

# Loss of self following brain injury: the task of building a new identity

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**Disclosure: Rolf B. Gainer, Ph.D. has business relationships with the Neurologic Rehabilitation Institute of Ontario, the Neurologic Rehabilitation Institute at Brookhaven Hospital, Community Neuro Rehabilitation of Iowa and Rehabilitation Institutes of America. The NRIO Outcome Validation Study is supported by the Neurologic Rehabilitation Institute of Ontario, the NRI Outcome Validation Study is supported by Brookhaven Hospital and the CNR Outcome Study is supported by Community Neuro Rehabilitation of Iowa.**

**A**fter more than a century of looking for it, brain researchers have long since concluded that there is no conceivable place for a self to be located in the physical brain, and that it simply does not exist.

*TIME* MAGAZINE

**5**

**W E D N E S D A Y**

**A U G U S T**

**2 0 1 5**

**“How could I live with a  
deficient brain? My head injury  
had been bearable only  
because it was temporary.  
Permanent injury meant I had  
already lost. My job, my  
identity, my life, the real me.”**

# Objectives:

# **Understanding the cumulative process of loss and bereavement**

**Assessing the  
components related to  
the changes in  
perception and value of  
self**



**Examining the  
relationship losses  
experienced by the  
person**



# **Defining the post-injury experience**



**Ambiguous  
loss creates  
stress and  
defies closure**



**Uncertainty  
about self**



**The erosion  
of  
competency  
and self  
worth**



**Struggling  
with issues  
of post-  
injury  
identity**

# Three categories of loss

A black and white close-up photograph of a woman's face. She is looking down, with her right hand near her eye, suggesting a moment of grief or loss. The lighting is dramatic, with strong highlights and shadows.

Nochi, 1998

**Loss of clear self knowledge**





**Loss of self by comparison**



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



“....imagine waking up each day with a pounding headache, always feeling like you have a hangover plus a bad flu after being up three nights in a row; having trouble concentrating, remembering, and getting your thoughts together; losing your temper and snapping at people for no reason. On top of that, nobody believes you or thinks you are crazy...”

**Injury created barriers**

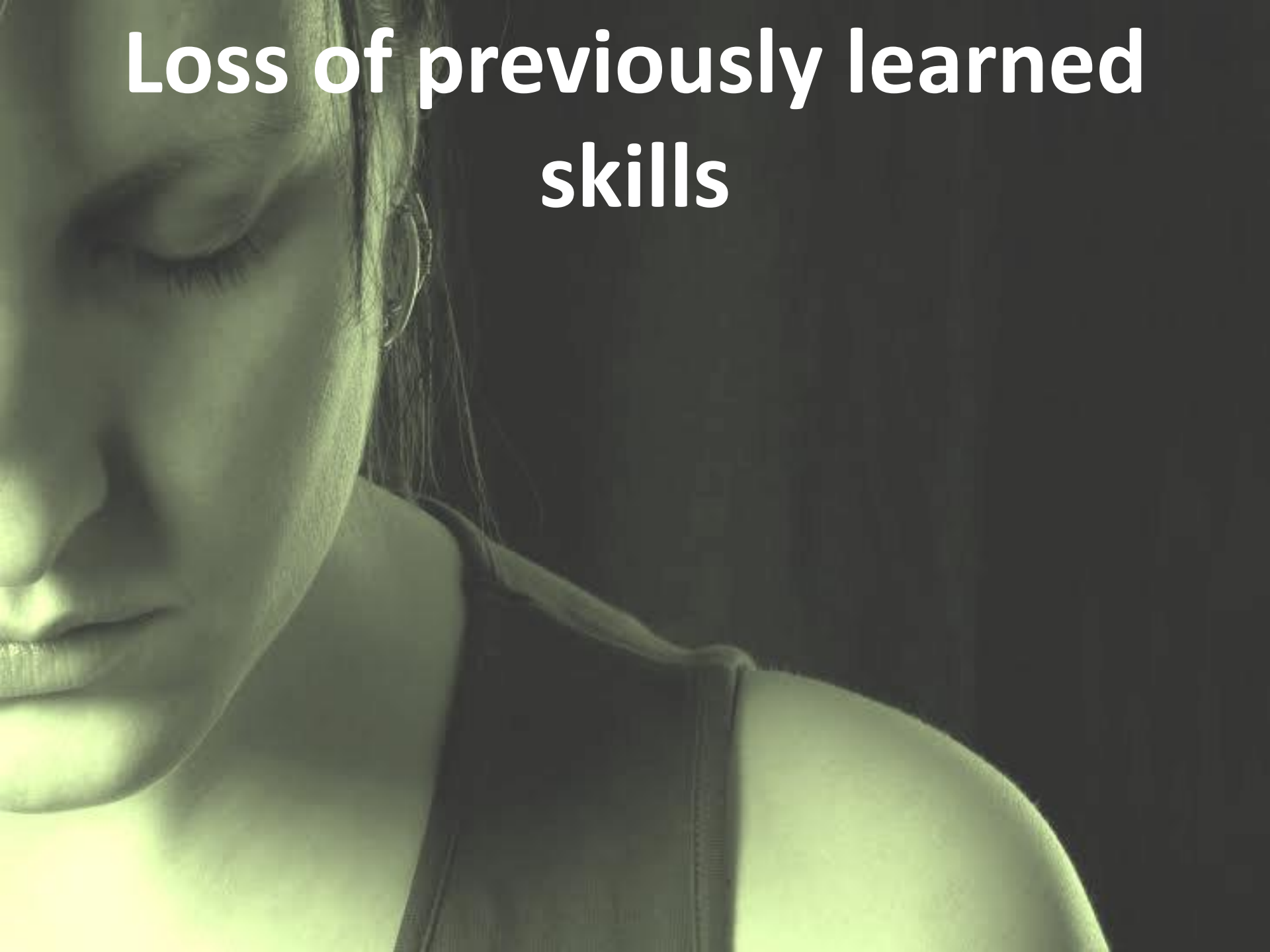


**affecting the person**

**Loss of one's sense of  
competency**



# Loss of previously learned skills







**Loss of life focus**

# Becoming dependent on others





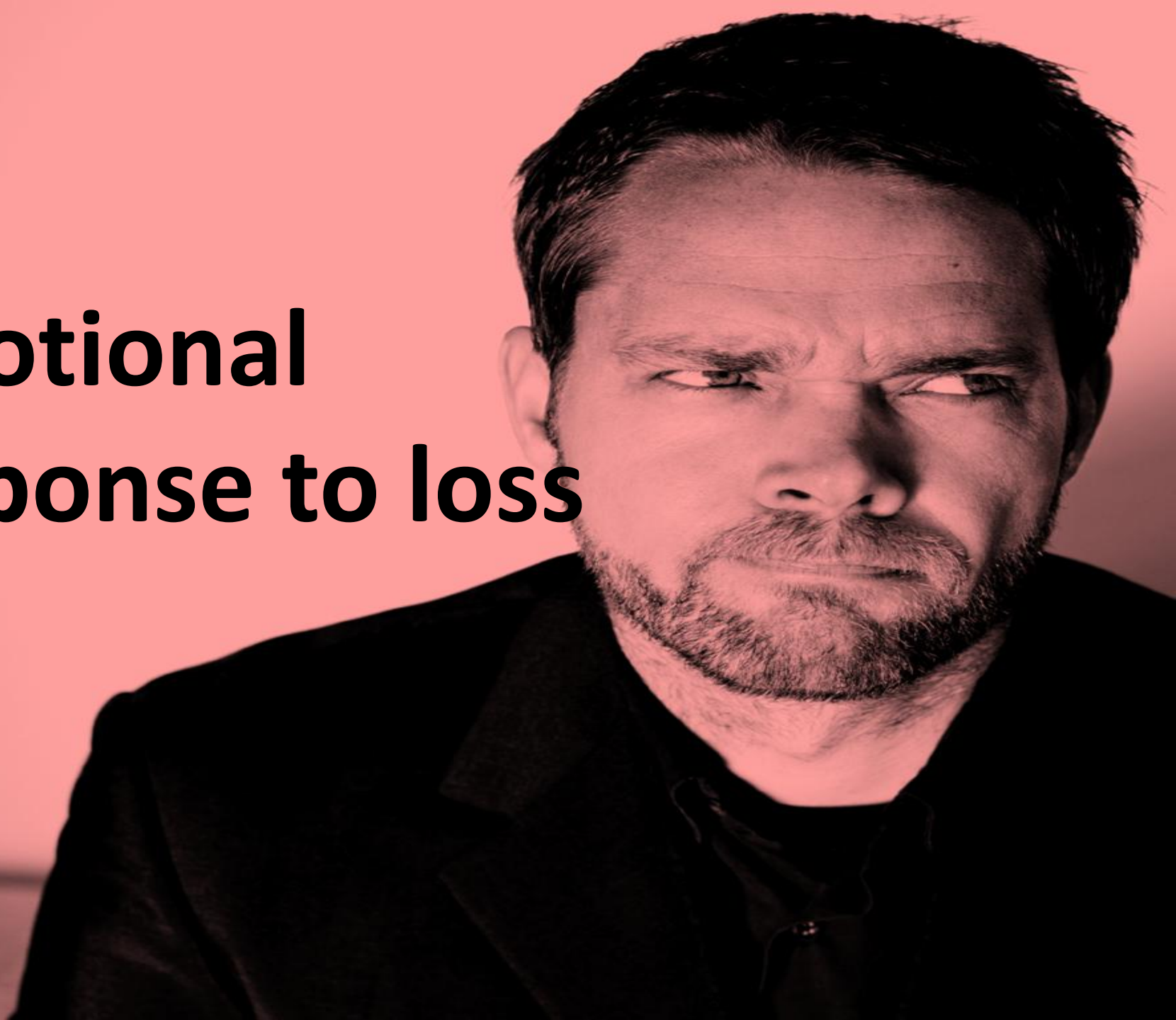


# Experiencing changes in relationships

# The challenges of relearning

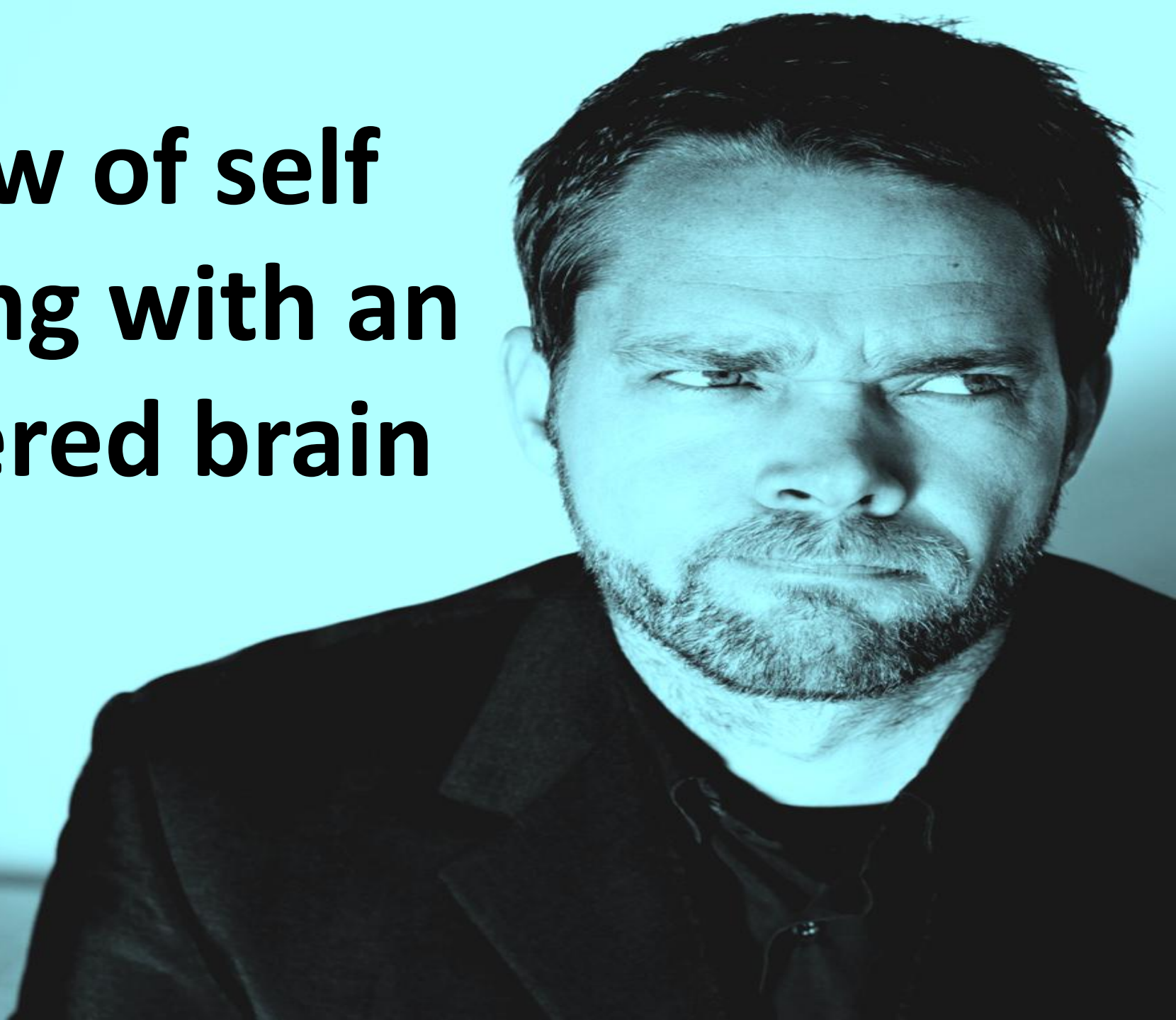


# **Emotional response to loss**





**View of self  
living with an  
altered brain**



# Cognitive changes



# Emotional changes





# Behavioral changes



**Reduced  
coping skills**





**Physical  
changes**



# **Loss of self**

## **Perception of self worth**

## **Process of disengagement**

# Loss of social capital

Bronfenbrenner, U. Measuring Environment Across the Lifespan. Freidman SL, Wachs TD ed. Washington, DC, Amer. Psych Corp; 1999, 3-28

# Disengagement from naturally occurring social units

Lewin K. Field Theory in Social Science. Oxford: Harpers;  
1951

Christakis C, Fowler J., 2008

**Forced change in  
employment**

**Creating economic changes**

**View of self as ineffective**

# Encountering barriers

**Internal: injury-based**

**External: resource and access-  
based**

**Ability to access to  
information**

**Availability of adequate  
social supports**



**Systems and policies which  
provide for needed  
resources**

# **Economic resources to support living and participation**

Hammel J, et al Environmental Barriers and Supports to  
Everyday Participation: A Qualitative Insider Perspective  
from People with Disabilities, ACRM, Arch of Phys Med  
and Reh. Reston VA. Elsevier April 2015 578-588

**Living with changes**

# What has happened to me?

Recognizing the changes  
to competencies and capacities





**“It’s me, but it’s not me”**

**Struggling with insight into  
deficits and changes**





**“It’s not the same person”**

**Dealing with responses  
from others**





# Experiencing withdrawal and isolation

A man in a dark suit and tie is shown from the chest up, leaning against a textured wall. He has a distressed expression, with his right hand covering his face and eyes. The image is tinted with a blue-green color.

From others  
By others

**Understanding that happiness is  
a property of groups of people.**

**A person with a brain injury and  
those around them may be  
unhappy**

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



**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

**Can we better  
understand this process  
through the people  
involved?**

**Can we use their stories to  
understand the impact of  
brain injury on their lives?**

**How did they deal with the  
losses created by their  
injuries?**

# People 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 61, 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.**

# Craig

Craig was injured at age 10. He remembers waking up in traction and feeling his forehead which felt like a shallow bowl. He had been in a coma for 3 weeks. Craig went back to school, attended several colleges, eventually graduating with a Master's degree in Rehabilitation Counseling, but failed at every job. He now operates Second Chance to Live and shares his self awareness with others.

**“I grew up in perfectionism and  
constantly was saying ‘sorry’  
for things. I felt responsible for  
everything”**

**“I had to struggle with living  
with an invisible disability.  
Once the external wounds  
heal-brain injury is never  
considered to be an issue”**

**“I felt I was different, couldn’t  
put my finger on it... absorbing  
it internally, it was something  
wrong with me”**

**“I had difficulties in my  
practicum and internship .The  
Dean at my graduate school  
told me that he couldn’t tell me  
if I was graduating until an hour  
before I graduated.”**

**“I got a job and got fired. I got another job at the Department of Voc Rehab and they made me a client. Then I got another job and got fired. In 1998 I was found to be unemployable and granted disability”**



**“I started training in different martial arts to develop my brain on both sides and improve fine and gross motor skills. Through martial arts I learned the journey is more important than the destination”**

**“ 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”**

**“I fumbled my way to  
learning to use what I  
had to work for me.”**

**“People are told to identify themselves within the box where they are placed. People need hope and freedom for exclusion. I needed to have self-empathy to allow myself to leave the box”**

**Craig, now 58, is determined to “give back” to others struggling with brain injury. He has developed a website, A Second Chance to Live, and writes self-help books which he makes available through his site and others. He asks rehabilitation professionals to change their attitudes towards survivors and consider them as peers and partners.**

# **Dan**

**A 45- year old corporate vice president  
who was injured in a plane crash and  
left with severe physical impairments  
and faced divorce and separation from  
his daughter**

**“Do you know what it’s like  
to hear your doctor tell  
your wife that it’s never  
going to be the same, that I  
probably wouldn’t walk or  
talk again?”**

**“I knew that if I worked  
harder than anybody else I  
would get back what I lost”**



**“ My wife told me that she  
was divorcing me and  
taking my daughter. How  
can she do that to me? ”**

**“I’ve been back at work for a few weeks now and its just not the same. People aren’t the same around me, its like they don’t trust me. I can do my job but it doesn’t feel right”**

**“It’s been over a year since I’ve been back at work and but my job isn’t the same for me. I started the legal process to regain custody of my daughter. I started looking into getting a Masters’ degree in Social Work. I want to help other people with brain injuries”**

**“Last night was my first date since my divorce. It was hard to tell someone that I had a brain injury. Once I got that over with, the evening went a lot better”**

**Dan completed his degree in social work and regained custody of his daughter. He works with people with disabilities who are returning to university. We laugh about his “first date”**

# **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**

# **Vladimir**

**A 55-year old electrical engineer with a wife and 3 older children. He was experiencing cognitive problems at work and having angry outbursts**

**“I don’t know what’s wrong  
with me. It’s like my brain  
isn’t working. Things I used  
to know how to do, I can’t  
anymore”**

**“I don’t like asking anyone  
for help, my wife or you or  
anybody. People used to  
come to me for help and  
now I’m coming to you”**

**“I got so mad I was going to  
kill my wife and my  
daughters and then kill  
myself. I knew that I needed  
to call before I did  
something”**



**“I don’t like to need help,  
it’s not my nature. I put  
myself through school and  
earned money to take care  
of my family. This accident  
took that away in a second”**

**“Things started to get better when my therapist gave me some tools to remember things. I’m still a smart man, but I needed to prove that to myself”**

**Vladimir's recovery didn't take him back to where he was pre-injury and he struggled with depression and asking for help. Eventually, he allowed his wife to help in his business.**

# Jamil

**A recent university graduate, Jamil, 23, was opening a business to support his mother and younger siblings. A motor vehicle accident left him with cognitive and psychological problems**

**“you know that I’ve been  
dealt a bad hand with this  
brain injury. I was just  
getting my business going  
when this happened”**

**“As the eldest, my mother was  
my responsibility after my  
father died. And now, I can’t do  
what I need to do. I’m  
supposed to be taking care of  
her, but look how she has to  
take care of me”**

**“I need rehab to get myself  
back on track, to learn what  
I need to do to run my  
business. I don’t know if  
you guys understand that”**

**“Sometimes I get so angry  
at myself, you and  
everybody around me.  
Other times, I’m sort of  
thankful that I came here”**



**“I started working with my  
cousin. He’s going to help  
me out in the business. Its  
not what I planned, but at  
least I can take care of my  
responsibilities”**

**Jamil returned to his business and was able to take care of his family.**

**For a few years, he came back every few months and would lead a group discussion about life after rehab. After a while, he said he was too busy at work. But, I heard he was married and became a father.**

# What are the tasks to be done?



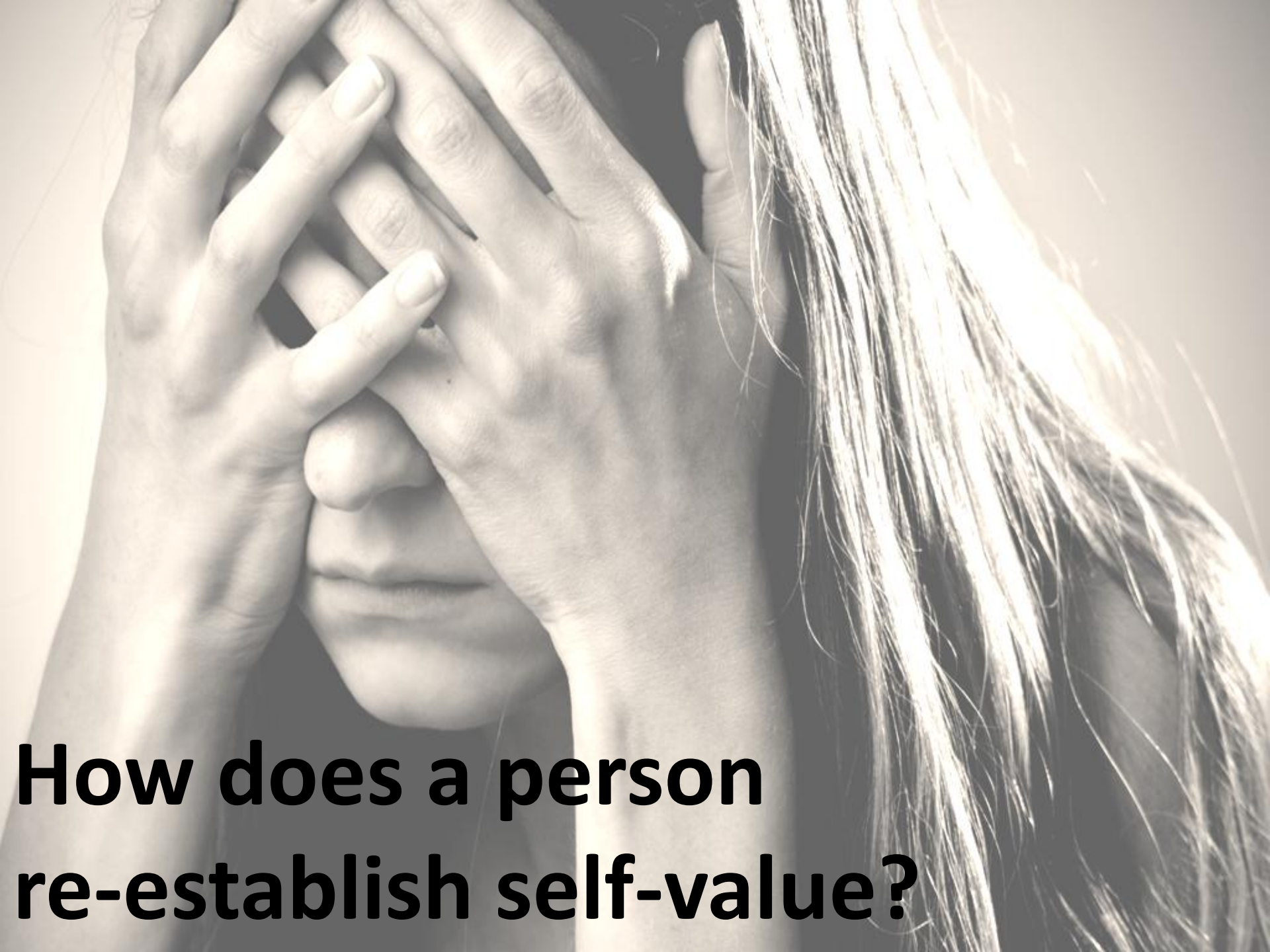


**How does life get put  
back on track?**



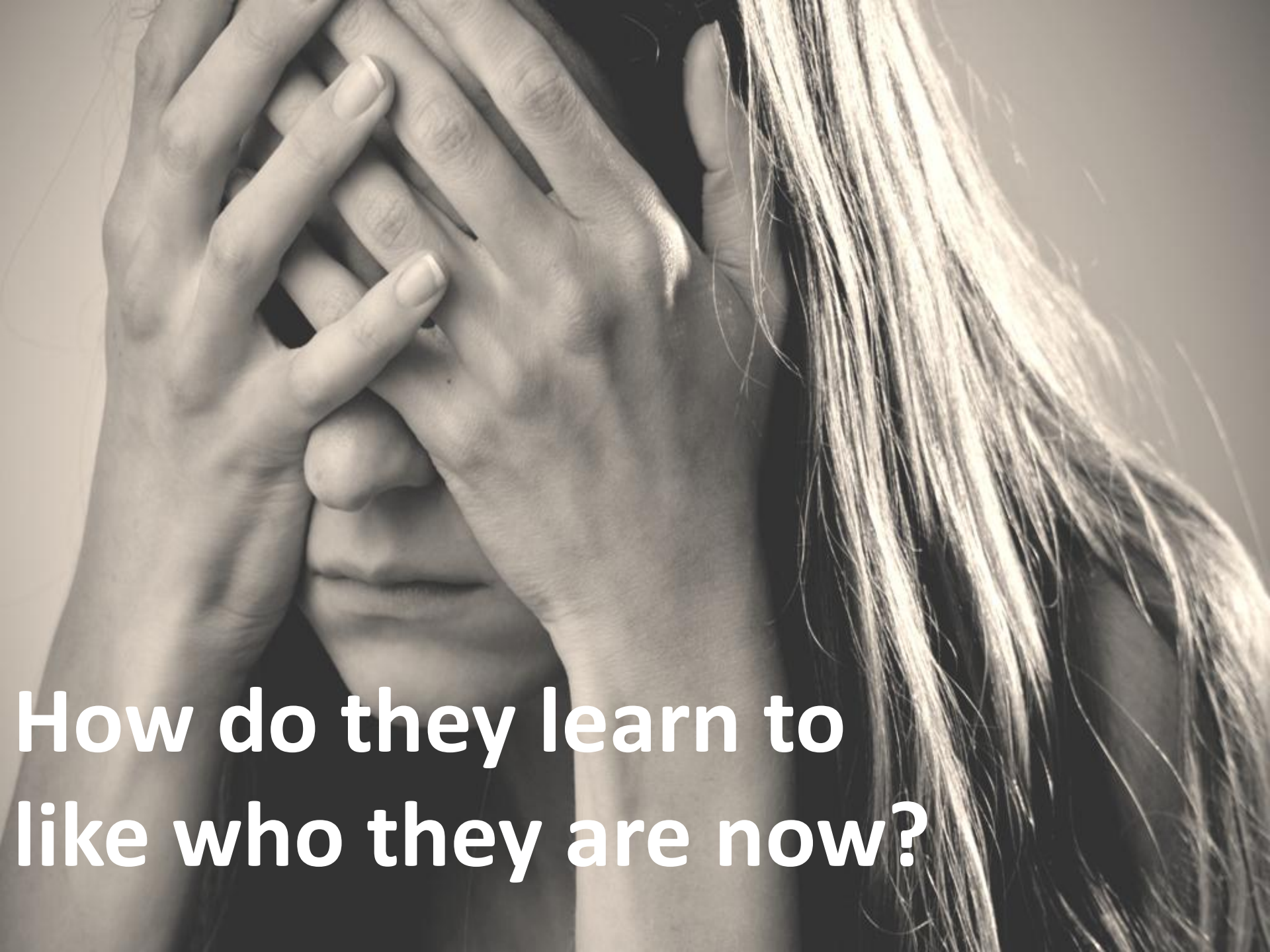
**Or, find another track?**





**How does a person  
re-establish self-value?**



A close-up, black and white photograph of a person's face, partially obscured by their hands. The person's eyes are closed, and their hands are pressed against their face, with fingers interlaced. The lighting is dramatic, highlighting the texture of the skin and the strands of hair. The overall mood is one of vulnerability, distress, or shame.

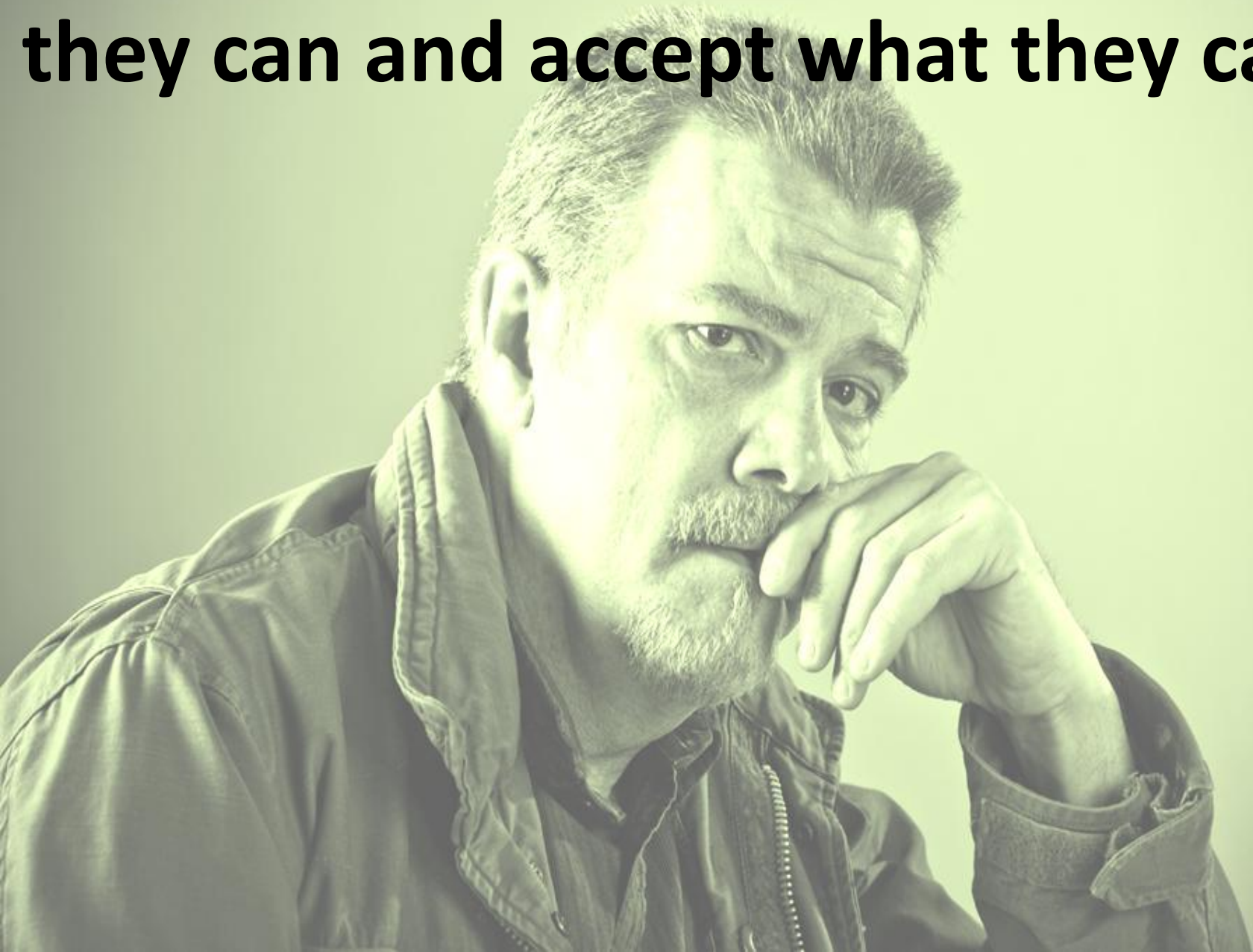
**How do they learn to  
like who they are now?**



**Or, grieve for  
what was lost?**



**How do they learn to change what they can and accept what they can't?**



**Can they start their life again?**




# How can the person respond to depression?





A close-up photograph of a woman with short, dark, wavy hair. She is looking off to the right with a serious, slightly concerned expression. Her mouth is slightly open. In the background, a man is visible but out of focus, looking in the same direction. The entire image has a warm, orange-toned overlay.

**How can they  
rebuild relationships?**



**What part of this  
work is solely theirs  
to accomplish?**



**And, what part  
belongs to other people?**

# **Facilitating the recovery phase**

**What can work?**

# **Disordered Mind, Wounded Soul: The Emerging Role of Psychotherapy in Rehabilitation After Brain Injury**



# **Denial of changes of functioning, not a deficit of self- awareness**

Prigatano, G., 1999

**Rehabilitation must focus  
on the disordered mind and  
the wounded soul**

Prigatano G. 1991

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

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

Prigatano G., 1991

# **Examined Lives: Outcomes After Holistic Rehabilitation**

**Ben-Yishay, Daniels-Zide, 2000**

**Viewing their life as  
meaningful**

**Wellness includes:  
environmental mastery,  
personal growth, positive  
relationships, purpose in life  
and self-acceptance**

**Does attainment of  
optimal outcomes  
require that the  
individual achieve an  
examined self?**



**Clinical professionals need a  
better understanding of how  
people make sense of  
themselves, especially after  
extreme circumstances**

Medved, M, Brockmeir, J., 2008

**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

**What people search for in a  
rehabilitation professional?**

**One who listens to them**

**One who respected their goals**

**One who showed an  
understanding of their situation**

Jumisko E, Lexell J, Soderberg S., 2005

# **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**

**Experiencing distress over  
the loss of competency:  
Anger, depression, anxiety,  
grief**

**Treatment occurs in the  
context of reconciling the  
post-injury self with the  
pre-injury person**



# Pre-injury self

**Profession**

**Creative**

**ME**

**Competent**

**Work life**

# Post-injury self

**Not able to  
use skills**

**Loss of  
creativity**

**ME**

**Feeling  
incompetent**

**Loss of Work  
life**

**The person arrives at a  
painful self-awareness  
between their pre-and post-  
injury capabilities**

**Through experiencing the self in context the person can move away from the negative view of self**

**Creating a safe place to experience the changes from injury and identify a new 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

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

**The person becomes “stuck”  
due to fear**

**The healthy alternative is to  
“act”**

**A**ccept your reactions

**C**hoose a valued direction

**T**ake action

Myles S., 2004

**Person experiences intense  
anxiety post-injury  
Conceptualized as a defense  
of pre-injury self-concept**

Myles S., 2004



**Guiding the person to accept  
their post-injury functioning  
Supports building a new self-  
concept**

**Supports pursuit of key life  
values**

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

# Mindfulness supports the increasing awareness of self

Bedard M, Felteau M et al. Mindfulness-Based Cognitive Therapy Reduces Symptoms of Depression in People With a Traumatic Brain Injury. J Head Trauma Rehabil, 2013

**Supporting the separation of  
distressing symptoms from the  
person without encouraging  
denial**

**Using therapy to address the  
inconsistency between pre-  
injury self concepts and post-  
injury functioning**

# **Perception of control enhances resiliency**

**Can we teach people to exert  
control over what has happened  
to them?**

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

**Reframing negative reactions to  
real situations:**

**You can do it!**

**“This injury does not define  
my life, I define it. Life can  
be powerfully lived in this  
condition”**



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

**How can rehabilitation  
professionals help with  
the process of recovery  
of self?**

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

James Joyce

**Hope and fear are both  
phantoms that arise from  
thinking of self. When we  
don't see the self as self,  
what do we have to fear?**

**Lao-tzu**

**My personal thanks to the  
many people and their families  
who shared their experiences  
with me and helped me to  
understand the process of loss  
and recovery of self.**

**Thanks!**

**Questions?**

**This presentation can be found at  
traumaticbraininjury.net  
under “Resources” and  
“Community Presentations”.**

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