

How To Successfully Overcome Major Life Challenges after Brain Injury

- ⇒ Appreciating and coping with change
- ⇒ Recognizing and coping with stress and crises
- ⇒ Overcoming loneliness and building lasting relationships
- ⇒ Communicating effectively



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Major Challenges after Brain Injury



- ⇒ Appreciating and coping with change
- ⇒ Recognizing and coping with stress
- ⇒ Overcoming loneliness and building lasting relationships
- ⇒ Communicating effectively

Important Notice

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



Physical Concerns Brain Injury Problem Checklist

- | | |
|--|---|
| <input type="checkbox"/> tired | <input type="checkbox"/> weak |
| <input type="checkbox"/> moves slowly | <input type="checkbox"/> trouble sleeping |
| <input type="checkbox"/> loses balance | <input type="checkbox"/> dizziness |
| <input type="checkbox"/> headaches | <input type="checkbox"/> muscles tingle or twitch |
| <input type="checkbox"/> drops things | <input type="checkbox"/> other |



Cognitive Concerns Brain Injury Problem Checklist

- | | |
|---|--|
| <input type="checkbox"/> confused | <input type="checkbox"/> forgets if he has done things |
| <input type="checkbox"/> misplaces things | <input type="checkbox"/> forgets what he or she reads |
| <input type="checkbox"/> loses train of thought | <input type="checkbox"/> forgets names |
| <input type="checkbox"/> thinks slowly | <input type="checkbox"/> easily distracted |
| <input type="checkbox"/> trouble making decisions | <input type="checkbox"/> other..... |
| <input type="checkbox"/> poor concentration | |

Behavioral and Emotional Concerns Brain Injury Problem Checklist

- | | |
|-------------------------------------|--|
| <input type="checkbox"/> frustrated | <input type="checkbox"/> complains |
| <input type="checkbox"/> bored | <input type="checkbox"/> difficulty getting things started |
| <input type="checkbox"/> restless | <input type="checkbox"/> misunderstood by others |
| <input type="checkbox"/> impatient | <input type="checkbox"/> jumpy, irritable |
| <input type="checkbox"/> sad, blue | <input type="checkbox"/> other |
| <input type="checkbox"/> lonely | |



Communication and Social Concerns Brain Injury Problem Checklist

- | | |
|--|--|
| <input type="checkbox"/> difficulty thinking of the right word | <input type="checkbox"/> writes slowly |
| <input type="checkbox"/> argues | <input type="checkbox"/> trouble making conversation |
| <input type="checkbox"/> makes spelling mistakes | <input type="checkbox"/> writing is hard to read |
| <input type="checkbox"/> thinks only of self | <input type="checkbox"/> other..... |
| <input type="checkbox"/> uncomfortable around others | |





Major Challenges after Brain Injury



- ⇒ Appreciating and coping with change
- ⇒ Recognizing and coping with stress
- ⇒ Overcoming loneliness and building lasting relationships
- ⇒ Communicating effectively

Social Readjustment Rating Scale

Life Event	Value
death of spouse	99
divorce	91
marriage	85
death of close family member	84
fired at work	83
marital separation	78
jail term	72



Holmes and Raye 1967

Social Readjustment Rating Scale

Life Event	Value
personal injury or illness	68
death of close friend	68
retirement	68
change in financial state	61
spouse begins or stops work	58
change - family member's health	56



Holmes and Raye 1967

Social Readjustment Rating Scale

Life Event	Value
change line of work	51
residence change	47
increased arguments w/spouse	46
change in work responsibilities	46
trouble with boss	45
revision of personal habits	44

Holmes and Raye 1967

Social Readjustment Rating Scale

Life Event	Value
trouble with in-laws	43
change in living conditions	42
change in work hours/conditions	36
minor violations of law	30
change in sleeping habits	27
change in recreation	26

Holmes and Raye 1967

Brain Injury and The Family

Mauss-Clum & Ryan
Journal of Neurosurgical Nursing

Changes in the Patient

Decreased memory	87%
Dependency	73%
Depression	57%
Impatience	57%
Decreased ambition	53%
Irritability	53%
Temper outbursts	50%



from Mauss-Clum & Ryan

Family Reactions

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

from Mauss-Clum & Ryan

Family Reactions

	<u>Mothers</u>	<u>Wives</u>
Less time for self	36%	58%
Financial insecurity	18%	58%
Guilt	18%	47%
Feeling trapped	45%	42%
Little respite	9%	32%

from Mauss-Clum & Ryan

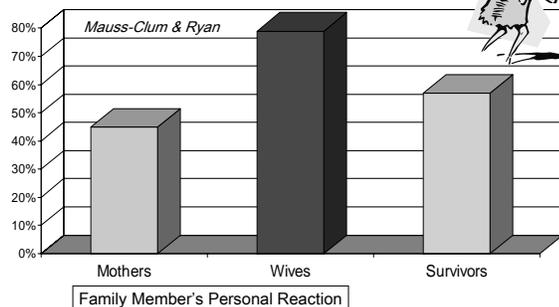
Unique Reactions of Wives

- ▶ 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

Depression After Brain Injury

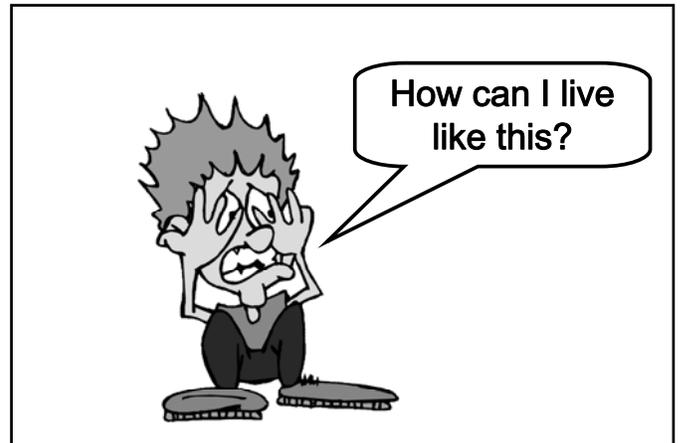
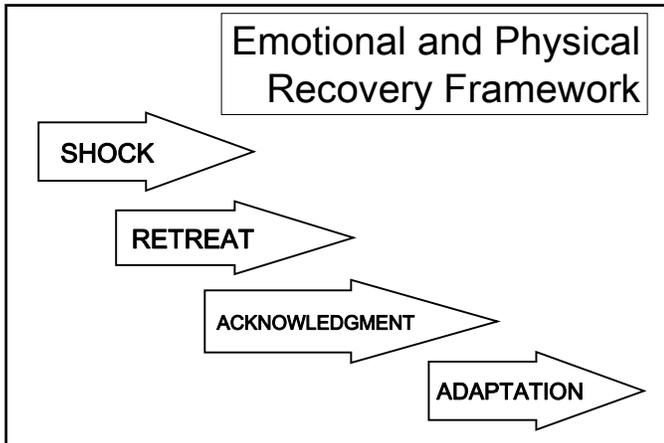


Family Member's Personal Reaction

Theories of Reaction and Adjustment to Illness



How do people normally react and adjust to injury or illness?



The Challenge of Living with a Neurological Disorder

the challenge of -

- ▶ appreciating
- ▶ living with
- ▶ adjusting to

unexpected and undesirable **change**

Emotional Adjustment after Brain Injury

- ⓪ "I'm just fine."
- ⓪ "What happened?"
- ⓪ "I can't afford to be hurt?"
- ⓪ "I can't live like this."
- ⓪ "I can't stand to live like this?:"
- ⓪ "Maybe I can find a way."
- ⓪ "Some things are OK, some are better."

Psychological Recovery Requirements

- ➡ arranging and building on successful experiences
- ➡ learning from experience and avoiding repeated failure
- ➡ successfully finding empathetic, accepting, supportive others

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Appreciating Change



I am just overwhelmed.
Help me understand what's
happening.



The Family Change Questionnaire

1. How did you feel when you first learned that your injured family member was hurt?
2. How did you feel when you realized that your injured family member was going to live.

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The Family Change Questionnaire

3. How did you feel when you began to recognize that the brain injury might have long-term effects?
4. How have other family members reacted to the injury and the injured person?



The Family Change Questionnaire

5. Have you made yourself available to provide more emotional support to your injured family member and other family members? If yes, how so?
6. Before the brain injury, what were the most important plans for your future and the family's future.

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The Family Change Questionnaire

7. How has the brain injury affected your plans for the future?
8. What responsibilities do you now have to care for your injured family member?
9. In what ways do you help your injured family member get back and forth to appointments?



The Family Change Questionnaire

10. Do you attend therapy and doctors' visit with your injured family member? Please explain.
11. Do you help your injured family member with filling out insurance, registration, medical, and disability forms? Please explain.

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The Family Change Questionnaire

12. Do you help your injured family member get authorizations for medical and rehabilitative care? Please explain.

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The Family Change Questionnaire

13. Have you taken over responsibilities from your injured family member or uninjured family members? If yes, what new responsibilities do you have caring for house or car, working, paying bills, and caring for children?

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The Family Change Questionnaire

14. Have you changed your work responsibilities or hours since the injury, so that you could help your injured family member or the family? Please explain.
15. How was your family's income affected by the injury?

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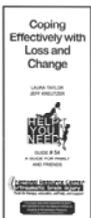
The Family Change Questionnaire

16. What new expenses are you facing because of the injury?
17. How have your sports, social, and recreational activities changed because of the injury?

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Things Often Heard From Family Members

each section of the guide has a different helping role



- I miss the way things used to be. 
- He's more like my child than my husband. 
- I have to be the mother and father of our children. 
- Now I have to take care of everything by myself. 
- Our 29 year old daughter is living with us again. 
- Why is my dad so different? 
- There's no way we can have another child now. 
- I feel like I am living with a stranger. 



Drastic Changes in Personalities, Relationships, and Responsibilities

- ... often follow neurological illness and injury.
- As a result many people have a mixture of feelings including sadness, fear, hopelessness, and frustration.

normalization



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Changes or Losses You May Have Noticed

- Drastic changes in the survivor's personality and abilities
- Increase in stress and responsibility
- Loss of support and companionship
- Decreased ability to work and have fun.
- Financial difficulties



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Changes or Losses You May Have Noticed

- Diminished sense of security.
- Worry about health problems and the future.
- Lessened confidence in yourself and others.
- Changes in plans for the future.
- Loss of social life and time for friends.

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How Have You Reacted To Changes or Losses?

- Crying spells
- Sleep problems
- Feeling guilty or worthless
- Low energy or getting tired easily
- Restless or difficulty sitting still
- Irritability or frustration



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How Have You Reacted To Changes or Losses?

- Eating a lot more or less
- Worry about the future
- Difficulty making decisions, concentrating, or remembering
- Not enjoying things like before
- Keeping to yourself
- Wondering whether life is worth living



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How can I live like this?

Coping Effectively with Loss and Change



Please help me find a way to make things better?

“There is in the worst of fortune the best chances for a happy change.”



Euripedes 485-406 B.C.

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Coping Effectively

- ★ Be kind to yourself and allow yourself and others time to adjust. 
- ★ Realize that your feelings are a common, normal response to a difficult situation. 
- ★ Appreciate the value of patience and persistence in reaching your goals. 
- ★ Recognize the natural human tendency to worry and focus on the negative.
- ★ Learn to focus on your successes, strengths, and resources.
- ★ Focus on what your loved one can do instead of what they can't. 

- ★ Be hopeful and say positive things (e.g., “We will make it through this,” “We’ve come so far.”) 
- ★ Take one step at a time, set goals for each day.
- ★ Avoid thinking about and making comparisons to how things were.
- ★ Give up some old responsibilities when you take on new responsibilities. 
- ★ Distract yourself with music, a book, a movie, or television.
- ★ Remain active, try to do things you enjoy.

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Coping Effectively

- ★ Think about the future you want and the best ways to get there.
- ★ Join a support group. Talk to other survivors for support and ideas for coping. 
- ★ Get to know this “different” person. Try to do fun things together.
- ★ Talk to and spend time with people who care about you.

- ★ Remember, you must take care of yourself so that you can better take care of the survivor and other family members. 
- ★ Give yourself breaks and learn when and how to ask for help. 
- ★ Learn about treatments, resources, and recovery. 
- ★ Talk with a professional about your concerns.

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Coping Effectively with Loss and Change

SARAH DEMM
JEFF KREUTZER

HELP YOU NEED

GUIDE #2

National Resource Center for Traumatic Brain Injury
Tools for therapy, education, self-help, and research

Brain injury often brings about drastic life changes. Feelings of sadness, hopelessness, frustration, and fears about the future may continue for weeks, months, or years. Many survivors want to feel better but don't know where to turn.



WHICH OF THE FOLLOWING HAVE YOU NOTICED?

Check all items that apply to you:

- Feeling down, blue, or hopeless
- Crying spells
- Irritability, restlessness
- Feeling guilty or worthless
- Getting frustrated easily
- Difficulty falling or staying asleep, or sleeping too much
- Low energy

- Appetite increase or decrease
- Can't stop thinking about problems
- Difficulty making decisions, concentrating, or remembering things
- Not enjoying things
- Avoiding others
- Wondering whether or not life is worth living

Scoring: The more items you check, the greater your distress and the more likely you are to need professional help.

COMMON LOSSES OR CHANGES

- ✗ Loss of health and well-being 
- ✗ Change in daily activities and responsibilities
- ✗ Loss of skills and abilities
- ✗ Less able to care for family members
- ✗ Loss of independence 
- ✗ Unable to live on your own or manage finances
- ✗ No longer able to drive or work
- ✗ Loss of confidence
- ✗ Can't go out by yourself or be left alone 
- ✗ Feeling alone and different than others
- ✗ No longer have an active social life, including dating

11

HOW CAN YOU HELP YOURSELF?

- Talk to and spend time with people who care about you.
- Allow yourself to ask for help.
- Realize that your feelings are a common, normal response to your experience.
- Be kind to yourself and allow yourself time to adjust.
- Take one step at a time, set goals for each day.
- Recognize the good things in your life and changes for the better.
- Focus on what you can do instead of what you can't.
- Be hopeful. Say positive things to yourself and others (e.g., "I will make it through this," "I've come so far").
- Remain active, do things you enjoy.
- Distract yourself with music, a book, a movie, or television.
- Try to find new activities and interests.
- Make a list of things that you are thankful for and qualities you like about yourself, refer to the list often.

- Build new relationships and improve old relationships.
- Join a support group. Talk to other survivors for support and ideas for coping.
- Appreciate the value of patience and persistence in reaching your goals.
- Apply coping strategies that have worked in the past.
- Learn about brain injury, resources, and recovery.
- Remember that others face similar or more challenging problems.

**If you're unable to help yourself...
Loss and change can cause severe depression, a serious problem. If you have questions or concerns, consult a professional.**

National Resource Center for Traumatic Brain Injury
Tools for therapy, education, self-help, and support
Virginia Commonwealth University Health System
P.O. Box 980542
Richmond, VA 23298-0542
(804) 828-9055
FAX: (804) 828-2378
www.neuro.pmr.vcu.edu

Layout and design — Debbie West

Important Notice

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



The National Resource Center for Traumatic Brain Injury
www.neuro.pmr.vcu.edu



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How to Overcome Loneliness and Build Lasting Relationships after Brain Injury



Dr. Jeff Kreutzer

Virginia Commonwealth University
Medical Center

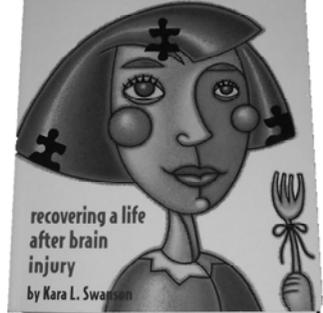


Photo by Kim Scholtz

"I wrote this book because the understanding of traumatic brain injury is limited even among medical professionals, much less the average 'civilian.' Every year, thousands of people unknowingly bid farewell to the lives they have known. Whether the diagnosis is termed severe concussion or traumatic brain injury or closed head injury, many survivors are finding out that sometimes when your life ends, you don't actually die."

Kara L. Swanson

I'll Carry the Fork!



Catching 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



Catching 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



Catching 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



Postinjury Relationship Changes

Loss of good relationships with friends, families, and coworkers may be one of the greatest casualties of injury.

- Best friends may disappear and family members may seem distant or unhelpful.
- Many survivors describe feeling lonely, isolated, and misunderstood.

Loneliness and Other Common Feelings after Brain Injury

- | | |
|------------------------------------|--|
| <input type="checkbox"/> lonely | <input type="checkbox"/> disrespected |
| <input type="checkbox"/> neglected | <input type="checkbox"/> disliked |
| <input type="checkbox"/> abandoned | <input type="checkbox"/> unworthy |
| <input type="checkbox"/> ignored | <input type="checkbox"/> different |
| <input type="checkbox"/> isolated | <input type="checkbox"/> unsupported |
| <input type="checkbox"/> rejected | <input type="checkbox"/> misunderstood |



Understanding is Important

No doubt that brain injury causes medical and physical problems.

- Brain injury also changes the way you think, feel, and act toward others.
- Understanding how brain injury has affected the way you feel and act is an important first step.

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



Understanding is Important

By better understanding your situation, you can learn to –

- improve old relationships
- develop new relationships
- feel better about yourself and your life

Have you found yourself saying ...

- “What happened to all the friends who came to visit me in the hospital?”
- “People seem to avoid me.”
- “My wife threatens to leave me at least twice a week.”



Have you found yourself saying ...

- "I wonder why no one returns my calls."
- "Seems like everyone at work has lost my phone number."
- "Other people don't want to be around me."



Have you found yourself saying ...

- "Nobody has any idea what I'm going through."
- "I can't relate to other people. It's easier to be by myself."
- "Seems like nobody wants to talk to me."



How Are You Treating Other People?

- Are you thinking a lot about how others treat you?
- Have you noticed that friends, family members, and co-workers are treating you differently?

Relationships Are A Two-Way Street



- Just as important is thinking about "How you treat other people"
- The way you act toward other people affects the way they treat you.

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

The "Are You Pushing Other People Away" Questionnaire

Are you pushing others away by.....

- focusing on what's wrong in your life and the world
- not listening when others speak, interrupting or talking too much.
- arguing or disagreeing
- not thinking about other people's needs or feelings



The “Are You Pushing Other People Away” Questionnaire

Are you pushing others away by.....

- talking only about yourself
- asking people very personal questions
- talking mostly about your brain injury and how your life has changed for the worse
- repeatedly rejecting other’s advice, suggestions, or offers of help



The “Are You Pushing Other People Away” Questionnaire

Are you pushing others away by.....

- touching people without asking if it’s okay or standing too near them
- talking without thinking or saying things that hurt other peoples’ feelings
- not using good hygiene



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

Why Many Survivors Feel Lonely Even When Around Family and Friends

- ⇒ Communication problems can make relating to other people very difficult.
- ⇒ After injury, some survivors have trouble talking to other people or understanding what others are saying.



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

Why Many Survivors Feel Lonely Even When Around Family and Friends

- ⇒ Many survivors worry about being different or less capable than others.
- ⇒ Feeling self-conscious can make it difficult to be around other people or seek new relationships.



Why Many Survivors Feel Lonely Even When Around Family and Friends

- ⇒ Pain and physical problems may make it harder to travel or visit other people.
- ⇒ Many survivors describe feeling nervous about being around other people.
- ⇒ Some survivors may be afraid of being hurt or rejected by others.

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

Why Many Survivors Feel Lonely Even When Around Family and Friends

- ⇒ Many survivors notice being irritable.
- ⇒ Some notice that they do or say things they regret later on.
- ⇒ People you know may avoid you because they are worried about what you might say or do.

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

Why Many Survivors Feel Lonely Even When Around Family and Friends

Your friends and family may feel uncomfortable because they don't know -

- ⇒ what to do or say
- ⇒ how to act
- ⇒ how to help



It wasn't what people said, mind you. It was what people didn't say that scared me. I would sometimes catch them trading "those looks."

Kara L. Swanson

Why Many Survivors Feel Lonely Even When Around Family and Friends

- ⇒ People generally make friends through work or being involved in social or recreational activities.
- ⇒ After injury many survivors stop working and may not be involved in sports, church or other activities.
- ⇒ People lose contact with co-workers and friends.

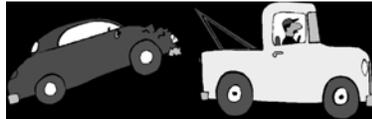
Why Many Survivors Feel Lonely Even When Around Family and Friends

- ⇒ Fatigue and loss of energy are common after injury.
- ⇒ Many say they don't have the energy to enjoy spending time with friends and family.



Why Many Survivors Feel Lonely Even When Around Family and Friends

- ⇒ Many survivors are not able to drive or work.
- ⇒ Lack of transportation and money can prevent you from joining others involved in activities.



Can I make and keep relationships if I don't have much money?

What you should be thinking....

Being kind doesn't necessarily mean spending lots of money

- We've made a list of ideas about how you can be nice to other people.
- Try out the ideas.
- Be creative, add and try out some of your own ideas.



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Be Kind to Others

- Don't be shy about complimenting others. Think about what you like about other people and tell them.
- Pick flowers or vegetables from your garden and give them to others.
- Share a comic strip, story, joke, magazine article or book.
- Hold the door or elevator for someone.
- If someone drops something, pick it up for them.



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Be Kind to Others

- Tell someone who helps you how much you appreciate them.
- Offer to baby sit for someone, take care of a pet, or help with their chores.
- Buy someone a snack, coffee, tea, or soda.
- Bake someone cookies, brownies, or a cake.
- Make a meal for someone.



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Be Kind to Others

- Listen carefully, patiently, and politely when other people are talking.
- Offer to keep someone company.
- Write someone a kind note, letter, or email.
- Draw someone a picture or make and send a friendly card by personal delivery or (e)mail.
- Mow your neighbors lawn, rake their leaves, or shovel their walk.



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Be Kind to Others

- When you find a helpful web site, share the address with others.
- Offer a ride to a friend or family member
- Offer to help someone carry their bags at the store.
- On a nice day, invite a friend for a walk or visit to the park.
- Drop a few coins in someone's parking meter if the time has run out.
- Donate blood.



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Be Kind to Others

- Share a stick of gum from every pack you buy.
- Help a friend or neighbor move in or out.
- Donate clothes, books, or other things you don't use to someone in need.
- Give family or friends home-made coupons they can use in for favors from you.
- Adopt a pet from a shelter.



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Be Kind to Others

- Offer to help someone organize or clean their house, basement, or garage.
- Offer to pick up your neighbor's mail and newspaper when they go away, and water their plants.
- Volunteer your time to your church, local library, Red Cross, or other community organization.
- Smile and say, "Hello" to people.



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Building Lasting Relationships

Learn to communicate in positive and helpful ways.

- Avoid being too quick to share negative thoughts and feelings with others.
- Work at finding and talking about the good things in your life and the world around you.

Building Lasting Relationships

Be careful not to be overcome by your problems and the challenges you face.

- Look for the good in other people as well as yourself.
- Remember that most people have a good heart and enjoy helping others.

Building Lasting Relationships

Before you speak, think carefully about what you want to say and how others might react.

- Try to say things in a way that brings a positive reaction.
- Avoid confrontation and try to be agreeable.

.... the dogs were just happy I'm home.... They've been sitting here all morning smiling and wagging their tails.

Kara L. Swanson

Building Lasting Relationships

Adopt a pet.

- There are many pets out there without anyone to take care of them.
- You can offer them a loving home and find yourself a grateful companion in return.



Building Lasting Relationships

Talk to and spend time with people who care about you.

- Write, call, or email your family and friends even if you're just saying "Hi."



Show a commitment to helping yourself.

- People will be more supportive and respectful if you do.

Building Lasting Relationships

No matter how you feel, don't let the basics go undone.

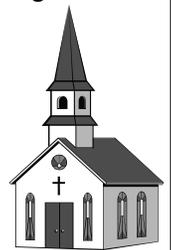
- Wear clean clothes, brush your teeth, comb your hair.
- People will have a better view of you and you'll feel better about yourself if you take care of your appearance.



Building Lasting Relationships

Don't lose track of your faith.

- You have a good chance of meeting understanding and kind-hearted people at your house of worship.



Building Lasting Relationships

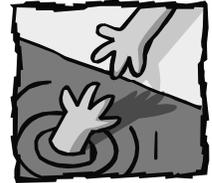
Learn about brain injury, community resources, and recovery.

- ❑ Contact the local brain injury association to find out about support groups and other resources available in your area.

Building Lasting Relationships

To help you get started in building better relationships

--- try to do at least one good thing for someone else every single day



Our ultimate wish, our ultimate vision is that no one ever has to face recovery from a brain injury. For now, the wish and the vision are simply that no one has to face it alone.

Kara L. Swanson

We don't know what tomorrow will bring. We have no idea what waits around the corner, whispering our name in the darkness. We can stay in our homes and refuse to be injured, refuse to be changed, refuse to be damaged.

Kara L. Swanson

Or we can live, even if unexpected circumstances throw us sinking curve balls. We can stop thinking we're untouchable. And we can surround ourselves with quality people who will help us and whom we will help, should fate put either of us on board the bus at its next stop.

Kara L. Swanson



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Major Challenges Faced by Family Members after Brain Injury

⇒ Communicating effectively



Faulty communication is pervasive and one of the greatest impediments to postinjury adjustment.



Therapists can provide a forum for all family members to appreciate and constructively discuss their needs, feelings, ideas, and plans.



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Factors Underlying Lack of Communication The Survivor's Point of View

"I am so confused. I just can't think or say what I mean."

"They just don't understand."

underlying emotions?

Factors Underlying Lack of Communication The Survivor's Point of View

"Maybe I'm just crazy."

"Why bother? Nobody seems to care."

underlying emotions?

Factors Underlying Lack of Communication The Family Member's Point of View

"He never listens to me anymore."

underlying emotions?

VCU Health System

**Factors Underlying Lack of Communication
The Family Member's Point of View**

"He's completely different. I can't talk to him."

"I feel like I'm the one with the injury."

underlying emotions?

Families in which nothing is ever discussed usually have a lot not to discuss.



Mason Cooley

The most important thing in communication is to hear what isn't being said.



Peter Drucker

VCU Health System

Communication Avoidance

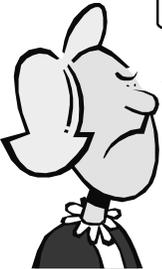
Family members may avoid giving the survivor negative feedback -

- ▶ to avoid confrontation, stress, being worn down
- ▶ to avoid adding to the survivor's negative self-esteem
- ▶ hoping the problems will go away soon or on their own



⇒ **Communication Failure**

If I tell him how I really feel he'll worry or be mad at me



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⇒ **Communication Failure?**

I refuse to tell you how I feel!

- ❑ May increase confusion, worry, paranoia.
- ❑ May be misperceived as anger or lack of caring.
- ❑ Non-verbal communication can not be avoided.



Good or Bad Advice?

- ❑ Family members often encourage the use of ineffective coping strategies...
- ❑ strategies that are personally effective for themselves in very different situations.
- ❑ Persistent bad advice only leads to feelings of discouragement and being misunderstood



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Conversation Stoppers

Things you might not want to say to a survivor.



“Stop worrying.”



“Stop worrying.
Everything will be OK.”



“Stop worrying.
Why do you worry
so much?”



“You look great.
When are you going
back to work?”

“I know how you feel.”



“You think about your problems too much. You would feel better if you didn’t.”

“You are just acting this way to get attention.”



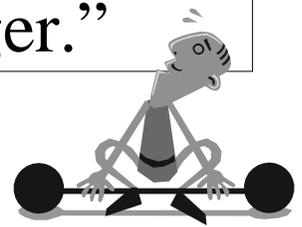
“Why can’t you be like you used to?”



“If you try hard enough everything will work out.”



“You just need to be stronger.”



“Everything happens for a reason.”

“Would you just snap out of it?”



Communication Questionnaire

Read each statement below and decide if each statement is True or False about you. Circle T for True or F for False.

- T F 1. My feelings change from day to day.
- T F 2. Nobody understands what I am going through.
- T F 3. I feel uncomfortable around other people.
- T F 4. I'm worried about what others think of me.
- T F 5. Nobody cares about me.
- T F 6. I have a hard time describing my feelings.
- T F 7. I don't want to burden people with my feelings.
- T F 8. I feel uncomfortable talking about my feelings.
- T F 9. I don't know where to turn for help.
- T F 10. I can't hide my feelings like I used to.
- T F 11. I'm afraid to show my true feelings.
- T F 12. I don't want to upset people by talking about my feelings.
- T F 13. I'm afraid to let my guard down.
- T F 14. I keep my feelings bottled up.
- T F 15. I don't know how I'm feeling.
- T F 16. I don't feel anything anymore.

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Brain Injury Family Intervention

What should I tell people about the injury?



Things to Think About Before Responding to People's Questions

- ✓ Remember you can make choices about what to tell people about your injury.
- ✓ Only tell people what they need to know and what you feel comfortable telling them.
- ✓ Keep your answers short, simple, and to the point.

Things to Think About Before Responding to People's Questions

- ✓ Remember you can always change the topic to something you feel more comfortable talking about.
- ✓ Politely decline answering or give little information if you do not feel comfortable talking about your injury.
- ✓ Talk to other survivors about how they deal with difficult questions.

Things to Think About Before Responding to People's Questions

- ✓ Tell people you trust what you would like to say about your injury and get their reactions.
- ✓ Make a list of the questions you find the hardest to answer. Talk to trusted family and friends about ways to answer the questions. Practice saying the answers ahead of time.

Things to Think About Before Responding to People's Questions

- ✓ Disclose the most personal information only to people you really trust – like family, close friends, doctors, and therapists.
- ✓ Before giving out personal information, ask the other person to agree to keep what you say in confidence.



Ways You Can Respond To Specific Questions

- ⊖ Q: "What happened?" A: "I was in an accident a while ago."
- ⊖ Q: "What type of medical care does he need?" A: "He sees his doctors every now and then."
- ⊖ Q: "How much longer will you need treatment?" A: "My doctors are helping me recover as quickly as possible."

Ways You Can Respond To Specific Questions

- ⊖ Q: "What are his current symptoms?" A: "He tires easily." (or) "He has to pay attention to things more carefully now."
- ⊖ Q: "How are you doing now?" A: "I'm getting better slowly but surely."
- ⊖ Q: "When will he be able to come back to work?" A: "We're working on a plan right now; I hope to know soon."



Remember, most people who ask about the injury are people who care about you.
Think about that before you reply.

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