

To Root & To Rise

ACCEPTING BRAIN INJURY

Carole J. Starr, M.S.

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This excerpt contains the following sections from the
print version of
To Root & To Rise: Accepting Brain Injury

- Table of Contents—page 3
- Introduction—page 4
- Chapter 1—Defining Acceptance—page 12
- Appendix—A List of all the ‘Making it Your Own’ Workbook Topics & Pages—page 17
- Index—page 20
- About the Author—page 25

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Table of Contents

Preface--Uprooted.....	vii
Introduction	xv
1. Defining Acceptance	1
2. The First Year: If I Knew Then What I Know Now	7
3. Word by Word: The Journey toward Acceptance.....	21
4. Facing Forward: Overcoming Denial.....	31
5. Beyond Denial: Lost in the Middle	47
6. Resolutions for Brain Injury Survivors	55
7. Word Power: Change your Words, Change your Brain.....	63
8. Crafting a New Life	79
9. The Brain Injury Portfolio: Documenting Progress, Pride & Purpose	107
10. Transforming Grief: Coping with Brain Injury Anniversary Day	117
11. Oh, The Things People Say	127
12. In a Different Light The Power of Humor	139
13. A Glimmer of Good: Finding Silver Linings.....	145
14. Choosing Gratitude	153
15. If At First You Don't Succeed, Letting Go May Be What You Need.....	167
Conclusion.....	185
Appendix--List of Workbook Topics	189
Acknowledgments	193
Bibliography.....	195
Index	197

Introduction

*We do not learn from experience...
we learn from reflecting on experience.*

~John Dewey

This book is a reflection on my experience as a brain injury survivor. I've spent a lot of time thinking deeply about my journey and how I can use what I've learned to help others living with brain injury. I didn't think I could ever accept this changed life, but I eventually did. Now I'm sharing the strategies that worked for me. I'd like this book to offer hope to others who are struggling to come to terms with brain injury. Reaching acceptance may not be easy, but it is possible.

Why Acceptance?

In my opinion, accepting brain injury and its impact on our lives is one of the most important tasks we face as survivors. It can also be one of the most difficult. When your life has been uprooted by brain injury symptoms and you don't recognize the person in the mirror anymore,

acceptance of the new you can seem like an impossible task. It's hard to imagine that life after brain injury can ever be happy or purposeful.

It seems unlikely, but coming to acceptance can be a key that opens the door to happiness and purpose after brain injury. Even though acceptance doesn't change the reality or the challenge of brain injury symptoms, it can change how you experience those symptoms. Acceptance is like looking at the world through a different lens. Coming to terms with brain injury can mean the difference between a mournful life spent looking backward at what was and a meaningful life spent moving forward with what is.

Coming to acceptance is a process, a journey. The poems on the next two pages describe some of that journey. They're also the inspiration for the title of this book.

I wrote the first poem, *Phoenix*, about nine months after my brain injury, when fear and uncertainty about the future loomed large. I wrote the second poem, *Phoenix—Revisited*, about four years post-injury, when acceptance was just beginning to take root in me. Although I wrote these poems from a deeply personal place, it's my hope that they speak to you too, wherever you are in your own journey.

Phoenix

At the end
of my street,
on the edge
of the marsh,
stands a tree.

She does more than stand.
She commands
your attention,
full of her fall flash.
No ordinary red, orange and yellow for her.
She sparkles with crimson, magenta, umber & ocher plumage,
A rising phoenix with outstretched wings,
confident and bold.

But her time is brief.
Perhaps her colors burned too brightly.
Her plumage dulls,
darkens
and drops,
exposing frail, gray bones,
pale and naked.

Who
is she now?

The tree will have her time again.
Will I?

Phoenix—Revisited

At the end
of my street,
on the edge
of the marsh,
stands that same tree.

The haunting, hoping desire,
‘The tree will have her time again.
Will I?’
finally answered with a quiet confidence—
No.

For that is the wrong question.
I am no longer that tree.
I am a new being, on a new journey,
spinning, sailing, falling, flailing, writhing, wailing,
Landing
in my own soft space.
Safe
to root and to rise,
to live,
this new time.

The Story of this Book

Reaching acceptance is a process; writing a book is too. I started working on this book about five years after my brain injury. At this writing in 2017, I'm approaching eighteen years as a survivor. It's taken me so long to complete this project for a couple reasons. First, my brain injury symptoms slowed the process down and increased the challenge. I'm no longer able to write and think quickly or consistently, so everything takes more time.

Second, and more important, I had to be ready to write this specific type of book. I knew from the start that I didn't want to tell my brain injury story beginning to end, in chronological order. There are already many excellent books out there that cover the brain injury survivor experience in that way. I wanted to write a different kind of book.

Because I've always been a teacher, I tend to think about everything in terms of learning and lessons. I like to look for the bigger picture and the meaning in experiences. I wanted to use my story as a vehicle to share what I'd learned as a brain injury survivor. I envisioned that each book chapter would be a different lesson or strategy. I wanted the final product to be a book of wisdom about living with brain injury.

During my first several years of writing, I produced many half-finished chapters. I knew I wanted to expand them beyond telling only my brain injury story, but I didn't have enough insight to do that yet. It takes many years in life to gain wisdom. Similarly, it takes many years of living with brain injury to be able to look back and see the bigger picture of that experience.

From 2010-2015, I didn't work on the book. I felt stuck and couldn't seem to turn my vision into reality. Instead, I focused on what I could do with my ten-plus years of experience as a brain injury survivor.

I co-founded the survivor education, advocacy and peer mentoring group Brain Injury Voices. I led workshops, advocated for brain injury issues, facilitated a support group and mentored other survivors. I wrote two keynote speeches on happiness and resilience and delivered them at brain injury conferences. My dream of writing a book didn't die, but it did recede into the background.

I didn't realize it at the time, but even though I wasn't working on this book, I was laying its groundwork. Through all those activities, I was learning how to look at my brain injury journey and see patterns in how it had unfolded.

At the end of 2015, I realized what the book needed—an overall theme to the individual chapters. In a big 'Aha!' moment, I knew that acceptance was that theme. There are times when life snaps into sudden focus. This was one of those times.

I realized that I wanted to help other survivors move toward acceptance. Because I'd struggled so much with acceptance before finding my own peace, I wanted to share what I'd learned. I also knew that I'd gained enough distance from my own acceptance journey to be able to see the patterns in it and to write about the process. I was finally ready to write the book I'd envisioned back in 2004. In 2016, I rededicated myself to writing the book and finished it in 2017.

The Structure of this Book

I've put the chapters of this book in an order that makes sense to me, based on my own brain injury acceptance journey. However, you don't have to read them in that order. Each chapter is a separate essay, not dependent on what comes before it. For example, you don't have to read chapters one and two in order to understand chapter three. I did that on purpose, so you can read this book in any order that makes sense to you. It's about whatever is most helpful for you, wherever you may be on your brain injury journey.

The chapters have also been designed with you, the brain injury survivor, in mind. Most of them are relatively short, since many of us struggle with reading and remembering long texts. The longer chapters have been divided into sections, so they can be processed one small chunk at a time. The font size is larger than average, to improve the readability for those with visual issues. There are also spaces between each paragraph, to reduce the overwhelmed feeling that can come from looking at too much text. I made these design decisions to make this book as readable as possible for brain injury survivors.

As survivors, each of us is on a journey that is uniquely ours. I hope that sharing my brain injury acceptance journey will help you navigate yours. Powerful learning can happen from reading about another survivor's experience.

However, when you can also think, write and talk about your own brain injury experience, the learning multiplies and becomes even more powerful. Therefore, in the spirit of learning by reflecting on experience, I've structured this book as a workbook.

The workbook format allows you to take my experience of accepting brain injury and make it your own. There are questions for thought or discussion in each chapter, as well as space to write your answers, if you choose to. The questions are designed to make you think about your experience. They're also a way for you to record your own brain injury acceptance journey.

Use the questions in whatever way works best for you. You can think and write about them on your own or discuss them with family, friends or medical professionals. You can also answer the questions in a group setting, such as a brain injury support group. Some of the ideas in this book may be challenging, so I encourage you to take whatever time and help you may need to work through them.

Let's begin the journey.

Defining Acceptance

*The world as we have created it is a product of our thinking.
It cannot be changed without changing our thinking.*

~Albert Einstein

Acceptance is an abstract concept that's hard to define. What does accepting brain injury really mean? What does acceptance look like? How do you know when you've accepted your injury?

Acceptance is a term that gets thrown at brain injury survivors a lot. Perhaps you've heard statements like 'You have to accept what's happened to you' or 'It's time to accept your brain injury and move on'. Statements like that make it sound so easy. We all know it's incredibly difficult. The first step in moving toward acceptance is being clear about what it is. Let's start by defining it.

Acceptance is acknowledging the reality of a situation. It's about recognizing the difference between what can be changed and what can't. It's being able to say—without any internal resistance—'It is what it is'.

There are many misconceptions about acceptance. When I first heard the word acceptance, here's what I thought about it:

- Acceptance means I have to give up on healing my brain.
- Acceptance means that where I am now is where I will always be.
- Acceptance means being resigned to the fact that brain injury has ruined my life forever.
- Acceptance means that I have to like having a brain injury and to welcome the symptoms into my life.

It turns out that my ideas about acceptance were wrong. Here's what I've learned about brain injury acceptance:

- Acceptance isn't a one-time event. It happens in many small pieces over time.
- Acceptance isn't agreeing with or liking what's happened to me. I can wish my brain injury never happened while still accepting the symptoms and their impact on me.
- Acceptance isn't giving up on making progress. It's letting go of trying to get back to the old me. It's about becoming the new me.
- Acceptance isn't the end of my brain injury symptoms, but it is the end of suffering emotionally when they affect my life.
- Acceptance is knowing that brain injury has changed me forever. I will deal with brain injury symptoms for the rest of my life.
- Acceptance is acknowledging my limitations—what I can and can't do—and working with them instead of fighting against them.

- Acceptance is recognizing when I need help and listening to advice from the people who know me best.
- Acceptance is letting go of what I can't control and focusing my energy on what I can control.
- Acceptance is being ok with where I am right now, even as I strive for more.
- Acceptance is focusing on what I can do.
- Acceptance is recognizing that even though my life is different than I thought it would be, it's not ruined. Life with a brain injury can still be good.
- Acceptance is a courageous choice I make for myself.

My favorite definition of acceptance comes from one of its synonyms: the word acquiescence. It's derived from the Latin word that means 'to take rest in'. We've reached acceptance when we've found our own place of peace, even as the storms of brain injury swirl all around us.

Defining acceptance is the beginning of the journey. Now that you know where we're going, it's time to focus on moving in that direction. The rest of this book is focused on strategies that can lead toward accepting brain injury.

Making it Your Own

Defining Acceptance

Have you had any of these misconceptions about acceptance?

- Acceptance means I have to give up on healing my brain.
- Acceptance means that where I am now is where I will always be.
- Acceptance means being resigned to the fact that brain injury has ruined my life forever.
- Acceptance means that I have to like having a brain injury and to welcome the symptoms into my life.

Which of these statements about brain injury acceptance stand out to you the most?

- Acceptance happens in many small pieces over time.
- Acceptance isn't agreeing with or liking what's happened to me.
- Acceptance isn't giving up on making progress.
- Acceptance is the end of suffering emotionally when brain injury symptoms affect my life.
- Acceptance is knowing that brain injury has changed me forever.
- Acceptance is acknowledging my limitations
- Acceptance is recognizing when I need help

- Acceptance is letting go of what I can't control and focusing my energy on what I can control.
- Acceptance is being ok with where I am right now, even as I strive for more.
- Acceptance is focusing on what I can do.
- Acceptance is recognizing that even though my life is different than I thought it would be, it's not ruined.
- Acceptance is a courageous choice I make for myself.

Taking it Further

What's one thing you learned from reading this chapter?

What action are you ready to take?

Appendix

A List of all the 'Making it Your Own' Workbook Topics and Pages

Chapter 1

Defining Acceptance4

Chapter 2

Why am I so Tired?..... 11

Why Don't People Believe Me? 15

Why Do I Need Strategies? 18

If I Knew Then What I Know Now..... 20

Chapter 3

The Journey toward Acceptance..... 28

Chapter 4

Recognizing Denial 34

Learn about Brain Injury 37

Connect with Other Survivors 40

Reflect on Failure 43

Overcoming Denial 46

Chapter 5	
Beyond Denial	53
Chapter 6	
Resolutions	60
Chapter 7	
Use Inspirational Words	67
Repeat Positive Affirmations	71
Talk Back to Negative Language	75
Chapter 8	
Get to Know your New Self.....	82
Listen for the Wisdom of the Little Voice Inside	86
Take Action	89
Start Small, Find Success and Build on It.....	91
Find Ways to Give to Others.....	95
Take Risks: Feel the Fear and Move Forward Anyway	98
Make Something: Create Meaning out of Suffering.....	101
Crafting a New Life.....	103
Chapter 9	
The Brain Injury Portfolio	115
Chapter 10	
Transforming Grief.....	123
Chapter 11	
Oh, The Things People Say.....	136

Chapter 12	
The Power of Humor.....	143
Chapter 13	
Finding Silver Linings.....	150
Chapter 14	
Choosing Gratitude.....	161
Grateful for Brain Injury?!.....	165
Chapter 15	
Letting Go—Applying the River Metaphor.....	169
Resistance to Letting Go.....	171
Recognizing when it’s Time to Let Go.....	173
Acknowledge the Reality of Brain Injury.....	175
Stop Resisting Brain Injury Symptoms	178
Strategies for Letting Go	182

Index

Acceptance

Definition of, 1-3
Importance of, xv, xvi
Moving forward, xvi, 42, 56-57, 96,
112, 119, 122, 139, 149, 179, 181
Misconceptions about, 2
New normal, 17, 21, 56
Spiral journey, 21-23
 Denial and lack of awareness, 24
 Feeling lost and confused, 24-25
 Sadness, anger and loss, 25
 Acceptance growing, 25-26

Action

Acceptance as action, 57
And success, 90
Importance of, 87-88
Words versus actions, 64

Advocacy

Educating others, 96-97, 135

Affirmations

Benefits of, 69, 133
Definition of, 69, 133
Examples of, 69, 133
How to use, 70

Brain Injury

Invisible disability, 13, 129
New self
 Getting to know, 47, 51-52, 80-81,
131, 186
 Hating, xii, 25, 48, 80, 109, 118, 163
 Versus old self, vii, xiii, 26, 42, 48,
50-51, 56, 84, 107, 118
 Rehab, 16-17, 38, 94, 176
 Support group, xxii, 39, 58, 97
 Symptoms—List of, 178
Symptoms
 Attention & concentration, xi,
13, 87-88
 Balance, viii, xi, 8, 179

Brain Injury, continued

Symptoms, continued

- Confusion, viii, xi, xii, 8, 24, 32, 81, 158
- Difficulty making decisions, xi, 8, 32
- Emotional issues, xii, 8-9, 13, 22, 25, 64, 155, 157, 176
- Fatigue, x, 8-10, 13, 22, 32, 51, 65, 87, 141, 158, 179
- Headache, x, 8
- Light sensitivity, ix, 13, 32, 179
- Memory, ix, x, xi, xii, xxi, 32, 64
- Overload, xii, 176-177, 179
- Sound Sensitivity, xi, xii, 8-9, 13, 32, 176, 179

Choices

- Choosing acceptance, 3
- Choosing gratitude, 157
- Choosing happiness, 180
- Choosing humor, 140
- Choosing life-affirming activities, 120-121
- Choosing to make meaning, 99
- Choosing to move forward, 164
- Choosing to take risks, 96-97

Comparisons

- Fair, 120
- Unfair, 57-58, 107, 109, 118-119, 133
- Ways to stop comparing, 110-112,

Denial

- Defining, 31
- Overcoming, 35-36, 38-39, 41-42
- Recognizing, 24, 32-33, 80, 174
- Types of, 32

Failure

- At return to old life, 24, 33, 65, 174
- Feeling like a, xii, 9, 69, 108
- Impact of, 17, 73, 90, 96, 167
- Reflecting on, 41-42, 58, 172, 174

Focus

- On the present, the right now, 3, 17, 26, 51, 69, 81, 84, 112, 148, 154, 179-181
- On what you can control, 3, 57, 129-130, 139, 146, 157, 181
- On what you can do, 3, 17, 19, 26, 58, 90, 107, 111-112, 130, 139, 147, 179

Giving to Others

- Benefits of, 93-94
- Examples of, 93

Gratitude

- Benefits of, 153-155, 157, 159
- Defining, 154
- Keys to, 142, 158-160, 164
- Model of, 156-157, 163

Gratitude, continued

Resistance to, 155-156
Ways to express, 159-160

Grief and Loss

Grief triggers, 57, 80, 108-109, 117-118, 176
Loss of self, xiii, 24-25, 47-48, 55-56, 128, 145
Recognizing grief, 25, 118, 153
Transforming grief, 25-26, 50-51, 118-122, 148

Happiness

Finding, xvi, 26, 79-80, 93-94, 102, 179-180

Help from Others

Importance of, xiii, xxii, 2, 17, 38-39, 41, 45, 52, 65, 73, 80-81, 90, 110-111, 113-114, 118, 120, 134, 148, 158, 180-181
Resisting, xii, 33, 81

Humor

Benefits of, 140, 142
Choosing, 140
In brain injury, 141-142

Learning

About brain injury, 35-36, 132, 186
From brain injury, xxi, 51, 163, 181, 186
From failure, 41-42, 58, 174
From peers, 19, 38-39, 133

Letting Go

Benefits of, 174, 179
Definition of, 167, 170
Resistance to, 170
Signs it's time to let go, 172
Stages of, 174, 176-177

Living a Good Life

Possibility of, 3, 26, 58, 170, 186

Meaning

Finding, 51, 99-100, 146, 186

Mindsets

Importance of, 55-57
Examples of, 57-58

Poems

Phoenix, xvii
Phoenix—Revisited, xviii

Portfolio

Benefits of, 112
How to create, 113-114

Pride in Oneself

Finding, 81, 107-108, 110-114

Progress

Celebrating, 57, 119-120
Measuring, 2, 26, 51, 58
Recording, 27, 107-114

Purpose

Finding, xvi, 26, 96-97, 99-100,
148-149

Recording the Journey

Benefits of, 26
Challenges of, 22
How to, 26-27

Risks

Examples of calculated risks, 97
Impulsive vs. calculated risks, 96
Pushing boundaries, 96-97

Self-Esteem

Building, 88, 90, 93, 96, 107, 155

Self-Talk

Danger of negative words, 64, 73
Overcoming negative self-talk, 73-
74
Positive words, 65-66
Power of, 63-64

Silver Linings

Examples of, 65, 147-148
Finding, 142, 146-147
Value of, 146, 149

Strategies

Importance of, 17, 38-39
Resistance to, 16, 33, 38

Strategy List

Affirmations, 70
Anniversaries, 119
Calculated risks, 97
Creating a new life, 79
Gratitude practices, 160
Humor in brain injury, 142
Keys to Gratitude, 158, 164
Letting Go, 181
Life-affirming activities, 121
Loss of self, 52
Making meaning, 99
Negative self-talk, 65
Overcoming denial, 35

Strategy List, continued

Portfolio, 113-114

Recording the journey, 27

Silver Linings, 149

Words that Hurt, 131

Success

Importance of, 17, 38, 51, 57, 88,
90, 110, 112

Words that Hurt

Examples of, 9, 13, 63, 128, 156

Impact of, 13-14, 64, 128-129

Responding to, 65-66, 69-70, 73-
74, 131-135

Workbook

About, xxi, xxii

List of topics, 189

ABOUT THE AUTHOR

Carole J. Starr has a master's degree in Adult Education. In June of 1999, she was 32 years old, and living a busy life in her home state of Maine. She was building a career as an educator and spent much of her free time playing the violin in a community orchestra and singing soprano in a chorale. She loved to travel and enjoyed spending time with her family and friends.

That life ended in July of 1999, when Carole sustained a brain injury in a car accident. She had to give up her teaching career and her classical music hobby. Carole grieved the loss of her old life and her sense of self. It took her many years to accept her brain injury and the new person she became. She's reinvented herself by focusing on what she can do, one small step at a time.

Carole now delivers inspiring keynote speeches at brain injury conferences. She's also the founder and facilitator of Brain Injury Voices, an award-winning survivor education, advocacy and peer mentoring volunteer group in Maine. She wrote *To Root & To Rise* to share what she's learned about accepting an unexpected new life. Through these activities, Carole has found a new way to be a teacher. She is happy again, even while living with a disability.

Please visit the websites below to contact Carole, watch videos of her keynotes, or learn more about Brain Injury Voices.

StarrSpeakerAuthor.com

BrainInjuryVoices.org