

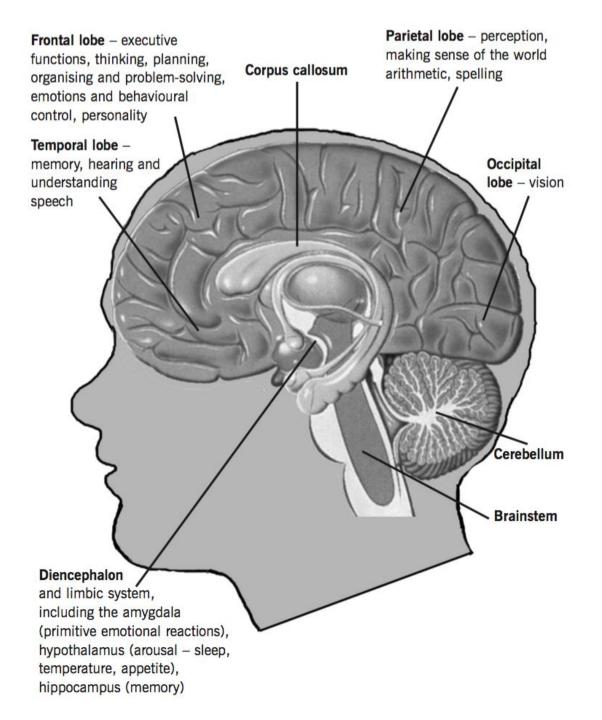
The loss of the sense of self following brain injury

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## What is a Brain Injury?

- Acquired Brain Injury (ABI). An injury caused to the brain after birth
- Traumatic Brain Injury (TBI). Caused by a blow to the head. Can be minor or severe with second and third injuries following on (due to lack of oxygen, bleeding, swelling)
- Other types of ABI:
  - Anoxia (lack of oxygen to the brain e.g. due to cardiac failure)
  - Encephalitis
  - Stroke
  - Tumour



## **Impact of Brain Injury**

- Behavioural disinhibition, impulsiveness, loss of motivation, obsessiveness, irritability, aggression, fatigue
- Cognitive memory, executive function, visuo-spatial awareness
- Emotional
- Physical motor function, co-ordination
- Communication speech & language difficulties
- Coma and Reduced States of Awareness
- Social
- Employment
- Relationships

TABLE 1. Domains and core indicators of quality of life.

Domains	Indicators	Item examples
Emotional well- being (EW)	Mental stability; satisfaction, self- concept; lack of stress/negative feelings	He/she shows symptoms of depression.
Interpersonal relations (IR)	Social relationships; family relationships to have stable and clearly identifies	s;He/she complains about his/her relationships with friends.
	friends; to have positive and gratifying social contacts	
Material well-being (MW)	Housing conditions; workplace conditions; Services conditions; employment; incomes/salary; possessions	His/her incomes are not enough to afford whims.
Personal development (PD)	Education; learning opportunities; work abilities; functional abilities (personal competency; adaptive behavior, etc.); activities of daily living.	He/she is involved in the development of his/her individual planning.
Physical wellbeing (PW)	Health care; sleep; health consequences (sorrow, medication, etc.); health; mobility; technical assistance	He/she has sleep problems.
Self-determination (SD)	Autonomy; goals and personal preferences; decisions; choices	Other people decide how to spend his/her money.
Social inclusion (SI)	Participation; integration; supports	His/her family supports him/her.
Rights (RI)	Knowledge of rights; defense of rights; exercise of rights; privacy; respect	He/she suffers exploitation, violence or abuse.

Source: Verdugo et.al. "Development of an objective instrument to assess quality of life in social services: Reliability and validity in Spain." *International Journal of Clinical and Health Psychology 2010, Vol. 10, No 1, pp. 105-123.* 

## **Challenges of Brain Injury**

- Sudden, life changing event. No preparation
- Brain Injury challenges potentially everything we take for granted as part of being human, and in relationship with other people
- Range of interacting difficulties emotion, social interactions, behaviour, cognitions
- Experienced as a threat to self, loved ones, family
- Profound sense of loss may be experienced
- Rehab tasks individual team members to help re-build person physical, behavioural, cognitive
- Counselling/Psychotherapy has potential to enhance holistic aspect of rehab



## **Ambiguous Loss**

- "A situation where a loved one is perceived as physically present while psychologically absent, or physically absent but kept psychologically present because their status as dead or alive, dying, or in remission remains unclear". s
- "When illness cannot be cured, people must simultaneously hold two opposing ideas in their minds: 'The person as she or he was is gone, but that person is still in my life'."
- "Research has supported the idea that ambiguity creates a powerful block to coping and grieving, predicting symptoms such as depression, anxiety, loss of mastery, hopelessness, and conflict which erode couple and family relationships".
- "Lack of clarity about prognosis, daily physical condition, and fluctuating capabilities create relationship confusion, preoccupation with the illness or avoidance of the individual"

Pauline Boss

## **Ambiguous loss**

- Loss without social recognition
- No opportunities to mourn what has been lost or never had
- Sense of isolation
- Can lead to withdrawal

I have done everything for her but she is so selfish now. I feel like I am walking on eggshells all the time

I feel so sorry for him

— he has lost
everything. But, I
know it sounds
selfish, I can't stand
being around him

It's so difficult to get feeling blessed and grieving on the

same page

I feel like I am

stranger

sleeping next to a

I'm scared of my own husband... he can blow off at any time

The whole family dynamics have changed

We are getting glimpses of the old John

# **Grief Work Process in non-finite loss**

- 1. Loss
- 2. Searching

May include searching for a new means of survival, a cure or a miracle.

3. Re-finding

This may be real or imaginary, which may contain an element of denial.

4. Re-loss

The realisation that the re-found person or belief, in the return to normality, is not the same.

5. Awareness

May follow a period of grief – work, a moving between stages 3 and 4. They may gain a fuller understanding their or their relatives' position

6. Burial

The final stage, which involves the person 'putting to rest' that version of himself with which he began the process.

## **Personal Impact**

- Age of injury (often under 25)
- Effect on whole person, all aspects of life

## **Emotional Difficulties**

- Primary changes as direct result of brain damage
- •Secondary changes as the person struggles to cope with effects
- Post PTA emotional agitation common

There are two frontiers to recovery from any traumatic injury. The emotional damage must be dealt with as diligently as the physical damage. Each area has the ability to strengthen or weaken the other.

Kara L. Swanson

I didnt realise that the mental side came first – I thought if he could do more physically he would start to feel better. I didn't realise that it was the other way round – he can't use rehab until he starts to feel better about himself"

## Changes in emotional expression

- Heightened/flattened affect. Emotional responses may be increased or decreased in response to events
- Emotional lability loss of emotional control. Common in early stages. Easily moved to tears or laughter

## **Anxiety & depression**

- Common early reactions to trauma & disability
- May develop with sense of helplessness in effort to regain life skills
- Repeated failures may lead to loss of confidence and/or despair
- Increased awareness increases chances of anxiety and/or depression.
- May be greater reaction to apparently less severe difficulties due to awareness

## **Frustration and Anger**

- Loss of everyday skills leads to frustration
- Uncertain nature of recovery
- Bitterness about injuries
- Anger at those deemed responsible
- Anger can be source of determination (s/t)
- L/t may impede progress & adjustment

## Self concept

- Mild injuries. Sense of being changed
- More severe injuries. Array of disability outside of previous experience
- Loss of confidence
- · Loss of self-esteem
- Loss of self concept in relation to personal relationships and work

#### Leisure

- Physical difficulties preclude many activities
- Loss of dexterity limits more sedentary pursuits
- Cognitive changes affects hobbies eg chess, bridge
- Alternative options difficult to envision with limited imagination or initiative

### **Social life**

- Restrictions in leisure increase social isolation
- May avoid pursuing a social life due to
  - Lack of confidence
  - Low mood
  - Intolerance to noise
  - Difficulty in contributing to conversations
- Loss of former friends due to changes

## **Daily Activities**

- Struggle to manage basic tasks
- Communication difficulties may cause frustration & isolation
- Memory problems. Unable to keep to commitments. Lack of continuity
- Perceptual & spatial disorders. Confusion
- Executive difficulties
- Loss of control of emotions & behaviour

# Family life

- Family relationships
- Personal relationships
- Sexual functioning

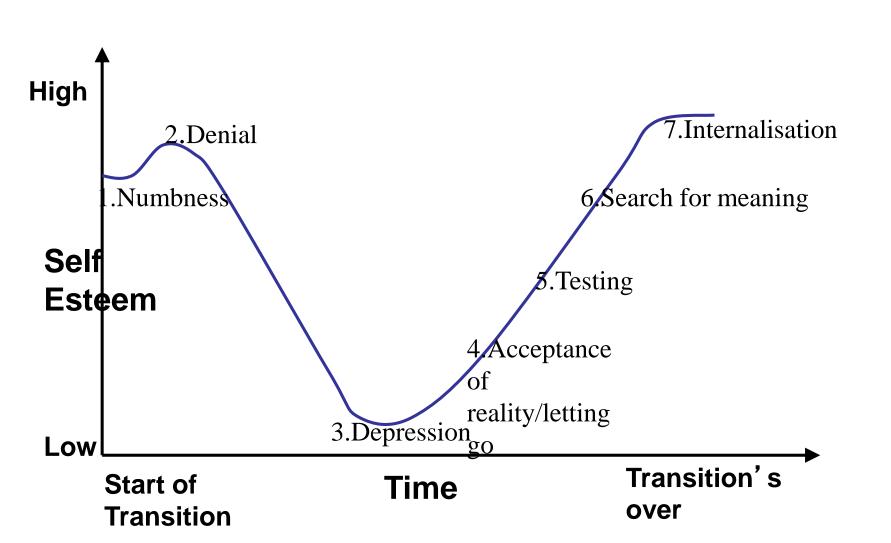
## **Sexual problems**

- Types of problems:
  - Reduction in interest/activity
  - Increase in interest/activity
  - Physical difficulties
  - Emotional problems e.g. loss of confidence, poor self image
  - Vulnerability
- Who is it a problem for?
  - Individual
  - Partner
  - General contacts and society

## **Tasks**

- Awareness
- Acceptance
- Adjustment

#### **Transition Curve**



## **Adjustment Issues**

- Initially view changes as temporary
- Confronted by limitations when attempt to return to activities
- Process of realisation of extent of residual difficulties.
- Recognition of loss of former life
- May be periods of depression with frustration & uncertainty
- Challenges in all areas home, work, social
- Sense of helplessness & futility
- New sense of direction & meaning
- Re-evaluate goals & aspirations

## Sense of Self and Identity

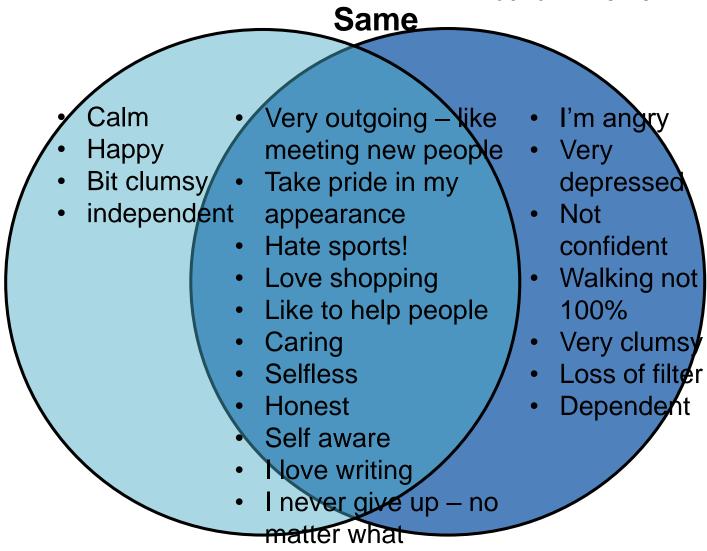
- "Old self" v "new self"
- Concept of self drawn from previous life experiences
- Continuous integration of events affected by memory loss
- Integrity of the self and the core identity feels threatened
- Loss of clear self-knowledge
- Loss of self by comparison (with past self)
- Loss of self in the eyes of others
- A "crisis of the conceptualised self"
- · Feelings of insecurity, vulnerability and uncertainty

a reminder of how I used to be husband anymore progress I become space what I can't do

### 5<sup>th</sup> July 2017

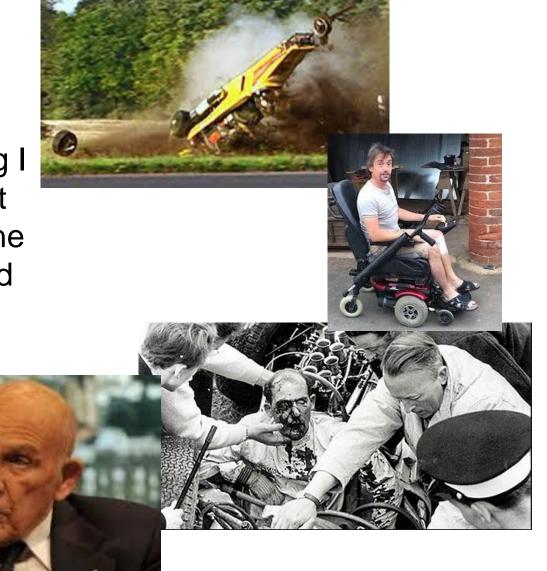
What I was like before...

What I am like now...



Richard Hammond
"when I was recovering I
felt like having a T-shirt
printed that said 'I'm fine
thanks' on the front and
on the back 'I'm still
poorly'

Stirling Moss "I'm lost"



# Difficulties in Long Term Adjustment

- Preoccupation with lost skills/roles
- Striving for 100% recovery
- Cycle of failure and loss of confidence/self belief
- Stuck/trapped in past
- Frustration with current restrictions
- Fear of loss of control
- Lack of continuity and direction
- Strained relationships/social isolation
- Limited self-/social awareness
- Difficulties with problem solving

# The client as part of a family system

- Client's perception of self in context within personal relationships
- Perceived change of role within the family can trigger a 'catastrophic reaction'
- WHO. Social outcome is defined as the ultimate expression of diseases, impairments & disabilities. Therefore, it is the experience of the effects of the injury in a social context that is significant.
- The sense of threat to self is related to the meaning given to the trauma.
   Ameliorated or exacerbated by family circumstances.

## **Possible family reactions**

#### **Parents**

- Realisation that caring may never end
- Loss of potential within own stage of life
- Return to an earlier stage of parenting
- One partner may feel neglected
- Marital conflict and divorce are common
- Sense of competition with new partner

## Family reactions (2)

#### Children

- Sense of neglect may be inadvertent
- May take on added responsibilities practical and emotional
- Sense of confusion at changed relationship
- May be bullied by brain-injured parent
- Older children may appear more troublesome, but the long-term effects are not so profound

## Family reactions (3)

#### **Siblings**

- Often neglected by authorities
- May experience 'survivor' s guilt'
- Inadvertent neglect from parents
- Loss of relationship with sibling

## Family reactions (4)

#### **Partner**

- Ability to cope affected by quality of pre-injury relationship
- Loss of practical and emotional support
- Reduced income
- Pressure. Time taken up with distant hospital visiting
- Major practical issues concurrent with emotional adjustment
- Fears for the future
- Increased risk of separation and divorce
- Isolation

## Mauss-Clum & Ryan in Kreutzer et al 2002

	Mothers	Wives	Patients
Depression	45%	79%	57%
Irritability	55%	74%	53%
Angry			
outbursts	45%	63%	50%

#### **Personal Relationships**

- Loss of support
- Loss of intimacy
- Changed dynamics
- Possible egocentricity of affected partner
- Loss of empathy
- Exhaustion
- Sexual difficulties

#### **Caregiver distress**

- Social support moderates caregiver distress
- The degree of neuro-behavioural disturbance is the greatest predictor of caregiver distress
- Social support is the strongest predictor of family function.
- Types of disability that cause greatest family burden:
  - Behavioural, affective and personality changes worst
  - Cognitive changes next

#### Relationships

- 30% of marriages ended in divorce within 7 years of severe H.I. Stillwell et al 1997
- 40% separation rate (Ticehurst)
- Most severe and least severe effects resulted in partner most likely to stay
  - If client in work, less likely to separate
  - In need of 24 hour care, less likely to separate
  - Presence of children reduces separation
  - Presence of children reduces life satisfaction for injured partner
  - No age or gender differences

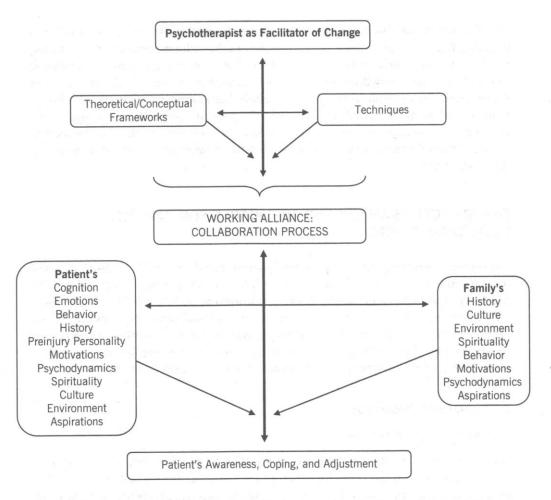
#### **Tasks and transitions**

- Information
- Awareness
- Understanding
- Support
- Opportunities
- "Meaning"
- ? Resolution

#### **Psychotherapy after BI**

"collaborative working relationship between a psychotherapist and a brain-injured patient, with the goals of increasing the patient's awareness of, and acceptance of, and realism about his or her predicament. At the same time the psychotherapist educates and supports the patient's family and community connections, so as to facilitate the patient's renewed sense of identity, hope and meaning"

Pamela Klonoff, 2010



**FIGURE 1.1.** A collaborative model of psychotherapy after brain injury. Adapted from Klonoff (2004).

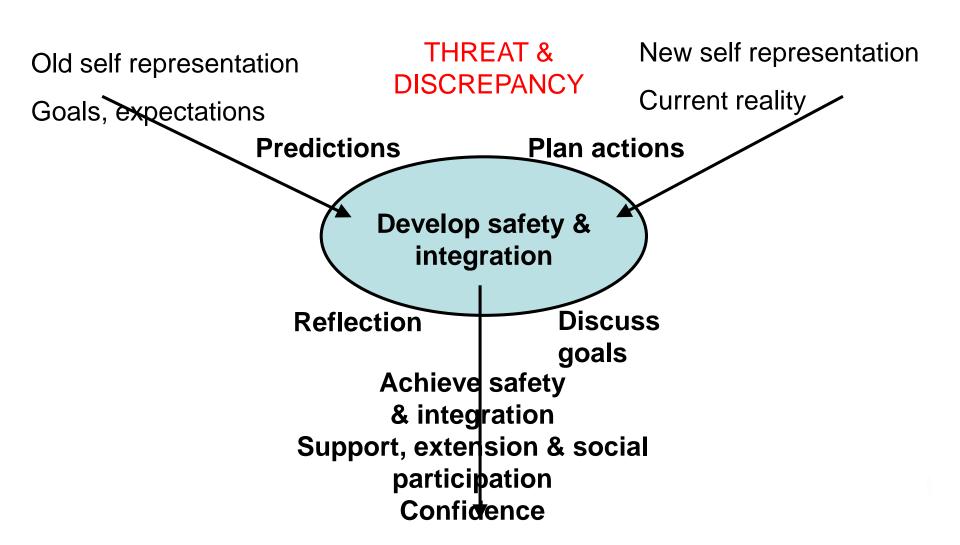
#### **Aims**

- To understand what has happened
- Self-acceptance
- Foster a sense of realistic hope
- Manage difficult emotions
- To find meaning in life

#### Individual

- Prigatano No matter how impaired a brain injured patient is, he or she eventually asks the question "what has happened to me?"
- Klonoff
- Goldstein "Catastrophic Reaction" (post war)
- Ownsworth As well as affecting potentially any aspect of functioning, BI can alter sense of self, or essential qualities that define who we are

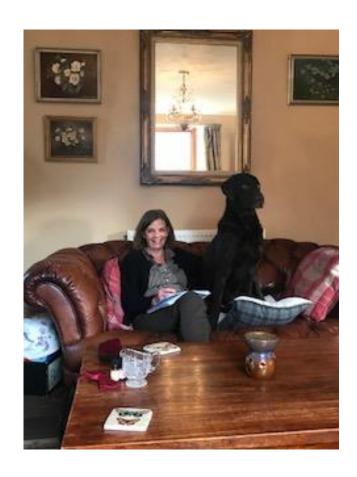
### Y - shaped Process Model



# Y – shaped Process Model a case example

THREAT Old self representation New self representation (BRAIN INJURY) Work ethic Loss of Cognition & Physical Affect control communication Charm Depression Good Power Power recovery balance Aphasia **Develop safety &** Money change integration Thinking Glamour Low self difficulties esteem Shared formulation Loss of role Information Impotence Involvement of partner Work with community support Integration **Social Participation** 

Reconstruction of new self



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