Steps for Living

Recovery Support for Chronic Brain Disorders

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Preface: Terry M's Story

I was repeatedly told I was a bright child, enough so that I began to believe it. But I was also told that I "didn't work up to my capacity." Those very words appeared next to a box that was checked on almost every report card I brought home. So I knew, fairly early, that there was something wrong with me, because I certainly *felt* as though I was working up to my capacity.

We moved from a city neighborhood/parochial school, to a small suburban town/public school. It was obvious I didn't fit in, and I was bullied relentlessly. My response was to antagonize, provoke and manipulate the bullies, and tell myself I was fine, because everyone in my new town and school were stupid hicks unworthy of my friendship.

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I stayed miserable, resentful, angry, and largely friendless throughout middle school, and so uncomfortable in high school that I exerted myself to complete it in two years, taking extra courses and summer school sessions. I got migraines so debilitating I was sent to the hospital for a neurological exam. They found nothing treatable.

After I went to University, things started going wrong. I was diagnosed with asthma. I'd had hayfever and allergies all my life, but the draining chronic shortness of breath, the scary incidents of not being able to get enough air, were new. I became very sedentary, quit the theater club, and decided not to audition for choir. I was gaining weight. I tried yoga, but I wasn't motivated, I preferred to sleep. I hated myself.

One year I slept, ate, studied just enough to get decent grades, and went to some classes. That was all. A typical day went: Wake up, shower, eat cereal in my room. Go to class, come back to the room and nap. Go to another class, go to the dining hall for lunch, go back to the room and nap. Go to the library and study a little, cut the next class and nap. Grab some food from the dining hall, take it back to the room to study, and go to bed. Anything beyond that overwhelmed me.

About this time I realized part of the reason I'd never dated in high school was I couldn't make up my mind whether I liked boys or girls. I wanted both. I began a relationship with a woman; she'd just had a baby, and we co-parented an amazing, beautiful human being. She still calls me her "other mom," and it's one of the things I'm proudest of in my whole life.

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But my partner was an alcoholic, and I dropped out of school to be a full-time codependent. We did crazy things together. I did a number of crazy things on my own, too: Followed rock bands, tried performing in one, went the "sexual adventurer" route for a while.

One day the New Orleans police found me wandering around the docks area in what they called a "fugue state." (As if they knew.) I was incapable of communicating; they thought I was drugged. They couldn't get any useful information out of me, so they jailed me "for my own protection."

Everyone assumed that "what was going on with Terry" was related to drugs. (It wasn't.) I didn't know what *was* happening, but I was glad to let them think "drugs." That had more cachet than "mental illness." I felt stuck behind a thick, dirty, scratched pane of glass that separated me from everything good about life, everything other people enjoyed.

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During my lifetime, two members of my extended family have committed suicide. I was sorry for the pain my family experienced, but my attitude was somewhere between envy and resentment: They'd found a way to escape the pain of being alive! I was thirty-two when I first decided to kill myself. I told no one about my decision. I had the means at hand, and I planned the circumstances. No one would know it was suicide. It would look like an accident.

At that point, a bout with pneumonia (I was having them pretty much annually,) sent me to a new doctor. He listened to my symptoms, narrowed his eyes, then administered a simple depression inventory. I walked out with a diagnosis, prescription for an anti-depressant, and a referral to a therapist. The medication was like waking up. The therapist introduced me to cognitive behavioral scripting that helped me recognize and manage my depression symptoms. The pane of glass was gone. I could see why other people enjoyed this. I thought I had it licked. I was cured!

But I wasn't. Few medications work at that "I'm cured!" level for very long. The "overwhelmed" feeling kept coming back. I saw no problem with racking up a large credit card bill, then the debt became a stress point.

I decided I needed "stress relief" and joined a gym and began working out. A lot. When it got up to five hours a day at the gym, I decided I needed a different strategy. A new job—that would be the answer! It wasn't.

I went through plenty of sex partners, both genders. Some ended up as friends, some I never saw again. I travelled to meet people, spent a lot of time on intense, temporary relationships. I fucked married people and connived in them cheating on partners. I didn't see the rabbit hole, but I was already deep in it.

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I went into business for myself, and was moderately successful. I began to pay off some of the debt, but I was struggling. I realized I had failed, and I would never get better again. Once again, I had the means at hand, and the plan was easy.

A man I'd become close to was also a recovering alcoholic. Among the things that he left at my house was a copy of the Big Book of Alcoholics Anonymous. One January afternoon, I decided it was time to go, but I wanted to call my friend to say good-bye. But he wasn't home; the phone rang and rang. And then for some reason, I picked up the book he'd left.

I'm not an alcoholic. But those words hit me like a ton of bricks. I found myself reading it, and where it talked about "alcohol" I read "depression." And I thought, as so many have, "I want what they have." It was too bad, I thought, that there wasn't a "Twelve Steps" program for those of us who struggle with mental illness.

Which brain am I using to plan my fighting strategy? Why, the distorted one, of course. There has to be a better way.

I decided I wasn't ready to chicken out yet. If they could go on with their kind of pain, looking for hope and a way out in spite of it all, so could I. If there was a way for them, maybe there'd be a way for me.

I got lucky. My life partner found me. It does help, having a person who loves you steadily and well and smart. But even love isn't a cure. A painful reality of a chronic brain disorder like depression is that medication regimens rarely work consistently well for long periods of time. The brain adapts, and goes right back to trying to kill you.

It doesn't go away (chronic.) It distorts my thinking (brain,) which can lead to stupid and self-destructive choices that damage my health and well-being (disorder.)

How to fight this? Fighting is exhausting. Fighting spirals me further down the rabbit hole. Which brain am I using to plan my fighting strategy? Why, the distorted one, of course. There has to be a better way.

I looked to the Big Book and other key Twelve Step literature. And finally, after twenty years of stopping and starting, dipping my toe in, running screaming in the other direction, the penny dropped: "I'm powerless over my chronic brain disorder, and it makes my life unmanageable."

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1. Promise Fulfilled

These Steps for Living are the result. We can't claim credit for them, the old saw about "standing on the shoulders of giants" applies here. We didn't re-formulate them on our own. We had help from many who suffer with chronic brain disorders—not just depression, but compulsive disorders, eating disorders, attention deficit disorders—they read and talked and helped edit this work to reflect their experiences.

Terry says: "I wish I could say that the morning after I decided to begin living the Steps, my brain gave up trying to kill me and blue birds of happiness descended upon me. It doesn't work that way. It does work. It provides a structure for supporting my recovery. For helping me be rigorously honest, meticulous about applying the spiritual and mental practices of sanity."

Lifetime patterns of self-destructive responses to events, people, places, words, and other 'triggers' are not undone in a day. The answer for a long, slow, steady improvement is to replace those patterns with healthy, sane responses.

Practicing the Steps helps us be kinder to ourselves and others, to minimize the damage our disorders create. It helps us avoid habits of mind and body, built up over years, that collude with our disordered brains to yank us into "insane thinking" territory. It helps us live one twenty-four hour period at a time. The benefits of only having to worry about this day, rather than an infinity of misery, are incalculable.

No one and nothing external is a guarantee of long-term happiness. Lifetime patterns of self-destructive responses to events, people, places, words, and other 'triggers' are not undone in a day. The answer for a long, slow, steady improvement is to replace those patterns with healthy, sane responses.

Because we can't trust our disordered brains to know what a healthy response is, we rely on the practices the Steps teach: Acknowledge our inability to control the uncontrollable. Seek and accept sane guidance from an external source. Identify our own self-defeating patterns, and pay attention to them. Understand how and why they are damaging. Commit ourselves to undoing that damage as much as possible. Stay committed, practicing every day.

Mess up? Fine. Back on the "stairmaster," keep trying.

It helps in many small ways that add up to sanity, over time. We can't see them at any given moment, but when we look back to where we were, and where we are now, we can see the distance travelled in the recovery of sanity.

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2. Chronic Brain Disorders

Certain disorders feature distortions of thinking or feeling that interfere with a person's ability to function. When it persists for an extended period, we refer to it as chronic (long lasting). Common examples include depression, anxiety, or panic; attention problems including hyperactivity; obsessions or compulsions; and behavioral disorders involving excessive gambling, spending, or sexual activity (among others). We believe these are best addressed as chronic brain disorders with their own unique causes, course, and treatment.

Many of these disorders have complex origins, both genetic and environmental, with multiple factors influencing their development. Some are easily diagnosed while others present real challenges to the diagnostician— challenges that can lead to failed treatments until a correct diagnosis is made.

Pathophysiology: the physiology of abnormal states; specifically: the functional changes that accompany a particular syndrome or disease.

It helps to remember that the human brain— yes, everyone's— is the most complex organ yet discovered. Most of what we understand about its function is less than a hundred years old. Yet the brain is who we are. We can't transplant a brain into another person the way we can replace a liver, kidney, or heart, because we *are* our brains. Everything we think, feel, choose, create, imagine starts in our brain. Likewise, every choice we make, every action we perform, every goal we pursue, every emotion we experience, originates in brain activity.

Logically, then, so do chronic brain disorders. Even those we may have in the past considered largely 'mental' or psychological in origin have a pathophysiology: functional changes within the brain related to the disorder.

The origins of each disorder may be different, and symptoms can and do vary widely, but there are some common characteristics. People with these disorders experience painful physical, spiritual, and/or psychological consequences. Our disordered thinking or emotions may interfere with our ability to form healthy relationships, achieve worthwhile employment, or maintain comfortable lifestyle. Sometimes it can lead us to make choices that later seem catastrophic. The impact of these choices can extend the consequences outward to the people we love or who care about us. We often experience shame and guilt over actions connected with our disorder.

We may make repeated attempts to control our disordered thinking or emotions, attempts that fail, increasing our frustration and continuing the cycle of pain. That is, until we discover a way out.

2.a The Challenge of Treatment

Something else these disorders have in common: lack of an obvious cure. Meaning there isn't a pill, a surgical procedure, etc., that will permanently restore us to normal. But there are treatments that can help a great deal.

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Some treatments are aimed at alleviating the symptoms of the disease. Others focus on behavior, by making positive changes in our thinking patterns and lifestyle. This can include a variety of therapies, from psychodynamic to experiential, from cognitive-behavioral to motivational, from mainstream to alternative healing. Most are of great benefit to some of us, but not all, and part of the task of recovery is finding what works best for each of us, in all our uniqueness.

Still other treatments focus on boosting our body's ability to build and maintain optimal health. Exercise, stress management, nutrition, relaxation and meditation— all have been found to offer real benefit to those who suffer.

For most of us, recovery includes more than one treatment. It helps to pay ongoing attention to how well our recovery regimen is working, by monitoring our symptoms, consulting regularly with professionals, making sure we remain connected with recovery-positive people, and making changes as needed. Sometimes it takes us a while to identify the professionals who really understand our disease and its management. But they're out there.

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Relapse is a continuing issue, because of behavioral inertia that seems to want to go back to old ways of doing things, even if it's harmful to us. It helps to identify triggers that activate our old thinking and behavior patterns so we can plan to avoid them entirely or at least manage the challenges they present.

Good treatment can be expensive, and many of us lack access to some treatment options. In that sense, it helps if we ourselves become to some extent expert in the treatment of our own illnesses. An informed consumer—knowledge is power.

It would be so easier if there were one right way to treat each disorder that worked for everybody, but right now, there's not. No use complaining. We need to learn all we can about our symptoms and ourselves. That's how we improve our chances of successful recovery.

2.b Managing a Chronic Brain Disorder

We who have a chronic brain disorder may have to confront several challenges to our recovery, including:

Stigma: Most people don't understand these illnesses, and many wrongly assume they represent a character or moral defect, and may even insist we control them through willpower. Stigma can be a powerful disincentive to getting help. It can contribute to our own negative feelings about ourselves. But if we're determined to recover, we can't allow their ignorance to affect us too much. We do have lives to live—rewarding ones.

Our health care system is designed to treat acute (immediate) problems rather than the sort of chronic or long-lasting challenges that we face. That limits the number of effective, affordable, accessible options to assist us. It takes management,

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determination, and persistence to work around those limitations.

Treatments have varying levels of effectiveness and some really aren't effective at all. We'll need help identifying what will work best for us. That means trusting someone, probably a professional, to guide us. And trust may not come easy to us.

We've already experienced damage, possibly physical as well as psychological, from our disease. We're not starting at square one. We may have to go back and clean a few messes, particularly in our most important relationships. And form new relationships that are healthy—or as we like to say, 'recovery positive'.

And of course, there's that **tendency to go back to old ways** of thinking and behaving—something we need always to be alert to. Then again, we already tried those ways, and how'd it work for us?

When we've finally faced the reality of our own distorted thinking, we recognize the need to seek feedback and guidance from others—even if it isn't always what we want to hear.

Not surprisingly, many of us struggle with motivation. This is a marathon, not a sprint. We have doubts, perhaps there will be lapses and relapses. When we've finally faced the reality of our own distorted thinking, we recognize the need to seek feedback and guidance from others—even if it isn't always what we want to hear.

For most of us, successful recovery will involve three elements:

- Education and treatment: This is not a situation where we can "set it and forget it", like those TV ads for miracle cookers. We have a lifetime of mindfulness ahead of us. It starts when educate ourselves about our disease and treatments, and seek to keep our knowledge current. We search out new information and evaluate new options as they appear.
- Individual-specific strategies: Helping professionals can help us to review potential treatments, and identify particular behaviors that may be contributing to our problems and design strategies to deal successfully with various challenges. We're all somewhat unique, and so will be our approach to recovery.
- A commitment to sane living: It's not enough to manage symptoms. We need to learn and practice patterns of thinking and acting that will help "rewire" our brain, little by little, to live a happier, more fulfilling existence. Learning how to live well in spite of our problems is like going on offense in football—we're playing not just to stay even, but to win.

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3. A Path to Sanity

No one understands the principle of "get better or get worse" more profoundly than someone in recovery from an incurable, progressive, potentially fatal condition. Diabetes, asthma, chronic hypertension, and other incurable diseases require sustained changes in behavior and lifestyle to remedy damage and stave off worse effects.

It's true for people who suffer from chronic brain disorders, too. There are no once-and-for-all "cures." Medications may alleviate symptoms— but taking them, and managing them well, is a behavior change, sometimes a challenging one. Few medications work consistently well over the long haul.

Many treatments for chronic brain disorders focus on changing behavior and lifestyle to prevent relapses, minimize the effects of the disease and live well in spite of it.

One chronic brain disease, addiction, has produced a groundbreaking, highly effective regimen for this kind of change. By observation, trial and error, and repeated experiments, the founders of Alcoholics Anonymous identified twelve steps that have helped millions maintain recovery and live progressively more satisfying lives.

Formulated in an era when understanding of chronic disease processes was less developed- and understanding of mental health was strongly influenced by dominant religious and cultural norms, the Steps' language today may seem quaint. Even off-putting, in an era of religious diversity and wide-ranging self-help ideologies.

But AA has a long track record of helping people maintain recovery, and today's AA is highly diverse. If some AA groups choose to form around common characteristics like gender, sexual orientation, military service, etc., there are thousands more that welcome anyone who simply desires to recover. And it remains effective, in spite of an "instruction manual" published in 1939 and updated very little since.

What is it about the Steps, and their practice, that enables desperately miserable individuals, terminally ill with a disease that distorts thinking and hijacks brain function, to interrupt that disease process? And further, to embark on rewarding, productive, fulfilling lives?

And can we apply it to other chronic brain disorders? Maybe, with a little re-thinking, the Steps can expand to meet a whole new set of needs.

What is it about the Steps, and their practice, that enables desperately miserable individuals, terminally ill with a disease that distorts thinking and hijacks brain function, to interrupt that disease process?

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3.a Spirituality ≠ Religion

Many of us find great help and comfort in religious beliefs. But many of us also have troubled relationships with religion in our past or present. And some of us simply don't believe in a deity and are weary of and/or annoyed at attempts to make us change that.

Thus, any program that has strong spiritual foundations is already operating in a minefield of assumptions about what "spiritual" does mean, or should mean. And whether it's for us.

The Big Book of Alcoholics Anonymous has a whole chapter called "We Agnostics," that addresses the issue of whether any particular religion or religious belief is intrinsic to the AA program. It makes the point clearly that for any kind of believer at all, the program offers no conflict to their particular doctrine or beliefs. And for the many non-denominational agnostics who choose to define deity on their own terms, it works just fine.

Pretty good, for 1936. But what about those of us who simply don't believe in a deity at all, or who have a definite bias against anything irrational? Can a program based on spiritual growth and practice work for us, too?

We take the approach that while spiritual insight and growth are foundations of the program's effectiveness, "spiritual" is an aspect of human nature that is not based only in religious faith or even in belief in a deity

In (re)formulating the Steps for Living, we take the approach that while spiritual insight and growth are foundations of the program's effectiveness, "spiritual" is an aspect of human nature that is not based only in religious faith or even in belief in a deity. Even nonbelievers experience wonder, hope, aspiration for experiences and awareness. And believers in a deity have no monopoly on commitment to principles of human development, individually and in communities.

So when we refer to a 'higher power,' to the ability of spiritual growth to bring meaning to our lives, and similar concepts, we leave these definitions up to each individual. The most concrete-minded rationalist will acknowledge that there are things more powerful than we individual humans. Our universe is full of imponderable factors that influence the shape of our lives, and whether it is chaos theory or theology, finding ways to coexist with unknowns requires some leaps of faith.

For most of us, our chronic brain disorders don't impair some types of thinking at all. Various cognitive skills still work fine for us. We might be excellent at maths, or able to do a complex historical analysis, or write program code, or design gardens, or discover why a car engine isn't performing.

Other types of thinking— often thought processes that deal with uncertainties like the future, relationships, choices, wants and fears— these are targeted by our disorder, and distorted over time. Maybe it's because of the type of thinking that gets distorted, that it helps to ground ongoing recovery on spiritual foundations.

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3.b Steps for Living

Step One: Recognize that trying to control life's uncontrollable circumstances is futile, and that the harder we try, the more miserable we become.

Step Two: Have faith that good, orderly direction exists outside of ourselves, and can help us change.

Step Three: Accept good orderly direction as a Higher Power for accomplishing change, rather than relying exclusively on our own judgment.

Step Four: Look carefully at our actions and choices, and identify the flaws of character they reveal.

Step Five: Extend trust to share what we learn about ourselves, and accept feedback based in good orderly direction.

Step Six: Accept the need for change and become ready to transform our attitudes and choices.

Step Seven: Humbly embrace transformation based on the good orderly direction of our Higher Power.

Step Eight: Identify others harmed by our actions and choices, and become willing to make amends.

Step Nine: Make amends directly to those we have harmed, except where doing so may cause more harm.

Step Ten: Watch for harmful trends in our attitudes and thinking, and promptly admit to our mistakes.

Step Eleven: Continue learning from daily practice, self-examination, and attention to the Higher Power of good orderly direction.

Step Twelve: Carry the message about the power of this program, not just to assist others seeking aid, but to help us stay on the path and practice these principles in all our affairs.

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4. Making it a Program

The Steps for Living are a blueprint for mental and spiritual health that extend far beyond their origin as tools for maintaining abstinence from an addictive substance. These principles offer hope to anyone coping with chaos or misery— whether because of a chronic brain disorder, or a pattern of self-defeat based on co-dependency, bad choice-making, or chronic unhappiness with how we live and how the world treats us.

It is only a blueprint. It has to be implemented to work.

There, too, we can learn from the successes of AA. The principles that make practicing the Steps into a program are simple:

Daily practice of study, self-education, and self-diagnosis

Using the Steps, helpful literature, insights from others, on a daily basis take time to review the principles of this commitment to health, and apply them to ourselves. Using meditation, reading, journaling, prayer, or whatever other solitary practice(s) work for us, continue to build our understanding, insight, and depth of commitment to this program.

Sponsorship

Or mentorship, if you prefer. The essence of sponsorship is guidance through these Steps, by someone who is willing to share their experience with the program. A sponsor also reinforces our commitment to practice through being 'accountable' to someone else in the program. In time, we'll make the same commitment to help someone else.

Mutual support

Ideally, this happens when a few of us who have made the commitment to transforming our lives with this tool can get together regularly, and discuss our struggles and accomplishments in living the program. In person is best, of course, but online or in a conference call or any way we can share will be a powerful source of strength in sticking to this blueprint and making progress.

Carrying the message

This doesn't mean proselytize or urge the program on anyone and everyone. It doesn't mean wear the program on your sleeve or make a parade of it. But when we encounter another struggling, suffering person, wrapped and trapped in their own misery, we can reach out to them. We can share our experience with these Steps, with this program, and offer them the information needed to connect with us. By helping them, we help ourselves.

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4.a Steps for Living Program Principles

One of the most important things the founders of AA did to ensure that it would not be distorted or used for purposes other than mutual help in recovery was to set out some principles for the program. They wanted to keep the simple practices simple, and prevent them from being commercialized, co-opted by charismatic leaders, or discredited by controversy and overreaching.

Although called "Traditions," the principles that emerged were initially based less on universally-practiced and accepted norms, than on hard lessons about leadership and the relationship of temporal authority to spiritual power.

As of this writing, there are no "Steps for Living" groups meeting regularly, that we know of. In the hopes that those who find help and comfort in this program will reach out and share in accordance with Step 12, and that groups will form and organizational principles will be useful, we have similarly adapted the Traditions into these Program Principles.

1. Our common well-being is our priority: Personal progress in recovery depends on the strength of the program.
2. For our common purpose the ultimate authority is our Higher Power as we conceive it. Leaders in the program are but trusted servants, they do not govern.
3. The only requirement for inclusion is the desire to live and grow in recovery via Steps for Living.
4. Each Steps for Living group should be autonomous except in matters that concern another group or the program as a whole.
5. Each Steps for Living group has but one purpose: To carry this message of recovery to those still suffering.
6. Steps for Living will not endorse, affiliate, finance, or allow the use of its name for any related program or enterprise; issues of prestige, money, etc. can only distract from our purpose.
7. Steps for Living groups must be self-supporting, declining outside sponsorship, contributions, or monetary support of any kind.
8. Steps for Living work remains forever non-professional, but individual groups or the Program may purchase services or employ individuals to provide administrative assistance.
9. Steps for Living is neither organized nor incorporated, but may create service committees responsible to those served by the Program.
10. Steps for Living has no opinion on outside issues, and will make no statements or permit any activities that may involve us in public or professional controversy.

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11. Our work is based on attraction, not promotion; we should maintain functional anonymity at the level of media attention and public policy.

12. Our Program is based on the principles and practices, not on individuals' work; the "functional anonymity" we require is to preserve the subordination of personal aims and advantage to the benefits of the Program for all.

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