

# **Resilience after Brain Injury Disability**

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# **Disclosure**

**Rolf B. Gainer, PhD has business relationships with Rehabilitation Institutes of America, Brookhaven Hospital, Community NeuroRehab of Iowa and their related companies.**

**No commercial interest is related to this presentation.**

# Objectives



**To examine the concept  
of psychological  
resiliency in relation to  
disability**

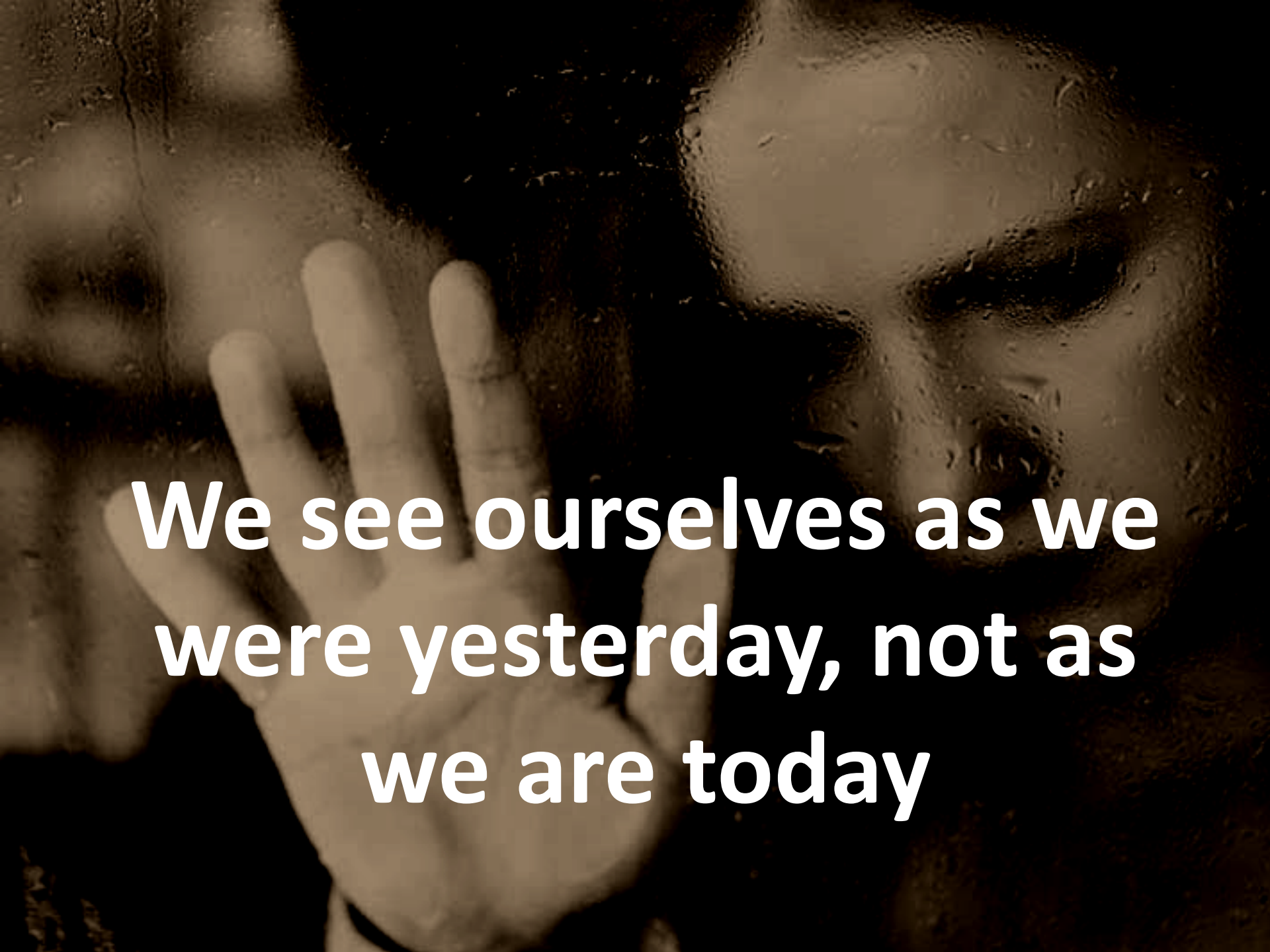
**To identify the processes  
of change associated  
with resiliency**

**To understand the  
significance of personal  
narrative in relationship  
to resiliency**

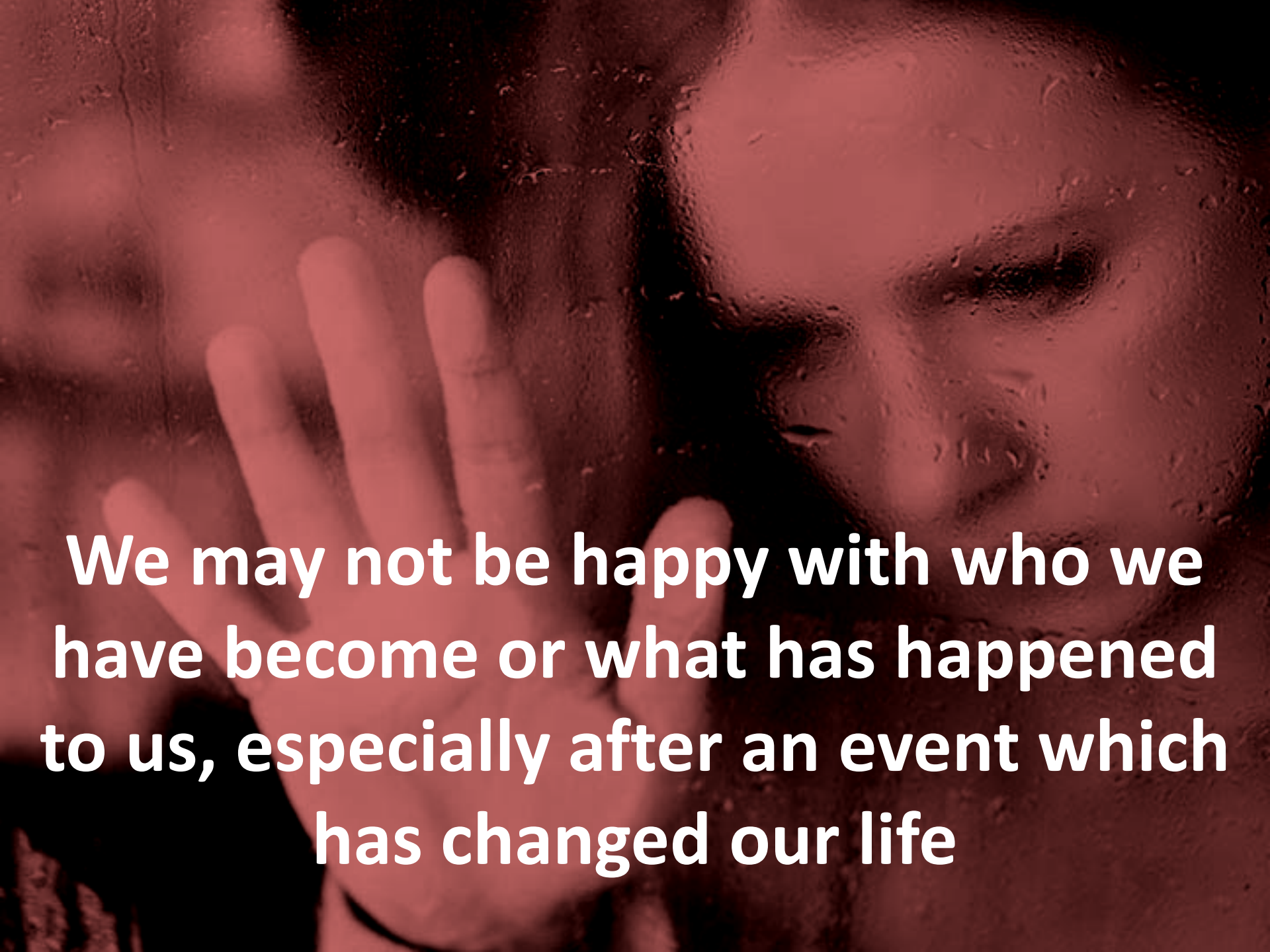
***Resilience:***

**1. The capability of a strained body to recover its size and shape after deformation caused especially by compressive stress;**

**2. an ability to recover  
from or adjust easily  
to misfortune or  
change**



**We see ourselves as we  
were yesterday, not as  
we are today**



**We may not be happy with who we  
have become or what has happened  
to us, especially after an event which  
has changed our life**



**“The most devastating  
loss of all becomes a loss  
of the meeting of the  
minds”**

**Paula Freed, 2002**

**Crisis opens up a  
can of worms...**



**...which we have long  
suppressed and repressed**

**-Larry Gould, MD**

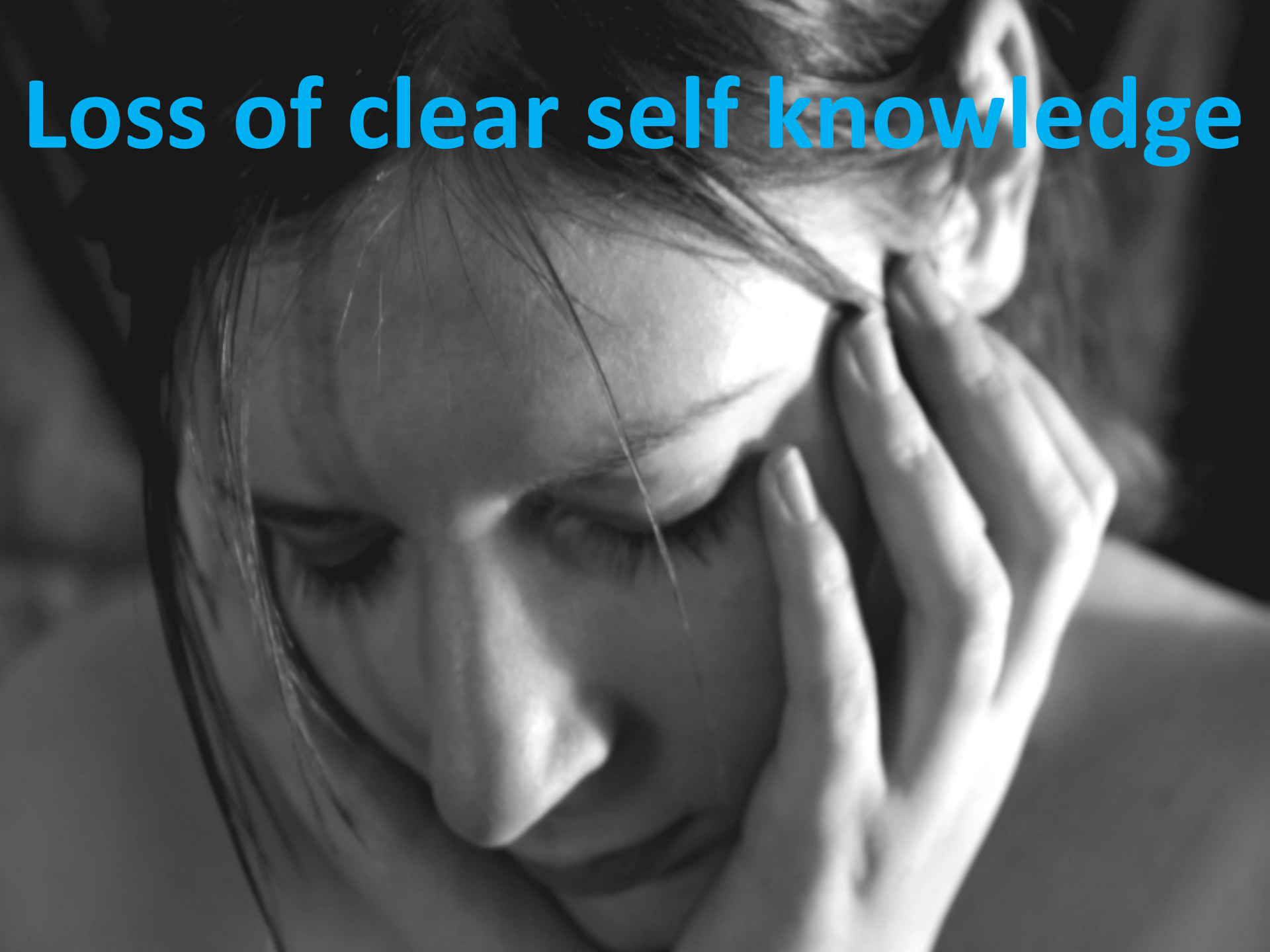


# Three categories of loss

A black and white close-up photograph of a woman's face. She is looking down, and her right hand is raised towards her eye, with fingers slightly curled. Her expression is one of deep sadness or grief. The lighting is soft, highlighting the contours of her face and the texture of her hair. The background is dark and out of focus.

Nochi, 1998

**Loss of clear self knowledge**



**Loss of self by comparison**



**Loss of self in the eyes of others**



**Everybody has a  
plan...  
until they get  
punched in the face**

Mike Tyson



**Brain injury is destabilizing**



**How does a person deal  
with the **changes** in their  
life created by brain  
injury disability?**

**Fundamental changes  
following TBI result in  
feelings of:**

**Pessimism**

**Hopelessness**

**Generalized Anxiety**

**Kreutzer, J. et al 2001**

**Reeves, R and Laizer, J. 2012**

A person's history is  
key to  
understanding how  
they will react to  
their brain injury

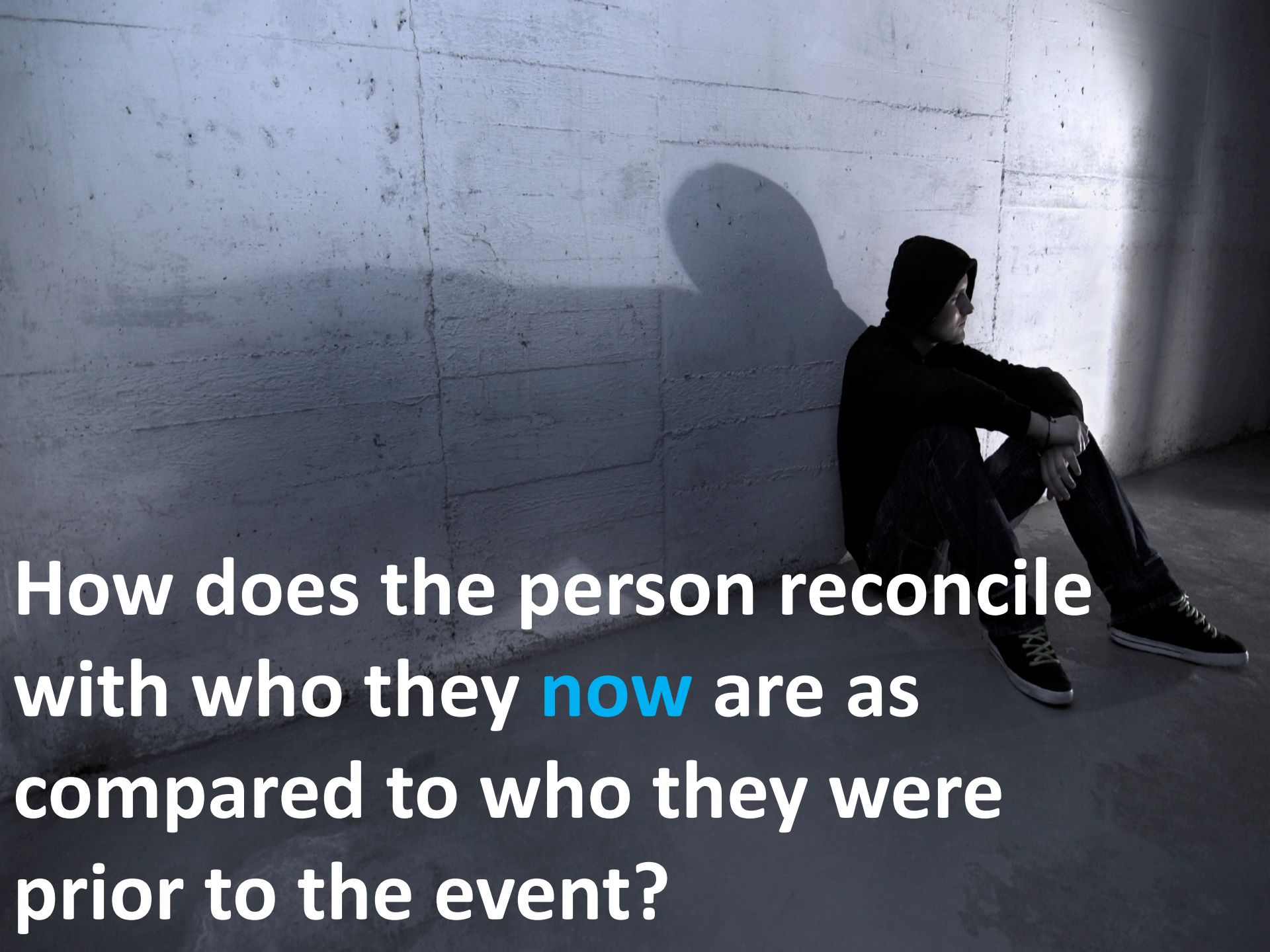
Prigatano G, 1986, 2008

**“The tragedy of the human  
brain is that it is aware of  
what it has lost and where it  
is headed-both at the same  
time”**

**Walter Mosley, “When the Thrill is Gone”, 2011**

# Loss creates:



A person wearing a dark hoodie and jeans is sitting on the floor against a light-colored, textured wall. Their shadow is cast onto the wall behind them. The lighting is dramatic, with a strong light source from the right creating a bright spot on the wall and floor. The person is looking down and to the right.

How does the person reconcile  
with who they **now** are as  
compared to who they were  
prior to the event?



There is no measure for  
resilience, it is the person's  
**response to adversity,**  
obstacles and threat which  
determines how the person  
will fare with each event

Emmy Werner, 1989



**Resilience is a constant  
recalculation of factors  
relating to multiple  
stressors over time**

Emmy Werner, 1989

**“Events are not traumatic  
until we experience them as  
traumatic”**

George Bonanno, 2016

Loss, Trauma and Emotion Lab, Columbia University

**“Events are not predictive  
until there is a negative  
response”**

George Bonanno, 2016

Memory and attention  
impairments effect the  
quality of relationships





personal  
losses  
created by  
disability  
affect a  
person's  
social  
capital

As social capital  
decreases, stress  
increases



Kawachi Ichiro

Resilience  
requires social  
capital

**Does brain injury disability create  
“a cloak of competence”?**

**For the person ?**

**And, in the perception of others?**



**How does the person  
deal with the changes  
in their perception of  
self?**

Brian Little refers to “our multiple selves” made up of our “fixed” or biogenic traits and our “free” or sociogenic traits

**How does injury exert  
change on  
the person's biogenic  
traits and their  
sociogenic traits?**

**Brian Little, 2014**

Brain injury impacts both  
the “fixed” and the “free”  
aspects

**How does the person  
perceive the control of  
their life after an  
adverse event?**

**Internal or External?**

Shifting to  
**internal control** can  
lead to  
**positive responses** and  
changes

**Externalizing control  
prevents the person  
from addressing the  
changes in their life**

**How do other people  
respond to the person?**





**Do the responses of others  
effect how the person views  
their life?**




A close-up, sepia-toned photograph of a person's face, partially obscured by a hand pressed against a glass surface. The hand is in the foreground, with fingers spread, and the face is visible through the glass behind it. The lighting is warm and dramatic, with strong highlights and shadows.

Friendship, connections and  
loneliness

“As many people die  
from social isolation as  
smoking related  
diseases annually”

Al Condelucci, 2017



People who are “at  
social risk” have fewer  
relationships which  
align them with others  
leading to loneliness

- Al Condelucci, 2017





Resilience  
benefits from  
connectivity

# **“connectedness”**

**The perception of relationships**

**The recognition of emotion and  
affect**

**The ability to exercise decision  
making over behavior**

The “**cascade**” effect occurs  
in illness and disability as a  
source of unhappiness for  
the person and others

Christakis, N, Fowler, J: Dynamic Spread of  
Happiness in a large social network. BJM 2008;  
337: a2338, 2008

**Relatives' criticism influences  
adjustment and outcome  
after brain injury:**  
**Association between distress,  
coping and recovery**

Weddell R. Arch Phys Med Rehab. Vol 91, June  
2010, 897-904

A person with long, dark hair is seen from behind, looking out a large window. The person is wearing a dark, long-sleeved top. Their right hand is pressed against the glass. The scene is bathed in a cool blue light, suggesting a clear sky or a specific lighting choice. The window frame is visible, and the background outside is slightly blurred.

**“You look great!”**



A person wearing a black hoodie is seen from behind, looking out of a large window. The person's right hand is pressed against the glass. The scene is dimly lit, with bright light coming from the window, creating a silhouette effect. The background outside the window is blurry, showing what appears to be a cityscape or industrial area.

**“Why don’t I feel great?”**

**Why do some people  
lose their sense of self?**

Why do some people  
“bounce back”?

**Are people inherently  
different in their  
psychological resiliency?**

**What can we learn from  
people with  
psychological resilience?**

**Can we teach or enhance  
the skills associated with  
psychological resilience?**

Laurie Rippon  
commented on  
“changes”

**Defining “loss of self”**

**“How could I accept the  
changes from my ‘before’  
life?”**



**“What can I actually do?  
I felt useless with no  
purpose... I was  
depressed”**

**“The better I got, the more  
aware I became of my  
deficits which made me  
even more depressed  
about my prospects of the  
future”**

Understanding the process  
of **recovery of self** may  
help us to understand  
**resilience**

**Do people have different  
“susceptibility” factors?**

**And, can those factors  
change over time?**

**Can we enhance a person's  
likelihood of a positive  
response to an adverse  
event?**

**What is key to  
changing?**



**Resilience Theory: resilience  
is a positive adaption in the  
face of a traumatic event**

Newman, R., 2005

# Core Traits Associated with Resilience

Even Tempered, Stable Emotionally

Positive Outlook, Optimism

Self-regulatory skills

Social Perception, “Liked” by others

Insightful modification of behavior

Good problem-solving skills

Effective communication



**Resilient**

**or**

**dysfunctional reintegration**

# Traits vs. Skills

**We can't learn new  
“traits” but we can  
learn new “skills”**

A tall, clear glass filled with water to the halfway mark. The glass is set against a light blue background and sits on a reflective surface. The water level is clearly visible in the center of the glass.

**My cup is half empty**

A tall, clear glass filled with water to the halfway mark. The glass is set against a light blue background and sits on a reflective surface. The water level is clearly visible in the center of the glass.

**My cup is half full**

**Attitude or personal  
belief?**

**Trait or skill?**

**How does a person  
change their narrative?**

**“If there is no change...**  
**...nothing changes”**

**“Every day passes  
whether you  
participate or not”**

**Deng Ming-Dao**



**The tasks for the person  
are defining what they  
can change ... and  
making the changes**

**Which skills are  
“teachable”?**

**Can others assist in the  
process of redefinition?**

# **Do some people “catastrophize” barriers?**

**The perception of personal and  
environmental obstacles affects  
resilience and ability to participate**

Ravesloot, et al. Can people catastrophize barriers?,  
Disability and Health Journal, (2017), 10, Elsevier, NY, pp  
65-72

**Can we learn about  
resiliency from stories?**



# Ray

Ray, was a promising middleweight boxer who started his career at age 14. By his early 20's he had experienced multiple concussions and left boxing. At age 44 he was diagnosed with Parkinson Syndrome and Dementia Pugilistica

**“...I had my first concussion  
at 16 in Buffalo, New York  
when I took a right hook to  
the back of my head...”**

**“one week later I was  
scheduled to fight in  
Syracuse. I knew something  
was wrong- I got my “bell  
rung” in the first round...”**



**“...I vomited in my water bucket but stayed in the fight. I didn’t even remember that I lost the fight in the post-fight interview....”**

**“...the fog lingered. I started  
having problems in school,  
trouble concentrating,  
headaches, sleeping  
excessively and resenting  
authority...”**

**“...I battled through and asked a trainer about the headaches and fatigue. He told me to “gut it out”.**

**“...In 1971 I failed the required EEG for the New York State Boxing Commission license. I fought in places where no license was required. I returned in 1973 for a re-test and my EEG was grossly abnormal...”**

**“....In 1974 I took a break from boxing-the symptoms didn’t go away. I threw out my boxing memorabilia . I went into a mental health facility and was diagnosed with severe depression...”**

**“... I took to the road for a while and avoided everybody. I took refuge in the National Parks....”**

**“...14 years later I couldn’t  
continue working at my job due  
to tremors. I was diagnosed  
with Parkinson Syndrome and  
Dementia Pugilistica...”**

**“...The only thing I could do  
was prevent another  
athlete from going down  
my path...”**



**Now, at 63, Ray is the founder of The Second Impact, a not-for-profit brain injury prevention program. He provides talks to athletes-amateurs, university and professional teams about concussion recognition and prevention. He has turned his losses from brain injury into a way to help others.**

# Melissa

Melissa was injured at 30 in a motor vehicle accident while at work. She was the Director of Public Relations at a large teaching hospital. A self-defined “workaholic” and she enjoyed an active social life with friends and family and participated in sports.

**“...I received 64 floral  
arrangements from my  
friends... nobody came to visit  
me after my discharge...”**

**“...right after the accident  
my parents, younger sister  
and brother were my  
support network...”**

**“...my parents replaced my functions in the home. They took care of everything...”**

**“...my parents replaced my functions in the home. They took care of everything...”**

**“...I tried to go back to  
work...”**

**“...my job could not  
accommodate post-injury  
needs...”**



**“...my social relationships  
fell off as people recognized  
my deficits...”**

**“...they didn’t know how to  
make it comfortable...”**

**“...we weren’t  
operating in the  
same social circles  
anymore...”**

**“...people withdrew  
from me, too.”**

**“...I felt vulnerable  
due to my brain  
injury...”**

**“...I started to feel OK about myself when I started volunteering and getting involved in peer counseling...”**

**“...I started to develop  
self-compassion...”**

**“I began to explore myself  
through meditation”**



**“...I started going back to  
school... its been over 10  
years since my brain  
injury”**

**“...the third hurdle was  
getting my master’s  
degree...”**

**Now, 24+ years since her injury,  
Melissa is an accomplished  
researcher in Mindfulness, a  
published journal author, a sought  
after conference speaker and  
teacher. She can reflect back on her  
journey and share the process she  
went through to find herself.**

# Jerry

I met Jerry when he was a 20-year old university student, injured at 19. Following a short period of acute rehabilitation he experienced a deep depression which didn't clear

**“ I tried to go back to  
school, but I couldn’t  
concentrate”**

**“getting C’s and B’s just  
wasn’t me. I was used to  
getting straight A’s”**

**“It was hard to hang out  
with my friends. Somehow  
we weren’t the same  
anymore. It was easier to  
be alone”**

**“ I thought about killing myself a lot. I went up to the roof and thought about jumping, or taking an overdose. It was impossible to tell my family about how I felt”**



**“I stole Sherri’s car and I  
thought today was the day.  
I looked into the back seat  
and I saw the baby’s car  
seat. I had to bring the car  
back”**

**Jerry ended his life by driving his car into a bridge abutment about 3 years after he left our program. He was finishing university. I see his mother often. She has become very involved in advocacy work**

**All hit bottom...**

**One stayed there**

**Two came back**

**Why?**

# Laurie Rippon

addressed that process

**“When life was turned upside down I began to focus on what really mattered to me. That set me on the way to a new life-one I could be proud of”**

**Laurie Rippon**

**“I always look forward – setting  
aside regrets of the past and  
instead, imagining a future, I still  
love to learn, grow and move”**

**Laurie Rippon**

**“ I learned to feel good about  
each small step of progress,  
which gave me the confidence  
to look to the next step... until I  
felt more whole”**

**Laurie Rippon**



**Changing the narrative  
is vital to defining  
“self” after injury**

# Psychotherapy and Change

**Can we help the person  
change their narrative?**

**“Focus on discovering  
the meaning of their  
lives in the face of, not  
despite, the brain injury”**

Prigatano, G., 1999

**“Teaching the person to  
behave in their own  
self-interest”**

Prigatano G., 1991

# Helping the person in viewing their life as meaningful

Ben-Yishay, Daniels-Zide, 2000. Examined Lives:  
Outcomes After Holistic Rehabilitation

**These strategies create a  
safe place to experience  
the changes from injury  
and identify a new self**

# **Rational Frame Theory**

## **Developing a new self-concept**

Myles S. 2004, Intl. J of Psychology and  
Psych Therapy, 2004 V.4, N.3. 487-504

# Redefining Self

Conceptualized Self

Self as an ongoing process of  
verbal knowledge

Self as context



**Experiencing loss in the  
context of perceived loss  
of competencies- the  
“then and now”**

**Working through the anger,  
depression, anxiety, grief:  
aspects of distress over the  
loss of competency**

# **Acceptance and Commitment Therapy (ACT)**

**Assisting the person in  
recognizing being “stuck” due  
to fear vs. relearning to “act”**

**A**ccept your reactions

**C**hoose a valued direction

**T**ake action

Myles S., 2004

**Working through the  
experience of intense  
anxiety post-injury  
Conceptualized as a defense  
of pre-injury self-concept**

Myles S., 2004

**Teaching the person to  
become non-judgmental  
and accepting of self**

**“...Identity is a growing and  
changeable thing ... the  
tragedy which occurred can  
be inserted into one’s  
narrative and shape their  
identity...”**

McAdams, 1993, 1994

**Helping survivors of a traumatic  
event see the positive and assist  
the survivor in de-victimizing  
themselves- creating  
opportunities for positive  
thinking and growth**

Taylor, Wood, Lichtman, 1983



# **Emotion-focused Therapy** **helps the person make sense** **of their internal experience** **after trauma**

Greenberg, LS, Clin Psychology and Psychotherapy, 11, 3-16, 2004, John Wiley and Sons, Ltd.

**A person cannot leave  
a place until they have  
arrived at it**

The process of **Emotion Awareness, Emotional Regulation and Emotion Transformation** is key to that process

**Change**  
occurs through  
arriving and leaving



**Assist the person in  
attempting an alternative  
to “failure”**

**Reframing negative reactions to  
real situations:**

**You can do it!**

**As we look at the models of  
treatment, there is a  
commonality:**

**Acceptance of the new self  
is critical to adjustment**


**Moving beyond therapy**

**“ I could replace perfectionism with the pursuit of excellence. I had to get to a place where I could move beyond the pain of denial and not accepting my reality, before I could grieve my reality.”**

**Craig Phillips, 2015**



How can we help people in  
this process of **finding**  
themselves and, in a way,  
**reinventing** themselves?

Two ginkgo leaves are shown on a single stem, positioned on the left side of the image. The leaves are fan-shaped with distinct venation and serrated edges. The background is a solid dark gray.

How can we  
facilitate  
**resiliency**  
through a  
therapeutic  
relationship?

**How can a person start  
the process of  
rewriting their  
narrative?**

**“The longest way round  
is the shortest way  
home”**

James Joyce

**“The only way to make sense out of change is to plunge into it, move with it, and join the dance.”**

**Alan Watts**

**“We all have two lives.  
The second one begins  
when you realize you  
only have one.”**

**Confucius**





**No one road or formula  
leads to change**





C

H

A


N

G

E

Maybe  
more than one person  
is involved



A black and white photograph of two hands, one from a darker-skinned person and one from a lighter-skinned person, joined at the fingers to form a heart shape. The hands are positioned symmetrically, with the thumbs and index fingers touching at the top and bottom points of the heart. The background is a soft, out-of-focus grey.

**Can we look to a person's  
immediate network and support  
system?**

**How can we help the person and  
their system to mobilize and change?**



# Thanks

## Questions?

This presentation can be found at  
**TraumaticBrainInjury.net**

under “Resources” and “Community  
Presentations”

# Resources and References

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