

APPENDIX A: AN ANNOTATED BIBLIOGRAPHY OF GOOD BOOKS, CHAPTERS, AND ARTICLES ON HEAD INJURY REHABILITATION AND RECOVERY

As they say, keep it simple, stupid! It would be stupid of us to recommend complicated books filled with twenty-dollar words before first recommending a set of basic readings in plain language:

1. Head injury: The facts, 2nd edition by Gronwall, Wrightson, & Waddell (1998). New York: Oxford University Press. While there are a number of “introductory” books about brain injury, this is the one written by top professionals. It is somewhat slanted toward the system of care in Australia, so do not be surprised that some of the services they describe do not match what is available here.
2. Over My Head by Claudia Osborne (1998). Kansas City: Andrews McMeel Publishing. This is the only survivor autobiography I recommend. Claudia Osborne is a physician who struggled with her head injury on her own for months before turning to one of America’s top treatment programs. This book is wonderfully honest, an “inside” view of what it is like to not realize that you have a head injury, and how therapy and life experiences slowly bring a person to awareness and readiness to adapt.

Learn as much about the brain as you can. The more you learn, the clearer recovery issues become. What I have done here is to create a series of books for you that begin with books you could pick up and start reading easily. They get gradually more complicated. There is no denying that much of the important information about the brain is only available in difficult books, but if you start with the easiest ones, and make heavy use of a medical dictionary along the way, you will find that you can make sense of harder and harder books as you get more knowledgeable.

1. How Brains Think by William Calvin (1996). Calvin is one of America’s top brain biologists, but he has a remarkable knack for explaining the complicated systems of the brain clear and simple terms.
2. Lovers, Liars, and Heroes by Stephen Quartz and Terrence Sejnowski (2002). Written in plain English, this is a very thorough story of current information processing concepts about the brain, including some thought-provoking ideas about brain evolution.
3. The Executive Brain by Elkhonon Goldberg (2001). Luria’s major student explains the workings of the part of the brain that is most vulnerable to traumatic brain injury. This book is delightfully easy to read and vivid.

4. Descartes Error by Antonio Damasio (1994). Is emotion the enemy of rational thought? That is what Descartes claimed. Damasio takes the opposite tack, and supports it with research results. This is a wonderful book full of interesting examples and references to literature and the arts.

5. Human Nature in Light of Psychopathology by Kurt Goldstein (1963). This book is a little harder to read, but it is the most readable to the books written by a remarkable man who was the first to explain how the mind and the brain affect one another. Many modern brain experts root their thinking in Goldstein's ideas.

6. Emotional Intelligence (1995) and Social Intelligence (2002) by Daniel Goleman. These are both books written for the popular press, so they are pretty readable. Both books summarize a lot of recent scientific research on the brain's special capabilities reasonably well. Not science, but the next best thing.

7. Two Sides of the Brain by Sidney Segalowitz (1988). The topic of "left brain versus right brain" has entered pop culture in the form of some terrible books. This one is accurate and written by an expert.

8. The Cerebral Symphony by William Calvin (1989). New York: Bantam Books. Beautifully written, takes its time getting to the point, but you leave with a better understanding of the brain as a total system.

9. Wet Mind by S. Kosslyn & A. Koenig (1992). This is written at a college difficulty level but it covers the emergence of issues in cognitive science with considerable wisdom.

10. On the Self-Regulation of Behavior by Charles Carver & Michael Scheier (2001). This is a complete book on the social psychology of information processing. The ideas are complex, sharp, and sage.

11. In Search of Memory by Daniel Schacter. I am not crazy about this book, and it spends too much time talking about non-brain-injury related memory issues, but Schacter is a memory expert and he does tell the story clearly, so this is a decent read.

This is where the difficulty level starts to get higher. These are all at least college-level books. I recommend them because they are worth the effort to decode.

1. Cognitive Neuroscience by Gazzaniga, Ivry, & Magnun (2002). This is a mid-level psychology textbook and so fairly tough to read, but it does provide a very detailed and sensible survey of information about the brain from laboratory research studies.

2. The Working Brain by A. R. Luria (1973). This book is as close to a modern "Bible" of how the brain works as there is. It focuses on explaining the brain's networks, and goes into considerable detail. The main sections are remarkably easy to read given that Luria was a Russian neurologist and neuropsychologist. Passages that go into great detail

about Russian psychology and about the history of neurological concepts are impossible to read, and can be skipped without losing the meaning of the chapters.

3. Plans and the Structure of Behavior by G. Miller, E. Galanter, and K. Pribram (1960). This book launched the “cognitive revolution” in psychology by explaining a way to understand how the brain processes information. This is a very difficult read, as it is written in technical language throughout.

4. The Mind and the Brain by Jeffrey Schwartz and Sharon Begley (1999). This out-of-the-mainstream book by a UCLA Neuropsychiatric Institute staff member explores the ways in which mental effort can be used to conquer varied brain disorders.

5. Principles of Neuropsychological Rehabilitation by George Prigatano (1999). You cannot be in Who’s Who without reading at least one book by Prigatano. His most general book cuts a wide swath in explaining how rehabilitation involves psychotherapy.

6. Awareness of Deficit After Brain Injury by George Prigatano and Daniel Schacter (1991). Reading this one will get you into Who’s Who a second time. This is must reading to understand why it is so hard to education people about the traumatic deficits.

7. Human Memory by Allan Baddeley (1992). Baddeley is a top British memory researcher who popularized the concept of working memory that is now used by everyone.

8. The Organization of Behavior by Donald O. Hebb (1949). Strictly for brain history buffs--this is the book that started modern thinking about how the brain works as a set of networks.

9. Cognitive Rehabilitation by McKay Moore Sohlberg and Catherine Mateer (2001). These two authors wrote the original encyclopedia on how brain rehabilitation is done. The quality of their work is consistently excellent, and in this book they cover almost everything except how to harness motivation.

10. How to do cognitive rehabilitation therapy. Malia, K., & Brannagan, A. (2005).

Surrey, England:
Brain Tree Training. Kit Malia was kind enough to send me a copy of their book. It is an amazing scrapbook of simple, useful bits of information and wise sayings about how to do brain rehabilitation. It is the perfect complement to Sohlberg and Mateer for the beginning student.

Here are the most difficult books for those who are willing to pound their brains into tapioca in the search for high-tech wisdom about the brain and about doing therapy.

1. Principles of Cognitive and Behavioral Neurology by M. Marsel Mesulam (2000). Mesulam is virtually impossible to read, but he also has by far the most advanced model of the brain presented in any textbook.
2. Languages of the Brain by Karl Pribram (1971). Compared to Pribram, Mesulam is like A. A. Milne. Pribram could well be the genius of our generation. If you can figure out this book, we have a matching set of Karl Pribram beer mugs to award.
3. Principles of Frontal Lobe Function, edited by Donald Stuss and Robert Knights (2002). There is no better collection of major theories about this part of the brain.
4. The Parietal Lobes by MacDonald Critchley (1953). 1953? Yes--no one has written a scholarly book since this old gem. Critchley only has part of the picture, but he understands that part thoroughly.
5. The Neuropsychology of Anxiety by Gray and McNaughton (2000). Curiously, this book is neither about neuropsychology nor is it particularly about anxiety. Instead, it is a explains how the emotional system and the cognitive control center communicate.
6. Affect Regulation and the Origin of the Self by Allan Schore (1994). This book has enough information in it to pickle your brain completely. It explains how brain development and early social experience hard-wire your personality.
7. Cortex and Mind (2005) and Memory in the Cerebral Cortex (1999) by Joaquin Fuster. Fuster is a top laboratory scientist with a genius mind for theory. He is easier to understand than Pribram. I wish he were as smart, but at least he's close.
8. Brain and Perception by Karl Pribram (1993). If you are not yet ready to commit hara-kiri from all of this tough reading, I promise you that this Pribram book will push you right over the edge.
9. From Neuropsychology to Mental Structure by Tim Shallice (1988). It may seem like Shallice is trying to make this hard to read on purpose, but I really think he can't write any better than this. The ideas are profound.
10. Ego Psychology and the Problem of Adaptation by Heinz Hartmann (1938). Hartmann took Freud's system and gave the ego the ability to cope. Brilliant!
11. The Collected Works of John Hughlings Jackson (1958). If it was a good idea, you can be sure that Jackson came up with it first, a hundred years before anyone else. We are still learning from him.

Many neuropsychologists, including this one, will tell you that helping people to recover is so difficult that you need the very best techniques from psychotherapy to do so. Most therapists have developed their own styles, blending the influence of many theorists. Here are the influences that shaped my approach:

1. Effective Psychotherapy by Hellmuth Kaiser (1965). If you want people to listen and make sense of their experiences, don't lie to them. Don't bulls**t them. The truth can be refreshing and inspirational.
2. The Interpersonal Theory of Psychotherapy by Harry Stack Sullivan (1955). Sullivan preaches that hard truths must be presented a bit at a time, allowing the person to deal with them as they are tolerated.
3. Participant Observation by Leston Havens (1983). This is a brilliant Yale psychiatrist's explanation of Sullivan's theories of therapy.
4. Stress Response Styles by Mardi Horowitz.(1977). Every person needs to be approached in a way that is best suited for their particular make-up and personal issues.
5. Modern Psychopathology by Theodore Millon (1968). More specifics about individualizing to the person.
6. Self-Efficacy: The Exercise of Control by Albert Bandura (1997). How to feel like you can cope.
7. Motivational Interviewing by William Miller & Ron Rollnick (2002). How to convince a patient that he or she really wants to recover. Not very profound, but very helpful.
8. Cognitive Behavior Modification by Donald Meichenbaum (1977). Self-control techniques that are very applicable to TBI.
9. Stress, Appraisal, and Coping by Arnold Lazarus and Susan Folkman (1984). Critical study of adaptation.
10. Narrative Therapy by Jill Friedman and Gene Combs (1993). How you tell your story mirrors how you run your life. I find this way of thinking easy to understand and use.

Chapters and Papers on How to do Rehabilitation

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APPENDIX B: RECOMMENDED VIDEO GAMES FOR THERAPIES

Best:

- Tetris Elements
- Classic Atari games
 - Super Breakout (original Breakout even better)
 - Frogger
 - Asteroids
 - Missile Command
 - Space Invaders
- Need For Speed--Underground
- Gran Turismo

Good:

- Zaxxon
- Super Mario Brothers games
- Classic Atari games
 - Ms. Pac-Man
 - Donkey Kong
- Final Fantasy VII
- NBA Street
- Grand Theft Auto
- Mortal Combat
- Street Fighter

Okay:

- Doom/Halo/other first-person shooter games
- Tom Clancy games
- Star Wars Battlefront
- Legend of Zelda

APPENDIX C: THE RECOVERY CREED

- 1. "I have a head injury that damaged my brain and changed my life."**
- 2. "Hope and prayer can give me strength, but I'm the only one who can fix my life."**
- 3. "My injury hides itself from me, but I can teach myself to see what it's doing to me."**
- 4. "Usually I can do everything I try to do, but sometimes I have head-injured moments."**
- 5. "I can't feel or sense my head-injured moments; I learn about them by studying my actions."**
- 6. "If I pay attention to them, those moments can teach me how my new brain works."**
- 7. "My head-injured moments are like gold--the more I treasure them the faster I will recover."**
- 8. "To make sure that I remember and learn from them, I try to write down as many as I can."**
- 9. "No head-injured moment is too small to matter; they all teach me something about my new brain."**
- 10. "The more carefully I analyze my head injured moments, the better I know when to expect them."**
- 11. "There is a pattern to my head injured moments. They affect me in certain, specific ways."**
- 12. "For example, I tend to forget certain kinds of information that I need to remember."**
- 13. "By knowing how severe my injury is, I can understand how much disability to expect from it."**
- 14. "I want to teach myself how to live like a self-therapist so that I can have more recovery."**
- 15. "I learn how to do self-therapy by watching other recoverers, and by reading recovery stories."**

16. “I know that by making recovery techniques a part of my day, I commit myself to recover.”

17. “Every Analysis Form I write takes me one more step closer to my recovery goals.”

18. “When I have learned to do self-therapy, I will give back by helping others to learn it.”

AN EXPLANATION OF THE STATEMENTS OF THE RECOVERY CREED

1. “I have a head injury that damaged my brain and changed my life.”

Maybe your life seems okay, but if you look at it hard, is it really going the way you need it to go? Are you earning the kind of money you expect to earn? Are you earning the kind of respect you need to earn? Do you have the kind of love in your life that you need? Do you have the kind of friends? Do people trust you and count on you? Would it be okay with you if things stay the way they are for the rest of your life? If that hard look shows that your life is not okay, if it has gone off track, that would put you in the same boat with the other people in the World of Head Injury. Whether it seems that way to you right now or not, the head injury is probably the main problem. The brain you are using right now feels like the one you got from the factory, but it's not. Head injuries change brains, simple as that. And then the survivors forget about their injuries, and the injury ends up running the person's life. If you want things to get better, it starts with admitting what happened to you, and accepting that it has changed you.

2. Hope and prayer can give me strength, but I'm the only one who can fix my life.

Nobody else is going to fix your life for you. There is no cure for head injury. There is no way to go back to being your old self--your old self and your old life are gone. You have every right to pray for a miracle, but among the many miracles I've seen, there hasn't been a single case of somebody praying and then waking up the next morning and being okay. Every miracle I've seen involves a person being given the strength to fix himself or herself. Your family and friends can help you to work on yourself, but they can't fix you. It really is up to you.

3. To fix my life, I have to fix the head-injured moments from my head injury.

The problem is the head-injured moments. The problem is not the person who caused your accident. The problem is not the restrictions the doctors have put on you, or your family members who enforce those restrictions. The problem is that your brain doesn't work the way it used to work. When you try to do things the way you did them all your life, this new brain doesn't do them well enough, or consistently enough, or without having you do or say something that gives others a bad impression of you. The only thing you can change that will make your life work better is the way the head-injured moments

affect your behavior. You need to learn a way to do things that works in spite of having the head-injured moments. There is a way to do that, but you have to learn what it is.

4. I can fix my head-injured moments only as I discover what they are.

You don't know what's wrong with you--them's fightin' words! How can I tell an intelligent adult that he/she doesn't understand his/her own flaws? You feel totally certain that you know exactly what's wrong with you. But you don't. Head injury does that to people--it leaves them unaware of what it has done to them. They can't feel their head-injured moments. They can't see their head-injured moments. Their feelings tell them that there *aren't* any head-injured moments. And if they believe their feelings, they never become able to fix the head-injured moments. You can't fix what you don't know is broken--that's just common sense. Are head injury survivors naturally ignorant of their head-injured moments? Ask anyone from the World of Head Injury. Ask successful survivors--they'll tell you that they started out believing that they had no head-injured moments, and found out that wasn't true. Ask family members. They'll tell you that their survivor doesn't know his/her symptoms, and argues if they mention them. Ask therapy professionals--they'll tell you that lack of awareness of deficit is one of the most serious and universal problems of head injury--it totally blocks recovery. Are you going to be a victim to the lack of awareness, or are you going to force yourself to discover what your injury has really done to you? If you choose to discover your injury, you can move forward toward a recovery.

5. I can't feel or sense my head-injured moments; I learn about them by studying my actions.

Remember, there is no such thing as feeling head injured. Unlike your body, your brain has no nerves in it to sense damage. And your injury has broken the system we use to notice changes in ourselves. You have to *study* yourself to find the evidence that tells you what's changed. Here's an example: Do you have a different personality now than you had before your injury? It doesn't seem different to you. But watch a videotape of yourself. The person on the tape will act in ways that are nothing like your old personality. Ask a family member or friend who is able to be truly honest with you. They will tell you that you act like a different person now. How can you figure out who the new you is? You have to reach for every bit of information you can get--and it's hard to get that information. Try to look at your behavior objectively. Make the best use of any feedback other people give you. If they tell you something about yourself that doesn't sound right to you, it's probably something you need to learn about yourself--don't throw it away just because it sounds like they're talking about somebody else--learn from it!

6. I will always need to learn more about my head-injured moments and my new self.

It's so hard to learn about your new self that you will never get it all learned. There will always be things to discover that you haven't learned yet. I've worked with many people who have had their injury for longer than ten years. Nobody has gotten their new self figured out yet. Every one of the people who have the very best recoveries will

tell you that they are still actively working on trying to understand their new selves better, and finding out new things all the time. If you work hard, get lots of honest feedback from the people around you, and are very honest with yourself in admitting your flaws, you can probably learn all the main facts about your new self in two or three years. But there will always be some new surprises. That's how it works.

7. Every mistake I make is gold to me--I will let it teach me about a head-injured moment.

Mistakes are the things that teach you the most about your new self. When you make a mistake, it means that you expected yourself to be able to do something that you can't do anymore, or you failed to notice something you should have noticed. It probably means you didn't switch off automatic pilot and activate enough of your brain to think the task through. If you notice your mistake, admit your mistake, don't look for an excuse or someone to blame it on, study your mistake learn how you made it, figure out what you might have done differently to have prevented the mistake, then you have just learned a lesson about how to use your new brain effectively.

8. I will put every lesson mistakes teach me down on paper where I can't forget them. Every Analysis Form I write will be one more step toward recovery.

Noticing your mistakes is only the first step. You have to *do* something about them. It's incredibly easy to see a mistake, go on, and forget the mistake ever happened. It's human nature to do that. But if you do that, nothing is learned. A golden opportunity has been thrown away. And you will repeat the mistake. A person whose memory has been damaged by a head injury can easily forget almost every mistake he/she makes in this way. If you don't write down your mistakes when you make them, you will probably forget most of them. A form called an Analysis Form is used not only to record mistakes, but to indicate how they happened and how to fix them. It is through the Analysis Form that you fix the head-injured moment. It is through the Analysis Form that you teach yourself the new habit that prevents the mistake from happening again. Each Analysis Form is a promise to yourself to take a step of recovery, and a guide for yourself about where to take that step. The more Analysis Forms you do, the more recovery you are making happen. If you aren't doing any, you really can't say that you're on the road to recovery. Do as many as you can, and treat each one as an opportunity to make a better future for yourself.

9. When I know how I made each mistake, I will plan a better way to do that thing.

The core of the Analysis Form is making a better plan for the next time you do that task. By analyzing what went wrong, and only by doing that, you will know exactly what to do next time..

10. I will keep trying a better plan until I find one that prevents the mistake

Once you write an Analysis Form, you need to make sure that your better plan

worked. If it didn't work, you need to change it, until you find a better plan that will work. It is important to have a time and place to keep track of how your Analysis Forms are working, and to develop better plans if you're having a hard time coming up with one on your own. This is why it is recommended that you have a Therapy Team Meeting once a week. This is the time to review your Analysis Forms and see how well your better plans are working out. If you have had to write more than one Analysis Form for a particular task, that should alert you to discuss the better plan in your meeting. If your Therapy Team can't come up with a better plan that works, that is the time to seek advice from outside experts. Don't quit until you come up with an answer--there is always an answer!

11. I will remind myself to use the better plan until it becomes my way of doing things.

It may prove difficult to remember to use your better plan. If that turns out to be the case, it means your better plan is incomplete. The plan needs to include some method of reminding yourself to use it. That might just be a matter of planning ahead when you think about what you are going to do the next day, reminding yourself to use the better plans you have made for yourself. It might be a matter of making a reminder note or using some special object as a reminder signal (the way some people wind yarn around a finger to remind themselves to do something). You may have to work on making a proper reminder system for awhile before you come up with one that works every time. Once you remember to use a better plan, each time you do it you will get closer to doing it as a habit, every time. It may take a few months or a few years, but if you always use the plan eventually it will become second nature to you.

12. I will commit my time and effort to work hard on my self-therapy every day.

Successful Self-Therapy takes work. Most successful graduates say it was the hardest work they ever did. It takes hundreds of hours to learn, practice and master the techniques. The techniques themselves take time--many hours every week, for the rest of your life. And if you are going to get all this work done, it requires a commitment. You need to set aside the time each day to work on it, or it simply won't get done.

13. I will ask for and accept only the help I need to make my self-therapy successful.

What kind of help do you need to do your Self-Therapy Program? Do you want some help to get started, to get organized? Most people benefit from getting that kind of help. If your family can help you to plan your program, that's good. If they plan it for you, that's bad. In fact, that just about guarantees that it won't work. If they help you by reminding you that it's time to do your scheduled work, or they suggest that you should write an Analysis Form, or they give you feedback on something you did wrong, that's good. If they do your forms for you, that's bad. In fact, that's not a program. If they always have to remind you, and convince you, to do your self therapy, then it's not your program, it's theirs. That won't work. You can't leave that up to them. If you do, you're not moving toward recovery--you're stuck where you are!

Are you asking God to help? People who do that tend to have better recoveries. What kind of help do you want from Him? Do you want Him to do your therapy for you? Or do you want Him to help you become a great Self-Therapist? If I had to do Self-Therapy, I'd want Him on my Therapy Team.

14. When I have learned to do self-therapy, I will give back by helping others to learn, too.

When you have become an expert Self-Therapist, you will be ready to give others the kind of help that made it easier for you to learn Self-Therapy. Don't just be thankful for the blessings you got--pass them on!