FULLY REVISED AND UPDATED

"This a tremendously important book. Peter Levine has carefully and accurately brought together complex research findings from both basic neuroscience and clinical rehabilitation. Not only that, but he has made the material both accessible and enjoyable to read."

—**Sarah A. Raskin, PhD, ABBP/ABCN**, Department of Psychology and Neuroscience Program, Trinity College

STRONGER AFTER STROKE

YOUR ROADMAP TO RECOVERY

Second Edition

PETER G. LEVINE

Stronger After Stroke

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Foreword

The year was 1999. I was in the first year of a postdoctoral fellowship at the Kessler Institute for Rehabilitation, where Christopher Reeve, Dudley Moore, and others had carried out their rehabilitation. I had just been awarded my first research grant, which was going to apply mental practice to improve arm movement after stroke (you will learn more about this technique later in this book). I was hoping to hire a research assistant to help me carry out the grant.

My first (and only) interview to fill this position was with an unassuming, tall, physical therapy assistant with brown-rimmed glasses named Peter Levine. As we spoke, he told me that he was from many parts of the World but had settled in New Jersey (where Kessler was located), had been working in a subacute rehabilitation facility, and that performing research sounded "interesting" to him. While there was other research going on at Kessler, I told Pete that the position would only have him working on this study, and that the work would be temporary. To be honest, the grant was only slated to last for two years. Plus, I had already performed some pilot work suggesting that mental practice improved arm movement in stroke patients; however, I wasn't sure how this larger study was going to work out, or if the technique would even be effective when applied to a larger and more diverse group of people with stroke.

In the following weeks, it became increasingly clear that this unassuming, reserved clinician was an astute observer of human nature and of the strengths and limitations of the medical system. Pete had a refreshing "outsider" mentality that resonated with me; neither of us had strong rehabilitation research lineage (nor did we care), were not necessarily impressed by names and titles, and we were both skeptical about widely accepted practices

in medical rehabilitation that were blithely followed by our colleagues. For instance, other members of the Kessler scientific staff would ask Pete where he did his training (I still don't understand why this is such a conversation-starter for people in research), and he would reply "Union County College." Pete and I relished the confused look that individuals would give in response to his truthful reply. On other occasions, we attended presentations by "renowned" clinicians and scientists. We noticed that these individuals often experienced difficulty communicating their knowledge to laypersons and non-experts, and that they had trouble relating their work to everyday clinical stroke practice. Pete and I would talk frequently about how their approaches could be implemented in clinical practice, and how we would have formatted their presentations differently to make them more accessible to larger audiences.

As weeks and months passed, Pete and I began talking more openly about our personal lives, and eventually how stroke care should be provided if our family members—or others' family members—had a stroke. We expanded our "outsider" perspective to look critically at accepted and emerging approaches in stroke research, such as constraint-induced movement therapy (also discussed later in this book). At the time, constraint-induced therapy was generating great excitement, and it had been developed by some of the best minds in our field. Yet, Pete and I were amazed that no one seemed to have considered whether an average therapy clinic or stroke patient could tolerate or practically administer this six-hour-per-day protocol. What about reimbursement from insurance companies? Attitudes of the patients and their family members? Compliance? Attitudes of the clinicians administering the therapy for six hours per day? Discussions of these disconnects with Pete and other team members led directly to our pioneering work in developing a reimbursable, outpatient version of constraint-induced therapy called "modified constraint-induced movement therapy."

As the months turned into years, Pete, now a research associate, and I acquired grants to develop and test a variety of approaches targeting hand function, shoulder pain, walking, and other abilities compromised after stroke. More research was coming out of our laboratory, and the notion having an entire stable of practical, easy-to-use approaches that were based on decades of learning and cognitive psychology research (as opposed to simply giving patients more and more hours of therapy) was beginning to take hold. Yet, as we communicated more with clinicians "in the trenches," we noticed that they had little familiarity with the promising techniques coming out of research laboratories like ours. From our own experiences (and from communicating with other clinicians and with Pete's wife Aila, who is a physical therapist), we

knew that therapists were busy (and often disinterested) in reading research articles. To better disseminate information on best stroke practices to these individuals, we began presenting all-day seminars to clinicians, in which we would teach therapists evidence based techniques in stroke rehabilitation, including the approaches that we had been developing.

I have never known Peter Levine to be bad at anything. He is a quick and agile basketball player, a gifted musician, a great dad and husband, and a great friend. Most of all, he is true, and without airs. So it was no surprise that he was good at delivering the seminars as well. Likewise, it was unsurprising that Pete was astute, commonsensical, and—well—true in his delivery of these seminars. Pete recognized that information in this forum had to be delivered in an accessible language if it was to truly be understood and integrated into clinical practice. To this day, Pete and I still teach these seminars, implementing the same practical, clinician- and patient-centered approach that we began almost 15 years ago. And I am proud to say that the "outsider" mentality is still there. In fact, I would argue that such an approach is necessary to taking an objective, critical look at what works and what needs improvement in stroke rehabilitation.

This second edition of *Stronger After Stroke* describes the science and application of techniques from our laboratory, as well as those reviewed in our seminars. This new edition again incorporates a straightforward, common-sense, "outsider" perspective. The combination of Pete's voice as a writer and his veracity for "science over sentiment" distinguish this book from the rest of the pack. You will also learn that, as Pete likes to say, stroke rehabilitation is "not for wimps." Both Pete and I agree that stroke patients are similar to athletes and musicians in that they need well-defined goals, knowledge about the rationale for the training strategies that they are undertaking, and an obsession with practice. While straightforward and supported by evidence, Pete's emphasis on these facets are additional, distinguishing features of this book.

I hope that you enjoy this quick yet detailed read, and know that you will be "stronger after stroke" as a result of it.

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Preface

The first edition of *Stronger After Stroke* had a simple message: *When it comes to recovery, stroke survivors are in control.* Only survivors can leverage the power of brain plasticity for recovery. *Stronger* wasn't the first source to advocate a "neuroplastic model of stroke recovery." It was, however, the first to pull the idea from scientific journals and books, explain it so everyone could understand it, and bundle it with tools survivors could use. This 2nd edition is an expansion of the same theme with new insights from psychology, psychiatry, rehabilitation, exercise science, and, most importantly, neuroscience. But don't blink. Scientists from around the world are adding their voices, and expanding our understanding of how to rewire to recover. To catch a glimpse of this ever-expanding perspective, have a look at the book's companion website, The Stroke Recovery Blog (RecoverFromStroke.blogspot.com).

HOW FASCINATION WITH THE BRAIN HAS HELPED SURVIVORS

Hippocrates first defined stroke 2400 years ago. For most of the time since, rehabilitation was a patchwork of techniques based on clinical expertise and educated guesses. Within the last two decades, these techniques have been forced to give way to rigorous scientific consideration. Sheer curiosity has driven scientists to stroke recovery. Recovery from stroke provides a unique perspective on the capability of the brain. And that's the hook: Science finds the brain a world of wonderment. At the same time, a huge amount of other

(non-stroke) brain science research is going on. This research, into the brain and into recovery from brain injury, will rapidly continue to provide new insights. In the meantime, the extent to which the brain is able to rewire is not yet known. What we do know is that every time the brain is asked to do extraordinary things, it responds. That's the good news. The bad news is that the response takes a tremendous amount of hard work. This book celebrates and gives the scientific justification for that hard work.

THE SUPER-SURVIVOR

Every stroke survivor has a certain level of potential recovery. Few reach that potential. Stroke survivors who *do* reach their potential do so because they have no choice. This breed of "super-survivor" is so unwilling to let go of their career, their independence, or personal passions that they are compelled to recover. They intertwine recovery with what they love to do. Sometimes recovery is so much a part of what they love doing that they don't even notice they're recovering. For the super-survivor, recovery is a vision quest. The challenge of recovery is no different from other challenges they've conquered in life. They get on with it. They put in the time. They fall in love with the process. It's much the same reason athletes are driven to always get better. Stroke survivors who recover see the process of recovery as an opportunity for growth.

This book is not for stroke survivors who are OK with where they are. This is a book for stroke survivors who want to *get better*.

If you are not a stroke survivor, this book may have meaning for you as well. The same thing that drives recovery from stroke can drive any form of learning. Learning involves the most important scientific discovery since fire: *Neuroplasticity*. Humans have always used their plastic brain. But the discovery of *how* the brain changes allow us to wonder: How much more can we make it change? How plastic is it? Answering these questions will help develop the best ways to recovery from stroke.

NEUROPLASTICITY AND HOW SCIENCE GOT IT WRONG

In the mid-1800s, scientists began mapping the brain. Each portion of the brain was sectioned off. Each section was proclaimed as the *only* possible site for everything, from the ability to do math to wiggling your toes. One section, on the left side of the brain, always controlled speech. Another section, near the top of the brain, controls the hand. The back of the brain processes vision, the front solves problems. These early attempts defined the brain as static. Sure, in our youth, perhaps before five years old, there were some changes in the brain. But after that initial wiring the brain was fixed, frozen, and locked. This was bad news for stroke survivors. What happened, for instance, if the stroke killed the language portion of the brain? Because science thought the brain unchangeable, attempting to use different parts of the brain for language was, well … *unthinkable*. Once language, or limb movement, or sensation, or anything else was knocked out by the stroke, it was gone. *Forever*.

There is good news, however: *These early attempts to define the brain were wrong.*

Scientists had a "mechanistic view" of the brain. Galileo and Copernicus had mechanized the heavens and Leonardo da Vinci had mechanized pretty much everything else. Our fascination with machines profoundly influenced our study of the human body. Scientists viewed the body as a machine, with smaller machines inside. Muscles were pulleys, bones were levers, the kidneys were filters, the heart was a pump, etc. Certainly the brain was some sort of machine as well. Scientists tended to compare the brain to whatever the latest technology is. "The brain is like a clock." "The brain is like an engine." "The brain is like a calculator." Whatever the latest technology was, that's what the brain was like.

And then, in the mid-1900s, scientists started to realize that the brain did not operate like any other machine. Consider computers. If you ask two identical computers to do the same thing, they'll do the same thing in exactly the same way over and over and over again. But if you asked the same person the same question, once on Monday and once on Wednesday, she may very well give you different answers. She's "changed her mind." That change was actually a physical change in her brain. Her neurons changed their structure and/or function.

Most of the work challenging the idea that "the brain is just another machine" came from neuroscience. Neuroscience studies the entire nervous system but is fascinated with the brain. Neuroscientists are especially interested in developing and testing ways of rewiring the brain neuroplasticity. And this is good for folks that have brain injury, including stroke. Neuroplasticity is at the core of recovery. Neuroscience will lead the way in developing systems to drive neuroplasticity.

The ability the brain has to change, the ability to learn, comes at a cost. Our brain is inconsistent. A computer might always express A = B = C. We might say "A = C but I left out B because I'm in the process of adding D." As neuroscientists Sam Wang and Sandra Aamodt put it, the brain is less like machine and more like a busy Chinese restaurant. If you've ever been in a crowded Chinese restaurant, it's chaos. Some people are getting their orders taken, other people are being seated, orders are being yelled, food is being eaten, and plates are clanging.

But everything gets done.

Your brain is less like a computer and more like a busy Chinese restaurant. As new connections between neurons are made in the brain, different answers, different perspectives, and different solutions to problems are created. What we lose in the linear (A always = B which always = C) we gain in the ability to do what no other machine can do. And that's the point: Brains change, machines don't. As you read this book you may associate exercise with neurons and neurons with recovery and recovery with your own personal story. Machines can only associate what you tell them to associate. The brain can associate anything with anything else. Simply, brains learn, machines don't.

NEUROPLASTICITY: SIMPLICITY IN A BOX

The brain can be rewired and, under certain conditions, radically rearranged. It turns out that the brain, 100 billion neurons strong, can be changed into whatever kind of tool we want. And there is more good news: Some of the best tools needed for rewiring the brain after stroke are very simple. Although the brain is the most complex entity in the known universe, it responds and

rewires according to simple instructions. All a person needs to change his or her brain is a whole lot of focused and dedicated practice. And it happens *fast*. Large portions of our brains can be rewired in a matter of hours, days, or weeks. Understand: This is not some sort of vague "new-age" concept; this is an actual physical event, measurable by brain-scanning technology. From learning to control emotions to hitting a baseball, the core of change involves rewiring the brain.

You might suspect that there is a bit more to it, and there is. While the idea of "practice makes perfect" is simple, how to practice is more complicated. This book defines the elements needed to drive neuroplastic change. Beyond focused and dedicated practice, rewiring the brain also involves another rather large pink elephant in the room: Motivation. Neuroplasticity takes a tremendous amount of work. It does not necessarily involve a long period of time, just a lot of focused effort. Your hard work is the most essential aspect of successful recovery. Clearly, the most important person involved in the recovery from stroke is the survivor. Much of the work can be done at home with help from family and friends while under the guidance of doctors and therapists. While clinicians are essential to the recovery process, you and your caregivers should not wait for health professionals to chaperon you toward your highest level of potential recovery. There is no doctor, therapist, minister, guru, or shaman in a better position to run your master recovery plan. There is no one who cares as much. Accept the challenge, empower yourself, focus on recovery, work hard, don't give up, and watch an upward spiral emerge that allows for the highest level of recovery.

I wrote this book because I couldn't figure out why it hadn't already been written. *So much* has been discovered about recovery in the last two decades, but it wasn't getting to survivors. If you search magazines and the Internet you might get a smattering of related information, but there was no singular source. *Stronger After Stroke* is a "field manual" of information unifying and simplifying *most* of what is currently known about recovery. The word most is emphasized here because one of the clear messages of this book is held within the proverb: "Give a man a fish, feed him for a day. *Teach* a man to fish and feed him for a lifetime." Recovery requires knowing the latest and greatest research. The "Resources" section includes quick and easy ways of discovering what is new and effective in stroke-recovery research.

Billions have been spent on stroke recovery research. You should benefit.

Introduction

We are what we repeatedly do.

—Aristotle

In the last decade or so, stroke-recovery research has focused on a few basic core concepts. Understanding these building blocks of recovery will help you decide which of the growing number of treatment options is right for you. All of the following will provide insight into developing a great recovery plan.

ELEMENTS ESSENTIAL TO RECOVERY FROM STROKE

Mixing the following elements has been shown to the drive neuroplastic (brain rewiring) change necessary for recovery:

1. *Repetitive*. Pick options that use repetitive practice. Movements that you want to relearn should be performed over and over. For instance, if you want to lift your foot better, then you would concentrate on doing that movement repeatedly and with the highest possible quality of movement. Use of repetition requires "nipping at the edges" of your

current ability. With each attempt, try to extend beyond your present ability a little bit more. Repetitive practice changes the part of the brain that controls movement. But how many repetitions are needed to change the brain? Let's consider elbow extension (going from the elbow bent to the elbow straight). Approximately 2000 repetitions are needed to make the brain better at controlling that movement. Not perfect, but better. And that's for a single-joint movement. Most of the movements we make involve many joints moving in a variety of directions. So how many repetitions are needed to do complex "every day" movements? The numbers of repetitions needed get very large very quickly. Most practical everyday movements will require tens of thousands, if not hundreds of thousands, of repetitions. This is one of the reasons that working only when a therapist is around is not practical. There is simply not enough time with therapists to accomplish the number of repetitions needed.

2. *Task specific*. Neuroplastic (brain rewiring) change is much more likely to occur if the movement you are trying to relearn is part of a real-world task. The task has to be meaningful (important, essential, engaging) to you. The more important the task is to you, the more it will drive recovery. For instance, if you are trying to regain the ability to pick up objects, make it part of a real-world task that is meaningful to you. *Recover to do what you care about and use what you care about to drive recovery*. If you love to paint, practice picking up a paintbrush. But what if you can't pick up a paintbrush? You only need to practice a portion of the task. It is not necessary to have the ability to accomplish the entire task to make it task specific. If the task is picking up a paintbrush, you may only be able to get the hand to the table but not be able to actually grasp the brush. As you bring the hand up to the table, have the paintbrush there to provide a meaningful goal.
3. *Massed practice*. In rehabilitation clinics, therapy is usually scheduled as distributed practice. This sort of schedule involves relatively short sessions (15 minutes to 2 hours) distributed over a long period of time (weeks, months, years). Massed practice schedules involve sessions that last 5 to 8 hours, but the sessions are distributed over a short period of 1 to a few weeks. Research indicates that massed practice produces much more of the vital sort of brain rewiring needed to recover from stroke. Some researchers believe that practice should be distributed. In this case, instead of doing 5 hours a day with all

the hours bunched together, that 5 hours should be distributed throughout the day. For instance, the survivor would still work for 5 hours, but they might distribute the work throughout the day; 2 hours in the morning, 2 hours in the afternoon, and 1 hour in the evening. The bottom line is that recovery involves many hours a day of work, however those hours are scheduled.

4. *Novel*. Work on movements that are novel (new) to you. Of course, the movements are not really new. You may have been doing the movements for 50 years prior to your stroke, but it is considered novel if it has yet to be learned since your stroke. Researchers use the word "novel," but a better word may be "challenging." Focus on relearning challenging movements. Attempting movements that are too easy will not help you recover. As soon as you can perform a movement at a quality that reaches about 80% of your pre-stroke ability, move on to another novel movement.

THE P.E.N.S. CONCEPT

The P.E.N.S. concept provides an effective way to decide whether or not an option is worthy of consideration. It includes:

P is for *Patient driven*.

- Can you do the therapy by yourself, or does it require supervision?
- Is it intuitive, or does it require a lot of training? Is it expensive or is it affordable?
- Is it available in your area or do you have to travel to get to it?

Lean toward options that have the potential to be used at home, relatively easily, and with little cost and set-up.

E is for *Evidence-based*. Has the option been researched? The amount of scientific testing of recovery options is highly variable. Some have …

- Have never been tested
- Have been tested in small poorly run studies

- Have been tested by people who will make money if the product sells
- Have done poorly in well-run studies
- Have done poorly in multiple well-run studies
- Have done well in well-run studies
- Have done well in multiple well-run studies.

When researching the recovery option, ask the question: Did it shine or was it a lemon? In the "Resources" section of this book there are websites and other sources of information to help you pick and choose.

N is for *Neuroplastic*. Does the recovery option promote neuroplastic change? That is, will it rewire the brain in a way that helps recovery? The problem is, science may not have yet proven that the option you've chosen actually rewires the brain. There are few recovery options that have been tested this way. Try to determine if the therapy has all the earmarks of neuroplasticity included in Essential Elements of Recovery From Stroke, discussed in the previous section.

S is for *Simulations* vectors. This is a fancy way of saying, "Consider multiple options as you plan your recovery." There is no one magic bullet for stroke recovery. Therapists tend to use a small group of therapies that they know well. Researchers tend to focus on a small group of related treatment options. Both therapists and researchers bring important perspectives to stroke recovery. But in some ways, both lack a sufficiently broad perspective. When stroke recovery is viewed globally, a hidden secret emerges: It's not anything, it's everything. Imagine stroke recovery as a picture puzzle. Solving the stroke-recovery puzzle involves using the puzzle pieces (recovery options) to build as complete a picture as possible (recovery). If the puzzle is done correctly, the highest possible level of recovery is achieved.

The stroke-recovery puzzle has two added dimensions that picture puzzles don't:

1. The number of pieces (treatment options) is continually changing. This is a result of increased research, including research of new technologies. At the same time, research is sifting out other, ineffective treatments.
2. The background picture (where you are in the recovery arc) changes.

Figuring out …

- what puzzle piece fits
- when it fits
- and how it fits

… is essential to an effective recovery plan.

GOOD NEWS AND BAD NEWS

Recovery takes hard work and commitment. It's not easy. Simply, it will most likely be the hardest thing you've ever done.

- The good news: The process of recovering from stroke is both intuitive and simple.
- The bad news: Recovery takes a lot of hard work.

If someone is telling you that they can help you recover, and they have special ways of doing it without you working hard, grab your wallet and leave!

ONE LAST BIT OF HOUSEKEEPING …

While limbs on one side of the body are most impacted, research has found that all four limbs are affected by the brain damage caused by stroke. Because all four limbs are affected, researchers use the terms "more affected" and "less affected" when describing the relative deficit in the limbs after stroke. Please note that for the sake of brevity and simplicity, this book sometimes uses the following terms:

- "Bad"—the limbs more affected by the stroke.
- "Good"—the limbs less affected by the stroke.

These terms are not meant to reflect the potential for recovery, nor the relative importance of the limb.