, but you deny it?
- Are you exhausted or having sleep problems?
- Is your health beginning to deteriorate?

- Have your eating, exercise and/or sleeping patterns changed?
- Have you become withdrawn socially, and/or are you giving up previously satisfying activities or goals?
- Do you find you are having difficulty concentrating?
- These are possible indications of clinical depression that may continue to worsen if not treated.

- Taking care of yourself is serving as a role model for your loved one
- So is not taking care of yourself

What can help:

- Learn. Learn as much as you can about your loved one's condition.
- Know your limits. Be realistic about how much of your time and yourself you can afford to give.
- Pace visitation so that you do not become exhausted.
- Communicate your limits to staff and when appropriate, your loved one.

- Accept your feelings. Experiencing a host of difficult emotions when you care about someone with a brain injury or chronic illness is common.
- Allow yourself to feel what you feel.
- Confide in others. Talk to people about what you feel. Don't keep your emotions bottled up. Trusted family members and friends can help too.
- You may also benefit from seeing a therapist or counselor.

- Take pleasure. Incorporate activities that give you pleasure even when you don't really feel like it. Listen to music, work in the garden, engage in a hobby...whatever it is that you enjoy.
- Pamper yourself. By taking care of yourself, you will be better able to address decisions and support your loved one.
- Care for yourself. Eat balanced meals to nurture your body. Find time to exercise even if it's a short walk everyday.
- Do the best you can to sleep at least 7 hours a night.

- Maintain your routine. Try to maintain a schedule that is as regular as possible.
- Laughter really can be the best medicine. Buy a light-hearted book or rent a comedy.
- Whenever you can, try to find some humor in everyday situations.

- Accept support from others. Sometimes it can be challenging to accept a favor or ask for help from other family members or friends.
- Give yourself permission to do so.
- Share. Share the journey with your significant other and with us. Realize that rehabilitation can be a slow, sometimes frustrating process.

The End

Thank you!

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