

Moving through the lifespan with a brain injury: What really happens to people?



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Disclaimer

Rolf B. Gainer, PhD has business relationships with Brookhaven Hospital, the Neurologic Rehabilitation Institute of Ontario (NRIO) and Community Neuro Rehab (CNR) and Rehabilitation Institutes of America.

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Learning Objectives

- To consider outcomes as dynamic and evolving in the years post-injury
- To conceptualize brain injury as a chronic disease which affects the person as they age
- To regard social role return as a key aspect of the person's post-injury life
- To examine factors which effect the person as they age



**In an ideal world, where
would we start?**

**“create a new baseline and
not go back to where they
were”**

Alya Reeve, MD,

**“Every 21 seconds or why I scream at the refrigerator” a film by Laura
Napier and Doug Claybourne, New Mexico Brain Injury Advisory
Council, 2006**



**Brain Injury:
a
cumulative
disability**

Brain Injury is a lifetime disability



What are the long term issues associated with brain injury?



before we get to the long-term issues, let's regard

Brain Injury as a chronic disease

What defines a chronic disease?

World Health Organization, 2002

- ✓ Permanent**
- ✓ Leaves a residual disability**
- ✓ Caused by a non-reversible pathological alteration**
- ✓ Requires special training of the person**
- ✓ May be expected to require a long period of supervision, observation and care**

Brain injury: a disease process

TBI is not solely an event

**...but a process which
continues to exert
changes over the course
of a person's life....**

Brain injury: an illness?

**this view isolates the impact
of the injury on the entire
person**

**it creates expectations of a
person's return to their pre-
injury status without
problems**

**when we look at the effects of a
brain injury on a person, we need
to regard the chronic nature of the
disabling conditions**

**let's consider what
parts of brain injury
we see**



**Icebergs and
brain injury:**

**Why are they
alike?**



**10% of an
iceberg is
visible**



**We see the 10% of the iceberg
that occurs in the first 18-24
months following the injury**

Most peoples' lives post-rehabilitation are not followed to observe how their brain injury has changed their lives.....

that's the 90% we don't easily see

Brain injury creates changes

for the person



**and, for the people
around them**



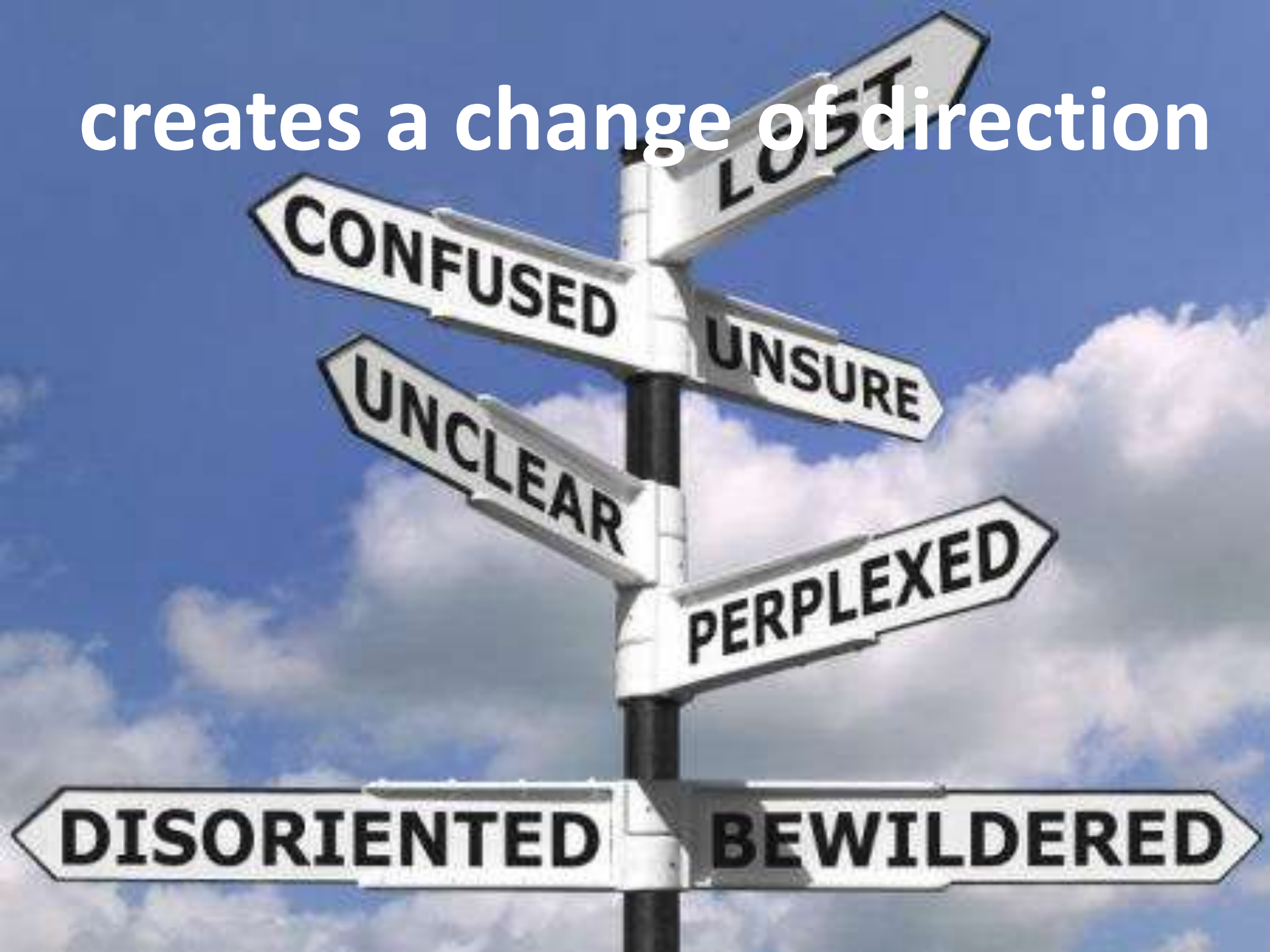
TBI: not a static process

Impact on organ systems

**Disease causative and
accelerative**

**Affects the person over the
course of time**

creates a change of direction



**Focus on the
“residual effects”**

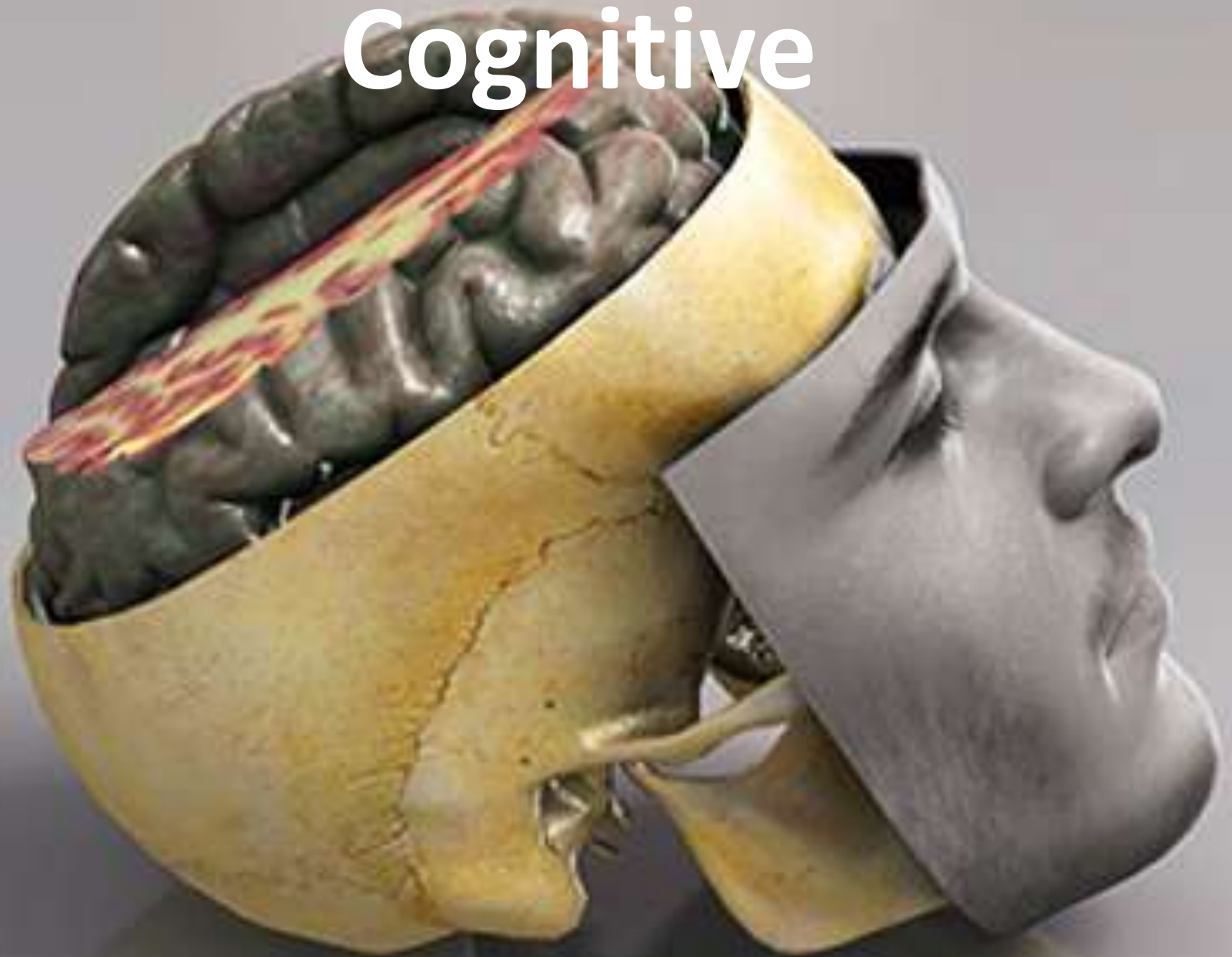
**What are the
barriers?**



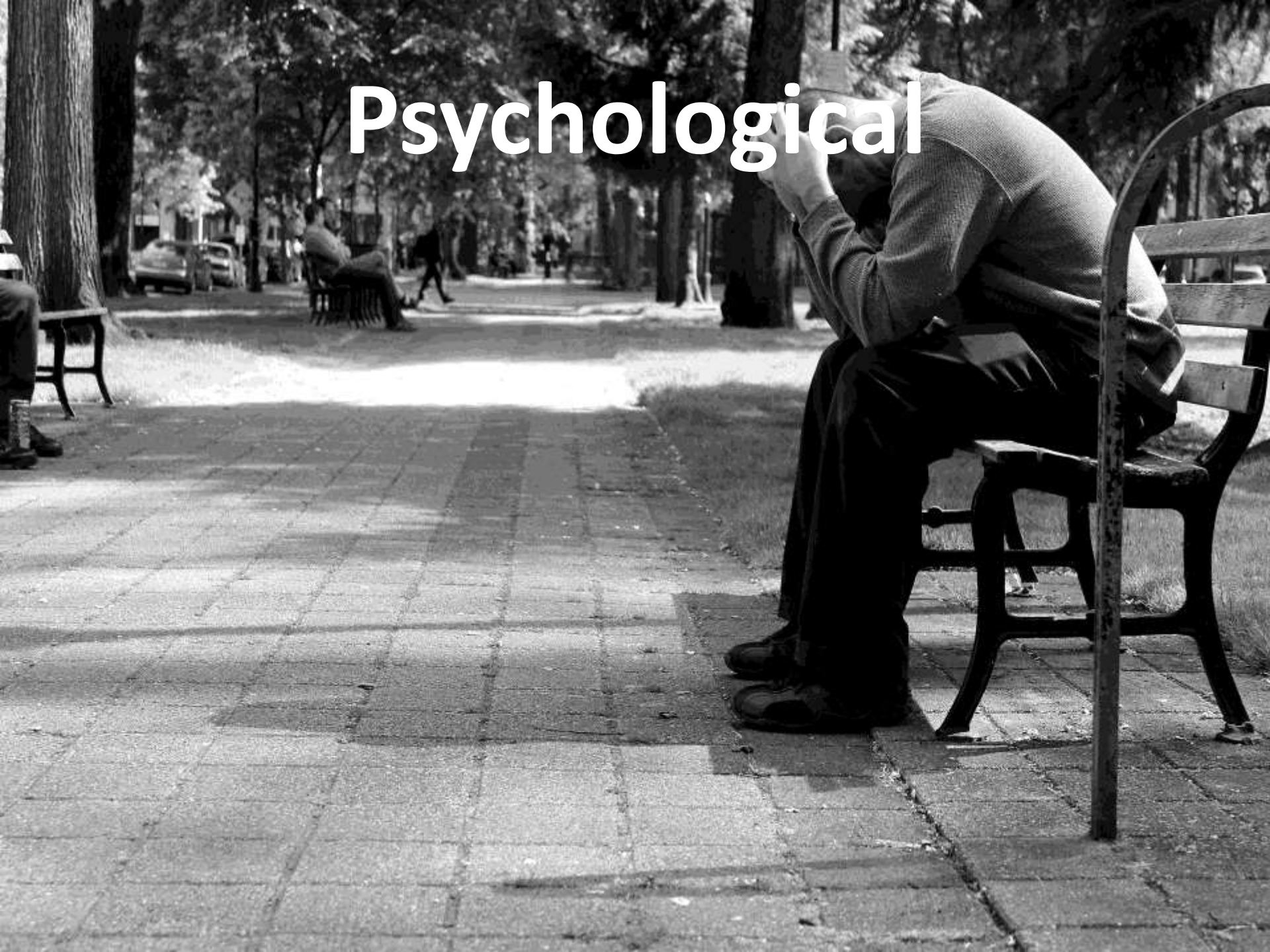


Physical

Cognitive



Psychological



Behavioral



Post-injury medical problems:



- Hearing, vision problems
- Diabetes
- Skin integrity problems
- Swallowing problems
- Sleep apnea
- Parkinson's Disease
- Circulatory problems

**Let's expand our view to include
the impact of brain injury on
others**



**The impact of disruptions
in the living situation**

And, the effects on others



Including Caregivers





**Let's consider what's
important to caregivers...**

Intimate relationships



Family



Children



Friends



Co-workers

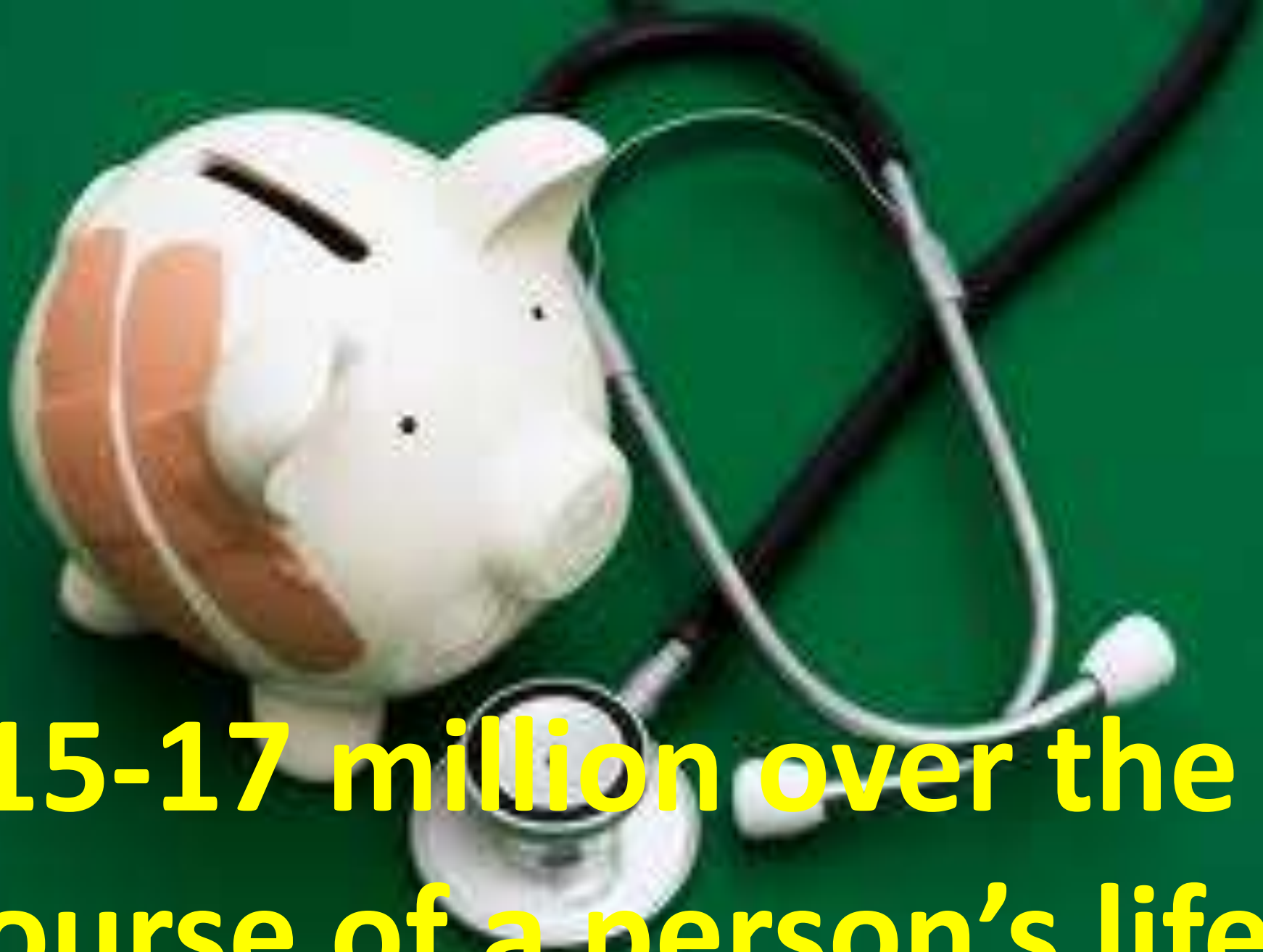


The impact on personal finances



A close-up photograph of a pink piggy bank being crushed by a metal tool, likely a hammer or a similar heavy-duty instrument. The tool is positioned vertically, pressing down on the top of the piggy bank. The piggy bank is cracked and deformed, with its internal structure visible. The background is a plain, light-colored surface.

**The true cost of brain
injury**



**\$15-17 million over the
course of a person's life**

The effects of caring for a disabled family member



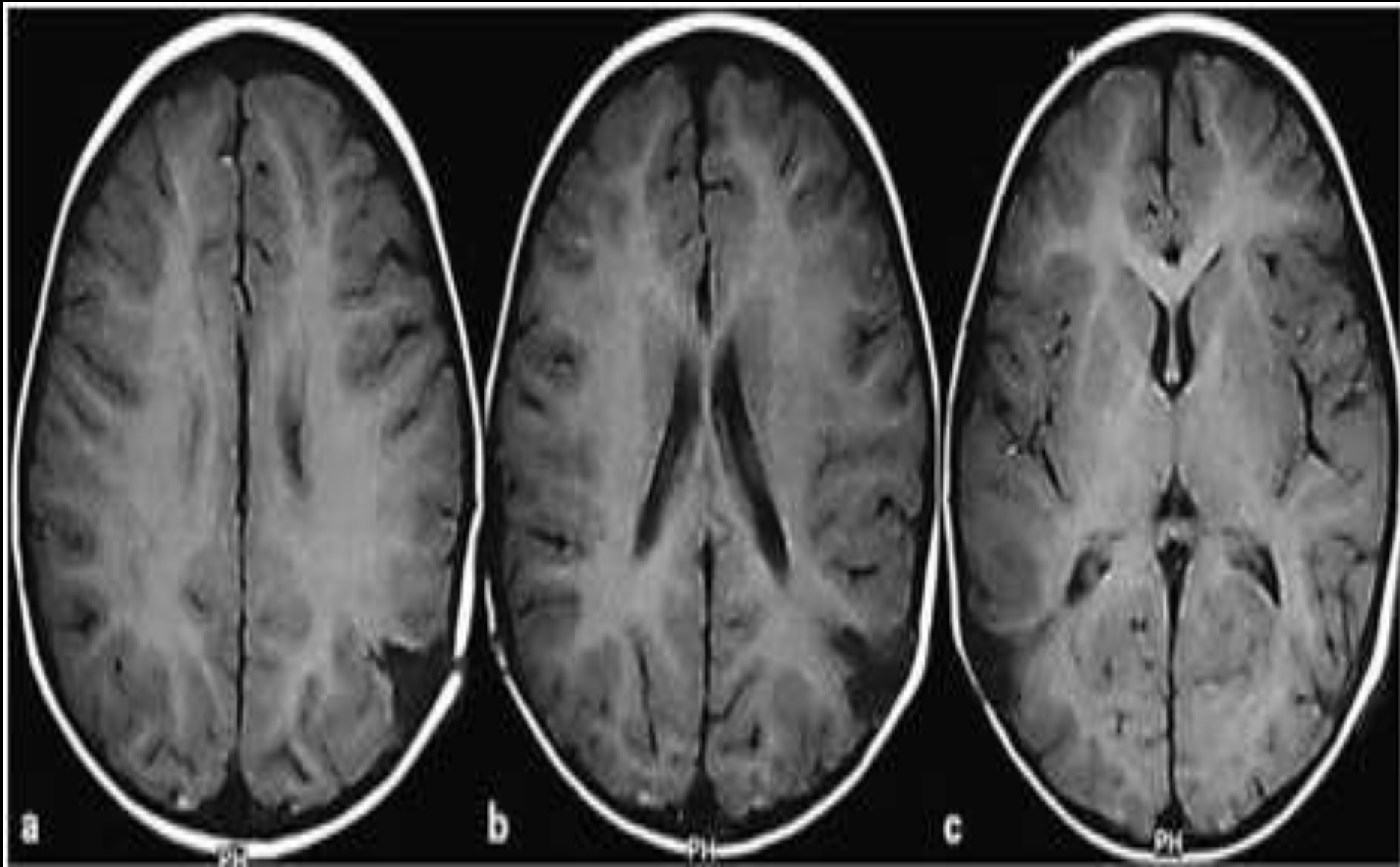
there caregiver support?



what
resources
are
available
for the
caregivers
such as...



Information about brain injury





**Social support from family,
friends, community**

I need a vacation so badly,
I've resorted to
plotting my own
kidnapping.





Long-term planning

A collage of medical supplies and US dollar bills. A stethoscope is prominently placed in the upper right. Various pills and capsules are scattered across the image. US dollar bills, including a \$100 bill, are visible in the background. The text "What happens as caregivers age?" is overlaid in yellow.

**What happens as
caregivers age?**

How to deal with the increase in medical conditions



Increased sense of burden





**Addressing disruptions
caused by new or
exacerbated problems**

**and, the
impact on
medical and
social
support
needs long
after the
injury**





What happens when a caregiver dies?

Other family members or caregivers?





**Finding an
alternative
living
situation**

How can we assist people in maintaining independence?



Can

vs.

Can't



Transportation

Can vs. Can't



Housing

Can vs. Can't

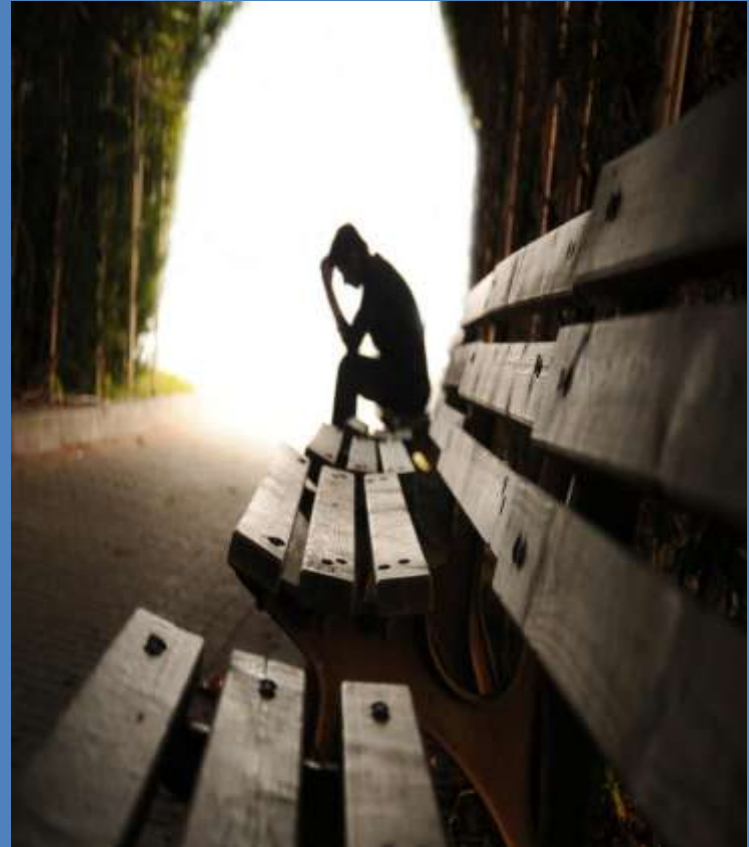


Healthcare Services

Can

vs.

Can't



Social supports

**Sustained community
integration:
what's involved?**

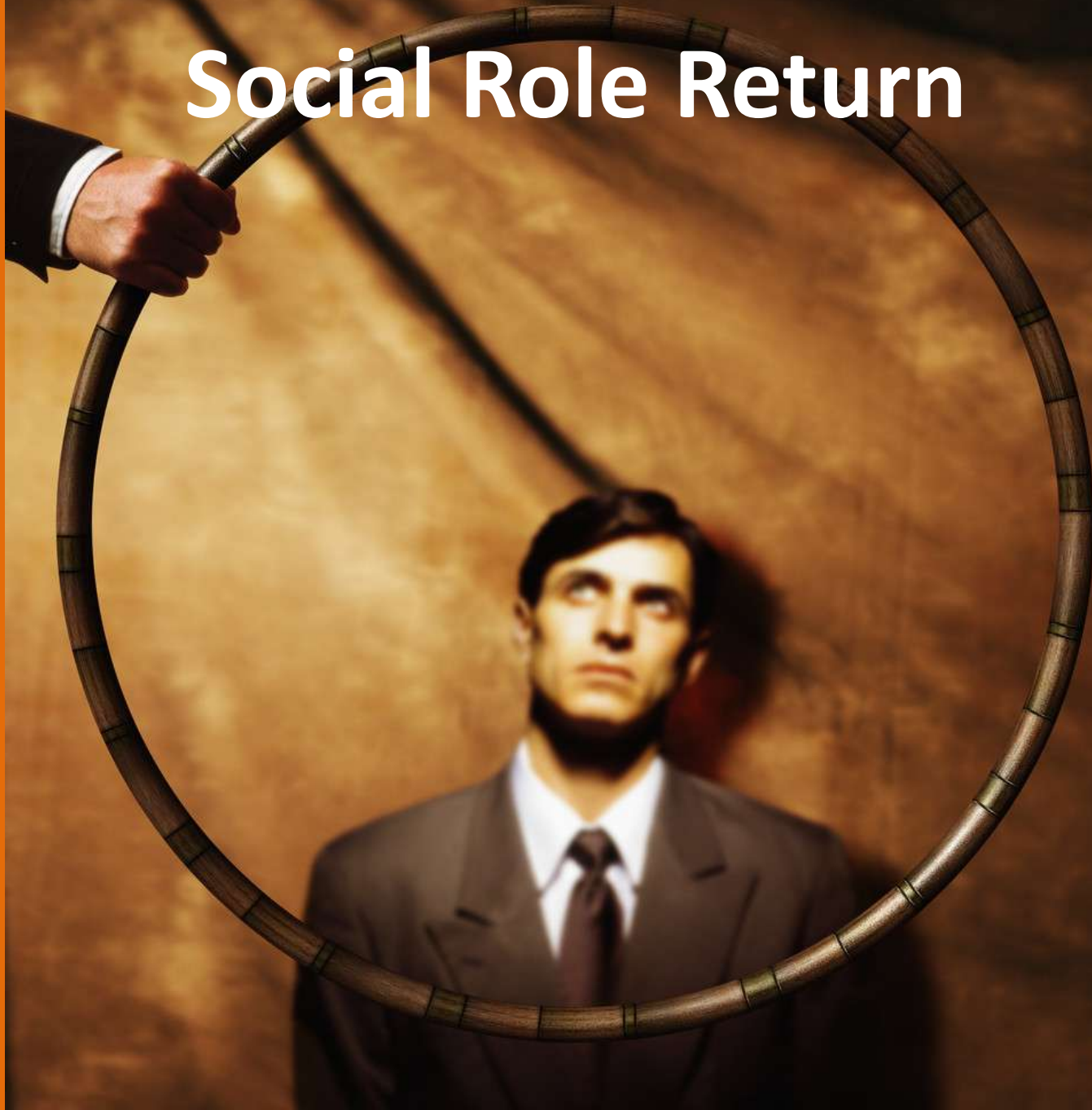
Let's consider:

what's important to people?

Personal Life & Relationships



Social Role Return





**Meaningful
life
activities**

Community participation



Eliminating health disparities



Brain Injury



Exit Here

A close-up photograph of a chain-link fence. The fence is made of galvanized steel and is secured with a heavy-duty padlock and a chain. The padlock is black and has a small loop at the bottom. The chain is made of dark, rusty links. The fence is set against a background of a blue sky with light, wispy clouds. The text "what are the barriers to sustained outcomes?" is overlaid in white, bold, sans-serif font in the center of the image.

**what are the barriers to
sustained outcomes?**

A black and white photograph of a person's face, partially obscured by their hand. The person's hand is raised to their face, with fingers spread, covering the lower half of their face. The lighting is dramatic, with strong highlights on the hand and the upper part of the face, and deep shadows elsewhere. The background is dark. The text "Mental health problems" is overlaid in a large, white, sans-serif font across the middle of the image.

Mental health problems

The likelihood of psychological problems over the course of time





Substance Abuse Issues

High risk individuals



Responding to mental health crisis





and, the
onset of
health
problems

**What do the long-term
studies tell us?**

Can rehabilitation outcomes be sustained?

- Life functioning and community integration gains can be sustained after rehabilitation
- Areas studied included:
- Living accommodations
- Employment
- Hours of care needed
- Source: Geurtsen G et al. (2010)

Functional Outcomes 10 years after injury

- High levels of anxiety and depression = poorer outcome attainment
- Level of ability to participate = poorer outcomes
- Social isolation related to functional deficits
- Psychiatric diagnosis and cognitive deficits are best regarded as components rather than outcomes
- Source: Ponsford J et al (2008)

30-year study of mental health issues and brain injury

- **Temporary disruption of brain function leading to the development of psychiatric symptoms**
- **Increased, long-standing vulnerability and even permanent psychiatric disorder**

30-year study of mental health issues and brain injury

- 61.7 had an Axis 1 (DSM-IV) diagnosis in their life time
- 48.8% had an Axis 1 diagnosis following their injury
- 40.0% had a current, post-injury Axis 1 diagnosis
- Depression (MDD) was the most common diagnosis
- Source: Kaponen A et al (2002)

HMO Study of mental health issues

- Severe TBI related to higher rates of depression (MDD), dysthymia, OCD, phobias, panic disorders, substance abuse/ dependence, bipolar disorders as compared to the non-TBI group
- “Poorer physical or emotional health and higher likelihood of receiving welfare for the TBI cohort”
- Negative symptoms of psychiatric disorders enforce social isolation and social network failure
- Source: Silver, J et al (2001)

Monash University Study: Likelihood of post-injury psychiatric disorders

- **Psychiatric disorders occurring in 60% of the post-injury population in a 5.5 year period**
- **Greater likelihood of psychiatric disorder found in relationship to pre-injury substance abuse, major depressive and anxiety disorders**
- **Source: Whelan-Goodinson, Johnston, Ponsford, Grant (2009)**

Dawson and Chipman's study of social adjustment

- Based on life satisfaction of individuals >15 years post-injury
- Measures included: personal assistance required; employment status; socialization; contact by telephone
- Social isolation and lack of opportunities identified as a key factor in adjustment difficulties
- Source: Dawson and Chipman (1994)

What happens when rehab is over?

What happens as life goes on?

**Can we sustain the gains made in
rehab over the course of time?**

What does it take?

**What's changing
tomorrow's outcomes?**

Increased survivability



Earlier medical intervention



but, shorter medical rehab



The background of the slide features a blue gradient with black silhouettes of a woman on the left and a person in a wheelchair on the right. The woman is walking and has her hand on the back of the person in the wheelchair, suggesting assistance or support. The person in the wheelchair is facing right.

**Individuals with greater disabling
conditions being sent home**

“sicker and quicker”

**17 days of acute medical
care in 2012 vs. 57 days in
1990 for high moderate to
severe injuries**

**What services will individuals
who are discharged at 17 days
post-injury need?**

How does that **impact** on
outcome?

Are community-based
services available?

Adequate?

Is there caregiver support?

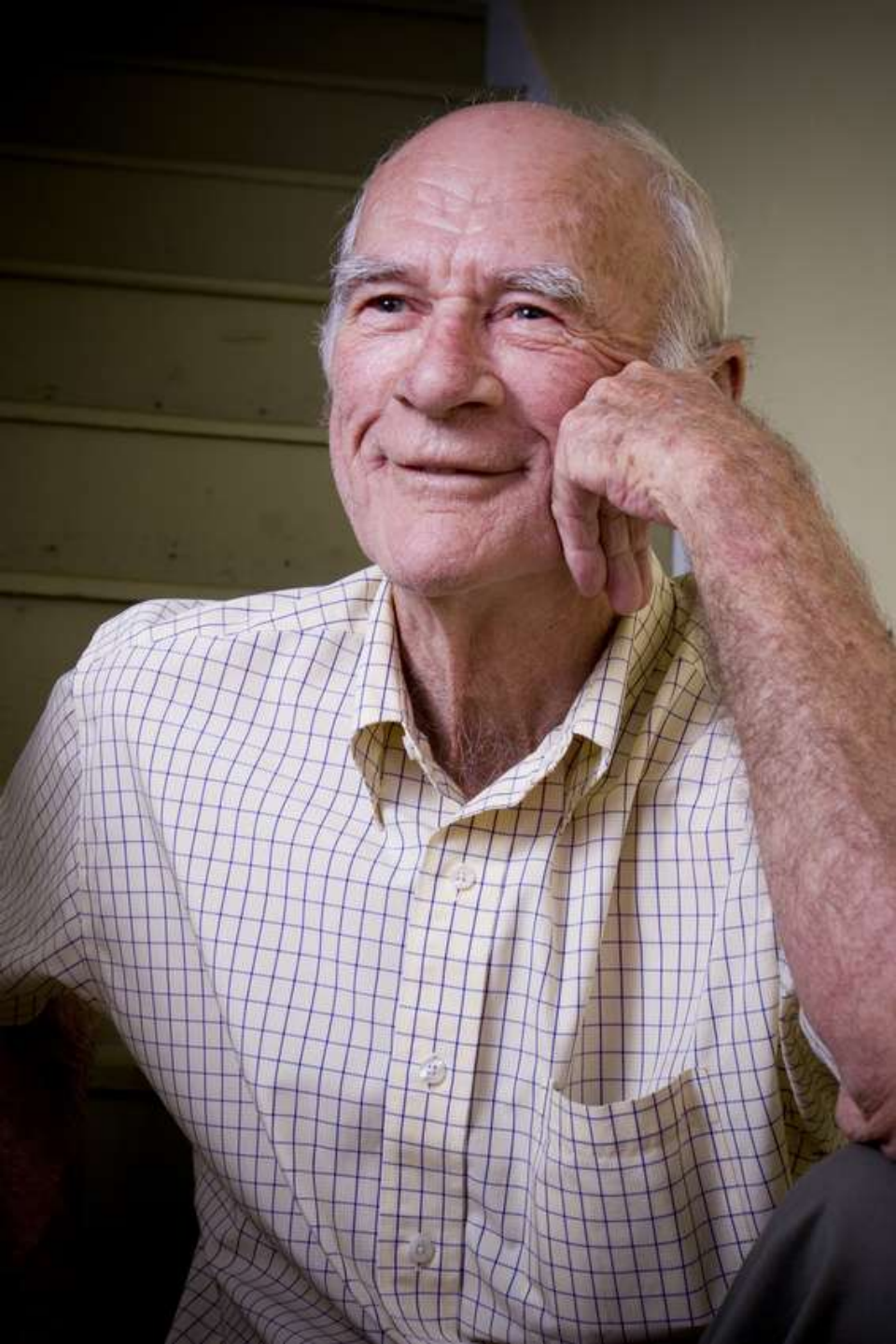
Cumulative effects of stress on caregivers

Limited resources for caregivers



Priority issues for caregivers





**What happens as
caregivers age?**

**What
happens
when a
caregiver
dies?**



The long view of living with a brain injury disability



The Canadian Study, Dawson and Chipman, 1994

**A view of the complex effects on
the person**

Dawson and Chipman

Level of life satisfaction

Personal care requirements

**Return to sustained
employment**

Restricted social contacts

Sustained community integration: what's involved

Housing?

Transportation?

Healthcare services?

Social supports

A photograph of a man and a woman smiling and embracing. The woman is on the left, wearing a red long-sleeved top, and the man is on the right, wearing a dark shirt. They are positioned in front of a blue background with white, star-like bokeh lights. The text "Support for social role return" is overlaid in white on the image.

Support for social role return

Key elements to consider:

Isolation and loneliness

Withdrawal

High level of dependence on others

Limited socialization opportunities

Loss of life focusing activities

Onset/presence of barriers

**Let's examine outcomes from
several ongoing studies**

**What can we
observe?**

NRI/Brookhaven Study 1996-2012

**inpatient neurobehavioral
program**

**Return to home and community
with moderate supports <6
hours/day**

**6% required minimal to moderate
supports in 2012**

**94% required extended to full
supports > 6 hours/day**

Social Role Return

14% returned to their primary social role with independence or minimal modifications

19% returned in a dependent care status

33% required 24 hour/day supervision

Interfering behavior and psychological problems

**23% required no ongoing psychological
or behavioral supports**

**67% required weekly or greater
psychological or behavioral supports**

Return to Work

**6% returned to competitive employment,
vocational training or school**

**22% returned to supported employment
and volunteering**

**44% were unable to sustain any work or
volunteering activity**

**there needs to be a
bridge back into the
community**

NRIO Study 1997 to 2012

**Community-based
rehabilitation**

**From 1997 to 2011 the age at
injury increased**

**37.6 years in 2011 vs. 30.7 in
2001 in the Adult cohort**

**Home support needs following
discharge**

**25% requiring a level of paid
support in the home**

**Community participation and
access**

**51% requiring full to partial
support for community
participation**

Adults returning to their pre-injury social role without supports

40.9% in 2012 vs. 29% in 2001

Focus on Social Role Return

- 14% unable to maintain pre-injury role in primary relationships**
- 14% report change in role due to functional status**
- 40.9% report remaining in role but experiencing minor problems**

Interfering factors to social role return

- **31.8% reporting post-rehab substance abuse problems**
- **40.9% reporting post-rehab behavioral health problems**

Pre- and post-injury psychological/psychiatric problems

- 33% report pre-injury
psychological/psychiatric problems**
- 56% report post-injury
psychological psychiatric problems**

Psychiatric Problems Pre- and Post-Injury

- 22% report pre-injury depression
- 38.9% report post-injury depression
- 11.1 % report pre-injury mood disorders
- 16.7% report post-injury mood disorders
- 11.1% report pre-injury anxiety disorders
- 44.4% report post-injury anxiety disorders

Pre- and post-injury substance use/abuse

- **38.9% experience pre-injury substance use/abuse problems**
- **50% experience post-injury substance use/abuse problems**

Return to Work

- 50% unable to return to work due to injury related problems
- 14% returned to their pre-injury job
- 7% required job modification/changes/supports to return to work
- 7% “volunteering” or retraining

Durability of outcome

- 0% regression in social role return level
- 0% increase in paid attendant care services
- General trend towards increased independence over time

**post-rehab supports are
needed**

Community Neuro Rehab Study

2010-2012

**Community-based neurobehavioral
rehabilitation**

Age at injury: 36.33

Return to pre-injury social role

25% return to their pre-injury social role with no to minimal supports

Focus on social role return

- **25% are unable to maintain their pre-injury role without moderate to maximum supports**
- **25% are experiencing a substantially changed social role due to functional problems**

Home support needs

**75% requiring more
than 2 hours/day of
paid support**

Community participation and access

75% require paid support to access the community

Pre- and post-injury substance use/abuse problems

- 75% had pre-injury substance abuse problems**
- 50% had post-injury substance abuse problems**

Pre- and post-injury psychological/psychiatric problems

- 37.5% had pre-injury
psychiatric problems**
- 100% had post-injury
psychiatric problems**

Return to work

- 62% were not able to return to their pre-injury job**
- 25% returned to work with job supports and modifications**
- 25% participated in further vocational training**
- 25% engaged in volunteer activities**

What can we learn from outcome studies that can improve long term outcomes?

**Impact of physical,
cognitive, behavioral and
functional symptoms on
relationships**

**Marital stability, divorce and
separation rates range from 15%
to 78%**

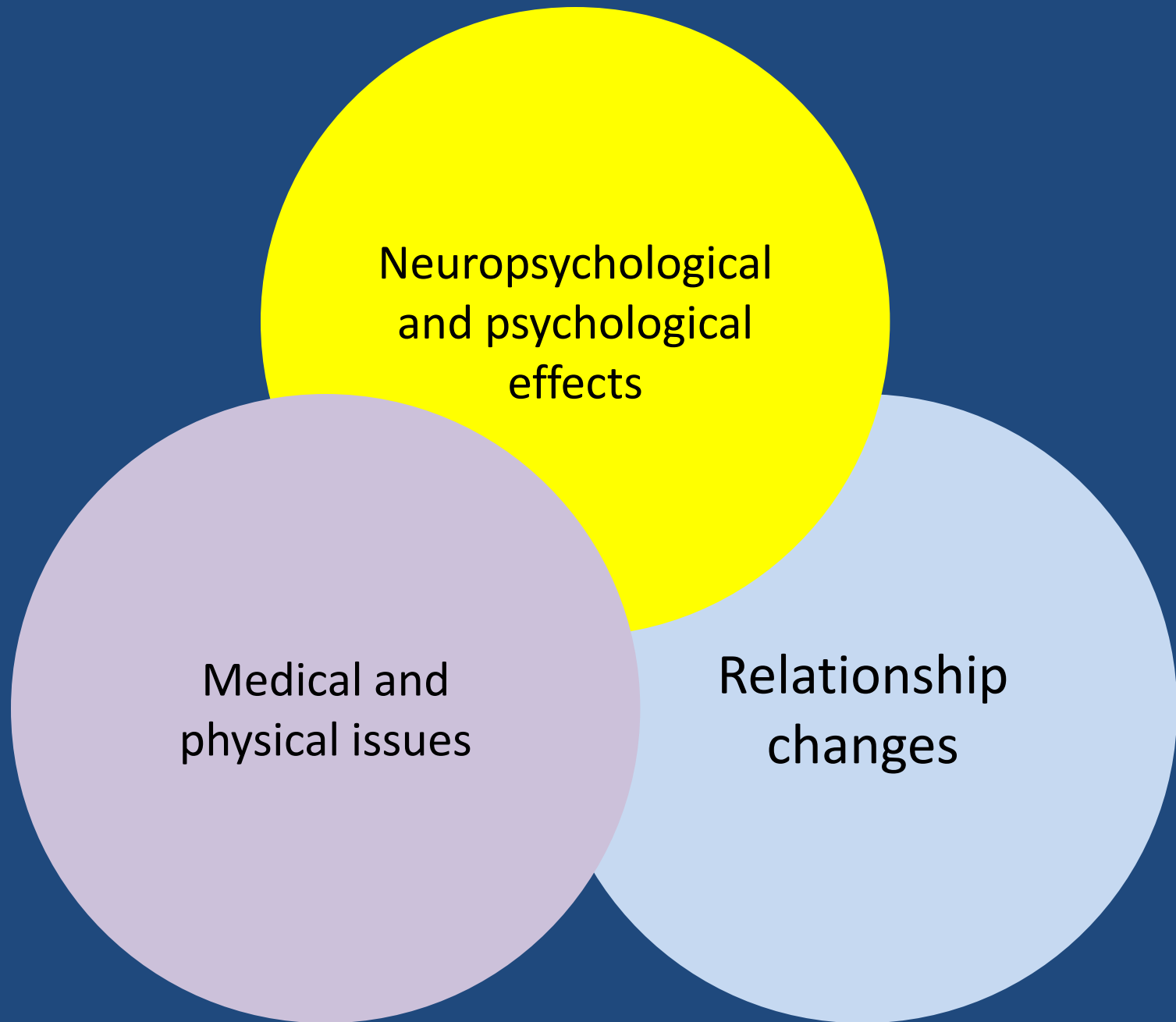
Arango-Lasprilla, et al, 2008

**Goodwin, Kreutzer, Arango-Lasprilla,
Lehan, 2011**

Johnson et al., 2010

**not significantly different from
the general population studies**

**but, what can we do to
enhance supports to
sustain relationships?**



Impact on caregivers due to family stress, revised roles, isolation, increased dependence

Boschen, Gargaro, Gan, Gerber, Brandys, 2007

Gosling and Oddy, 1999

Oddy, 2001

Oddy, Coughlan, Tyerman , Jenkins, 1985

Psychological changes effecting the person, their mood and behavior

Kaponen et al, 2002

Whelan-Goodinson, Johnston,
Ponsford, Grant, 2009

Fann, et al., 2004

Injury severity and the latent onset of mental health problems

Fann, et al., 2004

Gillett L, 2007

Van Reekum, et al, 2000

Silver, et al., 2001


Pre-injury problems and post-injury psychiatric and substance abuse

Dikmen, et al., 2004

Jorge, et al, 1993

Federoff, et al., 1992

Gomes-Henerandez et al., 1997

A large, round, dark-colored magnet with a gold chain is positioned in the upper left corner. A large bunch of keys, including various types of keys and a large metal ring, is clustered together and is being pulled towards the magnet by its magnetic force. The keys are made of various metals, including brass and steel. The background is a solid green color.

What are the key questions to consider?

**What issues are barriers to
community participation?**

**What are the types and
frequency of support
needs?**

**How can we identify the
barriers to attaining greater
independence?**

**How can we help to identify
realistic goals for the
person?**

**How can we determine
resources needed by family
caregivers over the course
of time?**

What about aging?



Aging with a brain injury

**Brain injury is a
cumulative disability**

**By the age of 80, the average
person has at least three
disabling conditions**

**Doesn't that occur much
earlier for people with
brain injuries**

**Let's look at a cohort of 8
individuals in a community-based
supported living environment**

The demographics:

- 7 males, 1 female, >20 years post-injury
- 55-69 years of age
- 88% Motor Vehicle Accidents
- 100% were employed pre-injury

Changes to their family support systems since their injury

- 12% have no contact with family**
- 50% have experienced the death of one or both parents**
- 75% have reduced contact with family members**

**What health problems are they
facing now that they are > 20
years post injury?**

Decreased mobility

- 25% using walkers
- 25% using wheelchairs

Development of medical problems post-injury

Diabetes in 25%

Skin integrity problems 25%

Circulatory problems 25%

Seizure disorder 12%

Swallowing problems 25%

Sleep apnea 25%

Parkinson's Disease 25%

Hearing, vision problems 75%

Psychological/Psychiatric Problems

- 50% report ongoing depressed mood
- 50% report problems with anxiety
- 100% report problems with fatigue

**Let's also look at people
who are living successfully
with their brain injury
disability**

Some people do well

**What can we learn
from their successes?**

What characteristics can be associated with positive long term outcomes ?



The person

- **Strong, resilient personality**
- **Positive, forward looking**
- **Manages day-to-day life needs**
- **Understands their need for support**
- **Minimal psychological issues**
- **Maintains focus on meaningful life activities**
- **Maintains social role**

Their family

- **Oriented towards mutual help**
- **Identifies and accesses supports/resources**
- **Supports maximum independence**
- **Maintaining their own health/wellness**
- **Maintains other life interests**
- **Adequate financial resources**
- **Supports social roles within and outside of family**

Their social network

- **Friends and social life available outside of the home and family**
- **Frequent social contacts through multiple means: activities, telephone, electronic**
- **Combination of old and new friends**
- **Positive social experiences**

The available resources

- **Finances to support life style**
- **Adequate, accessible housing**
- **Access to transportation**
- **Access to routine and specialized healthcare**
- **Access to community activities**
- **Addressing the process of aging with a disability**

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The background of the slide features a collection of grey silhouettes of people in various poses, suggesting movement and activity. Some are walking, some are standing, and one appears to be sitting or crouching. These silhouettes are scattered across the slide, with some overlapping the text.

Questions?

**Note: this presentation can be downloaded at
www.traumaticbraininjury.net under
“Resources”**

The impact of disruptions in the living situation

Finding an alternative living situation

**Addressing disruptions caused by
new or exacerbated problems**

**What about support for
participation?**

**How can we assist
people in returning to
independence?**