

# Ambiguous Loss

## and Identity Reformulation after Brain Injury

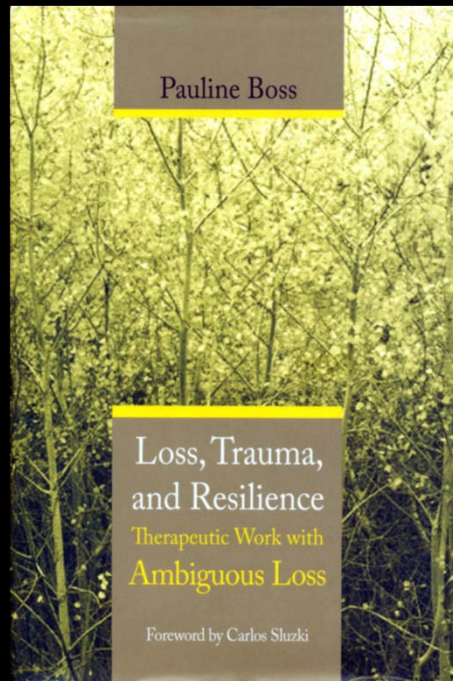
I'm married but  
have no husband

I'm married to a  
stranger



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[www.tbinrc.com](http://www.tbinrc.com)



(2006) New York:  
W.W. Norton and  
Company

## Ambiguous Loss

Pauline Boss

- ▶ 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.
- ▶ The most stressful losses are those that are ambiguous.

## Ambiguous Loss

Pauline Boss

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.

## Ambiguous Loss

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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.”

## Ambiguous Loss

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Lack of clarity about prognosis, daily physical condition, and fluctuating capabilities create relationship confusion, preoccupation with the illness or avoidance of the individual.



## Ambiguous Loss

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When loved ones go missing physically or psychologically, the human capacity for survival is often frozen by the confusion that all too often cements into a rigid tenacity of hope that the missing will come back or recover.

## Ambiguous Loss

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With death, there is official certification of loss, and mourning rituals allow one to say goodbye. With ambiguous loss, none of these markers exists.

# Ambiguous Loss

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People plummet from hope to hopelessness and back again. Depression, anxiety, and somatic illnesses often set in.

# Family Reactions

	<u>Mothers</u>	<u>Wives</u>
Frustration	100%	84%
Irritability	55%	74%
Annoyance	55%	68%
Depression	45%	79%
Social isolation	27%	74%

## Unique Reactions of Wives

- ▶ No sexual outlet 42%
- ▶ I'm married but don't have a husband 42%
- ▶ I'm married to a stranger 32%



from Mauss-Clum & Ryan

## Ambiguous Loss

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The symptoms affect the individual first, but can radiate in a ripple effect that impacts the whole family, as people are ignored or, worse yet, abandoned. Family members can become so preoccupied with the loss that they withdraw from one another. The family becomes a system with nobody in it.

## Ambiguous Loss

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Ambiguous loss blurs the tidy boundaries of a couple or a family, causing people to question the most intimate relationships. Who is in and who is out remains cloudy. Fear and anger mix with the confusion.

## Ambiguous Loss

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As a family therapist, I often hear questions such as, “Am I still a mother?” “Do I have a husband or not?” “Am I really married?”



# Ambiguous Loss

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Therapy based on the recognition of ambiguity of the loss frees people to understand, cope, and move on after the loss even if it remains unclear.

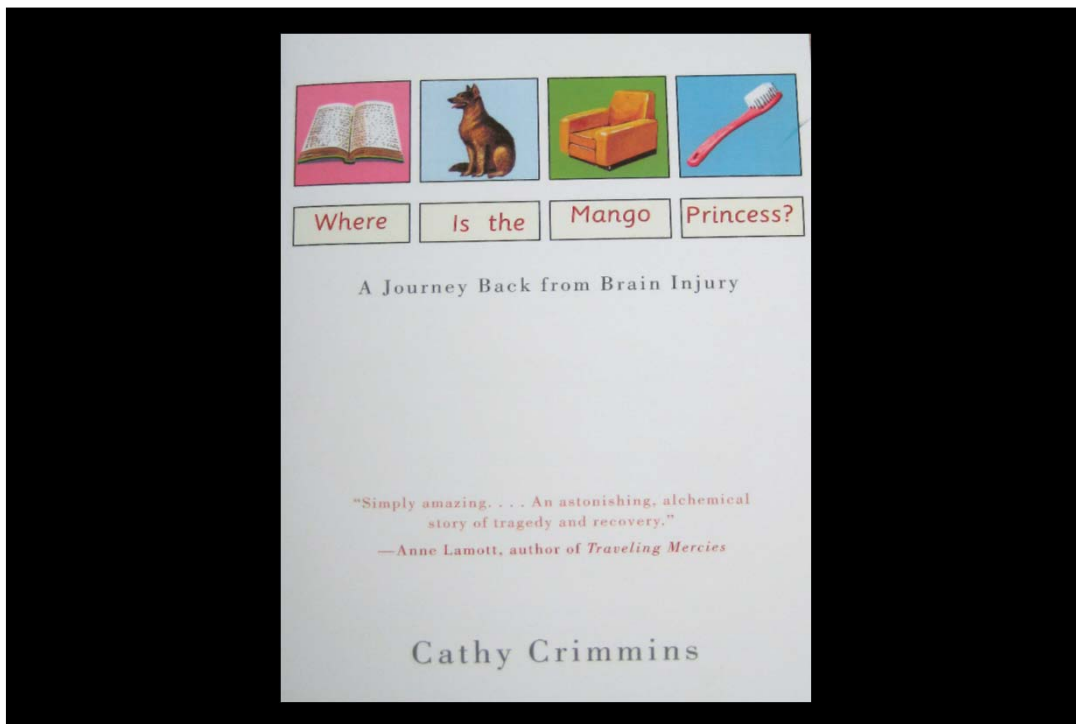
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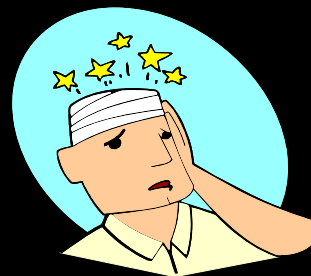
## To increase success -

- ▶ isolation should shift to social connection,
- ▶ helplessness to believing one can do something to change things
- ▶ confusion to a trust in the world as coherent and manageable





TBI is like an incomplete death:  
you've lost a person, or parts of that  
person, but he's still here.



## Education and Psychological Support Help Resolve Ambiguous Loss

- ❑ Help the family appreciate the normal consequences of brain injury and recovery patterns.
- ❑ Help the family appreciate the patient's injury, consequences, and prognosis.
- ❑ Work hard to identify positive aspects of the situation.
- ❑ Instill hope for improvement.

## Learning to Like and Live With a Stranger

- ⇒ Not everything has changed. Recognize the good qualities that are still there.
- ⇒ Post-injury change is a continuing process. Recognize the injured person's ability to change for the better. Point out what you see and like. Encourage the person to speak in ways that are appreciated.

## Learning to Like and Live With a Stranger

- ⇒ Communicate and get to know this “different” person better. Ask about their feelings, what they like and dislike, and how you can help. Try to share your feelings, good and bad, with them.



## Learning to Like and Live With a Stranger

The injured person's acting different is partly related to being treated differently by other family members, friends, and co-workers. Understand that you are probably acting and treating the injured person differently too.



## Learning to Like and Live With a Stranger

Perhaps you are treating your husband more like a child. Maybe you are treating your injured child like he is several years younger.



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## Learning to Like and Live With a Stranger

A focus on the positive will improve the injured person's motivation to change for the better, their self-esteem, and the quality of your relationship. Appreciate your ability to have a positive influence.

*from Getting Better and Better after Brain Injury: A Guide for Families, Friends, and Caregivers*

## Learning to Like and Live With a Stranger

- ⇒ Recognize the possibility of changing for the better as many survivors do. Many develop wisdom from their experience. Some develop an appreciation for the “little things in life,” that many people take for granted.
- ⇒ Try to do some of the things you used to enjoy together. Taking a walk, seeing a movie, or visiting mutual friends can bring back good memories and good feelings.

## The Change Recognition Questionnaire

1. What changes have you noticed in the way the injured person treats you?
2. What changes in the injured person are most upsetting?
3. What can you do to encourage the injured person to change for the better?
4. What familiar qualities do you still see in the injured person?



## The Change Recognition Questionnaire

5. Are there new qualities that you can appreciate?
6. How are you treating the injured person differently?
7. How are other family members treating the injured person differently?



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## The Change Recognition Questionnaire

8. How are friends, neighbors, and colleagues treating the injured person differently?
9. What things that you used to do together can you still enjoy?
10. What new activities can you enjoy together?



## Learning to Like and Live With a Stranger

- ⇒ Most of all, try to be patient. The injury related changes that occurred were sudden, but getting better is a long-term process. Over time your family member will seem more familiar, understandable, and predictable.



## Important Notice

Brain injury is an unexpected, catastrophic event, often affecting family members' lives for many years.



# Important Notice

Learning about the normal effects of injury, adjusting expectations, learning from experience, and developing new skills helps make life better.



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