


### Ambiguous Loss: A Family Perspective

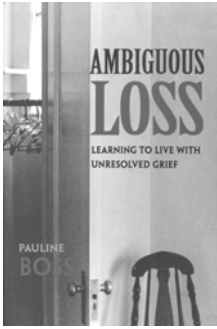
I'm married but have no husband

I'm married to a stranger



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The research that enabled me to identify the phenomenon of ambiguous loss was conducted with the families of pilots declared missing in action in Vietnam and Cambodia. It was 1974, and I was collaborating with staff at the Center of Prisoner of War Studies in the U.S. Naval Health Research Institute in San Diego. We interviewed the wives of missing pilots in their homes, and it was from them I first learned about the power of ambiguity in complicating loss. I tried to determine how to ease their stress in spite of the ambiguity they had to live with – in many cases for a lifetime.

### 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.
- ▶ Our premise is that 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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... In the second type of ambiguous loss, a person is perceived as present but *psychologically absent*. This condition is illustrated in the extreme by people with Alzheimer’s disease... can also occur when a person experiences serious head trauma, first becoming comatose and then waking up a different person.

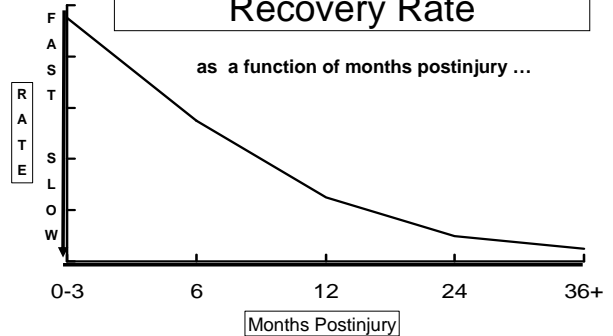
## Ambiguous Loss

Pauline Boss

- ▶ Lack of clarity about prognosis, daily physical condition, and fluctuating capabilities create relationship confusion, preoccupation with the illness or avoidance of the individual.
- ▶ Immobilization, depression, and relationship collapse may occur in response to features of chronic illness over which there is no control.

## Cognitive and Physical Recovery Rate

as a function of months postinjury ...

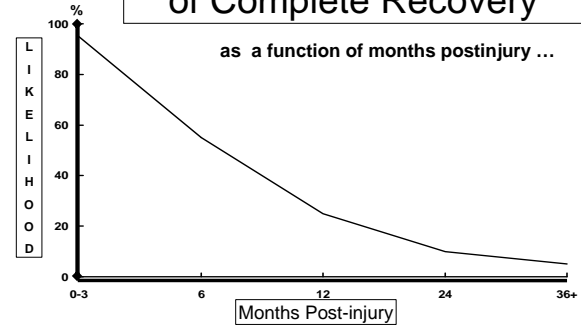


In the parlance of social workers, we are in the transition from the acute to the chronic phase of traumatic brain injury. It's a frustrating phase. Al's progress was so dramatic in the first few weeks: awakening from coma, speaking, walking. All these events seemed like miracles. But now the progress is gradual, difficult to see... Is anything happening?

from Where is the Mango Princess?

## Estimated Likelihood of Complete Recovery

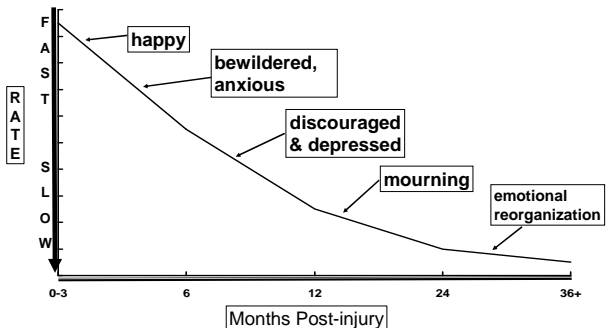
as a function of months postinjury ...



It's beginning to sink in that Alan's recovery will be a long process. Dr. Ellis tells me that it takes six months to a year to recover from the physical and some of the cognitive symptoms of brain injury, although there is a catch: during recovery a patient may get "stuck" in any phase and few recover fully... So the way that Alan is now could be the way he remains forever.

from Where is the Mango Princess?

## Family Reactions to Improvement Rates



Recovery from brain injury is a long process, I tell myself every day. I try to dwell on the positive and the potential for improvement... And in between the fits of anger, there are fits of loving too, when Alan tells me and Kelly how terrific we are and he would never have survived the accident without us.

from Where is the Mango Princess?

## Ambiguous Loss

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Ambiguous loss can cause personal and family problems, not because of flaws in the psyches of those experiencing loss, but because of situations beyond their control or outside constraints that block the coping and grieving process.

## Ambiguous Loss

Pauline Boss

With death, there is official certification of loss, and mourning rituals allow one to say goodbye. With ambiguous loss, none of these markers exists. The persisting ambiguity blocks cognition, coping, and meaning-making and freezes the grief process.

## Ambiguous Loss

Pauline Boss

The major theoretical premise underlying therapy is this: the greater the ambiguity surrounding one's loss, the more difficult it is to master it and the greater one's depression, anxiety, and family conflict.

## Ambiguous Loss

Pauline Boss

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.

## Ambiguous Loss

Pauline Boss

After loss and trauma, it is essential to gradually replace responses that fuel helplessness with empowering behaviors. When people learn that trauma is clearly uncontrollable, "fear gives way to depression."

## Ambiguous Loss

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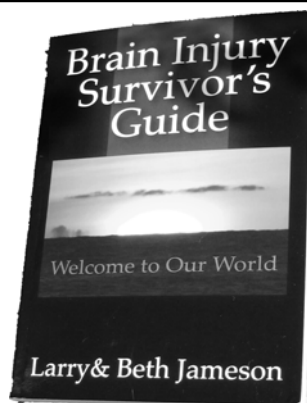
To increase success -

- ▶ 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

## Ambiguous Loss

Pauline Boss

The goals of recovery and empowerment are to find and construct options, information, social support, and some new hopes and dreams.



A doctor I'd never seen before stepped from the room and walked toward me. "I don't expect her to survive the trauma... what happens in the next 24 hours is critical"



p. 8, *Brain Injury Survivor's Guide*

"ARDS"...one of the leading causes of death in Vietnam. Beth was discovered near death by a nurse. She wasn't breathing. Emergency procedures were quickly initiated. The surgeon's office was called. Time passed. A pulmonary specialist was called.

p. 9, *Brain Injury Survivor's Guide*

Beth did not know she was married. She did not know she had two children. She did not know where she lived. More memory problems would surface.



p. 12, *Brain Injury Survivor's Guide*

Months passed after she was released from the hospital before we discovered that Beth had suffered an anoxic stroke in the hospital that resulted in a brain injury.

p. 11, *Brain Injury Survivor's Guide*

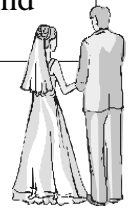
You look normal so people expect you to be normal. If you had a piece of shrapnel sticking out through your skin, people would be more understanding. But you don't, do you?

p. 13, *Brain Injury Survivor's Guide*

There will be a large number of family and friends who will treat you as though nothing has happened. This includes family members and close friends who simply do not have any knowledge about brain injury and how it affects you.

p. 81, *Brain Injury Survivor's Guide*

In May of 1970, I married a beautiful young girl and began the journey as a husband for the first time. In August of 1990, I began living with a completely different person and began a second journey as a husband.



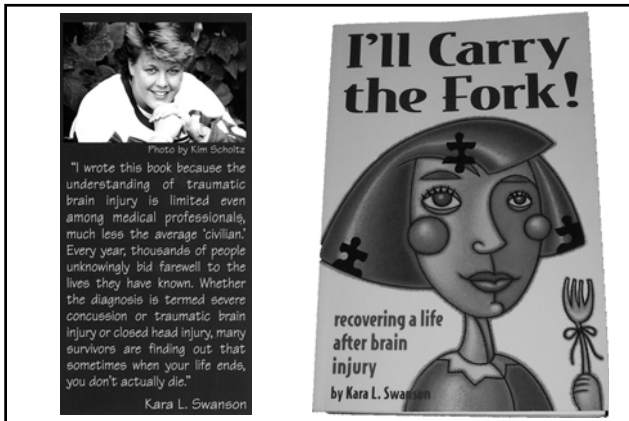
Larry Jameson, p. 28,  
*Brain Injury Survivor's Guide*

Beth, of course, is both of those people, and they are almost as different as night and day. As she has pointed out, brain injury affects different people in different ways but there are few constants.

Larry Jameson, p. 28,  
*Brain Injury Survivor's Guide*

Living with a brain injured person will require adjustments in your life. Your loved one is still the same person, but is a different person as well.

p. 38, *Brain Injury Survivor's Guide*



## Getting on the Bus

The curious thing about the auto accident that ended my life was that I lived through it. On January 31, 1996, Death sneaked through a red light disguised as a minivan going 50 miles an hour.

Kara L. Swanson

## Getting on the Bus



‘Course, nobody told me that when they finished pulling me out of my car, they were putting me right on the bus. That’s what I call the process of recovering from traumatic brain injury: “getting on the bus.”

Kara L. Swanson

## Getting on the Bus



It’s a good thing they strapped me down and fastened my head to a board. Had I understood even a little of the journey that had just begun, I would have hit the ground running.

Kara L. Swanson

...and others didn’t understand. How could they. They couldn’t see the hundred and one things I was doing behind the scenes to present myself as normal. I looked the same (except for the extra poundage).

Kara L. Swanson

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 got angry at nothing. One night something irked me and I tore down the wallpaper in my living room. I interrupted people. They could tell me they just found the cure for cancer and I would cut them off and talk about how pretty the car next to us was.

Kara L. Swanson

One of the most important steps in recovering from any traumatic event is realizing that you need help – that you can't always make it by yourself – and finding the strength to seek it out.

Kara L. Swanson

The inability to organize my thoughts confounded me. I had some idea of what I wanted to say, but I couldn't keep other ideas from popping in here and there, and my first few attempts were a tangled mess.... It was like trying to get gum out of my hair with mittens.

Kara L. Swanson

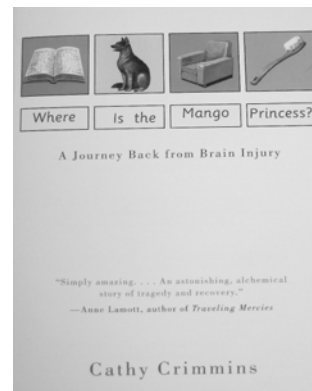
June 4, 1996. I was standing in line at Target. All of a sudden, I was furious with the young woman behind the register. I just wanted to KILL her! I don't know why. Diana ended up taking me home. I'm so embarrassed.



Kara L. Swanson

My family and friends didn't know anything about head injury. We didn't know how to interpret what we were seeing.

Kara L. Swanson



# Introduction

In 1996, Cathy Crimmins, her husband Alan, and their daughter Kelly were on an idyllic lakeside holiday when a boating accident left Alan in a deep coma, with severe damage to the frontal lobes of his brain, the area that controls speech, memory, movement, and personality. *Where is the Mango Princess?* is the story of what happened to Cathy and her family after Alan woke up.

They gave Alan the Glasgow Coma Scale test as soon as he was admitted, rating his stimulus response, eye opening, and awareness. The highest score, one that indicates normal consciousness and brain function, is a 15.

p. 26, *Where is the Mango Princess?*

At a score of 3 to 5, it is likely that the patient will remain in a vegetative or semi-vegetative state for life. Alan is a Glasgow Coma Scale 5, which means that he will probably wake up, but beyond that no one has any idea of what will happen.

p. 6, *Where is the Mango Princess?*

He doesn't know that a meteor hit him. He will never know really. He only knows that he has spent a lot of time in a dark, confusing place. He left a lot of stuff behind, the stuff he was carrying with him, down in that big black hole, and it's impossible to get it all back.

p. 4, *Where is the Mango Princess?*

Overnight, Alan's brain continues to swell and bleed. He starts to spike a fever. When Alan's second CT results show up, the ICU nurse grabs my arm and holds tight. "Oh Cathy – I'm so afraid you'll not be getting your Alan back. The scans are bad. So much bleeding. Oh, it's bad. He'll be much changed, eh? He might be mean and all nasty-like. He won't be the same man."

p. 30, *Where is the Mango Princess?*

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



p. 218, *Where is the Mango Princess?*

“I am beginning to understand the phrase ‘lack of companionship,’ ” I say to my mother and mother-in-law as we sit eating dinner in a nice outdoor café on Kingston’s main thoroughfare. “He’s not here,” I say tearfully. “He might never be here again.” They don’t know how to answer.

from *Where is the Mango Princess?*

The Ghost of Alan past. He haunts me even more than Phineas Gage does. The worst thing you can do... is to remind the brain-injured person of what he was like before, of what he could do back then he can’t do now. But how can you help remembering?

from *Where is the Mango Princess?*

... when we’re in a restaurant or at a play he usually acts appropriately. Then I can see glimpses of the Old Alan. These experiences remind me of the dreams I had after my father died, when he would be alive again and I would be hugging him or talking to him eagerly.

from *Where is the Mango Princess?*

When I awoke, I’d be depressed that my father really was gone but happy that I could still imagine him in his fullness. I feel the same way about the brief and tantalizing brushes I have with the Ghost of Alan past.

from *Where is the Mango Princess?*

How can I explain the personality oddities of brain injury to people who think Alan is the same as he was before? I ask for Bill’s advice. “Just tell them to imagine the things they hate about their spouses most and then multiply that trait a hundred times,” he advises. How true.

from *Where is the Mango Princess?*

Travel is very difficult because I can’t anticipate frustrations or long waits or even what could go wrong... On the way home... Al pops up and starts screaming... He begins smashing the inside of the windshield again, and what follows is my least proud moment as a TBI caregiver.

from *Where is the Mango Princess?*

I go crazy. I'm still holding the cell phone and I begin beating him on the head (the head!) with it, screaming through clenched teeth, "Alan, I hate you! I will kill you if you keep this up! I cannot live this way. Do you understand? I will *kill* you? I intend to *kill* you!"

from *Where is the Mango Princess?*

"Mom, Mom, stop! He can't help it, he's brain injured. His brain is making him do it," says Kelly from the backseat as she reaches between us to wrest the phone from her psychotic mother. A nine-year-old forced to be the voice of reason.

from *Where is the Mango Princess?*

I continue to seethe. I've had it. I'm ashamed of behaving like that in front of Kelly but convinced that if I had killed Alan right there in the car, I could claim he wasn't my husband at all, just some angry, addled alien inhabiting my husband's former body.

from *Where is the Mango Princess?*

The next morning Alan takes his shower first. When I step out of the shower stall, the mirror over the sink is steamed up and there is writing on it. "Help me. I have a TBI," it says, in Alan's new babyish handwriting.

from *Where is the Mango Princess?*

We go out to dinner at about ten every night. "Just think of me as your third husband," Al says at dinner that night. I laugh. He's never really gotten over the fact that he's my second husband – he hates the idea of my brief unhappy marriage that ended when I was twenty one.

"Oh yeah?" I say. "But where did my second husband go?"

from *Where is the Mango Princess?*

His brain has been damaged and will never be the same. His rehabilitation counselor says that the "old" Alan died on July 1, 1996, and a new one arose, created by the rivers and lakes of bruises that coursed over his brain as he lay unconscious in the days after his injury. He is a man with different frontal lobes and a different personality to match.

from *Where is the Mango Princess?*

### 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 about the person with the injury 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.

One small portion of your support will come as praise. You should develop a habit of praising correct behavior. Positive reinforcement is essential to helping your loved one along the road of becoming a successful brain injury survivor.



p. 28, *Brain Injury Survivor's Guide?*

You must adjust to the new person, and you must reward them when they make progress. A pat on the back is good, words of praise are good. You need to add reward activities to the list of rewards. Beth and I had so many celebration meals we had to begin a diet and fitness program.



p. 38 - 39, *Brain Injury Survivor's Guide*

### 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.



[www.nrc.pmr.vcu.edu](http://www.nrc.pmr.vcu.edu)

### Learning to Like and Live With a Stranger

Perhaps you aren't noticing the good things they do. Try to avoid a natural tendency to focus on the things you don't like.

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

### 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 survivor's 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?



## 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.



“I feel like I was divorced on the day my wife was injured,” says a friend of mine (his wife, whose car was run over by a large truck, now has substantial frontal lobe damage), “and then there was a hastily arranged marriage to a woman I barely know.”

p. 219, *Where is the Mango Princess?*

I mentioned earlier about being married to Beth Number One (before brain injury) and Beth Number Two (after brain injury). I have been fortunate to be married to *two* wonderful ladies. The second one has a more independent spirit and is far more willing to explore new ideas.

Larry Jameson, p. 112, *Brain Injury Survivor's Guide*

Of course she tried for some time to become the way she once had been. She wanted to be Beth Number One, but she finally decided to improve Beth Number Two. That decision is probably one of the most important ones she made that has led to a successful life style.

Larry Jameson, p. 113, *Brain Injury Survivor's Guide*

She began to imagine a better life with brain injury playing a minor part. Her brain is still injured; she still has those *memory moments* and she still has problems with her vision. But she no longer concentrates on the things that are not perfect.

Larry Jameson, p. 113, *Brain Injury Survivor's Guide*

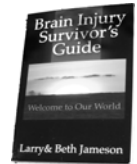
I must say that my family's support has helped me over many, many hurdles I have faced during the years... Let your family help you and never give up.



Beth Jameson, p. 22.  
*Brain Injury Survivor's Guide*

## Never Give Up

- ⇒ Never give up on your dreams.
- ⇒ Never give up on becoming the kind of person you want to be.
- ⇒ Never give up on yourself.



Beth Jameson, p. 115.  
*Brain Injury Survivor's Guide*

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