

### The Greatest Challenges Families Face after Brain Injury (and how to overcome them)

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an injured person's point of view ...

"I lost my friends because they didn't know how to deal with my injury. Neither did I."

from the VA statewide community based needs assessment

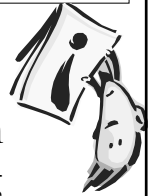
### Important Notice

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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### Major Challenges Faced by Families after Brain Injury

- ⇒ Appreciating and coping with change
- ⇒ Recognizing and coping with stresses and crises
- ⇒ Managing intense emotions
- ⇒ Avoiding guilt and blame
- ⇒ Taking care of one's self as well as the survivor



### Family Support Principles

- ▶ Brain injury causes drastic life changes for everyone in the family
- ▶ Most people want their old life back
- ▶ Well informed people do better
- ▶ Every person deserves respect
- ▶ Every person in the family is important



## Family Support Principles



- ▶ Each adult family member has the right to make choices, good or bad
- ▶ In the long-term, the family ends up taking the most responsibility for helping the patient
- ▶ You have to take care of yourself to effectively help other family members

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## Major Challenges after Brain Injury

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  - ⇒ Taking care of one's self (as well as the survivor)



### 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 .....              |

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### 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           |  |





## 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.



## 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?

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## 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.



## Coping with Losses and Changing Demands and Roles

- Realize that your feelings are a common, normal response to your experience.
- Recognize there is a natural human tendency to worry and focus on the negative.
- Learn to focus on your accomplishments, strengths, and resources.
- Think about the future you want and the best ways to get there.



## Coping with Losses and Changing Demands and Roles

- Be kind to yourself and allow yourself and others time to adjust.
- Remain active, try to do things you enjoy.
- Build new relationships and improve old relationships.
- Try to give up some old responsibilities when you take on new responsibilities.



## Remaining Patient and Learning to Live with the Idea that Recovery Takes Time

- Realize that recovery is a long process and solving big problems takes time.
- Try to view recovery on a daily basis.
- Avoid comparing things to how they were before the injury.
- Remember that taking on too much too soon can easily lead to failure.

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⇒ Remaining Patient and Learning to Live with the Idea that Recovery Takes Time

- ❑ Focus on accomplishments and progress instead of failures.
- ❑ Remember that no one is perfect and everyone makes mistakes. Try to learn from your mistakes to make the future better.
- ❑ Avoid pushing yourself too hard or putting yourself down.

⇒ Major Challenges after Brain Injury

- ⇒ Appreciating and coping with change
- ⇒ Recognizing and coping with stresses and crises



- ⇒ Managing intense emotions
- ⇒ Avoiding guilt and blame
- ⇒ Taking care of one's self (as well as the survivor)

**Stress Overload Signs**

Disorganization

- ❑ forgetting keys
- ❑ losing things
- ❑ making dumb mistakes

Dependency Fantasies

- ❑ daydreaming about spending a few days somewhere, even in the hospital - to sleep, read, be taken care of



**Stress Overload Signs**

Overwhelmed by Small Decisions

- ❑ can't decide what to wear
- ❑ stumped about what to have for lunch

Discouragement and Incapacitation

- ❑ desire to curl up in bed, pull covers up over head, sleep for a week



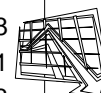
**Social Readjustment Rating Scale**

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



**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



### 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

### 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

### Major Sources of Stress for People without Brain Injury

- ☹ Lack of financial resources.
- ☹ Relationship difficulties.
- ☹ Work related problems.



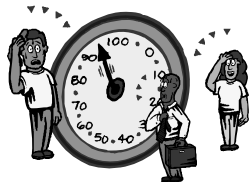
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### Managing Crises and Stress

- Check your "temperature" often.
- Practice effective problem solving. Brainstorm ways to solve problems and try out different solutions.
- Have a back up plan.
- Take time for yourself, do things you enjoy.

### Take Your Temperature Often

- How am I feeling?
- Am I upset?
- What am I worrying about?



### The 13 Item Stress Test

True or False?

- ▶ I have a lot to do.
- ▶ I have more to do than I can handle.
- ▶ I'm not being productive.
- ▶ I'm trying really hard but getting nothing done.
- ▶ I'm feeling unhealthy.
- ▶ I can't afford to take breaks for time off.
- ▶ I'm pushing myself too hard.



## The 13 Item Stress Test *True or False?*



- ▶ I don't sleep very well.
- ▶ Too many people are telling me what to do.
- ▶ I am not treating people well.
- ▶ I feel totally exhausted.
- ▶ Nobody is happy with what I do.
- ▶ I can't stand living like this.

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## Stress Management Worksheet



- What are the main sources of stress in my life?
- What do I do now that helps me manage stress more effectively?
- What do I do that makes it harder to manage stress?
- What can I do to better manage stress?
- Where should I start to make things better?

## ➡ Managing Crises and Stress

- Tell yourself to relax, breathe slowly and deeply.
- Close your eyes, imagine yourself in a pleasant situation or place.
- Keep up a healthy lifestyle - exercise, eat right, avoid caffeine, alcohol, drugs, and tobacco.
- Seek support from trusted friends and family.
- Talk to others about how they cope successfully.

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## To successfully manage the multitude of problems, remember ...

- You have more responsibilities now than before the injury
- You have lots of new sources of stress in your life
- Everyone has limits
- You will be less effective doing anything if you do too much
- Your emotional well being may be the greatest casualty of over-commitment



## ➡ Major Challenges after Brain Injury

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- ⇒ Taking care of one's self (as well as the survivor)



## The Feelings Checklist



### Directions

- ⇒ Take a moment to think about how you feel.
- ⇒ Check off the boxes next to the sentences that describe you.

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## The Feelings Checklist

- I often feel frustrated.
- I get angry easily.
- I don't like much about myself.
- I worry a lot.
- I have made many mistakes.
- I worry about the future.



## The Feelings Checklist

- I am lonely.
- I believe that I am at fault for many of our problems.
- I feel sad.
- People don't understand me.
- I feel overwhelmed.
- My feelings change from minute to minute.



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## The Feelings Checklist

- I get upset easily.
- Very few people care about me.
- I have many fears.
- I feel like I should be doing more.
- I'm disappointed in myself.
- I wish my life could be the way it was before.
- I am often grouchy.



## The Feelings Checklist Scoring and Interpretation



- The more items you've checked, the more intense your emotions are likely to be.
- To better understand your feelings, review the items you've checked and the ones you haven't.
- Is there a pattern to the items you've checked?
- Show your checklist to someone you know and trust. Do you agree on the items that should be checked.

## Managing Intense Emotions that You and Other Family Members Have

- As a first step, recognize your intense emotions. Keep a diary of your feelings.
- Recognize your power to control your emotions.
- Remember that having bad feelings will only make things worse. Instead, focus on solving problems one at a time.
- Under-react. Ask yourself if a problem is worth getting upset about. If not, then try to let it go.

## Managing Intense Emotions that You and Other Family Members Have

- Talk to trusted others about your feelings and positive ways to cope.
- Recognize the difference between what you think and how you feel.
- Strong emotions can undermine your best problem solving efforts.
- Avoid making decisions when you have strong emotions.

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## ⇒ Major Challenges after Brain Injury

⇒ Appreciating and coping with change



⇒ Coping with stress

⇒ Managing intense emotions

⇒ Avoiding guilt and blame

⇒ Taking care of one's self (as well as the survivor)

## Baby on Board

Wanting to get to work "extra early," Linda convinced her husband to drop their 11 month old daughter, Lilly, off at child care on his way to work. Distracted by a cell phone call, Paul went through a stop sign and was broadsided by a pickup truck. Lilly sustained a subdural hematoma and was hospitalized for six weeks, initially "hanging on by a thread." Paul was hospitalized overnight for observation and released. Before the accident, Paul and Linda had an enviable relationship. Afterward, they argued all the time, mostly about money, schedules, and responsibilities.

## Guilt and Blame Core Areas

1. family troubles and bad choices made well before the injury
2. causing or failing to prevent the injury
3. failing to help the patient get better
4. causing new family problems after the injury

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## Normalizing Guilt

Feeling discouraged about the past and having less hope for the future leads people to focus on mistakes. Some people blame themselves. Others get caught up blaming family members, professional, agencies, and organizations.

What a horrible thing you have done! You've ruined our lives.



What a horrible thing I have done! I have ruined our lives.

www.bifi.us

**Guilt is anger directed toward ourselves -- for what we did or did not do.**

Peter McWilliams

## Thinking Bad Things About Yourself

- ⇒ A way of punishing yourself.
- ⇒ Your negative feelings are a natural response to an unpleasant situation.
- ⇒ Punishing yourself won't make things better.
- ⇒ Enough bad things have happened to you and your family.



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## Guilty or Not Guilty?

- ❑ Sometimes I wish I was the one who was hurt instead.
- ❑ I should be doing more to help.
- ❑ I wish I would have done something to prevent the accident.
- ❑ What happened is my fault.



## Guilty or Not Guilty?

- ❑ I can't let this happen again.
- ❑ I have made many mistakes.
- ❑ Everyone else blames me for what happened.
- ❑ Now I get blamed for everything that goes wrong.



## Guilty or Not Guilty?

- ❑ I feel so bad about the way he treats me now. Still, he was the one who was hurt.



## ➡ Avoiding Guilt and Blame

- ❑ Recognize the dangers and sources of guilt and blame.
- ❑ Try to realize when you are blaming others or feeling guilty.
- ❑ Recognize that getting help from others may depend on the feelings you convey.
- ❑ Remember, you'll reach your goals much quicker with a positive attitude.



## ➡ Avoiding Guilt and Blame

- ❑ Make a commitment to strengthen your family and fight the temptation to blame others.
- ❑ Be careful not to become preoccupied with other people's faults and problems. Instead focus on what you can do to make things better now.
- ❑ Focus on positive, constructive approaches to problem solving.



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## "How Well Am I Taking Care of Myself?" Questionnaire

- T F 1. I try to get enough sleep at night.
- T F 2. I take time out to rest and relax.
- T F 3. I eat things that are good for me.
- T F 4. I have hobbies or other activities that I enjoy on a regular basis.
- T F 5. I get together with friends and family regularly.
- T F 6. I ask others for help when I need it.



## "How Well Am I Taking Care of Myself?" Questionnaire

- T F 7. I avoid taking on new projects or responsibilities when I am stressed.
- T F 8. I talk to people I trust about my worries and concerns.
- T F 9. I have a fitness or exercise program.
- T F 10. I set small goals for myself that are meaningful.
- T F 11. I give myself credit for taking small steps forward and reaching my goals.



## "How Well Am I Taking Care of Myself?" Questionnaire

- T F 12. I monitor my stress level and emotions and seek support when I need it.
- T F 13. I avoid alcohol and drugs.
- T F 14. I ask others to take on responsibilities when I am not able to handle them.
- T F 15. I monitor my health and seek medical care when needed.
- T F 16. I recognize my limits and adjust my activities accordingly.
- T F 17. I let others help me.



## Taking Care of One's Self as Well as the Survivor

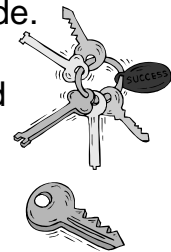
- Realize that injury affects the whole family.
- Remember, you must take care of yourself so that you can better take care of the survivor and other family members.
- Think about what you need to be healthy and strong.
- Give yourself breaks and learn when and how to ask for help.



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## Fundamentals for Success

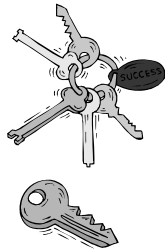
- ▶ Recognize the benefits of hope and a positive attitude.
- ▶ Be patient and persistent.
- ▶ Get better by learning and trying.



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## Success Fundamentals

- ▶ Create or find a supportive environment.
  - ▶ Live according to your good values.
  - ▶ Define success in your own terms.
- 



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